



# CELEBRATING COMMUNITY

## The Les Turner ALS Foundation Annual Report 2012

Advancing scientific research ■ Providing care and support ■ Increasing awareness





## A BRIEF HISTORY

Amyotrophic Lateral Sclerosis (ALS), more commonly known as Lou Gehrig's disease for the New York Yankees icon, is a progressive, degenerative disease affecting motor neurons. Motor neurons carrying impulses from the brain to the muscles cease function and eventually die, causing muscle weakness, difficulty speaking and swallowing, and ultimately total paralysis and death. The disease is not bound by race, culture or socioeconomic status and, at any given time, approximately 35,000 people in the U.S. are living with ALS. Onset of symptoms typically occurs between the ages of 35 and 65, but ALS can strike at any age. While treatments and interventions can help alleviate some symptoms, enhance quality of life and prolong survival – *there is no cure.*



Les Turner, after being diagnosed with ALS in 1976, was frustrated by the lack of information and research on ALS. Shortly before his death in 1978, Les, along with his family and friends, established the Les Turner

ALS Foundation so that ALS patients and their families could have the resources, support and hope for a cure that Les did not have.

For more than three decades, the Foundation has been the only independent, publicly-supported non-profit organization in Chicagoland dedicated solely to the treatment and elimination of ALS. The Foundation is a nationally recognized leader in patient services, research and education for ALS and other motor neuron diseases.

The Foundation partnered with Northwestern University Feinberg School of Medicine in 1979 where it supports a large multi-disciplinary clinical program and two cutting-edge scientific research laboratories. The full spectrum of patient services includes professional consultation

services, support groups, medical equipment loan programs, respite grants and educational programs.

The mission of the Les Turner ALS Foundation is to raise funds 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
- Increase awareness and education of ALS



## A MESSAGE FROM THE PRESIDENT AND THE EXECUTIVE DIRECTOR

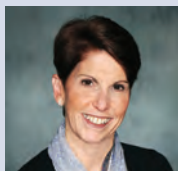
Dear Friends,

It is opportunities like this that we so appreciate the chance to thank all of you – the devoted members of the ALS Community! It's because of your dedication, generosity and support that we have many reasons to celebrate 2012.

- In September, a record number of participants came together in celebration and support at the 11th annual ALS Walk4Life. The day started out a bit chilly, but that didn't discourage the more than 6,000 walkers who got to experience the event's new location at iconic Soldier Field!
- At the age of 70, philanthropist, Board Member, and long-time supporter of ALS, Bob Lee, rode his bike 964 miles along the West Coast of the United States to raise money for ALS research, cancer and hospice care. Bob Lee touched so many people



**Harvey Gaffen**  
President



**Wendy Abrams**  
Executive Director

along his journey, expanding the reach of the Foundation and raising an amazing \$279,500 for our ALS research labs.

- And we were grateful to meet the energetic financial blogger, Mike "Mish" Shedlock, whose Cash Raffle raised more than \$241,000! Mish also nominated the Foundation in JP Morgan Chase's Community Giving Contest and, thanks to his huge fan base, the Foundation won \$20,000. In 2012, Mish's multiple fundraising efforts raised more than \$261,000!

We encounter inspirational people each year, and they are truly what helps to keep us fighting for a cure! Whether your efforts were large or small, you made an impact! This year would not have given us so much to celebrate if it weren't for our generous donors and our tireless volunteers.

We hope that these stories continue to inspire you. Because we won't stop until effective treatments and ultimately, a cure, for ALS is found. Then we will truly celebrate.



In 1979, the first Les Turner ALS Research Laboratory was established with a staff of four dedicated to finding a cure for ALS. In 2012, dozens of scientists worked tirelessly to continue the quest for answers.

#### Les Turner ALS Research Initiative

Led by **Teepu Siddique**, MD, since 1991, the Foundation's first research lab focuses on the genetic origin, development and treatment of ALS. Dr. Siddique and his team maintain an extensive blood, cerebrospinal fluid, brain and spinal cord tissue bank collected from people both with and without ALS for their studies. Major achievements include:

- **Linked** the pathway of pathogenesis of sporadic ALS, familial ALS and ALS/dementia with the ubiquitin-proteasome system (UPS) and the autophagosome – lysosome pathway in neurons affected by these disorders. This connects the dysfunction discovered in recycling pathways, the dysfunctional mitochondria in SOD1 that cannot be recycled, and the novel primary defect in the new gene with a mitochondrial address.

This is noteworthy because **these pathways are disrupted in all types of ALS**. This means that drugs that improve or correct functioning in these pathways offer the prospect of a targeted and therefore effective treatment for ALS.

*If you are interested in participating in a Les Turner ALS Foundation Laboratory Tour, please contact the Foundation Office.*

- **Developed** a UBQLN2 transgenic mouse to further study the mutations of the UBQLN2 and SQSTM1 (p-62) genes. This mutation was discovered in 2011 and was the first time a causative mechanism for ALS had been identified.



Led by **P. Hande Ozdinler**, PhD, the Foundation's second lab focuses on corticospinal motor neurons (CSMN) – tiny neurons that live in the cortex of the brain and send out messages to the spinal cord. ALS attacks these neurons, along with the neurons that live in the spinal cord itself. In 2012, the Ozdinler lab achieved the following major accomplishments:

- **Developed** AAV-mediated gene delivery approach to transduce only the neurons of interest in the cerebral cortex. This has not been possible before and it has the potential to target the neurons of interest and develop targeted treatment strategies in the motor cortex of ALS patients.
- **Hosted** the 2nd annual Symposium on ALS and Neurodegeneration, where scientists from inherently different fields come together to present on similar issues, thus contributing to the field of neurodegeneration at large.



The Foundation administers a comprehensive continuum of care that provides critical support to improve a patient's quality of life. Patient service programs and resources are available to ALS patients and caregivers in the Chicagoland area – at no cost. In 2012 the Foundation:

- **Conducted** 708 patient visits by an ALS nurse consultant or Social Worker
- **Provided** financial assistance to 19 families through the Ralph Russo Patient and Family Services Grant Program
- **Awarded** 15 grants through the Dan Nelson ALS Respite Grant Program
- **Facilitated** support groups for 229 patients and caregivers
- **Provided** transportation to 24 families to the Les Turner/Lois Insolia ALS Center through the Stuart Rosen Transportation Fund

**The Les Turner/Lois Insolia ALS Center** at Northwestern in Chicago is considered one of the nation's top treatment centers for ALS patients. A multi-disciplinary team approach provides comprehensive treatment and support of people with ALS, their families and caregivers. In 2012, there were 565 patient visits to the Center.



Members of the international ALS community gathered in Chicago in December, for the Annual Meeting of the International Alliance of ALS/MND Associations and the **International Symposium on ALS/MND**. These unique events brought together some of the best and brightest from around the world to share initiatives and develop strategies for fighting ALS/MND. As the local host, the Les Turner ALS Foundation hosted two events: Ask the Experts and the Allied Professionals Forum.

*The Foundation honored Denise DiMarzo and Chris Benyo as our Patients of the Year, Elsa Cherwak as our Volunteer of the Year, and Delaney Gibbons & Taylor Morrissey as our Junior Volunteers of the Year at the 2012 Education Forum and Volunteer Reception.*



# CELEBRATE PHILANTHROPY



**M**ost of the Foundation's supporters are individuals – people like you who give their money, time and effort in support of the ALS community.

**Hope Through Caring Award Dinner** – Honors those who have shown outstanding commitment to the ALS community. In 2012, the Foundation honored the family of A. William “Bill” Haarlow, III. Held at the Four Seasons in Chicago, the event was a great success and raised more than \$573,000.

**Tag Days** – Each May, these locally organized fundraising drives can be found at intersections, shopping malls and train stations in communities across Chicagoland in celebration of ALS Awareness Month. From Union Station to Barrington, Tag Days Captains organized 25 drives and raised \$73,000.

**Run4ALS Program** – Avid runners and weekend warriors alike support the ALS community one race at a time. This program has grown leaps and bounds in only two short years. In 2012, 613 runners raised more

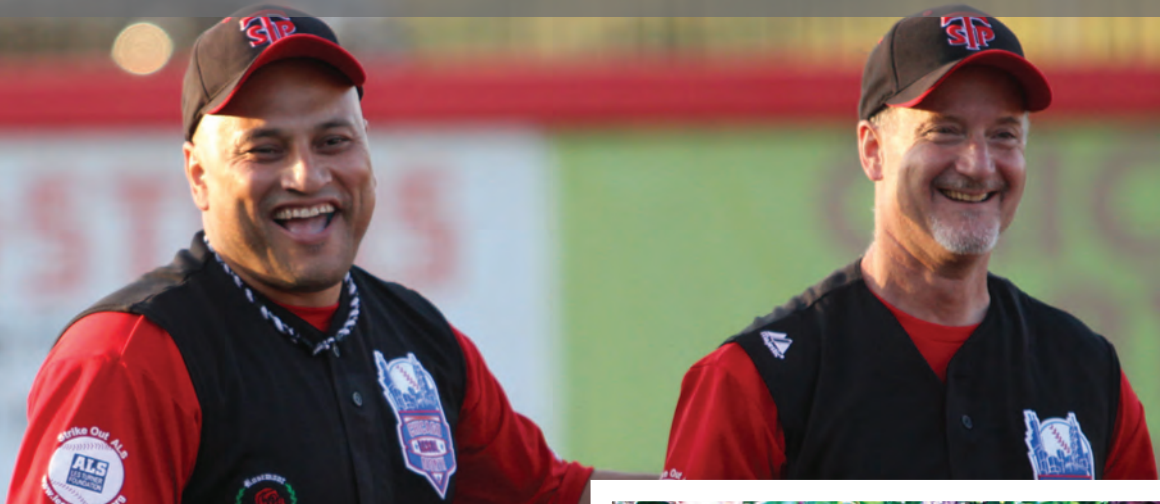
than \$219,000! The program's signature event, Strike Out ALS, 5K gives runners the one in a lifetime opportunity to run the warning track at U.S. Cellular Field.

## **ALS Walk4Life**

– A chilly start did not deter the more than 6,000 supporters from walking along the beautiful Chicago lakefront and gather at a new and exciting location – Soldier Field! More than 230 teams got the chance to walk through Soldier Field and their efforts helped to raise a record breaking \$850,000!



# CELEBRATE COMMUNITY



Each year, members of the ALS community – families, businesses and community groups – join the Foundation in our effort to raise funds and awareness for ALS. In 2012, these third party fundraisers brought in more than \$678,000!

**Cash Raffle** – Mike “Mish” Shedlock, one of the nation’s top financial bloggers, lost his dear wife, Joanne, to ALS in 2012. He turned his grief into an amazing fundraising effort that touched more than 40 countries. Mish’s Cash Raffle generated more than \$241,000 in net revenue for the Foundation’s ALS research laboratories!

**Ride for 3 Reasons** – Bob Lee, at the age of 70, pedaled his way from Canada to Mexico – at total of 964 miles – to raise funds for ALS Research, Cancer and Hospice Care. On his third and final ride, Bob raised an amazing \$279,000 in support of the Foundation’s ALS research laboratories.



Joanne Shedlock

**Dodgin’ 4 Lou Gehrig’s Disease** – In 2012, Delaney Gibbons and Taylor Morrissey, junior high students, organized a dodgeball tournament in honor of their former PE teacher, Chris Benyo, whose wife, Denise, had been diagnosed with ALS. What started out as a way to support a beloved teacher, turned out to be a successful fundraising event, raising more than \$13,000 in its first year!”



*“What gives me the drive is the passion for people who can’t . . . they give me the pedal power.”*

*~Bob Lee*

# FINANCIAL REPORT

## Fiscal Year 2012

Consolidated Financial Summary for the year ending December 31, 2012.

	Unrestricted	Temporarily Restricted	Total Year
<b>Statement of Financial Position</b>			
Total Assets	2,439,859	457,034	2,896,893
Liabilities and Net Assets			
Current Liabilities	1,442,856	0	1,442,856
Net Assets	997,003	457,034	1,454,037
Total Liabilities & Net Assets	2,439,859	457,034	2,896,893

## Statement of Activities

### Public Support & Revenue

Fund-Raising Events (net)	1,479,800	303,894	1,783,694
Grants	83,802	93,500	177,302
Contributions & Bequests	581,173	153,930	735,103
Memorials	151,804	3,180	154,984
Annual Appeal	130,645	0	130,645
Investment Income	16,752	0	16,752
Rental Fees	140	0	140
Net Assets released from Restrictions	195,547	(195,547)	0

### Total Public Support,

<b>Revenue and Reclassification</b>	2,639,663	358,957	2,998,620
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### Expenses

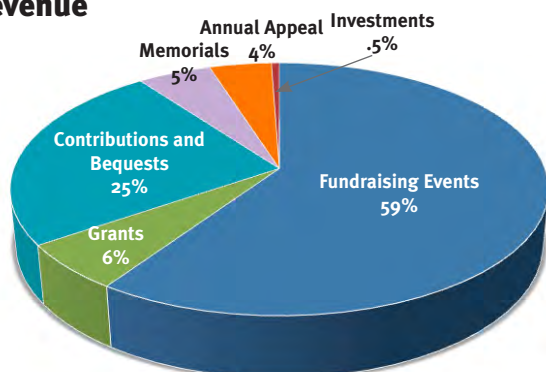
Program Services			
Research	755,793		
Les Turner/Lois Insolia ALS Center	573,005		
Patient & Family Services Expensers	591,502		
Education Expenses	126,201		
Supporting Services Expenses			
Financial Development and Campaign	120,245		
Management and General	309,001		

### Total Expenses

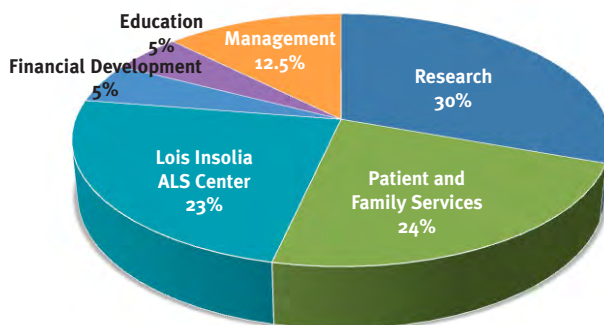
Total Expenses	2,475,747		
Increase in Net Assets	163,916	358,957	522,873
Net Assets - Beginning of year	833,087	98,077	931,164
Net Assets - End of year	997,003	457,034	1,454,037

The foregoing condensed financial statements have been derived from the audited financial statements, which are available for public inspection at the offices of the Les Turner ALS Foundation.

## Revenue



## Expense



# OUR GENEROUS SUPPORTERS



Every effort has been made to include all donors of \$500 or more. We apologize if we have made errors or omissions. Please contact us so we may correctly acknowledge your support in the future. The Foundation is appreciative of every donation, regardless of the amount. Unfortunately, we are unable to recognize all donors in this annual report.

## Honored Friends

### (\$100,000 and above)

50/50 Cash Raffle (Mike "Mish" Shedlock)  
Anonymous  
Patricia Nelson Stiede Trust  
Ride for 3 Reasons (Bob Lee)

## Sustaining Friends

### (\$50,000 - \$99,999)

Diamond Dare (Ross Wolfson)  
Gilbert and Jacqueline R. Fern Foundation  
Mrs. Evangeline R. Haarlow  
James V. Insolvia Family Foundation

## Inspiring Friends

### (\$25,000 - \$49,999)

A Long Swim: Catalina Island  
(Doug McConnell)  
Mr. J. Douglas Esson  
Dr. and Mrs. William N. Haarlow  
Mr. and Mrs. Blair Haarlow  
Haarlow Family Charitable Foundation  
Herbert C. Wenske Foundation  
Mr. and Mrs. Richard M. Hirsch  
Paul A. & Joan S. Rubschlager Foundation  
Mr. and Mrs. Richard Templer  
The Gilbert Family Foundation

## Devoted Friends

### (\$10,000 - \$24,999)

Armin & Esther Hirsch Foundation  
Blowitz-Ridgeway Foundation  
Estate of Madeleine Camilleri  
Charles & M.R. Shapiro Foundation  
Mr. and Mrs. Gerald Cohen  
Davidson, Dawson & Clark LLP  
Ms. Robin D. Fern  
First Bank of Highland Park Foundation  
Ms. Cindy Fluxgold and  
Mr. Terry Peigh  
Frances Schilling Vermillion Memorial Golf  
Outing  
Full Circle Foundation  
Garry Griffith Golf Outing  
Mr. and Mrs. Joseph B. Glossberg  
Mr. and Mrs. Kenneth A. Hoffman  
Illinois Tool Works, Inc.  
Mr. and Mrs. Robert Jones  
Joseph and Bessie Feinberg Foundation  
JP Morgan Chase & Co.  
Judd A. & Marjorie Weinberg Family  
Foundation  
Mr. Fred A. Krehbiel  
Lew Blond Memorial  
5K Run/ Walk

Mr. and Mrs. W. Scott Nehs  
Net-Gold Services  
Northwestern University Feinberg School  
of Medicine  
ROAR (Ralph Russo Memorial Golf Classic)  
Mr. and Mrs. Gary V. Saqui  
Mr. and Mrs. Loren H. Semler  
Sitka Pacific Capital Management LLC  
Ms. Nancy R. Stamm  
Sunshine Charitable Foundation  
Mr. and Mrs. Theodore D. Thompson  
Universal Holding Corporation  
Vanguard Charitable Endowment Program  
Walgreens Infusion and Respiratory  
Services  
Willow Springs Foundation

## Supporting Friends

### (\$5,000 - \$9,999)

Alpha Tau Omega Foundation  
ALS Awareness 5K (Lori Lessen)  
Arthur J. Gallagher & Co.  
Mr. and Mrs. Peter Barrett  
Mr. Neil Berg  
Berrien Community Foundation  
Boughton Materials, Inc.  
Mr. R. Jacob Bump  
Cardinal Health Foundation Inc.  
Dr. Cynthia Charlier D.V.M.  
Mr. and Mrs. John R. Collins  
Dellora A. and Lester J. Norris Foundation  
Mr. Jos Evans  
Ms. Megan Fisher  
Mr. and Mrs. Torrey N. Foster  
Mr. and Mrs. Harvey Gaffan  
Game Night (Wendy Adams)  
Gofen and Glossberg, L.L.C.  
Mr. and Mrs. Stephen Goulding  
Mr. and Mrs. Steven Heronemus  
Hill-Rom  
John W. Anderson Foundation  
Kathleen R. Whelan Family Trust  
Mr. and Mrs. Jeffrey R. Kautz  
Dr. and Mrs. Robert Kushner  
Mr. and Mrs. Michael Macakanja  
Mr. and Mrs. Jim I. McClure  
Dr. Sheila M. McCullough  
Meelia Family Foundation  
Mr. and Mrs. E.J. Mooney  
Pearl W. Hagemann Living Trust  
RR Donnelley  
Mr. and Mrs. Rick Sanchez  
Dr. and Mrs. Richard B. Silverman  
The Dennis O'Toole Family Foundation  
The Berner Charitable & Scholarship  
Foundation

The Cooper Foundation  
The Davee Foundation  
The Dennis J. Smith Legacy Foundation Inc.  
The Dr. Donald Lies and Helen Lies Fund  
The Duchossois Family Foundation  
Unbridled Eve  
(York Management)  
United Displaycraft

## Discovering Friends

### (\$1,000 - \$4,999)

Ms. Wendy M. Abrams  
ABT Electronics, Inc.  
Abt Family Charitable Foundation  
Mr. Lakshman Achuthan  
Ms. Mary Adams  
Adreani Foundation  
Mr. Todd Ahlsten  
Allan L. Maca Foundation  
American Chartered Bank  
Mr. Alexi Anastasio  
Mr. Jon Anda  
Mr. Wayne Andersen  
Mr. and Mrs. Gerard V. Anderson  
Ms. M. Louise Anderson  
Mr. Gregory G. Andresen  
Mr. and Mrs. Gregory S. Apter  
Arts4ALS (Eve Brownstone)  
Mrs. Dawn Ashner  
Astellas  
Augustana College  
Mr. Bruce Bachmann  
Mr. Gary Bahre  
Mrs. Millicent S. Bates  
Mr. Navnit Batheja  
Mr. Randy Beeman  
Benchmark Construction Company, Inc.  
Mr. and Mrs. Armand H. Bendersky  
Ms. Sonja Berggren and Mr. Patrick Seaver  
Mr. Steve Berliant  
Mr. and Mrs. Rody Biggett  
Mr. James I. Black III  
Mr. and Mrs. Geoffrey L. Bloomingdale  
Blum-Kovler Foundation  
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Mr. Brad Bourland  
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Mrs. Rhona Bresler  
Mr. Matthew O. Briggs  
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Mr. and Mrs. David Brule  
Mr. and Mrs. Douglas Bryant

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Mr. Brian Cartmell  
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Mr. and Mrs. Dennis Chaplin  
Mr. and Mrs. Bryce S. Chase  
Mrs. Rochelle Chasin  
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Chicago White Sox Charities, Inc.  
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Mr. and Mrs. Tom Clausen  
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Mr. and Mrs. Alfred Contarino  
Mr. Doug Cook  
Mrs. Anna Cordeiro and Miss Malaika  
Cordeiro  
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Mr. James Cornehlson  
Mr. Kenneth M. Crane  
Mr. and Mrs. Marv Crook  
Mr. Thomas Culliton and Ms. Susan  
Sambor  
Mr. John T. Culliton  
Mr. and Mrs. Patrick Cunningham  
Mr. William Cuthbert  
Damico Family Foundation  
Dance for ALS (Kobi Dvora)  
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Delaware Place Bank  
Delta Dental of Kentucky  
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Mr. and Mrs. Patrick D. Dillon  
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Mr. Chris Benyo  
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Mr. Mitchell Cobey  
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Schilling Construction, Inc.  
Mr. Jeffrey Schlammans  
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Schooler  
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Mr. Henry Seurer  
Seymour A. Cohen Family  
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Ms. Rose L. Shure  
Dr. and Mrs. Norman Silverstein  
Dr. Gerald Silverstein  
Mr. and Mrs. Jorge Simes  
Ms. Kathryn J. Simonds  
Mr. Jeffrey Singer  
Mr. and Mrs. Peter G. Skelly  
Mr. Harold Skolnick  
Mr. and Mrs. Charles F. Smith  
Mr. Gregg Smith  
Mrs. Katherine Somerfield  
Mr. and Mrs. Edward J. Spiegel  
St. Thomas of Villanova Parish  
Mr. Robert Stafford  
Mr. and Mrs. Gary J. Stanko  
Ms. Sara Star  
Mr. and Mrs. Peter Stewart  
Mrs. Charles Stinnett  
Mr. David Stockman  
Mr. Don Strasser  
Ms. Suzan Suer  
Mr. and Mrs. William J. Sullivan  
Synapse Biomedical, Inc.  
Ms. Judy Szatkowski  
Dr. Bee Wan Tan  
Taxman Family Foundation  
Mr. and Mrs. Andreas D. Taylor  
Mr. and Mrs. Roger L. Taylor  
The Chamberlain Group  
The Coughlin Family  
Thanksgiving Fund  
The Helping Hand Sales, Inc.  
The Horwich Family Foundation  
The J&M Thompson Family Gift  
Fund  
The Private Bank  
Mr. Ross Thomas  
Mr. Mark Thompson  
Total Control Sports, Inc.  
Transco Inc. Charitable  
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## Matching/Workplace

Abbott Laboratories Employee  
 Giving Campaign  
 Allstate Giving Campaign  
 AON Foundation  
 AT&T United Way Employee  
 Giving Campaign  
 Bank of America - Matching Gift  
 Program  
 Bank of America United Way  
 Campaign  
 Baxter Employee Giving  
 Campaign  
 Baxter International Foundation  
 Baxter International, Inc.  
 BlackRock Matching Gift Program  
 BP Fabric of America Fund  
 Cardinal Health  
 Cardinal Health Foundation Inc.  
 Carmax Foundation  
 CNA Foundation  
 Community Health Charities of  
 Illinois  
 Davis Selected Advisers-NY Inc.  
 Dell Direct Giving Campaign  
 Deutsche Bank Americas  
 Foundation  
 FactSet Research Systems, Inc.  
 Fitch Ratings Matching Gifts  
 Program  
 Give with Liberty  
 Heart of Florida United Way, Inc.  
 Houghton Mifflin Harcourt  
 Matching Gift Program

HSBC Philanthropic Programs  
 IBM Employee Services Center  
 IBM Retiree Charitable Campaign  
 Illinois Tool Works, Inc.  
 Johnson & Johnson Family of  
 Companies  
 JPMorgan Chase Foundation  
 Kimberly Clark Foundation  
 Kirkland & Ellis  
 Macy's Foundation  
 McDonald's Corporation  
 McMaster-Carr Supply Company  
 Merck Partnership for Giving  
 Microsoft Matching Gifts  
 Program  
 Morgan Stanley  
 Motorola Solutions Foundation  
 Network for Good  
 Passport Health  
 Communications, Inc.  
 PepsiCo Foundation  
 Pfizer Foundation Matching Gifts  
 Program  
 Pharmaceutical Research and  
 Manufacturers of America  
 Quest Diagnostics  
 Salesforce Foundation  
 SAP Matching Gift Program  
 The GE Foundation  
 The RDI Group  
 The Warranty Group  
 Truist  
 UBS Matching Gift Program  
 United Way of Central  
 Illinois, Inc.  
 United Way of Greater  
 Philadelphia & SNJ  
 United Way of Lake County  
 United Way of Metropolitan  
 Chicago  
 UnitedHealth Group Employee  
 Giving Campaign  
 W.W. Grainger, Inc. Matching  
 Charitable Gifts Program  
 Wells Fargo Community Support  
 Campaign

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104.3 K-Hits FM/WJMK-FM  
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 Arlington Park  
 Autobahn Country Club  
 Avanti Skin Centers of Chicago  
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 Chicago Bandits  
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 Chicago Botanic Garden  
 Chicago Cubs  
 Chicago Historical Society  
 Chicago White Sox  
 Chicago Zoological Society  
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 Crown Plaza Avenue Chicago  
 Downtown  
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 Jenna Culliton  
 DeSoto House  
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 North Shore Conference Center  
 East Bank Club  
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 The Helping Hand Sales, Inc.  
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 Uncommon Ground  
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Information is current as of the printing  
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