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A patient's perspective
Kylie Miller

I wish to submit these comments to the Review of Australia's Plasma Fractionation Arrangements.

I am a young Australian whose good health relies on a fortnightly infusion of Intragam P; one of a group of stakeholders I feel is often overlooked in the debate about the blood supply and its cost.

Six years ago, my world fell apart.

It started slowly, with small changes. I would trip over when I was jogging. I stumbled on tram tracks when crossing the road. I found I needed to use the handrail to climb stairs, had trouble lifting groceries from the boot of the car and often felt exhausted after a long day at work.

Then, during an unrelated consultation, my doctor noticed damage to the nerves in my legs. I was referred to a neurologist who quickly diagnosed a degenerative nerve disease. The disease is known as multifocal motor neuropathy (MMN). It is a rare autoimmune disease – my body has developed antibodies that, instead of fighting disease, are attacking the myelin lining around my motor nerves.

As far as nerve diseases go, it's relatively minor. I have no pain or significant discomfort, and my life expectancy is unchanged.

But I hate it. Within a few months I changed from being independent, fit and active to struggling with basic things – walking up stairs, stepping into the bath, climbing out of my low-slung car. In the months following diagnosis, it grew slowly, progressively, worse. I was 30 years old.

I spent two weeks in hospital having plasmapheresis, a process in which blood is siphoned from the body and the components separated by centrifuge. My plasma, which carries the auto-antibodies – the antibodies that attack my nerves, was removed and replaced with donor plasma. It was an unpleasant process and it didn't work.

Then I was prescribed Intragam P, an immunoglobulin product made from donor blood by the Commonwealth Serum Laboratories.

The improvement was close to immediate and, by the end of the week, I felt like a new person. I was placed on a list of "approved patients".

Now, every two weeks for half a day, I attend the Alfred Hospital in Melbourne for treatment which, happily, keeps my disease in remission and me a healthy, active and productive member of the community. I work hard and pay tax.

But unfortunately it is not that simple. On many occasions I have attended the hospital to find that the full dose is not available. Why? Supply shortages.

The only alternative treatment for my disease is a toxic chemotherapy drug, cyclophosphamide. If it works – and it has only a 50 per cent success rate – I would need six months of treatment every two years. It would be severely detrimental to my health and I would be unable to work during treatment. It is hardly an attractive alternative.

In March 2004, stocks of Intragam P ran out altogether. Although government policy was changed to allow the purchase of imported intravenous immunoglobulin, the delay in approval meant a rapid decline in my health.

When I don't get a full dose, or there is a delay in it being delivered, the impact on my health is immediate. For a couple of months my health deteriorates. I need a larger dose, more often, to regain normal strength. It isn't life threatening, it doesn't always affect my work or my ability to function (although it does have an impact) but it is very frustrating.

No one source is to blame. It is not the fault of the hospital or the Australian Red Cross Blood Service. Perhaps it is just that there aren't enough people out there willing or able to give half an hour of their time and a few pints of their blood.

It takes 18,000 donations to manufacture a small batch of Intragam P, enough to treat me for a year. I will need this treatment for the rest of my life. And I am just one patient.

Thousands of Australians rely on donor blood every year; the vast majority of recipients, like me, use blood products to survive day to day.

Your committee holds the lives of Australians such as me in your hands. I urge you to remember us when you make decisions about the future of Australia's blood supply and fractionation arrangements, and to keep the supply of blood products consistently available and safe to use for those of us whose lives depend upon it.

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