HI,

my name is Steffi
I am 29 years old and this is my story....

At the age of 18, I realized that something was wrong with me... Until then, I was allowed to spend a normal childhood and youth, was active in sports and liked to get involved in every party. Through my training as a medical assistant, it was clear to me that my symptoms, which I had gotten in the meantime, with repeated stumbling and the difficult climbing of stairs, did not correspond to the norm. After intensive research, I found out who I had to contact and ended up in the University Hospital Erlangen, which in 2013, after a few examination procedures, was able to give the whole thing a name

-> muscular dystrophy type LGMD 2A/R1.

... and suddenly everything changed ...

Over time, the symptoms got worse and my little ideal world broke up bit by bit. At that time there were neither treatment options to stop the disease nor a chance of a cure. I mean when an 18/19 year old is told that they will soon end up in a wheelchair and you don't know how fast and far the disease will progress, that's quite a stroke of fate, you automatically assume the worst and nothing will be more like it used to be.

Thanks to the support of my partner, who has been with me from the start, as well as my family, I have been able to keep my head up. The motivation that a wheelchair is not a handicap, but that you can use it to regain your independence and participation in life as much as possible, made it easier for me to use the wheelchair. Likewise, other tools that can even be fun, by the way. 😄

In the meantime, I also have significant limitations that affect the arm muscles, I have also learned to deal with this and small "helpers", such as gripping tongs at home by advice.

In my everyday life, not only my boyfriend accompanies me, but also our little Yorkidae, who has become accustomed to the wheelchair in an exemplary manner. For walks, we practiced walking on my train, she masters it with flying colors. 😊

In our free time, my loved ones try to make almost everything possible for me. We like to go karting, play laser tag, do handicrafts, travel and even diving has already been made possible for me and now someone should say that nothing is possible with physical limitations.

A lot is possible, often the right way of the feasible is found.

Of course you often need help, but most people, no matter where, can be very helpful, you just have to dare to speak to them.

Besides all the tools I have, I am also very proud of my converted car which has been converted to hand throttle and has a wheelchair loading system.

As you can see, a lot can work, even if it is sometimes a bit more complicated and slower, but it can work. In any case, the head is never left hanging due to the illness! Yes, it is a part of me and accompanies me every day, which is not easy either, but I don't let it get me down and shape life almost the way I want it to.

Through the study, which is co-financed by the association SFCM e.V., there is a chance of healing for LGMD sufferers, including me!