Eve, 19

Living with PNH for five years, Melbourne

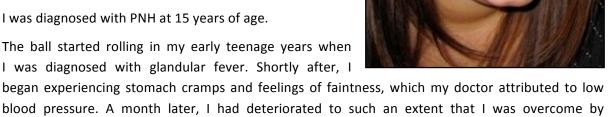
At the tender age of 15, Eve was diagnosed with Paroxysmal Nocturnal Haemoglobinuria (PNH) - a rare and life-threatening blood disease that stripped her of the chance of engaging in the customary late night parties and boy-chasing of adolescence. Overwhelmed by exhaustive and painful symptoms, PNH turned 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.

only 96 people Australia-wide suffer from.

The ball started rolling in my early teenage years when I was diagnosed with glandular fever. Shortly after, I



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

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.

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.