

Jenny, 28

Diagnosed with PNH in January 2010

Jenny was diagnosed with Paroxysmal Nocturnal Haemoglobinuria (PNH) in January 2010 after a sudden collapse and subsequent emergency medical treatment while in Sydney on a business trip. The diagnosis took seven days.

Jenny treats her PNH with regular blood transfusions, but can not afford access to Soliris® – the only medication available to treat her condition. This is her story.



What symptoms lead to your PNH diagnosis?

I was feeling particularly fatigued, but I'm a shift-worker, so I had attributed it to work and my lack of routine. I had also been trying to get back into regular exercise and noticed that I was short of breath and would get a tingling in my legs during a work-out. Like anyone, I thought I was just out of shape and needed to work harder.

While I didn't realise that I was ill, in hindsight there were several indications that I should have sought medical treatment in the six months leading to my diagnosis.

How did you feel when you were diagnosed with PNH?

Being diagnosed with PNH was horrific – I felt like my whole world had been turned upside down. I was only 28, newly married and it was really heartbreaking to think that my life expectancy had been chopped in half.

After I was diagnosed with PNH, my condition progressed rapidly; I experienced severe chest pains, frequent vomiting and sleepless nights.

How do you manage your PNH?

I'm treating PNH with blood transfusions every three-to-four weeks because I don't have access to Soliris. Regular blood transfusions are the only way my body's coping, but they're really just a band-aid solution to a serious condition.

How has PNH affected your quality of life?

PNH has been absolutely crippling; I can no longer work full-time and I can't enjoy the quality of life that I should be able to as a 28 year-old.

I've also been told that without medication it's too risky for my husband and I to try starting a family. I really need to be medicated for my body to be able to cope with pregnancy and provide for a baby.

How important is Government funding of PNH treatment to you?

Support from the government would be life-saving. It's frustrating knowing that there is a better treatment out there and I can't access it.

How did you feel when you heard about the Government's recent decision not to fund PNH treatment?

When I heard about the Government's decision not to fund PNH treatment, I was angry and terrified. The Australians living with PNH had all been led to believe that the funding would go ahead. Now, I have to live each day knowing that I no longer get to live a full and happy life because of a decision that the government has made.

I can't believe they're putting a price on one of their citizen's lives.

If you were able to meet with the people responsible for making funding decisions on life saving treatments, what would you say to them?

I've never broken a law, I'm a hard worker, I'm honest and caring and the one time that I relied on the Government to help me out, I've been put on the backburner.

I'm fearful, not just for myself – with perhaps another five-to-10 years to live – but for other people with PNH who don't have long at all.

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For more information, or to coordinate an interview with Jenny, please contact Kirsten Bruce or Sarah Mathiesen from VIVA! Communications on 02 9884 9100 or 0401 717 566 / 0400 712 861.