Newsletter 3, April 2019

Preface

For several years now, I have actively participated in the discussions of the largest Facebook group in France for people living with Myotonic Dystrophy. The group, “Pour lutter contre la maladie de Steinert”, founded as a private initiative, now has 402 members.

Last year, I posted a map to the group, asking members to flag their home area so that other members pf the Facebook group could see the regions represented in the group. With this map, I wanted to encourage that DM-affected individuals and their family members to connect more easily with others in their area.

During my trip to France last March, I saw that this idea is actually working: I contacted group members along my itinerary, and asked them if they were ready for a meeting and an interview for the project “Our Voices – our Life»”.

On this journey, I met 15 unique and wonderful people who live with Myotonic Dystrophy. I've experienced strong moments, seen tears and heard laughter. This connection, which connects the lives of people with the same rare disease, knows neither national nor language boundaries. It is universal and it is wonderful.

In this newsletter, we introduce you to some of these people, with excerpts from their interviews. We also announce the debut of video interviews on our YouTube channel which will be available to all known Facebook groups.

I wish you lots of love and new insights to our Life with Myotonic Dystrophy and to the wonderful DM-community in France.

Erich
project leader

Myotone Dystrophie
Myotonic Dystrophy
Dystrophie Myotonique

Our Voices – Our Life

Florence, Haute-Saône, France

No progession of symptoms

Between my birth and today, the disease’s symptoms have not further developed. They have been stable, they are there, and they have always been the same. I hope this is going to last. When I was born, I had a lot of trouble walking, I felt down a countless number of times, etc. I used to swim a lot and nobody could ever understand, that when I was pushed into the water, I was ready to drown. I could not swim right away. Nobody was able to understand. They said, “You are a good swimmer, but If we throw you in the water, we are obliged to save you 10 seconds later because you are drowning.”

Medicines

I had taken a treatment for a while, then I stopped. Sure, it gave me wings. But since I wasn't used to living like this, it bothered me. I took it the time when the doctor needed me to be part of the study to write his thesis, and after he had completed the study, I stopped. I stopped, because somewhere it was not me. It was no longer me with my body when I took the medicine. It was me in someone else's body. I did not feel like myself.

My wish

What I wish for myself is to continue living with this disease... sometimes I have said, it is a disease, we’re getting along well with each other. We're cohabiting. For 57 years we've both been here, sometimes fighting each other. It may be my positive and optimistic side. This attitude may not be given to everyone. It is who and how I am. I do not blame anyone, because it is nobody's fault. I’m trying to live at the best that I can. . No, I don’t laugh when I fall down. I get up and move on. That’s it. But, I know, climbing the stairs is horrible.

Accepting help

You don't find many people who will support others. It's a social skill that is getting lost more and more. I do not want to be supported or assisted either. I'm like that, I was born like this... that’s it. There are moments that are not funny, moments when you fall down or you cannot control your body. It doesn't make you laugh. But you're telling yourself that the person in front of you cannot understand. Because people can't understand this disease. I don't even ask them to understand it.

Christine and Jean-Claude, Rhône-Alpes, France

The basic philosophy of volunteering at AFM-Téléthon

Only If the work on myotonic dystrophy research is influenced by people who know the problem and who are experiencing the problem, can the research move in the right direction. We know what we're talking about. It's like running a business. If someone already knows the work at the bottom of the ladder, they will know what to do at its top. We are parents and patients affected, so we know what we're talking about and we know what we need. We know which way to go and which road to take. We know which doctor to go to, and we're shaking up the scientists. I recently met with Cécile Martinat who is the Director of the I-Stem and who works on Steinert disease. She told me that she found it extraordinary to talk with the families. That is, they are not mere researchers, all the time in their laboratory in front of their small specimens. They see dads, moms, kids, who can tell them what's important to them. They know for whom they work and suddenly they realize, for example, that the cognitive impact of the disease is really important. Before, they focused on physical problems only. So by listening they opened up some other fields of research. That's why we, the affected families, can make things happen. We are the first concerned: the parents, the affected. It is up to us to lead the ship. It's clear.

Olivier, Provence-Alpes, France

Raising funds for AFM-Téléthon

We create Telethon events everywhere in France. There are several thousand events. Each one organizes an event as it seems to fit. I sell homemade cakes and Telethon items with candy bags. Food that we recover and that we transform. We sell these items and collect the money for Telethon. People are donating money easily when they see that it is for the Telethon. The Telethon is non-stop on TV for 24 hours during this yearly event. It's very publicized. When people see that it is for the AFM (Telethon), they give 5 or 10 euros for a slice of cake instead of 2 euros. They don't count. So, we are easily able to collect money that we will pay directly to the Telethon for medical research. I'm doing this with friends, a group of 5 or 6 people. My daughter helps with the fundraising. It works well with children. My daughter is 12 years old. Girls dress up and wear big signs. They talk to people on the street and tell them "give a little bit of money for the Telethon. Then people give easily.

AFM-Téléthon is the largest organization in France dedicated to people with neuromuscular disease. It consists of those affected and their families. With thousands of volunteers, so-called Bénévoles, she has raised some 86 million euros in donations over the last year, which she invests in research, in counseling and accompanying the affected.

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 September 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, following our suggestions and submit it on our website www.dm-voices.com

More Information

English:
www.dm-voices.com
info@dm-voices.com

Deutsch:
www.dm-meinegeschichte.com
info@dm-meinegeschichte.com

Français:
www.dm-temoignages.com
info@dm-temoignages.com