

## Jacqui

### Watched a daughter living with PNH lose everything

Jacqui has two chronically ill daughters – Glyn has rheumatoid arthritis, a common and debilitating condition and Linda has paroxysmal nocturnal haemoglobinuria (PNH), an ultra-rare and life-threatening blood disease.

A recent decision by the Federal Government has forced Jacqui to watch in fear as Glyn receives funding for the cocktail of medication needed to abate her joint pain, while Linda faces far worse consequences without affordable access to a treatment that could save her life. This is Jacqui's story.



#### **When was Linda diagnosed with PNH?**

Linda was diagnosed with PNH just on five years ago. This means that she is now in the real 'danger zone', as most people living with PNH are not expected to survive for more than five-to-10 years after their diagnosis.

#### **How long did it take for a doctor to diagnose Linda with PNH?**

Linda and I spent months and months in and out of doctors' clinics before she was diagnosed. At one stage, I was taking Linda to see some kind of doctor four out of every five days. After some time of thinking that Linda may have had leukaemia, our doctor finally told us that it was in fact PNH.

#### **What were you told to expect when Linda was diagnosed with PNH?**

When Linda's doctor told us that Linda had PNH, he suggested we go home and research the disease on the internet. In all his years of practising, he had only ever encountered one other person with PNH and therefore couldn't tell us too much about the disease himself.

#### **How did Linda's life change after she was diagnosed with PNH?**

Linda's health went downhill rapidly after she was diagnosed. As a consequence, she lost almost everything she cared about – her job, her partner and the house they were buying together. Linda had to move back in with me, so that I could look after her and I did so for many, many months.

#### **Fortunately, Linda has had access to PNH treatment through a temporary Compassionate Use program for the last 12 months. How has this treatment improved Linda's health and wellbeing?**

The PNH treatment has made an extraordinary difference to Linda's quality of life – you wouldn't believe that she is the same person who was bed-ridden four years ago. While Linda still has to have blood transfusions every few months to replace the red blood cells destroyed by PNH, she is far more active and independent than we could have ever hoped.

#### **How did you feel when you heard that the Government would not subsidise treatment for people living with PNH?**

When I heard that the PNH community would not be granted affordable access to treatment, my first thought was 'Well, what's the point?'. What is the point in approving a treatment for use in Australia when the people who need it can't even afford it?

**As the mother of two daughters in need of ongoing medical treatment, how does it feel to see one have access to the treatment she needs, while the other faces going without?**

I am outraged that anybody should have the authority to decide that one of my daughters can live while the other is left to die. The worst thing of all is that while Glyn's condition is certainly debilitating, it won't kill her. Linda's disease is fatal, but because it's not considered a common disease, she and the small group of Australians with PNH have been overlooked.

**As President of the PNH Support Association of Australia (PNHSAA), Linda has become a beam of hope for Australia's entire PNH community. How does that make you feel?**

I am very proud of the amazing job Linda has done in giving people with PNH a voice. She's a very passionate person. However, I do worry about her over exerting herself in her efforts and hope that she will soon influence the Government decision makers to approve a subsidy for PNH treatment so that she can have a well-deserved break.

**If you were able to say one thing to the Government's decision makers, what would that be?**

My message to the Government decision makers is simple – "There's no Australian worth more than any other".

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**For more information or to arrange an interview with Jacqui, please contact Kirsten Bruce or Sarah Mathiesen from VIVA! Communications on 02 9884 9011 or m. 0401 717 566 / 0400 712 861.**