2018 ANNUAL REPORT
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VISION AND MISSION

VISION:
A world without ALS.

MISSION:
To discover treatments and a cure for ALS, and to serve, advocate for, and empower people affected by ALS through collaboration and open dialogue, so that ALS patients may live their best quality of life.
OUR LEADERSHIP

"This past year, a new chapter opened in the fight against ALS when the FDA approved the first new drug to treat the disease in 22 years, Radicava. Several more potential treatments are currently in clinical trials. I am honored to begin my tenure as president and CEO at this exciting time. It is critical that The ALS Association maintain its leadership supporting research, life-enhancing clinical care, and better public policies. Three years after the ALS Ice Bucket Challenge, the Association’s investments in our core mission is starting to pay dividends and create real momentum in the search for a cure while empowering people with ALS to live their lives to the fullest. We are deeply thankful for the part that you and all our partners and supporters have played in the fight to end ALS."

Very Best Regards,

Calaneet Balas,
President & CEO

Stephen Winthrop,
Chair, The ALS Association Board of Trustees

“We are deeply thankful for the part that you and all our partners and supporters have played in the fight to end ALS.”
The following unaudited summary reflects Association-wide financial activity for the year that ended January 31, 2018.

**REVENUE AND EXPENSES**

- **Total combined revenue**: $85,936,441
  - Research: $19,224,349
  - Other Program Activities: $53,785,369
  - Fundraising: $11,527,795
  - Administration: $5,949,163
  - **Total combined expenses**: $90,486,676
  - Change in net assets: $(4,550,235)

**ASSETS AND LIABILITIES**

- **Total combined assets**: $163,788,015
- **Total combined liabilities**: $4,731,363
- **Total combined net assets**: $159,006,652
During the 2018 fiscal year, The ALS Association committed over $18 million to support promising projects all over the globe, funding over 61 new projects in 9 countries and continuing our role as a global leader in ALS research.

New research discoveries and collaborations accelerated the momentum toward finding treatments and a cure for ALS throughout the year. Enrollment in clinical trials is higher than ever, new biomarkers are being discovered, and drug development is taking off.

- The Nuedexta trial is showing significant palliative effects on speech, swallowing, and salivation.
- A new urinary biomarker now helps researchers monitor ALS disease progressions, and a novel C9orf72 biomarker was identified, paving the way toward an upcoming clinical trial.
- A new test was developed to more accurately and quickly determine the rate of decline for people living with ALS.

**BREAKTHROUGH PRIZE IN LIFE SCIENCES**

IN FISCAL 2018, ALS RESEARCHER DR. DON CLEVELAND WON THE $3 MILLION BREAKTHROUGH PRIZE IN LIFE SCIENCES, ALLOWING HIM TO CONTINUE HIS WORK IN ALS ANTISENSE TECHNOLOGY.

“I’M INCREDIBLY GRATEFUL TO THE ALS ASSOCIATION FOR THEIR SUPPORT – RIGHT FROM THE BEGINNING AND CONTINUING TO TODAY – THAT ENABLED THE SUCCESS THAT IS NOW BEING CELEBRATED.”

– DR. DON CLEVELAND
In fiscal year 2018, The ALS Association’s chapter network served 19,114 people, while The ALS Association’s Certified Treatment Centers of Excellence and Recognized Treatment Centers served 8,975 people living with ALS. Our certified center program provided $4 million in grants during the fiscal year.

Educational resources were accessed by 61,200 people through website views, downloads, or online orders. These resources included the *Living with ALS and Families* brochure, ALS resource guides and medical information packets.

The ALS Association rose to a unique challenge during the fiscal year in response to the devastating effects of Hurricane Harvey. The Association established a Disaster Relief Fund to make sure people living with ALS and their families in affected areas continued to receive services and programs.
During the 2018 fiscal year, The ALS Association’s 16,000 advocates generated 18,427 messages to members of Congress. During our annual Advocacy Fly-In and National Advocacy Conference, our advocates initiated and implemented over 770 meetings with members of Congress.

That advocacy paid off.

During the 2018 fiscal year, The ALS Association successfully protected the ALS Research Program at the Department of Defense, which resulted in $10 million in appropriations. We also led the charge to secure $10 million in appropriations for the National ALS Registry to find treatments and a cure for ALS.

The Association also played a critical role in winning support for legislation to convince the Centers for Medicare and Medicaid Services to make sure people with ALS have access to wheelchairs and complex rehab technology.
THE WALK TO DEFEAT ALS®
More than 174 walks were hosted by ALS Association chapters across the country last year, raising $25 million to advance the mission to find a treatments and a cure for ALS.

TEAM CHALLENGE ALS
This year the Association’s Team Challenge ALS program spread across the country as participants in endurance events including marathons, cycling, obstacle courses, and winter sports events came together to combine their passions with a commitment to help.

In August, The ALS Association partnered with Major League Baseball to raise awareness of the high cost of home health care for people living with ALS.
The ALS Association appreciates the generous support of the following national partners.

We are delighted to recognize these corporations for their support of our research, services, and advocacy efforts this year.

We appreciate your continued work to help move our mission forward to fight against ALS.

**QUANTUM REHAB**

Quantum Rehab’s commitment as a global innovator to improve the quality-of-life needs for people with various kinds of functional disabilities has proven invaluable to The ALS Association. Quantum Rehab is a long-standing national partner of The ALS Association. Having contributed to the work of the Association since 2002, Quantum Rehab officially became a national partner in 2012. Quantum Rehab has contributed just over $1.6 million to advance the mission of The ALS Association through direct cash sponsorships to support national programs, in direct chapter sponsorship support, and in-kind donations of product.

**PERMOBIL**

Permobil has been committed for more than 40 years to helping people with various kinds of functional disabilities. Permobil is the longest standing national partner of The ALS Association. Since the inception of this partnership in 2006, Permobil has contributed just over $1.2 million to advance the mission of The ALS Association through direct cash sponsorships to support national programs, in direct chapter sponsorship support, and in-kind donations of product.

**MITSUBISHI TANABE PHARMA AMERICA**

Mitsubishi Tanabe Pharma America became an official national corporate partner of The ALS Association in 2016, with a premier sponsorship of the Walk to Defeat ALS program. This sponsorship provided local support to care service programs, cutting-edge research, and nationwide advocacy efforts for people with ALS and their families. Mitsubishi Tanabe Pharma America has contributed over $700,000 to the ALS Association.
**CYTOKINETICS**

Cytokinetics is dedicated to changing the progression of ALS. With few treatment options, Cytokinetics lives this through their work every day to develop a treatment for ALS. They have been a long time partner of the ALS Association. Their generosity has resulted in over $300,000, contributed at the local and national level, supporting ALS Association programs, research and care services.

**NUMOTION**

Numotion is committed in its leadership as the nation’s leading provider of Complex Rehab Technology. Numotion became a national partner of The ALS Association in 2013. Since the inception of this partnership, Numotion has contributed over $900,000 to advance the mission of The ALS Association through direct cash sponsorships to support national programs, direct chapter sponsorship support, and in-kind donations of product, continuing its support to helping improve the lives of those living with ALS and their families.

**BIOHAVEN PHARMACEUTICALS**

Biohaven Pharmaceuticals is a clinical-stage biopharmaceutical company with proven leadership in industry and academic settings. An ALS Association partner since 2017, Biohaven has contributed over $150,000 to the ALS Association through direct cash contributions to support national programs, direct chapter support, and in-kind donations of product, continuing its support to helping improve the lives of those living with ALS and their families.
BOARD OF TRUSTEES

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