



Mike

### My Story - Mike Stenton Never Smoker & Stage 4 Lung Cancer Survivor

Firstly, many thanks for taking the time to read my story. I have decided to tell it in case it helps anyone else and to make everyone aware that lung cancer is not always a smoker's disease. I am now 56 years of age and married to Elaine for 31 years. We have three children ranging in age from 24 to 17 years. I Joined Horsenden Tennis club back in 1999 when I was 36. I really enjoyed attending the friendly club sessions which helped me to improve my tennis and become the wild top spinner as many of you know me (with a few too many moon shots as well :-). Horsenden LTC was and is my first and only club as had only played at school and with friends before this. I really enjoyed the game and progressed through the teams to become the captain of both the men's and mixed first teams for a number of years. I also served on the club committee. Along the way I have managed to reach just over thirty of the annual club tournament finals and somehow won twenty of them in both singles and doubles. I have really enjoyed playing in the Aylesbury and Bucks leagues over the years and have met so many nice people on the way. I have mentioned to many of you when playing fixtures the plans to run a fund raising event.

As many of you that know me may be aware, I was diagnosed back in September 2017 with incurable inoperable stage 4 lung cancer even though I had never smoked in my life. About fifteen percent of lung cancer sufferers are non-smokers and very little is mentioned about this as it's thought to be a smokers disease. I have carried on playing tennis throughout the time I have been suffering with this disease even with my right hand lung blocked for a number of months. I had always pursued a healthy lifestyle and diet. I have regularly played tennis at Horsenden for the past nineteen years.

Just over two years ago I went to the doctors with a persistent dry cough. I was seen by a trainee GP who thought it may be caused by acid re-flux. I took some tablets and the cough subsided for quite a while. About mid-June 2017 I suddenly began experiencing breathlessness when playing at tennis matches. I went to the doctors and they sent me to get a chest X-ray. The results were negative so they ruled out anything serious and began testing for late onset asthma. After about 6 weeks I was getting no improvement from the Asthma inhalers so asked if I could use my private healthcare insurance to see a specialist at the Chiltern Hospital. The specialist thought that my symptoms were Asthma related and started testing me all over again, so another six weeks went by. I kept on playing tennis and at the time was still the 1st team men's captain. We played an away match at Cheddington and gave everything to win three of the sets but getting pretty exhausted in-between many of the points. I was unaware at this point that the main airway to my right lung was blocked by a large tumour. After the match I coughed a lot and noticed a small spec of blood. I photographed it and showed it to the specialist at the next appointment. I was then sent to get a CT scan and a day or two later was told there was a suspicious shadow in my lung. Following this a Bronchoscopy was booked and about a week after that I was told that I had advanced Lung Cancer that had at this point spread to the Lymph system. I had a small tumour just under my collar bone.

As you will see from the above, playing tennis helped me to get diagnosed earlier than I would have done as it made me aware of a couple of the symptoms. It has also helped me to keep positive in fighting this disease. I am now on my second Targeted therapy drug which has worked so well that virtually all of the cancer is gone. I can now play tennis without the breathlessness I had before. Despite this I will never be cured as it is stage 4. The biopsy results showed that I have a type of cancer that has a particular type of mutation. It's known as ALK (the abbreviated name). About 3-5 percent of lung cancer patients have this type. The vast majority are non-smokers. The good news, if there can be any, is that this type responds well to targeted therapies. A handful of these have been developed since 2007 and generally work better than normal chemotherapy. The way they work is that they stop the body producing the protein that the cancer needs to grow. In other words the cancer is starved. Unfortunately there are always a few cancer cells that survive and these usually become resistant to the treatment or find another source to fuel their growth.

I started off on the first line treatment (NHS approved) which worked well for about four months reducing the size of the tumours. My breathlessness cleared and for two months I could again play singles. But in January 2018 the breathlessness returned followed two months later by coughing considerable amount of blood. During June I used my private insurance to get a brain MRI done as the policy of Bucks NHS trust is only to get one done if there are symptoms of brain tumours such as seizures etc. On my next meeting with my Oncologist at Wycombe hospital the bad news was given to me that the cancer had spread to multiple areas in the brain and the brain lining. As a result I had to tell the DVLA and am no longer able to drive.

Unfortunately the first line drug has little protection for the brain and a high percentage of those with lung cancer have progression in this area. Realising the seriousness of this news, I asked my Oncologist to get a second opinion from the UK

specialist Dr Popat at the Marsden in London. Thankfully I did this and he outlined how they could apply directly to a drug company to get early access to a new drug that has been proved to be very effective on patients in the USA both in the lungs and brain. The drug Brigatinib is not yet licenced by NICE in the UK.

I began the treatment mid-June and by early August when I got a second MRI scan the disease was virtually gone in the brain! By October 2018 the disease had also virtually vanished from the Lymph nodes and Lungs. The tumour that had been blocking my airway had totally gone and for the primary tumour, only a cavity was visible on the scans, where it had been in the bottom of my right lung.

If I had been diagnosed fifteen years earlier, the chances are that I would not have survived as long as I already have. New advances in medicine such as targeted therapies and immunotherapy are giving sufferers a much better prognosis than in the past. I am still hearing of newly diagnosed lung cancer sufferers with the ALK mutation, some only teenagers or with young families.

I feel deeply indebted to all the organisations that are there for anyone going through this journey, so I decided to ask our club committee if we could do something to both raise awareness as well as some funds to go to the main cancer charities that have helped me along with many others so far.

If you would like to donate via the Virgin money giving site I will direct this to the newly started Charity / Support group ALK Positive UK which aims to provide help and support for those diagnosed with this specific type of Lung cancer which can affect all age groups and is not linked to smoking. Our sister organisation in the USA and worldwide is also funding research into new therapies and treatments for this disease. It is estimated that about two thousand or more in the UK have this form of lung cancer and we aim to be able to work with other organisations to push forward research in this field.