Newsletter 2/2018

Preface

Barely six months after the start of the project, over twenty DM-stories are already available on our website and on our YouTube channel. These are receiving a lot of attention in social media on all five continents and in over thirty countries. A huge success in such a short time!

My gratitude goes primarily to the contributors on three continents who have been working tirelessly to make this project possible. We all live with Myotonic Dystrophy – either as patients or family members- and show through this project that we are capable of enormous achievements despite this condition.

In November I attended the annual meeting of the diagnostic group in Germany with Andreas for the first time. Please read his report in this newsletter. In addition to the competent and motivating lectures, we both took the opportunity to talk to those affected and their relatives, making new contacts and recording video interviews. These videos were created spontaneously without special preparation and thus show an unvarnished picture of our lives with Myotonic Dystrophy.

The testimonials that have reached us are well thought through and have been well prepared. It is already becoming visible how differently affected persons and families handle the challenges of this disease: Read Ann's story in this newsletter. Odile, from France, meets completely different challenges: You can find her story on our website.

Both formats - the written testimonials and the spontaneous video interviews - are important for our project. Over time, these different voices will combine into one image: The picture of our life with Myotonic Dystrophy. I am looking forward to what will come of it.

Erich
project leader

Myotone Dystrophie
Myotonic Dystrophy
Dystrophie Myotonique

Our Voices – Our Life

Annual Conference in Germany

After a long journey, Bernhard, Erich and I arrived at the Hotelpark Hohenroda in Hessen on November 09, 2018. The well maintained hotel complex from the eighties with its attentive staff, offers a worthy setting for the annual conference of the diagnosis group Myotone Dystrophy of the Deutsche Gesellschaft für Muskelkranke e.V.

As a not personally affected person, this was the first time that I participated in such a large event for this diagnosis group and I was very curious about the program content and the encounters with interested people from all over Germany.

Immediately after arrival, I participated in a group discussion for relatives: The excellent moderation of the presentation, without the presence of those affected, allowed a very open exchange of opinions and experiences in a trusting atmosphere. In my opinion, this group formation is ideal, so that topics can be addressed which are often concealed out of shame or out of consideration for the affected persons.

The next day a very tight schedule awaited us with highly motivating and competent lectures, i.e. from the fields of psychology and respiratory medicine. After that we learned more about the results of a study on the early symptoms in DM2 patients. I benefited directly from the lecture on the topic of coping with an illness and dealing with progression anxiety from Dr. med. Nadine Sasse, who showed, from a psychological point of view, that even difficult situations contain a positive potential. Her advice and suggestions helped me to develop new strategies and define solutions.

On Sunday morning we heard some surprising news from Mr. Alexander Dassel of the N.A.P. Akademie-Berlin: According to current studies, muscle building is effectively possible in DM patients and also makes sense for the vast majority of those affected. This underlines the importance of regular training, taking into account the cardiovascular load. Additionally this promotes an oxygen and CO2 exchange

Between the program points, we also used the time for personal encounters and exchanges with others. We were able to record 10 video interviews for our project this weekend (which are now available on our YouTube channel) and I finally got to meet Steffi in person, who has been part of the project's team for months.

Andreas, Basel-Landschaft, Switzerland

The Story of Ann, Utah, USA

My name is Ann and in 1998, over the space of five or six months, I found out that all 4 of my children and my husband had DM1. The oldest was 20 and the youngest was 7. The 2 oldest were diagnosed with adult onset and the 2 youngest, childhood onset. After I found out I thought, “What do I do now? All my children have this, and I don’t even know what this is!” Through years of doctor’s appointments, we slowly discovered more and more about this disease, some of it not far behind the doctors themselves or the specialists at MDA, who didn’t know that much about this particular form of muscular dystrophy. In fact, genetic tests on this disease were not able to be performed until 1991, so we were part of discovering a new frontier.

Eventually, I started to look back and see little things that just weren’t normal in all of my children. For instance, there’s a condition called tent mouth, and it happens when someone with DM’s upper lip sits up higher than the rest of their mouth, making their teeth visible. It’s a classic symptom of those suffering with DM, and after the youngest was diagnosed, I started looking back at pictures of him taken before the diagnosis, and I could see the tent mouth. It had been there all along; I just didn’t know what to look for.

The most common effects of DM are muscle problems, including muscle weakness (myopathy), trouble relaxing a muscle (myotonia), and muscle wasting that gets worse over time (atrophy). It also affects many other body functions, including the heart, the muscles that control breathing, and the gastrointestinal (GI) system. The disorder can also cause problems with cognitive function, personality, and vision. Not everyone with DM will have all or even most of the possible symptoms.

So what drives me in my life? It’s not who I am, it’s who I’ve become and who I’m becoming by being the main caregiver for my husband and children. And the process isn’t finished. So many of the other parents and people I know who have to deal with this disease—who have loved ones with this disease—suffer too much. It’s a suffering way of life. We deal with a ton of trouble. This is truly a life full of heavy responsibility, but I feel that I have found both purpose and joy in my life.

Ann has kindly provided "Our Voices - Our Life" with an electronic copy of her book "Living with Myotonic Dystrophy: My Family's Story." With her consent, we have added it to our project:
https://drive.google.com/file/d/1IzMJRZP45faeVeO1jAgfLDD85Rmr_-7-/view?usp=sharing

Read more stories and submit your own at www.dm-voices.com => How to participate => The Stories

Next Steps

2019
Tour de France: Meeting Facebook-group members in France and Belgium

June 2019
IDMC12 in Goteborg/Sweden

September 13th-14th 2019
MDF-Conference in Philadelphia/USA

November 2019
DGM-Annual Conference in Hohenroda / DE

Next Newsletter
Late April 2019

Next Story

Each of our quarterly newsletters will present a selected story of a DM-affected person or of a family member.

The story in our next newsletter could be yours! Write your own and submit it on our website www.dm-voices.com

More information

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