

Letter of intent by Lynna Held:

The motivation for founding the "Junge DE (Young German Epilepsy Association)" is closely linked to my life story.

I am 25 years old and studying educational sciences in Göttingen. I was diagnosed with epilepsy four years ago. Especially from the early days, when I had to come to terms with the new situation and the attached consequences, I encountered many lasting and shaping experiences. I quickly learned that it was of considerable importance to involve those around me, in relation to my illness, and to educate them on how to react if I had a seizure. Would they know how to react if I just fell over and started convulsing?

You might know how to react if someone had an acute epileptic seizure. In this case, if I were to have a seizure in your presence, you would be an enormously important person to me, as you could help appropriately.

However, through my personal experiences, I found that a large part of the population is unclear about what an adequate response is in relation to an epileptic seizure. For this reason, I educated my entire environment about how and what to look out for in epileptic seizures. Since then, I feel much safer.

In the course of these discussions, I became aware of how many prejudices and also reservations still exist towards people affected by epilepsy.

In addition, at the beginning of the illness I was looking for an exchange of ideas and stories with other people affected, but it was not possible for me to find platforms, self-help groups or other exchange possibilities for young people. There were contact points, but they were focused around advanced age groups. For me, however, there were other challenges. Especially at a young age, a chronic disease is a big challenge and can present other obstacles than at an older age.

This incident led to the founding of "Junge DE" at the beginning of 2019, a self-help group for young people. And later on, with the combined strength of the young self-help group, to a film campaign which aims at raising awareness about epilepsy.

The self-help group is aimed at people with epilepsy between the ages of 16 and 35 who would like to talk about their condition with others of the same age, or who would also like to change something in the way society perceives them. We, the young people, come from all over Germany, meet regularly, at the moment on Zoom, and twice a year in person. Due to Corona and the challenges that came with it, we moved our current project to Zoom. With the project called "Film ab" we create short explanatory videos on the topic of epilepsy in everyday life. These videos cover various topics in which we educate and inform about the topic of epilepsy. The videos are aimed at people with epilepsy, interested people and also family members of people with epilepsy. With the videos, we hope to reduce prejudices, educate and especially inform about seizures and first aid in the event of a seizure, and thus guarantee better first aid for those affected in an emergency and take away the public's fear of contact. Furthermore, barriers towards epileptics are to be broken down and public awareness is to be promoted.

The aim of the self-help group is not only to provide information about epilepsy, but also to establish contact between people affected. Through contact with each other and the resulting exchange, self-confidence is strengthened, and people benefit from the experiences of others.

Further projects are planned for the future with the aim of further informing and raising awareness about the topic. Only through continuous exchange between affected persons and with the public can we reduce the stigmatization of the topic and counteract the illness by educating people about what to do in an emergency and by promoting acceptance in society, thus making a small contribution to the quality of life of all people affected.