

Dagmar, 37

A mother's plea to see her little girl grow up

Dagmar Cummings, 37, of Yandina Queensland, was diagnosed with Paroxysmal Nocturnal Haemoglobinuria (PNH) – an ultra-rare, life-threatening blood disease – when pregnant in 2003. Despite the availability of an effective treatment, Dagmar's hopes of seeing her seven year old daughter grow up have been crushed by the recent exclusion of PNH treatment on the Federal Government's Life Saving Drugs Program. This is her story.



When were you diagnosed with PNH and what led to your diagnosis?

I was diagnosed with PNH shortly after I fell pregnant in 2003 – seven years ago. At my first ante-natal check-up, my doctor detected abnormally low haemoglobin levels in a routine blood test. I was hospitalised immediately for further urgent investigation and this led to my diagnosis of PNH.

What health complications have you experienced as a result of PNH?

In the last two years my condition has worsened – the degree of haemolysis (red blood cell destruction) has increased and caused many unpleasant symptoms. I experience extreme fatigue – sometimes there are days when I can't even get out of bed. I experience a great deal of physical pain – all-over body cramps, severe abdominal pain, dizziness, headaches, and shortness of breath. Then there are the mental health problems I have battled since my diagnosis. I go through periods where I am riddled with bouts of depression and anxiety.

The hardest part for me and my family is the unpredictable and inconsistent nature of my disease.

How has PNH affected your quality of life?

PNH has turned my life upside down. I had to resign from my job as a restaurant manager at the end of 2009, as I could no longer meet the physical demands of the job.

Before my diagnosis I was an active, out-going and sporty young woman, but I am now merely a shadow of my former self – I can no longer participate in any of the physical activities that I used to do because I just don't have the energy.

I am also unable to travel overseas for long periods of time because I am dependent on monthly blood transfusions. I was raised in Switzerland and my entire family still reside there. Visiting them for more than a few weeks is sadly out of the question.

How has PNH affected your family?

PNH has placed a lot of strain on my family. My extended family feels helpless because they are so far away, in Switzerland – but they remain supportive and do as much as possible to help from afar.

I feel sorry for my husband because he married an energetic and outgoing girl – but PNH has stolen my identity. My husband has also been suffering from long-term mental illness, PNH has undoubtedly exacerbated his mental problems.

My daughter is only seven years old – she is very understanding of my illness, but it is so hard for her as sometimes I can't even get out of bed. One of my greatest fears is for her to grow up without her mummy.

How important is Federal Government funding of PNH treatment to you?

Obviously it is very important to me that the Federal Government funds PNH treatment. When I was diagnosed in 2003, the treatment was in a trial phase, so there was hope that it would soon be available. With this hope, fears of an early death and not seeing my daughter grow up evaporated. But when the Government denied treatment funding, all my fears came rushing back. I was devastated, and my hopes for a better and longer life were diminished. Now, my future is uncertain.

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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.