'My story' transcripts from the old Forum (called Meeting Space) –edited

Years 2013 and 2012

Note: The value of these stories lies in what can be learned from one person's story and applied to benefit others. Not all are happy stories – some are about those who have died from CUP as well as those that have lived (either with a CUP diagnosis or with a site specific diagnosis) but all say something about CUP and its impact, its treatment etc.

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POSTINGS ON DIAGNOSIS AND DURING TREATMENT

Ray's story Posted on: August 26th, 2013 by RayG

I was well aware of the high probability of getting some form of cancer in later life. But I never thought it would come out me from such a strange direction: having a serious form of cancer I'd never heard of, in lymph nodes I'd never heard of – and yet with no symptoms so far. It's been, consequently, very encouraging to find the Jo's Friends site. Without putting down the excellent purely factual material that exists – for instance, the Macmillan information sheets – it's good to find CUP tackled from a more personal level that recognises the peculiarity of the situation that sufferers face. The story briefly. I'm 57, semi-retired, living in East Devon, and I was diagnosed with CUP in late 2012. I'd had a bug over Christmas 2011 that left me with a cough that wasn't clearing up, and in July they eventually sent me for a chest x-ray. Oddly enough, the cough had gone by that time – it's unclear if was connected. Anyhow, the x-ray showed an enlarged lymph node my GP called "suspicious", and this led rapidly to a CT scan and an EBUS biopsy (a biopsy where they feed a little ultrasound probe down into your lung, and take a sample through the wall – painless, but you cough a lot). Because of the tumour locations, this investigation was coordinated through the hospital's lung department, and that still is my point of contact.By this time, the picture had become clear that it was metastatic cancer, in a string of lymph nodes in my chest and neck. The consultant didn't especially stress the seriousness, but we could tell that from the way, half-way through the consultation, they brought a suspiciously kind nurse into the office to sit next to us. At this point it was explained that a primary tumour hadn't been found, so I had further tests: a needle biopsy in my neck, a nose and throat endoscopy, and finally a trip to Plymouth for a PET scan. Nothing showed up except the secondaries, and I was then passed on to an oncologist to assess treatment.After a couple of very stressed months, it was a relief to hear a name for the problem – metastatic carcinoma of unknown primary – and finally see treatment in sight, though the news wasn't good. They didn't put as bluntly as "this is incurable"; but their understated "the aim is to keep you well as long as possible" was if anything more chilling – especially when you don't even feel ill.Surgery wasn't an option. The general sketch of the plan was chemotherapy, perhaps with radiotherapy later, and in September I started a six-session course of cisplatin/docetaxel, involving a day as an outpatient every three weeks. This wasn't too bad. I'd heard all the horror stories about constant nausea, but this is very well managed with anti-nausea drugs. The chemotherapy days were chiefly boring – 9am to 6pm on a drip – and I wasn't too unwell in between. I was chiefly very tired with a constant 'heavy legs' feeling. I lost my hair (but not eyebrows, for some reason) and sense of taste. It was a very draggy four months, being unable to go a country walks, one of my favourite leisure activities. But by January 2013, scans showed a significant shrinkage of the affected lymph nodes, and I was signed off, with repeat scans scheduled every three months. After as little as a month, I was up to a small cliff walk, and by late March I felt back to normal – hair, taste, and general energy back – if a little unfit from a few months' enforced inactivity.The treatment gave me about six months' remission, during which time I've been very active. Unfortunately the cancer is on the move again, and the plan currently is to give me another treatment with a different drug combination – GemCarbo – starting in October. This timing was my choice – given the fairly poor prognosis, I felt I'd rather enjoy what's turned out to be a beautiful summer, and get treated later.I'm not sure what advice I can give; I've approached this by the most mundane route possible. I've never had any wish to follow any treatment plan except the evidence-based NHS one, which has been great in quality of treatment, care, and general outcome. I've no interest in alternative therapies, seeking experimental approaches (though I'll happily take part in clinical trials if

that's offered), or counselling (though I don't rule that out for later).Everyone has different coping strategies: for me, it's been to live life as normally as possible. I went through a stage of major panic immediately after the diagnosis – it felt like the film *D.O.A.*, whose protagonist finds he has been terminally poisoned. I couldn't imagine how "living with cancer", as the CUP leaflets put it, was possible. But you can't panic forever. I'm not remotely brave or stoical, but I get by, by not letting cancer occupy my thoughts any more than necessary. I'm still around a year after diagnosis, which is a lot better than I'd feared. And there it stands at present.- Ray

> Hello Ray,Sorry to hear your diagnosis. I was diagnosed in the Autumn of 2007 and went through the six sessions of Taxol/ Carbo & they added etoposide to the mix. To date I have not had an occurance.People tell me I have a "great attitude" but sometimes I feel a little lonely.When I was told on September 17, 2007 that I have cancer, my life took a new direction.I retired from work, took up some new hobbies, moved back to the community I grew up in. I must say I now enjoy life.
> I don't know if, or when, CUP will rear it's ugly head again. It's always there.
> Dianne*Dianne* says on August 26, 2013 at 8:50 pm
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> Well from my experience your post seems very positve and it's nice to hear that you had some remission time. You were right to delay treatment to enjoy the summer and sounds like you are making the most of every opportunity. Good for you! I wish you all the best in your future treatments. Clair*clairg* says on August 26, 2013 at 10:58 pm
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> Thanks! Fortunately we don't live expensively, so I was also able to retire. Though the circumstances are hardly what I'd have wanted, to say the least, it has been strangely liberating.Spring and summer have been great: plenty of free time to get involved in the local music scene, work on a half-finished book, see my Dad, and go with my wife on walks and visits we'd never got around to doing – and we're only a few days from our 25th wedding anniversary. "Closure" is a bit of a hackneyed word, but I feel OK on that front; even if the repeat treatment doesn't go well, I'm not left feeling that anything major has been left un-done.I do get a trifle fed up with people telling me I'm doing well because of positive attitude. It's pretty easy to be upbeat when you don't have any symptoms.*RayG* says on August 28, 2013 at 8:56 pm
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> I came across this the other day: 'life isn't about waiting for the storm to pass. It's about learning how to dance in the rain.' (Vivian Greene).Seems like you've been making the most of the 'dancing' Ray and, unusually, we've had a pretty good Summer with less rain than usual!*John (Moderator)* says on August 29, 2013 at 9:05 am
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> Hello rayYour story is my story and the thought of having a break from treatment sounds good. You have inspired me no end… Thanks*kazhaz@hotmail.com* says on August 29, 2013 at 10:56 am
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> Thanks, Kaz, John and others. My impression is that the situation has improved a lot, even over the past 2-3 years. Now it's far more common with CUP to get at least some remission. A year's good – however it goes now, I'm not unhappy with how it's gone.

Looking for Kate? Or anyone with squamous cell carcinoma? *Posted on:* March 8th, 2013 *by* elma

Kate I just saw your post from August. I was diagnosed in September with squamous cell carcinoma although I was not told this until November. What happened was in June I was told I had ovarian cancer, in July I was told it was sarcoma of the bones & soft tissue, in August they said the sarcomas are not the primary so I believed I had CUP (sarcoma). I now know I have squamous cell carcinoma in my pelvis &after many procedures no primary has been found. From January 2012 my left leg & foot had been swelling this was caused by the large tumour eating its way through the ilium & preventing the lymph fluid draining from my leg.It grew so big that by July I was unable to walk. In October I had palliative radiotherapy to reduce the lymphodema so I now can walk again which is wonderful. There is nothing else can be done but I would love to hear how you are keeping Kate. Or from anyone else in a like situation. By the way I am aged 77 & live in Scotland. I think we all must keep hope & love in our hearts. Wishing you all the very best that can be got for you. Love Elma

> Hello Elma,I registered on this site last year when my own experience started. I am very sorry to hear that there is nothing else that can be done for you. I don't know what I can offer you other than heartfelt thoughts and best wishes. My experience is/was similar in some aspects. My story is actually elsewhere already on this website (I think under the "My Story" link). I was diagnosed with SCC last February. I discovered an enlarged lymph node in my groin – absolutely no other symptoms or flags has occurred prior. The many tests failed to identify a primary tumour, so like you, it is CUP. I had a complete (deep and superficial) groin node dissection a year ago March and follow up radiation therapy. I now have lymphedema which is permanent as the entire chain/system in my groin was purposely destroyed. I've been actively managing the lymphedema – it's a daily time-consuming chore and I've been experimenting with many different types of compression, aids, etc. Not sure how I stumbled on this website as I live in Canada – just turned 50. Hope & love – the one good that came out of my ordeal was that, at the same time I was going through this, my own mother (80) was suffering from debilitating leg ulcers – my experience with the compression and elevation required to treat my condition helped me understand how to take care of my mom and, as I was home recovering, I was able to also be with her full time until she healed. I hope you can find what you need, whether it is answers or simply many quality days. Love and best wishes.*sid* says on March 14, 2013 at 4:34 am
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> Hello Elma,So sorry for the slow reply – the notification went to my SPAM folder for some reason.It sounds as if you have been having a really hard time. All the confusion and different diagnoses are hard to take, I know. Each time you think you have got an understanding of what is going on, it changes and you have a new situation to come to terms with. I'm glad you are able to walk again – it must make a lot of difference to be out and about and more independent. Sad to hear nothing more can be done. My aunt died of cancer in the summer and was actually strangely calm once she knew there was nothing more to be done. She said 'well, the worst has happened now, so there's nothing more to be afraid of' which I understand better than I would have done a year ago. I guess no-one knows how they will cope until they are there. I wonder if you have had support in dealing with this?I'm doing quite well I think. A CT scan after radiotherapy to the affected lymph nodes showed that it had been

effective. I've recently had a clear PET, although there was a bit of tracer activity which has to be investigated they are pretty sure it is not cancer.I was offered chemo and decided not to do it. No-one knows if it would help or not – our situation is uncommon so there's not a great deal of research on which to base a decision. I look at my kids and feel caught between wanting to give myself the best chance of being around as long as possible, and not wasting 6 months feeling horrible on something that may or may not have any effect on the cancer. I have another appointment with the oncologist in two weeks to discuss what comes next, including a discussion about chemo, but now that I am 5 months on from the radiotherapy with no further signs, they seem to think there is even less justification for it.Sid, I'm glad you seem to have got some strategies for dealing with the lymphoedema but it sounds tough going. I have some 'congestion' and aching in the leg from the radiotherapy and am constantly worried that it might turn into lymphoedema. It sounds pretty unpleasant. I'm trying to exercise more and that seems to help.Love to both of you. Kate*Kate120* says on March 15, 2013 at 10:17 pm

Hello Kate & Sid,I must say sorry for the delay in answering your kind replies. Several things have happened since my posting. I have seen the oncologist who was amazed at my good health, the prognosis only gave me till now. Two days later I fell so hard I thought I had broken my back. However not only did the X-ray show no bone damage but the previously very fragile pelvic bones were very much improved. Most clouds do have a silver lining.I was so happy to hear from both of you. Your LAB 21 query caught my eye Kate & SCC. I think you about the same time Sid. I'm newish to PCs (3yrs.) & couldn't find you again so feared the worst. So very pleased to hear from you both, thank you. I've since kind of tracked you. What is so heartwarming about you both is that you no sooner found yourselves lost in scary CUPland than you both jumped in to help guide others to a more peaceful area.Sid, I hope your Mum is doing O.K. Under your loving care.Kate,how are your twins? I always wanted twins!I feel I am doing very well…..have had many quality days this year(can't get out for now…bad back…who cares….it is snowing here).We three have a similar SCC journey you're the first I've contacted.About lymphoedema, I wear compression tights & do leg exercises, & I think walking, if you can, is best. Since October I have lost over 2ltrs. lymph fluid from my leg &some from higher up. Hope you get relief.It's no fun being a CUP maybe better a saucer?!!
It would be so good to be kept informed just to know someone cares.
When you are feeling well the black cloud flies far away, but never compleately, you have been to a strange place that most people, thankfully, never visit & a little bit of you will always stay there. There is a little silver lining in as much as our priorities are easier to find?In your shoes Kate I would think as you re chemo. Xxx
Love & kindest thoughts to Kate & Sid & all on this space. XXX.ELMA*elma* says on March 18, 2013 at 11:27 pm

And Sid, how about you? And your Mum?My twins are doing well thanks. They seem to take it all in their stride but as I have so far been well most of the time we have been able to keep the worst of it off them. However, I've just posted an update in 'My Story' because I'm no longer CUP. My cancer has 'declared itself' as they say. Sending good vibes and kind thoughts to you both. Hope you have found ways to get some little pleasures.Kate xx*Kate120* says on April 27, 2013 at 9:06 pm

Elma and Kate,Thank-you both for your wishes.Elma I'm glad to hear you have had quality days. You are doing great on the computer! My mom is still doing well, although I wish she was closer – she is a thousand miles away so I can't do things to ensure her continuing health – things that would be very easy to do on even a weekly basis. Regarding the lymphedema – I definitely have it but I am quite fit so except for one time I have not let it get away on me. I wear compression every day and also walk, swim (cool water and compression is very soothing) and use a treadmill regularly. The management is and always will be a big part of my daily life now. Elma I hope you are able to manage the swelling in your leg – do you do bandaging or just the compression stocking? I do both along with quite a few other things – I vary what I use during the day and at night to target different areas.Kate, my last CT scan was clear but I do worry because it seems that it was a PET that revealed your primary. So again thanks to you I intent to discuss your scan and results when I next see my oncologist in June. Do you know whether the biopsy showed HPV positive. A personal question so don't feel you have to answer. The biopsy on my groin node was HPV negative which is why my oncologist and dermatologist are less suspect that it is gynecological. Take care both.
Sid

Mother diagnosed with CUP – I'm lost here. *Posted on:* January 18th, 2013 *by* Canotuna

My mother was diagnosed with CUP a couple of weeks ago. After many tests, they still cannot find the source. As I am completely new to all of this, I am looking for any advice as to what to do next. It seems hopeless and I am beyond frusterated. The best hospital in the world (Rochester Mayo) is basically telling her that no more tests can be done.Why can't doctors do somthing? Does any treatment work? I can't find any real statistics about prognosis's out in the real world. It sounds like at this point all we can do is make her comfortable? REALLY?

I am so sorry to hear of your Mother's diagnosis of CUP. I went through this with my husband last year, and sadly the prognosis is often grim. We went to MD Anderson in Houston and saw a Doctor there who specializes in CUP. There is also a Doctor at Vanderbilt in Nashville who specializes in CUP. I wish we had gone there perhsps, but im not certain the outcome would have been different. It is difficult because you don't know WHAT you are fighting. Feel free to reach out to me by email at Stacy dot Grosso at gmail dot com if you have any questions.*StacyG* says on January 18, 2013 at 9:00 pm

Hi,I mainly just wanted to say I'm so, so sorry to hear about your mother. Any cancer diagnosis is a shock of the most brutal kind but when you are being told no more can be done that is very hard to process. Do you have a specialist nurse to talk to? Or a local cancer centre, like Maggies, or similar? My local cancer centre was fantastic at offering counselling support which helped me to deal with some of my worst fears and bleakest thoughts. Such centres usually offer support to anyone in the patient's circle as well as the patient themselves.I'm not a medical person so I don't want to comment on your mother's situation. I do know that sometimes palliative care is actually better than putting someone through tests and treatment that are not going to help them and may have a big negative impact on their remaining quality of life. I know that is very hard to take. We are led to believe that the medical profession can

work miracles and sometimes they can. But sometimes they can't. I think the doctors themselves find it very difficult to say that they don't know and so they don't always handle that news very well for the patient and the family, in my experience. The NICE CUP guidelines can be helpful in indicating what kind of path ought to be taken in different situations.Thinking of you and sending love and compassion to you and your family.Kate*Kate120* says on January 18, 2013 at 9:21 pm

Thank you both for the nice replies back. Kate, I appreciate your honesty with this. Stacy, I am sorry for your loss and will probably reach out in a seperate email to get your thoughts on MD Anderson. Everything I read about them is that they are the best.*Canotuna* says on January 18, 2013 at 11:24 pm

Like canotunas mother I was diagnosed with CUP & yes it is a big shock. I am not easily shocked but this was aBIG ONE!!! I do agree with Kate that palative treatment can be better than endless searching which can weaken the body. They say sleep is the best medicine….it is very hard to sleep both for you & your mother; I say LOVE is the best…give your mother lots of it. Then try to find peace for yourself this way you will be able to help your mother to gain peace of mind & that's the best comfort anyone can give. My thoughts are with you both. Stay strong & keep hope in your hearts.*elma* says on January 18, 2013 at 11:54 pm

HiI wish you and you mother the best in her journey and your journey together. My mother was also diagnosed with CUP approximately 18months ago . I have not been able to get on this website since my mothers passing on Dec 23rd but after reading your story I am writing this as others did for me to help give you inspiration and hope as others did for me.My mother had aggressive CUP metasis to the brain, liver, lung, multiple abdomin masses right leg, cocksic and thigh muscle. All of these tumours were present during her 18months diagnosis however Mums willpower to live and her love for life defied all the odds and statistics. Even our oncologist who had been with us from the start wrote our family a letter stating it was an honour to be involved in Mas care and to see the wonderful love we all shared. As my Ma would say "no use complaining" so she decided from the beginning no stone unturned and she would continue treatment until she was unable to. with this mind set we went on 4 terrific family holidays, stage shows, family gatherings all spending time and love.. without this ongoing treatment that Ma wanted we would not have had this time together to share these wonderful memories. Ma wanted & had treatment up until a fortnight before her passing. And as a family we truly believe for my Mas journey this gave her the "hope" she needed to continue…. Please understand each persons journey is there own and this is Mas story but I wanted to share with you her hope and want to live. Thinking of you all, wishing you the best.. Trina B*Trina B* says on January 20, 2013 at 1:25 am

Sorry to hear of your Mom's diagnosis. I was diagnosed with CUP in May. Absolutely no signs of any tumor. But cancer has spread to ribs,bone marrow,spine. I have never smoked. It seems the cancer cells they are finding would be consistent with mouth, throat, stomache, lung, liver etc but I do not have traditional symptoms. I am seeing Dr John Finnie in St Louis at Pratt Center.outstanding. I have also been to Siteman but did not like bdside manner. I have used a holistic MD, Christine Salter, who has me on a rigorous, blood type based diet. Also using biomat and ion cleanse. Holistic spa/infrared treatments. My cancer has not spread but is still here. Positive

attitude. Faith in your doctor. Happy to chat more. Hang in. Bruce.*babarnhart* says on January 20, 2013 at 5:12 am

I was diagnosed with CUP five years ago. I was told that there was a treatment protocol depending on where the CUP presented itself. Mine was thought to be abdominal & I was given a combination of three chemos at once.
I have since heard it called the "shotgun approach".It certainly is hard on the body but I'm still here. .Have faith & be positive.Dianne*Dianne* says on January 20, 2013 at 3:05 pm

My partner received a CUP diagnosis in October 2012 after a tumour was found in hip socket in August (as result of an MRI to investigate supposed schiatica) … doctors proposed 'broad brush' chemo combo – which we started. BUT we then paid to have a LAB21 test done privately (with agreement of the NHS oncology team). Results came back with a 96% chance of renal… this has completely turned the treatment regime on its head and my partner is now off chemo and on a relatively new (by NHS standards) 'biological' treatment – based on our experience, I would say, go for the LAB21 test (or similar molecular profiling of the biopsies taken by your oncology team). It provides a chance of giving more clues (and rule-outs) of the origin. This could mean a change to a more direct treatment AND an improved progosis.Good luck and take heart.Di w*di w* says on January 21, 2013 at 6:23 pm

Thanks everyone for their comments…I've learned a lot just from the above info*Canotuna* says on January 21, 2013 at 7:55 pm

In case anyone wants to refer to the different tests that I know of this is the link http://www.cupfoundjo.org/diagnosis_and_treatment/special_tests.htmlI checked the prices last year but if anyone has more up-to-date info please advise.There is a new one in Australia developed at the Peter MacCallum Cancer Centre last year but I have yet to find a link with info about it.*John (Moderator)* says on January 23, 2013 at 10:26 am

I gather you are in the USA. I was diagnosed with stage IV metastisized CUP in Nov. 2007 by local MDs, given 8 mos. to live. I immediately was seen by Memorial Sloan Kettering in NYC. Many tests, never discovered primary, underwent 8 mos. of chemo. Tumors shrank, then disappeared and it's 2013 and I am still cancer free. Of course, I am scanned periodically and am still under their care. I feel blessed to have had a favorable outcome (thus far) and am grateful to the fine professionals at MSKCC. So, nothing is hopeless with the grace of God and doctors who are the best at what they do. My prayers are with you and all who suffer from this frightening disease.*balar53* says on January 28, 2013 at 3:40 pm

Canotuna so sorry as know only too well how you must feel. Me too have CUP groin tumour no symptoms spread Adnexal to ovarys, lungs, spleen. All tests negative. Had two chemo lots to date sick as a dog. Very bad cramps feet and lower legs. Two lots chemo Doctors changed minds three times to decide which kind would give me. I am very strong, was determined too battle/fight, however, now know cannot face more of same. If dying can mean go without this pain then so be it. It's been twelve days since last lot chemo, all pain medications work at first then fail. Palliative care nurse doing his best to find something for me. Doctors claim chemo not cause Baloney!Telling

> you this because if can't afford the special tests expensive (I can't) then follow what your Mum wants. She will know what is best for her. NO-ONE else. You have to experience this even though getting what advice you can. The hardest part I think is the horrible uncertainty of CUP we never knew of it and the Doctors hopeless in handling it. A lottery for us how long we have so I just hope and pray for you love and care from Katherine.*Katherine* says on January 29, 2013 at 12:59 am

New Supporter of CUP cause. *Posted on:* December 21st, 2012 *by* Barkerboy

I was diagnosed with secondary cancer in the lymph nodes in August 2010, I underwent chemotherapy at the end of 2010 and beginning of 2011. I have been lucky in leading a normal life since with regular check ups. Recent scans and biopsy showed that cancer was still present in the lymph nodes on the left side of my neck. I underwent a modified radical neck dissection which removes lymph nodes from the neck area. 40 were removed in the surgery and the majority were infected. even with all this cancerous tissue is has not been possible to detect a primary source or even be sure on the part of the body the cancer is coming from. I will be having radiotherapy on my neck in the coming weeks but have been told that there is a high risk that the cancer will continue to grow throughout my body. I have recently started reading up about CUP and am very impressed with this website. I would like to help support this charity and do my bit to raise awareness of CUP….my initial thoughts are to organise a golf day in the spring. Are there any specific projects at the moment and any target amounts that are needed?look forward to helping!Paul

re: advice anyone? *Posted on:* December 3rd, 2012 *by* Kate120

Hi everyone,I've reached a frustration point and am wondering if you can help. Does anyone have experience of a gynae oncologist who also knows about the Lab21 test (or similar)? I know it's a long shot…there may not even be one in existence!!I've recently paid for this test, which came back with 90% chance of the primary site being in the cervix. My gynae consultant doesn't know anything about the test, what to do with the information, how much to trust it etc. and says he's never had an unknown primary which turned out in the end to have originated in the cervix. My oncologist is very on the ball – he was the one who suggested doing it and thinks it is useful extra information but of course he's not expert on the gynae bit of it. As I understand it there would be one route to take if they had found a small cancer of the cervix, and a very different one if they had found metastatic cervical cancer. Obviously I don't fit neatly into either category. It's not that I think there is a 'right' answer out there, but I am at a point of looking for a second opinion.I do trust my team, they have been great so far, but today I felt let down. Many of you will no doubt have experience of the scary situation of sitting in front of an experienced consultant who says 'we don't know what to do next' and he's done that two weeks running now. I feel as if I need somewhere else to turn. Anyone's experience or suggestion very much welcomed and appreciated.Thanks,Kate

> Hi there Kate,By law (as I understand it) any patient on the NHS is entitled to a 'Second Medical Opinion'.While it sounds that you have a good team, it might be worth while speaking to them about getting one…I can't help with a specialist but I am sure someone else on the site will be able to suggest a centre of excellence e.g., London.It's your health here. Don't be afraid to ask.Good luck.Di w*di w* says on December 3, 2012 at 10:27 pm

Thanks for the encouragement. Without this site I probably wouldn't have even thought about getting a second opinion!Kate*Kate120* says on December 3, 2012 at 11:35 pm

Kate, definite second opinion recommended. But also, is usual to look at cervix for primary if the tumour has appeared in the groin. Oncologist would also look at other lower body organs. The 'rule' being above or below the diaphragm according to where the tumour has appeared in the lymphatic system.My tumour has appeared in left groin plus Adnexal mass, cysts left ovary, fibroids uterus with rest clear. But also, nodes on lungs and splenic mass thought to be metastic. Referred gynacological tests all negative. Say possible cervix primary which has now disappeared. The ovary cysts have had for years. So, is all very confusing and scary, especially when specialists seem so uncertain and can't give definitive answers. They say the upper body things too dangerous to biopsy are probably same to treat with chemo. Had second opinion no different. Have just finished two weeks radiotherapy which has given me major lymphadoema very sore, and worried about mobility. Nobody seems able to tell me what if anything I can do about it. Now, I am offered a choice of two chemo programs. The better one likely to give me tinnitus, the other carpal tunnel syndrome. Both additional to the usual known side effects. Waiting to get full details, but do not know what to do. Had first been told less than twelve months to live, since told surgeon (Prof. head of gyno. Dpt.) was wrong to say this as could be two to three years depending on how I respond to treatment.We really are in a sea of uncertainty, BUT means we must challenge and question all the way!*Katherine* says on December 4, 2012 at 12:37 am

Sorry to hear you've had such a tough and scary time. Lymphoedema sounds so uncomfortable and I know it's something they talk about 'managing' rather than curing. Do I remember reading that they do massage to help? as you say we have to keep asking.You really have been through it and more to come. Sounds as if you are choosing between a rock and a hard place at the moment with the chemo.They have already investigated all my gynae bits and found nothing which is why the consultant is a bit thrown by the Lab21 test saying most likely cervical. They've repeated the MRI and CT pelvic scans without finding it. The question is whether they do a hysterectomy based on the Lab21 test which is still so new and untried.

I do wish you all the best on the difficult road ahead. Be thinking of you and hope you have some 'cheer leaders' as my mum calls them.Kate*Kate120* says on December 4, 2012 at 1:14 am

Thank you Kate, yes managing is right but so far HOW is the question.
I have been self massaging, got off the Internet, and chasing advice.
Adelaide Sth.Australia have private expensive clinics. Trouble for me cost and getting there, limited transport Country area and very limited now ability to drive. No-one to assist. Also, told yesterday any local masseurs will not do, as think may affect tumour growth so are not recommending massage. Catch 22 ! Seeing my physio Friday, she has just phoned, hope to get program for mild exercise. I am trying to keep positive and do get courage from feedback. Much to fight for! the answer. If primary has disappeared, then metastasis already gone elsewhere/anywhere. So need to question/follow up further very carefully.*Katherine* says on December 4, 2012 at 1:40 am

Dear KateThe situation you are in is uncommon. The Lab21 test does however give useful additional information which can be used to guide treatment decisions.If you have seen a gynaecologist who has performed the necessary examinations, it looks like further investigations to look at the cervix for a primary will not add anything.Ultimately, if chemotherapy was necessary, drugs could be selected along the lines of those used for metastatic cervical cancer (rather than selecting the drug regimen almost at random). In other words, treatment selection along "primary-like" lines is a reasonable approach and the Lab21 result assists in determining the treatment choice.*Richard Osborne* says on December 4, 2012 at 11:36 am

Hi KateMaybe you could try Dr Richard Osborne at Poole Hospital, he is not a gynae but he is an oncologist and the only one im aware of who has a positive view on lab21. I understand your frustration i'm fighting my own battle. Good luck Mandy x*mandyb* says on December 4, 2012 at 1:55 pm

Thanks very much Richard for that clear and succinct opinion. That seems to chime with what is now being suggested although they are also doing a loop diathermy to have one more look at the cervix as they haven't done that one yet and it is a pretty straightforward procedure. Your post renews my confidence in my treatment plan and also gives me some good focused questions to ask my lovely oncologist next week. Would you feel able to give an opinion on chemo being used to to kill off anything floating about that remains undetected? Post-radiotherapy I currently have no detectable cancer meaning it has only ever been found in my groin lymph nodes (slow growing squamous cell carcinoma). I'll be having to make a decision next week about whether to have this kind of 'mopping up' chemo.When I posted I was very anxious for various reasons but I'm more settled today and trusting that good decisions will be made on my behalf. I'm lucky to have a highly regarded hospital on my doorstep. A good reminder from Katherine of why the NHS is such a brilliant institution. So sorry to hear help is not there when you need it most Katherine.Thanks for your help too Mandy and I wish you all courage in your own battle.*Kate120* says on December 5, 2012 at 12:42 am

Lisa – diagnosed July 2012 *Posted on:* November 15th, 2012 *by* lisabean

Hello everyone. I'm glad I found this site. I've been floating around the "cancer support" world feeling like no one really understands what I'm going through, so I'm glad to have found others who do understand. I write a blog to keep my friends and family up to date on what is going on, since the constant emails and texts got to be overwhelming, so please forgive me as I copy and paste my first entry from my blog here to give you my story:Let me start at the beginning. Or what I think is the beginning. It's hard to tell. A few years ago, about a year after my daughter was born, I started getting migraines. I'd had migraines before, back in the early 2000s, just before I was diagnosed with hypothyroidism, so I thought these were because my thyroid meds were still off after pregnancy. The doctor gave me Imitrex to help as I got them, and things were fine. I rarely got them. Maybe once every 2-3 months. Then about a year later, they started increasing in frequency, and pretty soon, by early 2011, I was getting 2-3 a week. Unacceptable. Clearly. I went back to my doc and she suggested an MRI, just to make sure. I got the MRI and went on my merry way, not thinking anything, but then I got a call from my doc. There was a lesion on my brain, very small, but I

needed to follow up. I scheduled an appointment with a neurologist who started the various (expensive) tests to try to figure out the cause. The lesion presented like MS, but I had no symptoms of MS, so it didn't add up. So blood test after blood test, scan after scan I went, and nothing. She put me on Topomax to curb the migraines, and although I lost 20 lbs. (side effect from the drug) and my family kept telling me to eat because I looked sick, I was finally feeling better. Around this time I also started with a new endocrinologist (who I credit for straightening me out more than anyone), and she started asking questions trying to discover why my meds would still be off, which they were. She finally asked if I had digestion issues. I said no. She said, "Well, I'm going to throw in a test for Celiac disease anyway. It might be preventing proper absorption of your meds." So she did. And what do you know? Positive for Celiac disease. I called the best gastroenterologist in the area specializing in the disease, yada yada yada, positive biopsy for celiac and it's confirmed. I'm officially gluten free. That was October of 2011. My next MRI showed the lesion was gone. Hurrah! By February the migraines had gone away and I was off the Topomax (and almost instantly gained back most of the lost weight). I finally felt healthy.In March of 2012, I noticed enlarged lymph nodes in my right groin. Knowing this could be nothing – a minor infection, irritation, whatever, – I took note but figured I'd ask my gyn when I went for my annual in May if they were still there. In May they were, so I asked, and she said yup, go get them checked out. She ordered an endometrial biopsy and ultrasound on her side, both of which came back normal except for a rupturing cyst in my right ovary, which was thought to be nothing of importance. I went to my primary care and she suggested a general surgeon to do a biopsy. I had that done in June.On Thursday, June 21, 2012, I got the phone call that would change my life. My biopsy came back positive for cancer. Now here's the thing. I knew it would at that point. Lymph nodes don't stay enlarged for 3 months for no reason. But what he told me would rock me to the core. Metastatic carcinoma. Metastatic. *What*? I thought he would say lymphoma. I still didn't process this was not possibly lymphoma even days later. Metastatic carcinoma, but they can't tell the origin. Possibly gyn or bladder. *What? But I've had a year of nothing but doctors and tests.* Do I need a recommendation for an oncologist? *What? Oh, no. There is only one place to go. Fox Chase.* I called and made my first appointment with Fox Chase Cancer Center for the next week, and thus began the ride.Here's the summary. I've been officially diagnosed with cancer of an unknown primary. At Fox Chase, I've seen a gastroenterology general oncologist (now my main doc), GI surgical oncologist, urological oncologist, gynecological oncologist, and more nurses, techs, and administrative staff than I can count (they are FABULOUS by the way. Highly recommend them!). I've been poked, prodded, had an ovary removed, a D&C, a flex sigmoidoscopy, cystoscopy, upper endoscopy, CT scan, PET scan, and had lots and lots and lots of blood taken. Oh, and a port insertion. Since the end of June. It's now August 11th. Just sayin. I hurt. All of those tests produced nothing. No source. The cancer is in my lymphatic system, clearly, and the blood stream, but there is no tumor present anywhere in my body. This does not mean hop up and down, jump for joy. This means oh crap, how do we *treat* this? So my doctor, Dr. Dotan, presented my case to various medical boards and this is what she said. The cancer seems to have broken up from wherever the original location was and is now floating around my body. So there is no surgery and there is no radiation. Because the cancer cells aren't taking a specific shape of any one type of cancer it's hard to tell what kind of cancer it is. The pathology says it's most likely upper GI – pancreas, stomach, esophogus. Aside from the pancreas, which feels fine but of course has not been biopsied, everything else looks normal and has no cancer in it. My blood work is all normal. No cancer markers. Nothing. But the pathology reports still say GI. So we're going with an aggressive chemotherapy plan. Three different drugs, every three weeks, for 12 weeks. To start, it was Cisplatin, Docetaxel, and 5-FU (fluorouricil), but the side effects of Cisplatin had me out for 2 weeks out of three for the first three treatments, so

that's been changed to Carboplatin. I go in on Monday for various antinausea drugs and the docetaxel and carboplatin infusions. Then they hook me up to a pump of the (appropriately named) 5-FU and that comes home with me and slowly drips over the next 5 days. That's fun. I go back on Friday and they take out the pump. On Saturday I go back in for a shot of Neulasta, which increases my white blood cell count. I am then home for 2 weeks before I go back and do it all again.My first CT scan since starting chemo was in October and news came back better than I expected! I will put the clinical findings here, since they sound so AWESOME."Previously prominent retroperitoneal lymph nodes have diminished in size and now appear normal. Previously enlarged mesenteric lymph nodes have also diminished in size…. Haziness of the mesenteric root has also improved and pelvic ascites has almost completely resolved. Right inguinal lymph nodes have decreased in size. The uterus and left ovary have diminished in size, likely physiologic."Woo-freaking-hoooooooooo!!!!!! I was hoping things were stable, but to be told they had reduced in size and some have gone back to normal – beyond my imagination!!! There are a couple of notes on the scan – specifically what they call a ground glass opacity in the lower lobe of my right lung – which need to be noted, but that was even stable since the last time and the report says it could be inflammatory, so it just needs to be noted and watched. Overall, fantastic news that even my doc was excited about! She even double checked with the radiologist because she wanted to be sure she was actually seeing what she thought she was seeing. hahahahahaha! Totally worth the hour and a half wait for that news, let me tell you!The results of the molecular profiling (genetic testing) came back inconclusive. What the report did show were treatments that my type of cancer would most likely respond to, and the top drugs are drugs I'm currently on, so that just reiterated the treatment is the right one. You know, aside from the fact that it's working and all. The report also gave some other drugs that are likely to have benefit once this treatment plan has run its course, which they all do. So down the line, as my doc said, we have more options she wouldn't have necessarily thought of.I just read about CancerTYPE ID through this site and I've printed out the form to give to my doc to get that testing done. I'm hoping for more conclusive results.The statistics for CUP are just something I'm not ready to fully accept. My cancer is not in my organs. It is in my lymphatic system and, at this point, appears only to be in the inguinal nodes. And they are shrinking. How this is an upper GI cancer I don't know. I can only imagine the Celiac disease has something to do with it. Nothing really makes sense.So that's my story. I hope to get more information through this group, this site, and raise awareness around so that we can get more attention brought to our cause, and beating cancer for good.Lisa

> That's quite a journey so far! Well done for staykng well-informed and seeking out the best treatment available to you. I've also had the experience of cancer found only in the inguinal nodes, despite extensive searching and have been told that this type of CUP has quite positive statistics.*Kate120* says on November 16, 2012 at 12:30 am
>
> Hi Kate. Thanks for the response! Do your doctors have a guess on where your primary might be? How are you being treated? I haven't gone through all of the stories yet so forgive me if yours is there. I'm glad you've been told this type of CUP has positive statistics. That's what I've read though my doctors won't give any sort of prognosis because of the unknown nature. I'm not sure which I prefer to be honest.*lisabean* says on November 16, 2012 at 6:57 pm
>
> Hi Kate, very pleased for you. However, be careful. So far unknown primary not curable just able to extend time so you must remain vigilant and in particular, don't stop asking questions.I have same as you in left inguinal nodes came up 6.9.12. Not

told until 31.10.12 without all the tests you have had. Most info. had to get from Internet I am very angry. Got second opinion further insights but doesn't change end result. Was told less than 12 months but now learn possible up to 3yrs. Doing two weeks radiotherapy then expected chemo so am interested in the details you have given. Will see how compares with what I am offered.Once it is in the lymph nodes very difficult to find primary often impossible as you have described. Metastases means it has distributed itself almost anywhere. May have been very small and even dissolved, can never find it. One other thing which bothered me.When appears in lower half of body, that's where they look. Vice versa for upper body BUT as I have suspected it ain't necessarily so. Me no symptoms except benign cysts ovaries had for years and fibroids. All other tests negative lower half. However, problems upper half from head down unresolved last five years despite investigations. Since, scans show lung nodules think is metastic, spleen mass may be cysts or metastic. Thyroid nodules existing 2yrs now is goitre and a cyst. Had breast cancer clear 7yrs with mastectomy different cell type. This is important as the cell type and location determines whether secondary (from original) or new primary thus how it is treated and possible prognosis. My second opinion agreed with me but unfortunately now makes no difference as the lymph node involvement is the issue. Sorry can't be more positive.One more thing to chase up. Our ABC TV NEWS N.S.W had snippet re new blood test found 90percent success in finding primary, but don't know when or if available yet.*Katherine* says on November 17, 2012 at 12:15 am

Just to agree your point: "One other thing which bothered me. When appears in lower half of body, that's where they look. Vice versa for upper body BUT as I have suspected it ain't necessarily so." About the only thing that is known about CUP is that its metastatic spread is 'atypical' so all the rules about where to look based on presentation go out of the window, or should do.*John (Moderator)* says on November 19, 2012

Just been diagnosed *Posted on:* November 15th, 2012 *by* Jean Macadam

I have been diagnosed with a primary breast cance and a CUP wich is undiagnosed after MRI Ct and bone scans . Have just had a PET scan trying to locate my second primary tumour . If it goes undiagnosed I am very frightened of how this will effect me will i die if untreated , because has not been found

Hi Jean,Sorry that you find yourself here but i dont understand your post fully you talk of a second primary cancer do you have two separate cancers as there can only be one primary. I am presumed breast cancer HER2 but they have never found the primary and so go by the information they have from bloods and biopsy. I was diagnosed August 2010 and have been in remission since 2011. There are several others on here that have been in remission for many years. Take a look also on the breast cancer care forum there are many many people on there that are 20 year survivors some of them stage 4 it doesnt have to be a death sentence. Keep positive. All the best Sallie.*salliew* says on November 15, 2012 at 8:54 am

> Hi Jean sorry to hear of your bad news like Sally I too didn't quite understand your diagnosis and no it doesn't necessarily mean that you will die keep asking questions till you understand all your options. Take care. Anne. Ibbotson

Neck Lump *Posted on:* October 30th, 2012 *by* susan

In July I found a lump in my right side neck. A visit to my GP suggested that I had a tooth infection as I did have extreme sensitivity, so antibiotics until I saw my dentist. After a molar extraction and more antibiotics the lump was still there. I then got a massive infection in the extraction so this time took myself up to A&E. The Dr. I saw did blood tests and xrays, prescribed yet more antibiotics, but told me that the lump in my neck had nothing to do with my tooth! An appointment was made for a scan. Two weeks later they scanned and aspired the lump, the result was squamous cell carcinoma. Within 2weeks I had a PET scan and an MRI. Results were that the primary site was at the back of my tongue. So admitted to hospital the next week for a biopsy of the tongue mass. Result was negative. A false positive PET scan. I was diagnosed with CUP. My consultant told me that the primary had been most definitely in the head and neck region, but either my immune system had got rid of it or it is so small that it is undetectable. I do not smoke or drink, and for the most part I am healthy.

The next week I was in for a neck dissection to remove the lump and 49 lymph nodes. I was in for 9 days and although the neck dissection was not that bad, yes you guessed it, I got an infection and was on more antibiotics.Results were that 48 lymph nodes were good but for the node with the tumour in it. Also unfortunately the cancer cells had spread intothe surrounding tissue of that node. The plan is one day of chemotherapy, 5 weeks of radiotherapy, one day of chemotherapy,and a final week of radiotherapy. To add my Consultant and teamhave been wonderful, and my specialist nurse has been incredible.

My neck dissection and all the stuff that comes with it are healing well, apart from of course! A couple more infections. Treatment starts on November 13 at The Royal Marsden, Chelsea. It is going to be a bit of a rough journey over the next couple of months. I will let you know how I get on.

> Sorry to hear you've been going through all that but it sounds as if your team are on the ball, now that they've worked out what is going on for you.Wish you all the best as you start chemo/radiotherapy.Kate*Kate120* says on October 30, 2012 at 11:16 am
>
> Kate. Thank you. I have a good team, however it still worries me as to where the primary site is or was. I hope and pray that the chemotherapy and radiotherapy get rid of it, and with all the side effects associated with that, I am trying to put on a brave face. xx*susan* says on October 30, 2012 at 1:07 pm
>
> Hi SusanSorry to hear what you've been through,
> Hope your treatment is not to tough on you and you recover well from it, hopefully there will be good news at the end of it,Good luckPat*patrick* says on October 30, 2012 at 1:59 pm
>
> Hi SusanSorry to hear your news, I know what a shock it is to be diagnosed with CUP (well certainly from a family perspective) especially when you have never heard of CUP and that's where this site is so amazing. Stay positive because amongst the sad

stories there are also happy ones. From what I have read on this site the Royal Marsden are very good with their knowledge of CUP, so I would say you are in good hands.I don't know much about it but have you had a look at the LAB 21 option? I realise it is expensive, but maybe you can ask when you are at the Royal Marsden and maybe they can advise you if any funding would be available.My thoughts are with you, let us know how you get onWith much loveTanya x*Tanya* says on October 30, 2012 at 8:25 pm

Tanya, thank you for your kind reply. I have read about Lab 21 on this site. I will ask my consultant about it. Face mask being made tomorrow for start of radiotherapy (pretty apt for Halloween). I will let you know how I get on with the treatment. Love xx*susan* says on October 30, 2012 at 10:34 pm

Hi SusanHow is the Treatment going? Mine is a very similar story! Diagnosed Jan this year – had radical neck dissection, radiotherapy with a couple of sessions of chemo. Now I have been given the all clear and am back at work full-time. I feel great.I'm sure it won't be too long before you do. if you want to know more detail about my treatment have a look here: http://www.pokerlibrarian.com
Go back to the first post – the recent ones are just me enjoying life again!
B xx*BerniW* says on November 23, 2012 at 11:13 am

B. Great to hear from you. I have already read your blog previously as I searched someone with the same cup as mine and it really set me up for the treatment, thank you I am encouraged and delighted that your are back to work and feeling great. As for me well …… I had the first chemotherapy on 14 Nov. It was a disaster and I felt so unwell with nausea. I was in hospital for 4 days! They say 25% of people react that way. Next one is on 11 Dec when they will give me a very 'expensive'! Anti sickness medicine for three days prior. I wonder why this was not given in the beginning. Anyhow, it helps 80% of people …. What is the betting I am in the 20% that it doesn't. 9 days into radiotherapy and that fine. I am getting quite attached to my mask Getting tired and everything tastes like nothing. I like milky coffee and I can taste coffee I don't know why. Neck dissection looking ok so far. Mouth getting dryer day by day. The last day of treatment is December 22, it should have been 24th but they are doing the Saturday instead. I do love having the weekend 'off'. Again, lovely to hear from you, lots of love xx*susan* says on November 23, 2012 at 10:11 pm

Oh good – your treatment will be over and done with by Christmas. You know how quickly that comes around! Yeah my first chemo was vile – I was very sick. So the second time I was given the more expensive drugs and it kept the sickness away. So fingers crossed for you on 11th. I brought my mask home with me when I had finished – it's still sitting on a shelf in my lounge 😃e taste does improve. I loved tea and chocolate before the treatment – but it made tea taste like hot water and choc like oil! But they are gradually tasting better so I can enjoy them again now. Am so glad to hear you are getting through this. You sound pretty upbeat 😃Wishing you all the best! Keep us updated when you feel like it! B xx*BerniW* says on November 24, 2012 at 12:47 am

Thanks Berni. Hope the expensive anti sickness will help me this time. Starting to feel very tired and my throat is so sore. Not eating that great so hope they don't do anything drastic next week if I drop a couple more pounds. I need a short nap in the

afternoons and a brisk walk even in this weather helps me recharge the batteries. Fed up feeling like this and can't wait for it all to be over. I will let you know how I get on after the 11th Susan x*susan* says on November 28, 2012 at 7:50 am

Hi! Hope today went ok – better than last time at least. I was thinking about you! I lived off little pots of custard and banana milkshakes when my throat was at its worst. The dietician gave me liquid food but I didnt use much of it. It won't be too long before you get back to normal. Fingers crossed! X*BerniW* says on December 11, 2012 at 11:00 pm

Hi Susan – I have just joined this site, I had a similar early journey to you in that my only symptom was a lump on the left side of my neck. I had this removed just because i was curious as to what it was not expecting anything to come back. The result was that i had cancer (this was in August 2010) so underwent a number of scans including a PET scan. This showed a likelihood that the Cancer was in my tonsils so had them removed but no cancer was found in them. I was then told that there was uncertainity as to whether the cancer originated from Head and Neck are or Upper GI – I was referreed to Upper GI and they put me on a 6 week Chemotherapy treatment, which as you note is horrendous due to all the sickness and problem with anti-sickness medicines. The lumps in my neck went down and it was assumed I was OK I went back to the clinic every 3 months for 18 months and everything seemed to be fine. After the 18months had elapsed I was told I could have another PET scan as they say you can't have one before that due to the fact that chemo distorts the results. The results of this PET initially looked positive only picking up a small area under my chin which they said could be a dental infection or something else not to worry about. For throroughness I was referred back to Head and Neck who sent me for an ultrasound and biopsy. This showed more disease and the next course of action was a Neck Dissection, the result of this was the removal of 40 Lymph nodes with the majority being affected and spread in to surrounding tissue. Shortly I will be having radiotherapy to target the neck area but as they still don't know where the cancer is I suspect this is merely a containing measure.The reason for writing to you and joining the CUP cause is that I believe I only had 1 or 2 infected Lymph nodes back in August 2010 but as so little is known about CUP I was treated with Chemotherapy regime specific to upper GI cancer but this obviously did not irradicate the disease. Hoping by sharing our stories we can raise awareness of CUP and help others to get more accurate and timely diagnosis.Wishing you all the best.PaulPaul Barker*Barkerboy* says on December 21, 2012 at 9:18 am

Just to add – I've been having all my treatments at Addenbrookes Cambridge and have to say they are all amazing people and my treatment has been first class.I just believe that there is lots to learn about CUP so the health professionals are doing all they can based on current knowledge. More research is required as with other Cancer types which have come on leaps and bounds in recent years!*Barkerboy* says on December 21, 2012 at 9:22 am

Hi Paul. I am so sorry to hear that they didn't get it right in 2010 so that you are now left with spread to 40 lymph nodes. Great strides have been taken since 2010. The treatment is tough. Nobody can prepare you for radiotherapy /chemotherapy to your neck. I will finish tomorrow with my final treatment. I was in hospital all week due to loss of weight and dehydration. Back in today for blood transfusion, so sitting here

writing your reply. I am living on Fortisip and can't eat anything else. I hope it will be better for you but do trust the regime, prognosis appears to be very positive. I am under Professor Nutting and his team at The Royal Marsden, Chelsea. There were times when I didn't want to carry on especially during the two chemo sessions but the whole team have been so supportive and I am less than 24 hours away from the end. Please let us know how you get on. God Bless. I will be thinking of you. Susan x

Hi Berni. I didn't see your post on December 11. Thank you. Yes the Aprepitant worked and I had no nausea on second chemo. I just can't eat and I am forced to get the Fortisip down me. Can't eat custard, soup or anything else. As you will see from my post to Paul have be in hospital all week and on a blood transfusion drip as I write. Oh well guess it is better than battling the shoppers! It is all over tomorrow, not looking to eat a christmas dinner but at least the daily trip here will be over and I can start to get myself better. Don't look that elegant either. My neck is so burnt and my hair underneath at the back has all come out. Not a pretty sight at the moment. Most definitely a sofa and tv christmas. On the bright side of things I don't have to cook but I shall be directing in the kitchen. All the best for Christmas and the New year. Keep in touch. Susan x*susan* says on December 21, 2012 at 3:41 pm (Edit)

Happy New Year Susan!
I hope that things are improving for you now. I know what you mean about the sore neck – but it is surprising how quickly that can heal. Mine looks pretty normal now. I thought I'd have to wear scarves for the rest of my life – but when I left them off no-one could tell I'd had anything done! I did lose all my hair eventually – but it is growing back dark and curly now!Hope the sore throat is getting a bit better. Still on the Fortisip? I'm guessing you didn't have a feeding tube put in then? I did – but was determined not to use it! It was such a relief to get it taken out!
You should start to enjoy real food again soon. This is going to be a MUCH better year!Berni xxx*BerniW* says on January 9, 2013 at 5:58 pm

Berni Happy New Year! I was thinking of you today and just about to write and ask you when I might possibly to able to taste again!! The red and sore neck is completely healed so that is a positive. I have lost about two and a half stone. I am supplementing uncomplicated soups and yoghurt (which taste like poison) with the fortisip. The dietician has given me only enough for another week and said that I should be eating and tasting better by then …. I hope so. I have only lost hair underneath at the back, so not that bad. I hope it grows back soon, its cold! Yes, here's to a much better year. Susan x*susan* says on January 11, 2013 at 1:53 pm

Hi SusanSo glad you are feeling somewhat better – and the neck has healed. That's great news. I think with the taste things come back gradually. It wasn't long before I could enjoy food again. The only things that took ages to return were my liking for tea and chocolate. I do like them again now – probably since the last couple of months. I'm not sure if they taste the same as before or I've just got used to how they taste now – but they seem pretty normal to me and I can enjoy them. I can't take spicy things like I could before – as one side of my mouth is still sensitive to hot stuff! (The side that got the radio) Even toothpaste still stings. They say everything looks okay though – so I guess some things just take time. Here's hoping you go from strength to strength!Berni xx*BerniW* says on January 16, 2013 at 4:12 pm

Hi SusanHow are things with you? We haven't heard from you in a little while. I really hope you are getting on okay. I just had my 12 month scan and all was well – so I am feeling relieved. I even did the Race for Life this month with 3 friends The Book Group 😃We raised over £700 for Cancer Research and we can't wait to do it again next year.Take care!Berni xx*BerniW* says on June 25, 2013 at 10:20 pm

Melanoma *Posted on:* October 29th, 2012 *by* patrick

Hi everyone, iv just found this site,I was diagnosed in 2009 with melanoma stage III
I had operation in feb 09 they removed lymph nodes under my right arm,
I now have a lump under my right arm, the reason I'm concerned is they couldn't
Find the primary source, is there anyone else in the same situation or similar,
To give advice or understanding of it,Thanks Pat.

HiIt is natural to worry about every new lump that appears. I am in the same boat, having testing of a lump in my left forearm this week. I am just 5 weeks post treatment for my first CUP mass, in my left lymph nodes in armpit. My philosophy is, they have just not invented the test, and/or machine to diagnose yet. Think how advanced the current testing is compared to 20 years ago. Perhaps in your case, since your first encounter was 2009, there will be something new for them to detect. In my case I was lucky that during the testing they discovered ovarian cancer in a very early stage – not related to orginal tumour. I have been very lucky in that any cancer found (metatastic lymph), ovarian, have been removable. My sister-in-law has just been diagnosed with multiple myeloma – blood and bone cancer …. can't live without those! I hope you are as lucky as I am with the compassionate care of professionals and the support of family and friends. My prayers are with you for strength and understanding during this difficult time. Best wishes. Janet (in Canada)*Janet Gillespie* says on October 29, 2012 at 5:06 pm

Thanks Janet, sorry to here that about your sister inlaw,
There is always someone worse than yourself,The one thing that has been positive is that although stage IIII was diagnosed early, after treatment I have been on clinical trialsSo they have been keeping a close eye on things, the last scans and X-rays was ok, I'm due to go back on the 20th Dec for more scans,It's just wether to leave it till then or go up just now,I don't want to be paranoid or a pain to the docs,Hope your are well, Pat*patrick* says on October 29, 2012 at 5:55 pm

Hi PatPlease remember this is your life and your health, don't ever think you are being paranoid or a pain to the doctors.20 December is a long way off – please, please chase for an earlier appointment, if only for your own peace of mind.My brother was always not wanting to bother doctors, so I drove him mad with my insistence!Never apologise for your right and your families right to know.Good luck – be assertive and don't ever apologise for that, that's what we pay into the system for.Take careLet us know how you get onMuch loveTanya x*Tanya* says on October 29, 2012 at 9:31 pm

Hi Pat, So sorry to hear your story. I agree with Tanya, December 20 is far too late to wait. You will have too many sleepless nights up to then. As you say the positive thing is that you are being closely monitored and there are government time lines which are strictly adhered to for cancer patients. You are not paranoid or a pain, ask

lots of questions to your consultant and his team, (through your key worker/specialist nurse, hopefully you have one) and keep us updated on how you get on. My best wishes, Susan x*susan* says on October 30, 2012 at 7:09 am

Hi Pat,Sorry to hear everything you've been going through. As everyone else says, do mention the lump to someone. As my helpful GP once said when I was apologising for being over-anxious "If you come and see me when you've noticed something, the worst that will happen is that I will tell you all is well and you can stop worrying. If you don't come and see me…"Wish you all the best,Kate x*Kate120* says on October 30, 2012 at 11:20 am

Thanks for all the advice, I suppose you woman do no best, I think with CUP you are always going to think of the worst when it might just be nothing, I will put appointment on before Dec and see what they say, thanks again, Pat*patrick* says on October 30, 2012 at 1:43 pm

Hi Tanya iv just ready your story,so sorry to hear about your brother,
I don't think there's any words that can comfort you,But he must have been very proud to have a sister like you,Hope the counselling is helping you get through this, Take care Pat*patrick* says on October 30, 2012 at 3:09 pm

Hi everyone hope you are all well,I had seen consultant on 15/11/12 about lump Under my left arm, just waiting on word to goFor ultrasound : scan & biopsy, it seems a longWait, mind working overtime at the moment,Thanks again for advice,Pat*patrick* says on November 13, 2012 at 3:00 pm Sry wrong date 8/11/12*patrick* says on November 13, 2012 at 3:17 pm

Hi, everyone I would like to thank all of you for advice,I got results from Ct scan and they are clear, phewwww what a relief, I think I cried everyday for the last month fearing the worst, that's the thing with not finding the primary, I can't believe how many horrendous stories there is with CUP why they can't find it, I would like to wish everyone all the best on there journeys.Pat x*patrick* says on November 28, 2012

Dee's Story – so far! *Posted on:* October 17th, 2012 *by* deej

My name is Dee. I am 45 years old, married with 3 children, aged 11, 12 and 14. And I have just been hit by the CUP train. I am a teacher, a vegetarian and all round fit and healthy person. (I was!) In August we dragged our children round Paris on foot! In September I started back at work for the new term. There was a niggle. For a couple of months I had felt uncomfortable after eating, my stomach always felt full, I couldn't lie comfortably on my front to do those essential core excercises at the gym! I joked to my husband that my liver felt as if it had fallen out from underneath my ribcage. Did he want to feel it? Certainly not! But I wasn't in any pain. Mother and sister, both nurses, insisted I went to the GP at the beginning of September.My GP sent me for blood tests and booked an ultrasound scan on my liver. I had the scan on the 10th September. I knew it was serious because the GP had the results within half an hour. He held my hand and told me it was metastasised cancer in my liver. Since then, I have had blood tests, a gynae ultrasound, CT scan on my abdomen, CT scan of my head, mammogram, MRI scan and a biopsy on my liver. The CT scan showed secondary cancer in my liver, as expected, but also in my lungs. The CA125 test was raised pointing to

ovarian cancer, but nothing showed on any of the scans. The tests from the biopsy suggested breast cancer, but neither the mammogram nor MRI scan revealed a primary site.During thelast few weeks as the medical team have tried to find the primary cancer, my has been coordinated by a handful of professionals. I was referred to a gastro/intestinal consultant initially, so all the tests and scans were coordinated by a specialist nurse from that team. She visited me in hospital when I had the biopsy and kept me informed of results for all the tests. The results were reviewed by a multi disciplinary team – and they decided what action to take next. Since no primary has been located my point of contact has become the specialist CUP oncology nurse and she has provided information and links to support.I think the last few weeks have been so stressful because nobody would tell us what was happening, although it was obvious to us that they all knew more than they were prepared to reveal. 'It's serious,' is as far as the diagnosis/ prognosis went. I have gratefully used this website and researched CUP extensively. Really, I have put the pieces together myself. Last week, when we finally met the CUP specialist for our area, he confirmed 12 months as a realistic life expectancy with chemotherapy to offer a little more time. We took the children away for a few days last week to give us all a chance to talk and be together, but we are reeling. I have tried to explain to friends and colleagues how devastating a diagnosis of CUP is. There is such positive news out there about cancer treatments and therapies and friends offer so much hope from this that I feel cruel in snatching this away from them. They think I have given up!I started the chemotherapy today. We have been told the chances of it slowing down or shrinking the tumours are 50/50. The drugs they are using are cistplatin and gemcitabine.I read Mel's story today. It is heart breaking.Thank you to Jo's friends. I have felt well informed attending appointments and this is due to the excellent information I have had at my fingertips.

> Hello Dee.I would just like to say – have you heard of Lab 21? You can read about it on this site. I had a tissue sample test done with them retrospectively for my husband and they found the primary tumour. We didn't know about Lab 21 when he was alive and only found out about it after joining this site. Lab 21 do a more intensive investigation of tissue samples and have a high success rate of finding the primary. It costs £2,600 and it's unlikely the NHS will fund it. I don't want to give you false hope, but I think at least if you research this information, you have a choice. My very best wishes to you and your family. Love Janet x*Janet Bell* says on October 17, 2012 at 6:38 pm
>
> Thanks for posting Dee. Very sorry to have to welcome you here. Re Janet's post you will find info here http://www.cupfoundjo.org/diagnosis_and_treatment/special_tests.htm I am delighted that you have a CUP nurse, a new departure. I wonder whereabouts you are being treated?*John (Moderator)* says on October 17, 2012 at 7:03 pm
>
> Hi Dee,You sound like my mum except her secondary's were everywhere in the lymph. Like you she had raised ca125 and ovarian scans clear. They did chemo of carboplatin and paclitaxel. She responded very very well and as they were guessing it was still gynae despite clear scans, they proceeded to hysterectomy. The cancer was found in the Fallopian tubes. Her prognosis is better than the original year. I hope you have a good outcome. Mum cut out dairy but otherwise stayed with the same diet. Penny Brohn cancer centre in Bristol were amazing too. Wishing you all the luck in the world for you and your family. Donna x*pomdon* says on October 17, 2012 at 7:09 pm

This made me cry. Well done for telling your story Dee. That must have been so hard to write down. It has been a whirlwind which is so hard to believe especially in this day and age. Fight this with every ounce of energy you can. I know that's easier said than done but you have so much to fight it for. You are such a strong person and I know you will. I admire your spirit and can't imagine what you are going through. Well done to Jo's friends for giving Dee somewhere to focus her thoughts. Xxx*Jo Lea* says on October 17, 2012 at 8:47 pm

Hello, Dee. I was diagnosed in Nov. 2008 at MSKCC in NYC, USA. I was on the same chemo (cisplatin & gemcta) as you are on. Chemo was for 8 mos. & have been cancer free since then. The follow up is CT scans every 3 to 6 mos. It was a miracle for me. I loved that chemo. I had stage 4 metacytized and thought I had 8 mos. to live. God bless my doctors and chemo! Take heart and laugh and be merry. Pray, too. Barb*balar53* says on October 17, 2012 at 10:10 pm

Hi Dee. I have a similar story to yours except mine started in 2007 and I'm still here. Please pm me if you like at carpetch@gmail.com and I can tell you what my treatment plan involved. Also are you based in London? If so, I would recommend my oncologist who specialises in "unknown primary".Kind regards.
Katherine*kplondon* says on October 18, 2012 at 8:51 am

Dear DeeThank you for replying. I am so sorry you are so poorly at the moment. It's hollow words I know coming from a stranger,but I couldn't stop thinking about you and your family today. Take heart from all the positive feedbacks above. Much love. Janet x*Janet Bell* says on October 18, 2012 at 4:23 pm

Dee stay positive-you are all the right things getting informed, pursuing treatment etc. accessing other specialist oncologists etc.
CUP adds another dimension to cancer but you must stay positive.
My Mel succumbed in the end but we fought, accessed CUP specialists in Clatterbridge and the Christie and always stayed positive seeking further diagnosis (Lab 21) and new treatment.Mel missed opportunity to access the SIRT treatment for her liver by a month to 5 weeks. Had she been treated in June when her CT Scan revealed every chance of success and the second chemo treatment had actually reduced the tumour-things might have been different. But this wasn't due to failures by the Oncologists-who were good. But we were delayed by funding decisions (not by our local north Wales health board who supported us but centrally in Wales). In the interim, between being refused funding and accessing the treatment (by registering in England), the cancer had started to grow again stopping access to SIRT treatment. However remember averages are just that-they don't match everyone. Read David Serban Schreiber's book 'Anticancer -a way of life'. David was diagnosed with terminal cancer with an average expectancy of 6 months. He died 20 years later. His book gives a number of approaches which complement treatment.
Don't despair-stay positive-for every case like ours there is one where the cancer has gone into remission.P*Peter MAc* says on October 19, 2012 at 12:40 am

Thank you to everyone for your positive messages. I will read up on all the suggestions and talk them over with family and Doctors. I am being treated by an outreach team from Clatterbridge Cancer Centre as this is where the specialist CUP consultant is based. I have found the CUP oncology nurse a really useful point of

contact and she has been able to do lots of chasing up of results for me.
The CUP consultant did not think that the lab 21 test would be useful, (!!) and he told me it would not change his choice of chemotherapy drugs. But I will ask again, and also about the SIRT treatment.I am trying hard to be positive and all your messages are helping, so thank you so much.Dee x*deej* says on October 19, 2012 at 4:02 am

Clatterbridge have taken CUP seriously (under the direction of Dr Marshal) so I'm surprised by your consultant's comments about Molecular Profiling. Sure, the NHS don't encourage it because it is not validated sufficiently and it is expensive; but for an oncologist to reject the offer of additional clues, if you are prepared to pay for it, is surprising. But he or she may have a very good reason….*John (Moderator)* says on October 23, 2012 at 12:18 pm

Dear Dee,My partner Paul (who has just turned 50) was very recently diagnosed with CUP (after a battery of tests starting post suspicious MRI on his hip) in August and after ruling out primary bone cancer (sarcoma)…It has been a difficult time 'not knowing'… however, I would echo the sentiments of other 'posts'… Don't give up… check out the LAB21 test (it is costly but a clue as to origin could help your oncology team refine the treatment…) their 'success rate' is 85% – and while that leaves a 15% chance of spending £2.2k to 'no avail' at least it doesn't leave a nagging stone unturned.My Paul has now started reading ANTICANCER by Dr David Servan-Schreiber – when I read the 1st couple of chaptres it brought a lump to my throat – because it was such a relief to hear someone from within the medical profession talk about the things we CAN DO to support our systems – even when the big 'C' (and worse, CUP) has been 'diagnosed'. It is an INCREDIBLE book – full of very credible references from global sources. In my view, the book (or something like it) should be required reading for anyone practicing in oncology today – and god knows I hope one day the impact of NUTRITON, Body and Mind will be a recognised part of how serious illness is treated in this country…It is too early to tell if a change in diet (non chemo offending supplements – including lashings of GREEN TEA and TUMERIC) combined with a form of yoga and possibly some accupuncture (to aid energy flows in teh lymph) among other things etc… will make a difference in our case… However, what I can say – without a doubt – is that 'feeling that you are not in a completely helpless/hopeless place' is already making a positive difference to Paul (and I).I am not particularly religious but I would like to say, 'God bless' and very best wishes to you and your family.With heart.Di w.*di w* says on October 26, 2012

Which 'New Frontier' test to go for? *Posted on:* September 25th, 2012 *by* di w

My partner has just been diagnosed with CUP – I don't want to leave a stone unturned and we are considering paying privately for one of the 'new frontier' test (Lab 21 etc) as the nature of the tests seems to vary, I would be grateful of any views on where to start in terms of which test to prioritise? And to hear of other people's experience on this. Thank you all in advance. D.

I'm sorry about the delay in responding Di – I'd hoped that others with more experience than me would jump in. But then I realised that it is going to be difficult to make comparisons, and prioritising the tests is a bit of a shot in the dark. They will all

offer some 85% plus of identifying a starting point or nearest neighbour of the cancer although they are coming at the tests in a slightly different way, scientifically. I don't think anyone can say which is the best method at this stage in their development. I'm very sorry about your partner's diagnosis and I think your 'no stone unturned' approach is absolutely right. I think as far as these tests are concerned it is best to research on the web and ring and ask questions. You could try asking your oncologist but as you've probably read in previous threads some are not enthusiastic.Please advise on how you get on.Best wishes, John*John (Moderator)* says on September 29, 2012 at 9:44 am

Thanks so much John – appreciate your candour (and support).As you suggest, I'll read back through the comments on the site.A piece of information you are probably aware of, there is currently a CUP One Clinical Trial in England (not sure about Wales/Scotland) – our Oncologist – in Glos has patients who are part of this. The reason I mention this is that it seems 'Gene Profiling' is part of the test.Because my partner has already started radiotherapy and because 'they don't want to delay' treatment for any longer (initial tests started in August – MRI/Xray/Blood etc) it seems he won't be able to participate BUT I did want to flag this in case other site members might benefit from being aware this trial has now begun. I think CUP One is intended to weigh the benefits of different types of chemo for CUP cases – but for me the fact that they are looking at 'other tests' in gene profiling etc is what was of particular interest.My simple view is that even if the LAB 21 etc tests can't give you an absolute – any clues that help refine treatment which may result in even a small incremental % chance of an improved prognosis has got to be a GOOD THING! Thank you again John.I would also like to echo the sentiments of other site users and say, 'Thank you' for your (and the team's) work in starting CUP Foundation. It has already helped us.*di w* says on September 29, 2012 at 10:26 am

Yes, I'm involved with CUP-One. It now has 203 patients with some trial centres still to open. There is more about it here
http://www.cupfoundjo.org/research_and_resources/trials.html
The clinical part is based around one particular chemo combination which is only suitable for some presentations.Encouragingly I'm going to a meeting on thurs which will start to discuss a follow-up trial – CUP-Two. This is much needed good news for the future but not of great help to the present day patients in terms of the validation of molecular profiling. I agree entirely that it is a 'good thing' but some oncologists……! The CUP lead in your area is, I think, Dr Farrugia who really understands CUP and is extremely clever and even if not being treated by him personally I imagine he will have influenced things.*John (Moderator)* says on September 30, 2012 at 10:26 am

Afternoon John – thanks for the reply (appreciated).
I'll follow with interest any updates on CUP Trials.We actually met with Dr Farrugia about 10 days ago and I mentioned the 'new frontier' tests/LAB 21 (and its predecessor to him) and he was aware of it. He mentioned the CUP One Trial also – I am not sure we will participate as it would further delay treatment – though hopefully any learnings can be applied – perhaps hand-in-hand with our own 'paid for' tests in the coming weeks…I will do some more digging on the test front – and provide any updates which might be of help to others. Many thanks again John. Sincerely appreciate your support.Di*di w* says on October 1, 2012 at 4:18 pm

anne Ibbotson *Posted on:* August 30th, 2012 *by* anne ibbotson

Hello from Australia In 2010 my husband Douglas was diagnosed with a tumour on his right Trigeminal Nerve this was after almost eighteen months of being told his symptoms were nothing more than either Neuralgia or an infected tooth we saw a new GP who after being told of weight loss decided to investigate the result being as above. He went in for surgery to remove tumour but on inspection it could not be removed due to being within the nerve itself.,scrapings were taken to try and identify what it was , the result being Large Cell Carcinoma Melanoma related they then told us that this was a secondary sight, and that further scans would be done to try and locate the Primary Site they did a Cat SCan and a Pet Scan and could not locate the Primary we were stunned having never heard of this before, Doug then had a course of radiation therapy and after further scans were told he was at the moment clear. Over the next 12 months they kept a close watch and up until December 2011 all was well, the in early 2012 a lesion appeared on the top of his head back to the doctor who sent him to a skin specialist who said it was not a skin cancer and to just watch it. Within weeks it had grown from 1mm to half a centimetre, so back to Dr. who then sent us to a General Surgeon who said he would book him on to his schedule to remove it, this took place early April by which time it had grown to over three centimetres and looked like piece of bad cauliflower, sixty stitches later it was gone. The Pathology said it was a Leiomyosarcoma a very aggressive cancer that usually only grows within the body on smooth muscle sheath.,again more scans and again no Primary site was found. So once again we sit back and wait to if it pops up again somewhere else. It was only when a Newspaper had run an Article and interview with another sufferer that we had heard of the term CUP our Doctors had never actually explained it in that way, anyway so far so good we hope that this will be the end of it Good luck to everyone else who are fighting this insidious disease Anne Ibbotson

> Well anne im pleased to hear your husband is well again, and hope this long continues. It is a very frightening disease, iv only known since Jan 2012 when i had my secondary removed and so far so good nothing has returned. Yet its the stress and worry that will never leave you but im trying to cope with it and i hope in time i will think about it less and less. Take care both of youmandy x*mandyb* says on August 30, 2012 at 3:21 pm
>
> Thanks for posting Anne. Very tough time for you and Doug. Mandy captures the characteristics of a CUP diagnosis very accurately. Best of luck and hopefully those like you who join this forum at least feel that you are not alone and not experiencing something totally unique*John (Moderator)* says on August 31, 2012 at 7:10 pm
>
> This is all new to me inguinal lymph node very large mass September, doubled by October. November surgeon was to operate now says no, is CUP too dangerous Radiotherapy only, maybe chemo if responds. Given less than year. Shell shocked. Very little info. never heard of it before. First treatment 14th Nov. same day getting second opinion as suspicious about long term problems nose, thyroid nodes, lung nodes. All being ignored to date. Problem being groin appearance of mass diagnosed squamous cell carcinoma by biopsy. All lower body tests negative although have cysts ovaries many years. Also, breast cancer 7yrs ago invasive ductal, mastectomy with lymph nodes clear.Have read is very rare but possible travel from upper body to lower. Anyone know anything? Know how you must feel Anne, you get the run around with so little info. My surgeon “away” three weeks to wait before told the

worst and passed on same day to radiology to be scan prepared taking two hours, a nightmare!*Katherine* says on November 10, 2012 at 8:47 am

Hi Katherine, sorry you are having such a tough time and suffering delays and confusion. Hope all goes as well as possible tomorrow. I've noticed noone has picked up on your question so will give a stab at an answer from my understanding (but I'm not a doctor). CUP behaves very differently in the way it spreads in comparison to other 'known' cancers. Doctors refer to the spread as 'atypical'. The pathologist who studied your biopsy will undobtedly have been looking out for breast cancer cells as the origin of your secondaries given your history and it is likely that they (unlike CUP cells) would have been identifiable.The trouble is that noone in the world understands the biology of CUP, what causes its peculiar spread or how it spreads and remains so difficult to identify. Doctors will be looking for every possible clue from the pathology and presentation in order to give you the best treatment possible. They will have identified the best options from the available evidence and we know from the literature and patients on this site that this can be very effective.CUP is different for every CUP patient and generalised advice and prognoses can't be reliable.*John (Moderator)* says on November 13, 2012 at 12:46 pm

My Husband *Posted on:* August 29th, 2012 *by* nickiwaterman

My wonderful husband was diagnosed December 2011 with CUP with likely primary site being biliary in origin (immunophenotype consistent with biliary tract tumor/ raised serum CA19 -9). The tumor was wrapped around his aorta and vena cava and was inoperable. He had 6 cycles of very strong chemo which shrunk the tumor by about 50% so our onchologist (Prof Justin Stebbing at the LOC) decided he should have the operation. He continued with two more cycles of strong chemo – but he couldn't cope with the strongest dose and is now on a regime of a much lighter chemo (5FU) every two weeks for at least a year. I'm frightened to talk too soon, but so far his CA count is normal and the MRI scans are clear. He's had every type of test and we still don't know where the primary site could be. The only side-affect he seems to have now is the terrible itchy feeling in his hands and feet. He has gone back to work and we have just started socializing for the first time. I really hope my story will encourage others and of course i will keep you all posted with his journey.

Thanks for posting Nicki – it is always a joy to hear good news and a real encouragement.*John (Moderator)* says on August 29, 2012 at 8:53 am

Thanks for sharing your good news, im really pleased for you both. And yes it does give out encouragement. All the best.Mandy x*mandyb* says on August 29, 2012 at 11:03 am

Thank you! Just wanted to let you know how it all started. My hubby had a slight pain in his tummy and it was just before Christmas (19.12.2011) so we thought it best to get him checked. Our doctor gave him a blood test which showed 'infection' so he went for an Ultra sound scan which was absolutely clear. We then thought it best to get an MRI on the 21.12.2011 and that's when the doctors saw the 'mass'. The first biopsy came back negative so he had another the next day which came back positive. We got these results on boxing day!! There are very few things scarier than being told you have cancer (let alone CUP). We were both in total shock. I actually did not want

to believe what the doctor had told us. I was too overwhelmed and am still very afraid. But I didn't let those feelings stop me from finding out as much as i could about his cancer and about the options we have. I felt the more I knew, the less helpless and afraid I felt. And the more I knew, the better I was/am able to work with our onchologist to make the best choices for treatment. This website has been my life support over these last few months, and I just hope my hubbys story is giving other people hope and encouragement.*nickiwaterman* says on August 29, 2012 at 3:01 pm

LAB21 test? *Posted on:* August 20th, 2012 *by* EleanorG

Hi there, My 75 year old Dad has been diagnosed with CUP.I see here that some people mention LAB21 test.What is it please?Is it helpful?Is it easy to get?Many thanks for your help,Eleanor

Hello Eleanor. I can only tell you my story. Lab 21 do a more detailed analysis of a tissue sample and can usually identify where the primary tumour is. I have just had this done retrospectively for my husband. The results are in and I have to see the consultant on Thursday to find out what they show. I believe they have an 89% success rate, but others may know more about this. It cost me £2,266.00. It took 5 days, but I believe it can take longer. The consultant has to request this investigation, but it will be the family that foot the bill I'm afraid. I hope this helps and my thoughts are with your dad and your family. Janet x*Janet Bell* says on August 20, 2012 at 4:54 pm

Hi Eleanor. Please have a look at this page for details. Janet and others best placed to advise on experiences http://www.cupfoundjo.org/diagnosis_and_treatment/special_tests.html *John (Moderator)* says on August 20, 2012 at 6:05 pm

Hi EleanorI don't have much to add to what Janet has said other than that, in my Dad's case, LAB21 were able to ascertain that his primary tumour was almost certainly kidney cancer (99% probability according to his test results). We didn't find this out in time to save him but, if we had known it earlier, he probably wouldn't have undergone weeks of gruelling ECX chemotherapy which made him very poorly – and he might instead have been given a more appropriate and effective course of treatment. As Janet says, you have to pay for the test yourself but it is all organised between LAB21 and your oncology department. We spoke to the oncologist first who agreed that the test might be useful, we then phoned LAB21 who then liaised with the oncology department. The lady my Mum spoke to on the phone at LAB21 was very helpful (and kind). Our test took 15 working days. If your oncologist agrees that the test would be useful, I would definitely go ahead and have it done. If your oncologist hasn't heard of LAB21 or doesn't think it would be useful, I would get a second opinionWishing you and your Dad all the best.Jeanette*jeanette* says on August 22, 2012 at 2:03 pm

Anyone had success with Lab21 etc? *Posted on:* August 8th, 2012 *by* Kate120

I've sent info to my team on Lab 21 but they are not keen. Obviously if it's not going to help me then I'll be glad not to spend the money but my impression is more that they don't know about it and therefore assume it is not valid. So I wondered if anyone on here has had a positive experience of this type of testing? I have squamous cell carcinoma.Many thank

> I don't know how helpful this is,but I will tell you my experience with lab 21. My husband had died, but tissue samples taken from him during a biopsy were sent to Lab 21. I paid just over £2,200 and within a week they had the results which were passed on to my husbands consultant. Due to him being on holiday I have had to wait for an appointment until 23rd August. I was told by Lab 21 that if they could not get any results from the sample, then they would not charge. So I would say If I'd known about lab 21 when my husband was alive I would have most definitely contacted them – a week to analyse the biopsy is vital for people living with this dreadful illness. I hope this has helped. Best wishes to you. Janet x*Janet Bell* says on August 8, 2012 at 12:00 pm
>
> I'm so, so sorry to hear about your husband.Many thanks for taking the time to reply and it is very useful to know about your experience.Wishing you all the best in the tough months to come.Kate*Kate120* says on August 8, 2012 at 12:14 pm
>
> Hi Kate, About this time last year my wife was diagnosed with ovarian cancer. After the operation back in October it was found that this was secondary and they were unsure of where it originated from so had a tour of different departments in which all sorted of washed their hands of us, that was until we were picked up by a CUP specialist who recommended that we use LAB21. The test came back with an 80% probability that it started in the Bowel so we agreed with the oncologist that we would go down the lines of it being bowel cancer and be treated with that. He did say that the primary would in all likelihood never be found. She is just coming to the end of a 4 chemo session where she was treated as though she had bowel cancer.
> Having this knowledge has helped us focus more on that and to explain to other people about it and to get on and enjoy the past year.I would say go for it as it will help you. Best wishes to you Paul*Paul* says on August 8, 2012 at 1:54 pm
>
> Hi Kate – I think you've guessed right! Molecular profiling isn't going to provide a miracle but its the best thing going at the moment. At our conference in April the world's thought leaders and leading researchers in CUP were clear that it is both the best show in town and the way forward for eliminating CUP. I'm afraid that some UK oncologists and particularly parhologists are not in favour, but with no good reasons. We used an early version for Jo and it completely changed the identification of the site of origin and therefore the treatment. This was totally at odds with the pathologist's view. I don't know if it was right but it was comforting. (Research we have done recently indicates that people would prefer a clearly identified primary site even if it is a wrong diagnosis than to have this awful uncertainty.) These tests now claim an 85% plus accuracy of identifing the likely primary or "nearest neighbours". I accept that the cancer may have changed a bit as it has migrated through the body but this would be true of any secondary cancer. I simply don't understand oncologists

who don't want more information (assuming patients are fit for treatment) to help target the treatment in a more triangulated way – its not as if they are paying for it! *John (Moderator)* says on August 8, 2012 at 2:11 pm

Really appreciate you all sharing your experiences. It has given me the impetus to go further in finding out whether the test could help me and I've emailed the comments I received from the histopathologist directly to someone at Lab21 who has said she is happy to look it over and respond. One of the things I find hard is getting up the energy to be an active participant in the treatment. This website is a good way to remind myself that it is worth it and helps me to keep informed. Thanks everyone. *Kate120* says on August 9, 2012 at 8:33 pm

Thanks again for the support on this. I contacted Lab 21 directly and they were very helpful. Meanwhile I met my oncologist who knew all about them and mentioned the test before I did as a possible way forward. So we are going ahead…*Kate120* says on August 21, 2012 at 11:41 am

Next step *Posted on:* July 27th, 2012 *by* mandyb

Hi again Had my appointment yesterday at DRI. John i live in doncaster south yorkshire. The Dr was very nice (i saw a different one this time, good or not im not sure) any way she has refered me to Leeds, i think only because iv asked and have the right,she said its not going to change the diagnosis! as for lab 21 she has never heard of it but that referal is in the hands of my gp, so im waiting for a decision from them. Janet i have tried phoning royal marsden i think me and you have had very different experiences with them. Any way on a positive note the Dr said im looking very well and gave me a quick check up, no lumps bumps or pain, so that is good and we are doing the "watchful waiting" (i hate that phase!!) I just keep thinking and clinging on to what Dianne wrote, she said she was diagnosed 5 years ago and nothing has happened so far so iv decied to follow in her footsteps!! Thank you all again for your time Mandy x

Leeds may well have expertise but I do I know that Dr Marshall and his team at Clatterbridge Centre for Oncology have expertise in CUP (Clatterbridge Rd, Bebington, Wirral, England, CH63 4JY Tel: 0151 334 1155). *John (Moderator)* says on July 27, 2012 at 1:53 pm

Thanks John, i rang Leeds hospital and they dont have a CUP specialist so iv phoned my oncologist and said i want to be refered to Dr Marshall, he had heard of him and this site and he said he will put a referal in. So thanks for your help.
Mandy x*mandyb* says on August 2, 2012 at 3:58 pm

Next step! *Posted on:* July 26th, 2012 *by* mandyb

A bit fed up at the moment, looks like the Royal Marsden are now to busy and have stopped doing 2nd opions, so im off to my appointment at our local hospital in 2 hours and will ask about another top hospital we could try. I have received a letter from my primary care trust about them funding lab 21 and although they havent said yes they havent said no, they want more details off my dr so who knows, its all a waiting game!! Mandy x

Mandy – very frustrating for you. May I suggest that it is not so much a "top hospital" but more importantly an oncologist who has experience with CUP. Which part of the country are you in? This might help others in Meeting Space to give their views on expertise.*John (Moderator)* says on July 26, 2012 at 12:01 pm

Hello Mandy. So frustrating isn't it, when things aren't moving as fast as they should. I emailed and spoke to a representative at the Royal Marsden when my husband was ill, and I found them very obliging. It might be worth you contacting them yourself and maybe they could at least suggest another hospital. After all if they reccomend it, knowing your situation, chances are it will be a good one with CUP experience. Just a thought anyway – just keep badgering. Good luck. Love Janet x*Janet Bell* says on July 26, 2012 at 1:05 pm

Hi Mandy,My mum has seen Dr Cornes at Bristol Royal oncology. He has been totally amazing with us and deals with CUP and rare cancers. His bedside manner and attentiveness to our family has been inspirational really. He finally found mums cancer and has filled us with hope based on his amazing knowledge base of which I have no doubts. He is well read, travelled and part of international and national research. Hope that vouches for him enough should you want to pursue that 2nd opinion. Good luck*pomdon* says on July 26, 2012 at 6:19 pm

Dad diagnosed with CUP – they think Lung Cancer though *Posted on:* July 25th, 2012 *by* hopeful777

Hi All, My dad was diagnosed with CUP, though they think its lung cancer, back in March following a chest infection. he had an xray too which detected fluid around the lungs. This was then drained and they found cancerous cells in the liquid. He had a ct scan but no tumor has ever been found. They have said that he has CUP as they are unable to find a tumor, there's just the cells in the fluid. They thinks its adenocarcinoma but unable to tell from numerous tests. He is now on chemo, carboplatin and premextred every 3 weeks for a 6 time course. he seems to be doing well on the chemo, going for his 4th session next week hopefully. his third session was delayed by a week as his white blood count wasn't quite up to the levels they like.Has anyone else suffered with CUP but suspected Lung cancer with cancerous cells in the fluid?Still seems surreal especially given he's never smoked and was so fit and active:(

Itching *Posted on:* July 15th, 2012 *by* ysalyer

Has anyone experienced itching that may be related to cancer? I've been through two rounds of chemotherapy (which had only mixed impact on the main tumor, which is on–not in–my bladder and one round of radiation therapy. The itching could be coming from anxiety or any number of other places. It's showed up and gone away a couple of times since my diagnosis, but post-radiation (again, there may or may not be a link) it's all over my body and it's fairly severe. My oncologist prescribed something called Atarax (Hydroxyzine) which is somewhat helpful but makes me feel drugged (sleepey, unable to concentrate, etc.) which I really don't like.If anyone's got a stop-itch remedy I would love to hear it. I read online about something called aqueous lotion–can anyone tell me what we might call such a thing in the US? I'm using somthing called "Sarna Lotion" which may be the same thing but it's not that effective. Help!

Hi ysalyer, I am so sorry to hear of what you are going through at the moment. My wife,(who sadly passed away last year) received chemo and radiotherapy and had intense itching mainly on her back and shoulders. This happened during her chemotherapy and was given Aqueous Cream by a nurse in the cancer ward at the Beatson Hospital in Glasgow, Scotland. This cream was very effective in relieving her itching. It is manufactured by Thornton and Ross Ltd,Huddersfield,HD7 5QH,UK. I dont know if it is available in the U.S. but your oncologist or cancer nurse may have information or you may be able to contact the manufacturer above of find more info online. Hope this is helpful to you and I wish you all the best. Post again if you are still having difficulty finding this cream. I can list the ingredients if you need to know them.*bewildered* says on July 16, 2012 at 10:35 pm

Hi ysalyer, I too have had this ailment following both chemotherapy and radiotherapy. the Aqueous cream was okay during treatment but since the severe itching started my Doctor has given me several lotions and creams but the only one to cure this itching has been Doublebase Gel in a pump dispenser, it is made by Dermal Laboratories, Hitchin, Herts SG4 7QR, UKI have found it on the internet so you should be able to purchase it okay, there are no side effects whatsoever with this product, I too can list the ingredients should you need to know them – good luck and I wish you a speedy recovery.*maureen* says on July 21, 2012 at 1:54 pm

Maureen and Bewildered, thank you so much for your kind replies to my query. I will search the internet for both of these products and hope for results.*ysalyer* says on August 6, 2012 at 1:03 am

It saddens me to find Yolande's post here — I did not know she contacted Jo. I am sorry to say that she died 10 days ago, on September 18, 2012, in my arms. Thank god. I could not bear another minute of he suffering — the itching, the sore, sensitive skin that couldn't stand clothing or sheets. The sores from scratching. Etc. Plus all the usual downhill symptoms. We were together for 27 years. She donated her body to University of California Davis but of course they could not or would not commit to saying this would be for research or med students & certainly nothing as unromantic as "CUP research." She rarely complained, which made it all the harder. I am still trying to get a grip and when I do, I want to be in touch with others across the world with CUP issues. What a gruesome diagnosis and even worse, what cold, impersonal people end up in oncology as doctors. Kathy ElliottDavis, CA USA*kathy@kathy-elliott.com* says on September 29, 2012 at 2:33 am

Dear Kathy – I'm so sorry. I recognise the relief that one has that the suffering of a loved one is over, but, of course, it is incredibly hard for you. Please accept my condolences.*John (Moderator)* says on September 29, 2012 at 9:01 am

Thank you, John. It means a lot to me to have this website because this entire experience is so isolating. The doctors guessed at what chemo therapies to give her. It probably had the toxicity level of road tar and waste from a nuclear reactor. They tried two of those recipes and the tumor grew! That was the last straw for Yolande. She later told me she gave up after that. And partly because not one medical person expressed any sympathy to her! Not one doctor, nurse or lab person said anything remotely like, "I'm sorry this did not work out." Or "This must be hard on you. We are sorry for the outcome." Not a peep of acknowledgment to let her know they cared.

AND, to make matters worse, late in the game we found out about these tests you are mentioning and inquired if Kaiser would give her one from Rosetta Genomics if we purchased the test. The Pathologist at Kaiser Permanente in Redwood City, CA BELLOWED into the phone that he had 44 slides on his desk that he needed to take care of and NO they wouldn't have anything to do with that kind of test, blah blah…"A shattering experience, to say the least. You would have thought that I'd asked him to pay for it out of his own pocket. You would have thought that he had the Authority to make these decisions in the first place, which he did not. Any novel medical concepts or changes outside of the tiny boxes from which these pavlovian medical personnel operate, seem to put them in a tailspin. I will go to my grave wondering why we trusted or respected any of them. There was one Primary Care Physician at Kaiser in Vacaville, CA, whom we'd only known about one month, who had the manners and professional courtesy to phone me and offer condolences the day after Yolande died. Kathy ElliottDavis, CA USASept 2012*kathy@kathy-elliott.com* says on September 30, 2012 at 12:38 am

That is terrible, Kathy. I'm afraid that some medical 'professionals' are overwhelmed by CUP – often because they are used to dealing in things they know about and hate to deal with things over which they have less understanding. But that does not excuse awful, unprofessional, patient care and behaviour. Very distressing*John (Moderator)* says on September 30, 2012 at 10:34 am

Thank you, John, for giving me a place to "vent." Until I saw this site I did not realize how completely alone I feel because of this particular diagnosis and subsequent death which goes on "behind the scenes" so to speak. Therefore, there was no one to bond with throughout this ordeal. Holly Gautier, Program Manager of Stanford Hospital Cancer Supportive Care Program, would not allow Yolande into ANY cancer support groups because she did not fit into a a neat little slot like breast cancer, or lung cancer. And she simply would not listen to my belief that people with cancer are all suffering with the same basic human emotional needs which are not bounded by a diagnosis. Very soon I will start an online spiritual class for cancer patients, especially CUP patients, and anyone in direct contact with same. Fortunately I can teach the Three Principles which give deep relief and peace of mind to those suffering from the fears and stresses that accompany living with cancer. At first I will be doing this in the U.S. but Three Principles of Mind Thought and Consciousness have caught on like wildfire in UK and a lot of information and connections are available online over there. Look up Three Principles Movies for starters.Also, I'd like to know more about helping in some way with people who are organizing CUP awareness projects — whether it is raising money or whatever — there must be something I can help with so that in the future others don't have to suffer the way we did.Many thanks, John.*kathy@kathy-elliott.com* says on October 1, 2012 at 5:25 pm

John, thank you for being there. I just tonight read of your own painful experience with your wife. I am sorry that happened. Thank you for this loving, understanding space you have created. It has certainly offered me relief and connection.
Thank you,Kathy Elliott*kathy@kathy-elliott.com* says on October 13, 2012 at 8:00 am

Next step! (Confussed!!!) *Posted on:* July 10th, 2012 *by* mandyb

Hope you all dont mind me posting this, it just helps to share. Just got back from gp's he is happy to refer me to Royal Marsden for a 2nd opion which is good. When i asked him if he had heard of Lab 21 surprise surprise he had never heard of it! I had printed a load of stuff off for him and asked if he thought our PCT would pay for it. He didnt think so but he said he would try. If not i will have to find the money myself but i need to know! I just feel better trying to do something so this is the first step. Well iv got 2 more shifts at work then on thursday we are going to spain for a week to get some sunshine. Hopefully i will come back to a letter from Royal Marsden (im not a paitent person!!) Mandy x

> Hello Mandy Good for you keep plugging away at getting a second oppinion – I'm sure the Royal Marsden will be quick to reply. But just to say they really don't mind anyone ringing for updates – they are very obliging. My doctor said that since my husbands case was delay upon delay,she now advises her patients to push and push for treatment to start – to stand their ground until notice is taken. Don't be fobbed off Mandy. Have a good holiday. Love Janetx*Janet Bell* says on July 10, 2012 at 1:33 pm
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> It is completely wrong and causes inequalities but being pushy works best. People who don't push can end up at the back of the NHS queue.Don't know of NHS ever paying for gene expression profile for CUP. We are trying to encourage a validation study to prove its cost effectiveness.*John (Moderator)* says on July 11, 2012 at 8:11 am
>
> Mandy: John and Janet are right you have to keep pushing-its unfortunate and shouldnt be the case on NHS but its true. We pushed for second opinion whichhave led to further biopsy tests and new chemo treatment and options, when the first chemo treatment wasn't working.Gene expression profiles such as Lab 21 should be part of the NHS diagnosis of CUP , along with a range of relevant biopsy tests. As we were told by the second opinion-in CUP its not necessarily where the original cancer is/was situated but what the cancer is made up of that needs looking at.Peter*Peter MAc* says on July 15, 2012 at 10:56 am
>
> Mandy:Just to add to my original comment my wife's original oncologist was very supportive of us going to second opinion and has developed subsequent treatment options in coordination.So try and relax over your holiday and come back in the knowledge that you wll see someone in Royal Marsden. We found that it helps us focus when we know there is an ongoing treatment planPeter*Peter MAc* says on July 15, 2012 at 12:00 pm

confused!!! *Posted on:* July 3rd, 2012 *by* mandyb

Thank you for this site i thought i was on my own. However im still confused. I really thought i would find someone with the same story as mine, but mine seems differant eventhough the oncologist diagnosed me as CUP some 6 months ago. I had a full hysterectomy in Dec 2011 due to fibroids. I had not been unwell but we do have a family history of fibroids so i was'nt worried and went for the op. When i went for my check up the consultant said that both ovaries had tumors on them which were malignant, but not with ovarian cancer, they thought bowel. I had a full MRI scan which showed nothing, all organs

were clear so i thought brilliant nothing is wrong with me. He then said that after a MDT meeting it was decided that i had CUP eventhough they think it could be from the stomach, as my ovaries had what they called Kruckenberg cells. He said i probably had had stomach cancer which had died but as it was dying its seedlings although invisible to the eye have floated around my body and some have settled in my ovaries thus giving me the Kruckenberg tumours. He then told me that i did not need any treatment or further tests as at the moment i am well and when these invisible seedlings do ever activate/attach themselves to another organ and i become ill they would not beable to cure me anyway! I am gratefull i am so well at the moment, i am 48 and have a full life, yet i feel very scared and feel that the NHS have given up on me already. I am taking aspirin daily as i heard about it being good at helping to stop the spred of cancer and my gp said i can go on it, i also take strong garlic tablets every day and i go and have raiki, but this has been all my doing. I have an appointment on July 26th and because of this site and your stories i am going to ask about a 2nd opion maybe at the royal marsden, and also ask about lab21. My world has been turned upside down and im trying to think positive and i do thank you all for some very positive comments that have been made to other people, this has helped me. Mandy x

> Hello MandyMy husband had CUP – but unfortunately the cancer had spread too far before it was diagnosed. While he was ill however I did contact The Royal Marsden in London. I heard they would see patients with CUP to give second oppinions and were undergoing trials. This was last year, but I really would advice you to give them a ring. They were extremely helpful to me and had made an appointment very quickly for my husband to get a second oppinion. Unfortunately it was too late for us, but don't delay Mandy on giving them a ring to ask their advice.Also Lab 21 charge about £2,500 for analysis of a tissue sample. Another thing I would have took up had I known about it sooner. I hope this information helps Mandy – Good luck and remember there are a lot of positive stories on this site. Janet x*Janet Bell* says on July 3, 2012 at 4:31 pm
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> Thank you janet for your comment, am so sorry about your husband but i will do as you suggest and ring them myself, and not wait till my appointment date. I will let you know how things go if thats ok. Thanks again. Mandy x*mandyb* says on July 3, 2012 at 4:57 pm
>
> Hi MandyHow awful for you to be going through this. Hopefully you can get a second opinion with the Royal Marsden and I wish you the best of luck and hope that they can find where your cancer originated from.When my brother was ill, I asked his oncologist about us using Lab21, although to be honest at this point it was too late for my brother as he was too weak to undergo anymore treatment. However, the oncologist told me that although Lab21 maybe able to advise you of where the cancer had originated (the primary tumour) what they wouldn't be able to tell was the treatment. She told me that although they may be able to define the primary source – CUP has a different footprint to other cancers. So my advice to you would be to ask either your current consultant of their opinion of Lab21 or somebody at Royal Marsden. It could be that each oncologist has their own opinion on Lab 21, but it is not cheap (although I realise that we would all be prepared to spend any amount of money to know the answers – I certainly was as were my family) but I would ask the question first from more than one oncologist.My thoughts are with you and remember that there are many success stories for CUP.Stay strong and above all think positive Tanya x*Tanya* says on July 3, 2012 at 8:02 pm

Hello MandyI too was told that the lump I felt (a lymph node) was “nothing”. My second opinion meant a biopsy and a multiple of tests. Yes it was diagnosed as CUP – somewhere in the abdomen & I was treated with Chemo. That was in 2007 and I am still here. I have CT scans on a regular basis and see my oncologist who is a CUP specialist. Don’t sit back. Be proactive.I found this site in June 2008.Dianne*Dianne* says on July 3, 2012 at 11:44 pm

Hi Mandy – I completely understand your worries and agree with the others that it is important to be proactive. I agree too about getting more than one opinion on the use of gene expression profiling such as that offered by Lab 21. It was very clear at our conference in 2009 and again in April this year that the world’s experts view this approach as the way forward for CUP. It is also the case that there is some resistance to this from conservative oncologists and pathologists in this country. No, it doesn’t guarantee to solve the problem but it has an 80% plus chance of identifying the genetic profile of the starting point of the cancer. Treatment is directed at the genetic fingerprints of the original cancer so if it ‘looks like’ cancer X then diagnostics can be directed at this part of the body with a better chance of finding a primary and then more directed treatment, if treatment is appropriate.*John (Moderator)* says on July 4, 2012 at 9:08 am

Hi Mandy,Feel for you – it is so scary, isn’t it. I also haven’t had any treatment, apart from them removing the lymph node where they originally found the secondary site. I’ll have a PET scan in July and another in October to keep an eye on things.Please don’t feel that they have ‘given up on you’ if they are not going ahead with chemo/radiotherapy. Cancer treatments carry their own risks. If they don’t think the treatment is likely to help it’s actually really sensible not to put you through something which could make you more sick rather than more well e.g make your immune system weaker. I was given the choice of chemo ‘just in case’ or ‘watchful waiting’. When I said I would rather avoid chemo if it wasn’t very likely to help me, the consultant said that that is what he would do himself in my situation – so it doesn’t mean they have washed their hands of you.Wishing you all the best in getting a helpful second opinion. Good luck in July – at least now you have a clearer idea of some of the things you want to ask about.Kate*Kate120* says on July 4, 2012 at 11:16 am

Thank you everyone for your replies. They have really helped and i am not waiting untill i see the oncologist on the 26th to ask for a referal, i have decided to go to my gp’s and have got an appointment for the 10th. Like you all say be positive and proactive. Thank you!Mandy x*mandyb* says on July 4, 2012 at 10:45 pm

Hi Mandy.We have similar issues. I had a hysterectomy to remove my ovaries which were surrounded by tumor. They had thought it was ovarian cancer but pathology said otherwise. The surgeon said he could tell by looking at the tumors they were not ovarian. Therefore, possible Krukenberg. Pathology pointed to the digestive track. However, endoscopy, colonoscopy, PET and CAT scans found nothing. Our stories depart here because at the time of surgery they saw thousands of very small tumors on my peritoneal lining. They are too small to register in scans. Anyway- I’ve been through 2 different chemo treatments. The first was necessary to sweep away the “sand tumors” the second because the 1st didn’t work and the cancer tried to shut down my ability to eat. It’s been 2 months since my last chemo and they can’t find

any signs of cancer. It's an ongoing battle since it's virtually impossible to see it. The only thing that works for me is tumor marker tests, which aren't necessarily reliable, and testing ascites in my abdomen. I'll be curious to see what happens with you. Your story is the closest to mine that I've seen. Good luck.*Ruralfox* says on August 8, 2012 at 6:53 pm

Hi ruralfoxIf you have read all my posts 'confused and next step' i have no update as yet. Still waiting for my 2nd opinion with Dr Marshall and still waiting to see if my primary care trust will fund Lab21. Im pleased to hear your treatment has been positive and no cancer can be seen. At the moment im very well and hoping to stay that way and i will keep you updated. Take careMandy x*mandyb* says on August 9, 2012 at 3:48 pm

Hello Mandy and ruralfox,I am new to this site. My story is very similar to both of your stories. I had surgery in February 2012 to remove what Dr.s thought was a benign cyst on my ovary. Surprise! They found what they diagnosed as Krukenberg tumors on both ovaries–suspecting either stomach or pancreatic cancer. I had absolutely no symptoms. Initially, a Routine colonoscopy found the mass on ovary..which was pushing against rectum. I went to Houston Texas (M.D.Anderson) for a second opinion. Same diagnosis was given to me. Malignant adenocarcinoma of unknown primary. CUP. I had the molecular testing done which came back as 37% possibility of gastric, 18% ovarian.. A chemotherapy treatment regimen was developed for me which I began in March 2012. I have finished chemotherapy and am feeling great. I decided to do the treatment because I worry too much about NOT having done all that I could to fight this disease. I have had cat scans every 3 months..no evidence of cancer. I will go for a PET scan in January…I have totally changed my diet. I exercise twice a day–walking–and am convinced that my emotional state and my physical state are completely connected. I have chosen to do acupuncture for stress and anxiety..just started. Planning to stay well and positive with this 'unknown".*kathyv56* says on October 22, 2012 at 10:06 pm

Hi KathyIts s**t isnt it!! How can we feel so well yet be told we have these signet cells floating around in our blood! Iv had a bit of a fright over the past 2 months with sever stomach pain and vomitting. Iv thought this is it this is the start! Anyway iv been to my gp's who has arranged an ultra sound scan. This i had last wednesday and im pleased to say i only have gallstones! The pain now comes and goes and is not to painfull, i may have it removed later but i was so releived as the scan showed nothing else and my stomach liver and kidneys are clear and how they should be. I know what you mean about not having any treatment but as you know im on "watchfull waiting" but i do agree that a positive mind must have a positive effect on our wellbeing, eventhough at times its hard!! Thank you for getting in touch i understatnd your stress but we will fight this! Ruralfox if you are reading this i hope all's well with yourself. mandy xx*mandyb* says on October 23, 2012 at 12:52 pm

Confirmed CUP diagnosis today – metastasis to bones, no organs *Posted on:* June 15th, 2012 *by* themerester

Hello Everyone, First, I hope this post finds you and your family well. This seems like a great community from what I've read so far and I look forward to being a part of it, as my family and I dive head-first into this new world of CUP. For the past several weeks, my dad (55 y/o

male) has undergone literally every possible test to pinpoint the primary site of his cancer. We did not find it. The only place the cancer exists is in the bone, all throughout the skeleton. He had and was treated for bladder cancer in Oct. 2011, but we've been assured by several doctors there is no relation. The only other possible clue, was an elevated level in the pancreas from a tumor marker. But scans show no masses in ANY organs. So, basically what we're dealing with is a Stage IV carcinoma of unknown primary, with metastasis to the bone. We had a very tough doctor's appointment this morning. Our doctor, who we are very pleased with, basically told us: a) Without chemo, my dad has "weeks" at most to live. b) The cancer is "incurable," and chemo will be used to "prolong" his life for as long as possible. He threw out the figure of "6-8 months," but only as a statistic. I don't know what to think. This is very hard. My dad is taking this very well, he's so good with dealing with emergencies and crises. The rest of us feel like we've been hit by a truck. This all started with him complaining of back pain a few weeks ago, and suddenly it's this catastrophic illness. Has anyone else here had a similar case in their family (or themselves personally)? I can't shake thinking about the prognosis…the word incurable…it's so scary. I just want to keep thinking positively and hope that we can beat the odds. Thank you to anyone with any words of support or encouragement.

> Hi thereFirstly I wish you all love and best wishes for your dads journey ahead and totally agree this is a wonderful community for support and information.
> My mother was diagnosed with CUP in July 2011 metastasis to the lung,liver & brain. She also has the prognosis using the word "incurable" and like your family at first this is a very scary place to be. Ma is living life to the fullest and continues chemo to keep the tumours on hold and she is doing well. I have no medical training however I do offer my positive thoughts and well wishes and with the support he has with you and your family he certainly has all love in his corner to beat the odds. Take care of each otherBest wishesTrina B*Trina B* says on June 15, 2012 at 1:02 pm
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> Hi Trina,I am glad to hear that your mother is thriving in such a difficult situation! Thank you for your encouraging words.*themerester* says on June 15, 2012 at 2:01 pm
>
> So sorry to hear you are all having to deal with the toughest of news. Remember that a prognosis is only an educated guess and no statistic can tell you what will happen to an individual. I don't know where you live, but if there is a cancer support centre near you and you haven't been in touch yet I would really recommend it. As well as supporting patients they will usually support families too. To talk to a good counsellor who has an understanding of the impact of such a diagnosis can really help you to find your balance and your own ways of coping, which will also help you to support your Dad. Having been both a cancer patient and the daughter of one, I think that it is just as difficult to be the family. Try to make sure you get some support for yourself.Will be thinking of you and your family,Kate*Kate120* says on June 16, 2012 at 8:29 pm
>
> Hello,I am sorry to hear you are all going through this. My mum was diagnosed in feb 12 and being the only child also felt like I had been hit by a truck. We were given the same prognosis. Since then mum responded very well to chemo. The team then decided as the cancer had oestrogen markers and they had opted to treat as ovarian, it was worth doing a debulking surgery (hysterectomy etc). They found the cancer in the Fallopian tubes. The prognosis seems better and chemo is now moping up the rogue cells in the lymph. As they has travelled to the nodes in the neck they suggested it could pop up again but from scan it appears to have gone. It feels like winning the

lottery from where we were but not able to spend a penny for fear it returns. But as harsh as chemo is…it has changed the prognosis.On a personal note, I did go to pieces initially but a strength will come for you and your family and we have learnt to cope, enjoy living each day with that elephant in the room. I did race for life and felt part of a very big community there too. Keep positive…I think it helps. Also mum followed a change in diet but not sure how much it did but certainly gave her a sense of control. Good luck x*pomdon* says on June 20, 2012 at 7:59 am

re: any advice on getting things moving more quickly? *Posted on:* April 28th, 2012 *by* Kate120

Hi, I was told some time ago that my most likely diagnosis is cancer of unknown primary (CUP). Since then something showed up in my tonsils on a PET scan, so I've been referred to the head and neck department. They don't think it is very likely that my tonsils are involved (my only other sign is in my groin lymph nodes) but they are being careful, which of course I'm glad about.The problem is that I'm now 8 weeks on from my diagnosis (4 months since the initial referral). By the time I see the head and neck consultant it will be 10 weeks and I still won't be getting treatment, just another investigation. I'm on my 4th department and each time I'm referred on I seem to start again at the back of the 'seen in 2 weeks' queue.The delay is very frustrating and it is quite hard to get a straight answer about whether I should be worried about it. When I ask I've been told that at each stage they will be weighing up the cons of delay with the pros of identifying the primary site and making sure the treatment I get is the right one. Of course I'm glad that they are doing all the possible tests and really trying to track it down, but I'm getting very anxious about the delay.Any tips on getting things to move a bit more quickly?Anyone be able to give me an idea of how long it took them to get to the point where treatment started? Were you referred to a CUP specialist once they thought this was the likely diagnosis or not until they had been through every possible test?Thanks!Kate

Hi Kate Firstly I wish you all the best in your journey ahead. And send you all the positive vibes possible I am currently caring for my Ma diagnosed with CUP cancer.On this site I have received very helpful information from the site itself and the people on it….My Mum went thru a similar diagnosis issue and did not start treatment for her advanced CUP cancer for 4months of many tests biopsys and scans.She is now still undergoing treatment. Mas oncologist has now changed her chemo to Paclitaxol (Taxol) after a first round of Carboplatin and vinorebline and we are all ready for the challenge ahead…Although I do not have many medical answers to assist you, on this site I have received some helpful information from others that I am happy to share with you …: If you have had a biopsy there are a number of tests that can be made on the biopsy material to assist in defining the nature/type of the cancer to further assist in chemo choice. You may want to discuss genetic/molecular tests on the biopsy material. There is a cost and its done in this the UK through Lab 21 (this site has details.) The Test is specifically for CUP and seeks to identify the genetic make up of the tumour.(of course weighing up the pros and cons of having a biopsy if you have not done so already)This site has helped me find out a lot of information and starting points to help my Ma…Again I wish you all the very best in your journey ahead Kate Trina B*Trina B* says on April 29, 2012 at 10:39 am

Hello Kate,Welcome to the world of CUP.It takes, what seems, "forever" to come up with a treatment plan. I was diagnosed with the big "C" on September 17, 2007.,

following a biopsy of a painless lymph node in my groin. One doctor told me it was "nothing" (come back in 6 months). A second doctor (a friend) sent me for a biopsy and life as I knew it completely changed.It then took till the end of November to come up with a diagnosis. Everything else Breast, ovarian, bowel, lung was ruled out. I did not realize that I was being followed by a CUP specialist from early October. This was before genetic testing was readily available.Even the treatment was a new protocol for the cancer centre. I was told it depends on where the affected lymph node are located.I wish you well on your journey.Dianne*Dianne* says on April 29, 2012 at 2:23 pm

Thanks for sharing your journey. Must have been scary to know they were using a new protocol. What a good job your dr friend sent you for that biopsy. I'm gathering that the length of time this is taking is not unusual. Interesting that a CUP specialist was involved you being aware. Hadn't thought of that but there is a CUP consultant so that could easily be the case for me too. I will ask as it would reassure me a bit if that is the case. Wonder why no-one told you? What a useful site this is.All the best to you on your bit of the journey.Kate*Kate120* says on April 29, 2012 at 7:44 pm

Kate,CUP is a big problem as the best treatment for the secondary cancer (you did not mention where this is) is normally the one used to treat the primary (as this is the type of cancer that has spread). My understanding is that the oncologist will have a reasonable idea of the area that the primary was from the results of the biopsy. My wife has secondary liver and lung and the oncologist said it is CUP but started somewhere in the upper GI (gastro intestinal) so started treatment with ECX which he calls the domestos of treatments for GI.That did not prove to be as positive as he wanted so has changed treatment to another (gemcitabine) drug that treats areas of upper GI and this has had some positive effects.If you have a consultant oncologist I would start by communicating your worries as they are normally very understanding people and will tell you what processes they are following and what the expected time frames are.If you are not happy with your oncologist you should go back to your GP and ask for a referral for a second opinion (I would do this anyway as it often confirms what is being done is the right thing which does help alleviate some worries). It is worth the effort to go to one of the specialist hospitals (we went to the royal Marsden for our second opinion) as you know they will have access to the latest research. I wish you well in your journey and hope that you get the support you will need and I will say that this forum and the CUP web site helped me a lot and gave me a better understanding of the problem and how to deal with it.*duvlin* says on April 30, 2012 at 1:12 pm

Thanks Duvlin – useful advice. I wasn't really sure if people here did the 2nd opinion thing – I know it is expected in the US – so it's good to know that is another possibility.At one point it looked as if they were going to treat me for rectal/gynae as the best guess primary (the only secondary cancer found was in the groin lymph nodes) but the PET scan has now thrown up the tonsils business. This means I'm on my 4th dept so it's hard to say who my 'consultant oncologist' is because it changes all the time. However, the specialist nurse in the head and neck dept was very helpful this morning and is going to chase things up for me so maybe it will all get moving again.I hope your wife continues to get some benefit from her new treatment.Best wishes,Kate*Kate120* says on April 30, 2012 at 4:16 pm

HI KateI would agree with Duvlin in the value of getting a second opinion and possibly an Oncologist with CUPspecialism.My wife was diagnosed with CUP and after a lengthy treatment of ECX found that very little had changed (although tumnour growth slowed down.) Following referral to second opinion and following his advice she is now on a new chemo (Irrinotecan) and the blood markers are showwing proaitiuve results. She has had a second biopsy (neither the first biopsy nor the LAb 21 test provided any strong positive lead as to what the original cancer was). The tests on the second biopsy has revelead a particular type of characteristic that responds well to Cetuximab so she will be transferring to that chemo shortly.
CUP diagnosis and treatment isn't easy as medical professionals have to weigh up the need for immediacy of treatment with identifying as much info on the tumour as possible. Bringing a second opinion often assist in decision making and our experience has been that the Oncologist welcomes and has no diff with sec opinion. Hope this helpsPeter*Peter MAc* says on May 1, 2012 at 3:00 pm

Thanks for the advice. It's good to know that a second opinion would be accepted or even welcomed. There is a CUP specialist but I haven't seen him yet. All these posts have been helpful!Hope your wife's new treatment plan brings benefits.All the best, Kate*Kate120* says on May 1, 2012 at 11:35 pm

In case anyone is reading this because they are in a similar position, this is what I've learned so far about keeping things moving:- The specialist nurses are your friends. As soon as you get transferred to a new department, get the names and contact details of the specialist nurses in that department. Phone and introduce yourself and ask how things work in that department e.g. when the multidisciplinary team meeting is, or whether the first step will be to see a consultant or be discussed in the meeting. Each department seems to do things slightly differently.- However, bear in mind that the specialist nurses you got to know in a previous department won't mind if you call them either.- The start of the working day (9 ish) seems to be a good time to get hold of someone.- Be prepared to ring several times before you get an answer to your question. Remember they are generally good people doing their best in difficult circumstances so stay polite. However, be firm and persistent, remember you have a right to be kept informed and treated like a human being.- Before you phone, get clear in your own mind what information/answer you need and why you need it. I find it helps to write down a few notes to make sure I say everything I want to, even if I start getting upset.- If they don't have the information right then, ask 'when would be a good time to ring back about this?' and call back at that time.- If you are getting distressed and anxious, don't hide it. Remember they are trained to deal with this as well as the medical side and your emotional wellbeing is also their concern.
- Keep your GP up to date (they will usually be the last to know your results etc). You can ask them to chase things up if you don't feel up to doing it yourself and are worried about delays.- If the specialist nurses can't seem to answer your question and it can't wait for the next appointment, speak to the consultant's secretary explaining why it is urgent/important and what else you have already done to try to get an answer. Sometimes it is possible to speak to the consultant on the phone.
- And finally…remember to thank people when they help you.*Kate120* says on May 3, 2012 at 9:00 pm

Excellent advice. It would be nice to think that one would have just one named nurse who would cross boundaries. This is the intention of the NICE Guideline but I know

reality is different and one has to work best with the system one finds. I think in USA they are sometimes called a Pathway Guide and this strikes me as a good descriptor. Every cancer patient should have a Cancer Nurse Specialist (CNS) but I know that even this is not always achieved. We live in the world we find, and work for the world we want*John (Moderator)* says on May 4, 2012 at 9:27 am

Thanks John. I thought the University of Southampton research presented at the CUP conference was spot on about what patients need with a Pathway Guide type person at the top of the list. As a teacher I keep saying I need a form tutor to track me through the system! Sorry to hear not everyone has access to a CNS. They have been the ones who have kept me sane. Hope Macmillan can help fill the gap for those people, although it is not the same as having someone with access to information about your appointments and test results.Glad places like this exist to help to work for the 'world we want' as you say.*Kate120* says on May 4, 2012 at 11:17 pm

I have a very similar story, groin lymph nodes with no identified primary. I had a biopsy mid Feb and started treatment mid March, 4 weeks after initial diagnosis. I have had 3 of four chemo cycles and due to start radiotherapy in 5 weeks. I am not seeing a cup specialist. Where are you being treated, I chose to go to the royal mars den and they have been superb. Whilst I accept why they want to try and find the primary I have been advised they may never do so. It makes it very hard to deal with and understand. I am only 32 and have a 15 month old baby girl so it has been really tough. More than happy to give you more details on my treatment/tests I have had. Jo*joanimal* says on May 7, 2012 at 8:40 am

Wow! That was quick. What investigations did they do? Did you have a PET scan? It's the PET that has held things up really because it flagged something in my tonsils. If that hadn't happened I would have started treatment a couple of weeks ago I think.Must be tough with a toddler. Hope you have some help there. I'm 46 and have 4 yr old twins. It's them I worry about of course. I saw head and neck doc on Fri and they are now investigating my tonsils. However he said if the only signs were groin and tonsils it would be so unusual they would publish it! I have some tests this week and then back to that clinic Frid. To get me in quickly I saw someone less experienced but am seeing the big man next week who I suspect may suggest no further investigation and to get on with treatment if nothing shows up on this week's tests. I think I'm going to ask for a 2nd opinion though, just in case. I'm at Guys and St Thomas's so I'm confident about the medical expertise, but I don't want to be an 'interesting case' if you know what I mean. I would be very interested to know more about your treatment.Thanks for your message and best of luck with it all. Kate*Kate120* says on May 7, 2012 at 11:58 am

I had CT, PET and MRI scans. PET showed nothing other than something minor on my lymph nodes on my neck but after a needle biopsy was inconclusive they ignored it. I have had full Gynae check and a Endscopy but both showed nothing. The Gynae oncologist I saw was pretty definite I may never find a primary. I am having a combination of Carboplatin and Etoposide and after two cycles a CT scan showed the lymph nodes had reduced down significantly so they are very happy. I know the Royal Marsden make a big thing of giving second opinions so may be worth a look. I have had private health insurance but my NHS GP was very quick and would have referred me to the Marsden if I wanted as I did discuss doing it on the NHS. My

consultant said it would not be any different in terms of treatment. I presume if you are at Guy and St Thomas's you are in London? If you ever wanted to meet to discuss any of it would be happy to do so, it is a funny one having CUP as you don't fall into any category so it is tough. Jo*joanimal* says on May 7, 2012 at 3:21 pm

Hi Jo,That all sounds very similar to my journey so far and it's useful to hear your experiences. Been talking it through with my husband and I think I'm going to see what the consultant says on Friday and go from there. If they have found nothing from the fine needle aspiration in my neck and CT scan of the neck but are still saying they want to biopsy or even remove my tonsils, I will ask for a second opinion. Although I guess waiting for that might cause as much delay anyway. I also had full gynae check and they also did a sigmoidoscoy and cystoscopy (rectal and bladder) at the same time so they have been pretty thorough. It just feels as if the tonsils are a bit of a red herring. I first noticed the lymph node back in August without being aware of the possible significance, so I do need to get on with some treatment.I am in London and would welcome a chance to talk it through with someone a bit further along the journey. Kate*Kate120* says on May 7, 2012 at 3:42 pm

Hi Kate and JoI would definitely recommend going for a second opinion. I believe that Duvlin and Sally who use this website used the Marsden for a second opinion and were v satisfied.The second opinion that Mel, my wife, had was a CUP specialist up here in the north and his advice really opened up the options for treatment which she is carrying through now. Though we are having to move hospitals out of Wales to access it.(There are several leading CUP specialists in London such as Dr Wassan who I believe was a speaker at the CUP conference.)In particular although Mel did have a PET scan her second opinion stressed that the key was not necesarily finding where the primary was, or had been, but rather trying to find out the nature and characteristics of the tumours. Though the Lab 21 test she had was not conclusive, Mel had a second biopsy which did identify something called KRAS mutant status (KRAS wild) in the tumour and the potential for Cetuximab as the chemo to treat. Her treatment is also likely to include SIRT treatment in addition to the Cetuximab.
Its interesting that you had a specialist nurse assigned. This option was not offered in our cancer centre at our current hospital as I don't think there was a CUP specialist nurse. It would have been a wonderful support. (Having said that, the care and clinical support from our original Onc and the nurses in the centre has been excellent.)
Hope this helpsPeter*Peter MAc* says on May 9, 2012 at 10:21 pm

Thanks Peter – that is all interesting and useful to know.I don't think there are any CUP specialist nurses. It's part of the problem – the specialist nurses have been great but they change each time I move department and I have to make new contacts. I think it would have made a world of difference to have been assigned one person from the beginning and I know it was one of the things recommended by the research presented at the conference.I wish you and your wife all the best. It certainly sounds as if you have kept yourselves as well-informed and engaged as possible to get the best treatment.Kate*Kate120* says on May 9, 2012 at 11:09 pm

Hello Kate and all,I was diagnosed with CUP (squamous cell – mets to groin node) in February. I had surgery to remove the whole chain (thigh to pelvis) on the right side in March and am now undergoing 15 sessions of radiation therapy. Only one of the nodes had cancer but it had breached its capsule, hence the radiation is required. I

wasn't given any treatment options – my understanding was that, given the presentation (3-4 cm lump in my groin), there weren't any options. Complete dissection was required. Period.The other fact is that it is HPV negative which means likely not gynecological in origin. I've had all the tests – CT, PET, endoscopy, ENT, and even a dermatologist examination – all negative.Not sure what the next steps will be for me after the radiation.My oncologist said there will surely be some lymphedema, at least in my upper leg, because of the complete dissection and I'll have to wear compression for the rest of my life. Wondering if anyone out there has had any experience with the lymphedema effects?Sid (my nickname)*sid* says on May 12, 2012 at 11:52 pm

Kate, Glad things appear to be moving on for you now. The Royal Marsden were quite quick withthe appointment for the second opinion and after they had a sample of the original biopsy they have undertaken further tests and have given us a high probability for the primary (cholangiocarcinoma). Our Oncologist does seem to have taken this on board (I am guessing that he has actually dicussed it directly with them) and my wife (Julie) now has her treatment tailored to this so we are hoping for good results. Julie did start with ECX, which looked positive from the blood markers but scan proved otherwise, then moved on to Gemcitabine. The next scan was very positive so stayed on this but last scan has showed more nodules. Julie is now going on to a mix of Gemcitabine and Cesplatin which is the recomended for cholangio (ceplatin is part of ECX so was probably residule in her body so worked with the Gemcitabine to give good result) Although Julie is being treated through our private health I do think that the specialist NHS hospitals have b etter research facilities and therefore the pathology tests carried out by them (Proffesor Stamp in our case) have a greater scope for determining types etc.As Peter has said we are very satisfied withthe support from the Marsden and would recomend that you ask you GP for a referal anyway as it can only do good and at the end of the day you need everybit of support you can to get through this. RegardsDavid*duvlin* says on May 15, 2012 at 12:07 pm

Hi ,Just catching up as I lie in bed recovering from a tonsillectomy. Not up for a long message just now but just to say thanks for messages and sharing experiences. Wishing everyone luck and be back when I'm less sleepy.Sorry to hear, Sid, you are likely to have lymphedema. Was warned about that possibility when they removed lymph node and it didn't sound like much fun. Part of this journey seems to be about learning to live with the lesser of two evils.Hope Julie's new treatment brings benefits.Kate*Kate120* says on May 17, 2012 at 3:06 pm

Kate and Dianne, I am wondering if your cancer is/was sqamous cell?
Mine was SCC which dictated the treatment (ie. surgery and radiation but no chemo). I am now done treatment and my oncologist also says they will likely never find the primary. I will now be followed up regularly with CT scans, etc.
By the way, my PET also threw out a red herring as there was elevated activity in my esophagus which turned out to be mild esophagitis*sid* says on June 8, 2012 at 5:06 pm

Yes, Sid – it was squamous cell and, like your oesophagus, my tonsils were a red herring, as suspected. Last week I went back to the colo-rectal dept – they were my point of first referral and have (apparently) been co-ordinating everything – wish I had known that earlier as it would have helped to know that one consultant was tracking me.They've confirmed I have no 'clinically detectable' cancer anywhere

currently. I was given the option of chemo as a ‘domestos approach’ to try to mop up any cancer cells not showing on a scan, or ‘watchful waiting’. I said I would rather avoid chemo if possible and the consultant said that is what he would do if he were me. So that is the plan.I’ll have a PET in 2 months and another 3 months after that. I have been very, very lucky so far, I know. Something slow growing (first noticed the lymph node back in August) and in a lymph node that was easy to spot rather than something internal. Apart from a thoughtful few, my friends and relatives are all going ‘hooray, it’s over!’ but of course it’s not quite as simple as that. As you will all know, not knowing the primary site also means uncertainty about how likely it is to come back etc.Do those of you who have finished treatment and been told ‘it’s gone’ have any tips for putting the worries to the back of your mind and making the most of your life? Or is it just one of those things which takes time to adjust?Kate*Kate120* says on June 8, 2012 at 7:17 pm

Hi Kate,Did you have just one lymph node removed? Or the whole chain? I had the entire lymph system in my right groin/pelvic area removed even though, like you, there was only one node involved.thanks – good to hear you are through this initial stage and results are very optimistic for you. I do understand what you mean though – I was given the same positive prognosis, but the little black cloud says that they can’t find it and it has a propensity to spread.*sid* says on June 12, 2012 at 3:26 am

I only had the one node removed and that was the excision biopsy which was what then provided the diagnosis. Compared both to what I was lead to expect (radiotherapy with possible chemo) and what I’ve heard from people like you in a similar situation, they’ve been very cautious. I think this is because the lymph node had not grown between August and January and was still only about 1.5 cm. I guess they have to do some tricky weighing up of the risks of treatment versus the risk from the cancer. Not something I would like to be responsible for! With regards to the little black cloud and ‘tendency to spread’ – that is just how I feel at the moment! I think that is also what others find hard to take in. They just hear the ‘it’s gone’ part. If you’re the patient I think you’ve had the rug pulled out from under you once and, even with a positive prognosis, it just isn’t possible to step straight back into life as it was when this was something that happened to other people.*Kate120* says on June 16, 2012 at 9:07 pm

Hi all,I haven’t posted in some time; life around you doesn’t go on hold for you while you are going through this. I had my 3 month CT scan, which was clear. But I remain mistrustful. Kate, I can really relate to what you have been saying – your comment about not being possible to step straight back into life is so true for me too. I am back into a mostly normal routine but the scar, the upcoming tests, the lymphedema, the worry every time I notice anything different in or on my body – perceived or real – they are all constant reminders.Hope all of you are doing well.*sid* says on September 22, 2012 at 5:38 am

And unfortunately the little black cloud didn’t go away. My last PET scan showed that the cancer was now in another lymph node. I’ve just finished week 3 of 4 weeks of radiotherapy which will hopefully zap it and am waiting on the LAB21 Cancertype ID test to see if this helps to narrow things down a bit. Glad to hear you’ve had your first all clear Sid – here’s to more of those for everyone here!*Kate120* says on September 22, 2012 at 8:42 pm

I'm so sorry to hear about your PET scan results. I sincerely hope the radiotherapy is successful. I find it so puzzling that your case sounds so similar to mine – both groin node squamous cell – but the treatment and tests are so different. I was told that a PET scan won't yield better results than CT scans and I don't even know what a LAB21 test is. My next test will again only be a CT scan.Good luck Kate *sid* says on October 27, 2012 at 5:27 am

Hi Sid – you can find details of Lab 21 and other companies offering 'tests' on this page of our website http://www.cupfoundjo.org/diagnosis_and_treatment/special_tests.html. Our policy as a charity is to make information available but not make particular recommendations and we don't receive donations from any of these companies.*John (Moderator)* says on October 28, 2012 at 8:10 am

Well, my cancer has 'declared itself' as they say (makes me think of a 19th Century duel) so I'm officially no longer a CUP patient. A follow up PET scan after the radiotherapy I had in Sept showed some activity in the anal area, which has already been thoroughly looked at and biopsied. I was told it was 'unlikely' to be anything but that the surgeon should have a look as they are better at visualising what is there. I think a total of four people looked and said they thought it was probably a pile or something but the consultant/surgeon said straight away that it needed to be biopsied. He was obviously right and a subsequent MRI showed a small tumour in the anal canal. At first it looked like it would be surgery and collostomy bag because I've already had radiotherapy to the groin but apparently they have a shiny new machine which can minimise overlap with the previous treatment and means they can do chemoradiation after all, which would be the best treatment in my situation.A friend who is dealing with cancer told me early on 'you'll find it's funny what starts to sound like good news'. Me and my sister came out of the appointment with the oncologist saying 'Great! They've found anal cancer and you can have chemoradiation!' I certainly wouldn't have thought that was good news a year ago. The treatment sounds pretty grim but the oncologist was upbeat about the chance of success. Of interest for those who are looking into Lab21 – my report said 90% chance of cervical but in my case that was wrong.So, officially I'm not CUP any more but I still feel affinity with all of you here and will stay in touch.Kind thoughts to you all and thanks for the support from this website which has seen me through some very dark days.Kate x*Kate120* says on April 27, 2013 at 9:28 pm

Thanks for the update Kate. As you say, strange to say good news. Have you told Lab21 people? They might be interested? Best wishes for the treatment.*John (Moderator)* says on April 29, 2013 at 2:21 pm

Thanks John. My consultant (who recommended the test) said he would feed back to them as, like you, he thought they would be interested.*Kate120* says on April 29, 2013 at 8:22 pm

Kate, First heartfelt wishes that the chemoradiation is successful. I hope that "small" tumour means that it is caught early and completely treatable. I have not been online in a while as I am back to work full time and work/life is as hectic as it was before my cancer journey started, but because I read that your cancer had declared itself, I made an extra effort to ensure I was examined more closely (not a PET – just a routine

dermatological visual exam), but they still found nothing. My last CT in March was also still clear. Take care and thank-you for making the effort to share and inform.*sid* says on May 26, 2013 at 3:55 pm

Pomdon *Posted on:* April 18th, 2012 *by* pomdon

Hi all, I contacted you in January after mum was diagnosed with a stage iv CUP. Cancer was found at 3 sites in the lymph and we were told the prognosis was a few years following a course of chemo. The cancer had oestrogen markers and had not spread as far as they knew but only did CT and not a PET. After 3 go's at chemo (carboplatin and paclitaxel) mum has had rescans and has been told the cancer has "gone"! This confirms the likely primary was ovarian according to the oncologist, so she is now to have a hysterectomy between her 4th and 5th chemo's. She has been doing a combo of the Jane Plant and Budwig diets which I am sure has helped. We are still stunned and slightly confused as well as elated. Like being told you have won the lottery but you can't check the numbers yourself and too scared to celebrate in case it isn't true. But just wanted to keep the positive stories going to help those new diagnosed as I don't know what I would have done without being able to contact John on this site at the start. will keep you posted.Donna

> Awesome news Donna! Thank you for sharing. It's uplifting to us al who struggle with the unknown. In the lottery of life the time that we have with each other is the true prize, Hugs Margo*ShovelWhenItSnows* says on April 18, 2012 at 2:42 pm

> Good luck or continued success! I have so far completed Chemo 1 & 2. Chemo 1 no problems, but in Week 3 of Chemo 2 suffered a major setback:rushed into hospital with blocked duodenum caused by 2 dying tumours crushing it.Solved by inserting DNG tube into nose to drain off gas & muck. Miracuosally it cleared itself and I got back home on Friday. On a liquid / pureed food diet permanently which is no great issue. Next step is to see if e are going to do `chemo 3 or not.*tortillatout* says on April 18, 2012 at 3:17 pm (Edit)

> Donna – I am absolutely delighted for your Mum, you and your entire family – what fantastic news.As you say it is good to post positive news, so newly diagnosed people visiting the site can feel positive.
> It is also interesting to know that your Mum followed the Budwig and Jane Plant diets.Keep us posted, once your Mum has had her hysterectomy.Tanya x*Tanya* says on April 18, 2012 at 6:45 pm

> Wow Donna you bring a happy tear to my eye.. thank you so much for your wonderful news for you and your Mum. I am also caring for my Ma and it just provides me that extra strength to keep staying positive. Congrats and good luck for the future to you both.Love and best wishesTrina B*Trina B* says on April 19, 2012 at 10:54 am

6 months in & still strong *Posted on:* March 26th, 2012 *by* VirginiaUSACarol

Hey there – diagnosed six months ago with Stage IV CUP, just started 3rd round of chemo – taxol/carboplatin combo -(had slightly positive progesteron marker on liver biopsy but

nothing else definitive and all organs are clean except for the metatasis in liver and the lymph nodes) - once every three weeks then PET scan. So far – 30-40% overall improvement over intial PET scan before Chemo, now stabilized after 2nd round of chemo. What I really want to know – who is the leading ongologist in the USA for this? My oncologist is absolutly fabulous – but as you all know this can be a crap shoot. She is mostly breast cancer specialist, faculty at Georgetown University, heavily involved in clinical trials (which I can find none for CUP). Anybody who can help on this would be great. Keep strong everyone. We are not average – and that's a good thing. Carol

> Welcome to Meeting Space Carol – the trials and oncologists with an interest in CUP that I know of are at Sarah Canon Cancer Centre and MD Anderson. We have a number of people on this site from the USA so hopefully they may chip in with more. If you look at this page http://www.cupfoundjo.org/research_and_resources/archive.html you can access an article which is the definitive way to treat CUP by Greco and Hainsworth (Sarah Canon) – you might want to make your oncologist aware of it. John*John (Moderator)* says on March 26, 2012 at 5:34 pm

My dad has possible CUP diagnosis *Posted on:* March 25th, 2012 *by* ktlylee

My dad was diagnosed with cancer of metastasis recently. They cannot find the primary tumour. He is awaiting a call from oncologist tomorrow to confirm if he has CUP. This has all happened very suddenly and I'm struggling to deal with seeing my dad so unwell (he had spinal surgery as one of his three tumours on his spine was pressing his spinal cord causing mobility difficulties) just found this website which is very comforting to find. Any advice much appreciated. Thanks

Just been diagnosed with CUPS *Posted on:* March 2nd, 2012 *by* tortillatout

A big shock to us as some 4 weeks ago I was fine and had never ever heard of this type of cancer diagnosis! Started chemo on Monday and we are fighting it with extreme willpower and family friend support. Early days for me, but whatever I can do to help beat this affliction for me and others we will do! Anybody want to chat just let me know – we are in Poole Oncology unit at the moment where they are doing a wonderful job to support and manage this unknown predator.

> You have a tough time ahead but you are in good hands – Dr Richard Osborne at Poole is the CUP lead clinician for Dorset Cancer Network and led the NICE Guideline development.*John (Moderator)* says on March 2, 2012 at 5:09 pm
>
> Unfortunately,I am too many miles away to drop in for a chat.
> I was diagnosed in the Fall of 2007and yes,I am still here. Two pieces of advice given to me.Remember – the statistics you read are other peoples`s numbers.Stay positive.Dianne (from Canada)*Dianne* says on March 3, 2012 at 1:24 pm
>
> My wife was diagnosed withCUP in Ocotber 2011 and started her chemo at Dorset County Hospital in May. We also have Dr Osbourne as our oncologist who has been brilliant. How's it been going with you?*Paul* says on July 12, 2012 at 10:02 am

I was diagnosed with CUP last July after finding a lump in my neck. After a grueling year of chemo and radiotherapy I have now returned to work as a Children's Therapist (albeit part-time!). It does take it out of you but I have tried to remain positive – thanks to my amazing family and friends. If you ever want to ask questions or just chat please do. Take care*Chris P* says on July 13, 2012 at 1:21 pm

I was diagnosed CUP in July 2012, no chance of finding primary, no cure, no treatment, I don't know where to get any help or answers. I'm in Sheffield. Laura*Laura* says on August 31, 2012 at 11:01 am

Hi Laura – I'm not sure if you've posted before but if not do please put some more details up so as a group we can try and offer some help. Or if you prefer email me direct John@cupfoundjo.org*John (Moderator)* says on August 31, 2012 at 7:16 pm

Where to go from here *Posted on:* February 22nd, 2012 *by* Trina B

Hi all I am new at this as my mother was diagnosed with CUP cancer in September 2011 at the age of 64It took approximately 3 months of mis-diagnosis with treatment commencing on a rare cancer named GIST cancer before the diagnosis for CUP cancer was providedChemo commenced Vinorelbine and carboplatin (as the thought was maybe the primary was from her lung) and she has just finalised her 4th cycleMa has had her scans taken which was approximately 2 months from the last ones…with devastating results with the cancer showing growth in the lung, liver, abdomin wall and thigh muscle and a new small growth in the brain.We go back to see the specialist today and i have been researching alot of information however have not been able to access the sister site for Jane in Australia….? has anyone else had any problems.I have found all your comments helpful with the LAB21 and CUP One trials etc to assist with the oncologist discussions today however I will respect and follow what ever my Ma wishes from this point.If there is any alternative medicines or any further medical information you may find helpful at this point that we may not be aware of I would be greatly appreciative.thanks again for this site… as you all know it is a very difficult and confusing time for all….Cheers Trina B

Hi TrinaMy thoughts are with you and your mum. I am not very medically savvy so am not able to comment on some of the things you mentioned – I will leave that to other members more qualified and knowledgeable than I.You mentioned the Australian website – are you in Australia? I have not been able to access this site either, it seems to have been closed. It is just the google ad that comes up. I have not seen any posts on here from Jane since last year, so dont know if she is still active here.I hope that others can give you some guidance about your choices and info which may help your mum. It sounds like you are doing everything you possibly can to support her Trina. Continue to check in.Sorry I could not offer more for you, but I do care and will keep you both in my thoughts.Take careLyn*aussieangel* says on February 23, 2012 at 1:40 am

I got into it this morning
http://www.actiononunknownprimary.org/index.html
BWJohn*John (Moderator)* says on February 23, 2012 at 9:24 am

Hi Trina,Just wanted to let you know we are going through it with my 63 year old mum too. On first cycle of chemo. Its a frightening and worrying time. lots of love Donna*pomdon* says on February 23, 2012 at 1:14 pm

Thank you all for responding I really appreciate your responses. You have all helped …CheersThanks heaps John for the link to the website i have now been able to access this. Lyn thank you for your lovely words and your thoughts it all really helps rite now… cheers again…And to you Donna, Hang in there I wish you and your Ma all the best of luck with her journey ahead….my love and well wishes to you both… Mas oncologist has now changed her chemo to Paclitaxol (Taxol) and we are all ready for the challenge ahead…have been looking into stereotactic gated radiotherapy treatment and will be speaking to doc to see if Ma is a candidate for this type of treatment.All the best and well wishes to you all…. Trina*Trina B* says on February 25, 2012 at 9:50 am

Hi Trinacan I alsosuggest that you consider second opinion with someone who also lists CUP as one of their specialisms and discuss this option with your Mum's oncologist. If your Mum has had a biopsy there are a number of tests that can be made on the biopsy material to assist in defining the nature/type of the cancer to further assist in chemo choice.My wife has been on ECX but it has not been succesfull so a second opinion has suggested further tests on biopsy material to identify one of three chemo options-based around Irritocan. Our Onc is now actioning this.How have you got on with the stereotactic radiotherapy options?Best wishesPeter*Peter MAc* says on February 27, 2012 at 10:24 pm

Hi PeterThank you for your suggestion, Ma has had two biopsys one from the lung and one from the stomach so i will certainly look into this and i will speak with Mas oncologist….I really appreciate your help with this.It sounds like you are on the rite track locating the correct options for the chemo for Irritocan for your wife…. My thoughts are with you both thru this difficult time and i send you all the positive vibes for success with her treatment.Unfortunately Ma is not a candidate for stereotactic radiotherapy options due to the sizes and amount of tumours present… but no stone left unturned…Thank you again PeterCheers and all the very best to you both Trina B*Trina B* says on March 2, 2012 at 10:05 am

HI TRina thanksyou may want your Mum to discuss genetic/molecular tasts on tyhe biopsy material. There is a cost unfortunately and its done in this country through Lab 21 (this site has details.) The Test is specidiaclly for CUP and seeks to identify the genetic make up of the tumour. We had it done and though it didn't provide relevant info for us -there are others who have found it valuable.Best wishesPeter*Peter MAc* says on March 4, 2012 at 6:45 pm

Dear TrinaI am so sorry you have been unable to connect to my website in Australia. Feedback about the site indicated I needed to make some changes which I have done. This involved a new address which has caused the confusion.I wonder how things are going for your Ma? Do both of you live in Australia? I wonder if the new chemo treatment has had any effect?CUP is gradually becoming visible in Australia and there is a little research taking place. You and your Ma have been in my thoughts. Please contact me via email: cupaction@gmail.com.

My CUP site is http://www.actiononunknownprimary.orgAll the best to you bothJane B*Janeb* says on April 10, 2012 at 6:46 am

News from OZ *Posted on:* February 17th, 2012 *by* aussieangel

Hi everyone and greetings from Australia, Just wanted to share some information with members that may help. As you may be aware from my story I am a 13 year CUP survivor and have been the facilitator of a general support group here in Australia for the past 11 years. In order to try and reach people who may not have the opportunity to physically attend a support group, either because of time, distance etc, my son and I have been doing a free weekly podcast for some time now and the feedback so far has been very encouraging. Please remember that we are amateurs, but are enjoying doing the podcasts, we do not give any medical advice but try to cover a different subject each week. Naturally some of it is relevant only to our local area but we have tried to include general information with the idea of encouraging people to seek out similar resources in their own areas/country.As we are also about to launch a local CUP group, the podcast this week has been about CUP, and I have included information about this site as well.I would be pleased to hear your feedback if you are able to listen to any of the podcasts [details below] as to whether they are helpful etc.We also do a daily quote and tip on twitter!Take care everyone and thank you for sharing your stories – this is how we learn and grow.Lyn

Don't know if we should be asking for more tests? *Posted on:* February 10th, 2012 *by* pomdon

Hello, Its been 3 days since my mum has been diagnosed with CUP. She has been told her cancer is hormone driven as there are oestrogen markers and the cancer is currently in 3 sites in the lymph. So far they have done mammogram and ultrasound, CT's of everywhere and ultrasound of ovaries/womb etc. They have told us PET scan not helpful here and she starts chemo on Tuesday which treats breast/ovary etc. They said her markers for gut etc were very low and CT clear and they did not want to delay treatment anymore with further tests. Mum currently has pain in her sides (abdo and kidney area). We are still in total shock and I am the only child so need to get very clued up quickly to support her and Dad. Is there anything else I can do? Also we have only 3 days to prepare for chemo….any advice?

Hi – I am so sorry to that your Mum has been diagnosed with CUP, it is really difficult to come to terms with.All, I can say to you is everybody reacts differently to chemo depending on the chemo given and the person. Your Mum will be given anti sickness medication that should help her lots.I was much the same with my brother worrying about how to support him and our elderly parents, but you find a strength that you never knew you had and you deal with everything that gets thrown at you. It will just come naturally to you.One thing is for sure you will lots of support from this site, there are a bunch of amazing people on hereStay strong and keep busy
I will be thinking of you allTanya x*Tanya* says on February 10, 2012 at 11:57 am

Very sorry to learn of your Mum's diagnosis. I can understand what a difficult time it is for you all. It is very difficult to know what helpful advice to give. Hopefully others will chip in. My take on the diagnosis (as a layman) from what you've said is: I can see that a PET scan may not add any more information. Presumably the clinicians have determined their course of action based on the evidence they do have from the

(immunohistochemistry) samples. This is what has led to the hormone relationship and therefore the logic of a breast/ovarian link. Has a biopsy been possible/taken if appropriate if there is an evident secondary?I think that you have to be sure that the treatment regimen is based on evidence rather than guess work – or if there is an element of guesswork it is based on the oncologist's considerable experience. Has he/she discussed with other experts? Always worth asking politely how many CUP cases the oncologist has treated and whilst no two CUP cases are the same, if there is an element of guesswork then it needs to be based on experience of reasonably smilar patients. The NICE guideline should be directing the way your Mum is being treated. You can see it here:
http://www.cupfoundjo.org/diagnosis_and_treatment/nhs.html
It is based on expert opinion and evidence. I'd suggest that you skim it to pick-up on any relevant parts. As you've indicated, carers of CUP patients are best to understand as much as possible about the disease and treatment. I'm a believer in informed patients and carers asking questions politely the whole time particularly if you are not being told things. Why are they using a particular chemo combination; what do they expect from it etc. ? Keep asking until you understand. Everything I know about CUP is on this website and coupled with the views of others who I hope will add their comments I hope you will find useful info here.*John (Moderator)* says on February 10, 2012 at 12:33 pm

Hi Tanya and John,Just wanted to thank you both for your replies. Both very helpful. I have read the nice guidelines and it was clear to me that we have so far only seen an oncology registrar on the ward and mum starts chemo on Tues with no key worker or specialist nurse. According to the guidelines she should at least know who is the lead clinician in her care. So on your advice John I called the oncology unit and asked those very questions about there experience etc……I had a call from the oncology manager and soon after an appointment arranged now to see the consultant on Monday. It is clear they don't have a specialist in the field of CUP nor a specialist nurse, which fails to meet the Nice recommendations. I have therefore requested a second opinion too from a CUP specialist. I would not have done anything without your sound advice. We are scared of the prognosis and what we might be told, but at least now we are seeing the organ grinder so to speak. thanks again. a great help.*pomdon* says on February 10, 2012 at 9:11 pm

Good – well done. "CUP specialists" are as rare as hens teeth, if they exist at all, but there are oncologists with different degrees of experience with CUP (given that 11,000 people a year are diagnosed each year in the UK there will be oncologists with considerable experience). If, in relation to the Guidelines, they say "they are only guidelines" they should be aware that there will be more force behind them when the Peer Review Measures come into force (was going to be this March but I suspect it is more likely to be April/ June). They will have to find a way of resourcing the "Measures". I think the most important point is to get your Mum's case reviewed by an oncologist with experience of CUP.*John (Moderator)* says on February 11, 2012 at 10:29 am

Often in dealing with CUP, it seems to take forever to settle on a diagnosis. I also had three days notice to start my chemo.I still have a lot of faith in my "team". They were honest "we don't know if the treatment will work" but encouraging when the lymph nodes started to shrink. I asked for a PET scan but was told it was not necessary. I

even paid for it myself. It didn't show the primary either. They were right. Above all stay positive. I glad you found this site.Dianne CUP survivor 4+ years*Dianne* says on May 17, 2012 at 7:13 pm

Daughter *Posted on:* February 7th, 2012 *by* delia

My father was recently diagnosed with CUP this Jan. His initial symptoms were abdominal pain and fatigue. After ultrasound, CT, biopsy, and PET they could not pinpoint a primary site. The scans, however, did find cancer in the liver and lungs. We got a second opinion that was the same as the first, which was very disappointing. We decided that starting the treatment (Folfox chemo) immediately was best. He has now completed his first round out of 4 of chemo with minimal side effects. The worst symptom he has now is increased fluid in his stomach. Just wondering if anyone has a similar case or shared experience. Thank you.

Delia, so sad to hear this. My wife has secondary Liver and Lung and was initially put on ECX and had a scan again after the first four cycles. This was not working and she is now on Gemcitabine which the recent scan does seem to be effective although her platletes are now getting low. We have not had Folfox Chemo but hope that it works for your dad and all I can say is you have to go with what the Oncologist suggests. As the Primary is unknown they do use their experience to intepreter any biopsy and scan results to try and define best treatment but this is not always right.We had a second opinion as well and the agreed witht he treatment regime my wife was on originally and said that Gemcitabine was their next option too.You have to try and keep strong and this site has a welath of info to help and the people are very supportive as we are all going through the same thing. RegardsDavid*duvlin* says on February 8, 2012 at 6:27 pm

Thank you David for your comment. It's nice to know my family is not alone in this fight against CUP. I also was wondering if your wife is having a hard time eating and/or sleeping and what have you been able to do to improve that? Does she also feel bloated? My dad always says he feels full and won't eat very much. We found that he likes drinking the Ensure though. He also feels really tired, but we encourage him to go for short walks. Thanks again.I really hope that your wife stays strong and that her next treatment is effective. Your story and encouragement were very helpful. Thank you.*delia* says on February 10, 2012 at 1:24 am

Delia, My wife has found that food just tastes awful but she does eat well, and has actually put on weight which is unusual (which is Ironic after watching her weight for years). In the early stages she did find it helpful to use the supliment drinks but has not used them for a while after things settled a bit. The main thing is to keep his weight up as they do work out the amount of chemo to use based on body factors including weight so if this drops the side effects may become more pronounced or the blood levels drop and chemo has to be dropped or delayed which you don't want. Sleep is the big issue as she does get very tired so needs to rest in the afternoon etc. but then is awake at odd time during the night which only compounds the day time issue. There are also times, especially just after Chemo, when she suffers hot flushes at night and can,t sleep but these tend only to be for a little while. The only way she has been able to manange this is to rest in the afternoon but not sleep (which is sometime hard to do). It is worse around the time of treatment but something that you

have to live with but you do get used to it and work out ways to manage.It is good to keep your Dad mobile and going for walks is really good as long as he does not over tire himself. My wife has just started doing Zumba again and she feels a lot better for it, although it worries the hell out of me as I don't want her to over do it!.

It is very hard to deal with all the issues that come up at first but it does get easier as you gain more knowledge about the cancer and people on this site will give a lot of insight in to things they have done to aleviate problems and you will see that different things work for different people.Keep strong and hope your dads treatment goes well.*duvlin* says on February 10, 2012 at 5:06 pm

hazy fantazy update *Posted on:* February 3rd, 2012 *by* lisarore

Hi guys hope your all well, its been a while since i have posted not had the energy since mum's passing on the 29th of november, but just wanted to give you all an update not sure if you will want to know, so sorry if i upset anyone.Mum had asked for a port mortem to be done after she died to find out the primary cancer for the sake of myself my sisters and our 7 children.So we got the results today and i wanted to share them with you just in case there were any similarities for future cup patients visiting the site. Please read previous posts for full info.Mum had non small cell lung cancer. We are all relieved that its not a hereditrey cancer but sad that this never showed on the many scans and tests she had done as the consultant told us this would have been more managable if not treatable if we had known what it was and she had shown signs of this a few months earlier.needless to say as an ex smoker myself i will never be tempted again.please feel free to email me for any further info i will always remain a friend of this site and have signed up to do a 10k in may with my sisters and family to raise as much money for the site as possibleTake care much loveLisa x x x

Hi LisaThough sad it is good to hear from you again. Your Mum's decision to have a post mortem was important . Any information that could help future thinking particularly for your family is important.How are you all otherwise?Love Peter*Peter MAc* says on February 3, 2012 at 3:45 pm

Hi Lisa – thanks for posting that. Very good of your Mum to want a PM to help you. But it is difficult to get a possible "answer" to the primary site now.Briliant that you are doing the run in her memory. I've put some info on our website http://www.cupfoundjo.org/support_our_work/events.html
If you'd like to email events@cupfoundjo.org and copy to supporters@cupfoundjo.org we can organise T shirts, and possibly local media coverage etc*John (Moderator)* says on February 3, 2012 at 6:25 pm

Hi Lisa , I too have not posted for a while since my wife died in September. Having great difficulty coming to terms with this. Its very sad that your mum has gone but great that she wanted a p.m. done to help you all and of course other sufferers. You are all very brave to have carried out what she wanted. My wife did not say that she wanted a p.m. done and in any event it seems to be taken that you have cancer and that"s that . No one mentioned or suggested to her/me about a p.m. Maybe the health authorities should think about talking to CUP sufferers before it becomes too late to talk about..I wish you and your family all the very best. xx Jim*bewildered* says on February 7, 2012 at 2:22 am

Hi guys thanks for the kind words.Peter i am ok i have good days and bad we seem to have thrown ourselves into raising funds and trying to make a diffrence, we have organised a race night for april and about 20 of us are running a 10k. so thats keeping us busy. I suppose we just feel like we need to leave some positive legacy after this awful situation we have found ourselves in.John thank you for info i will get on it in the next few days its much appricated.JIm we were astonished at the consultants reaction to our request for a pm she basically was stunned and did not have a clue about filling out the paper work ect, so i presume its not common practice!! Which to me is shocking surely if we want answers to this dreadful diagnosis then this is the only way forward mum was never told how bad the situation was until 24 hours before she died so we did not have time to discuss it in full but luckly she had mentioned to us that if the situation ever came up she was more than happy for a pm to be done. I must say it has given my sisters and myself some peace to know its not hereditry, selfish as that may sound we where all convinced our fate was sealed !! i think pm options should be discussed right at the begining before it becomes too late or too hard to talk about the consultant did say she had taken some positive information from the results which she will record and may be able to use in the future.Take care guys x x x*lisarore* says on February 7, 2012 at 10:43 pm

I entirely agree with you Lisa but would add a note of caution, so that people know, that even at PM it is not always possible to identify the primary site of the cancer.*John (Moderator)* says on February 8, 2012 at 10:49 am

Oh yeah of course John, we where told that it might be a waste of time sorry i did mean to say this just got carried away when we did actually get a primary x x x*lisarore* says on February 8, 2012 at 8:45 pm

Mum CUP after finding brain lesion *Posted on:* February 1st, 2012 *by* luckybug

My mum was diagnosed with CUP after the secondary cancer was found in her brain, the tumour was removed and all seemed well, she recently came off the steroids and has felt unwell ever since, she is off her food, feels sick and totally unwell, she has always been so fit and healthy her collapsing and the finding of the brain lesion was a total shock to everyone, and we are now at a loss, they tell us she has metastatic brain lung cancer but cannot find the primary.

I am so sorry to hear about your mum – this dreadful disease just continues to destroy lives. Never give up hope and take comfort from the replies you are bound to recieve from the lovely people on this site. You'll find that being diagnosed with CUP comes as a shock to patients and familes alike. I and many others had never heard of it until it entered our lives. I wish your mum and you and your family all the very best. I know some people have looked into Lab 21 – read up about it and see what you think.*Janet Bell* says on February 1, 2012 at 8:59 pm

I am sorry to hear about your Mum.I'd also check with your Mum's Oncologist to find out what he/she thinks about your mum feeling unwell after stopping the steroids? There could be a number of possible reasons. Also see if your Oncologist can prescribe something to ease your Mum's current unwell condition.As Janet says

there are possible tests that can sometimes be used to identify in more detail the nature/make up of the cancer -even though they can't physically find the primary. Many people have used Lab 21 successfully.(There is a cost unfrotunately as currently not on NHS). Though our results from Lab 21 were not conclusive enough it has given our Oncologist and Sec Opinion pointers to test for certian cancer types.Best wishesPeter*Peter MAc* says on February 1, 2012 at 9:18 pm

I am so sorry to hear about you mum, I know this ia a terrible shock to your family. Understanding this illness is impossible but makes sure your mum consults her oncologist about the sickness and feeling unwell as they can prescribe different medication to help with this. Being a mum I would say talk to your mum, tell her your concerns because believe me, she too will be worrying about you and any siblings you have, how you are coping with it, don't bottle it up I would rather know how my children feel than have them stay quiet, bottling it up inside. Talking to her will help both of you, the pain of the illness is nothing compared to the pain of knowing how hurt and confused your children are. You must also take care of yourself, be good to yourself, take downtime for yourself, see your friends try to find time with and without your mum where the cancer isn't the only thing on both your minds. There are still so many beautiful memories to be made and having a positive attitude can help to beat this awful illness. I'm sure your mum is so proud of you, Ill keep you both in my prayers. Best WishesAnne.x*willow* says on February 2, 2012 at 12:46 am

I too am so sorry to hear about your mum. I agree with other members who say to check with her oncologist why your mum is now feeling this way. I also agree that you and your family should take some time to yourselves. I lost my wife last September but I could never be away from her for a long time before she went. This did affect my own health very much but I could not be away from her. I don"t regret being with her all the time as I knew she wanted me there . I would suggest that you listen to your mum most of all and go by your own gut instinct as to what your mum and you both think about what"s going on. I sincerely wish that things get better for your mum .You are all in our thoughts xx Jim*bewildered* says on February 7, 2012 at 2:50 am

Several Biopsies *Posted on:* January 29th, 2012 *by* Peter MAc

Does anyone have any experience of taking a second biopsy. My wife had a biopsy prior to treatment and the material was alos enough to provide material for the Lab 21 test. However its now been suggested by Onc that a test for HER2 and KRAS Wild may be suitable to define second line treatment. However there is not enough material from the original biopsy to provide material for these tests.Has anyone experinece of having further biopsies taken. Are there more risks?ThanksPeter

Hi PeterUnfortunately, I don't know if there are any risks from taking further biopsies, but I am sure somebody from the site will some information to help you. Sorry I don't have an answer for you, but I am thinking of you and your wife and hope all will be fine.Tanya *Tanya* says on January 31, 2012 at 8:12 pm

Sorry Peter – no knowledge – don't think its come up before. Would guess it depends much on site – ease of access and type of biopsy – which will also impact on discomfort levels.*John (Moderator)* says on February 1, 2012 at 8:57 am

Hi Peter,Im pretty sure ive heard of breast cancer patients having a second biopsy taken because the first was inconclusive. However i think there is a risk of microscopic cells escaping but that is the same risk with any biopsy. Hope you are both bearing up, my mum is back in hospital and im still struggling with my broken wrist hence the lack of emails to you.Sal.*sallie* says on February 1, 2012 at 9:25 am

Thanks Sallie, John, Tanya: useful and encouraging advice and support
Our Oncologist has rightly asked us to weigh up the implications and potential discomfort of a second biopsy given that there is no guarantee that the tests on the subsequent material will prove conclusive.
I think its something we'll need to discuss in further detail with him and our second opinion.If there is anyone out there who has some experience of second biopsies (liver) it would help our deliberations.
Many thanks againPeter*Peter MAc* says on February 1, 2012 at 9:02 pm

So glad I found you all… *Posted on:* January 23rd, 2012 *by* BerniW

I had never heard of CUP either – until 9th January this year when I was diagnosed with it. All I have is a lump in my neck – no other symptoms! Mine is a similar story – I went to the doctor, after being told to by loved ones I really should, and was given antibiotics and told to come back.There then followed several visits to the hospital and many tests, biopsies and scans of various types. It seems I have adenacarcinoma in my lymph glands in my neck – but they can't find the primary site. I presumed it had disappeared – the way the consultant explained it – and all they had to do was treat the neck and all would be well. he said he is "looking at a cure".So next Tuesday (31st Jan) I go into hospital for a radical neck dissection, followed by radiotherapy. They'll decide how long when they've checked what they can find during the op.Have many of you had the neck dissection? I'd love to hear any recent experiences.If you want to read more details of my case – check here: http://pokerlibrarian.blogspot.com/

This site is an excellent support and potential resource. Keep positive and hope the treatment goes well next TuesdayPeter*Peter MAc* says on January 23, 2012 at 6:49 pm

I read your excellently written blog. Whilst no CUP patients are the same, the routes to diagnosis and the concerns of this particular phenomonen are all too familiar. Best of luck for next Tuesday.*John (Moderator)* says on January 24, 2012 at 8:31 am

Hi BerniI was diagnosed with CUP last year, biopsy from my neck lump contained squamous epithelial tissue in the lymph gland biopsied.I had a radical neck dissection in April last year, already having a scar on my neck the surgeon tidied that up at the same time so I ended up with a longer than usual scar. After coming round from surgery another patient on the ward offerred to come into the bathroom with me when I said I was off to see the wound before my visitors arrived! The wound was really scary looking and had been glued so there was no dressing, but apart from the sight of

it it really wasn't painful, I had a lot of numbness from my ear to my shoulder to below my collar bone at first this was difficult to learn to live with but over the last 9 months I have got some sensation back in areas other areas are still quite numb but I have got used to the strange feeling. I found the more I handled and creamed the area the quicker the nerves settled down. I am not by any stretch of the imagination a person who places importance on looks, my own or others so the issue of the scar and slight oedma on the left side of my face from reduced lymph drainage hasn't been important to me. My scar has settled down beautifully I applied the recommeded creams exactly as advised and once the wound healed I started using Bio oil which I am sure has helped to reduce the discolouration from radiotherapy. I had the results from an MRI last week and am hugely relieved to say that nothing further has shown up. My consultant remarked on how well the scar settled and even the radiotherapy discoloration is barely noticeable and agreed that the combination of cream, massage and Bio oil has proved effective.In all I have to say that the neck dissection was a lot less unpleasant than the tonsilectomy. I did have a bit of weakness in my left arm but found that living normally and walking my 4 dogs several times a day on lead soon built up the strength and I have no lasting weakness there.I was back on the dog agility training field 10 days post surgery and competed at championship level 3 weeks post op (we came second). I struggle to recognise that I have cancer as I haven't felt unwell throughout this illness and I won't allow this rogue cell to dictate my life.Apart from hospitalisation and immediately after I have taken very very little time off work, to the extent that I ended up with excess holiday because I saved it up just in case!!I work night shifts and was able to continue working throughout my radiotherapy and I drove myself the 60 miles daily too. I think I have been very fortunate to not suffer the debilitating side effects that some people do.
It is a very scary time but I think if you allow yourself to be the way you feel at that time and recognise it for what it is: angry at times, needing information at times, frustrated at the lack of co ordination at times and confused at times then you can get through it with sanity intact!I wish you all the best and am thinking of you going through this process. x*Teresa* says on January 24, 2012 at 5:53 pm

Hi Berni Having gone through all this with my brother, the frustration of the tests and various biopsies is all too familiar.Although I can't begin to understand what your going through, having shared my brothers journey with him, and watched the frustrations he faced, I would like to thing that offering people support will help them. So I would like to wish you the best of luck, I will be thinking of you on 31 January. Stay strong, positive and keep a sense of humour at all times, you would be amazed what a difference that make !keep us informedTanya x*Tanya* says on January 25, 2012 at 7:10 am

Thanks for taking the time to tell me about your experience, Teresa – you are so positive! I can't tell you how much that helped – with only days til my op. I have more confidence now that it won't stop me in my tracks – well not for long anyway 🙂So glad you feel so well and have had great results since.I'm really grateful for your support too, Tanya. I will certainly keep you updated! xx*BerniW* says on January 25, 2012 at 9:28 am

Hello BerniWelcome to our exclusive group.I was diagnosed in September 2007 and had a course of chemo until April. I had not found this site until after I finished my chemo in 2008.I`m still here and healthy. CUP changed my life path and did change

me. But life is full of many twists & turns and my CUP journey is just one of them. I will be thinking of you on January 31.Dianne*Dianne* says on January 27, 2012 at 1:10 am

Berni, Glad you found this group as it is very helpful. My wife has CUP and the frustration of not knowing the cause has been the worst bit for us. The CUP foundation site has been a great source of information and has helped me to deal with the issue better by gaining a bit more understanding.Hope your op goes well and you don't suffer too much witht he treatment.*duvlin* says on January 27, 2012 at 5:49 pm

Hi!I'm back! I had my op on Tuesday 31st and I just came home today. I am feeling pretty good. They did the radical neck dissection and I have some impressive scars and bruising at the moment. The surgeon said he found "lots of lumps" right round to the base of my skull. He is confident that he got it all though and even said radiotherapy might not be necessary. He'll decide when he's seen the reports from the labs. I have an appointment to see him on 20th Feb. I'll write more when I get chance – but I'm feeling positive, if tired! xx*BerniW* says on February 3, 2012 at 6:55 pm

Hi again! Just wanted to update my story. After the radical neck dissection back in January I did have to undergo 33 sessions of radiotherapy – wearing my specially tailored mask! To be on the safe side I was also given 2 days of chemo (Cisplatin) as they'd taken 46 lymph nodes and 23 were cancerous.
After all this was completed and I'd had 8 weeks to recover I had another CT scan. It was all clear! There was much celebrating 😀Since then I have gone back to work and life has returned to normal. I see a consultant every 4 weeks – so they (we) are being very vigilant! The chemo was the hardest part for me – never felt so ill. The rest was fine. I have now got all my energy back and have a new zest for life. I read this site still.- and wish you all the best. Every story is so different – which I guess is a feature of CUP. Keep fighting! xxhttp://www.pokerlibrarian.co.uk*BerniW* says on November 20, 2012 at 7:11 am

Hi! Just had my 12 month scan – and it had come back as All-Clear! It is a relief as we all know what Scanxiety can be like! Here's to the next 12 months Bernixhttp://www.pokerlibrarian.co.uk*BerniW* says on June 25, 2013 at 10:14 pm

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TRIBUTES AND DEATH NOTICES

Dee's story Posted on: December 20th, 2013 by Karl

Just over a year ago my beautiful wife posted her brave story here for everyone to read and hopefully to help them understand this CUP mystery. She finally passed away on the 7th of December this year having refused a second course of chemo. She did this in pursuit of an improved quality of life. The first course which she details in her entry shrank the lesions considerably but they returned at an alarming rate. So much so that repeating the exercise filled her with dread. The oncologist indicated that he had little hope that the same treatment would even be effective a second time, he offered an alternative combination of chemo which we were told were the 'big boys' of the chemo world. Forgive me for not being able to remember their names but everyone else we knew with knowledge of these drugs said they were guaranteed to make Dee feel very ill. As the oncologist could not be clear as to whether there was any hope of improvement she declined. Within a month the pain management was such a full time job that our quality of life fell almost to nothing. The last few months Dee was confined to her bed too weak to even sit in a chair and the last few weeks she was rarely conscious and alarmingly frail.Dee was a wonderful woman and an amazing mother. She kept herself fit and healthy and this diagnosis came completely out of the blue. I decided to share the end of Dee's story with everyone for a couple of reasons. Firstly because places like this need to inform others but secondly because in the early days Dee spent far too much time researching her condition rather than building memories with her children. I admired her enormously and supported her every step of the way but I want everyone to take a moment to reflect on what 'quality of life' means. We spent hours gathering and sharing information which led us exactly to the place the original diagnosis said it would. The hours we invested were when Dee was at her strongest. Please be sure to spend your time wisely, the professionals in my experience really do know what they're doing.

> Dear Karl,There is really nothing I can say that helps at a time like this. Just know that in time you will begin to feel better and thank god you have those lovely children to distract you and to keep you busy. This is my second Christmas without my Yolande who died September 2012. We were together for 27 yrs & 5 mos. Her diagnosis also struck out of left field. She was in the prime of her life, 52yo, healthy, brilliant, loving, creative, innocent, and trusting of the medical profession, which was our downfall. There was no chemo powerful enough to staunch the aggressive cancers which brought her down. The Kaiser Permanente Hospital system and the oncologists in Redwood City, CA, simply did not care about researching CUP – we found this website on our own. I am sorry you are going through this. Take care of yourself and know that you will heal from this devastating loss. Kathy Elliott California, USA

Eddie's battle Posted on: September 2nd, 2013 by Christine Macdonald

My husband died 20 August 2013 of CUP, something neither of us had heard of before, we had the diagnosis of cancer on 01 July, but felt it was just a word and we would fight to cure or prolong life with treatment. What we did not understand or were told is that the tests prior to diagnosis took a matter of a month to complete and in that time the spread was so aggressive and his weight loss and strength so diminished that no treatment would be offered,

he entered hospice care on 12 August and we were told to expect a couple of days, he lasted 8 more as he fought to stay with us, even a day before reminding the staff he would be having chemo treatment soon. His mild symptoms started in early 2013, by May abdominal pain and feeling sick after eating, three doctors visits later, all of them advising change his job due to symptoms put down to stress. We then asked for an abdominal ultrasound scan which they agreed to but with waiting lists it would be mid August, we booked a private scan and asked for referral letter from doctor and low and behold a scan appeared at our surgery the next week. It was from this scan results showed worrying signs of cancer, enlarged lymph nodes, hardening of bile duct and lesions on liver. On then to CT scan, liver biopsy and PET scan. Bloods tests for liver functions were OK, even though by now his abdomen was starting to extend due to fluid, which he eventually had drained in July. One trip to the hospital before that for dehydration and still only been offered Tramadol for pain relief. He took to bed at home after that and then many varied tablets, pills and potions arrived in the house for me to administer and try and control his pain relief and sickness. By start of August, Cancer nurses and District Nurses were in the house daily, pain relief now in syringe driver. It just was all so speedy and dramatic his decline, it was unexpected as we were still thinking of treatment, but it was not to be. He passed away in the hospice an emaciated shell of the fit and healthy man that he was, karate black belt, jogger and surfer. His legacy and what he asked us to do after his passing was to raise awareness and raise money for both CUP and hospice care, no one should have to suffer as he and his family have done, if we can find primary source of a cancer the chances are so much better. So now the fight starts in earnest, we have to find a way to eradicate CUP as it is so devastating for all. Thanks for reading, thoughts and prayers are with all sufferers of this disease.

> My sympathy and prayers are with you in your loss. It was VERY frightening to me to read of the problems and "gaps" in your husband's diagnosis and treatment. I'm in America and you may know of the changes and assaults on our medical system that are kicking in now. I was diagnosed with CUPS in 2007. I went to Memorial Sloan Kettering in NYC, where I was immediately put on chemo for eight months. I was cancer free until this spring. I had a tumor removed mid-August and am awaiting biopsy results that may give some clue as to primary origin. My fear is that the prompt excellent treatment I had will be changed and limited by the insane new law and regulations over here. I applaud Jo"s foundation and all of you who re fighting for better diagnosis and treatment of CUPS in Britain. I had never heard of CUPS before I was diagnosed, nor had my friends. I pray that your efforts to get better care and awareness will bring results. Again, your story is frightening and inexcusable in a country like Britain. *balar53* says on September 2, 2013 at 3:54 pm
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> Dear Christine, I am deeply sorry to hear of your loss and the suffering of your husband in such a compact period of time. I recall only too well how numbing it is for us when their condition suddenly worsens and we are so busy caring for them that we forget to say and do the things we wanted to because we don't realize that the end is so near. And further, we can't imagine an 'end' so we keep running in place administering as best we can to make them comfortable in the moment.I do not know how you managed to have the presence of mind to write a letter with such clarity and organization as you posted here, but I want to thank you for sharing your horrendous burden with us. My partner of 28 years died nearly one year ago but it seems like only yesterday. I too did not know she was going to die yet looking back, I don't know how she lived as long as she did. The Kaiser Permanente health care system here in California, USA, was of no help whatsoever. We finally somehow by the

grace of god found out about Jane Barrett's website in Australia, I think it was, and then this Jo's Cup soon after. These were our only links in the entire world to others with the same diagnosis! I know from experience that there is nothing I can offer to assuage what you must be going through at this time. However please accept my heart full of love and compassion for your loss that I am sending across the Atlantic Ocean right this moment. Please take good care of yourself: eat, sleep, and exercise every day so that you do not get depressed. Know that your husband is free now from his suffering. Kathy *kathy@kathy-elliott.com* says on September 2, 2013 at 7:29 pm

Hi Christine I am so so sorry for your loss, my thoughts are with you and your family at this very very sad time. Your story is heartbreaking and all too familiar with so many story's on this site.I like you had never heard of CUP until my brother was diagnosed following which during my research I came across Jo's friends which has been invaluable to me not only during my brothers illness for information but also the support I have received since losing him, there are truly some amazing people on this site. Also, like you my main priority now is to raise awareness of CUP, which I am delighted that the first awareness week will be 23 to 29 September with the badges which I for one hope will in time be as recognisable as the breast cancer ribbon and will therefore lead to much needed funding in order to research this rarely heard of cancer that takes so many lifes.I know for you it is early days, it is 20 months since I lost my brother and not a day goes by that I don't think of him or indeed have my daily chat with him, he can't answer, but I can still share my life with him! Everybody is different and have there own ways of dealing with their loss, I attended bereavement counseling at our local hospice for 12 months once a week and found it helped me no end.Your description of your husband being an emaciated shell of the fit healthy man that he was bought a tear to my eye, it is such an awful disease to watch somebody you love so much lose their life to. Until you have been through this you cannot understand what families go through.Once again Christine, I am so so sorry for your loss and my thoughts and prayers are with you and your family during this difficult time, message me anytime if you feel the need to chat – I can send you my number.Much love Tanya *Tanya* says on September 2, 2013 at 8:35 pm

I'm so sorry to hear about your husband. His tragic story is all too similar to others I have read on this site. I can only imagine the pain you and your family are in right now. It must have been terrible to watch someone fit and healthy deteriorate so quickly and suffer so much. I think it is absolutely fantastic that in the midst of all that you are determined to do something positive in his name. Warmest wishes to you and your family. I wish you courage for the next stage you have to go through. Kate*Kate120* says on September 2, 2013 at 9:24 pm

Thank you so much all who have left comments, this site is a reminder to us that we are never alone in our suffering, every comment helps us. We find it easier to be positive as Ed has an extremely positive approach to everything in life, in the hospice he was always asking us to check on others who were in pain or suffering, he was an extraordinarily compassionate man, we are just grateful that he is out of pain, of course it means ours is just starting, but we are so grateful for the kindness of strangers for taking the time to reply, thank you from the bottom of our hearts.xxx *Christine Macdonald* says on September 3, 2013 at 10:18 am

Christine-I am so sorry to read of you and Ed's story. You are right we must bring CUP, its diagnosis and treatment more publicity and ensure more rapid treatment regimes. My Mel died nearly a year ago -diagnosed with CUP 18 months earlier she went through a number of treatments and diagnosis and, unfortunately, some delays caused by the beauracracy of the Welsh Health Service delaying further treatment in England.All this time -this website : J's Friends, was an enormous support-both emotionally and practically.I share your pain and loss and your feeling that we need to raise awareness of CUP.My thoughts are with you-best wishesPeter*Peter MAc* says on September 8, 2013 at 5:47 pm

Hello Christine,I have read your moving post about Eddie after hearing about his death and about CUP through my dear friend and your's, Barry G. Please accept my and my family's sincerest condolences on the loss of your dear husband. My family sends its love and prayers to you and your family from the USA. I lost my husband to cancer 5 years ago after a 2 year battle and decline. I took care of him until his death, along with in-home hospice care for the last 6 weeks of his life. I know only too well what you are feeling and how difficult this has all been for you and your children. We will continue to keep you in our daily meditations and will send loving, positive thoughts your way in the coming year. They say "time heals"….in some ways you will find after a long time that it is partially true. We never forget, but hold the warm, wonderful memories of our beloved close to heart forever. My mother, Aiyana, is a native American Chippewa Indian and wrote a poem for Barry before he read at Eddie's funeral. He will be sending the poem to you in his card. Eddie was a very important friend in Barry's life. Through hearing about Eddie, I feel as if I knew him too. Again, our warmest, loving wishes to you and your family. Please take good care of yourselves and live in the loving legacies Eddie left you with….2 beautiful children and a lifetime of happy memories. Here is a native American poem for you….
SPIRITUAL WARRIOR

Life offers us the opportunity to become a Spiritual Warrior.
A warrior is one who bravely goes into those dark areas within
themselves to ferret out the Truth of their being.
It takes great courage, stamina and endurance to
become a Spiritual Warrior.

The path is narrow, the terrain rough and rocky.
You will walk alone: through the dark caves,
up those steep climbs and through the dense thick forest.
You will meet your dark side. The faces of fear, deceit, and
sadness all await your arrival

No one can take this journey but you.
There comes a time, in each of our lives,
when we are given the choice to follow this path.
Should we decide to embark on this journey,
we can never turn back…. Our lives are changed forever
On this journey, there are many different places we can
choose to slip into and hide. But the path goes on.
The Spiritual Warrior stays the course, wounded at times,
exhausted and out of energy. Many times, the Warrior will

struggle back to their feet to take only a few steps before
falling again.

Rested, they forge on,
continuing the treacherous path.
The journey continues. The Spiritual Warrior
stays the course. Weakened, but never broken.
One day, the battle, loneliness and desperate fights are over.
The sun breaks through the clouds; the birds begin to sing
their sweet melodies. There is a change in the energy.
A deep change within the self.

The warrior has fought the courageous fight.
The battle of the dark night of the soul is won.
New energy now fills the Warrior.
A new path is now laid before them.
A gentler path filled with the inner-knowing
of one who has personal empowerment.

With their personal battle won, they are filled with joy.
A new awareness that they are one with the Spirit beams
as they go forth to show others the way.
They are not permitted to walk the path for others.
They can only love, guide and be a living example
of the Truth of their being.

In Deepest Sympathy….Jess Martin and Family*jessmartin* says on September 19, 2013 at 3:38 pm

Thank you so much Jess for taking the time to leave this message, it was truly lovely and very inspiring. I am still struggling with what has happened, hard to believe he won't be walking in the door with his wide smile and kind words for us. He is so dearly missed but has left us so many happy memories. Nice to know Barry has a good friend in you Jess, he's very lucky. Best wishes to you and your family too.xx*Christine Macdonald* says on September 22, 2013 at 8:47 pm

Hello Christine….this is Jess. My thoughts and prayers have been with you since Eddie's passing and especially today, your first Christmas Day without his physical presence. I feel so much for you and your family today; I remember only too well the first Christmas without my husband after he passed away from cancer. It all seemed so unreal to me to realize Christmas Day was here, the family was together and Tim was gone. We lit a candle for him…felt his presence…and knew that where he was now was a better place for HIM, not for us. It will never be the same again without your life partner, your soul mate. Tim would have wanted me to be happy with the rest of my life. I have continued to work in my field as a veterinarian and spend time with my family and friends. I miss him in the garden, I miss him in the snow, I missed him as our son married this past year. I did feel him so close in heart, as I am sure you feel Eddie every day. I just wanted you to know that so many others feel your pain and send warmth and love to you, both here on this wonderful site and in your circle of friends and family. Be well….remember in grace…..keep Eddie close….he is

there. Love to you and your family.JessJessica L. artinjessmartin671@zoho.com*jessmartin* says on December 25, 2013 at 8:24 pm

I really appreciate your message Jess. Yes he is missed so much it is a physical pain always for me. It always will be that way as he was an exceptional man who has left a huge void for all of us. It was very hard for the girls who adored him, but thankfully I have an amazing family who took us in on Christmas Day and made it very special for us all. The same warmth comes back to you also across the ocean, I hope you had a lovely day yesterday. We are partying here today, as we always did, just this year it is in his memory, which will be hard but it was the girls wish. Prayers sent back and all best wishes for a happy and healthy 2014. I spoke to Barry recently and I'm sure it won't be long before you meet each other face to face. God Bless.xx*Christine Macdonald* says on December 26, 2013 at 9:39 am

Dear Christine,Thank you for your reply; I appreciated your kind wishes very much and was so happy to hear you were and are surrounded by family and so much love. Take good care of yourself and feel God's love all around you. I am leaving this message for you here on this site again, but also leaving my personal email address, if you would like to have contact via email rather than on an open website. If you would like to, please email me anytime.I would be very open to it. My email address is: jess.martin671@zoho.comLove to you and your family. Jess

Mum's story Posted on: May 7th, 2013 by MichelleDarracott

Mum had been ill off and on for the last two to three months. She had water infections, problems with her kidneys and most recently pneumonia and pleurisy. My dad was back and forth to the GP with my mum and on more than one occasion she had been taken to A&E with severe all over body pain. It kept getting put down to pleurisy. On mum's last visit to the GP (it wasn't her usual doctor) she asked if it could be cancer (particularly given her family history) and was told that she just had to accept that pleurisy could take a long time to get over. She couldn't keep down her antibiotics and started to refuse to take them as she didn't think they were doing in her any good even when she didn't throw them up.In the early hours of the 20th April (Saturday) 2013 she called her own ambulance and was admitted to a hospital in Southport, Lancashire. The last conversation I had with her was when she called me from her hospital bed on the Sunday evening and said that I had to help her get out of there and when I said that she was there to get better she said that she thought I would understand and then put the phone down on me. I put it down to the morphine that she was on. When I called the hospital the next day (I forgot to mention that I live in London and my parents are in Liverpool) the nurses asked how quickly I could get there, everything from that afternoon onwards is a bit of a blur but my husband sped me down the motorway to get to the hospital. It was then that I found that she had been diagnosed with cancer but they didn't know the source. This came from the blood count test that they did on her being admitted – this was the first time that she had the complete blood count done. Her cancer markers were over 21,000.It later transpired that the cancer was in her blood, bone marrow and she had lesions in her spine. She had been complaining about neck and back pain but the GP had put it down to a bit of sciatica and lifting her grandchildren up all of the time. They had more tests to do to try to identify were the cancer may be but concluded with a diagnosis of CUP.We gave the doctors my mum's family background – my mum's mum (my grandma) had breast cancer when she was in her mid 60s but had it treated and survived. My mum's grandparents also had cancer although we did not know and couldn't find out which cancer

and her cousin had died within the last couple of years of cancer. Mum used to be a smoker (although not heavy) and was brought up in smokey pubs. Despite the various scans my mum's cancer was not detected and we were told that they could not cure her or even provide treatment since she wasn't strong enough for the chemo – her various illnesses over the previous months had basically run down her reserves.We spent 10 hours a day by my mum's bed side over her last two weeks in hospital. She was on oxygen, sedated and had so many painkillers she couldn't feel a thing, which is one blessing. Her condition deteriorated rapidly, her mouth was completely ulcerated (with cold sores around her lips), she developed septicaemia and had a stroke which paralysed her left hand side and most likely damaged her sight. Her family are devastated that such a beautiful, vivacious, caring, wonderful wife, mum and grandmother could be subject to such a cruel illness.On the day before she passed (which was the 3rd May 2013 at 6:10am) we were passed across to palliative care who asked us when we wanted to switch off life support – we were not expecting that question. However, before we could make a decision mum passed away the following morning at age 65 years and within less than two weeks of being diagnosed of cancer. I had thought that we had plenty of time and had gone back to London for a couple of days to clear my head and think things through so wasn't there for my dad and sister when they got the call from the hospital.I only hope that her death wasn't in vain and that I can help in some way to raise awareness of CUP whether that is through fund raising, talking to people or sharing thoughts and partaking in discussions through this website.

> Michelle, What a sad story. How awful is it that most GPs have no time to thoroughly investigate their patients illnesses and your Mum suffered so much. It strikes a cord because I also live in London and my parents are in Southport, but in our case it was myself who was diagnosed with CUP. I am 4 months past radiotherapy and thank god my 3 month scan was disease free. I myself had no idea about CUP until diagnosed. I am so sorry for your loss. Love & Prayers, Susan*susan* says on May 7, 2013 at 8:54 pm
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> So sorry to hear your sad story. I lost my Dad to cancer when he was 62. Such a horrendous shock when you all asse you have plenty of time left. I was a CUP patient although my primary has since been discovered. I like the idea of CUP pins. It has been very hard explaining what CUP is many times over because people just don't know it exists. Sending lots of love to you and your family. You will be in my thoughts as you deal with what has happened and find a way to carry on. Xx*Kate120* says on May 7, 2013 at 10:43 pm

Sad passing *Posted on:* November 15th, 2012 *by* CarenS

Hello to all on the Forum. My wife Caren S was registered
with your site for around 2 years but unfortunately passed away last month on
16th October. Caren was initially diagnosed with CUP in April 2010. A
second opinion agreed with the first diagnosis but a third opinion 9 months
later re-did the pathology on her hysterectomy carried out 10 months previously
and found the primary cancer in one of her ovaries so re-classified it as Ovarian
cancer. During this time of limbo she had started a treatment at a private
clinic in Kent having mistletoe therapy. Mistletoe extract was injected into
her, the body's natural immune system heightened to fight the mistletoe poison
but the theory is that it also fights anything else that should not be there,

including the cancer cells. Caren had this treatment for over 2 years, her GP and oncologist were originally sceptical of this treatment, but after over 2 years were all convinced something was stopping the expected rapid spread of the cancer. The treatment is widely used in Europe, predominantly Switzerland and in Germany where they treat around 30,000 patients a year with it. Aberdeen University Hospital is now taking part in a trial with mistletoe in treatment against cancer. Caren's cancer had already spread to several areas but the mistletoe appeared to be holding things at bay, but in August things were obviously progressing but were still able to continue a happy family life, but in October things went rapidly downhill and she passed away peacefully at a hospice in Southampton. Useful links. Raphael Medical Centre http://www.raphaelmedicalcentre.co.uk/ www.mistletoeforcancer.org.uk/news/files/tag-aberdeen.html My best wishes go out to every one on this site and their families, Richard S

> Very sorry to hear your news about Caren, Richard. My condolences.
> I've never heard of mistletoe therapy which sounds very interesting. Thanks for the info and i can see the logic of boosting the immune system. I looked at the website but although it stated the aim 'to tell you more about mistletoe therapy for cancer', I didn't think it did! But your explantation was much better!*John (Moderator)* says on November 15, 2012 at 2:10 pm
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> Hi John, Thanks for your reply regarding Caren, is has been a difficult few weeks since her passing, but feel very grateful to all the medical staff over the two years of her mistletoe therapy, which I am convinced extended her life expectancy considerable. She was originally told she had around 12 months to live but beat those odds and lived for a 2 years and 8 months. During that time she also had one course of chemotherapy and radiotherapy. We had a fit, active, and happy time catching up on what time we had left and tried to do as much as we could. We managed to get around 4 holidays each year over that period including several Cruises and trips to Europe and USA including a trip to Las Vegas where we renewed our wedding vows. Our last trip was to Turkey only 7 weeks before she passed away. I have added some more web links for mistletoe treatment against cancer that you and others may find interesting reading.Best wishes, Richard S
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> http://www.cancer.gov/cancertopics/pdq/cam/mistletoe/patient/page2
> http://www.mistletoeforcancer.org.uk/therapy/mistletoetherapy.html
> http://www.iscador.com/index.aspx *CarenS* says on November 15, 2012 at 4:31 pm

Melanie's story *Posted on:* October 17th, 2012 *by* Peter MAc

After an 18 month battle with CUP, Mel, my darling wife, died on October 14th. Her story has been charted on this site. Secondary cancers on the liver were identified in August 2011 as a consequence of Mel's participation in a national screening programme for Ovarian Cancer. CUP was diagnosed and a course of ECX was prescribed which only stabilised the cancer and slowed down the growth. Following consultation with second opinion of CUP expert in Clatterbridge, a further biopsy and use of Lab 21 tests a different chemo (Irrinotecan) was used in February 2012 which did have a positive effect and it was agreed that use of the SIRT (insertion of radioactive pearls) programme at the Christie would be worth pursuing. However delayed by funding issues (we are based in Wales which does not

fund SIRT) meant that by the time we had resolved the issue the cancer had spread in the liver and the bilorubin count was too high for the SIRT procedure to be applied. Despite effforts by specialists at the Christie to reduce the bilorubin count the tumours continued to grow in the liver and treatment had to be stopped at the end of September.The care and support of the three oncologists in Mel's case was commendable but we can't help wondering whether the delay caused by the failure of Wales' health service to fund the SIRT programme and the subsequent delay contributed to the outcome.Above all its clear that patients diagnosed with CUP need specialist advice and support at an early stage from clinical staff informed about CUP so that tests and treatment options can be pursued rapidly and extensively.While other cancers have specialist oncologists and specialised nurses, the CUP patient is often left alone.Also given the lack of an identified primary it is the case that the CUP patient is often left without access to newer treatment options because of the lack of an evidence base to support funding decisions.Well that's it, rant over but it doesn't stop the deep loss we feel for Mel. Her positive attitude throughout the last eighteen months and her positive response when treatment had to be stopped were an inspiration to us all. In planning her funeral Mel and I agreed that donations would be plit between cancer research and Jo's friends.Love to all who have helped usPeter

> Peter,My Heart goes out to you tonight. I am sorry that you lost Melanie. Take very good care of yourself and let your friends float you along for a while. I lost my Yolande on Sept 18th —A Heart full of Love to you,Kathy*kathy@kathy-elliott.com* says on October 17, 2012 at 5:12 am
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> Oh Peter Im devastated for you, we hadnt been in touch this last few months as you know dealing with the death of my mother etc. My heart goes out to you. Keep in touch and take care my friend.*salliew* says on October 17, 2012 at 7:39 am
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> So sorry to hear your news Peter. The consolation is that Mel is now free from suffering but it will be very difficult for you. I completely agree: "Above all its clear that patients diagnosed with CUP need specialist advice and support at an early stage from clinical staff informed about CUP so that tests and treatment options can be pursued rapidly and extensively."*John (Moderator)* says on October 17, 2012 at 9:05 am
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> So sorry to hear your heart breaking news after such a painful journey for you all. You will miss her terribly. It sounds as if you did everything you could for her. Hope you have lots of support to help you cope as you find a way to carry on. I think it is wonderful that the memory of her will inspire donations which might help those of us still battling and perhaps help someone in the future get the specialist advice that was missing for your Mel.*Kate120* says on October 17, 2012 at 11:23 am
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> Dear Peter and Family,Thank you for sharing your (Mel's) story – so very sad to learn of your loss. Hope you find the strength from those around you and your memories of Mel to see you through this period.
> Sincere regards,D*di w* says on October 17, 2012 at 1:43 pm
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> Peter thanks so much for sharing both yours & Mel's story – my heart goes out to you and your family at this awful time. Never mind about the rant, I know how frustrated you feel. I will not pretend that the journey ahead of you will get any easier, I lost my best friend, my brother to CUP in December last year and what a journey it has been

for our entire family.We definitely all need to raise CUP awareness, a form of cancer I had certainly never heard of until Paul was diagnosed, which of course during my search bought me to this amazing site, which has helped me to realise we are not alone in our quest for more specialist care.Each to their own, but I have say that I attend bereavement counseling once at week at our local hospice, who were amazing to Paul and have found this service amazing for me. X Take care my thoughts and prayers are with you and your family x Please feel free to contact me should you wish to chat x*Tanya* says on October 18, 2012 at 9:02 pm

Thank you all for your kind commentsover 250 people attended Mel's funeral. Many of her ex students -she was a French teacher. We take each day as it comes but some days are tougher than others.We'#re checking with the funeral director how much ,oney was raised for Cancer research and this website-we were told that there were lots of donations.Tanya I might contact the local hospice to find out about bereavement counselling. Are you still going?LovePeter*Peter MAc* says on November 3, 2012

Lab 21 *Posted on:* September 20th, 2012 *by* Janet Bell

Just thought I would share this information with everybody – and that is all it is – information. My husband died of CUP last December. Because of needing to know where the primary cancer was and to hopefully rule out the possibility of it being genetic, I paid to have Lab 21 examine the tissue sample retrospectively. This took 5 days and came back as 95% positive for Mesothelioma. This came as a shock, but I felt these results acknowledged the acuracy of Lab 21, certainly in my husband's case. I don't know if this posting will be of any use to anyone, but I felt it necessary to share this. Janet

Thanks for sharing that information, Janet. I'm in the process of getting my biopsy tested by Lab21 myself so I will also let people know how I get on. Perhaps it will help others having to make tough decisions.

I'm so sorry about your husband. You must miss him very much.Kate*Kate120* says on September 20, 2012 at 4:14 pm

Hello KateYes I miss him so much.Good luck to you though Kate – knowledge is power, so make sure you are kept informed every step along the way. Janet x*Janet Bell* says on September 20, 2012 at 4:22 pm

Hello JanetThis is Anne from Australia so sorry for your loss my Husband Doug is the CUP sufferer I keep reading about Lab 21 What is it??? They have not used that term here unless it comes under another name in Australia.Good Luck and Take Care Anne x*anne ibbotson* says on September 21, 2012 at 12:18 am

Thanks for posting that information Janet. Was Mesothelioma mentioned / considered at all in the diagnostic process? (I had a friend who died recently from it and she thought a house she had once lived in had an asbestos problem but it hasn't affected her husband.) I do agree that knowledge is power and to a certain extent knowledge helps dispel fear. It is the unknown that is so frightening.Anne please see this page of our website for an explanation

http://www.cupfoundjo.org/diagnosis_and_treatment/special_tests.html
Just as bioTheranostics uses Lab 21 in the UK, some of these companies may have an arrangement with a supplier in Australia and its worth looking at their websites.*John (Moderator)* says on September 21, 2012 at 9:08 am

Hello againIn response to Anne – I only found out about Lab 21 after my husband had died and from this web site. So John's web site direction is the best thing for you to look at. I know from here in the UK that they are associated with Cambridge university. John, in answer to your question – the fact that my husband worked with asbestos in the sixties, he was aware of the possibility of asbestos related illness and always feared mesothelioma. This was the first thing he told doctors and specialist when symptoms appeared. He had many tests, scans and xrays, but none of them showed a problem. They seemed to rule out the connection quite early on and spent all their time searching for an unrelated primary tumour. I have since learned that a simple specific blood test should have picked up the indicators. I was also told that simply living in a house with asbestos or working where asbestos was, even if it was undisturbed, could still cause this dreadful illness to take hold. The fact that your friend but not her husband contracted it, seems quite common. In the same way, other people who had worked where my husband did, have managed to escape it. It's a cruel world where individuals are picked out like this. Janet x*Janet Bell* says on September 21, 2012 at 10:03 am

I've now had my Lab21 result. It came back with a 90% probability that the primary site is/was cervical, ruled out 2 cancer types with 100% probability and a whole load of others with 95% probability. Unlike the example report I've seen, it didn't suggest any other possibles. The oncologist did say that this is cutting edge, early days for this kind of test etc but as the probability is so high and makes sense given some other things in my history, this is now influencing what happens next . For example I've been referred back to the gynae dept for further searching, and the chemo they are considering is one that would be effective for cervical cancer. I would say it has been useful and has firmed up some 'best guesses'. On the other hand, it does throw up some difficult issues, for example whether to have a hysterectomy based on a test which has not yet proved itself in the eyes of the medical community.*Kate120* says on November 14, 2012 at 1:02 pm

Thank you all for info. Confirms my suspicions re oncologists using valuable time to concentrate on nearest upper/lower body sites where lump in lymph nodes appears. My case left groin, weeks looking at lower and reproductive area negative, benign cysts only, when all indications have had point to upperbody left side. Started several years ago non stop post nasal drip with bad taste and intermittent bleeding left nostril. Heaps testing all ruled out usual suspects, but thyroid nodes said benign cysts. Have history long term cysts various areas. Had one left side head removed still tender. Now they say is too late due to spread although liver still clear. Is it too late to find primary? My second opinion suggests oesaphagous or a skin cancer lesion gone unnoticed being biopsy showing squamous cell carcinoma. Iam told not much point further tests due to likely already spread e.g. nodes in lungs & spleen probably metastic. Who to believe, expensive private testing as pensioner.*Katherine* says on November 18, 2012

My Darling Daughter Sarah *Posted on:* August 19th, 2012 *by* lesley

My darling daughter Sarah lost her fight for life on the 27th June 2012. I was with her when she passed away in the early hours of the morning. Sarah was diagnosed with secondary liver cancer of unknown primary (CUP) in February 2011. Sarah had just turned 26 years of age in the January of that year. She passed away aged just 27. Prior to diagnosis, Sarah was fit and healthy throughout her short life, she had never smoked and rarely drank alcohol. She was a gym queen and was in her second year at university. Initially, Sarah had pains in her tummy and had begun to feel very tired. In time Sarah was offered a scan and this is when it was discovered that her liver was enlarged, a biopsy followed diagnosing CUP. Like many others we had never heard of CUP and was so very scared when we realised what it meant. It was as if we had walked into a nightmare that we would never wake up from. One of the things that shocked me was the medical profession and the way they delivered the prognosis. Although, Sarah had chemotherapy, all it did was to destroy her more and took away the vibrant girl she was.The first oncologist did not give us any hope and it seemed nothing in the medical world could help Sarah. we were all so frightened. The fear never ever left us because no one seemed to want to give us any hope. We are a postive family and we helped Sarah and each other without much help from anyone else other than Sarah's GP who was with us throughout. Needless to say we asked for a change in the oncologist and thankfully the second one was more human in his approached and did try to find the right chemotherapy to help her. Sadly, it did not work because like so many others with CUP, they could not detect the primary cancer, nor did they really try.Sarah fought for her life with every breath she had but the cancer spread to her young lungs and totally destroyed my beautiful daughter. More hope should be given to CUP and much more public awareness. I have been giving to cancer research for nearly 30 years, more of this research money should be made available for CUP. More awareness needs to be delivered worldwide, not in time, it needs to be now.I miss my girl so so much, it has broken my heart that her life could not be saved. They say times heals, to me it just seems to be getting harder. I miss her more and more each day. I will never get over losing my beautiful daughter.Lesley

> I'm so sorry to hear about your extemely sad and shocking news. My heart goes out to you and the rest of your family.This is the first time I have written on this site, although I have been a member for over a year. It was too difficult during my journey, but your post made me cry as did the previous post and I wanted to write something. I lost my Mum in february at the age of 58, she was just getting to retirement. She was a very young mum and we were like sisters, I have lost someone very special, it makes me cry just to write this. I think since February it has got much harder in lots of ways but there are times when I can get on with things and I have to, I have 4 little children, but it is very hard! I think a lot about how I should of insisted on a second opion etc and LAB21 however my Mum and Dad were just dealing with the shock of the news and I didn't want to worry them further, as they had faith in the Doctors. I also felt the Doctors gave us no hope and treated my Mum that way. Although my Mum was so strong and inspirational the whole 9 months, she stood no chance. Why can't all CUP patients go to a central specialist centre, where there would be a univeral service? There must be enough cases to warrant this! Anyway sorry I've gone on about my story, but what I wanted to say was that I am very passionate about spreading the news about CUP, like yourself. Therefore if anyone knows how I could go about raising money for the CUP charity or if I held a local event, can I get flyers or posters with official CUP info on, please let me know.

Again, so sorry to hear your story. I just hope in time things do get easier and that we can talk and smile about what our loved ones said and did with less sadness. I'm sorry if I haven't been able to give you anything more positve, I guess that is why I haven't posted before, but you are thought about by lots of people reading these posts and you have been courgeous in posting your story. It is a hard thing to do to write things down as it makes you face up to things yet again.I will say I wish I posted on here at the beginning of the journey as people are so helpful and supportive. So I would urge anyone who is a member but has not posted yet to tell their story as there may be some really helpful advice. Clair*clairg* says on August 19, 2012 at 11:11 pm

Dear Lesley. I just feel so awful for you and your lovely daughter. How could this dreadful disease take one so young and full of life. I lost my husband to CUP last year and my life has come to a stand still and all future hopes and plans just dashed. But I have two children (who unfortunately do live far away) and I can't even begin to imagine what pain that would be for anything to happen to them. I am sure you have lovely memories of your daughter's life when she was well, but nothing can make up for what you must be going through now. I just want you to know that each unhappy story like yours, touches us all. Just thinking of you and wishing you some peace eventually. love Janet x*Janet Bell* says on August 20, 2012 at 9:15 am

Lesley – desperately sad. Any death is a tragedy but somehow it seems even crueller in one so young. Thank you for telling us about Sarah. I'm afraid your experiences highlight how variable oncologists can be in their approach. It is a very difficult disease for oncolgogists but we need them to be much better informed about CUP and CUP patients. My sincere condolences.Clair has added some very thoughtful comments and the story of her Mum is also very moving. We are working to promote increased understanding of the disease amongst the medical community – for example our conference in April – and I think that there are increasingly oncologists with expertise in CUP but they are still too few and far between. The NICE Guidelines and the Peer Review Measures that will come in next year will raise standards for patients in the future. There is a research trial in progress in the UK called CUP One which we are actively supporting. It should help improve the diagnostic processes. We are pushing for more research.If you want brochures etc just let me know your address and I will send you some. I'm john@cupfoundjo.org Raising awareness is incredibly important in putting pressure on the NHS to do it better for CUP patients. We have an events co-ordinator and a supporters co-ordinator who can help with things if you need help. We also have a PR agent who can help get stories into local media as a means of raising awareness.*John (Moderator)* says on August 20, 2012 at 9:24 am

Hi Lesley I have e-mailed your before but just want to say again that my thoughts are with you and thank you for posting your story at this awful time.Whilst I cannot imagine what it is like to lose a child – (I am also a mother) watching my mum and dad go through what they are going through at losing their baby, whilst I also am grieving the lose of my brother is just so awful.I am definitely of the opinion that depending on which oncologist you get once CUP is diagnosed they give the patient no hope.We all have to ensure that awareness of CUP comes to the forefront and with the help of us all and this website hopefully this will be the case sooner rather than later. There is nothing I can say to ease your pain, as I watch my mum each day it is so awful, to see the pain of her losing her child, and I feel so helpless and sometimes guilty that my brother was the one taken by this awful disease.Take care and e-mail

me anytime, if you ever want a chat, I can give you my number Much loveTanya x*Tanya* says on August 21, 2012 at 9:19 pm

I can completely understand as my husband lost his battle this year, it is the fear that no one can understand in this diagnosis and the feeling of complete helplessness. No one has any answers or it seems any hope and you just watch the one you love deteriorating so fast. I have my faith as did my husband and it was worth more to be honest than any medical professional could give me. I am so sorry for your loss , thoughts and prayers are with you.Christinex*Christine Macdonald* says on August 31, 2013 at 8:00 am

Hi everyone, sorry for not being back in touch sooner to thank everyone for the kind and caring comments. I can't say it has got any easier not having my Sarah in my life. I am grateful Sarah is not suffering anymore but I'm still shocked and annoyed at what this terrible and cruel disease did to Sarah. It came from nowhere, and destroyed our world.Throughout Sarah's treatment, I never gave up hope. To me where there is life there is always hope.I have been reading others stories and feel so much sadness. I still feel there isn't enough information regarding CUP, often when adverts are on air regarding cancer, why isn't CUP ever mentioned, or have I missed it???For me, Christmas time will never be the same without Sarah but I try my best and paint a fixed smile on for others. I will be writing my Sarah a card with a special message. Take care, my thoughts and prayers are with you all over Christmas. Lesley xxx*lesley* says on December 20, 2013 at 10:52 am

Hi LesleyMy heart goes out to you, I know watching my Mum struggle from the loss of my brother, Paul breaks my heart everyday whilst also dealing with my own grief, it truly is so awful for a mother to lose her child.
We were the same with Paul never giving up hope, how true where there is life there is always hope.I have got myself involved in raising awareness of CUP, during the awareness week this year, I did an article in our local paper and sold the pin badges. The response I received was amazing, hardly anybody had heard of CUP. I am hoping to arrange more events around the awareness week next year, so that CUP hopefully becomes as recognised as all other types of cancer.I am sure Sarah will be with you in spirit over ChristmasTake care and my thoughts and prayers are with you and your family at Christmas – Tanya xxxx*Tanya* says on December 22, 2013 at 1:38 pm

My Dad's story *Posted on:* August 19th, 2012 *by* jeanette

This is the story of my lovely Dad who died in January this year, aged 71. I'm sharing it as I hope it may be useful to anyone else out there looking for answers in their fight against CUP.My Dad originally went to his GP in May 2011 complaining of back pain. After a couple more visits at which he was told it was most probably a muscle strain, the GP eventually found a lump in his side and sent him for a biopsy. He was diagnosed with a secondary tumour in his rib/chest wall in around August with the primary cancer unknown, although from the beginning his oncologist thought there was a strong possibility that the primary originated in the bowel. A colonoscopy came up clear but the oncologist still suspected bowel cancer and my Dad started on ECX1 chemotherapy on the CUP1 trial at Maidstone hospital in September. The plan was for him to have two cycles of chemotherapy if, after the first, scans showed some improvement in the size of his tumour.The

chemotherapy made my Dad extremely ill almost immediately. The sickness and constant nausea made him lose an awful lot of weight and most days he was unable to keep any food down at all, surviving almost exclusively on drinking yoghurt. Immediately after his diagnosis, my Mum had put my Dad on a cancer fighting diet (turmeric, green tea, lots of fresh fruit and veg, dark chocolate etc) but this went out the window once he started his chemotherapy and couldn't eat.It wasn't until scans showed that the first cycle of chemotherapy had had no effect and his secondary tumour was still growing that I discovered this website and found out about molecular profiling and LAB21. We had already asked my Dad's oncologist whether there were any other tests that could be done and hadn't been told about molecular profiling. We immediately arranged for the test to be done privately by LAB21 which they were able to do using my Dad's original biopsy. I believe it cost around £2500. Within 15 working days, LAB21′s tests showed that my Dad's primary cancer had a 99% probability of being cancer of the kidney.By this time, my Dad was too ill and weak to have a further course of chemotherapy targetted at kidney cancer but was told that, if he could build his strength up, this might be an option. Unfortunately, my Dad's secondary tumour was still growing and was by now spreading to his stomach. By November, the tumour on the rib and chest wall was so large that it pressed on his spinal column paralysing him below the waist. He was admitted to hospital for 2 weeks as he couldn't walk or go to the toilet but finally came home once we'd been able to set up a hospital bed etc in a downstairs room and arrange for carers to come in 4 times a day to help my Mum with his care. He deteriorated quickly, getting thinner and thinner and needing to take ever stronger pain medication which made him drowsy and incoherent, until he finally died at home on 21 January 2012, a shadow of the vital, funny, intelligent man we had known. His death certificate said cancer of the kidney.I've gone through the whole range of emotions before and after my Dad's death but one of my recurring thoughts has been "What if we'd had the LAB21 test done earlier?" Would we have known that he had kidney cancer in time for him to have received the right type of chemotherapy or even surgical removal of an affected kidney? We will, of course, never know. Regardless of the NICE guidelines which say that molecular profiling isn't available on the NHS, I do feel strongly that oncologists should make CUP patients aware of the availability of these tests. One of the hardest things about a CUP diagnosis is that feeling of helplessnesss, the feeling that the medical profession is simply stabbing around in the dark - and I don't feel patients should be denied any information which may just make the difference between a diagnosis of CUP and an accurate diagnosis of a "proper" known cancer.Initially, I was angry that my Dad's oncologist had made the decision not to tell us about molecular profiling and that we had to find out about it ourselves on this website. Now I just feel sad.Jeanette (daughter to John Archer)

> Dear Jeanette. Your story rings so familiar to my husband,Tony's. He was experiencing an ache in his ribs back in May 2011 and was sent for xray and various tests – these all came back clear. The pain didn't go away and he was keeping it under control to some extent with paracetamol. He was still going to the doctors on and off, but any results or blood tests that were done showed nothing. It was assumed he had shingles without the rash – which is more painful. By the beginning of September he was looking really poorly and in desperation we booked him in for a private appointment with the consultant. He was sent for a scan, but these results were delayed in getting back to us and we had to make another private appointment at the end of September to be told he had secondary cancer of the rib cage/chest wall. Primary unkown. From here it was down hill fast – he did have a biobsy, but no treatment, and died at the beginning of December. I knew nothing about lab 21 until accessing this site. I have now paid to have the biobsy sample analysed

retrospectively and will know the results when I see the consultant this week. It took five days for the results in my husbands case. I feel so angry about not knowing that we could have used lab 21 in the early days and maybe had had some positive result and medical action. He was only 66 and we have all been left devestated. I so feel for you and your family, it is such a terrible cancer and is over so quickly. My love to you all. Janet x*Janet Bell* says on August 20, 2012 at 9:06 am

I entirely agree with what you say Jeanette and I'm very sorry about your father. Many of the medical profession are'nt keen on molecular profiling for no good reason. Apart from the clinical benefits of getting more information to compare with the histochemistry etc. many do'nt understand the psychological benefits that come with having "the unknown" element removed and being given some hope (and some comfort for those left behind if the patient dies).Doctors are usually very clever people so I struggle to understand their attitude to this.*John (Moderator)* says on August 20, 2012 at 9:57 am

Hi JeanetteMy heart goes out to both you and your family, it is such an awful time for you all.Your storey is just like deja vu – one of my brothers first symptoms was back pain, as I think were quite a few.We lost Paul in December of last year and like you both myself and our family question if we had asked about Lab 21 earlier would Paul still be with us, along with the other million questions we ask ourselves that may of helped. I am of the opinion from our experience the minute you are diagnosed with CUP you are basically written off. My aim is to enhance awareness of CUP particularly for the medical profession. It may not help those we have lost, but hopefully it may help patients diagnosed with CUP in the future.My thoughts are with you and your family, the great think about this site is that we can all understand what the other is going through, which gives me great strength.Stay strong – take careTanya x*Tanya* says on August 22, 2012 at 9:55 pm

My Love My Life My Wife *Posted on:* August 8th, 2012 *by* duvlin

After a year long battle against CUP secondary liver cancer my wife's hard fought and brave battle has finally been lost. Her fight has been an inspiration to many people as she did not give in to the cancer and was determined to live as normal a life as possible. We did do many things over the year which has given us many memories to add to those we already had and she will remain in our hearts and minds for the rest of our lives. I do know that Julie and I have spent a lot of time over the last year trying to explain Cancer Unknown Primary to people and how the not knowing make treatment harder to define. Most people can not believe that they can not find the primary and have taken time to try and understand to the problem. We did have a second opinion by the royal marsden and they did further testing on the biopsy using a new method and did give us a high probability of the primary which did help steer the treatment.As we did not want flowers at the farewell many of our friends and family have chosen to make donation to the CUP foundation (I set up a just giving page linked to the CUP Pages) to try and help fund the research which is a credit to how my wife highlighted the problems.I also have to thanks everyone on this forum and the CUP foundation site for all the support and information provided as it has been a godsend to find others that know about the issue around CUP which helped me gain a better understanding of the problems we encountered.After the services at the church and crematorium we had afternoon tea (for 200+ that attended the farewell) as my wife had enjoyed many of these

over the last year with her friends and family. During the tea my Nephew sang a song that meant a lot to me and said everything I felt and wanted to say. It is a modified version of Full of You by Rick Astley (he was topping the charts when we met 25 years ago) and I would like to share this with you all. I am going to try and see if we can get permission to use this to raise further funds for the much needed research and will let you know how I get on with this. Link to song: http://www.youtube.com/watch?v=2QN6U_2CTJs&list=FLDI2be2OZ-LO8F9lcaVs7JA&index=1&feature=plpp_video This is an awful time but I am determined to do everything I can to support others that are suffering as we have and use Julies fighting spirit as my inspiration.David Knapp

> Dear DavidYour story made me reach for my ever-present tissues; again. One of the troubles with loving someone so much is that they become part of you, and when they are no longer there – part of you goes with them, the pain is emotional, physical and indescribable.I live in Southern Catalonia, last Christmas day my wife and I were messing about on the beach with our silly dog. Sandra was beautiful and as bright as a button. A while later she developed pains in her back which progressively got worse and she was admitted to hospital with, as they thought, severe sciatica. The medical services here are superb, she had masses of scans and things but to no avail – they couldn't find the source of the problem. In Spain it is usual to stay with the patient 24/7 if you wish, I did. On the 28th of March last Sandra died in my arms. We had been together and, for the majority of the time, very much in love, for fifty seven years. You'll no doubt get all sorts of advice from all sorts of folks. They'll range from "I'm so sorry I don't know what to say" which is easy to deal with; but you'll also get the well-meaning sorrowful "Oh you poor dear…." That's harder….My granddaughter is arranging a run in aid of the CUP foundation, the link is below.
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> http://www.justgiving.com/SarahHawley81
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> The 'Cruse' help web site is not at all bad and not as creepy as some similar American sitesIf you ever need to contact anyone who knows exactly what the numb-trauma you feel is like. Please feel free to mail me at scanna@spansurf.comWith my sincere regardsPeter*Peter R* says on August 8, 2012 at 12:46 pm
>
> I'm so sorry to hear your news David.This will be a very tough time for you, I know. It is very good of you to support our work for the benefit of others in Julie's memory. We use any money raised for us extremely carefully knowing how important it is to honour the memory of the person who has died; and we remain committed to working effectively to help "make the unknown, known".John*John (Moderator)* says on August 8, 2012 at 1:51 pm
>
> Dear DavidI am so sorry to hear of your loss, I lost my brother in December of last year to CUP and also found this site and the members both a godsend and an inspiration.Like many people neither Paul or I had heard of CUP before he was diagnosed, so this website proved invaluable to me in my quest for information (well truthfully in my search of a cure) hopefully with the help of this site and research this one day will happen.Take care David my thoughts are with you and your family Please give yourself time to grieveTanya xx*Tanya* says on August 8, 2012 at 10:45 pm

So sorry to hear your news. Not knowing your wife there is not much I can say that isn’t a cliche. But I do send you warm wishes as you come to terms with the huge Julie shaped hole in your life. I think it is amazing that you are doing something good for other CUP patients, like me, in her memory. Thank you.Kate xx*ate120* says on August 9, 2012 at 8:28 pm