

My Story of Melanoma

Gaining Time

I grew up in a tiny town smack bang in the middle of Victoria in the 80s and 90s. I was a child of the “slip, slap, slop” campaign and the “no hat, no play” school rule. Like all country kids I spent lots of time outside, playing with my cousins, exploring the farm and swimming in the irrigation channels. I wasn’t one of those kids to lie in the sun in search of a suntan but I still remember the searing pain and blisters those few times that I did get badly sunburned.



As I got into my teenage years I found that it wasn’t easy for my skin to tan and that a tan in a bottle was far more effective. However, I am guilty of using a solarium, again a handful of times, in search of a ‘healthy glow’ during the midst of a gloomy London winter.

I have Stage IV Melanoma- I could blame my childhood of sunshine, my stupidity for using a solarium or my genetics! The matter of the fact is that my history of sun exposure is pretty normal, in fact, it’s probably pretty similar to yours. I am genetically and environmentally susceptible to melanoma and attributing blame is not going to provide

any solution. I do believe there is a long term cure in sight for melanoma.

I am determined to raise awareness of melanoma, the importance of early detection and the value of immediate investment in research. As a starting point, I’d like to tell you about my journey with melanoma.

It was 2005, I was 24 years old, just returned from a year-long overseas adventure, starting my career as an Environmental Engineer in Melbourne and in love... I was on top of the world! I became aware of a funny lesion on the back of my neck, I have quite freckly skin and plenty of moles but this one stood out. I checked with my Mum who agreed that she couldn’t remember it and then went to a local GP. He referred me urgently to a dermatologist and it was removed by a surgeon within a week. Wow, I was scared, impressed by the professionalism and speed of my medical team, but seriously scared. Why was everyone so worried and why was time so important?

I soon learned that I was lucky as I had caught it early and the melanoma was removed before it had metastasised, or spread, to nearby or distant lymph nodes. This meant that I had a 5-year survival chance of around 90%. I was unaware of how this moment would define my life.

After the surgery my darling Ryno and I continued to set-up our life together, we worked hard, played harder, bought a house, climbed the corporate ladder and got married. In 2010 and eight months pregnant with our first child we made a huge life decision to move across Australia to raise our children in the Western Australian Wheatbelt. We

wanted our children to experience the same stress-free and community focussed childhood as we did. This was the best decision we ever made. We miss our family and my closest friends but the support and love I have received from the country communities in which I have lived is beyond words.

Not long after the birth of my little doll Ava in 2010 I noticed a lump on my neck not far from the original primary melanoma. I knew immediately what it was but had no idea what it meant for me and my family. The primary melanoma removed 5 years previously had metastasised maybe from the stress of pregnancy and childbirth, or maybe it was just time, we can't be sure. I don't attribute the blame either way, and I'm not willing to place any guilt it upon myself.



The first year of my daughter's life was a blur....not because of sleepless nights or the standard new parent issues...Ava was perfect and just adapted to the crazy life of my medical treatment involved a full neck dissection and interferon treatment which has since been removed from the recommended list of treatments. Only a handful of nodes were positive to melanoma – I was lucky again as we seemed to have caught it early. This being the case I still had a diagnosis of metastatic melanoma which gave me the sobering statistic of a 5-year survival rate of 59%. I have been fighting statistics ever since.

During my daily interferon treatment I befriended a fellow Mum. Her fight is now over, but had she been aware of her primary melanoma sooner, or if the treatments of today were available to her then, maybe she would still be here with her little boy.

The next year a routine scan (which is something you get used to when you have melanoma) picked up another hot spot in the same area. This involved another neck dissection and, due to the melanoma's quick recurrence, was followed by an eight week period of radiotherapy. Living away from home was tough on me and my little family but Ava's gorgeous and happy nature was a welcome distraction. Family and close friends from Victoria held my hand through this process, staying with me in Perth and kept me laughing and positive.

2012 was a relatively easy year, oh apart from deciding to take a risk by having another child- I had been clear for 18 months and the time seemed right. This was against advice from specialists but it was a risk that we were willing to take- our approach was that we would deal with whatever life threw at us....and in June of 2013 it threw us George Henry Ryan! A perfect, healthy sleeping baby (that is until he hit the age of 2...).

Just a month after I gave birth to George I had a scan which showed a positive lymph node within my left lung. The nodes were removed through keyhole surgery and no further treatment was required. I was back to normal in no time and once again I was cancer free!



We had two awesome years of clear scan results and I was determined to continue to be on the good side of the statistics.

I think one of the hardest things about the first couple of years of cancer is learning the system and building relationships with specialists. I still ask lots of questions and conduct my own research but I know my medical team have my back. The process of living scan to scan is hard but inevitable as the only way to find metastatic melanoma is via scans as you often can't feel or see melanoma growing. Going into those appointments with a positive attitude and having a bit of a laugh is the best thing I can do.

This year the melanoma returned, this time in my left lung. It had metastasised into the lung itself and presented as a tumour. Technically from this stage forward I have Stage IV Melanoma, but I don't feel like I do.

In March I had to have the top half (upper lobe) of my lung removed. I told my nurses the good news whilst in recovery after surgery; I still had a quarter of a lung more than Pope Francis! Surely that counts for something!

Unfortunately, I did not get much reprieve after this surgery as I found another small tumour in my abdomen. Since August 2016 I have been on a targeted combination therapy which targets a BRAF (&MEK) cell mutation that is present in my melanoma (and about 50% of other melanoma patients). The BRAF gene is present in every human and is necessary for normal cell growth. In my case I have a BRAF gene mutation which means it is always switched to "on" mode which allows the melanoma to grow and spread quickly by utilising this gene, rather than letting the immune system fight it. The drug suppresses the capability of melanoma to use the BRAF cell mutation. It has amazing results...and given that I did not have much disease present before I started this therapy my case looks pretty good! Three months into treatment my scan showed no visible cancer growths in my body. It has had some pretty terrible side effects but it is all worthwhile and I count myself as lucky as this treatment has only been available to patients for about 18 months.



The Future

I am determined to continue to fight the statistics. I am armed with plenty of ammunition to fight this disease thanks to the amount of research and new innovations in the melanoma field.

The longer I remain cancer free the more treatment options will be created by research groups such as the Melanoma Institute of Australia. This means that I get to watch my kids grow into the wonderful people I know they will be.

There are no regrets, I say yes to everything (maybe too many things) and make sure we have a hell of a lot of fun! We live life differently because of the disease but for the better.

I have the best memories from albeit the worst times in my life; Ryno walking into hospital after my first neck dissection with an air of arrogance holding Ava, then 8 weeks old. On asking why, he proudly told me she slept through for the first time, 7pm-7am, super dad! Or my darling friend Breeza, sitting by my side after having my big lung operation chatting to me about how hydrated I must be by the colour of my wee (which was just at her feet in the catheter bag!). The wheatbelt communities that have rallied around me, the pre scan jitters and tears on the lawn with my girlfriends and amazing visits from my closest friends and family, coming to look after me all the way from across the country and the world. We live a lot lighter because of our friends and these are just a few of the endless happy memories that this time has unwittingly created.

I have a great life, an amazing husband, two beautiful children and friends who make me laugh! I do not need sympathy, I just need *time* to enjoy these things and I am going to do my very best to see that the treatment available now and into the future will give me this!

A small town determined to make a big difference



I am passionate about raising awareness of Melanoma- prevention, detection and treatment. Melanoma research is travelling fast and I know a cure is in sight- it is only limited by one thing, \$\$\$\$.

In the last two years, I have raised over \$40,000 for the Melanoma Institute of Australia through the Western Australian HBF Run for a Reason. Imagine how much we can raise if we do this together? My 'moles' (four amazing friends) have organised the *Wongan Hills Lapathon in Support of the Melanoma Institute of Australia* on 11 March 2017. Our goal is to raise \$100,000, to go towards improving all melanoma patients' ammunition towards this disease.

Your assistance is vital to our success; you can help by:

- Sharing my story with others and with your networks.
- Sponsoring the *Wongan Hills Lapathon*, which is guaranteed to be an amazing event capturing all the communities of the WA Wheatbelt.
- Joining us on 11 March for the *Wongan Hills Lapathon*.
- If you can't join us, then you can donate to the Melanoma Institute of Australia via <https://melanomainstituteau2016.gofundraise.com.au/page/WHMML2017> - every contribution is valuable.
- Getting regular skin checks and seeking urgent medical advice on any unusual lesions or moles.

I am eternally grateful and humbled by my true supporters, my family and friends, who have rallied around me, Ryno, Ava and George throughout our journey with melanoma.