

CV Johannes



I was born in 1973 and studied law and philosophy. After completing my law studies in 1999, I worked as a legal trainee at the Hallein Bezirksgericht and at the Salzburger Landesgericht. This was followed by a position as an administrative lawyer at the Bundespolizeidirektion in Salzburg for almost three years. During this time I completed my doctoral studies in law and also my philosophy studies. Then I worked for 12 years in the Bezirkshauptmannschaft Salzburg-Umgebung as a lawyer for penalties and for the withdrawal of driving licences. In 2015 I was taken into early retirement due to my limb-girdle dystrophy of the calpainopathy type (LGMD 2a / R2). I am married and father of a nine years old daughter.

Compassion, Arthur Schopenhauer said, is the basis of all morality. When compassion goes beyond the small circle of family and friends, than it is called: social engagement. This concept reaches its peak in the thoughts of solidarity and

responsibility for others, which are the correctives for our freedom. Otherwise freedom is collapsing very quickly into selfishness, greed for profit and destruction – in the small as in the big world!

To be compassionate, it is very easy; YOU only have to imagine: what if, YOU would be ME?

Since fifteen years I have been bound to wheelchair because I am suffering from muscle dystrophy. A deletion prevents the Calpain-protein from performing its function, so my muscles are becoming weaker and weaker.

Since my youth I have always heard that this disease is incurable. I could not find help or even any hope until I met Prof. Spuler. She and her team developed technics, which will be able to cure this awful disease.

The preclinical results have already been amazing! But now there is one last challenge: the money!

The public sector cannot finance this clinical trial. The big pharma concerns do not want to invest in it, because this is an „orphan“ disease and therefore not profitable. And the patients themselves cannot afford it. That is the reason why we – the patients – founded a club, which is called: „Strong for cured muscles“. We want to help Prof. Spuler that all our dreams of curing this disease come true.

However, I don't want to spare you my bitter punchline in this story. This therapy will be too late for me. If muscles are too damaged or even dead – like a lot of mine are – the therapy will not work. If you are now asking yourself, why am I here making this speech? I will tell you this:

Compassion, Arthur Schopenhauer said, is the basis of all morality. That is the reason why I would like to do my small part for a better world without muscle dystrophy.