



Celebrating Impact

**LES
TURNER
ALS
FOUNDATION**

**Hope and help for
people with ALS**

Annual Report
2014



Photo (left to right):

Scott Heller, MD; Shari Diamond, RN, BSN; Ileana Mindel, RN; Steve Heronemus; Laurie Fieldman, MSW, LCSW; Suzanne Heronemus

About ALS

Amyotrophic Lateral Sclerosis (ALS), also known as Lou Gehrig's disease or motor neuron disease (MND), is a 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. In the US, someone is diagnosed with ALS every 90 minutes and every 90 minutes someone with ALS dies. There is no known cure for ALS and once diagnosed, patients typically live only three to five years.

Mission Statement

The Mission of the Les Turner ALS Foundation 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 increase awareness and education of ALS.

Front Cover Photo: The McNally Family

Dear Friends,

2014 was a transformational year for the Foundation.

In September, the Foundation enhanced its 35 year partnership with Northwestern Medicine with a \$10 million pledge to establish the **Les Turner ALS Research and Patient Center**, bringing under one umbrella the three facets of our mission: research, clinical care and education. We also announced an additional \$10 million commitment to Northwestern to endow the Center in perpetuity. We are confident the Center will be the nation's, and possibly even the world's, center of excellence in the study and treatment of ALS.

The summer of 2014 saw the game changing phenomenon many of you have heard of and, hopefully, participated in—the ALS Ice Bucket Challenge. This Challenge had a far-reaching impact; while it certainly raised funds to support ALS organizations across the world, it also significantly increased the public's level of awareness of this devastating disease.

Because of the ALS Ice Bucket Challenge and supporters like you, 2014 brought unprecedented fundraising success to the Foundation. We shattered fundraising and attendance records at several events and increased our operating revenue by 84%! Our 2015 program services are the largest to date, allowing for an even greater impact on ALS research and patient services.

2014 was also a year of transition for the Foundation. Nearly one year ago, Harvey Gaffen, founder and leader of the Foundation since 1977, transitioned from President to

President Emeritus. Later that year, Wendy Abrams, the Foundation's Executive Director for more than 35 years, announced her retirement, effective in March of 2015. Together, Harvey and Wendy worked tirelessly to build the Foundation from a grassroots organization to what it is today—a world renowned leader in the fight against ALS. Because of their relentless dedication, the Foundation is better positioned and stronger than ever before, poised to take off to even greater heights.

With all of this change, we want to assure you that our mission remains consistent: we will continue to increase awareness of ALS; we are committed to providing the best care for our PALS and their families; and we will support the world-class scientific ALS research until there is a cure.

For those of you who donated for the first time this year, welcome. For those of you who have been long time contributors, we are so grateful that you continue to put your faith in us. Regardless of how long or how much, your generosity has made an impact. Because of you, what began in someone's living room in 1977 has evolved into an organization with world-wide impact.

As we embark on this next chapter of the Foundation's history, we know the future is very bright and have never felt more optimistic. But the fight is far from over, and we need your help to continue. While we celebrate our impact on the ALS community, we vow to never stop working until we have a cure.

We won't let the ice melt!



Ken Hoffman
President



Andrea Pauls Backman
Executive Director

Celebrating Impact through **Collaboration**

In 2014, the 35-year partnership between Northwestern University Feinberg School of Medicine and the Les Turner ALS Foundation was strengthened with the Foundation's \$10 million commitment to create the **Les Turner ALS Research and Patient Center at Northwestern Medicine**. In addition, the Foundation and the Feinberg School are leading a major effort to raise \$10 million in endowed funds to establish the naming of the Les Turner ALS Center in perpetuity.

In the spring of 2015, the Foundation was pleased to fund the first \$1.1 million toward the endowment's \$10 million goal.



**Photo: NU and
Foundation Staff
(left to right)**

Dimitri Krainc, MD, PhD, Chair, Department of Neurology, Northwestern University Feinberg School of Medicine; Harvey Gaffen, President Emeritus, Les Turner ALS Foundation; Wendy Abrams, former Executive Director, Les Turner ALS Foundation; Ken Crane, Board Member, Les Turner ALS Foundation; Ken Hoffman, President, Les Turner ALS Foundation; Scott Heller, MD, Board Member, Les Turner ALS Foundation

Neuroscience at the Forefront

Within one institute, the Center will bring together the three Les Turner ALS Research Laboratories, the Lois Insolia ALS Clinic, an ALS Tissue Bank and other ALS research, clinical and education activities at Northwestern.

The gift to create the Center exemplifies the longstanding commitment and high-impact collaboration between the Foundation and Northwestern Medicine to raise awareness

about ALS and support for finding its cure. The Les Turner ALS Center sets the pace in the field of ALS and offers hope for the future of care, research, training, and outreach relating to ALS.

The establishment of the Center at Northwestern Medicine has created an unprecedented opportunity to further advance scientists' understanding of this very challenging disease and, consequently, enhance the care provided to people with ALS today and in the future.

Celebrating Impact in Patient Care

In 1986, the Foundation pioneered a comprehensive, patient-centered system of care that today serves as a model for other ALS organizations across the globe, including a multi-disciplinary outpatient clinic.

Nearly 90% of PALS in the Chicagoland area are touched in one way or another by services provided by the Les Turner ALS Foundation. The Foundation's patient services programs help people with ALS (PALS) and their loved ones cope with the day-to-day challenges of living with a chronic and debilitating disease. We offer a comprehensive continuum of care that provides critical support to improve a PALS' quality of life.

The Lois Insolita ALS Clinic at the Les Turner ALS Research and Patient Center at Northwestern Medicine has long been considered one of the nation's top treatment centers for ALS. Trained specialists use a multi-disciplinary approach to provide comprehensive diagnosis and disease management. They are dedicated to the total care and support of PALS, their families and caregivers.



Photo (left to right):

Michael Hall, RN; Jennifer L. Armstrong, RN, MSN/MHA, staff at the Lois Insolita ALS Clinic at the Les Turner ALS Research and Patient Center at Northwestern Medicine

815

Home visits conducted

808

Patient visits to the
Lois Insolita ALS Clinic

361

PALS, family members and
loved ones facilitated by
monthly support groups

24

Dan Nelson ALS
Respite Care Grants
awarded

4th

Monthly support group
added in Chicago

29

Equipment grants
distributed through
the Ralph Russo
Patient & Family
Services Grant
Program

84

PALS lost to ALS

89

Rides provided to PALS
through the Stuart Rosen
Transportation Fund

155

new PALS seen at the
Lois Insolita ALS Clinic

Celebrating Impact through **Research**

Northwestern University Feinberg School of Medicine is the focus of much of the ALS research in the United States. The Foundation supports three research laboratories through the Center at Northwestern Medicine.



Photo (left to right):

Evangelos Kiskinis, PhD; P. Hande Ozdinler, PhD; Teepu Siddique, MD

In January 2015, a third Les Turner ALS Research Laboratory was launched at the Center under the leadership of Evangelos Kiskinis, PhD, who was recruited from Harvard. The addition of Dr. Kiskinis' lab was made possible because of our generous donors.

While at Harvard, Dr. Kiskinis acquired expertise in human stem cell biology and his research efforts led to the discovery of molecular pathways that become dysfunctional in the motor neurons of ALS patients along with the discovery of a potential

small molecule therapeutic interventions that will be tested in clinical trials in 2015.

As a member of the Les Turner ALS research laboratories, Dr. Kiskinis and his colleagues are working to understand the level and nature of heterogeneity in ALS and to identify points of effective and targeted therapeutic intervention. He is conducting these research projects using a combination of in vitro, stem cell-based approaches and global genomic assays and in vivo mouse models of the disease.

“I am sincerely excited to become a part of the Northwestern Medical School community and I am particularly looking forward to working with the researchers and staff at the Les Turner ALS Foundation. I am humbled and grateful for their support—I am dedicated to the fight against ALS and I strongly believe that by working as a group, we can have a meaningful impact in the next few years.” ~ Dr. Kiskinis

The Les Turner ALS Research Laboratory led by Dr. P. Hande Ozdinler 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.

In 2014, Dr. Ozdinler's lab achieved the following major accomplishments:

- Became the first lab to generate the reporter line for upper motor neurons, making their mouse model publicly available and allowing scientists from all over the world to have equal access to it.
- Discovered one cellular mechanism to explain upper motor neuron vulnerability. This discovery has been accepted to be published in *Cerebral Cortex*, one of the highest impact journals in the field.
- Hosted the 4th Annual Les Turner Symposium on ALS and NeuroRepair in November. Seven different institutions from Chicago and the Midwest participated, with 18 speakers, 31 abstracts/posters and a keynote speaker from the National Institute of Health. For the first time, the Symposium included a parallel session for people with ALS (PALS) and their families. A total of 175 people were in attendance.

The Les Turner ALS Research Laboratory led by Dr. Teepu Siddique focuses on determining the genetic cause of inherited cases known as “familial ALS” (FALS). Recent projects have also uncovered genetic links to currently unexplained cases known as “sporadic ALS” (SALS).

In 2014, Dr. Siddique's lab achieved the following major accomplishments:

- Published a paper demonstrating a new mouse model of mutant UBQLN2-linked dementia. Mutations in the UBQLN2 gene, which encodes the ubiquitin-like protein ubiquilin2, have been shown to cause ALS and ALS/dementia. This mouse model proves a useful tool to further study dementia and develop rational therapies.
- Worked on a large scale discovery of genes in SALS and genes that cause FALS. For approximately 40% of families with FALS, the cause of their disease is unknown. Early experimental results using a technique called Whole Exome Sequencing suggest the lab identified additional genes for ALS research.
- Made significant progress on the investigation of how a specific type of mutation within the ATXN2 gene correlates to onset, development and severity of SALS. This lab is in a unique position to address SALS research due to its focus on gathering detailed family history information from its research participants, providing a solid foundation for differentiating sporadic from familial disease. While this work is ongoing, preliminary data was presented at the 44th Annual Society for Neuroscience meeting in Washington D.C. in November 2014.



Celebrating Impact in Awareness

During the course of a few weeks in August of 2014, the world was literally “soaked” by a social media phenomenon, the ALS Ice Bucket Challenge. Everyone from Bill Gates to Oprah Winfrey poured a bucket of ice water over his or her head in the name of ALS awareness. Facebook reported that 2.4 million videos related to the Ice Bucket Challenge were shared and more than 28 million people posted, commented or liked these posts.



Thanks to the thousands of people who chose the Les Turner ALS Foundation as the recipient of their Challenge donations, fundraising efforts reached record highs. In just six weeks, over **10,000 donors** gave the Foundation more than **\$1 million!**

Our website traffic increased by **474%** and our Facebook followers increased by **1,825%**. By year's end, the Foundation had increased its fundraising efforts by **84% over 2013** and significantly increased program services.

Even more impressive, the Challenge got people talking about ALS. What once was a rare disease was now part of everyday conversation. People were no longer asking, “What is ALS?” they were asking, “Have you done the ALS Ice Bucket Challenge?”

Despite this success, we aren't letting the ice melt...

The ALS Ice Bucket Challenge took the world by storm, but our work is far from over. Please do your part to make sure the ice doesn't melt.

Get involved!

Make a Donation

Create a Walk Team

Volunteer at a Fundraising Event

Like us on Facebook

Follow us on Twitter

Financial Report

More than 96% of the Foundation's revenue comes from donations—people like you who have seen the impact that bringing hope and help can have on an ALS patient and their family.

The Foundation is proud to continue to receive a four-star rating from Charity Navigator. This means we exceed industry standards and outperform nearly all charities in accountability and transparency. You can give with confidence.



The condensed financial statements have been derived from the audited financial statements, which are available on the Foundation website or at the offices of the Les Turner ALS Foundation

Statement of Financial Position

for the year ended December 31

	2014	2013
Total Assets	\$ 4,737,823	\$ 2,906,521
<i>(of which \$1,397,015 and \$122,525, respectively, is temporarily restricted)</i>		
Total Liabilities	1,971,675	1,657,021
Total Net Assets	2,766,148	1,249,500
Total Liabilities and Net Assets	\$ 4,737,823	\$ 2,906,521

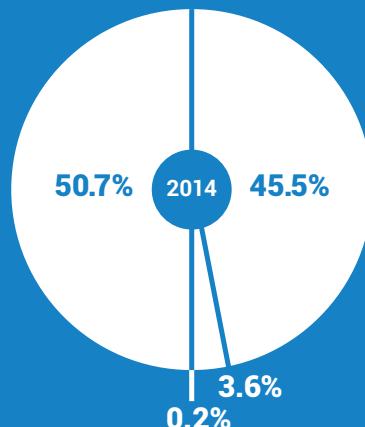
Statement of Activities

for the year ended December 31

Total Operating Revenue	\$ 4,680,889	\$ 2,540,970
<i>(of which \$1,274,490 is temporarily restricted as of 12/31/14)</i>		
Operating Expenses		
Program Services	2,587,833	2,218,299
Supporting Services	576,408	527,208
Total Operating Expenses	3,164,241	2,745,507
Change in Net Assets	1,516,648	-204,537
Net Assets, Beginning of Year	1,249,500	1,454,037
Net Assets, End of Year	\$ 2,766,148	\$ 1,249,500

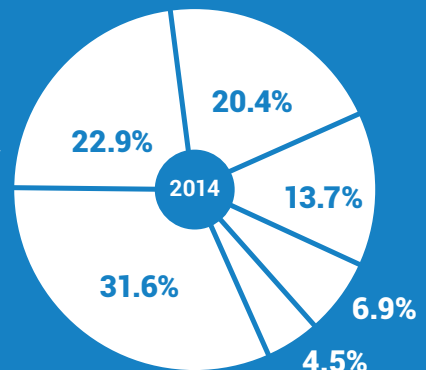
Revenues

50.7% Contributions & Bequests
45.5% Fundraising (net)
3.6% Grants
0.2% Investments



Expenses

31.6% Research/Endowment
22.9% Patient & Family Services
20.4% Lois Insolita ALS Clinic
13.7% Management
6.9% Education
4.5% Development



Leadership



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BIK & Co., LLP
Palatine, Illinois

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Northwestern University Feinberg
School of Medicine

Community Health
Charities of Illinois

International Alliance of ALS/
MND Associations

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

Editorial

Maria Zeller Brauer

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Ogilvy & Mather Chicago

Looking Ahead

In May 2015, through a joint collaboration with Northwestern Medicine, we launched a major campaign for ALS Awareness Month designed pro-bono by international marketing and communications company Ogilvy & Mather. Visit lesturnerals.org to learn more about this impactful project.

HELP
FREEZE
ALS

**LES
TURNER
ALS
FOUNDATION**

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