

Interview with Debra Montague, Chair ALK Positive Lung Cancer (UK), for the USA-based ALK Positive Group

1) Can you share a little about your journey with lung cancer?

I developed a cough over the summer of 2016 but I wasn't worried as I didn't have any other symptoms. I was working very long hours for a pharmaceutical company and couldn't really spare the time to see my GP about it. However, I finally found the time in September as many of my colleagues were getting fed up with my coughing. I was very slow to take the hint as I had a secret cough sweet deliverer who kept leaving cough sweets on my desk when I wasn't there, but it still took me weeks until I made the appt. Before I attended my appt, I googled my symptoms and thought I had adult-onset asthma which is what I suggested to my GP. She didn't think so, so I was sent to have a blood test and chest x-Ray.

These came back clear, so I was referred to a Respiratory Consultant at the local hospital. He repeated the same tests and got the same results - no surprise there and then sent me for a CT scan. I went for my results at 6.00pm on 6th October. I'm not likely to forget the date as that was when he told me he thought I had secondary lung cancer and he wanted to do another CT scan to find the primary source (I am summarising as he didn't actually say much, just had this sick look on his face - it took ages for him to say it and then only because I pushed him on it).

The following day, I had a full body CT scan and on Monday 10th October (my mother's birthday) I was given the news the second scan had shown up the primary in the lung. I was then referred for a PET scan and brain MRI and had fluid taken off my lung (between the beginning of October and the end of the month, the fluid on my lung had accumulated and 3 litres was drained off which they tested). I had to wait 3 weeks for those test results to come back before I knew I was ALK-positive which I had never heard of. A friend of mine, was a medic in the same company as myself so I rang her and she spent the evening talking to me about what being 'ALK' meant, the treatment options and the future. I was just extremely lucky as Crizotinib had only just been approved for use in the UK, so I was one of the first people to be prescribed it in the UK, outside of trial use.

For quite a few months, I had a permanent chest drain, until it fell out, and I also had diverticulitis and a perforated bowel.

I only managed 6 months on Crizotinib before I saw progression in my right supraclavicular lymph nodes, so I was switched to Alectinib. I developed oligometastatic progression in my lung after 18 months and received radiotherapy for that.

More recently, I have had oligometastatic progression in my abdomen, once successfully treated with radiotherapy, however, the recent occurrence can't be treated as it is in my solar plexus area and deemed too dangerous to radiate. We are now watching and waiting until my Oncologist feels it's time to switch to Lorlatinib. Unfortunately, my latest biopsy showed I don't have the G1202R mutation. You will find me celebrating my 5 year cancer anniversary this October and boy it'll be some celebration 😊

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2) Any advice you would give to a newly diagnosed patient? What do you know now that you wish you knew back then?

Trust your instincts, you are usually right! Inform yourself and be your strongest advocate. Nice Drs aren't always right so be prepared to challenge, if you don't demand the best how can you expect others to?

Try not to spend too much time looking backwards or yearning for the life you thought you were going to have as you are missing out on today and all that it can bring.

Sometimes all you can do is put your big pants on and face it, but that's so much better than trying to ignore it. I am living my best life since my diagnosis. Before cancer I was working 50+ hrs a week and now I have time to walk my dogs everyday. I have more time for friends and family (even the annoying ones 😊) and try to make the most of every day.

No-one actually knows how long they will live, so don't waste time counting the days, spend the time making the days count.

3) You are the Founder and Chairman of ALK Positive UK, a registered charity that aims to improve patient care and outcomes across the United Kingdom. What inspired you to start this charity? What would you like to see it accomplish in the coming years?

Once I had settled into my treatment and scans/blood tests had settled into a manageable pattern I realised that the treatment choices in the UK were quite different to other countries including the US. I had joined the US ALK Positive FB group once I knew I was ALK+ so benefitted from all the support I received in the early days. I noticed a few people from the UK had posted about getting progression, however many of the suggestions put forward by members of the FB group weren't appropriate for the UK as we have different guidelines. We aren't allowed to drive with brain mets in the UK and this differed from many countries as well. Finally, I also saw lots of post about people meeting up at Lung Cancer conferences which I thought was amazing but again not something we could do in the UK as they don't allow patients to attend such events.

So that's when I decided, if we couldn't attend UK events, we would have our own. I put a message on the US fb page asking if any people from the UK wanted to meet up. There were 54 people registered in the UK and I tagged all of them in my post. We eventually came up with the date of July 18th where 18 of us met in London.

I asked my oncologist, who happens to be one of the leading ALK experts in the UK, if he would come and speak to the group and he agreed. He even left a birthday party he was attending to get across London to speak to us. He had said he wouldn't have long so I allocated 30mins for him to talk and 15mins for questions. On the day, I practically had to drag him away after an hour and a half so he could get back to his party. He told us we should keep meeting as there was a real need for patient advocates for ALK-positive LC.

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So, I went home and set up our fb page and invited all 54 people to join the UK group as well. I believe we need both groups as they provide different support, for example the UK group can advise on what treatments are available and in what order, what scans people should be having and the frequency, the treatments available for bone mets, blood clots and very importantly advocate for routine brain MRIs. The US group is brilliant at sharing info on side effects of the different treatments and the latest research and trials taking place. The US has and continues to do the most amazing job of fundraising and driving new research into ALK which hopefully patients will benefit from going forward.

We formed the charity in December 2018 as this gave us a better opportunity to formally engage with pharmaceutical companies and NHS organisations. The charity has been involved with 3 TKI approvals for UK patients and we have been recognised for the quality of our submissions both by clinicians and NICE.

Going forward, I want to see every ALK-positive patient receive the best care irrespective of which hospital they attend. I want to ensure every patient receives CT scans every 3 months and brain MRIs every 6 months or 3 monthly if they already have brain mets. It would be great if everyone could also access PET scans regularly, however this is aspirational due to the structure of healthcare costs and reimbursement in the UK.

I also want to ensure anyone who develops a blood clot stays on blood thinning treatment for the rest of their life (to significantly reduce their likelihood of developing further clots).

Currently, the UK doesn't conduct any trials for ALK+ LC. However, I believe we can significantly improve our overall survival by ensuring all the above is implemented whilst we wait for new treatments to be approved. The charity is currently working with a pharmaceutical company on a piece of work looking at brain mets and their impact on patients and the families. We will be publishing this work early next year which will enable us to continue to advocate for routine brain MRIs for all ALK+ patients.

We are also working on a set of resources to support patients' mental health in collaboration with another pharma company as we recognise the enormous toll on mental health having cancer causes.

We will also continue to support future treatment applications for NICE approval. Whilst many of our members thank the charity for all the work it does,

I know that many people don't know we exist and so go through their diagnosis, treatment and living with ALK+ LC feeling isolated and alone. I hope one day every Oncologist across the UK will refer all their ALK+ patients to us with their endorsement so no-one had to go through this feeling un-supported and alone.

Earlier this year, we worked with 2 other LC charities to develop a campaign to highlight non-smoking LC amongst GPs to support earlier diagnosis. An advertising agency and publications agency worked with us pro bono (to the value of about £400k) to develop the campaign 'See Through the Symptoms' highlight the symptoms of LC amongst non-smokers. The world-famous photographer Rankin, gave his time freely to develop the visuals for the campaign so 4 of our members got the opportunity to meet him and have their photograph taken by him - what a silver lining to their ALK+ diagnosis! We plan on relaunching this again for Lung Cancer Awareness Month later this year.

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I am very proud of the work the charity does and the fact we now have over 400 members making us the largest group of ALK+ patients outside the US and we didn't even exist 3 years ago.

We now have exciting plans to take the charity to the next level.

4) Have you seen disparities in the standard of care that UK patients receive compared to, say, North American patients? If so, what would you say can/should be done to ensure that every ALK-positive patient can have access to the same testing, treatment options, clinical trial opportunities etc. no matter where in the world they are?

There are quite a few differences in access to treatment choices, scans and clinical trial opportunities between the UK and the US, unfortunately.

As I have already mentioned the US has greater choice of treatments, not only the number of TKIs but the order in which they can be prescribed, the opportunity for off-label dose escalation (1800mg of Alectinib for example) and the opportunity to add in treatments (adding chemo to Lorlatinib). We also see quite a variance in scan frequency and the availability of routine brain MRIs across the UK.

We have completed 2 member surveys, the latter was completed by over 120 members, so we have detailed data and the charity has been very busy raising awareness of differences in diagnosis and treatment at Lung Cancer conferences. We have also worked closely with several leading ALK experts in the UK to develop a Best Practice Guide for members to use when meeting with their Oncologists to advocate best care for themselves. The charity will continue to engage with pharmaceutical companies challenging the access to clinical trials across the UK. In the meantime, we will continue to work with them supplying vital desk research that many of our members provide through workshop attendance and questionnaires. We will continue to support the US group and work together whenever we can as there is strength in numbers. Between us, coming at it from different angles, we can improve the lives and overall survival of ALK-positive patients everywhere whilst we all wait, impatiently for new treatments and ultimately a cure.