

Aaron, 21

Music artist, entrepreneur and living with PNH, Central Coast, NSW

Aaron, 21, was an independent teenager who, upon completing high school, decided to bypass university and leap straight into establishing his own company – Here's Johnny! Promotions – a visual marketing company specialising in eye-catching posters, flyers and promotional material. However, in 2008 Aaron began to experience sudden fatigue and dizziness, loss of blood and extreme cases of common, usually mild, illnesses. Aaron was diagnosed with paroxysmal nocturnal haemolysis (PNH), an ultra-rare and highly debilitating blood disease. To date, Aaron has not let PNH hold him back – his business is the most successful of its kind on NSW's Central Coast and he is an internationally recognised musician and DJ. This is Aaron's story.



When were you diagnosed with PNH?

I was diagnosed with PNH when I was 18 years old. I had been experiencing bouts of sudden fatigue and dizziness, poor immunity and loss of blood, which left me looking pale and drawn.

What were you told to expect when you were diagnosed with PNH?

When I was diagnosed with PNH, I was told that the disease would affect my lifestyle significantly. I've been through a lot of physical upset; various tests and treatment methods; and find that I need to take things a lot easier than most people my age. My doctor warned me to be cautious of physical exertion, lack of blood and general sickness because it could all indicate further decline in my health.

How have you been managing your PNH?

I count myself as very fortunate to have a great specialist and to have had access to effective treatment, which is funded through a Compassionate Use program. However, this program will soon end and I will be left to rely on less effective and more frequent blood transfusions.

How has PNH affected your health?

PNH has caused me to have regular and ongoing bouts of extreme fatigue, a weakened immune system, constant migraines and a huge lack of physical strength. All of these symptoms can be put down to haemolysis, which is the destruction of red blood cells caused by the disease.

How has PNH affected your quality of life?

As the Director of my own company and a recording artist, I am expected to travel for work quite often however, having PNH can make this very difficult. There are many more personal goals that I would like to fulfil, but maintaining the stamina I need can be a bit tricky. If I over exert myself, or don't get timely treatment, I can end up having lengthy stays in hospital.

How do you feel about the Government's lack of action in funding PNH treatment?

While I understand that very few Australians are affected by PNH, I believe that the Government has an obligation to provide for the welfare of all Australians. The fact that an effective treatment is already available should only further encourage the Government to make it accessible to those whose lives depend on it.

How do you feel about the level of support provided to people living with PNH?

The amount of support available, and the appeals to Government made by the PNH community and its supporters, is outstanding. I am very thankful to the people who have come together to support improved access to treatment and it is comforting to know that the PNH Support Association of Australia (PNHSAA), healthcare professionals and complete strangers are out there championing the cause. Although it may seem out of reach, I believe that if everyone keeps pushing for a funding breakthrough, we will get results.

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