LGMD R1

Hello my name is

Julian and I am 27 years old.



I have limb muscular dystrophy 2A, also known as LGMDR1. The disease was diagnosed when I was 15 years old. As a child, I couldn't do much with the disease because I was still able to do quite a lot. A muscle disease meant nothing to me and my family at that time. Only after some things had stopped working or had gotten worse.

Today I am mainly limited in walking, getting up and climbing stairs. Despite these obstacles, I enjoy life. I like to do things with friends and try to explore the world with my converted car.

In my everyday social life, the illness is received positively, at work, for example, an extra workplace has been set up and everything is designed to be as barrier-free as possible. People come up to you openly and ask what a muscle disease actually is. These people are often surprised that I'm not only in a wheelchair, but can also walk.

Personally, I find that you learn to deal with the disease, you adapt to it.

As the disease progresses, new ways and means are always found to compensate the limitation.

The tongs, for example, help me to pick things up off the floor and have become a faithful companion.