

## Profile

# Eve, 19

## Living with PNH for five years, Melbourne

At the tender age of 15, Eve was diagnosed with Paroxysmal Nocturnal Haemoglobinuria (PNH) – a rare and life-threatening blood disease that stripped her of the chance of engaging in the customary late night parties and boy-chasing of adolescence. Overwhelmed by exhaustive and painful symptoms, PNH turned Eve's life upside down – that was until she was thrown a life line by a new treatment. This is her story.



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

I was diagnosed with PNH at 15 years of age.

The ball started rolling in my early teenage years when I was diagnosed with glandular fever. Shortly after, I began experiencing stomach cramps and feelings of faintness, which my doctor attributed to low blood pressure. A month later, I had deteriorated to such an extent that I was overcome by exhaustion, fatigue and was experiencing difficulty swallowing.

Blood tests revealed anaemia which was unsuccessfully resolved with iron supplements. Alarm bells started to go off as I endured blood transfusions and further investigation in hospital. Finally, more than a year after the symptoms started, I was diagnosed with PNH – an extremely rare disease that only 96 people Australia-wide suffer from.

**How did you feel when you were informed of your diagnosis?**

Initially both my family and I dealt with the news of my diagnosis quite well. However, two months later, our optimism faded and the world seemed to come crashing down around us. Frustration set in as I started to realise that I couldn't do any of the things that a normal 15 year old should be able to do.

**What health complications have you experienced due to PNH?**

PNH predisposed me to all sorts of illness. My immune system was so compromised that any common cold, flu or illness circulating I was guaranteed to catch.

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### **How has PNH affected your quality of life?**

PNH turned my life upside down. I spent a lot of time out of school because I was constantly sick – there were days when I couldn't even get out of bed in the mornings. I was no longer the young, energetic active teenager I had always been. I used to play netball five times per week, but PNH put an end to this and forced me into a very sedentary lifestyle. Consequently I gained weight, and this became another mental battle.

### **How are you currently treating your PNH?**

For a long time I managed my PNH with blood transfusion therapy every few weeks. This helped me get through each day, but did little to relieve my exhausting and painful symptoms. About a year ago I was granted access to PNH treatment on the manufacturer's Compassionate Use Program. This has proved to be life-changing. Instantly I felt the benefits of the treatment, and within a week, my PNH symptoms had resolved.

### **How has PNH affected your family?**

Since day one, my family and friends have operated as a fantastic support network. They can't believe the significant improvements that I've made since commencing PNH treatment. They are overcome with emotion that I am back to living and loving life.

### **How important is Government funding of PNH treatment to you?**

Government funding of PNH treatment is so important for me personally because I have experienced the positive effect of treatment. PNH treatment has restored my physical and mental strength, allowing me to do everything that I want to do in life.

At the same time, I desperately want the other PNH patients, not on the program, to have access to treatment too, so they can once again experience a normal life.

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

The benefits of treatment far out-weigh any monetary costs. With PNH, we are talking about life. This decision shouldn't be about money - it should be a moral decision. People will eventually die from this disease, and this is highly immoral, given that there is a way of avoiding this tragic outcome.

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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.**