

The CNDR Newsletter

2011 Issue March-June

The latest updates from the Canadian Neuromuscular Disease Registry (CNDR).

The CNDR is now Coast to Coast!

On June 9, 2011 the Canadian Neuromuscular Disease Registry (CNDR) officially announced its operations across Canada. Children and adults with a neuromuscular disease are now able to join the registry in Vancouver, Calgary, Ottawa, London, and Halifax. Erin Oak Kids in Mississauga Ontario and clinics in Kingston Ontario and Montreal Quebec have also received ethics approval and we expect them to be able to start signing patients up soon. Ethics submissions are under review in Edmonton, and in Toronto.

Data Release Procedures Approved

The CNDR is now able to receive requests for data from interested researchers, institutions, and organizations. Details on what types of data can be released and how to request data can be found on the CNDR's [website](#). You can also contact the CNDR Project Manager by email at admin@cnдр.org for more information.

ALS Medical Dataset

At the end of April 2011 just prior to the ALS Canada Research Forum, the CNDR gathered 12 medical and scientific experts in Amyotrophic Lateral Sclerosis (ALS) to derive a dataset to capture medical information on patients with ALS. The meeting was supported by ALS Canada and the CNDR will be undertaking design and construction of the software module for data collection over the coming months. Stay tuned for more news on the CNDR and ALS in our next newsletter.

News from Around the World

On March 1st 2011, the global FKRP (fukutin related protein) registry was launched. Based at the University of Munich, this registry is aimed at all patients with a diagnosis of limb girdle muscular dystrophy 2I (LGMD2I) and congenital muscular dystrophy 1C (MDC1C). Patients can self-register by visiting the website <https://www.fkrp-registry.org/registry/registration/index.en.html>. The registration process involves both the patient and the healthcare team involved in their treatment to ensure that accurate information is collected. The FKRP registry is an initiative of TREAT-NMD.

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