

# Project MinE

## “Why have I been diagnosed with ALS when so many other people have not?”

This is an all-too-common question of people living with the devastation of an ALS diagnosis, and the ALS Society of Canada (ALS Canada) wants to help answer it. We are leading Canada’s fundraising efforts for Project MinE to support the mapping and analysis of up to 1,000 DNA profiles.

Project MinE is a multi-national initiative with more than 15 participating countries. It will map the full DNA profiles of 15,000 people with ALS and 7,500 control subjects, establishing a global resource of human data that will enable scientists worldwide to understand the genetic signature that leads someone to develop ALS.

By accumulating such a large amount of data that no one country could achieve alone, it is expected that Project MinE will identify new genetic causes of the disease that will significantly accelerate our ability to advance treatment possibilities that will slow down or stop ALS.

In this video, ALS Canada’s ambassador for Project MinE, Chris McCauley, shares his hope for the initiative:

## What can you do to support Project MinE in Canada?

- **Make a donation**
- **Tweet to share info**
- **Tag three friends on Facebook**
- **Reach out to colleagues on LinkedIn**

## ALS Canada ambassador

**Chris McCauley**

**Social worker, policy research analyst and ALS patient**



Months after celebrating his first wedding anniversary in 2014, Chris McCauley noticed some unusual twitching in his arms and legs while vacationing with his wife in Costa Rica. Shortly thereafter, he was diagnosed with ALS at the age of 52. “Instead of looking forward to establishing a home and thriving in career and community, we were doing our best not to deny the opposite reality,” he says.

Since then, Chris – a policy research analyst and social worker – has become keenly interested in ALS research. Given the multiple causes, numerous disease pathways, and the different ways and rates at which ALS progresses and the variations in survival, he has been struck by the immense challenges researchers face in developing a treatment or cure for the disease.

To Chris, Project MinE holds tremendous promise as it will make ALS easier to study and has great potential to lead to effective treatments. He is bringing his voice to Project MinE in Canada so he can help make things better for

people who will be diagnosed with ALS in the future. As he puts it, “I think of others who will come after me and like me, lose the blossom of their health so insidiously. I want to do something to make it better.”

Support Project MinE by **donating to Team McCauley**.

Read **Chris’s article** in the Barrie Examiner.

## **Who else is involved?**

### **Project MinE Canadian research team**

The Canadian component of Project MinE brings together four of Canada’s leading ALS geneticists in Vancouver, Toronto, Montreal and Quebec City for their first ever cross-country collaboration. Each has led or been part of international consortia that have resulted in some of the most important genetic discoveries in the field. They also represent a geographical balance that provides a collaborative set of Canadian samples representative of ALS cases across the country.

Dr. Nicolas Dupré, Neurologist; Assistant Professor, Faculty of Medicine, Université Laval; Clinician-Scientist, Axe Neurosciences, CHU de Québec -

U Laval     Dr. Ian Mackenzie, University of British Columbia; Staff Neuropathologist, Vancouver Coastal Health; Consultant

Neuropathologist, BC Cancer Agency     Dr. Ekaterina Rogaeva, Chair in Research on Dementia with Lewy Bodies at Tanz Centre for Research in Neurodegenerative Disease; Professor, Department of Neurology,

Faculty of Medicine, University of Toronto, Department of Medicine

Dr. Guy Rouleau, Director, Montreal Neurological Institute and Hospital and Department of Neurology and Neurosurgery, McGill University

## **ALS clinics**

Other collaborators in Canada's Project MinE effort are the ALS clinics who will collect and in some cases store the blood samples being used for the initiative. Potential ALS clinic partners that have been identified to date are the **GF Strong Rehabilitation Centre's ALS Centre** in Vancouver, the **Sunnybrook Health Sciences Centre ALS Clinic** in Toronto, the **ALS Program at the Montreal Neurological Institute and Hospital**, and the **ALS Clinic at the CHU de Québec**.

## **About the ALS Canada research program**

The **ALS Canada Research Program**, of which Project MinE is a part, aims to accelerate research impact by translating scientific discoveries into treatments for ALS and fostering Canada's strong and networked ALS research community to build capacity and collaboration. Support for the ALS Canada Research Program is made possible by the generosity of donors, ALS Societies across Canada, Brain Canada and the federal government's Canada Brain Research Fund.