

## **CADASIL in Canada**

### **Landscape Overview (Canada + Global)**

CADASIL is a rare genetic condition and a leading inherited cause of stroke in adults, but it remains underdiagnosed and low-awareness, particularly in Canada.

In Canada, research and awareness are:

- Fragmented across a few academic centres (e.g., University Health Network, McGill University)
- Not coordinated nationally (no registry, limited dedicated funding)
- Well understood by specialists, but often missed in primary care

Globally, CADASIL is better characterized through:

- International research collaborations (Europe and the U.S. lead)
- Advancements in genetics and neuroimaging
- Growing recognition of variable severity across families

Bottom line:

CADASIL is clinically important but systemically overlooked, creating a clear opportunity to improve awareness, diagnosis, and research in Canada.

### **Objective**

Increase awareness, research, and funding for CADASIL in Canada by leveraging existing infrastructure rather than building from scratch.

### **Strategic Approach**

- 1) Integrate into existing national organizations for faster reach, credibility, and access to funding pathways. Partner with:
  - a. Heart and Stroke Foundation of Canada
  - b. Canadian Organization for Rare Disorders
  - c. Rare Diseases Foundation
- 2) Anchor with clinical leadership by engaging with 1–2 neurologists or neurogeneticists to validate messaging, enable research opportunities and support future funding applications. Starting points:
  - a. University Health Network (Toronto)
  - b. McGill University (Montreal)
- 3) Lead with a human story, using real patient/family experiences to drive engagement; position CADASIL as: “A hidden genetic cause of stroke affecting younger adults that is often missed.”

- 4) Build awareness first by focusing initial efforts on:
  - a. Media outreach (e.g., national health stories)
  - b. Alignment with Stroke Month / Rare Disease Day
  - c. Simple educational materials for physicians and families
- 5) Long term opportunity to progress toward research infrastructure:
  - a. Establish a Canadian CADASIL registry
    - i. Enables research funding
    - ii. Supports clinical trials
    - iii. Improves understanding of prevalence and outcomes

### **Immediate Next Steps**

1. Connect with a neurologist → Request a short call to explore collaboration
2. Share 1-page overview → CADASIL explained + why awareness matters + what you're trying to achieve
3. Engage one national organization → Explore integration into awareness/research initiatives
4. Set up a simple online presence → Basic landing page
5. Explore a media story → Focus on human impact + missed diagnosis

### **Bottom Line**

Leverage existing stroke and rare disease ecosystems, anchor with clinical expertise, and use real stories to drive awareness to unlock research and funding over time.