

Less than a year ago, a group of us had a meeting. Guida Clozza – Vice Chair, Ankie Werdekker – Secretary, Dawn Bellefeuille – Financial Director, Mandy Scott-McKnight – Financial Director, Natasha Gainford – former Financial Director, Suzanne Nurse – Director Partnerships, Carl Weatherell – Director Governance, Christine Chatelaine – Director Marketing and French Translation.

At that meeting, we decided to get Dravet.ca up and running and able to host a conference at one end of the International Epilepsy congress being held next week here in Montreal. We knew a similar opportunity would likely not come along for at least another twenty years. So with that as our goal, Dravet.ca was born.

We had our inaugural meeting June 7th and mapped out what we needed in place for a conference. First, we needed funds. For that we would need to be able to give out donation receipts. So we applied for status as a charitable organization. For this, we developed our Constitution and investigated which types of governance to pursue. We compiled what was eventually a seventy two page document to support our application to the Canadian Revenue Agency. We have a great group. What normally takes two years took us less than eight months. We officially gained our status February 26th, 2013.

Over this year, we have also had to deal with drug shortages, frisium, clobazam... and most importantly, Stiripentol. There were changes in language among the physicians prescribing for

our group that resulted in Special Access Program applications being denied. The ILAE classification system changed severe myoclonic epilepsy of/in infancy (smei) to Dravet syndrome. The doctors made the switch, but Health Canada had no record of Dravet syndrome and its relationship to Stiripentol. Guida worked closely with Suzanne and Durhane Wong-Reiger of CORD (Canadian Organization for Rare Disorders) to discover that it was simply a case of semantics. We then immediately needed to improve our external communication to spread this information. We soon discovered additional information and then had to let everyone know to also make sure to include what treatments had already been tried and failed and a brief clinical history of the patient.

We are still trying to keep up with the changes in Stiripentol access. We are keeping the Stiripentol/diacomit accessibility information updated on both our website and our FaceBook Group at Dravet.ca. We also post to Dravet Canada and other FaceBook pages when we have important information to share.

We had a booth at the SickKids Centre for Brain & Behaviour 3rd annual Epilepsy Family Education Day and are hosting a booth at next week's IEC (International Epilepsy Congress).

We've made some excellent connections. We are a member of CORD, have working partnerships with Dravet.org and the Canadian Epilepsy Association, and have a research partnership with CIHR. Dravet.ca is pleased to announce that we are awarding one prize in the amount of \$5000 through the CIHR

Fall Fellowship Competition in Institute of Neurosciences, Mental Health and Addiction. The opportunity will be available on the CIHR website in the coming weeks.

We have held various fundraisers and pursued grants from outside agencies. Mandy is a maniac, Dawn is no slouch, the rest of us are amazed by them, and Biocodex donated \$10,000 towards our conference.

We are developing two series of posters. One set for our use at events for ourselves and another set for use at other event to publicize our cause.

And in a couple of weeks, we will unveil our new website.

And here we are, less than a year later, with Dr. Dravet and Dr. Scheffer coming from France and Australia to speak with our group, and Canadian specialists such as Drs. Donner and Andrade happy to join us and share their knowledge.

We have Maria Zak who has already helped us so much with her advice, that she's the first person we've invited to sit on our Medical Advisory Board. And we even have Farley Flex here.

We think it has been a very good first year.

Thank you
Patti Bryant
Chair, Dravet.ca