



REPORTS AND UPDATES

Research Grant Award updates – open call for proposals, letters of intent

We are currently doing research calls as constant intake, so researchers can submit their applications any time. We will review the applications about four times a year, and considering how much funding we have available at the time, make awards.

So far, we have awarded \$247,500 to projects targeting treatment, care, cure, or understanding of Dravet spectrum disorders.

We are also partnering with the Rare Diseases Models and Mechanisms Network (RDMM). We each contribute \$12,500. They conduct the competition and select the best project(s) to pursue. We can decline to fund the chosen project, but so far, there have been three projects that have been helpful in advancing Dravet research.

Treasurer's Report

Highlights of Susan's report – we started the year with \$134,678.88, on March 31st we had \$80,006.47.

We held a number of events, costing \$10,171.70.

We awarded \$125,000 to research projects.

We have hired a bookkeeper. In this fiscal year, her work has cost \$1401.20 and saved us many hours.

Diagnosing Rare Epilepsies project

Knowing that diagnosis is a major roadblock in Dravet outcomes, in 2014, Dravet Canada decided to partner with a clinician to develop a series of Grand Rounds in Diagnosing Rare Epilepsies.

At this point, after three years, we have eighteen clinicians, researchers, patient advocates, technical support, and even representatives from the pharmaceutical industry on board. We are working on recruiting policy-makers and payers. We have Dravet Canada, Idic-15 Canada, the Lennox Gastaut Foundation, Canadian Epilepsy Alliance members, and undiagnosed patient representatives. British Columbia, Alberta, Ontario, Quebec, Nova Scotia, Newfoundland and Labrador, New Zealand, United States, United Kingdom are all represented in our core group.



Our main idea is still to have regular grand rounds presentations across Canada. We will have a lay presentation, then a lunch break, then the clinical presentation. This way, even if the patients and clinicians don't attend both sessions, they can still network over the sandwiches.

While we are seeking regular funding for this part of the project, we have started a series of webinars. Diagnosing Rare Epilepsies – the clinician perspective was held March 30th. Diagnosing Rare Epilepsies – the SUDEP perspective was held June 22nd, this past Thursday. The patient perspective will be presented in September.

We are also working towards developing a diagnostic app. We are working with Seizure Tracker to develop an interface between them. We will also be bringing in the ILAE (International League Against Epilepsy) once we have the basics built.

Patient Registry – proposal

We stay current with research and developments in health research, and particularly epilepsy and Dravet research. One thing that researchers and those who fund research are asking for is patient registries. We have been researching the best way to get our information into registries and seeing if it's important to have specifically Canadian information.

We have gathered a group of researchers, clinicians, and health economists to help develop our ontogenies (the field names and questions needed to make our registry as useful as possible).

We have found that researchers and payers want Canadian information. They want the information stored on Canadian servers, governed by Canadian copyright and intellectual property laws.

We have found a computer group willing to build this for us for \$10,000. They are including rebuilding our website in that price. We are investigating the possibility of a partnership with a pharmaceutical company for the funding.

Details and decisions will need to be finalized by the Board we elect today.