

Profile

Zara, 39

A nurse living with PNH, Perth

Soon after emigrating from England to Australia in 2005, and becoming an Australian citizen, Zara was diagnosed with Paroxysmal Nocturnal Haemoglobinuria (PNH) – an ultra-rare and life-threatening blood disease. Despite its short history, PNH has already taken a heavy physical and emotional toll on Zara's life. She, along with the 100-strong Australian PNH community, is hoping that PNH treatment will be placed on the Federal Government's Life Saving Drug's Program (LSDP) later this month. This is her story.



When were you diagnosed with PNH and what symptoms led to your diagnosis?

I was diagnosed with PNH in June this year (2010). However, in retrospect, the disease probably began in 2007 when blood test results routinely indicated a low platelet count. During this period I felt physically normal and had no other remarkable blood test results, so no action was taken except to monitor my health.

On one occasion, in mid-2009, my urine was dark red in colour. But once again, tests revealed nothing significant except my usual low platelet count.

This symptom occurred again in May this year, combined with extreme fatigue. However, this time, blood tests revealed significantly low platelets, haemoglobin and a sky-high LDH reading. These new results, accompanied by the random symptoms, prompted my haematologist to diagnose me with PNH.

How did you feel when you were diagnosed with PNH?

When I was diagnosed with PNH I was absolutely devastated. As a nurse, I consider myself to be well-informed about medical problems. So when I researched PNH, it hit home straight away. Everything I read about the disease was negative and the prognosis was the most disheartening – I thought I would die within five years.

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What health complications have you experienced since your diagnosis?

Since May this year, I have experienced very few physical symptoms apart from general fatigue. At this stage, PNH is having more of an emotional affect on my health. I have so many fears and negative thoughts which I try to push to the back on my mind, but my brave face is fading. I can't plan anything because I don't feel like I have much of a future to plan for.

How has PNH affected your quality of life?

I have only been living with PNH for a short period of time, but it has already made a significant impact on my quality of my life. I have always been a very active person. I do a lot of running, and just before my PNH diagnosis, I was training for the Perth City to Surf Marathon. My diagnosis thwarted this goal because I no longer had the energy to exercise.

I still manage to work full-time as a nurse despite experiencing extreme ongoing exhaustion. I have no other alternative because I have to support myself.

How are you currently treating your PNH?

I currently take iron and folic acid supplements to manage my PNH, and live in hope that the Federal Government will soon fund PNH treatment on the Life Saving Drugs Program so that I can treat my disease effectively and return to a normal life.

How important is Government funding of PNH treatment to you?

I currently live day-to-day, in fear that I could die at any time. Government funding of PNH treatment would dissolve these fears, because the treatment is designed to suppress symptoms and therefore restore quality and longevity of life.

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For more information, or to arrange an interview, please contact Kirsten Bruce or Tara Prowse from VIVA! Communications on 02 9884 9100 or m. 0401 717 566 / 0432 874 681.