

Secretary's report for Dravet.ca family and research conference, June 21-22, 2013

As secretary of the dravet.ca board, I have prepared a brief report of our activities this past year. We have met a total of 13 times, through SKYPE and Join.me networks. A quorum of 5 has always been present for these meetings, and in the decision making process. Our chairman of the board, Patti Bryant, has opened the meetings and all previous minutes are approved. We have focused our meetings on conference planning, fund raising, and medication issues which affect most of our families. We also report progress on our web site and continue to strive to remain current and accessible to families who seek our assistance.

The current challenges we face as board members for dravet.ca are many. Our primary concern and mandate is raising awareness of this devastating, chronic and life altering syndrome at the local level. This must be brought to the local level so every child in Canada has access to proper testing and appropriate treatment in a reasonable length of time. At present, children must travel to regional health care centres for diagnosis, and many children have travelled to the US for treatment plans. The awareness of this syndrome must be at the local level, where it is recognized and referred by the local pediatrician to the neurologist who can order the proper tests and initiate treatment. This will provide safe, effective treatment promptly, and save multiple hospitalizations and stress for the families involved. Standard care plans should be in place for the treatment of epilepsy and with this in mind, we would like to expand our horizons in our second year, by working with established organizations who strive after the same goals.

Another great concern to the families is the inconsistent supply of anti seizure medications across Canada. We have dealt with clobazam, frisium, phenytoin, valproic acid, gabapentin shortages, as well as the continued struggle to provide a regular affordable supply of stiripentol. We are working with Health Canada and legislators to raise awareness that an inconsistent supply is a life threatening crisis, and must be avoided. These medications are as essential as cardiac or diabetic medications and cannot be skipped or replaced with another medication when one is in short supply.

There are many research institutions in Canada, and we would like to work with them in the coming year. New treatments and alternative medicines are available for epilepsy and we would like to support such research. An example of this is the use of CBD in the treatment of epilepsy. We will hear more of this at the conference, however we need to open up the conversation with the medical community and we need to strive together with them in this new and exciting field. The laws are currently under review but we cannot afford to wait for Health Canada to change the laws, so we must work within the boundaries they have established and promote the use of CBD and MM in epilepsy.

In the field of education, awareness must also be increased. These children and adults are medically fragile, meaning they require constant supervision and attention to let them learn and grow to their fullest potential. We must work with local school boards and support parents in

their quest to obtain 1:1 EA coverage, not shared care, and to have medical staff available at the schools . They deserve the same education and opportunity as any other Canadian child or adult and all effort must be spent to allow this to happen./

Finally, another future project is the organization of a dravet .ca camp in 2014. We will strive to provide an opportunity for all to camp, and run and play while providing them with everything they require to be safe. We have found two locations in the Hamilton/Brantford area and would like to plan for the fall of 2014. With volunteer medical staff available, and the cooperation fo local EMS and ER departments at MUMC and BGH, we will make safety our priority. Meals will be provided and families can bring their own foods in for the keto kids. Bunk houses are available for the families, and volunteers are available for crafts, hikes, horseback riding, and “living on the farm”. We will actively pursue fundraising to offset some or all of the cost. This will allow time for families to meet and share , as well as siblings to be involved in a good environment with other siblings .

Thank you for your attention and for your time here, together we can make a difference in the lives of Dravet patients across Canada.