

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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Tom's story *Posted on: November 19th, 2009 by tommcveigh*

In July 2008 I had a 'lump' under my right armpit (I soon learned all the medical terms for such places). GP thought it was just a small problem with my lymph nodes, but anyway I was referred to Ulster Hospital, Dundonald, Belfast where they immediately diagnosed cancer. Underarm and in my neck (right side). I had all sorts of tests but they could not discover the primary, so in October 2008 I had 15 Radiotherapy visits and then 6 cycles of Chemo (Cisplatin plus 5FU). This finished in April 2009 and I have been great since then. However on a review and CT Scan in October 2009 a small cancer was noticed in the lymph nodes in my left groin, and another very small one in my neck (left side this time). Went to see consultant yesterday and he say not to worry , come back in 8 weeks time and they will consider another cycle of Chemo, Cisplatin and 5FU again. Basically that is my story so far, and I mean basically. There was alot of hospital visits,

Scans, worries (me and my family) and a lot of prayer, which I found most helpful too. Anyone who wishes to comment or to help/assist me or tell of similar problems or indeed just chat they are most welcome. After the Ulster Hosp, my treatment was carried out at the Cancer Centre, Belfast. Regards Tom

Cancer disappeared from scan *Posted on: September 30th, 2009 by June Courtney*

My husband just got the good news this morning that his latest scan after a very aggressive course of chemo shows no signs of any cancer cells in his body. We realise this is probably just a reprieve until it attacks again but would like to know if the cancer does return will it be diagnosed as a brand new cancer from whatever part of the body it appears or will the original diagnosis of secondary lung cancer with unknown primary still be the case? We would also like to know if the new drug Low Dose Naltroxene would be beneficial to him in building up his immune system and warding off any future cancer cells?

Hi June I am very interested in your post as my partner who is 55 has been diagnosed with unknown primary with lung secondaries. He has had 7 cycles of chemo that have had better results than they thought it would and are now talking about doing a genetic test to do with bowel cancer (they think that his primary might be in the bowel but they can't find it) I was so happy to read of your husband's fantastic news, long may it continue. Please keep us updated. So sorry that I can't help with any answers to your questions but I hope that someone else may have the knowledge that you need Diane xxxx *ladybug13* says on October 26, 2009 at 11:50 am

Was so sorry to read about Jean V. I hope that was not the fate of those who used to post comments but have been silent for months. I have been in the hospital so often since July and just got out again last week. The initial confinements were not directly related to CUPS but now it seems there is a problem with some lymph nodes compressing my Vena Cava causing my legs to swell and hurt. The radiation oncologist said she did not believe radiation would be a viable option as it would have to be low dose (cause of my moderate doses in 2007) and would not reduce the size of the node(s) or move it from the VC. So now I have to talk to my oncologist about going back on chemo. Been off for months cause of procrastinating about the spinal fusion surgery. I now have 3 compression fractures in my spine cause of severe osteoporosis and the degenerative disease has gotten worse on the lumbar spine. Seems only the surgeon thinks surgery, for some spinal stability, is a good idea. The other MD's don't seem to like the idea. "Quality" of life keeps popping up in conversation along with length of time and stress of rehab. Hope I'm wrong but it sounds like "the other shoe" may be falling and time is not going to be on my side. Within the next couple of weeks I am going to have a pain pump implanted in my spine. Had the trial last week and though I still had pain (they did not try for dosage but, rather, whether it would help. It certainly did. Felt better than I had in ages! Wasn't drowsy, didn't feel like a veil was over me, my appetite was good & the pain eased on the dose they used. Do any of you have a pain pump or know anyone who does? Pray all is well with all of you who used to be on this site—thanks John (case I don't get a chance to say it later) for setting up a site like this to communicate-or just to vent. Kathy *Kathy R* says on November 17, 2009 at 11:52 am

Insurance companies and paying for treatment *Posted on: July 10th, 2009 by John (Moderator)*

I wondered if I could pose a question which I suspect may have very different answers in different countries? The costs involved in cancer treatment can be very significant to the patient and family. Some people will be treated in their public health systems but there may still be treatment costs; some will be treated privately outside a country health system (where one exists). In some countries treatment regimens are determined by the nature of the cancer, and health care insurers – if you have one – will only pay for treatment which has proven benefits for a particular anatomical cancer. This is where we come back so often to the difficulties of

the Unknown and Orphan Status of CUP. Has anyone had problems with insurance companies because it is CUP? Are there any general lessons that might help others. I think it might be wiser not to include company names but please make clear what country your story relates to (we are currently being accessed by people from 67 different countries!)

😊 John-my entire work background has been in the health insurance industry. The changes in the USA health system has gone through incredible changes over the last several decades. Payments depends on so many factors. This is complicated by health care “laws” can change state to state and policy to policy. An HMO will not pay-at all-if you go to a provider not in their plan. A PPO policy (mine) is much more lenient. They will pay to out of network providers but some pay different than their normal benefits and all take some kind of penalty for going out of their network (like a 10% reduction in benefits and or different deductible and co-insurance amounts. Benefits also change depending on the plan your company (or you) are willing to pay for a premium. My company policy pays 100% of contracted amounts for all cancer services after my \$200 calendar year deductible. We have a million dollar calendar maximum (includes ALL claims not just cancer claims. My company pays the whole premium—if I wanted to take a leave of absence I’d have to pay \$256.00/wk for my coverage which includes life insurance, dental vision, medical. If I retire I have to pay \$100/month but it pays 80% after a \$100 deductible and maxes at \$150,000.00 a year which is one reason why I don’t retire. As far as a CUP diagnosis making a difference, the only problem I’ve had is that my doctor said she felt the insurance company wouldn’t cover some of my cocktails cause they aren’t FDA approved for “my” cancer. I told her how does she know it’s not used for my cancer if we don’t know where my cancer is. With my company this is not an issue but that is an exception. Most companies do “pre-cert” certain procedures and will not approve PET Scans or MRIs if they feel there is no evidence that it would be useful for my diagnosis. I know there are guidelines for what diagnosis PET scans will be covered. I have had two with no issue. They may also reject a treatment if they feel it is not under the FDA guidelines. These denials can always be appealed through the company. Yesterday at work I had to explain to a hospital that we rejected a \$121,000.00 hospital bill, on a retiree (who retired because of his cancer) who had already met his \$150,000 policy annual maximum. Hopefully they will work with the patient and write off a good portion! I know my oncologist rarely puts my true diagnosis. She’ll say a test is needed because of my “adnocarcinoma of pelvis/abdomen” and NOT write “unknown primary”. Or they’ll put my other cancer or combine the two. Gets me very frustrated. I remember, early on, I went to make an appointment for a CT Scan of pelvis/abdomen and she did put unknown primary. I had a dickens of a time trying to get the scheduler to understand what that was. She kept saying “but where is the prime site?” and “how can it be unknown”. She was hesitating to schedule it but I gave her my diagnosis code and she went ahead and set it up. Hope some of this helped.———Thanks, John, for keeping this site going.

Kathy *Kathy R* says on July 14, 2009 at 11:52 am

Thanks Kathy – that is really helpful. What you say about hiding the CUP diagnosis illustrates the difficult issue of needing to be pragmatic to ensure an acceptable outcome but by doing so perpetuating the problem of a disease with no name. (I think the oncologist very wise to do so, don’t get me wrong. You don’t want to be fighting a political battle at that time – you need treatment paid for without hassel.) *john symons* says on July 15, 2009 at 11:53 am

I had a lot of trouble with a private health insurer this year in the UK. My oncologist determined that Herceptin (the breast cancer drug) would likely be an effective drug for me (because the biopsy of my cancer showed that that it was “off the charts” for HER2, and Herceptin is specifically recommended in situations (albeit typically breast cancer situations) where HER2 is overexpressing. The insurance company denied coverage on the grounds that the “cancer was of unknown primary” and very rare. They cited their policy which provided that “Any form of treatment or drug therapy which in our reasonable opinion is experimental or unproven based on generally accepted medical practice” will not be covered. We did not give up. We called them, we emailed them, we had my oncologist write a letter, and my husband and I wrote letters tearing apart

their contract (we are both lawyers). Essentially our argument was that by refusing to authorise any treatment for my CUP, they were effectively saying that CUP was an excluded cancer and yet nowhere did their policy state that they did not cover CUP or rare cancers. Generally speaking, any ambiguity in an insurance contract is interpreted in favour of the insured. They still refused to cover me so we decided to sue them for breach of contract. We had to hire external counsel to do this because the insurance company's head office was in a different country, but within a few weeks they acquiesced and agreed to cover my treatment, which I am undergoing right now (and have had two cancer-free scans in the past four months 😊). I think it is terrible that insurance companies' first (and often only) reaction is to refuse to cover treatment for CUP, and I know that not everyone has the resources to wage a legal battle while they are also battling with their health. I would be happy to chat with anyone who wants to discuss this further. Katherine (kplondon) [kplondon](#) says on July 15, 2009 at 11:55 am

Another MD CUP patient *Posted on: July 5th, 2009 by Midge McBride*

I live in Woodbine, MD and I am receiving treatment in Rockville, MD. In the magazine Cure I found the article mentioned in another post called "No I.D." Very interesting, yet I find things are not too promising. Having had back trouble for a number of years, last fall, a new area of pain was reported (I called it butt pain) and I was sent to have an MRI and then bone scan. Metastatic cancer was the suspicion through out hips, pelvic bone, upper legs, and the largest spot on the sacrum. I had numerous other tests, and no other areas showed up, nor did the primary. A biopsy was taken from the largest area, the sacrum and it was determined to be cancer. I had 4 treatments, one each 3 weeks. At first it was taxol and carboplatin and the last 3 was taxotere and carboplatin. After the second treatment, the PT scan was clear!, but I still had to have treatments 3 and 4. Thereafter the PT scan was clear and I was told I was in remission. Four months later, May 2009 a PT scan showed it had returned in all spots except one. So, my story is now I have had one treatment this round so far, taxotere and carboplatin, and will have another next Wednesday. A few weeks thereafter, I will repeat CT and PT scans, and then, depending on result my oncologist will decide what to do. I guess my story is not unusual in this area, but these treatments lead to great fatigue, and I have had to cut way back on work. Of course I lost all my hair the first time (in the fall), and now I am starting to lose it again. I say I am semi retired. Oh, also, it was found I am allergic to contrast, so I don't have tests with contrast any longer. I am 68 years old and remarried 8 years ago. 10 years ago I lost my first husband shortly after surgery for esophageal cancer. I would welcome treatment information and drugs used on other CUP patients. Midge

Hi Midge I was diagnosed with CUP & started Chemo December 2007. I had 6 sessions till April 2008. They used Taxol, Carboplatin & Etoposide. The initial biopsy was in the right groin. The retrosternal lymph nodes were also enlarged. I'm 64 and a retired nurse. I live in Ontario Canada so benefit from the Canadian health care system. My big problem is I don't have the energy to do everything I want to do. I'm not sure if its a true fatigue or I'm just tired of being sick. I hope things go well with your treatment. There seems to be so few of us. My friends call me a cupcake. Dianne [Arcticnurse](#) says on July 7, 2009 at 11:19 am

😊 Hi Midge; Welcome to this site. Caarbo/Taxol was also my 1st treatment but after 3 cycles, the CT's (I also am now allergic to the dye and they do MRIs now) showed the retroperitoneal mass had grown so they changed my cocktail. Excuse my curiosity but did your doctor say why he is using the same treatment if the first time around you didn't stay in remission? I had been told that cancer cells are smart "little buggers" and they become immune to the drugs which is why treatments are changed. Another doctor told me that after a year they may consider revisiting a previously used drug. Dianne, I see you had taxol/carbo WITH etoposide. How were you on that combo? I asked about Etoposide (it's the only drug I've seen that actually states it's used for CUPS) last Nov and was told it is very toxic and that patients have a lot of trouble with it. They did not put me on it after the Xeloda. Just the 5fu AND AVASTIN. Midge—did they give you anything for the "butt" pain? I used to call mine "my pain in the a__". Nothing has really helps me but Dilaudid and my oncologist

and PCP both dislike me being on regular doses of it. Does help the side pain and most of the leg pain but not much good on the back pain. All scans (CT, PET MRI, bone scan, etc) show no cancer. None of the patches have helped either. What do you do for the pain? For treatment, etc, that we have all been through you might consider glancing at some of the past e-mails on this site. Wishing you the best.

Dianne—sorry to hear you are not up to snuff. It was SO GOOD to hear someone else say “I’m not sure if it’s true fatigue or I’m just tired of being sick”. I feel like such a wuss when I feel that way, especially since they all tell me that this is not a result of the cancer—tho all the 3 1/2 yrs of chemo and the radiation may have had some influence in progressing the decades long back problems. Too often I hear myself saying “I just can’t take this anymore”, “I just can’t do this anymore”, etc. How do you pull yourself out of that frame of mind? Hope your MD visit goes well. Kathy *Kathy R* says on July 14, 2009 at 11:20 am

Kathy, Thank you also. My doctor’s thought was we know that what we used worked and they go the same route again. However, I am having PT and CT scans tomorrow after two treatments to see if effective or if they need to change something. As for the butt pain, he offered radiation. I refused for now because I don’t want any more problems in that area and I am doing OK. ONLY problem, I can’t walk or stand longer than 5 minutes before it comes back on. I was already on Lyrica because of the preexisting vertebrae being out of line. I am just now trying to change to the generic, gabapentin. Things could be better, but if really bad I can take percocet. So I am really dealing with pain which may be because of the cancer or may be because of the spondylolisthesis. The pain I have now is not that low. I kind of think of it as the cancer is not active in the sacrum, but we’ll know by Friday. Wishing all with this horrible disease well and prayers. Midge *Midge McBride* says on July 22, 2009 at 11:21 am

I made an error in my last post. I was trying to get off Lyrica because it’s terribly expensive and I am paying for all drugs in full now (being in the “donut hole”). So, we are changing to 300 mg gabapentin (or neurontin) 3 times a day. There is NO general for Lyrica. Lyrica is great for nerve pain. I think I am just getting used to it or my tolerance for pain has increased. I had PT and CT scans today. I am very uncertain about the results. Just a feeling. Midge *Midge McBride* says on July 22, 2009 at 11:22 am

☹️ Dear Midge—sorry it has been a while since I have been on line but I have been in the hospital twice since my last posts! Evidently the fall June 4 started a hairline fracture that was not seen on the ER X-Rays and on Jul 19 I had a compression fracture of L-1 vertebra. They put me on Fentanyl patches 200mg, then 225 mg then on my DISCHARGE DATE 300 mg instead of observing me for 24-36 hrs on that dose esp since they skipped 250 and 275 mg. Was also put on Lidoderm patches for my flank area. They would not give me Avastin (cause I still have to decide about surgery and will have to be off it for several wks B4 surg) not the 5fu and Leuko... cause they said they can’t give “pushes”, only bags, as an in-patient and they can’t transport me to the treatment room for the pushes. Anyone one familiar with “Catch-22”? However—and this may help someone someday—one of the oncologists said that he would’ve just ordered 5ml of the 5-fu and of the Leuko... as that is equal to a “push” just in bag form. Man the bureaucracy!!!!!! It was a nightmare!!!! I got up the morning after discharge and — I swear to the heavens—I sat in my recliner—where I’ve been sleeping since the accident—and looked around wondering if I was dead or alive. I had no sense of being, no feeling—nothing. The doc said to remove one of the 100mg patches and next day—back to the hospital till 8/8. They played around with doses and combos (added Lyrica) to the Fentanyl and Lidoderm). The good news is that the CT of the abdomen and pelvis verified that this is unrelated to the cancer and the cancer is status quo. First my oncologist said she was concerned that spinal surgery is too close to the mass to risk the surgery not doing more harm than healing. Now she says, we should not consider the cancer when determining whether surgery should be done or not. I am so confused and scared regarding surgery that I can’t figure out what to do. They did a cementing of L-1 and it seems

to have worked well. They want to do a spinal fusion on L4-5 as they are “destroyed”. Midge—if you got through this episode, how were you on the Lyrica? Says it can cause blurred vision and, boy, did it. I do not believe the Lidoderm is helping the flank where the nerve pain is. Did it take time for the Lyrica to work? Neurontin is out cause they started me on 300mg and stopped at 3000 mg as the doc said he can’t go higher. It helped for 3 wks and was able to work et al. I have Percoset too. Shame it’s a no-no to send RX to other people cause I have sooooooooooooo many, expensive ones too!—that I could share. I have opiads bulging out of my cabinets. The real high doses may help with the pain but it makes me incoherent (in the middle of a sentence I’ve said “look at all the animals running down Austin (my street) or I’ll say “never mind that’s making no sense”. Why people want to feel like that is a puzzle to me. I was last discharged on 150mg Fentanyl plus Lyrica plus Lidoderm plus Dilaudid as needed. I am constantly dosing off (narcotics PLUS waking every 20 min to 1 1/2 hrs nightly) and still a bit out of it so reduced the Fentanyl to 100 but the “breakthrough” pain got too bad though I was way more lucid. Now we’re trying 125mg Fent, not taking Lyrica and haven’t taken Dilaudid in 2 days but pain goes from 2-4 (sitting) to 5-8 standing and walking. To add insult to injury, the patches are removing skin, too, when removed. Anyone else have this problem? What did you do? See the pain doc Thurs. Really don’t want surg (85% success rate and IF successful he believes there is a 90% chance the “majority” of the pain will be gone). Had a sleep study done last week cause the pain doc thinks I’m oxygen deprived and that’s another reason I dose and don’t sleep. Am on oxygen overnight till test results are in. Midge—you’re in my prayers and I hope your test results were positive. Please let me know. “Feelings” can be deceiving. I often “feel” negative cause it’s easier to be happily surprised than think positive and be totally let down. Patty—hopefully you will be lymphedema free. Are the TED hose support hose or compression hose? I know some insurance companies pay for the compression ones. I have those and they have helped. Chris—so glad things are looking up for your husband and he has been able to go back to work. This staying home is driving me up a wall. When I see my psin doc Thurs I want to ask her about the Oxynorm and Endone. Sorry for going on and on but this has been a godsend of a sight for me as I can “let it all out” to others who can grasp the frustration. Since I do not have a supportive family (does a 92 year old aunt count?) this site has been a blessing. My friends do what they can and that’s been everything—staying overnight if needed, shopping laundry, some cooking, doctor’s etc. Promise to try to keep it short in the future! Since all your e-mails are under various areas (Pleural Cavity, Another MD CUP Patient and Maryland CUP Story) I decided to just write on one site. Hope this computer illiterate isn’t confusing people. [Kathy R](#) says on August 18, 2009 at 11:23 am

Hi all, I have just finished treatment #4 in the second round. The same cocktail was used as before. I had a repeat PT scan yesterday and don’t know the results yet. I am now off Lyrica and successfully using gabapentin 600 mg 4 times a day. I do believe my tolerance for pain has increased. I have used those patches Kathy speaks of and had no problems except it hurt to take them off when I had to put them on the top of one leg. Don’t use them now, and have not had to use percocet for over 2 months. However, I have learned when I start to hurt, due to back issues, not the cancer, I sit as soon as possible. I can stand or walk only for 5 – 10 minutes before the back pain starts due to the vertebrae. I really have not detected any pain in the last several weeks in the sacrum (the largest area of metastatic cancer). When I have PT scan results, I will let you know. I will know for sure by next Wednesday (oncology appointment) if the doctor doesn’t call me before. Like you, Kathy, I am trying to avoid back surgery—the cancer problem is more important. I heard something today I will pass on that I liked. We are living with cancer (rather than fighting cancer), and we should live as richly as possible. Blessings to all, Midge [Midge McBride](#) says on September 3, 2009 at 11:24 am

Hello everyone, As an update, I recently went to the oncologist and learned that some of my areas of cancer are gone and a couple of the areas are still there, but smaller. I take this as good news. There will be no further chemo for now, and I will be retested in 3 months. Wishing everyone great improvement. Midge [Midge McBride](#) says on September 17, 2009 at 11:25 am

Hi everyone;What a difference a few months makes; I'm feeling great now, in fact, I'm going to the symposium in London next month.I return to my oncologist next week. I'm looking forward to the trip to London and may take in a show or two.Dianne [Arcticnurse](#) says on September 20, 2009 at 11:25 am

Pleural Cavity *Posted on: June 24th, 2009 by [chrisp47](#)*

My husband's CUP has metastasised into his pleural cavity (plaques – but its not Mesothelioma). This causes him chronic pain. He was diagnosed last Christmas (08) shortly before surgery for his AAA (Abdominal Aortic Anurism) when a blood test showed anemia. They didn't operate. I guess the good news is that since his chemo the mass hasn't gotten any bigger, but it didn't shrink at all. He goes for a PET scan tomorrow which we had to insist on, so maybe we'll find something out next week when the Onco gives us the results. He has been magnificent during this time, but the constant pain is dragging him down. The Fentanyl patches & Endone tablets are only just controlling the pain some of the time, and it still 'rages' (his words) often. I'm wondering if anyone else has a similar condition?Christine, South Australia.

Hi Chris;Thanks for your story. I hope the PET scan gived you some answers. Keep looking!. The statistics say that 4 out of 5 initial CUPs DX the prime sight is found after PETs, MRI's, CTs and utlrasounds etc.The fenyltal patches did not help me, nor did morphine pills. They are now trying Dilaudid (7 1/2 times stronger than morphine). The 6mgs take the edge off but the 8mgs helps for a while. Am also trying biofeedback and after 2 sessions, the breathing technique has helped a little during pain. Hopefully further sessions combined with the other steps will help even more.There is a very interesting article on curetoday.com by Katy Human called "No I.D." on CUPs. My sociopsychologist in the alternative therapy department gave it to me today. It's one of the more possitive articles I've read on the subject.Hopefully things will go better for your husband in the future. Please keep us posted.Kathy [Kathy R](#) says on June 26, 2009 at 10:08 am

Thanks Kathy,The PET scan showed up nothing new. The painkillers regime (Fentanyl patches and Endone) now includes Methadone which he's not tolerating very well and has already cut down his own dose because of the sleeping, cold sweats and depression. Also he has now lost a total of 15Kg. We see a Cancer Pain Management Specialist on Monday, so hopefully he can help us stabilise these medications. Chris [chrisp47](#) says on July 10, 2009 at 10:09 am

Chris-So sorry your husband is having such a ruogh time of it. Hopefully the Pain Management doctor can help. It is a good idea and my next visit I am going to ask my oncologist about going to a cancer pain specialist. The regular pain center only suggested epidural shots—which didi not help. My doc says this is not cancer pain because I get it intermittently and cancer pain is constant. This has been "constant" over 2 months—seems pretty constant to me! I'm sure there are cancer pain specialists in Chicago IL. The pain is what scares me the most.May he find relief soon.Kathy R [Kathy R](#) says on July 14, 2009 at 10:10 am

Hi,The Cancer pain specialist has helped a lot. It seems the 3-day Fentanyl patches were only lasting 2 days, and the days when he was very ill (even he thought he needed to go to a hospice last time) he was actually having withdrawals. So now we change patches every 2 days and he is now on Oxynorm instead of Endone and things are looking up. The pain guy even gave a name to the 'sore skin' he has – its nerve pain (forgot the name, but it starts with 'A'). Even clothing bothers his front chest skin – like sore skin when you get the flu. Thankfully he is feeling a lot better these days. Chris.But now its Friday and I spoke too soon. The universe decided to give him a savage bout of Vertigo just for the hell of it. That was scary until we knew what was happening – there was talk of brain tumor, mini-stroke and virus – but a brain CT scan showed completely normal. Things have settled down now. Wonder what it'll throw at him tomorrow? Chris. [chrisp47](#) says on July 16, 2009 at 10:11 am

☺Chris— my heart and thoughts go out to your husband—and to you. I was a caregiver to my mother during her 5 year fight with Lymphoma and sometimes being the caregiver is harder than being the patient! What dose is his Fentanyl patch? Mine was only 50mg so I'm not sure why she took me off instead of increasing the dose. I am going to look up the Oxynorm and Endone and talk to my oncologist next visit. Last week and this week are my 2 weeks off chemo so I'll see her the 29th. One of the things I so like about this site is the various information you get from people sharing their experiences. Who knows when something posted can help someone else. I see a neurological surgeon Weds. If he is no help I may try a spinal surgeon and when that fails my psychologist said she can refer me to a palliative care center and I may try MAYO Clinic. I have submitted a request to my company to pay for a power chair or scooter cause the pain is so bad when I walk. I cannot imagine what your husband is going through. At least he is so fortunate to have you there by his side. I've heard of too many cases where someone was diagnosed with cancer and their spouses couldn't deal with it and left the marriage, or their children were no where around to help out. Do people tell you, like they did me, "you'll get your reward in heaven"? Considering my situation, think a "reward" now would be nice. Hopefully, "tomorrow" will throw some really good days at him. Keep the faith. Kathy R *Kathy R* says on July 18, 2009 at 10:11 am

Hi Kathy, Thanks for your good wishes – they may have worked! The Vertigo is almost gone and changing the Fentanyl patches (75) every 2 days is working well. With taking half a Methadone each night, he is taking a few less Oxynorms during the day. He went to work (light duties) today for 3 hours. He works in a health services environment and enjoys the focus being on someone else for a change ☺ Have you asked about your power chair and did the neurological surgeon help you? Chris *chrisp47* says on July 27, 2009 at 10:12 am

Radiotherapy John is half way through a 12 day radiotherapy treatment. It is making him much more tired than Chemo did and the nausea is once daily if he forgets the Maxalon. The radiotherapist cheered us up by saying he'd "blast the crap out of it" ☺ Wish us luck! Chris *chrisp47* says on August 18, 2009 at 10:13 am

John completed his Radiotherapy in September and has had 2 CTscans since. Both have shown no reduction in the disease, but no increase either. 'Stable' is a good thing. He has relented and gone onto Anti-depressants which actually have helped him. The panic attacks were becoming debilitating. It did take a while to stabilize them and we're still not quite there yet. His weight is also stable (15Kg lower than his healthy weight). The pain management is under control. He now has Fentanyl 75 patches (every 2 days) and Oxynorm 10 (10 a day) and the Mirtazapine Anti-depressants (30mg one day & 15mg the next). For his bowels, he's taking 'Coloxyl with senna' and a bowl of Prunes with custard every night which he swears by. He was well enough to have some dental surgery in October and has had a swine flu vaccination with no ill effects. He'll never go back to work, but he can potter in the garden and every now and then is well enough to do some more intensive gardening or handyman type project. Considering we cancelled last Christmas – the fact that he wants to be involved this year is a treat for all of us. Peace, Chris. *chrisp47* says on November 27, 2009 at 10:15 am (

We had a nice Christmas but since New Years John was becoming more and more confused, sleepy and vague with an occasional vision or hallucination and CT scans showed the cancer has spread to his brain. There are 2 spots. One may be operated on and the other one, will be treated with Radiotherapy. If it had spread to other parts of the body as well apparently they wouldn't have treated him at all. As soon as he went on steroids to reduce the swelling he 'came back' to us. Its nice to be able to talk to him again. He knows what's happening to him and he is still my magnificent man. In the morning we see if the Neurosurgeon can/will indeed operate. If this all goes well and it reappears within 3-4 months, he can have another session of radiotherapy, but if it quickly returns ie, within about 1 month, they won't treat him. Chris. *chrisp47* says on January 27, 2010 at 10:28 am

☺Chris—so sorry to hear of all the additional problems John has been going through-though I am glad you had a good X-Mas.I'm sure part of his strength, and will, to fight comes from knowing how much you care and are there for him. That should also be of great comfort to him if treatment has to stop.On the higher doses of Fentanyl I would halucinate and be extremely tired and incoherent sometimes. They implanted a morphine pain pump in my abdomen and am MUCH better though we are still working on dosing. Recently I started to accumulate fluid in my right lung and they implanted a catheter that a home health nurse comes every day to drain. 3 wks now and sh'e still getting 250-300 ml/day. They believe the fluid is malignant but the 1st 2 of 3 tests show negative. I have been off chemo several months-for various reasons-and now they say they pretty much have nothing to offer but a low dose of Cytoxan (orally) just to try to make me more comfortable and try to put off the cancer spreading or growing. I am going to TRY, after 5 months, to go back to work on Monday though the oncologist doesn't think I will be able to sustain a work schedule. Won't know unless I try! If it doesn't work I'll have to look into retiring and early social security.My thoughts are with you and John. Please keep us posted on what the neurosurgeon says.KathyKathy R says on January 28, 2010 at 10:29 am

John had surgery on one of his tumours yesterday. The surgeon says he's got it all. One was in too dangerous a place to touch. John was chatting with me and our sons last night at the hospital and this morning he was sitting up in a chair when we spoke on the phone. I'll be there with him soon. He says he feels a lot better this morning. The radiotherapy will start next Wednesday. Kathy I hope you were able to get to work on Monday. All the best, Chris.chrisp47 says on February 1, 2010 at 10:30 am

☺Hi Chris:Great news about the one tumor! — AND that he was able to sit up in a chair to talk on the phone. Is the radiotherapy being used to attack the other tumor that the doc didn't touch? Are your sons older or are they too young to fully understand what's going on? Did John's M.D. say anything about an unknown primary being hereditary? I can't imagine that it would be but who knows. My M.D. has never said anything one way or another.Working 1/2 days this/next week. Feels great to be there. Feels ALIVE. Though I notice more back/leg pain probably cause I'm alot more active.Wish him well from me and I hope he handles the radiotherapy with minimal discomfort.Keep me posted-or if you just want to chat.Kathy RKathy R says on February 3, 2010 at 10:35 am

John came home on Saturday and is much better than before. He had the 24 staples out today which was a bit painful. He is exhausted, but apparently that is normal. He also found out that the 'fuzzy head' he has is due to the air space left in his brain where the tumor used to be. It should re-settle and get better over the next 2 weeks. Crazy stuff. The boys are in their 30s, and they have been great. One gave up a project in Europe to stay here and they were both with me on the day of surgery and are a great support. The 2 weeks of radiotherapy will start this week and he'll be on steroids to keep the swelling down until after that has finished. Unfortunately the pain medication that took us a year to stabilise is up the creek for a while, but we are working with the pain medication specialist to help get that back on track. Kathy, I'm happy you can enjoy some normality at work. Thanks, Chris.chrisp47 says on February 8, 2010 at 10:36 am

John is still doing ok-ish, but even a slow reduction in steroids has sent his pain medication into more turmoil. The original painful cancer site is giving lots of trouble. We've now been advised to increase the strength of the Fentanyl Patch to 100 (every 2 days) and increase the frequency of the Oxynorm if we need to. Also that Panadol seems to be an aid in getting the medication through the system quicker (but this had previously been responsible for debilitating sweats so will have to monitor this). Hoping to get him to exercise a bit when his pain diminishes as we both think it will help.chrisp47 says on March 13, 2010 at 10:36 am

The recent post-brain-surgery scans showed a good reduction of swelling around the remaining tumor. There is no new cancer anywhere. The original disease in his chest cavity site has 'thickened'

which is why his pain has increased. He was put on Lyrica for pain but the side-effects were too intense, so he stopped that. Instead he is taking Oxynorm 3 hourly. (The side effects were tingling fingertips, only waking up to eat, dramatic flinching, 'out of it', dropping plates and cups etc.) He's mostly doing ok in himself. [chrisp47](#) says on April 11, 2010 at 10:37 am

On the 5th May John had intense pain in his back which reminded him of the kidney stones he had when he was a young man, so we called an ambulance and went to A & E at the local hospital. Subsequent test over the next few days for kidney stones, leaking anurism and crush fracture caused by steroids were all negative, but a bone scan showed cancer in 3 of his ribs which was identified as the cause of the pain. They also claim to have found the 'primary', a spot in his bowel via x-ray. I haven't seen those films and the Onco doubts it considering all the CT scans and PET scans he's had over the past 16 months. The following week, he had a broad band radiotherapy treatment across the back which may help ease the pain after one to two weeks. But the day after that, he lost the use of his legs. This has been explained as a rare event – stroke of the spinal column. He has no feeling up to his buttocks (this includes the use of bowel and bladder). He is in the Palliative Care ward at the local hospital. Today he had an ok day but yesterday was not. One day at a time. Chris. [chrisp47](#) says on May 17, 2010 at 10:39 am

Maryland CUP story *Posted on: June 18th, 2009 by Patty*

Hello from Maryland~ I was diagnosed with Metastatic Squamous Cell Carcinoma in an inguinal lymph node 2 weeks ago. So far after the battery of tests they have found no primary site. I am 42 years old, mother of 2 beautiful girls (13 and 9) and live near Baltimore, MD and my oncologist is a Johns Hopkins Hospital professor one day a week and is taking my patho and case to them for a second opinion. My husband and I are waiting patiently until June 26th for the treatment plan. I am a nurse on a cardiac step-down unit and have been looking on the internet for sources to help myself understand CUP and be ready with questions and information to bring to him on the 26th and found this site. I found a couple of women who seemed to "fit" my story and would love to try to connect with them and see how they are doing. Also, would love any insite into talking to my kids about this. So, far they kow that Mom had a bump on her leg and the doctors want her to have more tests to see why it was there. We explained that nothing has changed, just they may see Dad not going to work some days because of the Dr appointments. We asked if they ahd questions and they both said "Great, can we go to the pool?" I think that is it for now. Would love to hear from people with similar stories. Patty

Patty, I am new on here, but since we have similar locations, wanted you to know I have read your story. We have similar but different CUP I think (location). Please know I am pulling for you. Please update your story when you can. Meanwhile my next treatment is Wednesday, and thereafter more tests. Needless to say, I am praying for remission once again. I guess this is the way the rest of my life will be. Treatments — tests— remission — tests —treatment, etc. etc. [Midge Midge McBride](#) says on July 5, 2009 at 11:46 am

Thank you Midge for replying. How was your treatment?? Had Right Inguinal Node dissection on July 14th. Really bigger surgery than the doctor led me to believe. I should have asked more questions. Anyway have a drain in and it is going on 2 weeks. I am really worried about lymphedema in my rt leg. Wearing TED hose. My next step is to talk to a Radiation doctor to see if radiation vs chemo is the next step. Where was your original location that they biopsied and how did it progress? Thank you and take care, [Patty Patty](#) says on July 26, 2009 at 11:47 am

Hi Patty, I posted another few comments on a site answering Kathy but wanted to respond to you specifically. My original biopsied site was the sacrum (the largest of the sites showing mestastic areas). Having had a repeat PT yesterday, I do not know the results yet, but I will post them at least next week when I have an appointment, unless the oncologist calls me earlier. Sorry you have had such a rough time with surgery. I have refused radiation because I asked the doctor, would it kill

cancer cells and he said, no; that it was for pain. I do not have that much pain to warrant more problems in that area. I think my tolerance for pain has increased; I haven't even used percocet in over 2 months. Hopefully the pain issue will remain a nonissue. Read the post in the other area for more info. Take care.Midge [Midge McBride](#) says on September 3, 2009 at 11:48 am

Unknown Primay – Upper GI area – HELP *Posted on: March 31st, 2009 by [jean.vickers](#)*

Hi my name is Jean, I am 55 and live in the West Midlands, UK. Two monthes ago I was diognosed with unknown primary within the Upper GI area. The hospital have decided to treat me with 5 FU and Oxyplatin (which is used for Bowl Cancer patients). I am currently on my third cycle of treatment and am having my scan on Wednesday to see if the chemo is working. I am looking to speak to people who also have an undiognosed cancer, as there has been pretty little information out there. I have found it very difficult to deal with my prognosis, together with the chemo, which has made me feel much worse and have not had many good days from the experience. I am looking for ways people cope and deal with their cancer, as I am finding it difficult. Interested in anybody that has tried any alternative treatments along with their chemo to help supress the side effects and even the cancer. Thanks for reading, please get in touch. Best wishes, Jean

Hello Jean – I am in Australia and am an almost 10 year survivor of Cancer Unknown Primary. Although mine was not in the GI and I had radiotherapy and no chemo, I hope that I will be able to offer some help and encouragement to you. From the point of diagnosis on our lives change very dramatically. The ability to cope is different for everyone, and some folk find it increasingly hard to deal with this monster. Do you have family to support you Jean? Also with regards to the chemo, have you mentioned your side effects and concerns to the nursing staff? If it is nausea, a lot of people here have benefited from ginger either as a drink or the crystallised type that you can just chew on [I actually prefer ginger dipped in chocolate but thats another story] Complementary or alternative therapies can help but it is vitally important that you let your oncologist/nurses know about anything you are thinking of taking [even over the counter stuff] as some of these interact with the chemo. Another way of coping is to keep a journal, try and write in it every day, even if it is to say that you are having a crappy day, write down your thoughts, your feelings, but also try and write down at least one good thing that happened each day [and we can usually find one even in the midst of all this upheaval] Set small goals and try not to let the cancer define who you are and what you do. If there is an oncology social worker available, can you have a chat with them? Have you considered seeking out a support group Jean? These really are the best places to get support, information and access to resources, plus you will be among people who truly understand what you are going through. It is also a great place to learn how others have coped and the sort of strategies they used. I am more than happy to exchange emails at any time Jean, and perhaps someone else on this site will have some suggestions for you to think about too. Maybe someone in the UK who would be more familiar with the system over there and what is available than I am. Stay strong Jean you are in my thoughts Lyn [aussieangel](#) says on April 1, 2009 at 11:05 am

Thanks for your response Lyn. I like the idea of writing a diary, my husband currently writes one. However, the support networks around me are abismall. Luckily I have my husband, my daughter steph 24 and my son lee 27, who have all been a great support network. So where abouts is your cancer? Have you looked into alternative treatment together with conventional treatment? We are currently looking into Miseltoe thereapy and supplements. Thanks again for you reply – would be great if there was a wider response network. Best wishes, Jean [jean.vickers](#) says on April 3, 2009 at 11:06 am

Hi Jean – my cancer was almost 10 years ago. It was in the right inguinal gland in the groin. I was initially told it was a small hernia and not to worry about it too much – just as well I persisted as I

might not be here otherwise! I am all for looking into other/alternative treatments but it is important to let your primary health care professional know that. While it is good that your family is so supportive it is a shame that the services around you are lacking. It is important too to remember that your family are also dealing with your diagnosis in their own way. It seems that there are not many active participants on here, which is a real shame as we benefit so much from others experiences and how they coped. Did you look into a support group at all? I don't know anything about the Mistletoe therapy you mentioned but will look it up and also ask a friend if she knows anything about it. I hope that you got a good report on Wednesday Jean – was there any changes?
Stay in touch and take care [Lynaussieangel](#) says on April 4, 2009 at 11:07 am

Hi there I had the results from my scan on Wednesday which said the chemo that I was on had not done anything and increased the lesions on my liver, which is scary. I am now set to go on Taxol and Carboplatin this Friday, so fingers crossed for this. Has anyone any experience of this chemo or any suggestions as to which chemo may be successful? Also does anyone know about any CUP specialists in the UK, as I am still being treated by NHS Doctor. I am quite interested in seeing Greco in USA but would like to see if there is any specialist consultants in the UK that anyone here may have used. Best wishes, Jean [jean.vickers](#) says on April 14, 2009 at 11:09 am

Hello Jean – Sorry to hear your results were not more encouraging, but please hang in there. As I am in Australia I obviously know nothing about the specialists in other countries so I am really hoping that someone on this site will respond to your enquiry. Can you ask a social worker at the treatment centre if they have a list of specialists or perhaps contact Cancer Backup [I think that spelling is correct]? Also if NHS is as I assume [National Health Service] do they have a list of specialists? I know our health insurance companies have lists of all the specialists but you have to ask for it. Perhaps one of the American members could give you more info from their end. This info would also apply to the chemo, but I can tell you that Taxol and Carboplatin are used successfully here in Australia. I will keep you in my thoughts and prayers and take care Jean [Lynaussieangel](#) says on April 16, 2009 at 11:09 am

Hi Jean-I'm Kathy R I was diagnosed in Dec 2005 with CUPS. I am so happy to see that there are some actual "survivors" of this disease. Unfortunately, that is not possible for me. Couldn't be surgically removed, radiation did not even reduce the mass' size and I just started my 5th different course of chemo– 5fu and Avastin. [aussieangel's](#) suggestion to keep a journal is an excellent idea. I use it to vent my frustration, feelings and to keep track of how I feel (pain, temps, etc) so when I see the MD every 3 weeks I can give accurate info instead of how I think I felt. I see you are on Carbo and Taxol. That was my 1st regimen. Had the most intensive pain in my knees down to my ankles for about 25-30 hours after treatment. When I told the oncology nurse she prescribed a nasal spray, used for menopause, prior to treatment. It really reduced the amount of pain I would get. I can't remember the name but maybe your nurses will know. I will check with my nurses. I agree with you and "aussie..." that I wish this site was more active. I put my story up and had no responses and I wrote to someone who had seen Dr Grecco (I live in Chicago IL, USA) but rec'd no response. I have gone to SLOAN-KETTERING CANCER CENTER in New York as there are six doctors who have CUPS as a special interest including one who does research. I saw a Dr Stephen Veech who is the International Consultant on CUPS. I really like him—great bedside manner and EXPLAINS everything. I have seen him twice and talked to him twice over the years—whenever RUSH (my hosp) isn't sure what direction to go or makes a mistake. I wish you well, I know that your regimen can be tiring for a few days. I was fortunate not to ever have nausea or vomiting though, in the states, they do put an anti-nausea drug in the porta-cath before treatment and they do prescribe anti-nausea drugs, if you need them. Though I think I'd try 'Aussie...'s idea of an alternate, non prescription, method. Don't we have enough toxins in us? Please let me know how you're doing or just want to chat. [Kathy R](#) says on April 16, 2009 at 11:12 am

Apologies for not reply sooner, I have been having terrible aches and pains all over my body and especially my legs, and so tired. Has anyone got any ideas of how to ease the pain and aches? I've tried having warm baths, hot water bottle, foot spa, massages, but to no avail. Kathy, what's that nasal spray you mentioned? Luckily, I haven't had any nausea or sickness. How are you all? It's such a shame to know how many people share this cancer and how few people there are on this site to share advice and information. If only there was some way to draw people to this helpful site. Wishing you all well, love Jean [xjean.vickers](#) says on April 27, 2009 at 11:12 am

Jean—I am soooooo sorry. On May 15th I THOUGHT I posted 2 responses. One was to a newcomer and the other was to you to tell you the name of the nasal spray was CALCITONIN. I must've not hit "submit". Taxol was the culprit that caused all my leg pain. Tomorrow I start my 2nd cycle of the 5FU/Avastin. As far as I can tell, there have been no side effects. However, I just had a sigmoidoscopy yesterday cause of all the horrific pain I have when mother nature calls. I have thrombosed hemorrhoids and if 2 wks of treatment doesn't help, I'll need to have them surgically removed. Problem is I'll have to be off Avastin several weeks before surgery can happen and don't know how long afterwards. I've now had 4 acupuncture treatments for the back pain with no positive results yet. All that's left is to see a neuro or spinal surgery though my doctor's don't believe any surgeon would touch me cause of the location of the lymph node mass (VERY close, but not touching) the spine. I'll try more acupuncture for a week or two. I may have to be relegated to a power chair or scooter cause the pain gets unbearable when I stand or walk. Seems like it never ends and ya never get a brake. It's really hard not to have "pity" parties for myself! Jean-I'm with you. I would love to hear from some other CUPS people as to how they dealt with the constant bad news and problems that pop up. No matter how many times I tell myself I'm fortunate that I don't have all the severe chemo side effects most people have—all my non-cancer problems are affected by the cancer cause they can't do things that can help the situation because of the cancer. It's like a catch 22. Do you sometimes feel that you're in a maze and every time you hit a wall, you turn around and hit another wall? Oooh, sound like I just had another pity party. Please let me know how the new treatment is going. I can tell you that it was the 4th drug regimen (but 6th drug) that they "think" may have at least considerably slowed the progression of the cancer and the drug that was totally unexpected to do any good at all. There's always the hope something will click. Kathy [Kathy R](#) says on May 19, 2009 at 11:13 am

Hi I am Jean's daughter Steph, 24 from West Midlands, UK. Mum sadly lost her fight with cancer at 6:45am on Saturday 15 August 2009. She was terribly brave all the way to the end. This forum and the Macmillan forum gave mum the support, comfort and hope that she needed in her quest to fight this cancer. When mum had been told that her 3rd set of chemo had not worked and was dismissed by the hospital, I got in contact with John who pointed us in the direction of Dr Harpreet Wassan at Hammersmith Hospital, London. Dr Wassan gave mum and us the first bit of hope we had been waiting for, and suggested we take tablets and be put on another type of chemo. Sadly when we returned from our 4 day trip to London, mum went very tired, jaundice and bloated, and after a week of rest she had to be admitted to hospital. We were told that she only had days to live... 2 days later she was outside eating half of my fish n chips! She was released back home after a week, where she had one really good week with us and the second week she sadly took a turn for the worse and lost her fight. We want to thank John and all of the users of this forum for the support and hope you gave mum. Fingers crossed the conference on Thursday highlights the immense importance and awareness of this terrible and deadly disease – so that more research and knowledge is out there for people like mum and the other users of this forum. All the very best to you all. Steph [jean.vickers](#) says on October 12, 2009 at 11:15 am

General Question *Posted on:* March 25th, 2009 *by* aussieangel

Hi everyone – Please don't think I am being forward in saying this but I notice that there are not many posts on the site. Active participation has also been a problem with some sites here in Australia and I also totally

respect the fact that some folk are just happy to browse and gather information from others discussions. I would be interested to hear from other survivors are out there living with CUP and how it impacts on their lives. Any comments from carers would be appreciated too! Take care Lyn

👉 I'm a little concerned about everyone's health. Lyn, Jackie, Lori and Jean have all, in the last couple of months, commented on how they wish this site was more active and they would like to hear from each other. I have asked questions of some of you and some of us have asked others to keep them updated on new treatments and test results. Yet there has been no activity (except for the new members) since my last posts in May—unless I have not been looking at the right sights. I am hoping everyone is doing well and not having setbacks. After my last e-mail I found out my problem wasn't hemorrhoids but an anal fissure. I was told that these are common amongst cancer patients. Am on an 8wk treatment and fortunately it appears to be healing slowly-but well. If it doesn't it gets surgically repaired. A couple of days after my e-mail I was admitted into the hospital for SEVERE pain in my right side and back. Was in 4 days and was told it is NOT cancer related but the side may be a pulled muscle and the back is just my decades long back problems getting worse. Came home and a couple days later fell out of the tub. Had a sharp pain in the side, turned to sit on the bath chair in the tub and slide off onto the floor. Fractured my little finger, pulled my chest muscles and did further injury to my back-though nothing fractured, chipped or anything else. No head or heart injuries or blood clots in my legs. Am still home from work but hope to return 7/6 part time. Still can't sleep in my bed cause of the pain lying down and getting out of the bed. Sleep in a recliner with ice packs. Since I live alone, my friends have done my laundry (can't do stairs) and my shopping, etc. Chemo was delayed a couple of sessions but started up again last week and today. The BEST news I've have recently is that the chest CT shows, for the FIRST time in 3 1/2 years of chemo, the peri-aorta mass has reduced, albeit minutely, in size. We had to cancel the MRIs on the abdomen and pelvis cause of the accident—no way can I lay on the MRI table for 2 60 minute sessions! This was the first test done since starting the 5FU/Avastin cocktail. However, it is also the first test since I started drinking this asparagus puree (have added celery and carrots) twice a day. It was in an e-mail article sent to me by a friend. The cancer stories seemed a bit far fetched but, what the heck, can't hurt by adding more vegetables daily. It was an article called "Asparagus for Cancer" printed in the Cancer News Journal, December 1979. Also, today one of my doctors gave me an article she found on curetoday.com. It was written by Katy Human called "No I.D.' A very reassuring article about CUPS. Finally, has anyone heard from artincurse? She had been fairly active on the site but nothing for a while. My best to all of you—I hope everyone is doing so well and are so busy you are too busy to get on-line. Kathy R *Kathy R* says on June 26, 2009 at 11:56 am

Hi Kathy – I'm sorry there hasn't been more activity. It seems to go in very unpredictable phases. Even if noone responds – and of course I hope they will – the information you put in here is very valuable to many people who are going through similar battles (although no 2 CUP patients are ever the same). I have received comments from people who don't like to comment, which is perfectly fine, but do value the comments of others at a difficult time which can often give help, guidance or encouragement. Best wishes and well done for such a positive attitude, John *john symons* says on June 27, 2009 at 11:57 am

Hi everyone. I am new to the site but just posted in the Meeting Space site about my insurance coverage issues. Thought I'd state a little about myself here too. I am 44 and a Canadian living in London, England and am married with one eight-year-old daughter. I was diagnosed with CUP in fall of 2007. I had major surgery to remove a tumour on my pancreas at that time which was followed up by chemo (cisplatin – yuck – and gemcitabine) for six months. All seemed good until fall of 2008 where another spot was found on my liver. That was removed through ablation. Am now undergoing another chemo regime – capecitabine (almost finished), epirubicin (only four cycles and all done now) and Herceptin (which is technically immunotherapy) which I will have for another six months. I have had two clear scans in four months – fingers crossed. That's the physical side. I'll discuss the emotional side when I get to know you all better 😊! Artincurse – why are you feeling

down? How did your appointment with your oncologist go? Katherine (kplondon) [kplondon](#) says on July 15, 2009 at 11:59 am

Hi all, I understand the feeling. I too was really feeling down, my imagination just running away with me, waiting for test results. My oncologist called today to say the news was not bad. The neulasta interfered with reading the PT scan. Two original sites seemed to be much the same, but they could not determine for sure if there were any new areas in the pelvic region. Anyway, I will be returning for treatment #3 next Wednesday and #4 3 weeks later. I hate how I feel days 4 – 6 afterwards. I guess I can do it. Have a well weekend, and blessings to all. Midge [Midge McBride](#) says on July 25, 2009 at 12:01 pm

My Story [Posted on: March 19th, 2009 by aussieangel](#)

Hi everyone and greetings from Australia. I found this site quite by accident while “surfing” the net for some information for a friend. Turns out this is more beneficial to me than her! I want to thank Jo’s family and friends for honouring her in this very constructive and positive way. My story began Christmas 1998 when I discovered a small lump in my groin while showering. I did not think a lot about it but remembered to ask my dr at the next visit. I was told it was “probably” a small hernia but not really big enough to do anything about and as it was not giving me any problems to just keep an eye on it. A few months later it was still there and as I was due for a flu shot I asked the visiting locum about it. Same story but he did give me cause for concern by the manner in which he spoke and asked me to follow up with my own dr on his return from leave. I did this but was more or less told I was worrying about nothing. As the lump was still there in July and the dr still insisted that it was a hernia I asked for written confirmation. He then reluctantly told me he would order a scan and blood test to dispel my concerns. Had these done and then returned to dr where he said it was inconclusive and they wanted to do a fine needle biopsy, which I had that afternoon. I was told it would take about 4 days for the results. Two days later at 4pm on a Friday I was contacted and asked if I could go over and see the dr before he left the practice that afternoon. I have to add here that cancer had never come into the equation at all, I just thought that it was the hernia but wanted confirmation, I never thought about cancer once. At 5.15pm I was rather nonchalantly told that my results were “metastatic squamous cell carcinoma” unknown primary as the cells were poorly differentiated. I did not understand any of this but the drs concern alarmed me even more as he organised tests, visits with surgeons etc etc. Within 2 weeks I had surgery to remove the tumour from the right inguinal gland. This was followed four weeks later by a total hysterectomy [still trying to locate the primary]. No evidence of the primary was found. In November I began 5.5 weeks of radiotherapy [just to catch any residual cells that may have been lurking about]. When all this was done I was put under the care of my oncologist/haematologist who has continued to monitor me since. Before I began my radiotherapy I asked the Radiology Oncologist what my chances were and was told “not great – most people with this type dont live past 5 years if that” My response to him was “well, that was before me!” 18 months after I completed all my treatment I began doing some voluntary work with the local area health service and cancer council. I became the first facilitator of a local cancer support group in 2001, a position I still hold today. The group offers information, support and friendship to anyone affected by this incidious disease from point of diagnosis on. I love the work I do with cancer families and have met the most inspiring and courageous people I would never have met if not for my own diagnosis. I believe the purpose of my diagnosis was the work I do today. I have a spinal condition which prevents me from being actively employed fulltime in the workforce, but it has not defined who I am and what I can do. I am 60 years old, almost divorced and currently studying for a Diploma in Counselling. I live each day as it presents and believe that hope, humour, and the right attitude will get me through most things. On 23rd July this year I will celebrate my 10th birthday – I will probably celebrate this one more than I did my 60th last year! I hope that my story will help someone else and I am happy to answer any questions. Take care Lyn

Hi Lyn I guess we can now call you a CUP cake. I am now celebrating one year after my chemo for CUP. I feel great and even went skiing in Vermont last week. I am 64 and haven’t skied in 20 years. I only fell twice and enjoyed being assisted up by nice young snowboarders. I have met one other

gentleman who is at year 5. I'm looking forward to many years. Your post was truly inspirational. Dianne AKA [Arcticnurse](#) says on March 27, 2009 at 12:02 pm

Thanks Dianne – I loved the CUP cake title – I will have some fun with that now! I appreciate your comments. Doctors and health care professionals can only tell us so much and offer so much in the way of being optimistic and hopeful. I believe that as survivors we have the opportunity to provide very real evidence that “anything is possible”. Skiing is something I have never tried – I remember when we were very young our Dad took us to the Snowy Mountains and we used to take turns in sitting in a plastic dish and sliding down the snow. Now well, I wouldn't fit in the dish for starters, but I am more a seaside person. More power to you for getting back to something you enjoyed from your earlier days [I suppose some things we never actually forget how to do, we just have to fine tune how we do them!] What sort of follow up treatment do you have Dianne? I see my oncologist on Wednesday this week for annual review. I don't get freaked out by the prospect of a “check-up” – I view it as confirmation from the dr that I am doing as well as I think I am. Thank you for taking the time to comment – I truly appreciate it. I too, hope that you have many happy cancer free years ahead. Take care [Lynaussieangel](#) says on March 28, 2009 at 12:02 pm

Hi Lyn I see you are on I go every three months to see my oncologist. I see her again next month. I had markers drawn last month. She has not ordered a CT scan this time. Dianne [Arcticnurse](#) says on March 28, 2009 at 12:03 pm

Hi Dianne – I went every three months for a little while then it went to 6 months then 9. Last year the dr said “I think I will see you in 12 months this time” to which I replied “So, are you trying to end this relationship?” He has the same weird sense of humour that I do, so replied “yes, but I am doing it slowly so you won't notice”. I almost don't look forward to that day when he doesn't want to see me, as in the back of my mind I feel secure knowing that he is still keeping an eye on me. I guess after almost 10 years though I probably have to put my big girl blouse on now and move on – lol. Funny coincidence that we both had a similar invasion by an unwanted intruder, right groin, poorly differentiated cells, carcinoma. Are you working in Canada still? [Lynaussieangel](#) says on March 28, 2009 at 12:04 pm

Hi Lyn, I have just joined the site and came across your post. Could I ask you why they went ahead with the total hysterectomy? I have had a colposcopy and was essentially negative. I have been told that chemotherapy is controversial with CUP and as in your case, are you glad you did not get advised to do that? Also, did you have any side effects from the radiation? Thank you so much for all the information in your post and looking forward to hearing from you~
[Patty](#) says on June 18, 2009 at 12:05 pm

My wife's story [Posted on: March 10th, 2009 by kieranlavin](#)

I browsed some of the other stories quickly and it seems that others are specifically being diagnosed with CUP. Maybe my wife isn't quite at that point yet but I suspect this might be the best explanation for what has happened to her. We're hoping to have more information at the end of next week though as we do go back. Ok, enough blabbering, here's the story. On Tuesday November 4 my wife had a scheduled eye doctor appointment. She had been having trouble seeing out of her right eye. She had been to the eye doctor once in the previous month for problems with her contact lenses so I kind of wrote it off as something similar. She did mention the previous Thursday at a friend's house that she wasn't able to see from that eye at all. It should've sent up a red flag but it didn't. Well, it only would've saved 3 days anyway. So she went to the eye doctor who diagnosed her with a detached retina and asked her to go to a specialist the following day. On Wednesday November 5 my wife got an afternoon appointment with a specialist about an hour from our house. They did more tests and determined that there was a tumor in her eye. They called Wills Eye in Philadelphia (who I've found out since are renowned worldwide for ocular oncology. The doctors at Wills Eye were heading out of town on Thursday for a conference but agreed to take her as long as it was early in

the morning. At this point I took off of work to go be with her. We went to Wills Eye on Thursday November 6. They did test after test after test. We were there for a good 4 hours. The end result was that there was a tumor in her eye wrapped completely around her optic nerve. I figured it'd be a simple laser zap and she'd be as good as new –eyesight and all. Well, no. They were suggesting plaque radiation which is that they sew a metal disc with radiation in it onto your eye and you sit in the hospital in confinement for 5 days. They wanted her there the following Thursday for the procedure. What they explained though was that usually the type of tumor they found does not form in the eye. Because the tumor was wrapped around the optic nerve she is only expected to regain peripheral vision. To date she has some peripheral vision but no central vision and it's never expected to return. After her radiation, they wanted her to go for MRI's, x-rays, and all kinds of other tests to find the origin of the cancer. She's gone through all of these tests and they've all come back negative. So as far as we know right now she had a tumor in her eye and that is it. She went in January for a checkup to the specialist an hour away from us and they said that the tumor is shrinking in size (it's supposed to take 4-12 months to reduce to as much as 1/2 the original size according to what I've read online) but that there is still too much fluid in her eye to re-attach her retina. At the end of next week we go back to Wills Eye for a checkup. When they did the radiation, they took a biopsy of the tumor for DNA testing. They tell us that we'll get the results next week and the results will determine the course of action going into the future. They tell us that the DNA testing determines how aggressive her type of cancer is and what the preventative actions should be going forward. But there's still the nagging question that my wife and I still have – where did the tumor come from and how did this happen? It seems that her eye cancer is similarly misunderstood. All that they were able to offer to us was that it mostly occurs in fair-skinned people with blue or green eyes. Rarely does it happen to someone with brown eyes. And the other thing is that they think it has to do with exposure to the sun. I was shocked to find that there is no definitive cause or preventative actions that you could take against getting eye cancer. It just happens sometimes. My wife is 29 and, although kind of shocking that it could happen to such a young person, I've read of true children who've gotten similar eye cancer before reaching their teens. We're hoping to have an answer next week but I guess I'll keep CUP in the back of my head and **** it out there at the end of the appointment if we still don't have any answers from them. Time will tell. Thanks for letting me share.

Just wanted to let you know I will be thinking of you and your wife – I hope that you can get some answers to your questions. Please post again with an update. Take care
Lynaussieangel says on March 19, 2009 at 9:30 am

We got excellent news yesterday. I was scared for the first half because it appeared that her vision in that eye had gotten worse when she was supposed to have at least gotten SOME restored peripheral vision. They didn't seem too alarmed at that. Then they started with some of the tests. They did an ultrasound of her eye and I could still see the tumor so I was alarmed. I know that they say that it takes 6-12 months for the tumor to shrink and I didn't remember how large it was previously so I didn't know how alarmed to be. Then they started doing this other test where they take multiple pictures of the eye. It seriously looked like either a mushroom was growing in the bad eye or there was some sort of explosion. I tried to look on the positive side and think it might be fluid or something that I just didn't know about. They put us in an exam room and we waited for a bit before someone from billing came in to explain that they might want to do some sort of laser treatment that's typically not covered by insurance and is on the costly side. But then one of the doctor's understudies came in and looked everything over and explained that the tumor had shrunk from 7.6mm to 4.2mm (don't forget, we're talking *IN* the eye). She was happy with that and we could only go by her reaction. I mean we knew it was roughly half the size but didn't know whether that was good or bad or if it should've been more. We were so excited by how happy she was that we almost forgot to ask for the results of the DNA test. Turns out that she has the less aggressive type of cancer. I think it was (forgive the spelling as I'm trying to relate what a woman with a thick Indian accent was telling us) monosomi and diosomi? Anyway, the mono was the less aggressive type and they tell us that there is only a 10-15% chance that the cancer cells have escaped her eye or that this would recur. Then the doctor who actually performed the surgery came in to check on my wife. She said that she was so delighted to hear the news about the tumor that she wanted to have a look for

herself. She specifically told my wife that she should go out for a drink (and we did) because the news was so good. Thanks for reading 😊 [kieranlavin](#) says on March 21, 2009 at 9:33 am

Wow – what a great report. It certainly gives you both encouragement. I would have had that drink too!!!! But then I tend to start dancing on tables after a drink so maybe it was best I wasn't with you [lol] What happens next? I am really interested to hear how you are both doing. I also know how difficult it is when you are the carer as sometimes you tend to be neglected, but I hope you know that your love and concern for your wife is an important part of her healing. Take care and give your wife a big hug from this aussie! [Lynaussieangel](#) says on March 22, 2009 at 9:33 am

We go back in another four months for them to check on the progress of the shrinking of the tumor. If all is well they'll check her out and send her home. If the shrinking and scarring isn't as far along as they hope, they'll recommend laser treatment. We're hoping that eventually we'll only need to go maybe once a year to the eye doctor and twice a year for bloodwork, MRI, chest CT, and all of the other miscellaneous tests. All of this combined with pre-existing conditions and mindsets have caused much stress on the marriage. I'm hoping to get us both to counseling very soon [kieranlavin](#) says on March 23, 2009 at 9:34 am

The times between appointments can seem like forever, I sometimes wonder if the drs know what that does to us and how that impacts on a family. I know it is not their fault, but I still wonder if they realise how hard it is for us to wait. I am so sorry that your marriage is under strain from all this. While there are plenty of people to offer the right advice on treatments etc etc there are very few resources available for the psychosocial support that we so desperately need. Please seek out the right counselling, someone who understands from the oncology field. It is important that you both continue to communicate with each other, don't be afraid to share the emotions that you are feeling. Talk about what concerns you, what fears you have, write down things you want answers to from your health care team, and then ask them. Don't leave any stone unturned, or any questions unasked. Do you have other family nearby? or friends that could maybe give you some support? Take up the offers of support that come, they will lessen the burden on you both too. A friend may not wash your floor or do some ironing the way you would, but hey, that has given you some time to spend on something else like going for a walk, just kicking back and listening to some music. And friends and family will want to help and feel that they are being supportive, but they need direction from you. We don't have control over things that happen to us, but we sure have control over how we deal with them. You mentioned pre-existing conditions and mindsets – please talk to someone who can help you work through some of this stuff. Stay in touch, Take care and know that I am thinking of you both. [Lynaussieangel](#) says on March 24, 2009 at 9:35 am

Yeah, we had problems before the cancer and I think my wife was hoping that the cancer would bring us closer. Where she got her treatment is 2 hours away (without traffic which there frequently was) and she was there for 5 days. I drove down there every day and spent 4 hours with her. Unfortunately she didn't see this as me caring for her 😞 She spent the following weekend after getting out driving a 50-something year old "friend" who is male and started out their friendship lusting for my wife to a motorcycle shop because he "didn't know how to get there" ... and she continues to spend more time with this friend than she does with me, her own husband. She has a lot of issues that we need to deal with but the most disturbing thing is that she is not going into counseling with an open mind. I'm hopeful but doubtful at the same time. We shall see. I have plenty of family and friends for support. Even her own family is on my side. Which almost makes it all the worse because she thinks everyone is ganging up on her and she just doesn't see it [kieranlavin](#) says on March 24, 2009 at 9:36 am

Just wanted to update but it's not cancer related. My wife and I have been going to counseling for a month and a half or so now and things are MUCH better between us. We go back for another

checkup at Wills in July so I'll have to remember to update the site [kieranlavin](#) says on May 22, 2009 at 9:40 am

Wow, I haven't been here in a while! I thought I'd give a little update. We've been back to Wills July of 2009, January of 2010, and July of 2010... all with high marks and no problems. The tumor was only expected to shrink to half the size and it's actually gone down to about 1/3 of the size. She still can only see vague shadows with that eye and that's all she'll ever be expected to see out of the eye. Since the cancer/radiation, she's had some serious weight loss which her primary doctor has looked into with no specific cause. She continues getting blood tests and MRI's every year along with her two visits per year to Wills Our personal relationship has had many ups and many downs. Right now we're kind of in a status quo... not really up and not really down. I need to make a committment to spend more time with her and give her more attention and affection. It's on me... so I need to just do it. We go back in January for another checkup but I don't expect any earth shattering relevations. We'll just keep keeping our fingers crossed [kieranlavin](#) says on October 6, 2010 at 9:41 am

New to site [Posted on: January 8th, 2009 by Kathy R](#)

Am so glad to have found this site!!!! Since diagnosis I have felt like I'm on a raft in the middle of the ocean and no one knows I'm there or can rescue me. Since the mid 1980s I have had severe abdominal pain every 18-36 months. Lasted 1-3 weeks and would go away. Scopes showed nothing. In Oct 2005 it happened again, on and off till it peaked in Dec. My MD decided to do a CT and it revealed a couple of enlarged lymph nodes. On 12/23/05, at age 59, the biopsy results were "moderately differentiated adenocarcinoma of unknown primary". On 12/31/05 the oncologist told me I had 5-6 months to live, maybe 2-3 more if I went on chemo, and should get my affairs in order. He felt no further testing was necessary. In 48 yrs of practice he had treated 20 cases of CUPS and he is very respected in the oncology field. I did not care for him as his bedside manner is non existant and he treated me as if I was already gone. My 2 MDs warned me he was very "gruff". I went for a second opinion at Northwestern U Med Ctr, one of the 2 best hosps in Chgo. They examined the biopsy and agreed with the original DX but felt testing was merited. I had tumor marker tests that were (still are) normal, MRIs, ultrasounds, bone scans, CTs, labs etc, of every part of my body! The only thing was the PET Scan that said "possible prime site is the colon". Made sense to me as my dad died (age 91) of recurrent colon cancer, as did a brother of his. One of my brothers was DX'd w/colon CA 7 mos before my DX (he passed Feb 2008)-and I always have polyps removed. More tests and scopes said NOT colon. They say the cells are "consistant w/gynecological CA" but not enough to call it that. They would've debulked and done a hysterectomy but I had one in 1972 w/one remaining ovary appeared normal on all the tests including the CA125. (the hyster wasn't done cause of cancer). Further testing showed a lesion in my pancreas. They biopsied and said that was probably the prime site. The biopsy revealed Neuroendocrine cancer of the pancreas w/mets to the liver. Then the 2 oncologists debated whether I had 1 or 2 cancers. The MD Onc at NWU specializes in Neuro endo (there are NO CUPS specialists in the city of Chicago (go Obama) Illinois USA). She said an Octreotide Scan would verify how many cancers as that test picks up ONLY neuro cells and nothing else. Neuro cells do not always show up on standard tests. The results were I have 2 different cancers. They then decided to do surgery to try to remove the retroperitoneal mass as maybe the mass was it's own cancer and not from some other site. After 4 hours they decided it was too dangerous to continue as the renal vein went through the middle of the mass. They removed the remaining ovary and said there was no sign of CA or any disease-it looked normal. I decided to have my treatment at RUSH Med Ctr , where surgery was, as they all suggested the same treatment, it has a real good rep and close to home and the surgeon was someone I knew and trusted for 20 years. My new oncologis (of 20 yrs) told me I was her 1st CUPS-she is a gyne onc and does a lot of genetics and research. She did tell me she often presented my file to the tumor board and consulted with the onc that usually gets the CUPS

cases. There was one other case there in 2008 but he passed after 7 months. I started chemo May 2006 (at that time she said she felt I had probably 1 yr, possibly 2 but certainly not 3 {from date of DX 12/05}). I had 3 cycles of Carboplatin and Taxol as they were gonna treat it as gyne. I understand that you usually have 6 cycles before Cts to see how it's going. They wanted only 3 cycles cause it was CUPS and they didn't know if they were on the right track. CT showed the mass grew. They switched to Doxil Aug 06 and after 2 cycles they CT'd and it showed the mass grew. In Aug I went to Sloan Kettering Cancer Center in NY and saw a Stephen Veech (anyone know him?). He is an International Consultant for CUPS and Sloan has 6 specialists in CUPS. I really like him. He agreed w/MDs in Chgo but made a few suggestions. Then, 12/06 they switched to high doses of Gemzar and Taxotere. Started to have severe pain by the gall bladder and several MDs felt I was having a GB attack but the test showed no GB attack. Called Veech and he said that Taxotere can cause pain within the tumor and the mass is close enough to the GB that the pain could be radiating there. He did not feel the pain was the mass itself. I told my onc I didn't want the Taxotere for the remaining cycle. The pain immediately left. He also said the Taxotere dose could've been divided in 2 and done each week I had Gemzar, not just the 2nd week of Gemzar. Why didn't my oncologist know these 2 facts???? The CTs showed the mass grew. During this time of treatment for the CUPS, we did not treat (Sandostatin injections) the Neuro Ca cause it is a very slow growing cancer and all the tests show it hasn't changed much and might have even shrunk in the pancreas -they said if you had to get CA in the pancreas this is the one to get. Approx 4 in one million get this cancer and you can live decades without knowing you have it and they found mine looking for something else. They then decided I should try radiation to reduce the mass. They said the amount needed to get rid of it would kill me but they (4 diff MDs) felt the mass would reduce by at least 50% so I agreed to do it Mar 2007. I had no chemo during radiation. They were shocked by the results cause the mass did not reduce at all and the other lymph nodes that are in my mediastinum and thoracic area all shrunk (they grew during chemo). They then decided, April 2007 to put me on an oral chemo called Xeloda which is not FDA approved for gyne but their argument is if it's CUPS how do we know it's not the cancer it is recommended for. I have been on it ever since. Until Jun 2008 the CTs showed "no significant change in the size of the mass". In June they said they was such minimal growth I should stay on the Xeloda. However, in Sept 2007 they saw a tiny lesion in my left kidney (same side as mass). It started to get to a "concerned" size in Feb of 2008 but they said they couldn't biopsy till it was 3 cm or my creatine levels went above 1 (they have been, and are, normal). Finally in Sept 2008 they told me it was 3 cm. I was told it would be a mets of the neuro CA (once it mets, it spreads faster-tho mine hadn't so far, or it would be it's own cancer and could be removed cause kidney CA doesn't respond to chemo. 3 MDs said it WOULD NOT be the CUPS as adenocarcinoma just RARELY mets to the kidney. Guess what?—it spread from the adenocarcinoma. So now they have just about closed the door on me. I can stay on the Xeloda tho they don't know if that is why the growth has been so slow in progressing and why it took so long for the kidney lesion to grow. The only other option they gave me was AVASTIN , possibly with a chemo. When I asked my oncologist which treatment would be more beneficial for me to go the response was "I don't know. I can't tell you". So I now feel that the closed the door in my face and I have to be my own doctor. I did go back to Dr Veech in Nov 2008 and he was suprised at how well I am doing. He did say AVASTIN would not be beneficial (who do you listen to?) but did recommend Tamoxifen, Etoposide and four other highly toxic possibilities but didn't know if they would be tolerable. I should have only one at a time. He thinks I should stay on the Xeloda, tho they don't know if it's beneficial, but it may be—that covers all bases. If I start to have side effects to the Xeloda or the mass grows at least 25% then I should consider the other options keeping quality of life in mind. I still work, live alone, and go to theater (my passion), etc. I have constant pain in my back and left leg when I stand or walk. Sitting/laying is ok (except for the very often charlie horses in both legs when I lay down). Onc, Primary MD, neurologist and pain clinic all say totally unrelated to the CA or the drug. Am on 3000 mg of Neurontin which no longer helps, nor do 3 Lidoderm

patches on the back. They want me to go to phys therapy again and have a series of nerve blocks. Has anyone had these shots? Has anyone heard of Anodyne Treatment for pain and neuropathies? I am so worn out from hearing the various doctors say my file is an enigma, interesting, fascinating, unusual, never read anything like it, etc, etc, etc. My favorite tho is the Urologist who said I have “remarkable longevity” and my file is the goofiest thing he’s ever seen. That nothing makes sense. My least favorite, from someone else, was “you’re still here?” Aug 2008 I was in the hosp for 101-103 temps. Infectious disease MD (amazing what you’ve been through and look great—you’re file is amazing) said there was NO infection in my system and it was probably Tumor Fever. The oncologists say no it wasn’t. One of the doctors came in with his entourage (teaching hosp) and told them to pay attention because they’ll probably never see another case like this. All these comments makes me realize the futility of this disease and that no one can do anything for me. At first all they would say is that “we don’t know how to answer your questions” or “I don’t know”. Sometimes I just want to scream—“is there anyone out there who is going through this”? I see an oncology psychologist who is terrific. I highly recommend therapy if you are having difficulties with this disease. It makes it harder since I don’t have a supportive family. My friends have been my angels and are the reason I’m still here and fighting. Has anyone combined alternative therapy along with cancer treatment? Has anyone tried acupuncture or biofeedback or imagery? Please, please tell me if anyone out there has survived more than 3 years (especially if treatments haven’t helped). I have been asking my MDs if they know ANYONE with CUPS that might want to talk with me. They say no one else their has my DX and the organizations they refer me to know nothing of CUPS and have no members with the DX. Do most of you have MDs that specialize in CUPS? If so, and in the USA, please let me know. Other than New York. all I’ve found is one at MD Anderson in Texas but only does research. I was told about Dr Greco in June by someone I met in May cause her husband had CUPS and was in one of Dr Greco’s clinical trials (for liver CA). She said he would not even think of discussing his illness cause was still in denial. Though she and I had a couple of conversations. He passed in July after 13 months. Have any of you been in trials for CUPS? I have been extremely fortunate in that I’ve never needed anti-nausea pills and never experienced nausea or vomiting or any mouth sores or rashes or peeling of skin. Had terrible leg pain for 1 1/2 days after Taxol and extreme fatigue from the Doxil. The VERY high dose of Xeloda caused the common side effect of my toes swelling and blistering so we reduced by 1 pill a day and the problem went away. I am the same weight as I was when I was diagnosed and have never had a problem with appetite. First time in my later adult life that I was told NOT to lose weight!!! Sorry for this epistle but—gads—it felt good to vent. When I clicked on to this site I started to cry at the thought that I found people who have experienced the frustration of dealing with this illness and can understand my frustration. I am amazed, though, at how different all of our experiences are. May all of your guardian angels be watching over you as they have, evidently, been in overdrive with me!

Hi Kathy – thank you so much for posting your story. I hope that others’ will respond too but I wanted you to know quickly that I’d read it. We only have a limited amount of people accessing the interactive area (only about 60 in total in the last 18 months). This doesn’t mean it won’t be read (we normally have a new joiner once a week on average) and hopefully others will respond, as I said. But you’ve very accurately identified that CUP tends to be so very different for everyone. In the UK there are no oncologists specialising in CUP and at the moment our health service has no clinical guidelines to help with diagnosis and treatment. I think many people here would have had the varied experiences you have received with oncologists saying different things. “We don’t know” is at least honest. I tend to feel that this is better than pretending to do something and facing the patient with many, many tests and treatment that is a “shot in the dark”. Your story of the varied tests and treatment attempts is far from unusual in terms of volume and impact. There are certainly people who have survived more than 3 years. If you want my take as a layman who has studied CUP on some of this in more detail look at the articles on the website on this page:

http://www.cupfoundjo.org/research_and...chive.html Although a UK charity, we have people from around the world accessing this site so it is good to get different national perspectives. I have to say, I think you are in the best country for tests and treatment. Thank you for bravely describing your condition and the problems. Maybe not today, but your story will help others. It is great for us that you found the site helpful – may your guardian angels and friends continue to give you support. I hope others can respond to some of the specific questions that you ask. Best wishes, John *john symons* says on January 10, 2009 at 12:18 pm

Hi Kathy I have just read your reply to Jean and have also read your story. You certainly have had a journey and a half. Like yourself I am disappointed that others don't use this site more, it could be a wonderful source of information, friendship and support. Just knowing that there are others out there who actually do have empathy with us little cups is comforting. In July I will celebrate 10 years as a survivor and like yourself heard the words "unusual" "unique" "different" "a mystery" etc etc. in relation to my diagnosis but what I really wanted to hear was "oh – here it is – this is where the primary came from". That was not the case however. I have tried not to let the uncertainty of the diagnosis dominate my life and define who I am, and I have been extremely lucky that I have had no other problems [cancer related] since the original diagnosis and treatment. It does help to talk with others and share our thoughts, and I hope that as I approach 10 years as a survivor I can give a little hope, encouragement and inspiration to others. I have back problems also Kathy [spinal canal stenosis] but am reluctant to have the suggested surgery as I have seen too many unsuccessful outcomes with others. A lot of Drs here in Australia frown upon the complimentary/alternative therapies, but there is now a bit of a shift towards incorporating them into a patient's health care plan. During my early days following diagnosis I did practice a lot of "visualisation" techniques, but I guess I really cannot say whether my survivorship is due to that factor or not. I am however a strong believer in letting people try whatever they believe will help them get through this difficult time [as long as it is not putting your life in any more danger I figure what have you got to lose] I am sure that Jean will appreciate your comments, as you are certainly much more experienced and knowledgeable than I but I just wanted to let you know that I had read your posts and to thank you for responding to Jean's request for information. Your guardian angels WILL continue to protect you Kathy and I look forward to sharing with you again. Stay strong and take care Lyn *aussieangel* says on April 18, 2009 at 12:20 pm

Hi Lyn - haven't been on internet for a while - sorry I haven't responded sooner. Appreciate our words of encouragement. Have you heard from Jean and how she's doing? Had a left selective epidural on Thurs. No real improvement yet but last one took four days for any relief. They said they only do 3 of these then you have to wait 6 months for another. However, they decided to give me a fourth one. For some reason I went into tachycardia on the table and my heart rate went to 200 so they put a monitor on me. I was fine after about 20 minutes. Can I ask, what made your doctor use the treatment they used if they didn't know where the prime site was? All the docs I saw said that if they can't find the prime site and they can rule out lung, breast, colon they will treat a woman first with gyne chemo and a man with prostate chemo. Seems like a few of the stories I've read here started with gastric drugs. What was your regimen? Weds I want to ask my oncologist about this Oxaliplatin that 2 members mentioned. One of them is on the Avastin/5FU that I'm on and the other is on just the 5FU and Oxal..... I also want to show her the info on the conference in London in October. I'd love to go but don't see how. Is this the right area to correspond with each other? I still haven't figured out a lot of this site and where to look for responses. Where do you live in Australia? That is the one country I've wanted to really see since I was a schoolgirl. 3 times I had reservations to go and 3 times they had to be cancelled. I read all I can on Australian animals as they totally fascinate me! Take care. Kathy *Kathy R* says on April 25, 2009 at 12:21 pm

My Story *Posted on: December 31st, 2008 by loyoung*

I am a 39 year old mother of 2 that was diagnosed with CUP in October of 2007. It all started with a routine ultrasound. Numerous lesions were found on my liver. I was given a CT scan and told not to worry that the lesions appeared benign and I should be rechecked in 6 months. I thought everything was just fine when out of the blue I had a gallbladder attack and had to have surgery to have it removed. I jokingly asked the surgeon to biopsy the liver lesions while he was in there. Well he did and the pathology report came back poorly differentiated adenocarcinoma and my life changed forever. I was in shock. I had every test out there – PET scan, MRI, colonoscopy, mammogram – I even swallowed a pill with a camera on it. The primary source could not be found. I was officially given the diagnosis of CUP. I started researching and could not find anything positive. Then my oncologist recommended that I see Dr. Greco at the Sarah Cannon Cancer Institute. He came up with a treatment plan – He told me even though this was not curable it was treatable. That was the first time I was given a little hope and I know I am here today because of Dr. Greco and the work he has done researching CUP. For treatment I was given taxol, carboplatin, and avastin every 3 weeks for a year and the pill tarceva everyday. What a long year! I lost my hair and was sick and very tired alot. I had to have 2 blood transfusions. Today I am off of everything except the tarceva pill and I am doing really well. My lesions have been reduced in size by 50% and my last PET scan showed that there is very little activity so they are mostly “dead” lesions. I will have scans every 2-3 months to look for changes or anything new but for now I am considered “stable”. I have finally come to terms with the fact that the source of my cancer will not be found. I still dread the question “what type of cancer do you have?” because it is so hard to explain. I am so glad I found this website – it helps to know that as terrible as it is there are others that understand. Thanks for letting me share my story! Lori (Alabama,USA)

Just wanted to update my story. I received the results from my latest scans and the news was not good. Looks like the lesions in my liver have grown significantly and new lesions were seen. So it is back to chemo. My oncologist is wanting to use a combination of Alimta and Avastin. I am not sure what to think of this as these are lung cancer drugs. If anyone has any knowledge or experience with this drug combo I would love any input you have. *Lori loyoung* says on January 31, 2009 at 12:10 p

Hi loyoung, I see that you have seen Dr Greco in Nashville TN USA. I have been doing a pro and con sheet about making an appt. Have been on Xeloda for 22 months (4000 mg/day) and since the last MRI showed 2 nodes in my pelvis have grown more than 25%, they want to change treatment. Problem is my oncologist—with NO CUPS experience wants to put me on 5fu and Avastin and the CUPS specialist a Sloan-Kattering in NY says absolutely no to Avastin since I have no free fluid and suggested 6-7 other single use drugs—none of which are 5fu. All but tamoxofin are very toxic. Was on carbo/taxol but mass grew. Can you give me any feedback about Greco? Was surprised to hear the nurse say I wouldn't have to mail by paperwork down before the visit – that he'd read it when I came down (that's over 7 inches of paperwork of RELEVANT results and reports) and that he did not need to look at any of the actual discs of CTs, MRIs or PET scans. Was this how it was with you? I am into my 4th yr of CUPS (they said I had 5-6 months) and would like to stay around a while longer. If I do go down, where did you stay? Did they do their own tests? How long did you have to stay? I hope your current regimen is working well for you. The Xeloda was an oral drug that they did not expect to do any good cause it's not used for the kind of cancer they “THINK” I have though they have never found, for sure, where the prime site is. So maybe the same will hold for you. The Xeloda didn't shrink or get rid of anything but it was the first drug (after 5 others) that kept it from growing. They said since it's “unknown” they're just taking shots in the dark. So you never know just what be the winning combination. Wishing you well, Kathy R. *Kathy R* says on February 27, 2009 at 12:12 pm

Hello to all, I am so happy i found this site, I just wish we were all on it more. My name is Jackie and I am 20 years old. I was diagnosed with CUP in October 2008. I saw a specialist at MD Anderson in Houston, TX by the name of Dr. Raber. What I was told is that he had the most experience treating CUP than anyone else. I flew down there and my doctor here in Michigan and Dr. Raber decided to put me on 5-FU, Oxyciplatin, Avastin, and Lukavorin (sp?). He said that this combination is commonly used for CUP. They have not found the primary tumor and probably never will but my

treatment has worked so far. I am not cancer free but all tumors have shrunk and some are not even there anymore! We are unique in that we really do not have a prognosis as there is soooooo much to still be learned about CUP. I hope this helped and if anybody wants to get in contact, my direct email is teaguej4@msu.edu. God bless [Teague27](#) says on April 13, 2009 at 12:14 pm

Hi Jackie, How are you doing on the 5FU/Avastin/Oxci? I was put on 5Fu/Avastin 8 wks ago. My cycle is 1 day a week 6 wks then 2 wks off (this week). Why did Dr Raber start you on GI drugs first? Where was your cancer found? When I saw your post I asked my onc about the oxaliplatin cause I read it was a GI drug but also used for advanced cases of ovarian- they “think” I may have a gyne cancer but can’t prove it and I had a hyster 15 yrs ago. The cell are similar to gyne-but not conclusive and EVERY gyne drug failed to reduce the mass. Was it difficult to get in to see Dr Raber? You said he decided to put you on this treatment. Do you fly back and forth or is your onc in MI following Dr Raber’s recommendations? I have been to a CUPS specialist at Sloan-Kattering in NY, who sent my onc a ltr of what he recommends now, and my onc has totally dismissed his recommendations though she has never treated CUPS before me. However, her logic made sense so I decided to try it as it is way less toxic than his suggestions. If this doesn’t show at least status quo, I will either quit treatment or see another CUPS specialist if there is someone more versed than the doc in NY—though I really like him. I am so sorry that someone as young as you are has to be burdened with this mysterious disease. I wish you the best and hope to hear from you. Have you looked under the FRIENDS section? A couple of us are communicating there. Please join us.
Kathy R [Kathy R](#) says on May 15, 2009 at 12:15 pm

Question for John *Posted on: September 20th, 2008 by ohifriend*

John, If you don’t mind, can you tell us more information about Jo? If it is still uncomfortable, I understand but those of us out here are inevitably going to face what you have and it may make it a softy landing if we had some insight as to what to expect. Questions I have are: how long from diagnosis until she passed, how you spent that time, your (both you and your wife’s) dealings with the medical community, family and friends. If I probe too much, please just ignore me. Michael

Hi Michael, thanks for keeping us updated on your wife’s condition. Jo was diagnosed in January 2006 and died in September 2006 (2 year anniversary on Saturday). One thing I’ve learnt is that no CUP patient is the same. Jo’s quality of life was very poor throughout as different chemo regimens were tried. We lived day by day and almost “lived” for the next treatment in the hope that it would do some good. I think the chemo prolonged her life a little but she suffered terribly from the side effects. Medical community did their best. They are as frustrated by CUP as the patient and many feel they are failing their patients. Friends and family a tricky area. It was a tremendous effort for Jo to face up to visitors when feeling so ill but they did boost morale. I came to realise as the “gatekeeper” that one had to judge the importance of the visitor to Jo and encourage or discourage appropriately. I had to realise that it wasn’t just Jo’s feelings that one was dealing with but also those of the visitor. Palliative care in the UK much improved since my father died of cancer in 1984 but not perfect. Jo died in hospital – I would have preferred a hospice (my sister died with CUP 2 years before Jo in a hospice). In my view palliative care should be an early part of the CUP pathway to ensure pain managed well at all times. By all means ask any questions not answered but I repeat: no CUP patient is the same. (I took the view that I had to face up to CUP and try and do something about it; but fully understand an opposite reaction that might want to try and wipe it to recover.) [john symons](#) says on September 21, 2008 at 11:33 am

John, Thank you so very much for your response. I am sad to hear you had so little time with Jo after her diagnosis and to have lost a sister just before to the same disease is simply terrible. I suppose for the treatment to include chemo, there must have been a location(s) in the body where the cancer was found, yet a biopsy gave them no indication of what type of cancer it was. In my wife’s biopsy, the resection of the largest brain tumor showed it to be mucinous adenocarcinoma, but nothing else, and

fortunately or unfortunately, located only in the 5 tumors found in her brain. Yet so far, no further symptoms...but the prognosis is still rather bleak as they say there are millions of cancer cells still floating around in her blood stream waiting for one opportunistic moment. You do a great service here. I hope the word gets around and there is more participation. Thanks again for your frankness. Michael [ohifriend](#) says on September 23, 2008 at 11:34 am

Thanks Michael. To fill in the missing bit on chemo – with comparatively strong patients where chemo is the best option (rather than hormone treatment for e.g.) oncologists tend to go for “empiric” chemotherapy. That is to say chemo based on their experience and best guess of where the origin of the cancer is. It is what I sometimes call the “thousand bomber raid” approach (Jo’s oncologist did not like this analogy!). It might hit the target whereas a precision guided weapon goes to the target exactly. Very Best wishes at this really difficult time of uncertainty for you both. John [john symons](#) says on September 25, 2008 at 11:34 am

Here to post an update! It has been nearly 6 months since I first logged on and I am happy to report that my wife is still doing well. Her cancer remains unidentified but likewise remains dormant. In March she will have survived 24 months, cancer symptom free. This would statistically put her in the 12% category, according to much of the information I have read at various sites. She still has monthly visits to her neurologist and oncologist for blood draws and marker checks. Her 90 day CT scan is due in March along with, I believe this time, a brain MRI to check for recurrence of tumors. Of course, the usual suspects still remain lung cancer first, then ovarian, adrenal and breast. And, of course, this has changed our life significantly. Although I continue to work and live pretty much as before, she lives with a stress I probably will never be able to fully understand. There seems to be a new urgency in both of our lives as mortality now seems inevitable rather than something intangible or nonexistent. For me it means there is less time than I thought to do what I want, to accomplish what I need to do, to reach the goals I have strived for. And to have her join me if she is willing. To her it means to slow down, enjoy the family, to live on day at a time with the priority on living. And to have me join her if I am willing. [ohifriend](#) says on January 30, 2009 at 11:35 am ([Edit](#))

Hey, In such a discouraging world, a positive word is always welcomed. My wife is now 28 months cancer-free, and thus far no brain deficits from the WBR. (keeping fingers crossed). Except for the daily dosage of Keprin and a little change in her gait as she walks due to the brain surgery, perhaps, she is just fine. Michael [ohifriend](#) says on July 11, 2009 at 11:36 am

another newcomer [Posted on: September 8th, 2008 by kath3kidz](#)

Hi all, I am a new member in UK. I am 51, average height and weight, apparently completely fit and healthy (!) with no obvious ill-health symptoms... BUT... I found a lump in my left armpit at the beginning of July 08 and went straight to my GP. He referred me on to our county Breast Cancer team immediately, and also took blood tests – some for thyroid levels as I have a low thyroid for which I have been on Levothyroxin for about 8 years. I also tend to be a bit anaemic, so he tested for that as well. The blood showed I was a bit anaemic and that my thyroid levels were a bit down, so he doubled the Levothyroxin to 100Mcg daily and put me on iron supplements, as he was anticipating that I would need surgery if my lump proved to be sinister. Other than this, my blood tests showed me to be a normal healthy person, no white cell abnormality or anything. I had my first check at the Breast care clinic and 6 swollen lymph glands were seen on the ultrasound, although the mammogram showed no breast abnormality. After a fine needle aspiration biopsy, I was told that abnormal (cancerous) cells had been found in that gland, and as I am allergic to some local anaesthetic they went on to remove one gland under general anaesthetic. I had a CT scan with contrast dye on all major organs – throat, abdomen, uterus, chest, lungs etc. – all came back completely clear. Following this, the biopsy on the gland removed showed that the cells were not lymphoma or leukaemia, but possibly melanoma; further tests for melanoma then came back negative, and at present have been told that the histology has proved inconclusive i.e. the tissue type does not match any known cancer cell type, therefore they do not know what type it is. I was advised that all the lymph glands in that armpit needed to be

removed, so all lymph glands in the area were taken out 2 weeks ago; of 16 glands taken I have been told 15 contained cancer... that is VERY scary !The consultant then set up an MRI breast scan, and I am due for the results in 2 days – this is because he says that 1 in 300 women have breast cancer that is not picked up in mammograms and does not show as a breast lump.If the MRI scan shows nothing I am to be referred on to the consultant oncologist for them to continue to try to find the primay cancer.I have several questions for members. One is – does anyone else have a similar story? Also – now I have no lymph glands to collect the cancer cells that are running through my lymph, where is the cancer going??? I have had to have the area drained twice so far (they warned me this would be necessary for a while, and as I don't want the cancer to settle elsewhere it seems a good idea to me). Does anyone know of any other tests I could ask for – what is a PET scan?? Also has anyone else had cancer in 15 out of 16 glands or worse? any advice or positive stories would be really helpful – I don't know about clinical trials for this type of thing, but my consultants all seem to thimnk I am a pretty unusual case... interesting for them but a bit scary for me!
Any advice or comments would be very welcome, thanks.

Hi KathI went through what you are going through exactly one year ago.
My CUP is abdominal and remains unknown. I went through Chemo Taxol, Carboplatin & Etoposide.I feel great now. I have CT scans every 3 months. Dont get discouraged
DianneArcticnurse says on September 16, 2008 at 1:06 pm

THanks for your encouragement Dianne – it really helps to know someone else has been here. John – I'm now booked to have a gynae checkout, a PET scan, a bone scan and a stomach/bowel CT scan, plus they are testing the cells for Triple Negative breast cancer and HER2.... my oncologist wants to get me started on chemo as soon as all these tests are done (by end of next week)as he says they can already see more tumours under my collarbone higher up in the lymph nodes that remain there.
So I guess something will soon start happening for me — I just hope it works.kath3kidz says on September 17, 2008 at 1:06 pm

Hi John,I'm now booked for a uterus CT scan and ultrasound tomorrow as well as the other lot of stuff, also they have done blood tests for tumour markers. I have recently been lent a marvellous book by Bernie Siegel called Love, Medicine and Miracles; it has really helped me to lose that sense of fear and dread, and I feel much more positive and in control. THERE are a lot of good positive thinking techniques that I have found really helpful. He's written a lot more I see, and there are meditation CDs too.I'm noticing that the meeting friends section of the website is fairly quiet – should I transfer to posting on there at this stage or carry on here?Thanks for the support, it really helps.Kathkath3kidz says on September 22, 2008 at 1:08 pm

Hi all,well... since I last posted I have now had CTscans on bowel, stomach, uterus and ovaries; bone scan on whole body; PET scan on whole body; ultrasound on uterus;plus HER2 blood test and tumour marker blood tests....! All test results returned negative!! Nothing has been seen in any of my major organs or anywhere, yet the spread of secondary cancer in the lymph glands, now presenting as tumours under my left collarbone are continuing to grow.They have decided that it is very possibly Triple Negative breast cancer, although it has now been accepted that they are unlikely to ever know for sure. My oncology team feel that chemo needs to get underway right away to deal with the lymph problems and I am having my first session on Friday this week. I'm being given TAC chemotherapy and have been warned that I am having a strong dose of it. My regime is one session every 3 weeks, and I've been told that each session will last 5 hours, which seems a very long time to me.Has anyone else had this drug combination, and were their sessions 5 hours too? Any hints or advice re side effects would be gratefully received.I am delighted that they didn't find anything else, because obviously it could have been a lot worse. Strange though....Kathkath3kidz says on September 29, 2008 at 1:09 pm

Hi KathI too had a combo therapy – Taxol, carboplatin and etoposide and my sessions lasted 5 hours .I was jealous of the patients who were in and out in an hour.Just stay positive and remember to

laugh. I used to run around the house without my wig. My daughter sent me a Tshirt "I'm too sexy for my hair" I seemed to always wear it when unexpected visitors came. Our new pastor at church was one of them. My hair has grown back & the new pastor gives me a wink every so often. I celebrated my first anniversary anniversary and I'll gladly take how many more I get. CUP is life altering but it gives us time to sort out what is important in life. Hang in there
Dianne *Arcticnurse* says on October 2, 2008 at 1:10 pm

Hi Dianne, Thanks for that. I've had the first one and it went really well! I didn't get any sickness or any real feeling of being ill. I have had one or 2 days where I feel a bit spaced out and I've had strange nerve pains in my knees and ankles, but that's about it. Its day 6 today so I'm feeling quite positive. I have got a slight sore throat today so I hope that's not a sign of getting a sore mouth – I just keep shrugging off any weird feelings and staying focused on visualising my cancer shrinking and dying. It seems to help. I am on docetaxel (TAXOTERE), doxorubicin and cyclophosphamide. I was so pleased that actually having the drugs was not unpleasant or painful at all – I thought I would feel it going in, like the strange contrast dyes they give you with CT scans, but I wasn't aware of any sensation at all, thank goodness. I hope you are still staying well, Dianne. I find myself wondering how all my new cancer survivor friends are doing each day. It really helps to be in a group, doesn't it? Thanks John for keeping us together! Kath *kath3kidz* says on October 9, 2008 at 1:11 pm

Hello, I had to respond to the reference to the Bernie Siegel books. His books have helped me immensely, too!! I would encourage others to read "Peace, Love, & Healing" by him, as well as "Love, Medicine, & Miracles". In his books, you will learn about a support group system he calls ECaP for exceptional cancer patients. I found out that ECaP retreats are held twice yearly in the USA & my husband & I attended one last month in Pennsylvania!! It was a very supportive experience & we came away with a lot of inspiring ideas to help us coping with my cancer diagnosis. I am going on 2 years of living with CUP. Mine appears to be gastrointestinal in origin & I have been treated with 20 chemo treatments of 5 FU & Leukovorin; 3 of Gemzar & Carboplatin, and now am on Taxol with Etoposide. It seems that the best we can do is keep it from advancing, as I am stage 4. The important thing I have learned is to focus on living, not dying, and NOT to get discouraged by statistics. Bernie's books help you get that perspective. I was so happy to find this website for CUP – thank you for establishing a place to talk to others. With peace, Mary *Mary wallingford* says on November 17, 2008 at 1:14 pm

New to this site *Posted on: June 24th, 2008 by Dianne*

I was diagnosed with this confusing situation last November. I noticed a lump in my right groin last June. I went to my GP who told me it was nothing & sent me on my way. By September it had doubled in size & I was thousands of miles from home working in Canada's arctic in an isolated Inuit village. I had been working there the last 18 years. Doctors visit the community once a month. I saw the visiting physician on September 12th and by September 19th I was back in the south having biopsies. At first they told me it was "a lymphoma". Then they were not sure. I would need more testing. I was referred to a cancer centre closer to my family. Canada is a very large geographically & I discovered that health care is provincial. I was not able to access some services until I became a resident of Ontario. My work up included core biopsies of the lymph node and a CT scan of my abdomen, MRI of my breasts and blood markers. They kept saying all the blood markers were "in the normal range" The word CUP was never mentioned until after I started my Chemo – Taxol, Etoposide and carboplatin which continued every 21 days for six sessions. Within two treatments the lymph node shrunk to normal size. What I am finding – I don't know what to ask for. Anything I have read about CUP is very negative but all the statistics are other people's. Should I request a PET scan? What would it show. CT scans and MRI did not show anything other than an enlarged lymph node. Apparently they are not covered by my health insurance. Are they used in other places for diagnosis? Arctic Nurse

Welcome to the site. I'm hoping others will comment from experience about PET scans. My understanding – others may correct this – was that it is possible to get on NHS but I'm not 100% sure

and surprised that it is not covered on your health insurance – the problem is scarcity. Not quite sure whether you are in UK or Canada at the moment? If UK, according to CRUK there are presently (summer of 2008) 5 NHS scanners in London and 10 in other parts of England (in Brighton, Cambridge, Manchester, Birmingham, Cheltenham, Nottingham, Oxford, Coventry, Preston and Guildford). There are also scanners in Aberdeen, Glasgow, Dublin and Belfast. (If you are Canadian and not British this won't help much)PET is more relevant for some conditions than others so I guess it is probably down to the judgment of your oncologist.On stats – they are pretty useless for anything to do with CUP because it is classified by all sorts of different names and is such a heterogeneous problem.[John symons](#) says on June 24, 2008 at 12:47 pm

Dear JohnThank you for your reply. I'm in Seoul Korea visiting with my granddaughter. I finished my Chemo in April and my last CT scan showed no change in the size of the lymph node. I have undifferentated carcinoma. I feel great, in fact my energy level is the best it has been in years. My years in the arctic have allowed me to accumulate enough air miles to travel business class. I will request a PET scan if any symptoms reappear. In Ontario Canada they are allowed if one is part of a study.[DianneArcticnurse](#) says on June 25, 2008 at 12:47 pm

Hi JohnI requested and received a Pet scan here in Korea. All it could tell me wasI had cells in the original lymph node but no new tomours. They gave me a CD with a copy of the Pet Scan to take home. The oncologist I met spoke excellent English.I guess I was so fixated on the Pet Scan – or having one would be the answer that I was not willing to accept the diagnosis of CUP. I now realize that it is what it is.I have another three weeks here in Korea enjoying the heat and food. [DianneArcticnurse](#) says on July 15, 2008 at 12:49 pm

Hello,I am brand new here, too. Diane aka arcticnurse, turned me on from another site. This isn't about me but about my wife who, after several days of tremors and light seizures was found to have 5 metastatic brain tumors, CUP. One was resected, 4 were treated with gamma knife, followed by 30 day of WBR.In an episode of "House" last night, one of the interns refused to be tested for Parkinson's because with a 50-50 chance she finds herself living life and risking more than due to the uncertainty. My wife is pretty much the same – she has chosen to live with her head in the sand and has requested only to be told what has to be told by the doctors. I can appreciate that with all the dreadful information available on the internet. It would be hard to remain optimistic at all reading what there is to read.Unfortunately, there is little information about her condition. The latest scan shows no activity, no cancer. From what I have read, all we can do is wait for that involuted tumor, wherever it is, to send out more metastasis or for the ones already floating in her blood to settle down to build a tumor or two. Supposedly, the brain mets are not really the issue right now, however the WBR might be down the road if dementia becomes an issue.Wait. That's what we do. Every twitch, every quirk, every sleepless night, every little pain is automatically cancer. The internet says anywhere from a median of 11 to 36 months. I haven't read anywhere where a CUP with brain metastasis has lived beyond 24 months. She is at 14 months now. Everything I read says that if the primary is discovered, it will be NSCLC. She was a heavy smoker who, ironically, quit 3 months before her dx.Anyway, that's her story. Thanks for listening and if anyone has anything to share, it would be greatly appreciated.[M. Paulohifriend](#) says on July 23, 2008 at 12:51 pm

Thanks for the post – I just wanted to reply quickly so that you knew someone had read your moving story. I'm sure there are others out there who will reply and will also have great sympathy for the very very difficult position you are both in. I too have read of the lung as the most frequent anatomical origin for brain mets but the book I'm looking at says 39-64% which means, if they are right, it doesn't have to be (I'm not a clinician and we don't give medical advice; I'm only applying logic – there seem to be no "rules" with CUP which is so little understood.Best wishes at this very difficult time,[JohnJohn symons](#) says on July 24, 2008 at 12:52 pm

Thank you John. I have frequented a brain cancer site where there are a lot of contributors, but the majority of them are dealing with GBM. I guess, like everyone else, I'm looking for a timeline, an actual experience that can be used to compare our situation with another's. The prognosis with metastatic tumors and GBM, according to the websites, is similar but I don't see it like that at all. At the other website, it seems that 80 percent of the patients die within a 18-24 months. They all seem to be fighting regrowth, memory problems, weakness from the diagnosis to the end. We cannot relate. There is no chemo. There are no real deficits. There seems to be nothing wrong with her. Only a bad prognosis. It is like being haunted by a ghost only you can see. Thanks again for listening. As Tom Petty says, "the waiting is the hardest part." MPaul [ohifriend](#) says on July 25, 2008 at 12:52 pm

Update on wife's condition. Now at month 18 with no new symptoms. Due for another brain and chest MRI. Most recently experience a swelling of the lymph glands above right collar bone/ neck and on the thighs. Anti biotic seems to have temporarily worked, but you know with every new symptom the first thought is the worst thought. How is everyone else? And who is this madman the posts now and then?? [ohifriend](#) says on September 20, 2008 at 12:54 pm

News update I am now approaching the one year anniversary of finishing my chemo. To date there are no new tumours. I am now in remission. I feel great and am enjoying life. My only fatigue is from jet lag from my air travel visiting all my grand kids. I would love to attend the conference in October. Keep me posted on dates. Dianne [Arcticnurse](#) says on February 15, 2009 at 12:56 pm [john symons](#) says on February 15, 2009 at 12:57 pm ([Edit](#))

Dianne/Arctic Nurse Just wondering how you're doing. I've been diagnosed with CUP (obviously) in the abdominal lymph glands too. I'm currently under going chemo but was wondering if you did anything else too? I'm following a strict diet which is supposed to stop cancer in it's tracks then start to "mend" the cells. It's very hard going though! It's nice to hear there's some hope out there – keeps us all going 😊 [Cheryl](#) says on September 12, 2011 at 10:32 am

Dear Cheryl The biggest thing is to stay positive. Do things to make others laugh. I had my bald head painted with henna flowers and wore a T-shirt that said "I'm too sexy for my hair" I did get hung up on a few things. I was convinced that a PET scan would be the answer. It didn't show anything new. I keep myself extremely busy. My most recent CT scan did not show anything new. I'm planning to attend the CUP conference next April. Dianne [Arcticnurse](#) says on September 13, 2011 at 2:22 am

squamous cell carcinoma *Posted on: May 16th, 2008 by Douglas*

I've been diagnosed with a squamous cell carcinoma of a mid cervical lymph node on the left side of my neck. CAT scans PET scans, X rays, blood tests etc. have come up with nothing. I feel fine... I had a dissection of the node and now an oncologist wants to do radiation therapy . I'm wondering if anyone has a similar story. What I may expect, all suggestions are welcome. I'm all ears... I'm not too fond of the oncologist I was referred to and am working now on getting a second opinion.. Thanks

Thanks for the reply John and thanks for the tip on the cancer backup site... I'm still in limbo on what's going to happen, I also have to go in for a second needle biopsy on a node in my thyroid. They don't think it's anything to worry about but it needs to be eliminated as a concern. The first needle biopsy came back as indeterminate because they didn't harvest enough cells. Same thing happened with a needle biopsy of the lymph node I had to have dissected. You'd think there would be a no charge on inconclusive biopsies wouldn't you? ah well... Doctors need to gas up their SUVs [Douglas](#) says on May 21, 2008 at 5:31 pm

yes, this business of being in limbo is very difficult and a characteristic of CUP patients. Really frustrating that you have to repeat biopsies. Again, my understanding as a layman is that the cells are

often “poorly differentiated” for those with a CUP diagnosis and this can make the clues from the samples more limited and more difficult to interpret. Frustrating though it is, it is important for the doctors to get as much evidence as possible before taking a course of action. Sounds like you haven’t lost your sense of humour – a much needed coping strategy [john symons](#) says on May 22, 2008 at 5:32 pm

Frustration being the key word on being a CUP patient. I ask questions to the doctors and I often get a shrug. I can tell you one thing about needle biopsies, it makes a huge difference on who the doctor is that does the poking. My first thyroid needle biopsy was VERY uncomfortable and painful. I did some whining and crying and pouting about needing a second biopsy. Well, a different doc did the poking this time and quite frankly it was a “piece of cake”. It went very quick and was pretty much painless. Guess it pays to shop around even in the medical field. Still in limbo but certain I will have to do radiation. It would be nice if someone happens to read this has a story to share, I’d love to hear one..and thanks again for the reply [John Douglas](#) says on May 25, 2008 at 5:34 pm

Anone else out there going through the investigation process or radiation therapy (themselves or a relative) who can help by sharing experiences with Douglas? [john symons](#) says on May 26, 2008 at 5:35 pm

Thyroid biopsies came back as benign and I’m giving up on a second opinion with my CUP. Looks like my primary is going to remain unknown. I’m going in for markings at the radiologist on Monday. I need to get this done and over with I’ll try and keep up in here in case someone later may need to hear what may happen to them. 🙄 until then [Douglas](#) says on May 31, 2008 at 5:37 pm

First, I’ve done a lot of web searching and that may be a mistake because what I find tends to be written years ago and quite frankly a bit scary... too much information can sometimes not be good. My daughter is a nurse and she says doctors hate the internet because patients get overloaded with information that isn’t applicable to themselves. Bottom line is every case is different

I went in for the prep work for my radiation therapy. It wasn’t much like the stories I found on the web so far. The only hard part was laying still while they did whatever it is they do to get me ready for treatment. It was painless and everyone was quite nice and very professional. It took maybe an hour of chatting, taking some CAT scan photos and being fitted with a mask that will keep me in the same spot everytime. I have to say it all was a bit interesting in an odd sort of way...

Treatment starts on Tuesday of next week [Douglas](#) says on June 4, 2008 at 5:40 pm

Thanks for the link John.. Common sense told me that the story of this site would have to be what it is.. I want to express my sympathy to everyone who knew Jo. Out of all tragedies I like to hope there is a shinning light somewhere. The purpose of this site to help CUP patients such as myself has to be part of that shinning light.. Thanks to all involved Radiation therapy still scheduled for Tuesday afternoon, I will do my best to keep this blog updated and hope that someone someday may get the questions answered that I was hoping to find.... later gators 😊 [Douglas](#) says on June 9, 2008 at 5:44 pm

Lots of stuff going on... My first treatment was fine but a few hours after my second treatment my mouth was going dry. When I told the radiation therapy girls this, they said it was impossible for my mouth to be dry because of treatment and I may have a bug of some kind. A few hours after my third treatment I lost all saliva... You do not know what that’s like until it happens. Internet sites use the loss of spit and quality of life in the same sentence a lot. Anyhow, radiologist says this side effect this early is impossible. After she looked in my mouth she first blamed the fluoride treatment I’m using and then second blamed the internet stories I read and anxiety I’m developing... I went home without doing my fourth treatment and I’m going to see a general practitioner I knew years ago that I like and trust for consultation on what to do, to ask for anxiety meds and have him look at all the white yucky stuff that started growing in my mouth this morning... My guess is I have thrush (?)

from the three treatments I received and that my radiation oncologist assured me I would have no side effects from until my second or third week of therapy... I'm going to also ask my GP to refer me to a different radiation therapy oncologist (I should of followed my first instincts and done so earlier) oh yeah btw.. I overheard the radiation oncology team talking about a power surge they recieved (we've had a lot of bad weather here lately and lightning apparently caused a power surge) ... but NO WAY could it have effected their human microwave machine... No wonder I'm going in search of anxiety meds today ... oh btw, saliva returned two day after last treatment ! thank God to be continued....[Douglas](#) says on June 16, 2008 at 5:45 pm

Yep, I have thrush.. it's treatable with a gargle solution and seems to be better today already. I'm still waiting on a phone call for when I can see another radiologist. I'm sure it's probably better to not prolong treatment but I cannot over emphasize that I should of followed my original instinct way back and talked to another radiologist. It is VERY important to trust your doctor... I've had that feeling confirmed when I saw my general practitioner from long ago.. That man is gold in my eyes right now and I need a radiation oncologist of his caliber .. to be continued[Douglas](#) says on June 18, 2008 at 5:46 pm

Hi Douglas I am new to this site as I was diagnosed on May 19th and didn't quite understand why they couldn't find my primary cancer so I, like you, started looking on the web and then found 'Jo's friends' in a magazine while at the hospital waiting to have blood tests to see if my kidneys are in good shape for the chemotherapy treatment ahead....I was meant to buy that magazine!! I am sorry to hear that you are not happy with your treatment, and hope that you have found someone that you have confidence in.I also have squamous cell carcinoma in the left neck lymph gland, following scans and biopsies and a left tonsillectomy nothing else has been found, and I like you, had not felt unwell and had no symptoms other than the lump. The oncologist at the hospital I attended has put me forward for both chemo and radiotherapy as the cells in the biopsy seem to come from the mouth/throat area, the base of the tongue seems the hardest place to detect so they have not ruled that out, although a base of tongue biopsy showed nothing. The chemo and radiotherapy hopefully will sort it all out and they are talking of a cure at this stage. The radiotherapy is to be from my sinus down to the top of chest and I have been warned that it is 'extremely nasty' by my oncologist, they do mention temporary loss of salava glands (there is a spray and mouthwash for this)- thrush – mucus at the back of the tongue and I also will not be able to eat at some stage so I am going into hospital next week to have a tube fitted into my stomach to have liquid feed when it is at it's worst. I was hoping that someone else had been down this route before me and could give words of comfort like 'it isn't that bad' but I don't think I am going to be that lucky. I also have had my mask fitted and do feel somewhat claustrophobic but hope that I will be able to cope for the 33 day duration of the treatment. I have certainly had the blackest picture painted of this treatment which is filling me with dread at the moment to the point I get panic attacks, I have been offered tablets to calm me and counselling (one session due next week), my treatment is due to start on 30th June so wish me luck. If you look on the cancer backup there is a fellow called Matt who seems a true inspiration for this type of treatment (although they know where his cancer is)- I just wish I had his strength and outlook.Regards Maureen[maureen](#) says on June 22, 2008 at 5:52 pm

Maureen, I'm sorry to hear of your problems and they do indeed sound familiar.. I have a meeting with a different radiation oncologist on Thursday. I just wanted to tell you that not one doctor I've seen so far has thought chemo was needed for this CUP cancer I have, a single mid cervical node with an unknown primary. I'm told the cancer cells found point to the throat and base of the tongue too... you may want to question the damage to the salivary glands that radiation will do because from what I understand it can be permanent... it's worth questioning as far as I'm concerned, after a few hours with a complete loss of saliva I'm quite certain that isn't a life I want on a permanent basis. perhaps it's because of the thrush or the thrush is because of the treatment? I do not know, but sucking on candy, chewing gum, sipping on water or the over the counter dry mouth sprays were pretty much worthless until I got that "little bit of spit" back where I had something to work with...

I guess my point is that I want control over my treatment and just because a doctor says it's so doesn't always make it that way... but what do I know ? thus my second opinion on Thursday [Douglas](#) says on June 24, 2008 at 5:54 pm

Hi Douglas I do hope that you have been successful in finding answers to your treatment. I also did question whether my treatment was the right kind. I went to The University College Hospital in London where they do Photodynamic Therapy, in the hope that their lazer would be able to find my cancer. But the Photodynamic Therapy treatment is only successful on known cancer sites. I spoke to Colin Hopper who is the top guy there and he was of the strong opinion that my team had done their best with all tests to find my cancer and that the treatment they are giving me has the best success rate for a cure and he advised me to go ahead even though he understands it is not pleasant. It is so difficult when the primary is unknown and especially in the head and neck. There may well be sacrifices but if it saves your life.....Have you been to the cancerbackup site and read Matt's story – similar to ours – he has so much information to give and is very supportive, although his primary site was known, he has gone through similar treatment to ours. All the best Maureen [maureen](#) says on June 29, 2008 at 5:56 pm

Hi Maureen and Douglas I found this site two weeks ago. I too have CUP but mine is “somewhere in the abdomen” I finished my chemo in late March and feel much better now. It is more than a year since I found my enlarged lymph node. Keep doing your research and asking questions. At first I was tired of answering the questions about CUP to friends and some doctors but this website has helped me realize that the world needs to know about us. I live in Canada. Dianne [Arcticnurse](#) says on July 4, 2008 at 5:57 pm

Hi, yes thank you. I have exactly the same as you, but it was two lymph nodes on my rite side neck, so the doc gave me a comprehensive neck dissection. Its been nearly two months now and i am still so sore and numb, cant feel my neck and i cant lift my arm very high. While they were taking out all of my nodes on my rite side they also did byopsis on back of my tounge and where my tonsils used to be. came back clear?? No primary.. But wait there is more!!! now i felt a tiny lump on the other side of my neck, doc wanted to do byopsy, when it came to lying down on bed with ultrasound machine, they couldnt get in confidently, i was so out of there. Now i am doing radiation starting next tue. Jeeeeeze i am so scaird. thanks again for info.. vicki, albion park, Australia [vicki](#) says on March 10, 2011 at 6:00 pm

Thank you to Jo' Friends site [Posted on: September 24th, 2007 by Kate](#)

As someone who had a very dear friend who was diagnosed with CUP I was interested in the content of this site. When my friend told me she had secondary cancers, the first question was- where did it come from? When the answer was that it couldn't be found, I didn't then appreciate the importance of finding the cancer origin in order to treat it effectively. I was unsure of what she was facing, & to begin with lacked understanding of her frustration with 'not knowing'. I know my friend, & her family found little support & information specific to CUP(outside her wonderful medical staff) to help her in her fight against CUP- especially on the internet where other cancers are well represented. This website is very informative, and seems easy to understand by a non-medical person! It will, hopefully, also bring fellow sufferers and their families & friends together to provide mutual support. I hope that CUP becomes better known generally through this & other initiatives, and awareness improves. Thank you Jo Friends. Kate

Hi Kate Sorry to hear your story, my father was diagnosed in March of this year with the primary source unknown and I am finding it equally difficult to deal with and find support. I am new to this website having met John for the first time over the weekend and have found it extemely useful – will do my best to help promote awareness as much as I can. Best wishes and my thoughts are with you, Nicki [Nicki](#) says on October 23, 2007 at 1:25 pm

