Partnerships and Collaborations

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Chief Executive Officer
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The Les Turner ALS Foundation is the leader in comprehensive ALS care in Chicagoland.
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

- Event Attendees: 9,025
- Donors: 8,584
- Social Media Followers: 7,470
- Education Participants: 1,115
- Volunteers: 577
- People Living with ALS: 233
- Staff Members: 17
- Board of Director Members: 19
- Clinicians: 31
- Researchers: 42
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

Northwestern Medicine
Feinberg School of Medicine

Les Turner ALS Center
Courage
We don’t shy away from discussing the challenges of ALS/MND

Kindness
We provide constant reassurance, comfort and compassion

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

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

Collaboration
We believe the best care comes from working together

Individuality
We treat each person as a unique individual with a valuable voice
Our Collaboration Partners

ALS Association
ANSWER ALS
I AM ALS
Muscular Dystrophy Association
HOPE LOVES COMPANY
ATSDR
Supporting ALS Families by Helping the Youngest Members

- 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

- 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!
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.

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

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

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

It’s OK to collaborate once and move on.
Our Most Important Partners
Thank you!

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