

LES
TURNER
ALS
FOUNDATION



INTERNATIONAL
ALLIANCE OF
ALS/MND
ASSOCIATIONS

Partnerships and Collaborations

Andrea Pauls Backman, MBA
Chief Executive Officer
December 2, 2019



Our Mission

To provide the most comprehensive care and support to people living with ALS and their families in Chicagoland so they can confidently navigate the disease, and advance scientific research for the prevention, treatment and cure of ALS.

Our Les Turner ALS Family

Since 1977, we've built a local community that feels like family. Together, we encourage and empower each other throughout our journey with the disease and beyond.



Creating a Local Community of Support



9,025

Event
Attendees



8,584

Donors



7,470

Social Media
Followers



1,115

Education
Participants



577

Volunteers



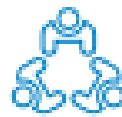
233

People Living
with ALS



17

Staff
Members



19

Board of
Director
Members



31

Clinicians



42

Researchers

Providing Individualized Care and Support



visits from our nurses & social workers to the homes of people living with ALS



appointments at our Lois Insolia ALS Clinic to people living with ALS



Support Group Participants received vital help through five monthly groups



in grant dollars to 80 families living with ALS to help ease the cost of basic necessities

M Northwestern Medicine
Feinberg School of Medicine

Les Turner ALS Center

Our Values

Courage

We don't shy away from discussing the challenges of ALS/MND

Individuality

We treat each person as a unique individual with a valuable voice

Kindness

We provide constant reassurance, comfort and compassion

Expertise

We bring together all ALS/MND disciplines under one umbrella, enhancing collaborations between families, researchers and clinicians to provide a full spectrum of treatment to ALS/MND patients while facilitating the development of new therapies

Tenacity

We are a committed and consistent resource to people affected by ALS/MND

Collaboration

We believe the best care comes from working together

Our Collaboration Partners



Supporting ALS Families by Helping the Youngest Members



HOPE
LOVES
COMPANY™

- Hope Loves Company created Camp HLC™ to give kids solace, understanding and their own community
- We brought Camp HLC™ to Chicago to offer our families a 3-day overnight retreat for children and young adults aged 6-21
- Important addition to our extensive wraparound programming for families dealing with ALS/MND



Supporting Awareness and Advocacy

I AM ALS



- A new patient-centric ALS/MND organization formed to empower patients and collaborate with existing organizations to increase awareness and funds for research
- We were asked to be the fiscal sponsor until I AM ALS received its charitable tax status
- Continued collaborations include a new national ALS/MND collaborative and shared advocacy efforts

Supporting Research

- Answer ALS is the largest coordinated research study in ALS/MND
 - Collects data, genomic information and stem cell lines from 1,000 people living with ALS
 - Makes 20 trillion bytes of data freely available to all researchers
 - Needed to reach its enrollment goal by the end of 2018
- We funded the costs of the study at our ALS clinic to help Answer ALS recruit faster.
- Enrollment goals were reached!



M Northwestern Medicine
Feinberg School of Medicine

Les Turner ALS Center

Supporting Research



- Tracks prevalence of ALS in the US
- Describes demographics of people with ALS
- Funds research to examine risk factors for ALS
- Patient notification tool helps connect industry clinical trials and other research studies with people with ALS
- As a partner, we assist with enrollment and promotional efforts



Lessons Learned from Collaborations

Collaborations are hard work and require mutual respect

You will need more precise and more frequent communication than you think

Guiding Principle:
How does this collaboration advance the field and help more people with ALS/MND?

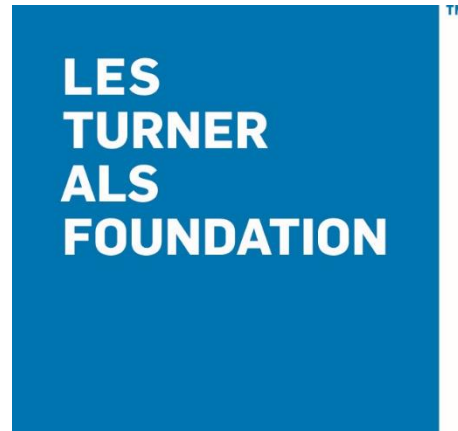
When beneficial to all parties, long term collaborations are effective uses of limited resources

It's OK to collaborate once and move on

Our Most Important Partners



Thank you!



lesturnerals.org

847 679 3311

 Facebook  Twitter  Instagram
@LesTurnerALS