

2016 Annual Report



# Celebrating Mission

LES  
TURNER  
ALS  
FOUNDATION

40  
years

# About us



## What is ALS

Amyotrophic Lateral Sclerosis (ALS), is a rapidly progressive disease that causes muscle weakness, difficulty speaking and swallowing and, generally, complete paralysis. In most cases, while the body continues to deteriorate, the mind remains unaffected. The disease does not discriminate, striking any age, gender and race. Every 90 minutes, someone in the US is diagnosed with ALS and every 90 minutes, someone in the US dies of ALS. There is no known cure for ALS and, once diagnosed, patients typically live only three to five years.

## What We Do

Our mission is to: advance scientific research into the causes, treatments and prevention of ALS; provide people living with ALS, their families and caregivers exceptional clinical care and support services; and to increase awareness and education of ALS.

## Who We Are

The Les Turner ALS Foundation, founded in 1977, is Chicago's leader in research, patient care and education about ALS, serving the vast majority of people with ALS in the area, offering help and hope when it's needed most. One of the nation's largest, independent ALS organizations, the Foundation allocates all funds to local research, clinical care and support services for people with ALS in the Chicagoland area. The Foundation's full spectrum patient service programs include: in-home consultations, support groups, equipment loans, grants and educational activities. The Foundation offers hope for a future without ALS by supporting the **Les Turner ALS Research and Patient Center at Northwestern Medicine**, bringing together all ALS research laboratories and a multidisciplinary patient clinic under one umbrella.

# Thankyou



## Dear Friends,

As we enter the Les Turner ALS Foundation's 40th year, we reflect on the milestones that have brought us to where we are today and we look toward the future with hope and determination.

What started as a grassroots group of family and friends to support a young man named Les Turner in 1977 has grown into a Foundation that today serves as a model in patient care and research to ALS organizations around the world and supports the Les Turner ALS Research and Patient Center at Northwestern Medicine, an integrated, world-class ALS Center.

Because of you, people with ALS are living longer, they're living more comfortably and they're living with greater hope for progress in treatments and ultimately, a cure. The Foundation has been able to serve the ALS community for four decades thanks to our many generous donors, volunteers and friends. Each one of you is critical to what we do.

One thing that has not changed in 40 years is the Foundation's commitment to its mission, which is why we have chosen the 2016 Annual Report to highlight the essential work you have helped us accomplish, all the while knowing there is still significant work to be done. Our mission will not be complete until there is a cure for ALS. And our promise to you is that we will not stop fighting until that cure is found. We hope you continue to join us.

Together toward a cure,

**Ken Hoffman**  
President



**Andrea Pauls Backman**  
Executive Director



## "They are our guardian angels."

Obviously, staying up to speed about the disease is hard and they are just there in the background trying to make it as easy as possible."

*-Sherlyn, lost husband to ALS*



# Collaboration



After partnering for more than three decades with Northwestern Medicine, the Les Turner ALS Foundation formally created the **Les Turner ALS Research and Patient Center**. In addition to providing at least \$1 million annually to fund ALS research and the Lois Insolia ALS Clinic, Northwestern and the Foundation are jointly raising \$10 million to permanently endow the Center, ensuring a legacy of hope and help for people living with ALS. At the end of 2016, nearly \$3.6 million has been pledged toward that endowment.

The Center brings together all ALS disciplines under one umbrella, enabling enhanced collaborations between researchers and clinicians to provide a full spectrum of treatment to ALS patients while facilitating the development of new therapies for ALS.

The mission of the Les Turner ALS Research and Patient Center at Northwestern Medicine is to strive for a future without ALS by accelerating leading-edge research while providing life-enhancing treatment to people living with ALS.

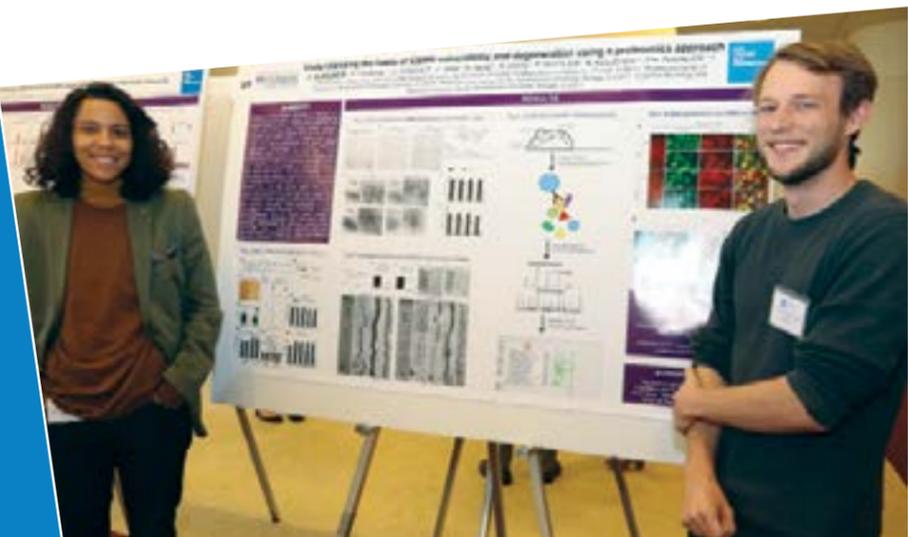


Les Turner ALS Research and Patient Center

“Your support helps draw the **most promising physician-scientists**

and allows them to pursue exciting research projects, thereby creating both new knowledge in complex areas and training the next generation of experts. As groundbreaking results are translated from the bench to the bedside, patients and families throughout the world will be positively impacted.”

—Dr. Jack Rozental, Interim Director, Les Turner ALS Research and Patient Center



Funding is critical to ensuring a world-renowned Center that will attract the greatest researchers and clinicians leading to more collaborative research and patient care.

# Patient Care



For more than 30 years, the Les Turner ALS Foundation has been a leader in providing a comprehensive, patient-centered system of care and support, serving as a model for other ALS organizations all over the world.

Receiving an ALS diagnosis is devastating and can send an entire family on a difficult and lonely path. The Foundation's Home and Community Services team provides uncompromising support to those living with ALS through a continuum of services designed to meet an individual's specific needs while supporting and educating the family, friends and community. Thousands of people with ALS (PALS) living in the Chicagoland area have been helped in some way by the wide array of services offered by the Foundation. **Our goal is to improve a PALS' quality of life and let each one of them know that they are not alone.**

The **Lois Insolia ALS Clinic** at the Les Turner ALS Research and Patient Center at Northwestern Medicine was established in 1986 as one of the first multidisciplinary ALS clinics in the country and the first one in Chicago, and today, **it remains Chicagoland's ONLY full service, multidisciplinary clinic for people living with ALS.** Patients are seen by a team of healthcare professionals who provide cutting-edge, comprehensive treatment and are dedicated to the total care and support of PALS, their families and caregivers.

“The Les Turner ALS Foundation has been nothing short of

**angels in our lives**

The doctors, nurses, social workers, support group members and all Les Turner supporters help us bear the burden of ALS together.”

—Jack, lost father to ALS

As a member of NEALS, the Northeast ALS Consortium, the Center is at the forefront of clinical trials in ALS. In 2016, the **Lois Insolia ALS Clinic** was the only clinic in the Chicagoland area to conduct Phase 3 trial of VITALITY-ALS (tirasemtiv), a muscle activator for the potential treatment of ALS. In addition, a multicenter Phase 2 trial of pyrimethamine was shown to lower cerebral spinal fluid SOD1 levels in patients with this genetic mutation, as reported by Dr. Senda Ajroud-Driss, the medical director of the Lois Insolia ALS Clinic. Drs. Teepu Siddique and Ajroud-Driss participated in the Airlie House ALS Clinical Trials Guidelines Workshop in March 2016, designed to forge modern guidelines for clinical trials.



# Research

The Les Turner ALS Foundation sponsors internationally recognized ALS research at the **Les Turner ALS Research and Patient Center at Northwestern Medicine** and other collaborative ALS research throughout the university and with other major research institutions. The Center also includes the Lois Insolia ALS Clinic, which allows for translational research and clinical work. The ALS laboratories' three distinctive investigative priorities focus on genetics, upper motor neurons and stem cells.

In 2017, the Center moved to a research granting model and awarded seven distinct ALS research seed grants in the areas of drug development, genetics, cellular mechanisms and novel ALS models. The Center's research grants provide funds for pilot projects. Pilot projects involve the acquisition of preliminary data, allowing promising projects the opportunity to be selected for application of Federal or other funding. By understanding how ALS operates, scientists can develop more effective treatments while working toward discovering a cure.



## Teepu Siddique, MD

The ALS laboratory led by Teepu Siddique, MD, focuses on the clinical and molecular characteristics of ALS and the development of novel therapeutics. The lab was first dedicated by the Les Turner ALS Foundation in 1979 and has been directed by Dr. Siddique since 1991.

Dr. Teepu Siddique is the founder of the Neuromuscular Disorders Program and the Neurogenetics Laboratory at Northwestern in 1991 with continuous support from the Les Turner ALS Foundation. His group's work focuses on the clinical and molecular characteristics of ALS and the development of novel therapeutics. Dr. Siddique, the Les Turner ALS Foundation/Herbert C. Wenske Foundation Professor, is Professor of both Neurology and Cell & Molecular Biology at Northwestern University. He is a physician-neuroscientist with expertise in the neurology, molecular genetics, biochemistry, cell biology and animal modeling of human neurodegenerative disease. Since 1991, Dr. Siddique has had a large clinical practice at the Lois Insolia ALS Clinic at the Les Turner ALS Research and Patient Center at Northwestern Medicine with a specialty in familial ALS cases.

In 2016, Dr. Siddique's lab achieved the following major accomplishments:

- **Northeast ALS Consortium:** The Siddique laboratory presented an abstract titled "Molecular dissection of ALS pathogenesis of ubiquilinopathy using CRISPR/Cas9," which won the Basic Science Poster Award. A second abstract from the Siddique lab, titled "Dense core vesicle defect underlies the pathogenesis of ALS5" was selected for poster presentation at the meeting in Clearwater Beach, Florida in October 2016.
- **CHCHD10 Mutations:** Obtained funding for a new five-year National Institutes of Health grant entitled "Investigation of ALS Caused by CHCHD10." The mutations in CHCHD10 that cause ALS were first discovered in the lab of Dr. Siddique in 2012 by Dr. Siddique and Dr. Senda Ajroud-Driss. This is the first direct causative link between mitochondria and ALS, as published in Neurogenetics.
- **Novel Gene Discovery:** Discovered a novel gene mutation, TMEM230, shown to cause Parkinson's disease as published in Nature Genetics. This research has strong implications for ALS as the TMEM230 protein is also present in motor neurons.
- **Primary Lateral Sclerosis (PLS):** Published findings from a genetic primary lateral sclerosis (PLS) study in Neurology Genetics. PLS is typically diagnosed between the ages of 40 and 60 years old and the study focused on a family with five patients who had the early disease onset. Whole exome sequencing was performed to identify the shared genetic variants in three affected members of the family. The study identified a compound heterozygote mutation in the Paraplegia gene (SPG7), the genetic defect linked to PLS in this family.

## P. Hande Ozdinler, PhD

Since 2008, Hande Ozdinler, PhD, assistant professor of Neurology, has led an ALS laboratory with a unique focus. Her laboratory focuses on the motor neurons which reside in the brain and connect with motor neurons in the spinal cord to initiate and control movement. These two motor neuron populations progressively degenerate in ALS patients, and therefore require immediate attention. Dr. Ozdinler became the first person to label, isolate and culture the corticospinal motor neurons in an effort to understand their requirements for survival. The Foundation has supported her research since 2008.

Each year, Dr. Ozdinler, on behalf of the Center, hosts the Les Turner Symposium on ALS and NeuroRepair, bringing together speakers and presenters from Northwestern and beyond. In 2016, the keynote speaker for this Symposium was Terry Heiman-Patterson, MD, Center Director for Neurodegenerative Disorders and Professor of Neurology Temple University, and Co-Founder of ALS Hope Foundation.

In 2016, the Ozdinler lab achieved the following major accomplishments:

- **Northeast ALS Consortium:** The Ozdinler laboratory presented an abstract titled "Understanding the cellular, molecular and genetic basis of upper motor neuron vulnerability and progressive degeneration in ALS."
- **Gene Replacement Therapies:** Published in Nature Gene Therapy evidence that lays a foundation for developing future gene replacement therapies to treat people with ALS. Using a nontoxic virus injected directly into the motor cortex of mouse models with ALS, the scientists showed they can deliver new genes to damaged upper motor neurons. This process of transferring DNA from a virus to neurons is called transduction.
- **Alsin Function and Corticospinal Motor Neuron Vulnerability:** Published findings in Human Molecular Genetics indicating in mouse models that the absence of Alsin function leads to corticospinal motor neuron vulnerability. It is known that mutations in the Alsin gene result in early-onset ALS and juvenile primary lateral sclerosis.
- **Cortical Dysfunction in ALS:** The development of hyperexcitability is an early intrinsic feature of sporadic and familial ALS. Dr. Ozdinler's work was published in Nature Reviews in Neurology, a joint effort with the Vucic group in Australia, which displayed how early cortical dysfunction can serve as an early marker to help diagnose ALS.
- **Novel Drugs for ALS:** Awarded a grant, in collaboration with Dr. Richard B. Silverman, Professor of Chemistry at Northwestern University, from NUCATS for their combined efforts to identify novel drugs for ALS and other motor neuron diseases by using motor neuron survival as a readout for success.



## Evangelos Kiskinis, PhD

Evangelos Kiskinis, PhD, assistant professor of Neurology, launched a third ALS research laboratory at the Les Turner ALS Research and Patient Center at Northwestern Medicine in 2015. Dr. Kiskinis is working on several promising and collaborative ALS research initiatives that are funded through the Foundation's support of the Center's research grant program.

Dr. Kiskinis and his colleagues seek to harness the power of pluripotent stem cells to understand how neuronal function and the neuromuscular circuitry are impaired in ALS. His laboratory utilizes patient-specific induced pluripotent stem cells (iPSCs) and direct reprogramming methods to generate different neuronal subtypes of the central nervous system, including spinal motor neurons and cortical neuronal subtypes. They then study these cells by using a combination of molecular, biochemical and functional electrophysiological assays.

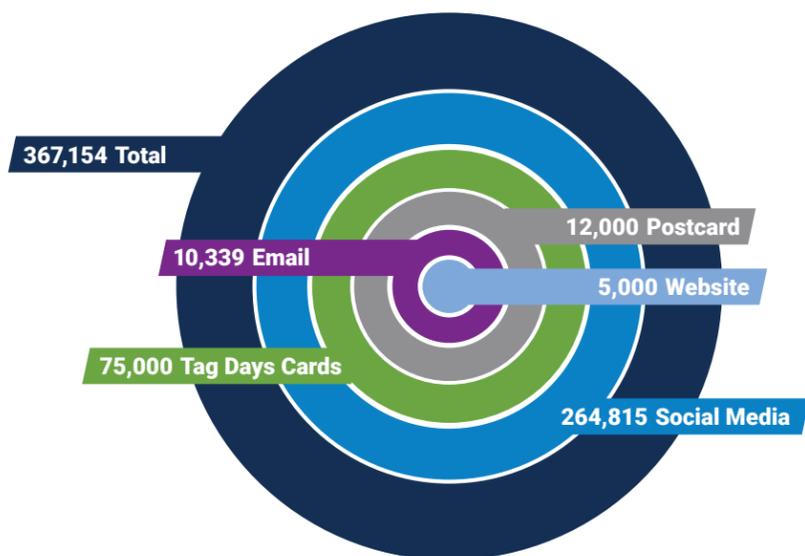
In 2016, the Kiskinis lab achieved the following significant achievements:

- **Phase 2 Clinical Trial for ALS:** Developed novel cellular models of ALS based on iPSC technology. As a postdoctoral researcher at Harvard, he and his colleagues discovered an interaction between ER related stress and electrophysiological abnormalities that are mediated by defective potassium currents and result in the selective death of patient motor neurons. This work directly led to the initiation of an ongoing Phase 2 clinical trial for ALS, currently taking place at Massachusetts General Hospital.
- **Urate-Elevating Therapy:** Received grant funding for an ongoing collaboration with researchers at Massachusetts General Hospital, Harvard Medical School, led by Michael Schwarzschild, MD, PhD, and Ghazaleh SadriVakili, MS, PhD, centered on deciphering the potential therapeutic effects of urate for treating ALS patient motor neurons. Urate appears to have a protective role against glutamate excitotoxicity and protects mutant SOD1 cells.
- **Stem Cell Repair:** Jointly published a study called "Comprehensive Protocols for CRISPR/Cas9based Gene Editing in Human Pluripotent Stem Cells" in Current Protocols in Stem Cell Biology describing new protocols to manipulate the genome of the human pluripotent stem cell. These methods are used to repair ALS-causing mutations in patient stem cells.

# Awareness



For national ALS Awareness Month in May 2016, the Les Turner ALS Foundation launched a grassroots marketing campaign that included local supporters handing out postcards and Freeze ALS stickers, playing off the theme of the astoundingly successful global 2014 ALS Bucket Challenge. This effort, combined with a robust email, website, social media and direct mail initiative plus the Foundation's Tag Days drives held in 13 communities around Chicagoland, led to a reach of over 367,000 during the month of May alone.



"I recently lost an aunt to ALS and want to run this race in her honor. She was a truly remarkable person who never let this disease get the best of her. I want to raise as much money as possible to help find a cure and to help aid other families stricken with this disease."

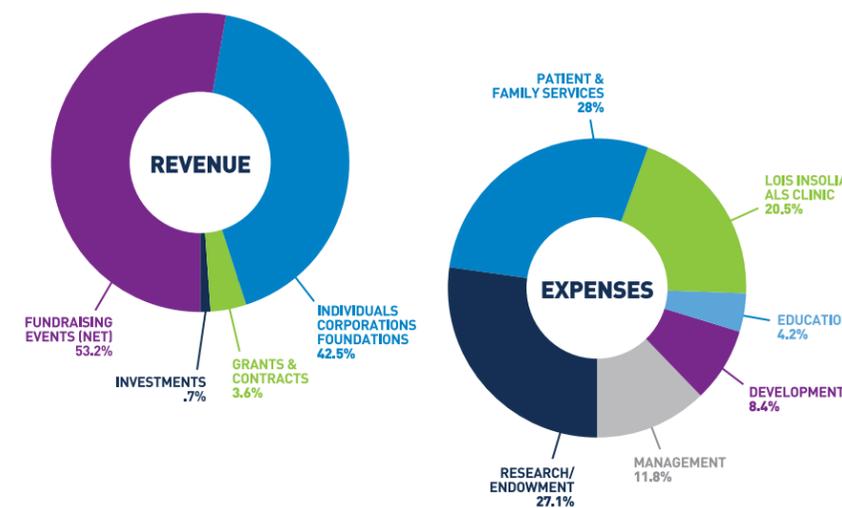
**I want to run for those that can't.**

-Carissa, lost aunt to ALS

# Financial Position

## 2016 AUDITED FINANCIAL STATEMENTS

The Les Turner ALS Foundation's 2016 Annual Report demonstrates how we strive to fulfill our mission to bring hope and help to those living with ALS, showcases our accomplishments, and details revenue and spending for the calendar year. We are proud to continue to receive a four-star rating from Charity Navigator for the fourth year in a row. This means that we exceed industry standards and outperform 90% of ranked charities in accountability and transparency. You can give with confidence.



### Statement of Financial Position

for the year ended December 31, 2016

	2016	2015
Total Assets (of which \$276,203 and \$655,429, respectively, is temporarily restricted)	\$2,510,840	\$3,027,507
Total Liabilities	1,199,125	1,384,922
Total Net Assets	1,311,715	1,642,585
Total Liabilities and Net Assets	\$2,510,840	\$3,027,507

### Statement of Activities

for the year ended December 31, 2016

	2016	2015
Total Operating Revenue	\$2,297,445	\$3,451,098
Operating Expenses		
Program Services	2,095,558	4,055,583
Supporting Services Expenses	532,757	519,078
Total Expenses	2,628,315	4,574,661
Change in Net Assets	(330,870)	(1,123,563)
Net Assets—beginning of year	\$1,642,585	\$2,766,148
Net Assets—end of year	\$1,311,715	\$1,642,585

The foregoing condensed financial statements have been derived from the audited financial statements, which are available for public inspection on the Foundation website [www.lesturnerals.org](http://www.lesturnerals.org) or at the offices of the Les Turner ALS Foundation.



# Leadership



## Board of Directors

- Ken Hoffman\***  
*President*
- Thomas F. Boleky\***  
*Vice President*
- Matthew Brown**
- Wendy J. Cohen**
- Kenneth M. Crane\***  
*Vice President*
- Robin Fern\***  
*Vice President, Staff Liaison*
- Vicki Flahaven**
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- David T. Hoppe**
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- Joan A. Parker**
- Mary Lou Pisone**
- Sue Randall**
- Joel A. Schechter\***  
*Vice President*

\*Executive Committee

## Foundation Staff

- Andrea Pauls Backman, MBA**  
*Executive Director*
- Shelby Anderson**  
*Fundraising Associate*
- Laura Embers**  
*Bookkeeper*
- Laurie B. Fieldman, MSW, LCSW**  
*Director of Social Services*
- Cara Gallagher, MA**  
*National ALS Registry Associate*
- Karen Gianni**  
*Office and Database Assistant*
- Jordyn Landberg**  
*Marketing and Communications Manager*
- Anne Lidsky, PhD**  
*Support Group Facilitator*
- Deb Marron**  
*Office and Human Resources Manager*
- Liz Melvin**  
*Director of Special Events*
- Ileane Mindel, RN**  
*Manager of Community Education*
- Judy Richman, RN, BSN**  
*Director of Patient Services*
- Lyndsey Rice**  
*Senior Fundraising Associate*
- Karen Steffens, RN, CHPN, CCM**  
*Patient and Family Advocate*
- Easton Stevenson, LCSW**  
*Patient and Family Advocate*
- Julie Stowell, RN, CHPN**  
*Patient and Family Advocate*
- Maria Zeller Brauer, MA**  
*Development Manager*

## Independent Auditors

**Wipfli**  
*Palatine, Illinois*

## Affiliations

**Northwestern Medicine\***  
*Feinberg School of Medicine*

**Les Turner ALS Research  
and Patient Center**

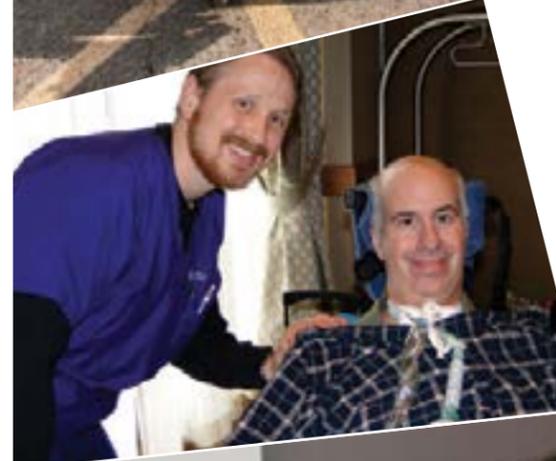
**COMMUNITY HEALTH CHARITIES**  
*Give. Connect. Help.™*

**INTERNATIONAL ALLIANCE  
OF ALS/MND ASSOCIATIONS**

*Information is current as of  
the printing of this report.*

**Maria Zeller Brauer, MA**  
*Editorial*

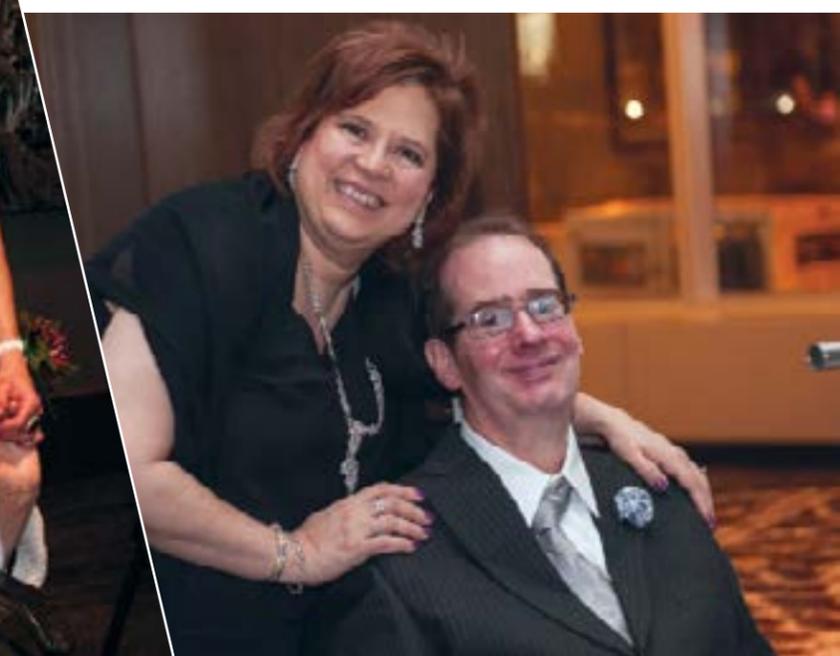
**Kirsten Goede**  
*Design/Layout*



"Through the years we have found ways to adapt to the changes. But without the Les Turner ALS Foundation we would be facing this journey in the dark. Through their efforts we feel anything is possible. With amazing dedicated skilled advocates that offer hope and help via the support groups, home team visits, awareness, the clinic, research and everything else that makes the organization great, the Les Turner ALS Foundation fights for us and

**makes a huge difference in  
many people's lives."**

*—Matt, person living with ALS*





# May

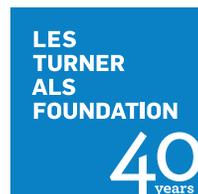
is ALS  
Awareness  
Month



Be an ALS Awareness Advocate  
this May! It's free and easy.

Contact us at [info@lesturnerals.org](mailto:info@lesturnerals.org)  
or call 847 679 3311  
to help people with ALS.

Hope and help for people with ALS.



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