

## **A Young Mother's Journey**

### **Tracey**

My name is Tracey and I am a 48-year-old woman. Before my diagnosis, I was noticing issues with blood clotting. I would have large bruises after little to no trauma and the bruises took a long time to heal. I also had occasional bruising around my eyes with no trauma. I learned later that was called Periorbital Purpura. When I asked my dermatologist about it because I was using a crème for my scalp, he mentioned Amyloidosis. However, after sending me for a blood test, he said I did not have it.

The next year I asked my primary physician and my OB/GYN about bruising, but nothing showed up in my blood work to explain the situation. Before I could pursue the bruising any further, I had a haemorrhagic ovarian cyst that ruptured. With emergency surgery to remove the left ovary and fallopian tube, my post-op process was not so smooth. Though the procedure was done laparoscopically, I had an unusual amount of bleeding from my bellybutton. I saw a haematologist who ordered a list of blood tests; one of which was factor X. I had an acquired factor X deficiency.

Fortunately, the haematologist suspected Amyloidosis. Though the bone marrow biopsy was negative, the subsequent GI biopsy was positive. Normally, a biopsy is done on the organ that is suspected to be involved. In my case, due to the risk of bleeding, we decided not to biopsy my spleen. At the time of diagnosis, I was 42 years old and had seen four doctors on my journey. Although the time to diagnosis (about one year) was not too long compared to other patients, I think the path would have been quite different had the ovarian cyst not ruptured. In addition, I had endometrium ablation two years before my diagnosis. The heavy menstrual cycles were attributed to hormones. In hindsight, the cause may have been the factor X deficiency from the Amyloidosis.

When facing the potential chemotherapy treatment and knowing it was a rare disease, we decided to get a second opinion on the diagnosis and treatment. My initial haematologist referred me to a haematologist that specialized in Amyloidosis, and she helped me initiate a second opinion. Because of the factor X deficiency and risk for bleeding, I was not an immediate candidate for an autologous stem cell transplant.

In the hopes of getting an organ response from my spleen, I started with Bortezomib. After a month, my light chains were worse. Cyclophosphamide was added to the Bortezomib for the second and third month of treatment. However, by the third month the side effects were way worse than any improvement in the light chains. We spent a month getting all tests and approvals to start Lenalidomide. Similar to the first group of chemo drugs, by the third month the side effects were way worse than any improvements in the light chains. In parallel to trying to get a response from the different chemo drugs we monitored my factor X. During the treatment it continued to drop at a solid rate.

Though the risk of bleeding had gotten worse, we decided to move forward with the stem cell transplant while we took the necessary precautions in regards to bleeding risk. Happily, I had a complete response to the stem cell transplant and a solid organ response within about six months of the transplant. As of today I am doing great.