YEAR AT A GLANCE 2016

OUR INTEGRATED MISSION OF RESEARCH, ADVOCACY, AND CARE SERVICES IS CRITICAL TO FINDING TREATMENTS AND A CURE FOR ALS.

RESEARCH

$38M
Committed to groundbreaking research.

125
Active research projects in 12 countries.

285
Studies funded by The ALS Association, published in leading scientific journals, critical knowledge to advance drug development and understanding of the disease.

ADVOCACY

1000
Advocates +109 people living with ALS came to Washington, D.C. to advance legislative priorities for people with ALS.

$8M
Secured for the National ALS Registry.

CARE SERVICES

12
New Certified Treatment Centers of Excellence, including the first-ever Veterans Administration facility in Ohio. Centers ensure patients receive the very best multidisciplinary care.

385
Medically professionals attended The Association's National Clinical Care Conference, learning valuable information to enhance care of people with ALS.

200
Members of Congress responded to ALS advocates by ensuring access to speech generating devices.

COLLABORATION

Launched groundbreaking initiative for legal guidance to help communities navigate the regulatory pathway with the U.S. Food and Drug Administration, including:

• 30 people with ALS
• 50 ALS organizations
• 48 ALS researchers
• NIH, pharmaceutical and biotech reps

FINDING TREATMENTS AND A CURE FOR ALS IS AT THE CENTER OF EVERYTHING WE DO.
VISION:

Create a world without ALS.

MISSION:

Leading the fight to treat and cure ALS through global research and nationwide advocacy while also empowering people with Lou Gehrig’s Disease and their families to live fuller lives by providing them with compassionate care and support.
"It has been a privilege to work on behalf of the ALS community during the most exciting time ever in the fight against ALS. With the 2014 ALS Ice Bucket Challenge came tremendous resources, and over the course of the last year, we put in place a plan to spend these dollars wisely and in ways that have had and will continue to have the biggest impact. Thank you to everyone who has supported our cause. We hope you will read the pages of this report and recognize your part in making a phenomenal difference in the lives of people living with this disease and those yet to be diagnosed."

Very best regards,

Barbara J. Newhouse,
President and CEO

Bill Thoet,
Chairman, National Board of Trustees
The ALS Association continued to utilize proceeds from the ALS Ice Bucket Challenge on research and care services initiatives during 2015.

For a full summary of financials, please visit ALSA.org/financials2016.

National Office and Chapters

The following unaudited summary reflects Association-wide financial activity for the year ended January 31, 2016.

**Total combined revenue** - $68,710,377

**Expenses:**
- Research - $17,271,304
- Other Program Activities - $47,087,088
- Fundraising - $12,400,891
- Administration - $6,892,446

**Total combined expenses** - $83,651,729

**Change in net assets** - <$14,941,352>

**Total combined assets** - $172,285,776
**Total combined liabilities** - $9,390,755
**Total combined net assets** - $162,895,021
Advancing the search for treatments and a cure

Major Research Collaborations
Fostering and funding collaborative research initiatives continued to be a major focus of The ALS Association during the past fiscal year. The Association contributed to the development of Answer ALS, partnering with Team Gleason and others to advance this important initiative.

Other collaborations included the Genomic Translation for ALS Clinical Care (GTAC), CReATe (Clinical Research in ALS and related disorders for Therapeutic Development) Consortium and ALS ONE. We also partnered with Prize4Life for the ALS Assistive Technology Challenge, which seeks to encourage the development of flexible, accessible technology to help people living with ALS communicate with ease.

Previously announced collaboratives, notably, the Neuro Collaborative in California, made considerable progress in advancing the search for treatments.

“The ALS Association, through its support of the Neuro Collaborative, has allowed us to approach therapeutics development for ALS with an urgency and at a scale that we could never do before.”

Steve Finkbeiner, M.D., Ph.D., Gladstone Institutes

Drug Development Contracts
A leader in linking academic institutions with industry, The ALS Association was pleased to have fostered partnerships to drive treatment approaches for ALS more rapidly to clinic, offering drug development contracts to Aquinnah Pharmaceuticals, Neurimmune AG, Treeway B.V., LTD, GlaxoSmithKline, Genentech, Voyager Therapeutics, Ionis Pharmaceuticals and Biogen.

Biomarker Discovery
The ALS Association is dedicated to the discovery of biomarkers, which are any measurable substance, like chemical changes in the blood or structural changes in the brain, that are desperately needed to improve diagnosis, follow disease progression and track response to therapy. Last fiscal year, we were able to fund many promising biomarker studies, bringing us closer to finding the first commercially available test for ALS.

Attracting Bright Young Scientists
This past year, The Association is proud to have supported eight young scientists through the Milton Safenowitz Postdoctoral Fellowship. The Safenowitz family, through The ALS Association Greater New York Chapter, founded the award in memory of Mr. Safenowitz, who died of ALS in 1998. These awards are to encourage and facilitate promising young scientists to enter the ALS field. Fellows work with a senior mentor and receive extensive exposure to the ALS research community through meetings and presentations.

“Javier Jara, Ph.D., Northwestern University Feinberg School of Medicine in Chicago, Former recipient of The Association’s Milton Safenowitz Postdoctoral Fellowship and Investigator-Initiated Starter Grant

“I want to give a big thank you to ALS Association donors for their support and trust. Without their generous contribution, I would not be where I am now. I am extremely grateful for not only the fellowship I received in 2010 but also my recent grant, which has kept me focused on how upper motor neurons die in ALS and how to intervene to prevent their death.”
Caring for people living with ALS

Care Services prioritized several areas in the realm of clinical quality, access to care, education programs and collaborations.

The Association supported 46 Certified Treatment Centers of Excellence and 10 Recognized Treatment Centers. These centers provide care through a multidisciplinary care team approach, which has proven to enhance both length and quality of life. In addition, The Association has formal relationships with 55 Affiliated Clinics.

We were pleased to be the host organization for the International ALS/MND Alliance meetings and allied health professionals symposium. The International Alliance of ALS/MND Associations was founded in 1992 to provide an international community for individual ALS/MND associations from around the world. Their goal is to promote optimal care and support for people living with ALS/MND worldwide, to facilitate information exchange and education at an international level, and to encourage collaboration, dissemination and translation of ALS/MND research. Approximately 110 representatives and 200 allied health professionals attended these meetings.

The Association also helped facilitate the MNDA (Motor Neuron Disease Association) International Symposium, which is the largest medical and scientific conference specifically on ALS/MND. It is the premier event on the ALS/MND research calendar, attracting over 900 delegates, representing the energy and dynamism of the global ALS/MND research community.

“We were honored to award Dallas Forshew, RN with our Lawrence A. Rand Prize, which recognizes the courage, passion, integrity and commitment of those serving the ALS community as volunteers, healthcare professionals, educators/communicators or in other ways contributing to the quality of life of people living with ALS.”

Dallas has dedicated over 30 years to providing care and support to people living with ALS. From her work in the clinic, to her coordination of research projects, to her hands-on support of families, Dallas has continued to bring her experience, expertise and commitment to this community.
Raising Awareness and Support

ALS Ice Bucket Challenge...Round 2!

In August 2015, The ALS Association teamed up with Facebook to present the ALS Ice Bucket Challenge Round 2, along with the founders, Pete Frates, Pat Quinn and Anthony Senerchia. We created infographics and videos to help jump-start the challenge again, resulting in $1 million in revenue across all channels and significant local and national media coverage. With the mantra, “Every August Until a Cure,” August will now and forever be linked to ALS Awareness.

Team Challenge ALS

This year we launched The ALS Association’s endurance program: Team Challenge ALS. From rides and winter sports to running events, there are many opportunities for constituents to take on a new challenge or join a team in a local endurance event. We’re excited to have a new microsite at teamchallengeals.org to provide constituents a full picture of all The ALS Association’s endurance activity.

“Heidi Smith, City, State

“This year we did the Spartan race as members of Team Challenge ALS and it was incredible. During the race, we climb over walls, crawl under barbed wire, slog through mud and jump over fire. Thinking about my husband Frank gives me the strength to keep going. Frank lost his battle with ALS. I still do it for him and others who have ALS. Those coping with the disease on a daily basis face a much bigger challenge simply going through daily tasks. Surely, we can face the hurdles of the Spartan race for one day. Join #TeamChallengeALS.”
Advocating for Legislative and Policy Priorities

The ALS Association and our nationwide network of over 17,000 advocates worked throughout the year to increase funding for ALS research, ensure access to care for people living with ALS, and improve the pathway for a treatment through the development of the first ever patient-focused guidance for ALS drug development.

Announced soon after and made possible by the ALS Ice Bucket Challenge, the guidance project was well underway with over 100 participants, including people living with ALS and representatives from academia and industry.

The guidance, to be completed next fiscal year, will serve as a roadmap to help industry navigate the regulatory process and provide the U.S. Food and Drug Administration with an ALS community-centered view of how the Agency should approach therapies for ALS.

Merit Cudkowicz, M.D., MSc, Director, Massachusetts General Hospital, MDA ALS Clinic

“This ALS Guidance—the first ever for the disease—will be a big asset to physicians, researchers, industry, and most importantly, our patients. It contains the most up-to-date information on key ALS research areas including biomarkers, disease progression and heterogeneity, and clinical trials and outcome measures; includes important information on diagnosis and the natural history of the disease, and barriers to diagnosis; and represents the work of the foremost ALS experts in the world, leading industry representatives and the patients and families that live with ALS every day.”

Other Advocacy Highlights include the following:

- Secured a 30 percent increase in funding for the National ALS Registry, bringing total annual funding to $10 million;
- Maintained $7.5 million in Congressionally-approved funding for the ALS Research Program at the Department of Defense (ALSRP);
- Secured the largest increase (7 percent) in funding for research at the National Institutes of Health (NIH) in more than a decade;
- Helped enact the Steve Gleason Act, changing Medicare’s coverage policy for speech generating devices to enable people living with ALS to access other critical technologies such as email and the internet; and
- Protected access to power wheelchair accessories as Congress passed legislation to delay implementation of cuts that would have limited the availability of these critical technologies.
CORPORATIONS MOVE OUR MISSION FORWARD

Thank you to our national partners for supporting research, care services, and our policy efforts, while engaging their customers and employees in the fight against ALS.

Pride Mobility Products/Quantum Rehab is The ALS Association’s largest national partner and the first company to sponsor every local ALS Association chapter. Since the inception of this partnership in 2012, the company has contributed more than $1.5 million to the fight against ALS. Pride Mobility Products/Quantum Rehab employees attend and host booths at more than 60 Walks annually.

Permobil is The ALS Association’s longest standing national partner. Permobil became our first national partner in 2006 and has since contributed more than $1.4 million to support our mission. The internal culture of the company makes the ALS community a priority. When an order is received for a person with ALS, it is immediately moved to the front of the production line.

Joining as a national partner in 2013, Numotion and its employees have proudly supported The ALS Association through various charitable activities including donations, in-kind services, and participation in dozens of Walk to Defeat ALS and Challenge ALS events across the country.

With 12,000 plus undergraduate members and approximately 150,000 living alumni, the Fraternity encourages all their chapters to partner with The ALS Association. During the 2015 school year alone, Phi Delta Theta’s undergraduate chapters contributed more than $1 million to philanthropic causes with $325,000 of that supporting research and services for The ALS Association and their chapters. The Fraternity’s members contribute countless hours of volunteer engagement across the country.

New York Yankee Hall of Famer Lou Gehrig was a member of the Phi Delta Theta Fraternity, and is now the heart and impetus of the group’s philanthropic endeavors.

BAYADA Home Health Care became a national partner of The ALS Association in 2012 and has since contributed more than $450,000. Hundreds of their employees engage in local chapter work and fundraising events. BAYADA developed an ALS education program for their staff in an effort to enhance their quality of care and better the lives of those living with ALS.

People fighting ALS have few treatment options. Cytokinetics is dedicated to changing the progression of this fatal disease. The company lives this through their work every day to develop a treatment for ALS, while also financially supporting ALS programs, research and care services at the local and national level.
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