LES TURNER ALS FOUNDATION

# Patient and Family Resource Guide to ALS

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### Forward

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LES TURNER ALS FOUNDATION

## The Les Turner ALS Foundation is here for you.

Contact the Director of Patient Services to learn how the Foundation has provided free support services for families like yours since 1977.

> lesturnerals.org 847 679 3311

## Welcome!

Welcome to the Les Turner ALS Foundation's Resource Guide.

We are the family of experts you never expected to need. We understand it can be overwhelming to hear that you or a family member has been diagnosed with Amyotrophic Lateral Sclerosis (ALS). ALS is a difficult and complex disease. Know that we are here to help guide you through a myriad of confusing medical jargon and a multitude of online resources at a time when you most need clear direction and understanding.

While there is no cure yet for ALS, scientists and clinicians have made much headway in not only uncovering causes of ALS, but also in offering medical interventions to improve the quality of life and possibly slow the progression of the disease. Our goal, as it has been for over 40 years, is to be **with you every step of the journey**, with support provided by our team of highly experienced nurses, social workers and other ALS health professionals who work seamlessly with your doctors and clinical team at the **Lois Insolia ALS Clinic at the Les Turner ALS Research and Patient Center at Northwestern Medicine.** Over the decades, the Les Turner ALS Foundation team of Patient and Family Advocates has developed the most comprehensive ALS support program in the country.

This updated resource guide is based on that experience. It offers sections on understanding the disease, coping with the aftermath of diagnosis and countless practical tips to improve your everyday life with ALS. You will find links to outside resources for clinical trials, assistance with speech issues and explanations of insurance and legal issues to protect you and your family, all of which are based on our many years of experience with people with ALS and their families. This resource guide is designed to provide the information you need when you need it. It is intended to be used alongside visits with your neurologist and pulmonologist and the multidisciplinary team at the Lois Insolia ALS Clinic as well support from the Foundation's Patient and Family Advocates, who can help you determine what works best for you. Even if you live outside Chicagoland and are not affiliated with Lois Insolia ALS Clinic or the Foundation, this resource guide is a tremendous wealth of knowledge.

We hope this revised version of our resource guide will serve as a helpful reference for you and your loved ones throughout this journey. When you have questions or concerns, we are only a phone call or email away.

Together towards a cure,

Judica Pauli Backman Andrea Pauls Backman Chief Executive Officer



## Learn More

Les Turner ALS Research and Patient Center at Northwestern Medicine Lois Insolia ALS Clinic Les Turner ALS Foundation Staff Les Turner ALS Foundation Support Group Facilitators