



# 2019

## ANNUAL REPORT



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# VISION AND MISSION

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## 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.





# LEADERSHIP

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## OUR LEADERSHIP

It has been an honor to lead another year with the dedicated staff, chapters, and volunteers of the National ALS Association, who work on behalf of people living with ALS. This past year, the Association brought together nearly 100 ALS stakeholders to provide targeted feedback and information to the FDA further inform the FDA's Draft Guidance on ALS Drug Development.

Support for ALS Disability Insurance Access Act spiked following our annual Advocacy Conference which included 500+ advocates that attended 130 meetings with congress members, resulting in 32 senators and 148 representatives who now co-sponsor the bill. The Association also renewed partnerships with several existing corporate sponsors, including Quantum, Permobil and Numotion.

We will continue our fight to create better public policies, to provide life-enhancing clinical care, and continue being a leader in life-changing research through drug development clinical trials that will bring better treatment for those with the devastating disease that is ALS.

We are forever grateful to the dedication and support of all our partners and stakeholders who continue to play a crucial part in the fight to end ALS.

Very Best Regards,

Calaneet Balas,  
President & CEO

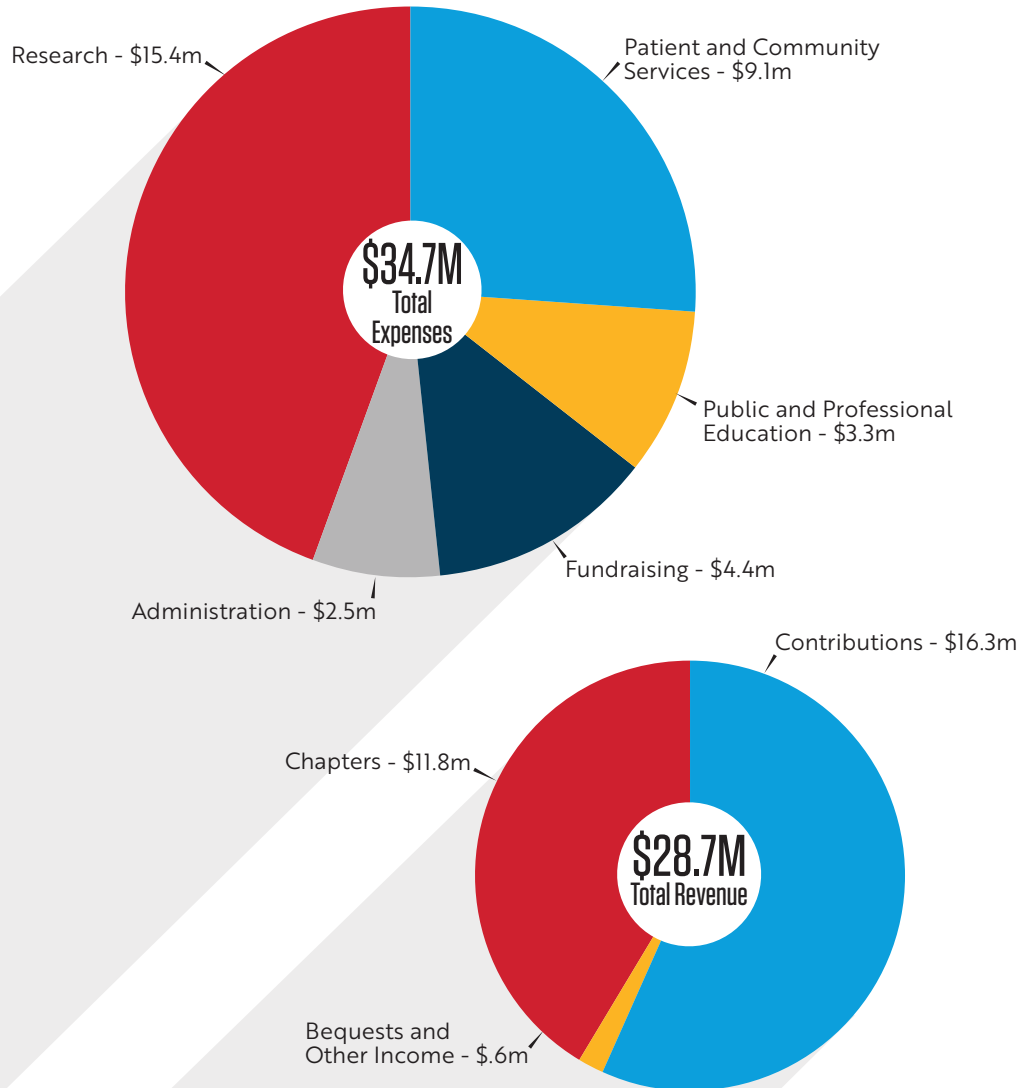
Sue Gorman,  
Chair, The ALS Association Board of Trustees





# FY19 FINANCIAL SUMMARY

## THE ALS ASSOCIATION NATIONAL OFFICE



## THE ALS ASSOCIATION NATIONAL OFFICE AND CHAPTERS

The following unaudited summary reflects Association-wide financial activity for the year that ended January 31, 2019.

### REVENUE AND EXPENSES

<b>Total combined revenue</b>	<b>\$85,636,205</b>
Research	\$15,436,780
Other Program Activities	\$53,924,821
Fundraising	\$12,760,692
Administration	\$7,643,336
<b>Total combined expenses</b>	<b>\$89,765,629</b>
<b>Change in net assets</b>	<b>(\$4,129,424)</b>

### ASSETS AND LIABILITIES

<b>Total combined assets</b>	<b>\$160,755,479</b>
<b>Total combined liabilities</b>	<b>\$10,016,402</b>
<b>Total combined net assets</b>	<b>\$150,739,077</b>



# THE SEARCH FOR BETTER TREATMENTS AND A CURE

**D**uring the 2019 fiscal year, The ALS Association committed over **\$18+** million to support promising projects all over the globe, funding over **62** new projects in **9** countries and continuing our role as a global leader in ALS research.

There were several advances in ALS research that will help to improve quality of life for people with ALS. State-of-the-art technology reached new research milestones, and there were continued advances and success in the discovery of new biomarkers and drug development.



- The KIF5A ALS gene was discovered by a large collaborative effort involving over 250 researchers from University of Massachusetts Medical School (UMass) and National Institutes of Health (NIH), together with several ALS Association - supported organizations. This new discovery will help to identify familial ALS genes for more families.
- An organ-on-a-chip was developed to recreate human blood vessels connected to motor neurons on a microchip to uncover novel ALS biomarkers and therapeutic targets.
- Research to improve noninvasive ventilation for people with ALS is underway using custom-printed 3D masks.
- Clinical trials using specially engineered cells transplanted into the brain's motor cortex were found to protect motor neurons and delay disease in animal models. We are hopeful that the same will result in human trials.

## BREAKTHROUGH PRIZE IN LIFE SCIENCES

In fiscal 2019 Pison Technology, winner of the 2016 ALS Assistive Technology Challenge, with a \$100,000 award, is close to getting its wearable muscle sensor technology is rapidly moving toward the market. The wrist worn device captures nerve signals and micromovements to control computers and home devices.

**“THE WORLD NEEDS TECHNOLOGIES LIKE OURS TO BE ABLE TO HELP ALL PATIENTS WORLDWIDE. THE ALS ASSOCIATION, WILL BE MAJOR PARTNERS WITH US AS WE DO OUR RESEARCH AND AS WE BEGIN DISTRIBUTION AND SALES OF OUR PRODUCT WORLDWIDE.”**



– Dexter Ange, CEO, Pison Technology



# EMPOWERING PEOPLE WITH ALS TO LIVE THEIR BEST LIVES

In fiscal year 2019, The ALS Association's chapter network served over 20,000 people, more than 2,400 of which were military veterans. The ALS Association's Certified Treatment Centers of Excellence and Recognized Treatment Centers served 8,975 people living with ALS, and more than \$4,069,784 in grants were provided through our Certified Center Program.

Additionally, educational resources were accessed by nearly 30,000 people that accumulated 538,441 website views, downloads, or online orders accessed on The ALS Care Services website pages. These resources included:

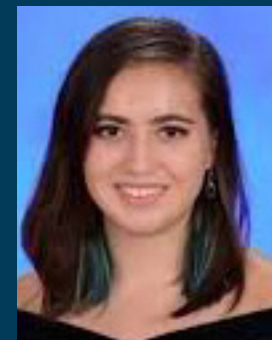
- 12 new *Living with ALS and Families* resource guides released in digital and print formats and translated into Spanish to help educate about challenges that people living with ALS may experience.
- 9 archived webinars, viewed 1,717 times either live or on-demand.
- ALS medical information packets and materials including ID cards and eye gaze charts.

To ensure that people with ALS receive the best care from ALS Association Certified Centers, in FY2019:

- 290 health care professionals participated in the first two webinars of a four-part webinar series designed for speech-language pathologists.
- 130+ clinical partnerships made, incorporating best practices as established by the American Academy of Neurology
- 25,751 support groups were offered through our vast U.S. chapter network.



The ALS Association grieved with the nation on February 14, 2018 when a shooting at Marjory Stoneman Douglas High School in Parkland, FL, took the lives of 17 people.



One of the students killed was Carmen Schentrup, a high school senior whose goal was to someday cure ALS. To honor Carmen, who wanted to become a medical researcher, the **Carmen Schentrup ALS Research Fund** was created, and has since raised **\$162,000** for ALS research. Said Carmen's mother, April Schentrup, **"WE ARE SO GRATEFUL AND HUMBLLED AT THE OUTPOURING OF SUPPORT FOR CARMEN AND HER DREAM. WE HAVE ALWAYS BELIEVED THAT CARMEN WOULD CHANGE THE WORLD AND WE'RE TOUCHED THAT HER STORY IS RESONATING WITH SO MANY PEOPLE."**



# FIGHTING FOR RESEARCH DOLLARS + ACCESS TO HEALTH CARE

**D**uring the 2019 fiscal year, The ALS Association's 16,000 advocates generated 10,016 messages to members of Congress. During our annual Advocacy Fly-In and National Advocacy Conference, our advocates initiated and implemented nearly 500 meetings with members of Congress.

That advocacy paid off.

During the 2019 fiscal year, we increased appropriations for Department of Defense's National ALS Registry from \$10 Million to \$20 Million to find treatments and a cure for ALS.

The ALS Association also enrolled bipartisan congressional champions to introduce the SMART (Safeguarding Medicare Access to Respiratory Therapy) Act to ensure Medicare beneficiaries with ALS can access noninvasive ventilators (NIV) by removing NIV from competitive bidding.





# GROWING SUPPORT FOR THE FIGHT

## THE WALK TO DEFEAT ALS®

More than 172 walks were hosted by ALS Association chapters across the country last year, raising \$25,586,336 to advance the mission to find treatments and a cure for ALS.

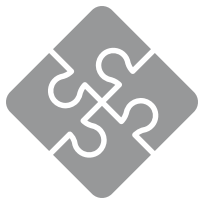
## TEAM CHALLENGE ALS

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. Team Challenge raised \$4,725,399 with 44 events.



**“OUR FAMILY WALKS SO THAT ALL PEOPLE WITH ALS AND THEIR FAMILIES HAVE ACCESS TO A WONDERFUL SUPPORT GROUP, TO AN EQUIPMENT LOAN POOL WHERE THEY CAN OBTAIN WALKERS, WHEELCHAIRS, AND SUPPLIES, AND TO FIGHT THIS DISEASE ON BEHALF OF OUR HUSBAND AND FATHER, MICHAEL GAGNER WHO PASSED AWAY IN NOVEMBER 2013 FROM THIS DREADED DISEASE.”**

– Stacy Inman, Golden West Chapter



# ALS CORPORATE SPONSORS

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 nearly \$1.9 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.



sponsorship support, and in-kind support through donations of seat elevators to people living with ALS.

## 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 \$1 million to The ALS Association, and continues to support the mission through additional funding for national programs focusing on research, advocacy, and care. Mitsubishi Tanabe Pharma America also funded the 2018 Mitsubishi Tanabe Pharma Care Grant, which enabled The ALS Association to award 41 grants - 35 for the expansion of existing programs and six for the implementation of new programs.



## PERMOBIL FOUNDATION

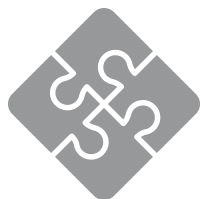
Permobil has been committed for more than 50 years to helping people with various kinds of functional disabilities. Permobil is the longest standing national partner of The ALS Association. Since the inception of this partnership in 2006, Permobil has contributed over \$1.6 million to advance the mission of The ALS Association through direct cash sponsorships to support national programs, such as the Walk to Defeat ALS®, National ALS Advocacy and Clinical Conference, direct chapter



## CYTOKINETICS

Cytokinetics is dedicated to changing the progression of ALS. With few





# ALS CORPORATE SPONSORS

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 \$1 million, contributed at the local and national level, supporting ALS Association programs, research and care services.

## NUMOTION FOUNDATION



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 \$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 in-kind donations of product. They now lead the effort as a premier Walk to Defeat ALS® partner.

## POPSOCKETS



PopSockets became a new partner to The ALS Association in 2018. During a three month give back campaign, PopSockets donated 10% of online sales of PopSockets grips, which help people with mobility issues hold their smartphones more securely. The result was over \$230,000 raised for The ALS Association. The campaign funds go directly toward supporting research into treatments and a cure for ALS, plus care services and advocacy for people living with the disease. PopSockets

help people use their phones more easily, and they are also allowing people to express their values and support to further The ALS Association mission.

## BIOHAVEN PHARMACEUTICALS

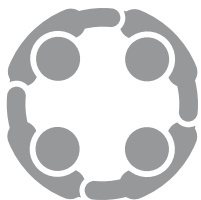


Biohaven Pharmaceuticals is a clinical-stage biopharmaceutical company with proven leadership in industry and academic settings. An ALS Association partner since 2017, Biohaven has contributed over \$150,000 to The ALS Association through direct cash contributions to support national programs, direct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

## HARRIS TEETER



Harris Teeter, a wholly-owned subsidiary of The Kroger Co. (NYSE: KR), was co-founded in 1960 by North Carolina grocers W.T. Harris and Willis Teeter. Harris Teeter operates over 230 stores and 14 fuel centers in seven states and the District of Columbia. Harris Teeter is headquartered in Matthews, NC and has approximately 30,000 associates. An ALS Association partner since 2017, Harris Teeter employees have contributed over \$126,500 through the Harris Teeter's Community Cares Associate Giving Program. In addition, Harris Teeter has supported through in-kind donations of product that enhance our mission to support people living with ALS and their families.



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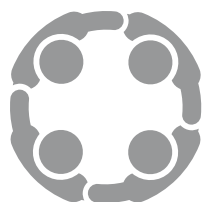
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