



Subject: ALLFTD Renewal

17 July 2025

**To: Richard Hodes, MD, Director of the National Institute on Aging
Walter Koroshetz, MD, Director of the National Institute of Neurological Disorders and Stroke
National Institutes of Health, 9000 Rockville Pike, Bethesda, MD 20892**

We are advocates for those impacted by the terminal and devastating condition Amyotrophic Lateral Sclerosis (ALS, also known in the United States as Lou Gehrig's disease). This disease is in desperate need of research breakthroughs, and there is broad agreement that a promising hope for those breakthroughs will come from studying people impacted by the genetic or inherited forms of the disease.

You regularly hear from us on the vital importance of research studies dedicated specifically to ALS. In this letter, we are letting you know about the importance to our community of a study focused instead on the related disorder of Frontotemporal Degeneration or FTD.

The most common genetic cause of ALS is also the most common genetic cause of FTD. ALLFTD, an ambitious multicenter NIH-funded study of those impacted by this genetic driver of ALS and FTD, has been ongoing for over 5 years and is currently under consideration for renewal by your centers. This study has hundreds of carriers of the gene mutation in question who may develop ALS or FTD, and the continued categorization of their biology over time is essential to continue to make breakthroughs in these linked diseases.

Genetic ALS & FTD: End the Legacy Executive Director Jean Swidler shares this message: "My family has had multiple people die from C9orf72 associated ALS in each of the generations before mine. As a public carrier of the C9orf72 expansion I know I face a great likelihood of developing either ALS or FTD or both. The continued development of the ALLFTD genetic cohort through continued funding by the NIH is an important tool for all impacted by these diseases but especially the many of us at risk for C9orf72 disease."

We call on you to fund this study and further propel ALS and FTD research for the many suffering now and the countless destined to suffer in the future if promising scientific research is not funded.

Sincerely,

Genetic ALS & FTD: End the Legacy

ALS Hope Foundation

ALS Strategy Consulting

ALS United

ALS Association

ALS United Greater New York

Les Turner ALS Foundation

I AM ALS

ALS Network