

Sean M. Healey & AMG Center for ALS launches new clinic to support individuals and families living with genetic risk



As genetic testing becomes more widely used, more people are learning they may carry a genetic change linked to amyotrophic lateral sclerosis (ALS) or other motor neuron diseases (MND). For many, this brings uncertainty, stress and a lot of questions – especially if they don't have symptoms.

Until now, there have been very few clinics designed to support people in this stage.

To meet the needs of people in this situation, the Healey & AMG Center launched the **Clinic for Motor Neuron Health** in partnership with End the Legacy, an advocacy organization supporting families affected by familial ALS. This clinic brings together neurology, genetics, and mental health care in one place to help individuals and their families better understand their risk and plan for the future.

Why this clinic matters now

New treatments are emerging for certain genetic forms of ALS, including tofersen and the experimental therapy ulefnersen. As a result, more individuals and families are choosing genetic testing and learning they may be at risk. This is especially important, as evidence suggests that earlier treatment after symptom onset improves outcomes and treatment prior to symptom onset is explored.

Research that helps answer questions about ALS and track changes in ALS over time is also expanding. Studies like PREVENT ALL ALS, which follows people who may be at genetic risk of developing ALS, are preparing us to transform our approach to ALS prevention.

With more information—and more decisions—comes a greater need for clinical guidance and support.



What the Clinic for Motor Neuron Health offers

The clinic provides care for individuals and families navigating genetic risk for ALS or MND, including:

- **Genetic counseling and neurologic care**

Understand testing, review results, and receive ongoing monitoring, including various biomarkers.

- **Mental health support**

Work with a mental health nurse practitioner to manage anxiety, uncertainty, and life decisions that come with genetic risk

- **Research opportunities and community resources**

Learn about and enroll in studies, including asymptomatic trials, and connect with support networks.

Building a model for the future

The Clinic for Motor Neuron Health is one of the first programs of its kind in New England, and among the first in the world.

Alongside patient care, the clinic will develop training resources to help other centers build similar models—expanding access and improving care for people at risk of ALS.

Clinic information

The Clinic for Motor Neuron Health is led by Jennifer Morganroth, MD, MBA and is open monthly in the ALS Multidisciplinary Clinic at the Wang Ambulatory Care Center, 15 Parkman Street, 8th Floor, Room 835, Boston, MA 02114. To learn more about the clinic or schedule a visit, please contact 617-724-3914.

