



Tanya Harrison: 'There is a fantastic forum and support network for people affected by CUP' Picture: JON GUEGAN (01979047)

Fighting a hidden enemy

SLANDER Paul Thorne was a healthy man. He never smoked, was not much of a drinker and his work as an engineer and plumber kept him active and fit.

So when he learned that he had developed cancer shortly after his 50th birthday, after feeling unwell for several months, he was willing to fight it. There was just one problem – the cancer had spread in Paul's body and the doctors couldn't find where it had originated.

After a short illness, Paul died in Jersey Hospice in December 2011 at the age of 52.

Paul had suffered from what is known as cancer of unknown primary – a condition affecting more than 10,000 people in the UK each year with a few cases in the Channel Islands.

Without knowing where the cancer started, it is very hard for doctors to treat the condition properly because chemotherapy is usually tailored to the site of the specific cancer – of which there are more than 50.

Deadly

Paul's sister Tanya Harrison (49), now wants to raise awareness of CUP, which affects between three and five per cent of cancer sufferers.

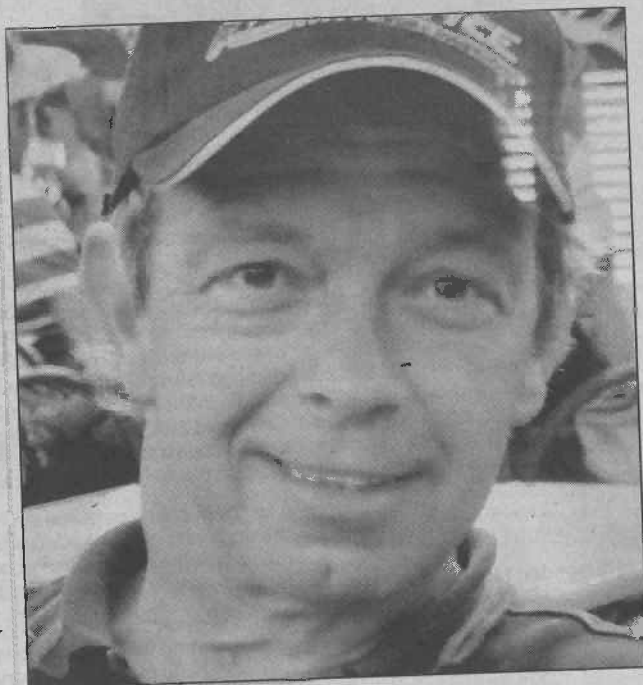
None of her family had heard of CUP and they were amazed to learn that someone can have such a deadly disease, which is effectively hidden in the body.

'Paul had various illnesses, including back pain, tiredness and the flu, on and off for about six months before he was diagnosed,' Tanya says.

'Before that Paul was very healthy. He did all the things that you're supposed to do and he worked hard.

'CUP is so difficult to diagnose. Paul was feeling unwell for several weeks but it was easily dismissed as him being run down or overworked. The first time that they took blood tests, the results indicated that he had cancer but because they couldn't find anything from scans or biopsies they thought it could be a very rare virus. Eventually, they carried out a further biopsy which came back cancerous – they then

Battling cancer is hard enough, but when the original source cannot be identified, it is even more difficult – but there is a foundation out there which aims to help those affected. By **Ramsay Cudlipp**



Paul Thorne was diagnosed with CUP at the age of 51

knew it was secondary, which meant they didn't know where the cancer had started.'

It is believed that the body's own immune system sometimes kills the primary tumour, so by the time the patient is diagnosed with secondary cancer, it is too late to track the original source.

Therefore, CUP patients have to deal with not only the fact that they have cancer but also the fact that the doctors can't tell them where it originated – this is a double blow for patients and their families.

'I think we were in denial, really,' Tanya says. 'You just think the doctors will find it. Also, Paul was

really positive about everything and wanted to fight it.

'Paul did have chemo, in Jersey and radiotherapy in Southampton. There are 50 different types of chemotherapy so they have to match it to the right cancer, which is driven by the primary, but they mixed several strains for Paul to try to cover different possibilities, based on what they had found out about his cancer. Looking back I think, Paul always knew it was a bit of a long shot.'

Tanya says that despite the chemotherapy not working, Paul was still upbeat and positive towards the end and that Jersey

Hospice, where he initially spent five weeks recovering from pneumonia before returning some weeks later for what was to be the last ten days of his life, was a huge comfort to all of the family.

'They were just fantastic,' Tanya says. 'Everything that people say about them is true – they are just like angels. They make the whole family so welcome all the time and their care is just phenomenal. The dignity they allow people is so comforting.'

After Paul was diagnosed with CUP, Tanya began researching the disease and found a very useful website, www.cupfoundjo.org, which

Understanding CUP

- Cancers are named after the area of the body (bowel, stomach, liver etc) where they first start develop.

- If cancer spreads from, say, the liver to the bowel, the disease will be treated as liver cancer because that is where it originated.

- There are several reasons why primary cancers can't be found. It may be too small to be picked up, the cancer may have spread to other areas, making it hard to tell where it started, or the original tumour might have disappeared after spreading to other parts of the body.

- People with CUP often have more than one secondary cancer, making it even harder to find the primary source.

- General symptoms of cancer are loss of appetite, feeling extremely tired, unexplained weight loss and anaemia. There are no specific symptoms for CUP.

- Specialists can suggest possible primary sites, based on test results and a patient's symptoms.

- CUP is more common in older people but can affect people of any age.



The specially commissioned badge

was created by Guernseyman John Symons, whose wife Jo died from CUP in 2006.

'Before Paul I had never heard of CUP and neither had anyone I know,' Tanya says.

'John started the Cancer of Unknown Primary Foundation, also known as Jo's Friends, because he had been unable to find any information on the disease. He's been fantastic and done an awful lot to raise awareness. The charity exists to provide information for patients and careers whilst raising awareness and stimulating research.

'There is also a fantastic forum and support network for people affected by CUP. The stories are all very similar and people really benefit from talking about it.'

'The nice thing about the charity is that because everyone involved are volunteers, all of the money raised goes towards research,' Tanya says.

'There are some great people there. One chap on the forum has just been given the all-clear and he has raised so much money for the charity.'

As part of that work, an awareness week will be held this year from 23-29 September, for which a special badge has been commissioned.

Tanya will be selling badges and she can be contacted by email at tanyaha@hotmail.co.uk or alternatively by calling or texting on her on 07797 827963. She will happily deliver the badges across the Island.

Tanya is also happy to speak to anyone who has been affected by CUP, pointing out that just talking about cancer can be very helpful for both patients and their families.