

Testimony of Karl-Heinz

1950: Year of birth

1970: Large deviations were found in my liver values in a medical checkup. After spending 4 months in the hospital and receiving multiple infusions to build up my liver values, I was released from the hospital without any change in my liver values and without any diagnosis.

1980: It was increasingly difficult for me to perform physical activities. I experienced minor breathing difficulties. I quit smoking during that year and hoped to get in a better physical condition.

1980-1985: General deterioration of my health. My breathing problems became increasingly severe to the extent that I started to need increasingly larger breaks during physical activities. I started to fall down during walking and climbing stairs became a difficult enterprise. I have been visiting multiple medical doctors including a cardiologist, an internist, a neurologist, a lung specialist, however, neither of them was able to provide me with any proper diagnosis or therapy. Even though I visited multiple doctors, my health deteriorated steadily. My working performance (as a salesman) started to decrease until the point that I became incapacitated for work.

1985-1990: Further deterioration of my health with increasing breathing problems during the day and night. I was able to walk short distances only. It started to become increasingly difficult for me to bend over and get up again. Because I started to doze off during the day, the neurologist prohibited me to drive. I dropped cups while drinking coffee. I was hospitalized twice during 1988. Even though I had various checkups, no proper diagnosis could be made. After the hospital I went on a cure with breathing therapy and inhalation near the North Sea. Nevertheless I did not get better. I was again hospitalized after multiple visits to doctors and enduring incapacity for work in 1989. During my stay in the hospital I was diagnosed with a serious heart disease. The cardiologist decided that a heart surgery was necessary. I refused this operation with the result that I had to leave the hospital. I collapsed at home two months afterwards (in October 1989). I was brought (by ambulance) to the University hospital where I received artificial ventilation which improved my well being. The final diagnosis was made after a muscle biopsy: I had Pompe's disease. My bad physical condition did not allow non-invasive ventilation (ventilation via nasal mask). To allow artificial ventilation, I received a trachea operation.

1990-1995: I was dismissed from the hospital in January 1990. From then on I received artificial ventilation which substantially improved my general well being. Physical training in combination with physiotherapy as well as nighttime artificial ventilation further improved my health. I was able to do boat-tours for a company during about 3 hours at the end of 1991. In addition, I was allowed to drive my car again. My daily routines made sense again.

1995-2000: My physical condition deteriorated to such an extent that I had to quit my side activities in 1997. I had severe difficulties to walk. My breathing abilities were strongly restricted. I had severe headaches. I got a wheelchair in 1998 since I was only able to walk short distances in my house. My breathing capacity became increasingly limited.

2000-2005: In 2001 my breathing capacity was reduced to the extent that a breathing mask and further ventilation became necessary during the day. My wheelchair was extended with an electromotor which also supported the breathing machinery. Since 2001 I receive 24-hours ventilation. In 2004 I had the change to start a medical therapy. Both, my breathing capacity as well as my muscle strength have increased since then.

Karl-Heinz