

FOR IMMEDIATE RELEASE

After Nearly 50 Years Living with Dystonia, Toronto Woman Shares Message of Hope at DMRF Canada's 50th Anniversary Health Fair

Toronto, Ontario (September 2nd, 2026) – Nearly 50 years ago, Denise Rogow was a young radio newscaster when her head suddenly locked to one side while standing on a street corner during her lunch break. What followed was years of pain, misdiagnoses, psychiatric referrals, and being told her symptoms were psychological before she finally received the correct diagnosis of cervical dystonia.

Dystonia affects an estimated **50,000 Canadians**, yet awareness remains low and delays in diagnosis are common. According to DMRF Canada's 2025 community survey:

- 59% of respondents waited more than one year for a diagnosis.
- 31% waited five years or more.
- Nearly 1 in 5 waited a decade or longer.

After years of unsuccessful treatments, Denise was referred to **Dr. Anthony E. Lang** and the Movement Disorders Clinic at Toronto Western Hospital. In 2010, she underwent Deep Brain Stimulation (DBS), a procedure that transformed her life.

"I spent years wondering if anyone would ever believe me," says Rogow. "Today, I live hands-free thanks to DBS and the incredible team at Toronto Western Hospital. I want others living with dystonia to know there is light at the end of the tunnel."

Now 73, Denise volunteers alongside her husband, Stephen, as a co-leader of the Greater Toronto Area Dystonia Support Group, helping others navigate the same journey she once faced alone.

Her story of hope and perseverance reflects the theme of the **Dystonia GTHA Patient Support Health Fair: 50 Years of Community**, taking place on **Sunday, October 25, 2026**, at the BMO Education & Conference Centre in Toronto.

Hosted by the Greater Toronto Area Dystonia Support Group and DMRF Canada, the free event will bring together people living with dystonia, caregivers, healthcare professionals, and researchers for a day of education, connection, and support. Attendees will hear from leading movement disorder specialists from University Health Network (UHN), participate in interactive Q&A sessions, and explore the Health Fair and Exhibitor Showcase featuring organizations and services available to the dystonia community.

As part of DMRF Canada's 50th anniversary, the organization will also recognize **Dr. Anthony E. Lang** for his lifetime of extraordinary leadership and contributions to dystonia research and patient care.

"For 50 years, DMRF Canada has been dedicated to ensuring Canadians affected by dystonia have access to trusted information, and a supportive community," said **Archana Castelino, National Director of DMRF Canada**. "This Health Fair honours how far we've come as a community while giving hope to those who are just beginning their journey."

DMRF Canada is the only national charity dedicated exclusively to supporting Canadians living with dystonia through research funding, education, advocacy, and patient support.

To learn more or register for the Dystonia GTHA Patient Support Health Fair, visit www.dystoniacanada.org/2026GTHASymposium.

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