

# The CNDR Newsletter

2011 Issue July - September

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

## 393 Patients and Counting

As of October 3, 2011 the Canadian Neuromuscular Disease Registry (CNDR) has enrolled 393 patients from across Canada. 10 clinics are now officially up and running with 3 more expected to join in the next few weeks. Ethics submissions are under review in Edmonton, and in Toronto.

## Accolades for our Team

On Saturday September 24, 2011 at the Muscular Dystrophy Canada Dr. David Green Awards Banquet, Dr. Lawrence Korngut, National Principal Investigator for the CNDR and a Clinical Assistant Professor at the University of Calgary was the recipient of the inaugural Dr. George Karpati award for Researcher of the Year. Dr. George Karpati devoted his life to research into neuromuscular disease with a passion for patients and the development of a cure. Dr. Korngut accepted the award on behalf of the CNDR team for his work leading the implementation of the CNDR which is bringing patients and researchers together working towards a common goal and provides an important framework to support collaborative neuromuscular research in the years to come. Muscular Dystrophy Canada has also awarded Dr. Craig Campbell, CNDR Pediatric Disease Expert, London Pediatric CNDR Principal Investigator and an Associate Professor at the University of Western Ontario with the Dr. George Karpati award for Ontario in recognition of his contributions to the establishment of the CNDR and other research in neuromuscular disease in Ontario.


## You can help the CNDR go online!

The CNDR is applying to the Aviva Community Fund to create the CNDR Patient Engagement Portal (CNDR-PEP). We want to create a Patient Engagement Portal to further fulfill our goal of increasing communication between patients and researchers. The portal would allow patients, their caregivers and their families the following options:

1. The ability to join the registry online, increasing access to the registry and its services.
2. Secure access to relevant medical information and their medical clinic team.
3. Secure access for patients to transmit clinical information required at their clinic visits to save time completing forms and paperwork at the clinic.
4. Secure access to information about research opportunities they may be eligible for.
5. Secure access to the most current and relevant information about their disease, treatment options, and other research findings that may be of interest.

This effort is important because it will increase access for patients across Canada who want to join the CNDR and it will reduce costs

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associated with operating the registry.

**Please visit [www.avivacommunityfund.org](http://www.avivacommunityfund.org) and Vote EVERY DAY for the CNDR-PEP idea! Tell your friends to vote, tell your family to vote, get your co-workers to vote, and help us to get the funding to engage our patients.**

**Round 1 Voting starts October 3 and ends October 19, 2011.**

## **The CNDR Around the World**

In October, the CNDR will be presenting a poster at the Canadian Association of Pediatric Health Centres (CAPHC) annual meeting in Ottawa. In November, the CNDR will be presenting a poster at the TREAT-NMD conference in Geneva Switzerland. The CNDR will also be presenting a poster on the creation of our ALS dataset at the International Symposium on ALS/MND in Sydney Australia in early December. We are very excited to share our successes achieved over the past year.



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