LGMD 1b

I am Dirk ,

DIRK_SCHUBERT_33

37 Year old and muscular dystrophy Emery Dreifuss (LGMD1b).
The EDMD controls my life since 2017.

My condition got worsen until I even was depending on an electrical wheel chair in 2019, now it was nearly impossible to handle the life on my own farm.

I life there with my wife and my 11 year old daughter, both always help my and take care of me. My great wish is to rebuild our house into a more disable accessible condition.

Muscle cramps on my shoulder and upper arm area making longer work activities almost impossible. My physical forces are there for very limited, so I relay permanently on help.

In addition I suffer eat and swallow problems, because the responsible muscles are Also effected. To seat I need an orthosis because of my limited torso stability .

With medical aids, medication and therapy I try to compensate my physical limitations. EDMD is a rare neuromuscular disease ratio is 1: 100000 and unfortunately not healable. Heart failures, muscular weakness and tendon shortening joining this disease.

The therapy method must individual fit to the individual symptomatic.
Means for me all medical aids playing a major role and are an important part to fight against this disease.

Because of the neurological pain and all muscular symptoms I am living always on my limits.

except muscles we are missing nothing