

Aaron's Story

Forging a career amongst 2 life-threatening diseases (Aplastic Anaemia & PNH).



I'm a 24 year old music producer and touring artist from The Central Coast of NSW, Australia. At around age 14 I was diagnosed with A-Plastic Anaemia and hospitalised due to severe loss of strength and immune system. Within 2 years of battling with A-plastic anaemia I received ATG treatment, which unfortunately proved as non-effective. With the only pending option for treatment being a bone marrow transplant (which I was quite fearful of as I've lost friends from graft vs host after transplants) I approached my circumstance with very faithful prayer and dependance on strength that wasn't my own.

In the determining appointment with my haematologist I received quite miraculous news, that practically overnight my blood levels had gone from deathly low to above average!

It was concluded over the coming months that I no longer suffered from A-Plastic Anaemia.

After a few years of disease-free-living, at age 19 I started experiencing anaemic-like symptoms once again. I was then diagnosed with PNH (Paroxysmal nocturnal hemoglobinuria – a rare disease that destroys red blood cells).

In 2013, after a flu infection that left me hospitalised in I.C.U for 2 weeks, my haematologist got me free funding of the one and only known treatment for PNH – Solaris Eculuzimab, an infused chemotherapy that suppresses the effects of PNH. Solaris is priced at roughly \$300,000 per patient per year. Thankfully, due to my severe circumstance the manufacturer (Alexion) funded it for me for free via their compassionate use program.

The Solaris treatment had immediate effectiveness, I felt SO better right after receiving it. Solaris targets the one cell that destroys the red blood cells and neutralises it. Solaris has proven highly effective in suppressing the diseases symptoms in me and does not have ANY side effects. It takes me a 30 minute infusion once a fortnight to receive – a miracle treatment indeed!

Around the time my compassionate use trial was coming to an end, more and more PNH sufferers were popping up. We ran a national petition campaign for the Australian government to fund Solaris on the Life Saving Drugs Program. An outstanding response of compassion from the public towards the 96 known patients was achieved and the treatment was passed by the Aus government.

Although there is no known cure yet for the ultra-rare PNH disease, thanks to the Solaris treatment and all who helped us attain funding I am able to live, operate, perform and travel as normal. Throughout the above history I was always working towards my music career which I am now doing (and loving!) full time.

I am determined that one day I'll be able to also live without dependancy on Solaris treatment, but right now it is a very small price to pay for quality of life.

I believe there's always hope no matter what circumstance we are in, and there's a purpose for everything we face to work together for the good of ourselves and others.

Find more about Aaron at www.northiemusic.com