

Good afternoon,

I'm Michiel Vandamme. I was asked to testify about diabetes and specifically about retinopathy.

I was diagnosed with diabetes in 1968. I was only 16 years old. At that time little was known about diabetes and its complications. The treatment was very simple: injecting with insulin (8 units of Organon) in the morning. There were no glucose testing machines. So a low or a high sugar level could not be controlled. I remember that my mother accused me of pretending having hypo's , that is a low

sugar level, so that I could eat sweets. I was very angry with my mother for that.

Every four months a medical visit was necessary. I had to cycle 10 kilometres to the doctors' office. The doctor took a blood sample. However, physical exercise decreases sugar levels in de blood, so cycling 10 kilometers helped me having low sugar levels. This way my treatment was never adapted.

No one told me about complications, so I had no fears. I suppose it was at the nursing school that I learned for the first time about complications.

In february 1980, when I was 28, I had my first eye bleeding. That was very annoying. You can compare an eye bleeding with having a spider's web in front of your eye all the time. Probably I had already problems before my first eye bleeding but I didn't notice them. So nothing to worry about. And by the way there was no control of eye sight by any doctor.

Only after my second eye bleeding, which was one year later, I was treated in Ghent by Professor De Laey and Dr Prims.

I was lasered, 8 times in each eye in total. I remember that I had to stay 3 months at home. As a consequence of the treatment, I had macula edema: I could only see through

a misty cloud. I couldn't drive, nor read a newspaper or help in the household. I was depending completely on my family.

The doctors promised that it would disappear after the lasering. And yes, it did, but my eye sight did not improve, on the contrary, it got worse very quickly. I was convinced that I would go blind. That was really hard. I still wanted to do so many things. That year I became very involved in the union, in local politics, social work and so on. I still am, by the way...

My vision went worse more slowly than I feared. I found ways of coping with my bad eyes: I started using a magnifying glass, I found my way to big letter print books, I

gladly moved to the computer era. But it all wasn't that easy...

Reading my paper with a magnifying glass is really tiresome: after 5 minutes reading I don't want to continue. Big letter print books are great, but there isn't that much choice.

The computer is the most promising: I adapted it with a large screen and use specific software such as Zoomtext and Kurzweil. So now I scan the books and magazines I want to read. My next step will be to learn how to read with the Digital Accessible Information System (DAISY).

In 1983 I stopped driving long distances. It wasn't an easy solution: my kids were between 5 and 9 at the time. I only drove short distances in my home city. But even that became more and more difficult. After several car accidents I definitely stopped driving. That was in 1999; I was 47 years old. Luckily my children could drive by that time. But I felt quite uncomfortable asking to be driven all the time. And I still feel that way. I need help to go wherever I want to go. It disturbed my privacy...

Due to my diabetes I started having heart problems. My first heart failure was in 1989 and I had a heart transplation on the 5th of May 2002. I was then 50 years old

and had not been able to work for two years.

At that time very little was known about the consequences of the transplantation on my eyes. The doctors wanted to make sure I wouldn't end up blind. I still had trouble with my sight, but I have to say it was the least of my problems: the heart was more urgent.

I made a complete recovery and I started working again in August 2002. Three years later I had a cataract operation on my left eye. My right eye was already too bad.

Sadly, in 2007 I had to quit my job. I was working as a diabetic consulting nurse and I couldn't recognise patients anymore. I

was no longer able to read their files and their glycemie results. For a long time I had been pretending there was no problem. At work, but also with my friends and family.

Recently, I learned to walk with a white stick. I was quite reluctant at the start: it was my wife who made me do it. But I must admit that it is quite comfortable now because passers-by see I have a bad eyesight. But there's so much I can't see anymore and it's hard enjoying a walk...

Knowing what we know today, I was treated too late. Now diabetes patients are followed more closely. They have to consult an eye doctor every year. That is really

necessary but there are still patients who don't want to believe that. The diabetes patients don't feel any pain, but their eyes have already gone bad. Vision complications start generally 15 years after the diagnose of diabetes.

Prevention is very important. Diabetes type 2 is often detected too late, even nowadays. This will have important consequences for the treatment of their eye problems and other complications.

Diabetes is becoming a real pandemic. I'm afraid that there will not be enough healthcare staff to coach the patients. Coaching is crucial to prevent

complications such as retinopathy and nephropathy, neuropathie (foot complications) and heartfailure. As I said before, as a diabetes patient, you don't feel any pain, so it's hard to keep up a consequent way of life. A lot of attention will thus have to go to prevention and support of the patients.

I thank you for your attention.