Garry, 39

Living with PNH for nine years, Esperance, WA

Garry Wilson, 39, from Esperance, Western Australia, was diagnosed with Paroxysmal Nocturnal Haemoglobinuria (PNH) – an ultra-rare and life-threatening blood disease – nine years ago. Since then, the father of six year old twins, Lucy and Andrew, has battled ongoing fatigue, abdominal cramps, all-over body welts and extreme itchiness. His get-up-and-go has taken an enormous dive as he struggles to combine full-time work, family commitments and his passion for hockey.
This is his story.

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

I am an avid hockey player. During the 2001 season I took two heavy knocks to my finger. My second injury was strangely accompanied by lethargy and blood in my urine, which, after a series of blood tests, led to my diagnosis of PNH nine years ago.

In retrospect, I was probably living with PNH well before my diagnosis, but it surfaced when my immune system was weakened through injury.

How did you feel about your diagnosis with PNH?

After being diagnosed with PNH, I did some of my own research on the disease. Unfortunately, there was fairly limited information on PNH at the time, and most of the literature was negative and demoralising. The grim prognosis frightened both my wife, Rachel, and I. We were shattered and shed many tears until we learnt more about the disease.

What health complications have you experienced due to PNH?

Since my diagnosis, my energy levels have tended to see-saw between normal and overwhelming exhaustion. PNH has also resulted in enlargement of my spleen, which, to-date, fortunately, has not overly impacted on my health. I experience painful abdominal cramps, and more recently have endured uncomfortable bouts of all-over body welts and extreme itchiness.

How has PNH affected your quality of life?

Prior to my diagnosis I was physically very active. I still manage to play hockey, but I can't participate to the same extent that I did previously. I just don't have the get-up-and-go anymore.

more#

I work full-time at the Department of Transport in WA where I have a diverse role, primarily dealing with Marine Safety compliance & education. Fortunately, PNH is yet to interfere with my work, except for when I leave for monthly iron infusion therapy. Luckily I have a very understanding manager who is aware of my situation.

How has PNH affected your family?

My family are very understanding and supportive of my chronic condition, but it is hard, especially for my six-year-old twins. I try my best to push through the fatigue and other disabling symptoms so that I can still play with them and work to support them.

How are you currently treating your PNH?

I carefully manage my PNH by monitoring my condition with routine monthly blood tests and iron infusion therapy every three months. I also ensure adequate iron supply with daily supplements.

How important is Government funding of PNH treatment to you?

Currently, my condition is manageable. But if, or when it takes a dramatic turn for the worse, access to PNH treatment will be essential. Without Government funding, treatment is far too expensive for me to obtain. But there are some people in the PNH community for whom treatment is essential now.

I have spoken to people on the PNH treatment Soliris® via the manufacturer's Compassionate Use Program, and they vouch that PNH treatment is the key to gaining a new lease on life. PNH treatment would give me the opportunity to live a sustainable and healthy life, so that I can be there for my family and build our future.

ends#

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.