

Paul Cooper Cancer Journey - an unforgettable start!

Tuesday 8th November 2016 – After suffering severe stomach pains, I am taken by ambulance to Ipswich Hospital where, after a few tests, I was told that it was just a bad case of acid reflux.

As I went to leave, I was again in immense pain, so I was sent for an x-ray which revealed nothing wrong in the stomach, but it showed up many shadows on my lungs. I was subsequently admitted and the following day I was taken for a CT scan.

When my wife came to visit, a doctor came to see us and revealed that the CT scan had shown what they believed was lung cancer and I was required to stay in for another night so that I could see a consultant.

An unforgettable start because the following morning was Sue's 60th birthday and the start of a planned long weekend of family celebrations and I'm still in hospital!

Sue also wasn't aware that I had booked for the two of us to go to Iceland the following week.

I was discharged on her birthday in time for the start of celebrations and since I was otherwise well, we went to Iceland trying to comprehend how I could have lung cancer. I had been going to a gym twice a week for a long workout followed by 30 minutes of lane swimming and I had no symptoms, so how could it be that I had lung cancer?



Sue & Paul

The biopsy confirmed lung cancer and I had what was a very sombre first meeting with my oncologist, who informed me that prior to commencing any treatment some further tests had been requested.

As soon as we walked into the room for the second the meeting, we could tell that the atmosphere was very different. My oncologist said to us, "if there can be any good news with a diagnosis of lung cancer we have some good news. You have a form of lung cancer known as ALK-positive which is treatable with drugs and, if you respond to the treatment, your outlook can be measured in years".

I immediately started taking Crizotinib and the first CT scan 3 months afterwards showed what was described as "a remarkable improvement." Most of the shadows had disappeared but a few small nodules and one larger nodule remained. At the second scan, only the larger nodule remained and that had reduced to something miniscule in size.

I then remained stable until a CT scan in October 2018 revealed some minor progression in the one remaining nodule. I was informed about a trial named 'The HALT Trial' which was taking place at the Royal Marsden. The aim of the trial was to use radiotherapy on the remaining nodule to try to obliterate it and as part of the eligibility tests, I was required to have a brain MRI, something which I hadn't previously had.

After the MRI, I was informed that I had numerous brain metastases with one sizeable tumour and that due to this I could not be accepted on to the trial. Not only was this one hell of a shock, to make matters worse I was told that I couldn't drive home so my wife had to take over.

My oncologist was very apologetic and admitted that he should have requested an MRI immediately after my diagnosis and had been remiss in not carrying one out to this date, which he hadn't done because I was asymptomatic.

He informed us that there was a new TKI called Brigatinib which hadn't yet been approved for use in the NHS but, because it was licenced for use in Europe (we were still in the EU) he would apply for compassionate access to the manufacturers for me. He explained that Brigatinib had a much better ability to penetrate the brain barrier and he was confident that his application would be approved. Unfortunately, radiotherapy wasn't an option due to the location of the main tumour. I started Brigatinib late December 2018.

I was informed by the DVLA that I had to surrender my driving licence for a minimum of 2 years, something that caused me a great deal of anger and stress because my main hobby over many years had been taking my specially prepared sports car on to racetracks, not just in the UK but also several tracks in Europe. It may sound strange, but it was a very relaxing hobby. Once on the track, my head would be clear of any form of daytime stress. My only focus was on that next corner!



Paul on the track in his Lotus

10 weeks after starting Brigatinib, I had an MRI which showed that many of the brain mets had either disappeared or reduced but more significantly the main tumour had reduced in size by 65%. I realised reading through the DVLA literature that they, at that time, did not include a section on brain metastases treated via targeted therapy - all brain metastases and tumours were treated the same. Armed with the results of my MRI scan, I started to communicate with the DVLA.

Fortunately, one of the DVLA doctors took an interest in my letters and soon afterward I received a letter informing me that targeted therapy would have its own section on the DVLA AFT document and that the 2-year driving restriction was to be reduced to 1 year.

Whilst communicating with the DVLA, I had a somewhat heated discussion with my oncologist who told me that he supported my actions but couldn't do so publicly and it was at this point that he told me about the ALK+ Charity Support Group, which I immediately joined. I instantly found not only the excellent support which the Charity offers but a particularly like-minded person in the late Michael Stenton who also wanted to try to effect change on the DVLA.

With the support of Graham & Deb, we composed some questionnaires to gather information from Charity members about seizures whilst taking a TKI. The results were very encouraging but alas we could not gain any interest from the DVLA.

Shortly afterwards Graham had the idea of forming a Charity DVLA Panel of the Charity's members. The aim was to continue to try to communicate with the DVLA and also advise Charity members on aspects of the law surrounding brain metastases and driving. The Panel was formed comprising myself, Duncan and Ian.

We have continued to try to persuade the DVLA to take a more lenient view towards brain metastases treated with targeted therapy and whilst having some success, work continues. We are pleased with the Guidance booklet that the Panel has produced and which is on the Charity's website.

My time on Brigatinib lasted 4.5 years until in March 2023 when an MRI scan showed some minor progression within the brain, hence another 1 year driving restriction beckoned even though I was still 100% asymptomatic. At this point I decided that I wasn't prepared to forgo my independence again and I purchased an EBike. To anyone who must give up their driving licence I can thoroughly recommend the EBike route. I never knew what a labyrinth of hardly used single track roads that we have. I found that I could get almost anywhere without having to spend too long on our busy roads. I commenced driving in March 2024 under Section 88 criteria and regained my driving licence in June 2024.



Sue & Paul

I commenced Lorlatinib but 3 days later felt unwell and was taken into hospital. We believe it was just my body reacting to the new drug since I was OK the day after. The very same thing happened previously within a few days of me starting Crizotinib.

However, whilst in the observation ward a doctor approached me and my wife and what followed was totally unbelievable. His exact words were "I see you have lung cancer, has anyone spoken to you about end-of-life care." When we replied "no, why" he then said, "do you know what a Do Not Resuscitate (DNR) order is, I need to raise one for you".

We immediately objected and tried to educate him about ALK+ lung cancer and how we can lead an active a lifestyle. He then put an arm around me and said, "you've had a good innings, you've survived 4 and a half years" (He couldn't count, it was six and a half!).

Upon my discharge I was handed the DNR and before I exited the hospital, I immediately went into the PALS office and raised a complaint.

What happened afterwards is also difficult to believe. This doctor, after realising that I had raised a complaint, started to write to me in an attempt to justify his actions. With the help of Graham Lavender and the Charity's Medical & Scientific Panel, I set about outlining why the DNR should not have been issued. The Panel also produced a

document which was subsequently tweaked into the Charity's Do Not Resuscitate Orders guidance publication. I also found the Hospital's own published procedure for issuing a DNR and it was evident that this Doctor had breached them.

I insisted that the complaint was now to be a formal complaint against the Doctor and was invited to a hearing with 2 senior hospital officials. By the time of the hearing, a further MRI scan had taken place which showed a further significant reduction in my brain tumour. In an attempt to keep the DNR in place, the Doctor raised the issue at an MDT meeting where he was told to withdraw it.

At the hearing, a very apologetic Hospital Director asked what we wanted from the hearing. Before I could answer, Sue immediately replied "education, we want your staff to be educated in such a way that they actually understand that some patients with lung cancer can lead a normal life".

In March 2024, it became clear that I was starting to struggle with Lorlatinib at 100mg and in May I agreed to a dose reduction to 75mg. I have been fine ever since.

When I look back, I realise that, despite having lung cancer with brain metastases, how fortunate I have been that I have tolerated the different TKI's very well. Any side effects have been minimal, and my heart goes out to those who find the TKI's less tolerant. I am in my 9th year since diagnosis and there is no trace of anything in my lungs, just these pesky brain mets to deal with but at least I have always been and still am asymptomatic to those.

Paul Cooper