

Life with muscular dystrophy

My brother

I was born in 1972.
 My brother was 3 ½ years old.
 At that time he began to show the first signs of muscle weakness, difficulty in running and climbing stairs.
 The right diagnosis was not made until he was 6.
 4 years later it was confirmed by open muscle biopsy. It said „progressive muscular dystrophy“



Situation in the 1970s:

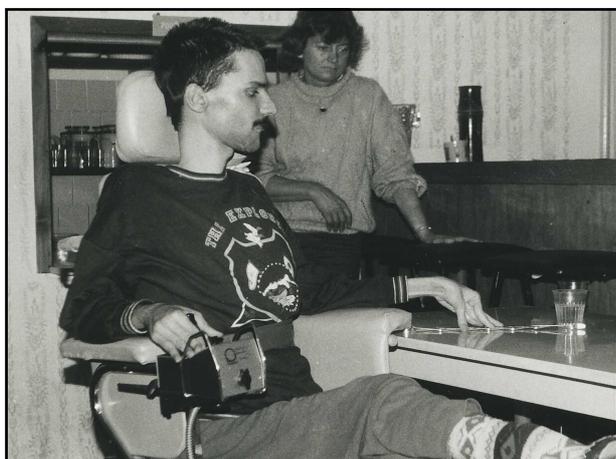
- ▶ Very little was known about muscular dystrophies
- ▶ No follow-up plan
- ▶ No guidelines
- ▶ No access to information, no internet
- ▶ No social support
- ▶ No psychological support
- ▶ Our parents did not know where to go for further information and support.

My brother's school years



- ▶ We lived in a flat on the 2nd floor. No lift.
- ▶ Local primary school had a lot of steps. No lift.
- ▶ stopped going to school when he was in the 3rd grade.
- ▶ Until the 8th grade educated at home by teachers and in Children Treatment Center in Janské Lázně where he took two-month treatment every year.

▶ By the age of 10 Mirek became unable to walk.



Imitating my brother !?? I wish I had ...



▶ From the age of 6 developing the same signs of muscle weakness as my brother.

- ▶ frequent falls
- ▶ difficulties in rising from the floor; from a chair
- ▶ Achille's tendons contractures
- ▶ tip-toe walking
- ▶ difficulty climbing stairs

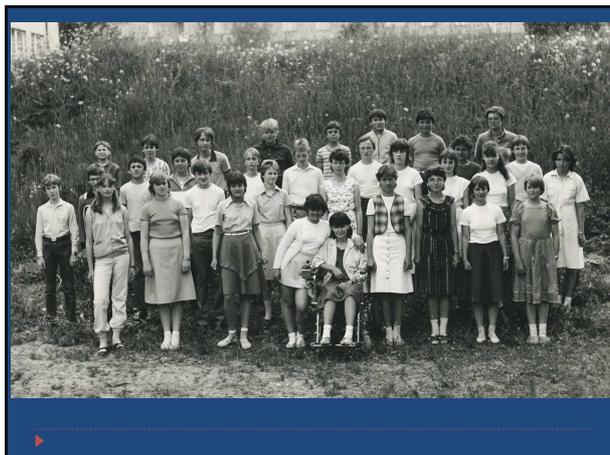
Education

Local primary school

- when I was in the 3rd grade my mother gave up her better paid job and started to work at the school as a secretary to be able to help me
- allowed to use the back entrance
- classrooms on the first floor for the whole of 8 years

Comprehensive secondary school

- next to the primary school
- ramp at the front entrance



Employment

1992 – 2000

teaching English at a local secondary school

2001 – moving to Prague

2001 – 2007

giving private lessons at home



since 2008 - employed with Medical supplies Setrans
- work for a photo studio (self-employed)

- ▶ 1995 - lower respiratory tract infection
 - could not swallow, cough, eat, sleep
 - hospitalized in neurological ICU
 - non-invasive ventilation
 - recommended using positive pressure ventilator with a nasal mask at night

