

Hope and help for people with ALS.

lesturnerals.org

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## ALS 101 with Robert Kalb, MD

DIRECTOR OF THE LES TURNER ALS CENTER AT NORTHWESTERN MEDICINE



A world free of ALS has always been our goal, plain and simple. In 2019 we gave over \$1 million to fund research and clinical care at our Les Turner ALS Center at Northwestern Medicine. From that gift, the Center awarded six research grants in areas like drug development, genetics, cellular mechanisms and novel ALS models.

Dr. Robert Kalb, Director of the Center, explains how the basic science research underway at the Center broadens our understanding of ALS.

**Before we can understand why we do the research we do, let's start with the most basic question – what is ALS?**

ALS is a terminal progressive disease causing muscle weakness, difficulty speaking and swallowing and, generally, complete paralysis.

In all of us there are “upper motor neurons” and “lower motor neurons.” The basic logic is upper motor neurons are connected to lower motor neurons and lower motor neurons are connected to muscles. The upper motor neurons stimulate lower motor neurons and this causes muscles to contract. In ALS, both of these populations of neurons degenerate and leads to progressive weakness.

**We now know the clinical progression of the disease and many of the genes affected in ALS. It's been eighty years since Lou Gehrig's famous farewell speech and five years since the Ice Bucket**

**Challenge took the world by storm. We're in an age where more people have heard of ALS than ever before.**

**So, the big question is, why haven't we found the cure yet?**

If there was an obvious solution, we would already have the answer. While we aren't there yet these are incredibly exciting times because of the enormous amount of new information we have acquired. We have learned cells in general and motor neurons specifically are incredibly complex. Cells have had billions of years of evolution to become very good at what they do and we just now have all the powerful tools to dig inside and find out what's going on.

The key is to understand the underlying basic biology going wrong in the motor neurons and cells supporting them. That will show us where we need to intervene. And that's exactly what we are doing with the various research initiatives happening at the Center.

**So, it's like a puzzle. We can't solve it because we're still missing important pieces. But by identifying the areas in the body going “wrong” in ALS, we would then be able to target it and find a solution to fix the problem.**

**What research are you and your team investigating at the Center to help us find those missing pieces?**

In my research, we think a major problem is the handling of misfolded proteins. My perspective is that proteins are the workhorse of the cell. They are the molecules doing much of the work in a cell. And they are constantly being synthesized and constantly being degraded. And just like a car wears over time, a protein or part of a car will wear out over time.

We think a central problem in ALS is the recognition of damaged proteins and their disposal. Because the recognition and disposal process is impaired, what ends up happening is an accumulation of damaged proteins. Cells don't like that.

If we can fix this process through drug therapy, we think that's going to be an opportunity to treat people living with ALS.

**What's your ultimate goal with your research?**

We're all very committed to taking care of people living with ALS and finding a cure. That's my goal, to get to a cure, to put myself out of business.

# Letter from the CEO

Dear Friends,

As the saying goes, knowledge is power. We at the Foundation talk a lot about the individualized care we champion and of the hope we provide through scientific research. What we spend less time talking about is our work in education and awareness. But this is a core piece of our mission and an essential part of empowering our community.

*Knowledge about ALS is power; power to people living with ALS, power to members of the medical community, power to our researchers, power to advocates and power to you, our devoted supporters.*

For people living with ALS, our model of individualized care addresses each person's unique needs. Not just the way ALS is affecting them today, but how it may affect them in the future, preparing them for what's to come and empowering them to live life with ALS to the fullest.

Our experts at the Les Turner ALS Center at Northwestern Medicine and those on our Support Services team conduct professional in-services for medical providers where we share our expertise on how to best care for people living with the disease, enabling the medical community to provide the finest level of care to people living with ALS all throughout Chicagoland.

Researchers in our labs and Clinic at the Center share research and clinical findings, speak at conferences and collaborate with others in their field, encouraging new thoughts and ideas about how to conduct research in unique and innovative ways.

And you, our Les Turner ALS family members-you tell your friends, your neighbors, your grocers, your hairdressers about the toll ALS takes on individuals and their families. You teach about the remarkable work the Foundation is doing and inspire others to get involved and join our devoted community.

*Together, we create a huge and invincible team of people committed to seeing a world free of ALS,* committed to the idea of sharing knowledge and committed to the idea of empowering ourselves and one another.

I hope you enjoy the pieces in this newsletter that teach us the importance of knowledge. Explore basic science research, life-saving breathing interventions, Lou Gehrig's profound legacy on ALS and the joy in giving back. And I hope you feel empowered to take this information, share it with your community and ask them to join us in our vision of seeing a world free of ALS. We won't win the fight against ALS alone. We're all in this together.

Together towards a cure,



Andrea Pauls Backman  
Chief Executive Officer

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#### Editorial

Jordyn Landberg

Hallie Kobylski

#### Layout

Bri Allen

Design

# Tagging for ALS

May is ALS Awareness month and, across the nation, ALS advocates work to raise awareness, encouraging others to join the cause. For 25 years, the Foundation's Tag Days Drives have been led by committed volunteers wearing bright yellow vests, canning for change and sharing information about ALS in their communities across Chicagoland throughout the month of May.



This volunteer-led program has raised nearly \$2 million and spread the word about ALS to hundreds of thousands of people. This year, over 420 volunteers canvassed the streets, handing out awareness cards and raising over \$40,000.

For Tag Days volunteers like Tiffany Banks, bringing together family and friends for this annual event is a special occasion. "Tag Days is one of the most important yearly events my family is privileged to be involved. We even have family members who drive several miles or fly in just to participate," says Tiffany.

Tiffany and her family Tag in memory of Tiffany's mother, Gloria, who lost her battle to ALS in 2013. "I can't forget the day when my mother was at Northwestern, on a ventilator and several of our family members were surrounding her bedside with distraught faces. To say that we were heartbroken, frightened and felt helpless is an understatement. A loving and compassionate nurse from the Les Turner ALS Foundation came right on time that day. Her knowledge, kindness and love were felt by all. The Les Turner ALS Foundation was with us every step of the way."

*"The Les Turner ALS Foundation truly expressed their genuine love and concern for our family from the very beginning of my mother's battle with ALS."*



Year after year, members of our Les Turner ALS family like Tiffany and hundreds of others step up to raise awareness so no one has to go through the journey of ALS alone, and we can't thank them enough.

Our amazing volunteers make sure everyone in Chicagoland knows hope and help is always within their reach.



Peg Lorden

## Breathing Function and Early Intervention in People Living with ALS

For people living with ALS, the leading cause of death is respiratory failure. At our Les Turner ALS Center at Northwestern Medicine, we have two pulmonologists, Dr. Lisa F. Wolfe and Dr. John M. Coleman III, helping people living with ALS live longer through early intervention in breathing function.

Take Peg Lorden, for instance. While working as a nurse, Peg began having difficulty raising her left arm to check a patient's blood pressure. In 2013, at 53, Peg was diagnosed with ALS. After attending a Les Turner ALS Foundation support group, Peg heard a fellow person living with ALS share how a pulmonologist at the Center "saved his life" after becoming sick with an upper respiratory infection.

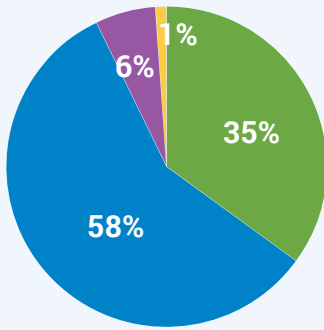
She made an appointment to see Dr. Wolfe at our Center the very next week.

"Seeing Dr. Wolfe and all of her ordered interventions has been life changing! She is so knowledgeable, kind and thoughtful. She will spend as much time with you as you need, never making you feel rushed," says Peg.

# Your Impact 2018

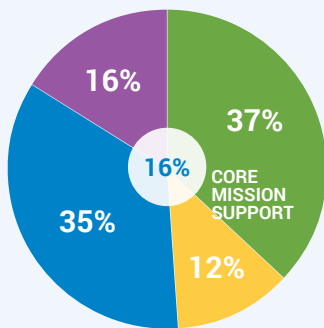
Thank you for being a part of the Les Turner ALS family. In 2018, we moved even closer to our shared vision of seeing a world free of ALS, all because of you. Here's how you impacted people living with ALS.

REVENUE\*



- Special Events (net)
- Individuals, Corporations, Foundations
- Grants and Contracts
- Investments

EXPENSES\*



- Research/Endowment
- Lois Insolia ALS Clinic
- Support Services
- Education

\*2018 Audited Financials



**1,670** visits from our nurses and social workers to the homes of people living with ALS in-between Clinic appointments, providing expert guidance, comfort and a continuum of care



**\$103K** in grant dollars to 80 families living with ALS to help ease the cost of basic necessities that make living with ALS more manageable, such as transportation to clinic, home modifications, respite care and communication technology assistance



**908** appointments at our Lois Insolia ALS Clinic to people living with ALS, with leading experts treating every aspect of the disease in one convenient appointment



**\$1.1M** in grant dollars to the Les Turner ALS Center at Northwestern Medicine, funding six unique research grants and a grant to fund multidisciplinary clinical care at the Lois Insolia ALS Clinic



**525** Support Group Participants received vital help through five monthly support groups

WE WOULD NOT BE HERE IF IT WEREN'T FOR YOU. **THANK YOU!**

Seven months after her diagnosis, Peg, with the support of Dr. Wolfe, her husband and their three sons, made the decision to have a diaphragm pacer (a lightweight, battery-powered electronic pacing system that electrically stimulates a "breath") inserted. This was followed by the addition of an airway clearance vest, nebulizer, cough assist and other interventions as part of Peg's comprehensive care plan.

*"We're proud to offer expert guidance and care in pulmonology at the Center. Early respiratory intervention can make a huge difference in extending the lives of people living with ALS," says Dr. Wolfe.*

Peg is grateful for all the respiratory support she's received at the Center, "This is what I personally feel has kept me around as long as it has...all these together can keep you healthy and might even extend your life."

While a cure for ALS eludes us for now, our team at the Les Turner ALS Center is focused on making real progress in treating ALS and helping people with ALS live longer, better lives.



This person is wearing nasal pillows which are connected via tubing to his portable, non-invasive ventilator. This allows him continuous ventilatory support and freedom to leave his home.



# Lin Brehmer Celebrates the 80th Anniversary of Lou Gehrig's Farewell Speech

Lou Gehrig looked unbreakable. Broad shoulders, powerful arms, he seemed as solid as the Adirondack ash trees that were tooled for baseball bats. His prodigious strength underscored a flare for the dramatic. His major league record 23 career grand slams stood for over 50 years.

Of all his accomplishments, the one that kept the luster on his legend was the streak that transformed him from flesh and bone into "The Iron Horse." He played in 2,130 consecutive games.

As a left-handed little league first baseman, I was captivated by the story of the Yankees' most famous first baseman. I devoured schoolboy biographies of the pride of Columbia University. As I pored over the endless numbers in the Baseball Encyclopedia, the achievements of Lou Gehrig were impossible to overlook. He had 12 seasons in a row where he drove in 120 runs or more. Later in life I learned so much more from Jonathan Eig's definitive biography: Luckiest Man, The Life and Death of Lou Gehrig.

My own involvement in the Les Turner ALS Foundation had nothing to do with Lou Gehrig although like many people, I was quick to invoke the disease's popular shorthand, "Lou Gehrig's disease." Les Turner had a fundraiser every year in the parking lot of the Old Orchard Shopping Center. It was the Mammoth Music Mart. WXRT, where I worked, always had hundreds and hundreds

of record albums both used and new that needed a good home. This radio station and the Mammoth Music Mart were a perfect fit. We did promotions and live broadcasts and we got to know the hard-working staff of the Foundation. We also learned about the disease that claimed the life of Lou Gehrig.

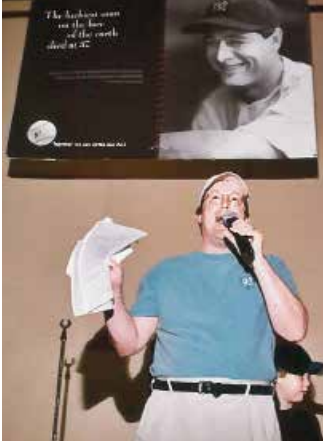
They call it a rare disease, but we all know friends or family or public figures who face the inevitability of ALS with hope and strength.

This July 4th marks the 80th anniversary of Lou Gehrig's public farewell at Yankee Stadium. It is more than fitting that we take this occasion to acknowledge the patients who face the challenges of this insidious disease every day. We celebrate the Herculean efforts of the Les Turner ALS Foundation to provide support and assistance. And we remember the tearful speech of a man who seemed unbreakable saying that this disease would not break his spirit.

*"Fans, for the past two weeks, you've been reading about a bad break. Today I consider myself the luckiest man on the face of the earth."*

On this July 4th, take nothing for granted. It's great to be alive.

**Lin Brehmer**  
Les Turner ALS Foundation  
Spokesperson  
WXRT Morning DJ



**IF YOU'D LIKE TO MAKE A DONATION AND JOIN OUR \$80 FOR 80 CLUB IN HONOR OF THIS HISTORIC MILESTONE, VISIT [HELPCUREALS.ORG](http://HELPCUREALS.ORG).**

# Join Us

## **CAMP HOPE LOVES COMPANY**

*Friday, September 6 – Sunday, September 8, 2019*  
*Camp Henry Horner, Ingleside, IL*  
847 679 3311

This free of charge overnight camp is being offered to children and families affected by ALS. Meet other children in the Chicagoland area going through similar circumstances and create lifelong friendships.

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## **ALS WALK FOR LIFE**

*Sunday, September 15, 2019*  
*Soldier Field, Chicago*  
[alswalkforlife.org](http://alswalkforlife.org)

Grab your friends and family and join us at the country's largest gathering of the ALS community as we Walk for Hope, Walk for Help and Walk for Life.