

Ian, 41

Living with PNH for 23 years

Ian, 41, was diagnosed with PNH when he was just 18 years old. The ultra-rare, life-threatening blood disease has left the husband and father of two fatigued, depressed, riddled with pain and unable to work. Ian's wife, Debbie shares his story.

How has PNH affected your husband's health?

Ian experiences regular thrombotic attacks, liver complications, constant pain and lethargy. This means that Ian can't work or do too many things around the house; just washing up the dishes can exhaust Ian and it's not unusual for him to go to bed and sleep for 14 hours straight. Ian can't work and this has caused him to become clinically depressed.

How does Ian currently manage his PNH?

Ian has to have regular iron infusions and has been hospitalised after missing these on several occasions. He also takes blood thinners to reduce his risk of fatal blood clots, folic acid to encourage growth of new red blood cells and what we call "happy pills" to help with his depression.

How has Ian's PNH affected your relationship?

PNH holds no sway whatsoever over our relationship. Before we were married, many people thought it was a bad idea for us to go ahead with the wedding, given Ian's disease. However, I know that an illness does not change who a person is. I love Ian and I will stick by him no matter what happens.

How has Ian's PNH affected your children?

Our two children, 17 and eight, have missed out on a lot of things that other children tend to take for granted, such as family holidays and playing sport with Dad in the backyard. Both kids are sad that their dad is sick and worried about what might happen around the corner.

How did you feel when you were told that the Government would not fund access to the PNH treatment recommended by the Pharmaceutical Benefits Advisory Committee?

When I heard that the PNH treatment would not be Government-funded I was annoyed. Here is a treatment that will reduce my husband's pain and fatigue and we just can't afford it ourselves. I don't care that Ian still wouldn't be able to go to work, or that he would be on this treatment for the rest of his life, all I care about is making his life better and this medication can do that.

Given the chance, what would you say to the Government's decision-makers?

I think the Government needs to wake up and understand that this treatment is vital for people living with PNH, which can be a very deadly disease. Just because these decision-makers don't know anyone living with the disease, should not mean that subsidised access to this treatment is denied.



What alternatives do you have that may help you to access effective PNH treatment?

There is no way that our family can realistically afford treatment. Our doctor had suggested that we move to the United States, where the treatment is funded. However, with two school-aged children and neither Ian or I able to work, this isn't an option either. We have no alternative but to continue hoping that the Government will see the need to subsidise treatment and do so.

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