

It is a privilege to continue my story in the 2<sup>nd</sup> addition of the Lungevity Stories. Before I begin I want to respectfully remember my friends who featured in the 1<sup>st</sup> edition and acknowledge their contribution and sad loss to the Lungevity family.

I write my story, this time as almost a 5 year survivor. I will reach this “landmark” on 27<sup>th</sup> August 2009. When I was diagnosed in August 2004, the percentage of being a 5 year survivor was around 3-5%. It has been one hell of a journey and one I would like to share with you.

My name is Roslyn Hogan, I am 62 years old, have 2 sons aged 36 and 34 and a beautiful 28 year old daughter. My gorgeous husband and I celebrated our 40<sup>th</sup> wedding anniversary earlier this year. I am a life long non smoker, as is everyone in my family – so a stage 4 non small cell lung cancer diagnosis came as a complete shock. I was fit, healthy, strong and attending at least 8 exercise sessions each week. I was not even sick. My aerobics instructor suggested I have a check up when she noticed my breathing was not returning to normal at the end of a workout.

My GP told me I was the fittest person he knew, checked my heart and sent me home. It was another 5 months before my perfect world was turned upside down. The first oncologist I saw told me I was terminal, gave me a graph showing the statistics of my disease and explained that I may not see Christmas and definitely would not be sitting there in 2 years. I left immediately thinking I would have to find a doctor who would treat me like a real person and not just a statistic. The next oncologist came recommended by a friend and I met with him the next day at a small private clinic, and whilst he didn't offer me a cure, he did make me feel welcome and comfortable.

I commenced chemotherapy with a combination of carboplatium and gemzitabein immediately. I was terrified and still in shock from my terminal, non operative diagnosis. I continued this standard protocol treatment still in shock, still in my trackies and ug boots, through until Christmas before a scan revealed some shrinkage. It was April 2005 when my bloods and scans indicated this chemotherapy had stopped working for me. I was sent home to “wait and see”.

What was I waiting for???? To see when the cancer would spread throughout my body???? I could not sit at home to “wait and see” so I went to Mexico for some alternative treatments. This was to be the turning point for me, both mentally and physically. I spent 18 days at this extremely professional, clean, caring hospital with my husband. I am not walking this road alone and for that I am grateful. My oncologist did not approve and told me “desperate people do desperate things”!! I came home empowered to be totally involved in my treatment. I became an active, interested, intelligent, resourceful patient.

I commenced my second line chemo in August 05 and by now my oncologist knew how much I loathed the term “standard protocol” so he treated me with Navelbine instead of Taxotere, and now 4 years on, I believe this is the reason I am still here today. The Navelbine was very easy, had no side effects for me and gave me 15 months of near normal life. I experienced considerable tumor shrinkage and my CEA blood marker was at its lowest, and I felt good.

At this stage I felt I could do more and I started seeing a Chinese doctor at Ryde. Qi Chen told me he could wake up my immune system with acupuncture and makes it fight the bad guys, he would give me a strong immune system which would support me through chemotherapy, along with Traditional Chinese herbal medicines. He insisted I follow a strict diet – no dairy, meat, alcohol, coffee, sugars. I eat organic, juice 1ltr. Vegetable juice daily, eat fish, fruit and lots of vegetables. He also added 50 pills per meal (added to the 10 per meal from Mexico) – I swallow 180 pills per day plus 10 crushed apricot kernels per meal. I have followed this regime of food, pills, juice, for the past 4 years now. I visit Qi Chen weekly and he has become a vital and very necessary part of my treatment plan. I am blessed to have found him and look forward to his positive and encouraging comments each week.

2 years into my treatment I was still searching for options. I started attending a Lung Cancer Support Group, it was something that I had not considered before but I did not want to leave any stone unturned. It is a very comfortable, caring, small group of both patients and facilitators who listen and share their most confronting concerns and treatment issues. It has also allowed me to give some hope to those patients who believed a 2 year survival to be impossible to achieve. It was when the friends around me continually passed away, together with the friends I made through the Lungevity group, that I needed to step back a little and get my mind in a more peaceful and positive position so that I could continue my own fight. I visit the Support Group occasionally and worry continually that I have let the group down. It is a very personal, peaceful and reflective gathering and I think it is so important for those of us on this journey.

During this period I sought out 2<sup>nd</sup> and 3<sup>rd</sup> opinions. I thought it was important to see an oncologist who specialized in lung cancer. I was searching for new drugs and treatments available here in Australia. I gathered much information and knowledge and I gained much hope from Professors at both RPA and RNS. I learnt so much my head was spinning. What next!

For my third line of treatment, I enrolled in a clinical trial of Zactima Vs Tarceva (double blinded trial). I started in January 06 and by April 06 my scans showed progression and I was removed from the trial. This was a crushing disappointment as I was considered to be the perfect patient for this trial. I had my original biopsy examined and my EGFR and Exon both indicated it should have worked for me however we had the trial unblinded and it was revealed I had been receiving Tarceva – my tumors had increased in number and size, although, thankfully still contained in my lungs.

I celebrated my 60<sup>th</sup> birthday in March 2007. I requested no presents but instead a donation to the Australian Lung Foundation. My much loved family and friends supported me in abundance and showered \$30,000 very generously for research into early detection of lung cancer.

I started my 4<sup>th</sup> line of treatment 2 weeks after I was removed from the Tarceva trial. After talking with the very professional lung cancer oncologist at RNS, I was convinced I needed to add Avastin to the Alimta, which my oncologist had suggested. I wanted to try both at once and not “wait and see” if the Alimta would have worked by itself. So in May 07 I commenced infusions of Alimta and Avastin at 21 day

intervals and this combination has kept me stable for over 2 years now. I have no side effects from the chemo itself however, the dexamethazone, which is “protocol” with Alimta, causes me much anxiety for a few days and I experience puffiness and swelling throughout my feet, legs, knees face and hands.

I support the wonderful work of the Australian Lung Foundation and as a result of their efforts to educate and inform both patients and professionals in the care of Lung Cancer, I have been able to talk with Professor Tony Mok from Hong Kong, Dr. Paul Bunn from University of Colorado Cancer Center and Dr. Roman Perez-Solar from the Einstein College of Medicine in New York – all 3 eminent and tireless workers for lung cancer.

My passion remains for Research into early detection of Lung Cancer and it was with my donations and the very generous Australian Lung Foundation contributions, that the Roslyn Hogan Research Grant for Early Detection of Lung Cancer was established in August 2008.

I was honoured to present Dr. Daniel Steinfert from Melbourne and Dr. Phan Nguyen from Brisbane, a 3-year scholarship for this purpose. It is my hope that because of these 2 brilliant doctors, we will one day establish an early detection program so that Lung Cancer will be detected long before it becomes a stage 4 incurable disease. We already have screening for Breast, Prostate, Cervical and Bowel – why not lung??, afterall, it is the biggest cancer killer by far.

I proudly hang an Australian Lung Foundation Volunteer of the Year Certificate in my study but really, it belongs to the fantastic dedicated doctors and nurses who work so tirelessly to help those of us who are walking this unforgiving journey.

Whats next for me is a mystery at the moment. While Alimta and Avastin hold me in a stable condition, I will continue however I am constantly looking for what my 5<sup>th</sup> line of treatment (7<sup>th</sup> chemo) will be. I research the net constantly but as a result of Tarceva failure, I have become ineligible for most of the new trials. There appears to be no interest in making a trial available to someone who is looking for chemo number 7. I have simply outlived all expectation and the pharmaceutical companies are not interested nor is the government willing to help with making such drugs as Avastin available for lung cancer patients, even though it is listed on the PBS for bowel cancer patients.

These 5 years has given me time to prepare and plan and has also allowed me to see my 2<sup>nd</sup> son and our only daughter marry, I have met 2 new grandchildren – Murphy and Hawkesbury and celebrated 40 years of marriage to my childhood sweetheart, all of which seemed impossible at diagnosis. I still exercise regularly, mind grandchildren, and enjoy holidays, lunches with family and friends. I remain an interested active and intelligent patient who refuses to sit around and “wait and see” and my doctor will never send me down the “standard protocol” path again. I respect and admire him immensely.

Everyone faces their challenges in many different ways, some go down the chemotherapy path, some find the diet too difficult, many find there is no place for alternative treatments (acupuncture and herbs) while there are those who only believe

in Western medicine. I have chosen what I feel is the complete package for me and I attribute all of this to my continued good quality of life. However, we are all individuals and must make our own life choices. Safe journey to all.

Note: today after 4 years and 10 months of treatment, scan No.35 reveals I am still stable. I have also had about 20% shrinkage over the past 4 months.

Roslyn Hogan