



**CIMDRN**  
Canadian Inherited Metabolic Diseases Research Network

# Newsletter 2015

## To our participating families,

A wholehearted thank you goes out to all the families across Canada who have enrolled into our research network. We greatly appreciate your enthusiasm to be part of our research and for taking the time to participate in our studies! Together we hope to generate the evidence needed to improve care for children with inherited metabolic disorders.



**There are currently 312 participants enrolled in CIMDRN!**

## RECRUITING CENTRES



CIMDRN is currently recruiting participants at the following treatment centres:

- Children's Hospital of Eastern Ontario (Ottawa)
- Montreal Children's Hospital (Montreal)
- BC Children's Hospital (Vancouver)
- Hospital for Sick Children (Toronto)
- Children's Hospital – HSC Winnipeg (Winnipeg)
- Alberta Children's Hospital (Calgary)
- Stollery Children's Hospital (Edmonton)
- IWK Health Centre (Halifax)

## PUBLICATIONS

Recent published CIMDRN papers:

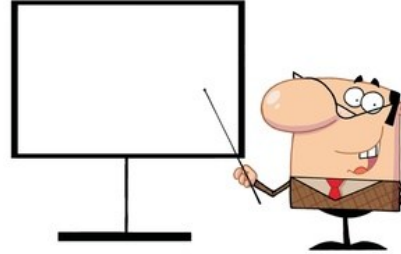
- “Metabolic clinic atlas: Organization of care for children with inherited metabolic disease in Canada” in *Journal of Inherited Metabolic Disease Reports* (2015)
- “Translating rare-disease therapies into improved care for patients and families: what are the right outcomes, designs, and engagement approaches in health-systems research?” in *Genetics In Medicine* (2015)
- “Scoping review of patient- and family-oriented outcomes and measures for chronic pediatric disease” in *BMC Pediatrics* (2015)
- “Achieving the “triple aim” for inborn errors of metabolism: a review of challenges to outcomes research and presentation of a new practice-based evidence framework “ *Genetics in Medicine* (2013)

# CONFERENCE PRESENTATIONS

CIMDRN is presenting its research at the following 2015 conferences:

- American College of Medical Genetics and Genomics Annual Clinical Genetics Meeting
- Canadian GE3LS and Health Services & Policy Research Conference
- Canadian Newborn & Child Screening Symposium
- Garrod Symposium
- The Canadian Society for Epidemiology and Biostatistics Conference

Please visit our website for more details!



## Clinical data collection

Our study is designed to create a long-term follow up research database of all children across Canada with inherited metabolic diseases.

At treatment centres currently enrolling participants, research staff are busy entering participants' medical information into a research database (housed at the Children's Hospital of Eastern Ontario in Ottawa).



## Interviews with guardians

CIMDRN is currently conducting telephone interviews with guardians of our participants. The purpose of these interviews is for guardians to share their personal experiences regarding their child's/children's inherited metabolic disease diagnosis and with the health care system. You may be contacted by the CIMDRN research team if you expressed interest in participating in an interview.



## Questionnaires for families

CIMDRN is developing a questionnaire to better understand how patients and their families are affected by a diagnosis of an inherited metabolic disease.

Families can expect a questionnaire by mail or e-mail in the coming year!



## STAY CONNECTED!

**Canadian Inherited Metabolic Diseases Research Network (CIMDRN)**  
University of Ottawa, Faculty of Medicine  
451 Smyth Road, Ottawa, ON  
K1H 8M5

**PRINCIPAL INVESTIGATORS:**

Dr. Beth Potter, [bpotter@uottawa.ca](mailto:bpotter@uottawa.ca)  
Dr. Pranesh Chakraborty, [pchakraborty@cheo.on.ca](mailto:pchakraborty@cheo.on.ca)  
**Research Manager:**  
Sara Khangura, [khangura@uottawa.ca](mailto:khangura@uottawa.ca)

For more information, visit our website: [www.cimdrn.ca](http://www.cimdrn.ca)

Administered by:



Follow us on Twitter @CIMDRN



**CIMDRN**  
RCRMMH

Funded by:

