

Noëlla's Story

My name is Noëlla, I am married to Marcel and have 1 grand daughter Rosie, daughter of our diseased sun, Peter. I was the 2nd child in our family, I do have 3 other sisters and 2 brothers, I am 60 years old and live in Belgium.

As far as I can remember, it started when I was 12 to 13 years. At that time I experienced difficulties during the hours of physical education. I had trouble doing the floor exercises and when we needed to do climbing proofs.

I purposely left my gymnastic suit at home, to avoid having to participate to these exercises. But, I was rather podgy and it was supposed that was the reason for my evasive behavior.

My parents took me to the doctor on regular bases, because I often complaint about having pain in the knees, the groins, my shoulders and hands. The diagnosis was that I had rheumatoid arthritis, a decease that was present in our family.

My grandmother from father's side did have to walk with a cane as from her 40th year and it was said, that she had Rheumatism.

So, many years passed by...

However, in the early 70ties (around my 30th birthday), I also got respiration problems. In the meantime, I changed general practitioner, who sent me to the University Hospital Leuven, where I – through muscle biopsy – was diagnosed having Pompe decease. It was also said that I would have to learn "to live with it", because no medication existed. One prescribed to follow physical therapy, 3 times a week.



Noëlla and her husband Marcel



Noëlla

From that moment, I muddled along, taking pain killers and using "puffertjes"

At that time, I still worked in Brussels, having to drive daily up and down with the train, but it was getting more and more difficult to walk the distance from the station to the office. So, I had to take a taxi every day, but that became too costly.

My husband and I decided to drive by car to solve this problem. He dropped me in front of the building and from the moment I was inside, I used walking sticks, until this became impossible and I got immobilized.

In 1993, at the age of 47, I had to give up working, was put on early retirement because of medical reasons and had to stay home.

Nevertheless, the problems got bigger, every movement became difficult and even more painful, I was almost constantly in pain and my husband had to put blocks under all the furniture that I was using, f.e. my bed, the coach, my chair. We also had to heighten the toilet to allow me to use it. I had to sleep in a sitting position to be able to breath and in the end I ended up in a wheelchair.

Meanwhile we visited specialist after specialist, but nobody could help me, until a year ago Genzyme became my rescuer, via my close girlfriend Simonne.

Starting in June 2006, I got my first infusion with Myozyme and after 6 months, in January 2007, I already felt some improvement: I was able to pull over in bed, something that was impossible before. Up to now, almost every day I am experiencing things that are going better and better: all the wooden blocks could be removed from our furniture, we even stopped taking all these aids with us when going on vacation. I will not say that it is easy, but I manage, slowly.

Also, before treatment, my days ended at noon, I had to lay down and take a rest for the remaining of the day. Now my days are lasting till 6 pm.

I am also able to take a step of about 7 cm high, before one of 2 cm was impossible.

On the other hand, I still get kiné-exercises for my lungs.

The other good news is, that I do no longer need to sleep in a sitting position.

I few weeks ago, I even managed to start practicing on a home-trainer, although with the help of my husband and I even live almost without pain killers and “puffertjes”.

All this, because of MYOZYME, which I get every 2 weeks at the Hospital in Hasselt.

Every 3 months I need to go for a follow-up to the UZ in Leuven.

Now, I have great prospects and I am sure that – one day – I will be able to realize my dream, namely riding a bike again.

Noëlla, 21/09/2007