C.U.P of Hope

Giving Hope to people diagnosed with
Cancer of Unknown Primary

On 17 January 2012 I was diagnosed with C.U.P. – Cancer of Unknown Primary.

I have developed this website to help other C.U.P. patients understand more about Cancer of Unknown Primary. Going public is a scary process however I am determined to continue to advocate for cancer of unknown primary, raise awareness of C.U.P., help inform other C.U.P. patients of what is ahead for them and offer as much support as I can.

Please note, this website is my story, in my words and I strongly advise you to always seek your own professional medical advice. Your qualified health professionals will advise you on your diagnosis and the best treatment for you. However, I hope this information will answer some your questions, help you think about questions to ask your doctors and also give you hope that you are not alone on your journey.

Refer to page reference material for references as to where I obtained some of the information used on my website and where you can go to for help and guidance.

Towards the end of my journey, I found out Cancer Council has a free C.U.P. Booklet available – Ph 131120.

Depending on your health professional, they may use other terms to describe your cancer diagnosis, including occult primary cancer, tumour of unknown origin or metastatic malignancy of unknown primary. To be consistent and relevant to my journey, I will always refer to it as cancer of unknown primary or C.U.P.

Robyns Journey ‘the dragonfly’

January 2012

Hello and welcome to my website and thank you so much for taking the time to read my story. I wish I didn’t have this website because that means I have been on an unwanted and unexpected cancer journey. But I am also so grateful that I am still here to tell my story and hopefully help others through their journey.

My name is Robyn Wagner and I live on the beautiful and sunny Gold Coast in Queensland. I consider myself to be a ‘young’ and reasonable fit 52 year old. I am a Personal Assistant during the week (which is a fancy name for a secretary) and a Marriage Celebrant in the weekend. I am very active with morning walks, gardening in the weekends and cramming as much into my crazy life as I can.

In January 2012, I felt a lump under my right ear. I initially didn’t think much of it as I didn’t feel sick and the lump wasn’t sore to touch. It just felt like a pea rolling under my skin. A few weeks later I mentioned it to the doctor who sent me for an ultra sound and biopsy. My husband and teenage daughter (20 yo) were in Sydney for the week visiting family, and my son (23 yo) and other daughter (17 yo) were home but I didn’t mention it to any of them, not wanting to cause any unnecessary worry until I had the results. A close friend at work had managed to get the news of my lump out of me and she was really worried but I wasn’t – she was doing enough worrying for both of us, so she came to the doctor with me on the Thursday morning to get the results.

My doctor said to me ‘you are in a bit of a pickle”. You have Squamous cell carcinoma (SCC for short). This is the secondary cancer so we need to find out where your primary is. My head went into a spin the next 10 minutes or so whilst she explained what this meant and I tried to ask questions and get answers in English and not doctor’s jargon, that would make it all make sense to me. I remember her talking but I felt like it was in another language. I remember not really listening – just hearing words while my mind went somewhere else.

I looked over and my friend was in tears – the friend who had come to support me LOL! So after convincing her I was ok we left the doctor’s surgery and went back to work.

I told my boss the doctor said I would need 3 months off work but I still had tests ahead of me to really determine what these 3 months would entail. I still couldn’t comprehend what I was actually hearing myself say to him. It seemed so surreal.

So when I arrived home I madly starting researching Squamous cell carcinoma (SCC) on my laptop and Wikipedia states:

SCC is a cancer of the epithelial cell, the squamous cell. These cells are the main part of the epidermis of the skin, and this cancer is one of the major forms of skin cancer. Squamous cells also occur in the lining of the digestive tract, lungs, and other areas of the body, and SCC occurs as a form of cancer in diverse tissues, including the lips, mouth, esophagus, urinary bladder, prostate, lung, vagina, and cervix, among others.

Now I was starting to think I should be a little worried as this sounded fairly serious and I still couldn’t understand how the doctors who are so marvellous with all the work they do, couldn’t find my primary cancer! That was the most frightening part – knowing that there was cancer in my body somewhere – but where? Where did it come from? How do they not know where it was or where it is now? When the doctor can tell you your cancer is in a specific area – bowel, lungs, liver – you can picture it in your mind and deal with it. But not knowing where it is, is really scary – how do you deal with the unknown?

So I decided not to worry about the ‘what ifs’ or ‘maybes’ and just focus on what I had been told so far. The doctors had decided the first priority was getting the cancer out of my neck and arranging for my neck operation.

The next evening, when my husband and daughter arrived home and the whole family was having dinner. I kept waiting for the right moment to tell them, but that was so hard as I love my family being together and was really enjoying watching them at the dinner table and listening to my 3 teenagers talk and laugh together and I didn’t want to interrupt such special family moments.
But eventually I told them and then there was silence. They too were trying to absorb what I was saying and also they couldn’t understand how the doctors didn’t know where the primary was. The children eventually accepted what I told them and they said ‘Mum you are the strongest person we know and you will be fine”. Steve on the other hand was a blubbing mess (I guess that’s a SNAG for you – sensitive new age guy). He was crying a little on the outside, but lots on the inside. He could feel my pain and fear.

I was always determined to stay strong and be positive – but CUP was always niggling in the back of my mind – what is going on inside my body? How can the source of my cancer be unknown? The primary needs to be found as the primary determines what treatment is required. The doctors arranged for more tests in the coming weeks. The waiting for results is unbelievably scary, nerve wracking. It is terrible when they tell you what they have found, but even worse when they tell you they can’t find anything. The unknowing is dreadful.

Then my journey began.

Every day of the following week I had another test. Every day I was asking my boss for more time off work to have an ultrasound today, CT scan the next day, visit to an ENT Specialist after that. who performed an exploratory procedure with a camera up my nostrils, then another down my throat. He told me instantly that my nose and throat looked fine which is good news – but still didn’t answer where my primary was. Again, I accepted what he told me but still had trouble understanding with all the latest equipment he used, it didn’t show up any traces of cancer having been present in my nose or throat. So I was still left wondering.

The next day I had an appointment at Gold Coast Hospital to meet with the ENT team of surgeons who would be performing my neck dissection.

Some of the tests showed I also had a mark on my liver and a mark on each lung. Now I was starting to get scared.

I prayed so hard that night and kept repeating:
‘God it’s ok I have cancer, I can deal with that – just don’t make it terminal – please don’t make it terminal – please don’t make it terminal – please don’t make it terminal – please don’t make it terminal ……..

I was advised I would have to have a neck dissection to cut out the cancer and explore what was going on. I would need 6 weeks recovery for the neck operation, followed by 6 weeks of daily radiation treatment at the Prince Alfred Hospital in Brisbane, which is a two hour return drive from the Gold Coast.

Now I was starting to panic – how can I have three months off work. I love my job as a Personal Assistant during the week and as a Marriage Celebrant in the weekends and I have weddings booked every weekend for the next 12 months. Then I got angry – I was too busy to be sick. I had a great job to go to, fabulous people to work with and brides to marry in the weekends.

I told my boss that I would need 3 months off work and had no idea what was ahead for me. He was wonderful, said to take as much time as I need.

After all the tests so far and the fact the primary was still unknown, the following week I had an ultrasound of my abdomen which would include the liver to determine what the mark was. Again I was a little worried but more anxious to find out where my primary site was so I would know more of what was going on inside my body.

The results came back that it was too small to diagnose and it was put to one side. The doctors decided not to worry about that now, just focus on the SCC (again something unknown and unexplained going on in my body).

Then I went then to Prince Alfred Hospital in Brisbane for a Positron Emission Tomography (PET) scan. The medical explanation of PET is:
(PET) is a powerful imaging technique that holds great promise in the diagnosis and treatment of many diseases, particularly cancer. A non-invasive test, PET scans accurately image the body's physiologic changes. A Computed Tomography (CT) scan shows the structure of the anatomy where the changes are taking place. Combining these two scans in one highly sophisticated PET/CT imaging technique provides, during a single outpatient exam, detailed information to physicians about the presence or spread of disease and accurately identifies its precise location.

PET/CT imaging combines two tests in one and provides a unique representation of what is happening in the body. This can help physicians accurately diagnose many diseases at earlier stages when treatment is more likely to be effective. Its accuracy may help to precisely localize disease to aid in planning the right treatment for each patient, reducing unnecessary procedures and saving valuable time. For patients undergoing treatment, a PET/CT scan can provide a clearer assessment of how each person is responding. This is how PET/CT imaging is truly impacting individual lives.

The following week I was back at GC Hospital for pre-op appointment. On Thursday 16 February I had my neck dissection operation. When I woke after the 4 hour operation I was vomiting from the general anaesthetic and on self administered morphine which was was making me sick. I kept coming in and out of conscious and feeling terrible, but not in pain. Many hours later I asked them to take the morphine away, which they did. I didn't go on any pain relief until the next morning when the nurse came around and gave me some panadol "just in case" the pain came, but I was never in any real pain, or discomfort, I was just sleepy – I didn't realise later that because they had taken out a lot of the nerves in my neck, I couldn't feel anything.

The doctor came to see me late in the afternoon and said it all went well. It was a four hour operation and they think they got it all but still had to wait for final histology reports to come back next week. They took out around 60 lymph nodes and many nerves were either destroyed or damaged. I found the right sound of my mouth droopy and hard to control and the main nerve leading down into my shoulder and right arm was damaged due to some of the tumours being wrapped around it, so I had restricted movement with my right arm. But this would be a waiting game to see what nerves recovered and healed and what movement would return. I was numb all over the right side of my face, neck and shoulder but it was not painful.

I had 2 drainage tubes coming out of my neck and was told not to let them fall out as I would have to go back into theatre and have them resewn in. Because I was so sick from the anaesthetic the first few hours after the op, there was no way I was going back into theatre in the coming days! Steve (my husband) would come in each day and help me shower – my wonderful Steve – what would I have done without him!!!!

I spent Thursday, Friday and Saturday in hospital. My lovely nurse took out one of my drainage tubes on Saturday. On Sunday morning when I got back into bed after going to the bathroom, I looked on the floor and my other drainage tube had come out. I immediately panicked and called the nurse who assured me it was fine but called the doctor who assessed the amount of fluid in the drainage tube and it had not increased overnight so it was fine for the tube to have come out – phew!!!!. So then I asked if I could go home as I felt fine and my drainage tubes were out, plus I was bored!

I spent the next week home resting on the lounge with lovely visitors coming and going and phoning and texting me – I started to feel a little bit special LOL! A beautiful friend and celebrant visited me who has been on her own cancer journey and told me so much about what she had been through and how it had changed her life, especially her diet. So I really started to think about my life, my diet, everything I put into my mouth, my make up, my hair dye, my shampoo, conditioner, lipstick ….. suddenly everything touching my skin on the outside and going into my body makes you wonder how you are made up. What has made your cells to be who they are. I researched lots of websites on cancer, health, nutrition, organic products. It was an exciting learning experience but also frightening. I really tried to stay focused on the reality of what I had but not to panic. Be careful and cautious without being paranoid. But that is easy when you know where your primary is …. I didn't.

Mon 27 Feb 2013 I was back to the PA Hospital for my initial radiation interview. Again more explanations from the doctors and more questions from me. And again no answers on where my primary was.

Wednesday 29 February, I had an afternoon appointment at Gold Coast Hospital to follow up on my neck dissection. They were amazed how quickly and how well I had healed – hardly any scarring. I told them I am not your average patient LOL!

The following week I stated physiotherapy on my neck and shoulder to help with the healing of my neck and shoulder and the nerves associated with that area. The aim was to get as much movement back into my right arm as soon as possible – little did I know this journey alone would take months and months of physio.

I also had to travel back to Brisbane to see the hospital dentist who specialises in cancer patients and get the all clear from him that I was ok to have radiation. They took x-rays of my teeth and again your mind is wondering – what will they find?? Maybe they will find the primary somewhere in my jaw, or cheek? They would have had to extract any teeth that they thought wouldn't stand up to the radiation as I can never have a tooth extraction again – how scary is that!

Luckily my teeth were in 'good munching order' so 2 weeks later I went back to Brisbane for a really good clean from the Hospital Hygienist.

In the meantime I noticed a lump my left thigh! At first the doctors were just guessing what it may be and were pretty certain it wasn't anything serious but we all agreed due to my 'unknown' history it should be investigated. The following week I went for an ultra sound of my left thigh and again my prayers were answered – it was a lymphoma – just some fatty tissue under the skin.

Three weeks after my neck operation and going crazy with day time T.V I went back to work. No point sitting around home waiting for radiation to start in 3-4 weeks time – I had a life to live and damn it, I'm going to live it!!!.

Planning Day!

Monday 19 March was probably the worst day of my whole journey. I had to go back to PA Hospital in Brisbane for what is called a ‘planning day’, which is where they make a face mask for you to wear during your radiation treatment. Some patients have little marks tattooed on the area for their radiation ie stomach, bladder etc but any radiation for the head and neck requires complete stillness and they do not want to tattoo your face. As I said I am of a very strong, positive mind and don’t consider myself to be claustrophobic but 20 minutes under a wet cloth that started to close in on my face and restrict my breathing was really difficult to deal with.

That day was very difficult and I will share what my beautiful 20 year old daughter, Laura said to me – “Mum, God will only give you as much as you can handle”. So I chose to believe this and prayed to God and thanked him for helping me through this terrible day. I was grateful that that was all I had to cope with that day. I believe things happen for a reason – changes in your life make you grow, and challenges make you stronger.

I thought about the recent television news story of the Beaconsfield Miners , one who had died in the mine collapse and two others who were trapped for days which made my 20 minute ordeal seem nothing in the big picture of life; I thought about people who were less fortunate than me; children living in poverty and dying of starvation in third world countries; I thought back to passages I had read during my illness – It’s Not About the Bike by Lance Armstrong – and Life without Limits by Nick Vujicic. And reminded myself my illness and treatment is insignificant compared to others. Another powerful person I owe thanks to is Hayley Okines, a beautiful little girl in the UK who has progeria. The courage and strength of that special little girl gave me so much inner strength and determination to get through each day – I really didn’t have much to complain about.

Colonoscopy – Oh Joy!

Prior to my radiation starting I had to have a colonoscopy (oh joy!!) as a precautionary measure and all results were negative. A good outcome, but again no sign of my primary.

Six Weeks of Daily Radiation

Wednesday 4 April – Angels Do Exist!!!

On Wednesday 4 April, my radiation started. The first day was the hardest but due to my wonderful Occupational Therapist, I got through it, along with my husband’s endless support and love and also lots of prayers.

A few weeks before I commenced treatment, the hospital rang to confirm my radiation dates. Whilst the nurse was explain the process to me, I finally choked up with tears on the phone and couldn’t talk. I had coped with the cancer until now and the neck dissection was fine but it finally hit me that the radiation was going to be a tough journey. The ‘mask’ was really bothering me.

During my 6 weeks of radiation, once a week I was also booked into see an O.T., speech therapist, dietician, physio therapist, cancer nurse, social worker ……. so they told my O.T. about my concerns and she telephoned me each week, for the three weeks prior to radiation starting, and just talked to me gently on the phone and together we worked on some relaxation techniques for me to try when under the mask.

When the doctors told me I had 30 days of radiation treatment ahead of me – 5 days a week for 6 weeks and Day 1 was the first day, I decided to rename my first day as Day 30, then Day 29, Day 28 and so on. I found it easier to count down the numbers rather than count upwards. It seemed more positive to get down to Day 1 than up to Day 30!!!

Angles do exist! I finally met her on my first day of radiation. She was there waiting to meet me and say hello. She was so gentle and supportive. She even came into the theatre to make sure I was settled. She was a tiny little angel, with a tiny little warm hand, yet I felt her strength as she held mine as they started to lock down my mask, and I could feel her inner strength and huge heart. I will never forget her and I was so blessed to have her come into my world that day. I saw her each week of my treatment and cannot thank her enough for 'just being there'. The silent bond between us was amazing.

Every day I faced the same challenge of being locked into my mask, with my hands and feet strapped to the table so you can't move. And every day I kept reminding myself I was strong and could cope with this. I would get scared some days that "what if I panic under the mask today"? "What if I just start screaming get me out of here"?

But the point is there is no point worrying about the 'what if's" in life. If you did that, you wouldn't get out of bed each day … "what if I get hit by a car today"? "What if I lose my job today"? You have 2 choices every day when you wake up – to sink or to fly – I chose to fly!!!

The staff are amazing and supportive. They go out of their way to make you feel relaxed and comfortable. Each day I would take in a CD to listen to – some days I would take in a spiritual CD, other days something more upbeat. My last day I took in Meatloaf – I was determined to go out rocking the theatre!!! The staff enjoyed the upbeat mood too!

As my farewell gift to all the staff, I gave each of them a thank you note and box of chocolates and reminded them never to forget the important work they do and how amazing they are!
The doctors had explained the side effects of the radiation – loss of taste, dry mouth, burnt neck, mouth ulcers etc. Again I thought – oh joy! I was worried that I wouldn't be able to perform my weddings – if I had a dry throat, burnt neck, raspy voice – not a good look for a celebrant.

My side effects didn't really start until week 3 with my mouth becoming dry. I recommend everyone find their own level of treatment as to what works best for you but I did as advised and performed daily mouth gargles (of equal parts of salt water and bicard soda) and every night I applied gallons of Aquaeous cream – brilliant product for me and it kept my redness to a minimum.

I lost taste for basically all food and everything I did try to eat tasted metallic. I started to lose weight (every girl's dream at some stage in their life – but not this way)! I started to live on protein shakes, smoothies and veges.

Keep the Faith.

In week 4 of my radiation I had the most amazing experience. It was a few minutes into treatment, I was strapped to the bed, my mask clipped on, my music playing and as always, I was feeling very claustrophobic. I was telling myself not to panic, I had to get through this, just like every other day. It would be over soon. I tried to take my mind to a happy place.

Then, all of a sudden, I couldn't really hear my music anymore yet a peaceful quietness filled the room. I suddenly felt very calm. I felt as if I was being lifted up from the bed and floating in this amazing tranquil space. I tried to turn my head to the left but due to the mask restricting my movement I could vaguely see a figure in the top left hand corner of the room, surrounded with amazing colours, like rainbows enveloping him. He was smiling down at me, hands reaching out. I kept rising closer and closer to him, as if climbing up a staircase, going through a valley of beautiful flowers and colours I had never seen before.

For a few moments I felt a peace, calmness, security I had never felt before. All these arms were wrapping around me, making me feel warm, loved, relaxed, elated. So many different emotions. Next minute my music returned, the nurse walked in to release me from me mask and the bed. I left the room knowing I was going to be ok.

My radiation finished on Wednesday 23rd May – Halleujah!!!!!

Tuesday 31 July – Another Lump under my Jaw!

Here I go again – oh no!!

I went to my lovely GP – who totally understands my illness – she ‘gets it’ without me having to go into long explanations of how I am feeling.

She felt the lump under my left jaw bone and sent me for an ultra sound and possible biopsy. The ultrasound showed it was a lymph gland within normal limits and therefore a biopsy was not required.

This was great news but again, due to being a CUP patient, I couldn’t help but think – are they sure? Should I insist on a biopsy? So I accepted their ‘professional’ opinion but I keep checking this lump every day and I will ask for it to be rechecked and have a biopsy in the coming months. I would prefer to be convinced it is benign.

12 months on

For the three months or so after treatment I began to feel better. Still battling poor taste buds and tiredness but each day, feeling better that it was behind me.

Then late October, early November I started to get more tired than ever before. Friends said this is because I am still working full time and also performing my weddings in the evenings and weekends. Even my doctor said I have recovered incredibly well and I should be tired. My mouth is continually sore on the inside from where I had the radiation, my neck is becoming stiff again and movement is restricted and now my lymph glands in my groin are up.

So back to the GP and then off for another ultrasound and xrays.

Again they said the swollen lymph glands are within normal range and it is probably just your body telling you that you are tired and run down. So again – do I accept this or being a CUP patient should I ask for more tests?

I will be asking for more tests!!! It’s my body – my future.

The Future

Even though the doctors think my cancer has not returned and I am fine (besides needing to slow down – ha!) I am living every day with the reminders of what I went through.

One of the specialists I saw said statistics show most CUP patients have a 2-5 year survival rate and I will never be told I'm 'in remission' because I am CUP patient but if I can get to 5 years cancer free "I should be fine"!

That is not good news to carry around in your head!

So I have decided to prove them wrong and live a very long, happy, healthy life. My cancer was just an annoying speed bump that may have slowed me down for a few months but I going ahead now, faster than before.

Part of me thanks cancer for coming my way because now I can cross that off my worry list. I don't have to worry now – I hope I never get cancer – been there, done that!!

Thanks to cancer I have met so many wonderful and amazing people and I now feel I am a stronger and better person for what I have been through. I am just sorry it caused my family and friends to suffer with worry.

My mission is to raise awareness for CUP and also have a support network for CUP patients and their family and friends.

Remember, no matter what your battle in life is – you are not alone!

I am here for you and with me and a higher being helping you on your way, you are not alone! Please feel free to contact me anytime, I would love to hear from you.

Remember my motto – LOVE DREAM BELIEVE

Love yourself

Follow your dreams

Always believe in the magic

September 2017 – 5 Years Later

My cancer returned in September 2017, with an SCC tumour found in my upper left lung. Again I didn't have any symptoms.

I started to feel unwell for a few months, nothing specific but I just felt things weren't right so I went to my GP and asked for some tests, but without symptoms there wasn't really anything specific they could test for, besides running some standard blood tests which all came back clear.

Since my first cancer diagnosis in January 2012 we spent the next 5 years ticking many places off my travel bucket list. In July 2017 we were traveling through Israel and a few times I heard a voice saying to me 'go now', 'go now', and I wasn't really sure what it meant. We had an amazing time in Israel and when we returned the voice appeared again.

So I went back to my doctor and asked for a private PET scan which showed a tumor in my upper left lung! A few weeks later I went in for a lobectomy and had my upper left lung removed. The operation was successful, all the cancer was removed.

Recovery was slow and painful as they had accidentally fractured 2 of my ribs but I eventually recovered well and returned to work and my daily life.

The following year Steve had a scan after having a melanoma removed from his right shoulder and the scan revealed he also had lung cancer and had to have his upper right lung removed! He recovered easily and quicker than I did, however during his operation a few ribs were broken and he had to have a steel plate put in to support his ribcage.

We often joke “my op was worse than yours”.

NEWS 3

Celebrant of weddings, funerals, anything

'I felt the most incredible feeling of peace and warmth'

'It's okay to cry, it does hurt – a lot – but you can get through it'

‘The Dragonfly’, Based on the story from author Heidi A. Mengis

Once, in a little pond, in the muddy water under the lily pads, there lived a little water beetle in a community of water beetles. They lived a simple and comfortable life in the pond with few disturbances and interruptions.

Once in a while, sadness would come to the community when one of their fellow beetles would climb the stem of a lily pad and would never be seen again. They knew when this happened; their friend was dead, gone forever.

Then, one day, one little water beetle felt an irresistible urge to climb up that stem. However, he was determined that he would not leave forever. He would come back and tell his friends what he had found at the top. When he reached the top and climbed out of the water onto the surface of the lily pad, he was so tired, and the sun felt so warm, that he decided he must take a nap.

As he slept, his body changed and when he woke up, he had turned into a beautiful blue-tailed dragonfly with broad wings and a slender body designed for flying. So, fly he did! And, as he soared he saw the beauty of a whole new world and a far superior way of life to what he had never known existed. Then he remembered his beetle friends and how they were thinking by now he was dead. He wanted to go back to tell them, and explain to them that he was now more alive than he had ever been before. His life had been fulfilled rather than ended. But, his new body would not go down into the water.

He could not get back to tell his friends the good news. Then he understood that their time would come, when they, too, would know what he now knew. So, he raised his wings and flew off into his joyous new life!

C.U.P of Hope

Giving Hope to people diagnosed with
Cancer of Unknown Primary

Summary of Our Cancer Journey – Robyn & Steve

I cant believe it's been 10 years since this journey started for us.

I was incredibly concerned when I was first diagnosed with CUP and given a life expectancy of 2-3 years to live. After my neck dissection, I had to wait 6 weeks before I could commence radiation. I wanted my body to be as 'clean and strong' as possible so I gave up alcohol and sugar, and reassessed every mouthful I put into my body. Ten years on, I am still happily a non drinker. I don't feel the need to drink, its not a struggle for me and I still don't eat sugar, again I don't crave it or feel like I am missing out on anything my friends are having.

My taste buds never returned to what they were so I am now a pescatarian and really happy with my new life.

A terminal cancer diagnosis makes you stop and think about your life, your past and your 'limited' future and more importantly the present! Suddenly it doesn't matter the car you drive, the type of house you live in…. all the material things you have worked your life for to achieve. It's about what to do next. I made a Bucket List of places I wanted to see (before I die one day). The first two places I wanted to see were the cherry blossoms in Japan and climb the great wall in China – tick! Then Taj Mahal In India, tick. Then Europe – the typical places – London, Stonehenge, Paris, Rome, Pompeii, Greece, The Maldives, Singapore. Then Asia – Malaysia, Bangkok, Vietnam, Cambodia.

Five years into my cancer diagnosis, Steve was diagnosed with terminal lung cancer and given 18 months to 2 years to live as the cancer was in both lungs and inoperable. He endured six months of a combination of chemotherapy and radiation. Then,12 months later the cancer had spread to behind his eye which involved a face mask and 4 weeks of radiation. Another 12 months, a new tumor was found in the upper right section of his lung so he had a lobectomy – I told him it's not a competition – just because I lost my top left lung he didn't have to lose his upper right in sympathy lol!
Steve's dream was to visit Egypt and a 7 day cruise down the Nile – sun rise hot air balloon ride over Luxor. Tick.

Another goal we both wanted to fulfill was to visit Israel – which we loved – an amazing experience. A few months before we left, I had a feeling something wasn't quite right with my health although I felt well and didn't have any symptoms. I went to my GP who said it was difficult to order any tests as 'what are they testing for'. So I ignored my 'inkling'. Whilst in Israel, I kept hearing a voice telling me 'go now', 'go now'. When I returned I had a PET scan which revealed a tumor which resulted in the removal of in my upper left lung – lobectomy.

Next step – get well and visit Turkey – sun rise hot air balloon ride over Cappadocia – amazing!

I guess I can thank cancer for making us 'live'.

Never give up hope that there is a better life waiting for you. Always believe in the magic of life and love your body everyday – its' the only one you have so be grateful for it.

Summary of Our Cancer Journey – Robyn & Steve

Robyn:

August 2006 – Removal BCCs centre of scalp

August 2007 – Removal SCC & BCC scalp and back

January 2012 – SCC in the lymph glands right side of neck – no symptoms except small lump smaller than a pea under my right jaw

Feb 2012 – Right neck dissection followed by 6 weeks of radiation PA Brisbane

Nov 2012 – Metastatic Carcinoma (CUP) on forehead with skin graft from left groin area

Dec 2014 – Removal of SCC from upper left anterior chest

Oct 2017 – CT Guided lung biopsy to determine type of tumor in lung – SCC confirmed

Nov 2017 – Lobectomy – removal of upper left lung – again no symptoms – I just knew something wasn't right and booked in for a private PET scan

SCC-Right-neck-dissection-Feb-2012

Personally made face mask for radiation treatment

BCC on back of neck

BCC on back of neck and hair removal

BCC on right shoulder removal

BCC on side of face removal

Tiny BCC on side of neck

Tiny BCC on side of neck with stitches

BCC removal inside forearm

BCC on side of nostril before surgery

After surgery 2nd time on forehead

Before surgery doctor marking my face

After surgery 2nd time on forehead

Removal of BCC on side of nose and down cheek

Before forehead surgery

Forehead showing skin graft from thigh

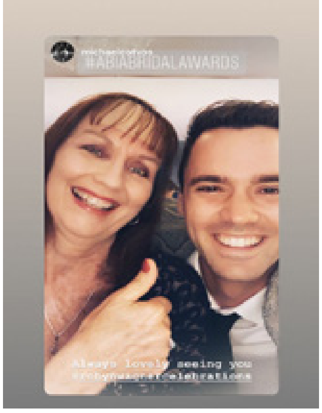
Forhead and lip

After forehead and nose surgery 2nd time

3 days after nose surgery

1st surgery on forehead

Brifge of nose BCC Op



Attending Wedding Awards night 1 week after forhead op

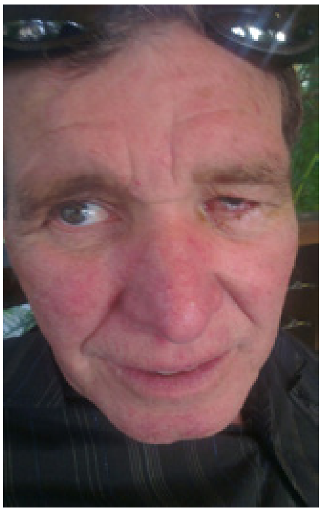
Robyn lobectomy November 2017

– Steve’s Journey

2007 Heart stent
April 2008 Heart stent
July 2010 Heart stent
Nov 2013 woke with blurred vision which led to retina detachment during the day, emergency surgery to repair the eye
Feb 2016 – DVT (deep venous thrombosis of lower left leg treated with clexane injections, self administered for 6 months
March 2016 – Removal of Melanoma on front of left shoulder after noticing a suspicious mole
August 2016 – Diagnosed via a CT scan of non small adeno carcinoma in upper right lung
January 2017 – PET scan showed multiple tumors inside and outside the lungs with one tumor right lower lobe outside the lung and another tumor between lung and ribs. Non operable so a course of intense chemo and radiation for 6 months
Nov 2017 – Surgery to repair another collapsed retina, this time in right eye
Nov 2019 – removal melanoma right shoulder
July 2020 – Surgery to repair Collapsed Retina of left eye
2020 – Non hodgkins lymphoma to eye orbit
Aug 2021 – CT Scan showed another non small adeno carcinoma
Lung cancer surgery to remove upper right lobe due to tumor


Biopsy of suspicious mole
Steves chest


Melanoma back of leg Steve


Steve eye tumor


Steve melanova on back


Steve lobectomy