



Ulrika



With my husband Daniel at our wedding



My treasures - Jens and Sara



### Ulrika Östberg, Sweden

My name is Ulrika. I am 34-years-old and I live with my husband Daniel and our two children, Jens and Sara in Halmstad, south of Sweden. Jens is six-years-old and Sara will soon be one.

I got my diagnosis at the age of six. The disease has been very active and, in early years, I lost my sight. I love to read books and enjoy music. I am stubborn and, for the most part, happy. I find it easy to laugh and, my siblings tell me, I am fun-loving.

I'm interested in politics and social issues. I have studied from time to time, when my health permitted and when I had the strength. However, I have no profession.

The disease has also turned me into tracheotomerad, where I have a hole in the trachea. With my rheumatism and medications, it makes me very susceptible to infections. Soon it will be time for a couple of neck operations.

I learned about the Stene Prize through the magazine Reumatikervärlden. I like to write and thought I had a story to tell.

## Babysteps

**When I turned four, I got a wonderful birthday present – a little sister. My memories of that day are fragmentary. My Dad took me to a shop and bought me a red dress and a bag in the same material as the dress. Then we went off to the maternity hospital to see my mum and my little sister.**

Two years later, my left knee swelled up. From then on, my life – and the lives of those dearest to me – was marked by illness, hospital stays, operations and a lot of pain. But there was also happiness, joy, a zest for life and a strong feeling of victory.

During the early years, my big worry was my eyes because they had been affected by rheumatism. I had one eye operation after another, and despondency would be followed by joy, only to give way to despondency once more. After

four years of fighting, the disease had won the first round and I had become blind in both eyes.

In a way, however, I found it a relief – for then, at the age of 12, I no longer had to endure all those operations that I truly loathed. I was left in peace – for around two months.

Major inflammation developed between my first and second vertebrae, and eventually I was sent to London for an operation to fuse the vertebrae in my neck. The doctors in Sweden had treated me with shock doses of cortisone, but when my bone marrow was compromised and my life was in danger, they did the best they could: they sent me to a specialist who had already performed the same operation on 12 children all over the world. The operation was very successful, and I went from having to take morphine just to lift my head from the pillow to being left with nothing more than post-operative pain when I came round from sedation a few days later. Dad and I travelled back home a week after the operation, and everyone was amazed that I had recovered so quickly. Those are words I have heard many times since.

**“The disease must never be allowed to win”**

Many times over the last 26 years I have had to fight my way back. The one thought that has kept me going during the tough times is that the disease must never be allowed to win.

I have lost my sight, I have become mobility impaired, I lost years of my childhood and youth; I can accept all that. What I cannot allow, however, is for my disease to rob me of my love of life and the motivation that drives me onwards. I have had to lower my sights over the years, but the feeling of having taught myself to find the bus stop and being able to get on the bus with my three-year-old son for the first time certainly bears comparison with the feeling of triumph someone else might experience on landing their dream job.

Several hospital stays and operations ensued during my teenage years. I would fight my way up, only to be knocked back down again.

When I was 24 I met my future husband, and one of my greatest dreams became a reality. It was one of those dreams that I had almost given up on for a number of years. Both my husband and I longed to have children, but that particular dream was much more difficult to achieve than I had imagined. From a young age I always had a strong desire and longing to start a family and have children. It was part of my vision for the future, you could say.

## **“One of my greatest dreams became a reality”**

Rheumatism has left its marks; and not only the obvious ones – the fact that I am blind and have fused vertebrae. My growth was also stunted as a result of all the cortisone I was treated with. My bones have become brittle for the same reason. My doctors advised me against trying to get pregnant for a variety of reasons: it would be too great a strain on my body; I would be putting myself at far too much risk. That was

the worst news I ever had to deal with. My future had turned bleak; I was filled with anguish and found it hard to sleep. Sorrow and despair gripped my soul, so to speak. I could not believe that rheumatism had robbed me of my future. After months of dread and despondency, I tried to haul myself out of the pit I found myself in. I decided to do my very best to get as physically fit as I possibly could and then take a chance on getting pregnant and having a child anyway. I had no choice but to try; that was just the way it was.

I underwent two operations – both my hips were replaced. After rehabilitation, I resumed my training programme in the gym, which I had started after commencing biologic treatment four years earlier. This medication had changed my life dramatically. I stopped taking the drugs that could be harmful to a foetus, and I ate to put on weight. I then somehow managed to put everything behind me, and hoped with all my heart that things would work out. Three months later I was pregnant.

After a wonderful pregnancy, I gave birth to our son in the 37th

week. He is now five years old, and has a little sister of seven months. My second pregnancy also passed without complications, and my happiness and gratitude are indescribable. The decision to try for a baby was more difficult the second time around. I would be risking even more. I was, after all, a mother already, and obviously I did not want to get worse and be unable to look after my son as I had done up until then.

The yearning to have a child and to give our son one of the best things I have myself, namely a sibling, won the day.

Today I feel great. My strength and fitness training means an awful lot to me, both for my body and for my mind. Even when I have relapses, and I have to start my training over and over again, I know that I am strong and that I can cope well.

I think the reason why I am able to live as well as I have done – and still do – despite a severe rheumatic disease has a lot to do with my outlook. I realise and accept that my illness and my functional disability affect my life, and I adapt to that. But I

am always finding challenges and goals, and that stops me losing my spark. When I am obliged to endure tough operations and treatments, I challenge myself to bounce back as quickly as possible. It then becomes a kind of competition.

Keeping both body and mind as strong as I can in the situation in which I find myself – that is my strategy for life.

## **“I challenge myself to bounce back as quickly as possible”**