For all of us, motor neurons, and the connections they make between the brain and spinal cord out to muscles in the rest of the body, make movement—and life—possible.

In people with amyotrophic lateral sclerosis (ALS), these tiny motor neurons degenerate. Connections break. And sadly, paralysis sets in and death becomes a matter of “when,” not “if.”

At The ALS Association, we recognize how vital connections are to facilitating movement—not only in people with Lou Gehrig’s Disease but also in the work we do every day to drive our mission forward.

These connections are essential in our fight to find treatments and a cure for ALS, and to provide care and support to the thousands of people suffering from this devastating disease.

Within the pages of this report, you will see what we’ve been doing along with our nationwide network of chapters to lead the fight to treat and cure ALS through global research and national advocacy. In addition, you will learn how we are on the front lines, helping people impacted by the disease achieve a better quality of life and gain access to the very best compassionate care.

All of this work would not have been possible without the support of our donors, who continue to amaze us with their generosity.

While we are pleased about the progress made in the past year, we are far from satisfied about the lack of effective treatments. To paraphrase Winston Churchill, who in November 1942 spoke of World War II: This is not the end, nor is it the beginning of the end, but perhaps the end of the beginning. Together, with your support, we will continue and intensify our quest to create a world without ALS.
2014 FINANCIAL STATEMENT
CONNECTING Revenue with Expenses
For Fiscal Year Ending January 31, 2014

REVENUE*

26%
23%
18%
14%
*

EXPENSES*

32%
19%
27%
14%
*

* Numbers have been rounded to the nearest million.

For more detailed financial information, please visit our website, www.alsa.org, and click on “Financial Information” in the “About Us” section.
FY 2014 brought major developments on the research front, fueled by The ALS Association’s ongoing efforts to foster collaboration within the scientific community. Through our global Translational Research Advancing Therapies for ALS (TREAT ALS®) program, Association-funded investigators identified key elements of disease pathogenesis—the many steps that lead to its onset—providing promise for new treatments or therapies to mitigate their effects. In particular, significant strides in understanding the disease mechanisms were achieved with the focused attention on mutations of the C9orf72 gene, discovered only two years ago as the most common genetic cause of ALS. To improve clinical trials, The Association cosponsored roundtable discussions with renowned ALS experts, which resulted in agreement to focus on the identification of relevant biomarkers to track disease progress and response to therapy, as well as confirm diagnosis. The ALS Association’s Chief Scientist directed Association-funded projects, engaged young scientists through our fellowship program, and counseled researchers by serving as chair of the ALS Research Program Panel of the Department of Defense and participating in other national and international activities relating to ALS. Through all of this, our TREAT ALS program provided guidance to investigators around the world.

**Research Highlights**

- **C9orf72 Gene Mutation:** Expanded research of this genetic abnormality builds understanding of this breakthrough
- **New Therapies:** Approaches that target gene mutations set the stage for new clinical trials
- **Drug Company Working Group:** Hosted annual meeting at the American Academy of Neurology Conference

**The ALS Association Research Awards**

- **Disease Mechanism**
  - 31 Projects
  - $5,146,463
  - 29%

- **Clinical Research**
  - 17 Projects
  - $4,327,271
  - 24%

- **Genetics**
  - 14 Projects
  - $2,038,872
  - 11%

- **Stem Cells**
  - 11 Projects
  - $2,199,511
  - 12%

- **Therapy Development**
  - 15 Projects
  - $2,938,493
  - 16%

- **Biomarkers**
  - 10 Projects
  - $1,498,370
  - 8%

**Total for New Grants Awarded to Accelerate the Development of ALS Treatments**

$6.6 Million
SUPPORT
CONNECTING with a Network for Compassionate Care

Our comprehensive portfolio of care services offered through our network of chapters and treatment centers enables people living with ALS and their families to cope with the day-to-day challenges of living with the disease. Among the many services offered in FY 2014 were equipment loan closets, care management, support groups and respite care, as well as education. Families also received additional assistance in the comfort of their homes by participating in monthly webinars. To continually provide the highest quality of care that address individual, family and caregiver needs, The ALS Association offered a multitude of educational opportunities for both chapter and clinical staff, with programs based on ongoing needs assessments and best practices.

Care Services Highlights

- **DVD Series:** Produced a three-part series, *Respiratory Decisions in ALS*, to help people with the disease make informed choices related to their care
- **Certification of Centers:** Ensured adherence to the multidisciplinary care that is the nationally recognized standard of practice
- **Education:** Presented sessions at our National Public Policy Conference, addressing issues ranging from genetic implications and alternative treatments to financial planning and Veteran’s benefits

NUMBER OF PEOPLE WITH ALS AND THEIR FAMILY MEMBERS SUPPORTED BY CHAPTERS, INCLUDING MORE THAN 2,000 VETERANS

14,000

NUMBER OF CERTIFIED CENTERS OF EXCELLENCE

33

NUMBER OF RECOGNIZED TREATMENT CENTERS OF EXCELLENCE

53

NUMBER OF CHAPTERS OF THE ALS ASSOCIATION

38
A key factor to finding treatments and a cure for this devastating disease is government support. As part of our concerted effort in conjunction with chapters, we have reached out to elected officials in the U.S. Congress and at the state and local levels, as well as agencies such as the Food and Drug Administration (FDA), Department of Defense (DOD), Centers for Disease Control and Prevention and the Department of Veterans Affairs. These activities have raised the profile of ALS, paving the way for policy development and funding from both public and private sources. The ALS Association continued support for the National ALS Registry, a nationwide research project collecting vital data that will help advance ALS research to identify what causes the disease and how it can be treated. The fact that military veterans are twice as likely to develop ALS as the general public was highlighted during the annual Veterans Day ALS Awareness Campaign.

**Public Policy Highlights**

- **FDA Public Hearing:** Partnered with agency to convene first ALS-specific hearing, providing forum with decision makers for new drug trials
- **Modernizing our Drug and Diagnostics Evaluation and Regulatory Network (MODDERN) Cures Act:** Introduced legislation that would breakdown barriers that have limited ALS drug development and provide new incentives to advance research into treatments for ALS
- **National ALS Advocacy Day and Public Policy Conference:** Hosted the 15th annual event, holding meetings with staff members for 90 percent of Congress

**Support from Capitol Hill**

- **$47 million**
  - Total DOD funding with $7.5 million secured in FY 2014
- **$40.5 million**
  - Total appropriated from Congress for the National ALS Registry with $6.5 million received in FY 2014—11% increase over last year

**Number of Letters Published in Print and Online Media Outlets as Part of the Veterans Day ALS Awareness Campaign, Nearly Double the Number Published the Previous Year**

- **50**

Retired Air Force Technical Sergeant David Masters, who has ALS
Until we live in a world without ALS, The Association is dedicated to spreading the word about this debilitating disease in order to connect people to the cause and fund important initiatives. During FY 2014, a number of high-visibility national campaigns were spearheaded, such as ALS Awareness Month, observed in May in the United States, and the Walk to Defeat ALS®, held primarily during the spring and fall in cities throughout the country. As of the end of FY 2014, the Walk has raised more than $182 million since its inception in 2000.

$5,066,885 IN-KIND MEDIA DONATIONS TO PROMOTE THE ALS ASSOCIATION’S ACTIVITIES

183% INCREASE IN TRAFFIC TO WWW.ALSA.ORG SITE DURING ALS AWARENESS MONTH

11,000,000 PEOPLE REACHED THROUGH RADIO INTERVIEWS CONDUCTED BY DAVID MASTERS, A VETERAN WITH ALS, DURING ALS AWARENESS MONTH

Development and Communications Highlights

• Walk to Defeat ALS: Expanded program participation by eight percent over previous year

• ALS Awareness Month: Aired public service announcements every hour on Times Square jumbotron for 30 days in May, during which AOL named ALS the “Cause of the Day”

• Partnership for Success: Award presented to Lou Gehrig’s fraternity, Phi Delta Theta, for the efforts of its 171,500 members, who have raised more than $100,000 for ALS research in the last two years

FY 2014 WALK TO DEFEAT ALS

$23.5 MILLION AMOUNT RAISED

175,000 NUMBER OF PARTICIPANTS

165 NUMBER OF WALKS
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.

VISION

Create a world without ALS.