June 9, 2011

Patients with neuromuscular disease will benefit from new national registry

A new national registry for patients with neuromuscular disease was launched in several Canadian cities today. The registry will help patients connect with researchers to participate in clinical research that will benefit patients by offering possible new therapies, treatments and understanding of their disease.

“This is a tremendous opportunity for patients, healthcare professionals, and researchers, to connect and improve research into neuromuscular diseases across Canada” says Dr. Lawrence Korngut the national principal investigator from the University of Calgary’s Faculty of Medicine, and a member of the Hotchkiss Brain Institute.

The Canadian Neuromuscular Disease Registry (CNDR) includes 17 clinics across Canada located in Vancouver, Calgary, Edmonton, Ottawa, Toronto, London, Kingston, Montreal and Halifax.

The CNDR is a Canada-wide database of patients who have been diagnosed with a neuromuscular disease. The term “neuromuscular disease” refers to a group of more than 40 diseases that affect how muscles and nerves work. ALS (amyotrophic lateral sclerosis) is the most prominent of these diseases in adults, and DMD (Duchenne muscular dystrophy) is the most common pediatric muscular dystrophy.

Shelagh Mikulak has ALS and joined the registry because it gives her hope that “with the information available to researchers there will be a significant increase in the number of studies leading to discovering the cause, treatment and cure of ALS”.

Finding treatments for these diseases has been challenging, as patients are scattered across the country. This registry will allow doctors and researchers to look at medical data from large groups of patients helping them to find better ways to manage each disease.

"We are very supportive of the registry. It is one more piece in the puzzle that will help us find a cure for this devastating disease," says ALS Canada CEO David Cameron.

All patients both adults and children across Canada who have been diagnosed with a neuromuscular disease are able to join the registry. Patients living outside the cities with affiliated clinics, or those not currently seeing a neuromuscular specialist, can register by contacting the CNDR National Office at the University of Calgary at 1-877-401-4494. More information is available on the CNDR’s website www.cndr.org.

The CNDR is supported by the ALS Society of Canada, Jesse’s Journey and the Marigold Foundation.
Calgary interviews:
Who: Calgary (lead site) – Dr. Lawrence Korngut & ALS patient

When: Thursday June 9 2011 10 am-noon MDT please call to book an interview
Where: Health Sciences Centre, 3330 Hospital Dr. NW Calgary AB

Other Canadian sites available for interviews:
Halifax – Dr. Tim Benstead and ALS patient, 930am-1130am ADT
media contact: John Gillis 902-458-5376 (pager)

Montreal – Dr. Angela Genge & ALS patient
media contact: Anita Kar 514-398-3376

Toronto (Mississauga): Dr. Gillian Hogan & DMD patient 10:00am – 12:00pm EDT
Media contact: David Silburt 905-491-4449

London – Dr. Craig Campbell
Media contact: Rachelle Wood
rachelle.wood@lhsc.on.ca 519-685-8500 ext 77642

ALS FACTS
- Amyotrophic lateral sclerosis (also known as Lou Gehrig's disease) is a fatal neurodegenerative disease.
- People living with the disease become progressively paralyzed due to degeneration of the upper and lower motor neurons in the brain and spinal cord.
- 80% of people with ALS die within two to five years of diagnosis – unable to breathe or swallow. Ten per cent of those affected may live for 10 years or longer.
- Approximately 2500 – 3000 Canadians over the age of 18 currently live with ALS.
- Every day two or three Canadians die of ALS.

DMD Facts
- Duchenne muscular dystrophy (DMD) is a fatal genetic disorder that gradually weakens the body's muscles.
- There are different types of muscular dystrophy: Duchenne is both the most common and the most severe form of the disease, affecting 1 in every 3,500 boys.
- Most kids with DMD are using a wheelchair by the time they are 12.