# David J. Tomassoni ALS Research Program

Report to the Minnesota State Legislature for Calendar Year 2025

January 15, 2026

UNIVERSITY OF MINNESOTA

# University Of Minnesota David J. Tomassoni ALS Research Program

## Report to the Minnesota Legislature

As required by 2025 Special Session, Chapter 5, Article 1, Section 4, subd. 3 (g)

## Submitted by:

Board of Regents

## Prepared by:

The report was prepared by staff in the University of Minnesota Medical School

## Report Preparation Costs:

Per the requirements set forth in Minnesota Statue 3.197, the cost to prepare this report was $500.00

## *OVERVIEW and BACKGROUND*

The Minnesota Legislature's investment in the David J. Tomassoni ALS Research Program is grounded in the personal advocacy and lived experience of the program's namesake, State Senator David Tomassoni. In 2022, the Legislature enacted a $25 million appropriation to the Office of Higher Education (OHE) to establish the David J. Tomassoni ALS Research and Care Program. Of this amount, $20 million was designated for ALS research grants.

In Fiscal Year 2024, OHE awarded $4.34 million to five competitive research grant proposals following a rigorous peer-review process. Grant funding was awarded to Minnesota's major research institutions, including the University of Minnesota (three projects) and the Mayo Clinic (two projects). The funded projects focus on key research priorities, including the development of MRI biomarkers for early disease detection, analysis of immune system factors related to ALS progression, and the establishment of a statewide biorepository to support and standardize future ALS research.

During the 2025 Legislative Session, with final action taken during the Special Session, the Legislature canceled the appropriation to the Office of Higher Education and reappropriated program funds to the University of Minnesota in a special revenue fund dedicated to research.

> (g) $15,262,000 in fiscal year 2026 is for a collaborative partnership with the Mayo Clinic to engage in ongoing research into amyotrophic lateral sclerosis (ALS), with the goal of bettering the lives of individuals with ALS and finding a cure for the disease. This is a one-time appropriation. Notwithstanding Minnesota Statutes, section 16A.28, unencumbered balances under this paragraph do not cancel until June 30, 2029. Beginning January 15, 2026, and annually thereafter until January 15, 2030, or until the money is fully expended, whichever occurs first, the Board of Regents must submit a report to the chairs and ranking minority members of the legislative committees with jurisdiction over higher education that identifies how the collaborative partnership used the money appropriated in this paragraph. The report must be filed according to Minnesota Statutes, section 3.195.

## *REPORTING PERIOD FINANCIALS*

There have been no research expenditures to date (fiscal year 2026) from this fund.

## *ALS RESEARCH in MINNESOTA*

The University of Minnesota Medical School (UMMS) is launching this ALS research program, from a position of strength, having a well-established program in the Department of Neurology. It possesses a robust clinical and research foundation that positions it for

rapid acceleration and success. The UMMS has a history of ALS research leadership in both clinical trials and translational research, and has brought in over $28,909,559 since 2022, including $9,524,494 from federal awards. Its clinical program is a Certified Treatment Center of Excellence, the highest level of certification granted by the ALS Association, and it provides comprehensive, multidisciplinary care to patients living with ALS. This established clinical infrastructure, under the leadership of David Walk, MD, FAAN, provides an invaluable platform for translational research, patient engagement, and clinical trials and care. Dr. Walk was a recipient of one of the initial awards from OHE, along with Pramod Pisharady, PhD. and Marija Cvetanovic, PhD., from UMMS.

The Mayo Clinic also has an ALS research program, primarily under the leadership of Nathan Staff, MD, PhD, a neurologist and the leader of the Translational Neuromuscular Disease Research Laboratory at Mayo Clinic. His research is highly translational, focusing on taking discoveries from the lab directly to human clinical trials. Dr. Staff's work bridges the gap between basic science and clinical application, particularly by pioneering stem cell treatments and leveraging AI to find new ways to treat and diagnose ALS. Dr. Staff was a recipient of one of the initial awards from OHE, along with Divyanshu Dubey, MBBS, from Mayo Clinic.

Minnesota's certified centers provide comprehensive clinical care coupled with robust research infrastructure essential for supporting large-scale clinical trials and specialized investigations.

University of Minnesota (UMN) Health Fairview ALS Clinic: This center is deeply committed to combining comprehensive patient care with an active clinical and translational research program. UMN operates as a major hub for developing national data standards and objective biomarkers.

Mayo Clinic (Rochester): Integrated within the globally recognized Mayo Clinic Neuroscience Department, the ALS research here emphasizes novel diagnostics and basic principles of motor nerve degeneration.

Hennepin Healthcare ALS Center of Excellence: As the first certified center in the state, Hennepin Healthcare focuses on providing high-quality care and actively participating in clinical research trials through the Hennepin Healthcare Research Institute (HHRI).

Minneapolis VA Health Care System ALS Center of Excellence: This center specializes in treating the veteran population, a cohort known to experience a disproportionately high incidence of ALS and is crucial for accessing federally supported research resources.

## *THE DAVID J TOMASSONI ALS RESEARCH PROGRAM*

### VISION

Our goal is to see the day when all people diagnosed with ALS will maintain independence and a normal lifespan.

By bringing together laboratory and translational scientists, clinical research professionals, and clinicians, the ALS Research Program boasts a broad range of expertise. Our priorities include:

- **Translational and Basic Science Discovery:** *Drive impactful scientific advances to* understand ALS disease mechanisms, discover new biomarkers, and develop methods for early diagnosis and pre-symptomatic screening, integrating and growing new research initiatives.
- **Clinical Research and Therapeutic Development:** Expand our work in developing an ALS biorepository, fostering clinical discovery, accelerating therapeutic development, and increasing statewide access to innovative clinical trials and translational research.
- **Cultivate ALS Leaders of the Future:** Attract and mentor the next generation of clinicians and scientists to develop dedicated careers in the ALS field, ensuring a pipeline of expertise.
- **Education, Engagement, and Outreach:** Serve as the regional hub for ALS education, quality improvement, and outreach by actively engaging providers, caregivers, community leaders, and people living with ALS throughout the region.
- **Program Sustainability and Growth:** Ensure the long-term viability of the program by growing and diversifying research funding, establishing a robust track record of success for philanthropic support, and retaining faculty and staff through structured career development and professional satisfaction.

## *PLANNED ACTIVITIES*

### Q1 2026:

- Develop a cross-institutional advisory group.
- Survey initial group of research funding recipients to determine outcomes of their projects and solicit ideas for new research proposals.
- Refine research program priorities, determine annual budgets, determine specific projects to be funded.
- Develop processes to solicit, review, and approve project proposals.

**Q2 2026:**

- Publicly launch the Tomassoni ALS Research Program in Spring 2026
- Initiate call for project proposals.
- Review, approve and fund the first round of project proposals.