

Prolactinoma – My Journey – Amanda



The year 1999 was a very busy year for me. I was working full-time at a very demanding and challenging job, studying full-time, looking for my first home to buy and organizing my wedding.

I ate well and exercised regularly. However, I began to develop various skin problems including rashes on my body and face, dark bruises and swelling around the eyes, urticaria and eczema. I was prescribed cortisone creams and sent to skin specialists. The diagnosis was stress and a flair up of childhood eczema. I began to take natural remedies to alleviate my condition but it continued to flair. My skin condition became so severe I was hospitalized several times.

I began to develop other symptoms including weight loss, hair loss, inability for my skin to heal, Staphylococcus Aureus (Golden Staph), extreme sensitivity to cold, hot flushes, irregular periods, changes in menstruation and a yellow substance leaking from my nipples. My skin condition continued to worsen and when prescribed oral prednisone my breasts began to leak alarmingly through my clothing and my hot flushes started to burn my skin. These cycles became more intense and frequent until my hands, feet and face began to swell and I could not work, do household duties or leave the house.

It was then I took sick leave and tried to work from home.

I went to many doctors and specialists but each said that it was “just eczema” and would not refer me to a specialist nor run tests. In desperation I consulted the phone book and I spoke to a specialist’s secretary telling her about my breast symptoms, she said come in straight away this sounds serious – even though I did not have a referral as my doctor would not write one out. I am so grateful for that one phone call and the help I received – it changed my life!

The specialist – thought that my breast leakage was not eczema – but lactation from an overproduction of prolactin - and he sent me for an MRI and blood tests. He said do not worry, this is very rare and I doubt that’s what it is but I will run the test anyway. Tests confirmed a 5mm pituitary tumor – a prolactinoma. I was very glad that I had found the cause to my health problems! I asked how soon I could have neurosurgery but I was told that drug therapy would be the first treatment. I was also told that the tumor would not be malignant as these sorts never are.

Then I began drug therapy of which consisted bromocriptine/parlodel (to shrink the tumor), HRT, the oral contraceptive pill to increase estrogen and prednisone. I also learnt that prednisone causes an increase in lactation because it makes prolactin rise so I stopped taking that for my skin and took antibiotics and topical treatments. This helped reduce the lactation. Now that I knew what it was I went to the maternity aisle and bought breast pads with mixed emotions. I then began to have lots of tests, CT scans, Ultrasounds, Xrays, bloods, MRIs and urines. I went back to hospital several times after the tumor was diagnosed for my skin – of which was finally attributed to the tumor disrupting hormone production.

MRIs began to show a decrease in the size of the tumor. As the tumor shrunk my skin began to settle. I put on 20 kg, began to develop body hair, depression, anxiety and craving sugary foods. I finally found a specialist who was able to re-interpret my results and symptoms and diagnosed PCOS, insulin resistance and an onset of diabetes. I then started taking Diaformin and shed the 20 kg I gained over a couple of years, my body hair returned to normal, my scalp hair thickened, I had no hot flushes and regular periods.

However, I was weak, fatigued and constantly going to doctors that I was forced to take a redundancy. I slept most days – all day and night – my body was very tired, for a long time. It has taken eight years to gain strength, control and energy to rebuild my life and I am so grateful for the positive results of drug therapy!

I have learnt to ask questions and if you feel that your body is not responding to the treatment or you are not being heard/managed by your current doctor it does produce positive results to get another opinion!

After being physically and mentally unable to work or study years, I have now completed my Masters, and have now worked in a full-time job for one year. I was also accepted into a Doctorate program which I have put on hold.

My condition is stable enough to require six monthly specialist appointments and going to the doctor and chemist is not the highlight of my everyday life. I am still taking bromocriptine, diaformin and other medication to stabilize my body so that I can continue to be in remission and my body is responding well – I feel very grateful.

I continue to have the loving support of my husband, family and of course the Australian Pituitary Foundation!

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