



# 2019 IMPACT REPORT

**ALS**  
ASSOCIATION  
Texas Chapter



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# OUR HOPE FOR THE FUTURE

At the ALS Association of Texas, we look for innovative ways to solve complex challenges for people with ALS and their families. This year, thanks to the support of the ALS community, we have expanded access to programs, focused our resources in areas of greatest need, and continually pushed to find ways to serve our community better.

**Local Care** – We expanded our clinic access through a partnership with the South Texas Veteran Healthcare System, adding two more clinics to our network. We also planned the implementation of new programs focused on supporting the needs of caregivers and children of people with ALS.

**Research** – The ALS Association invested strategically in research, including a collaboration with ALS Finding a Cure and the MDA to co-fund Houston Methodist Neurological Institute and Massachusetts General Hospital for a first in-human T-regulatory cell (Treg) clinical trial totaling more than \$2.5 million. Clinics across the state continue to perform clinical trials, enabling us to test promising future treatments.

**Advocacy** – Thanks to the advocacy efforts from the ALS community, we secured 2020 funding in the amount of \$20 million in appropriations for the ALS Registry at the Centers of Disease control (CDC), doubling the funding level of 2019.

As we look to the future, we will continue to harness the spirit of innovation to serve people with ALS and their families. **Together, we can create a world without ALS.**

Tanner Hockensmith  
Executive Director

Trent Parten  
Board President

## BOARD LEADERSHIP

**Trent Parten**  
PRESIDENT

**Rebecca Moss**  
VICE PRESIDENT

**John Spiekerman**  
SECRETARY

**Chris Clark**  
TREASURER

**Bob Ballou**

**Holly Crowder**

**Jeff Duncum**

**John Fleming**

**Kelly Hall**

**Sterling Hillman**

**Kristofer Knapstein**

**Phillip Russell**

**Alison Talarcek**

**Mary Klenke**  
BOARD MEMBER EMERITUS





# 2019 BY THE NUMBERS



1,207

PATIENTS ASSISTED



\$35,000

IN FINANCIAL ASSISTANCE GRANTS TO  
COVER DISEASE-RELATED EXPENSES



1,153

PATIENT VISITS AT OUR  
MULTI-DISCIPLINARY CLINICS



11

MULTI-DISCIPLINARY  
ALS CLINICS IN TEXAS



16

CLINICAL RESEARCH  
TRIALS IN TEXAS



3,046

PATIENT  
INTERACTIONS



\$1.6M

WORTH OF  
EQUIPMENT LOANED  
TO PATIENTS



1,390

PEOPLE  
ATTENDED

139

SUPPORT  
GROUPS



## NEW PROGRAMS

# SERVING THE NEEDS OF THE COMMUNITY

We've been listening closely to our ALS community to determine our impact and discover areas where additional resources are needed. Two big needs have emerged: greater support for caregivers and programs for youth and children. In 2019, we started planning for these new programs, and in 2020 we will begin gradually rolling out these new programs.

### Caregiver Program

Being the primary caregiver for a loved one with ALS can be stressful – not only are the on-call 24/7, but they may have additional outside responsibilities, like working a full- or part-time job. Often, caregivers are so busy supporting their loved ones that their own physical or mental health takes second priority. It's important that caregivers get the support and assistance they need so they can care for their loved one to the best of their ability. The Caregiver Program would provide caregivers with the tools they need to be successful, including hands-on training, workshops, support groups, and connections to caregiver-specific resources.

### Youth and Children Program

Young children and teens often have a difficult time understanding what is happening to a loved one who has been diagnosed with ALS, and there are very few resources currently available to help them. The Youth and Children program would address their unique needs and help them cope with a parent or grandparent's diagnosis of ALS. Through workshops, camps, therapy groups, and age-specific tools and resources, we can help young people navigate the disease and support parents in caring for the emotional well-being of their children.

11 Clinics  
throughout  
Texas

1,153 Patient visits  
through our clinics

16 Active clinical  
trials in Texas

## ALS CLINICS

# CONTINUED INVESTMENT

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As ALS progresses, the needs of patients increase significantly, and they find leaving their homes more and more difficult. Patient care clinics house all the doctors and medical professionals that an ALS patient needs to see in one place. These specialists work together to ensure that each patient receives high-quality, comprehensive care. This multidisciplinary approach is scientifically proven to extend patient's lives and improve their quality of life.

Our goal is to provide access to clinical care for all people living with ALS across Texas. This year, we continued our investment in 11 clinics across the state, watching them grow and serve more patients than ever before. As we continue to partner and invest in these clinics, we will put them on the path to becoming Certified Centers of Excellence, which means more funding, more clinical trials, and better resources for people with ALS.





Access to  
high quality,  
specialized care  
is key to improving  
the quality of life  
for people  
living with ALS.

EXPANDING ACCESS TO CARE

# PARTNERING WITH THE VA ALS CLINICS

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## DR. QINGSHAN TENG

*Dr. Qingshan Teng funnels his passion for Neuromuscular Medicine into serving our country's veterans, specifically those who have ALS. For the past four years he has been part of the South Texas Veterans Health Care System, and has been director of the ALS clinic for the last two.*

In addition to having ALS, Dr. Teng's patients face challenges related to the hazards of their occupation - military combat experience. He sees more incidences of Traumatic Brain Injury (TBI), Post Traumatic Stress Disorder (PTSD) and chronic back pain than in others who are living with ALS. Anxiety and hearing loss are also common in the veterans he treats.

During his first year of running the program, the clinic treated 22 veterans with ALS. Over the past 12 months Dr. Teng and his staff have seen 55 veterans with ALS. He credits the ALS Association of Texas and community hospitals with the increase, saying, "If they see a veteran, they suggest that he or she comes to our hospital to get care." Some veterans paid up to \$1500 for a visit to the community hospital before finding out about Dr. Teng's clinic. For most people, that simply is not a sustainable option. Dr. Teng views access to affordable care as one of the primary gaps in clinical care for the ALS community.

The joint effort between the VA and the ALS Association of Texas is vital to the well-being of veterans in our state who have ALS. Dr. Teng feels strongly that our organizations have many ways we can collaborate and much we can learn from one another. Access to high quality, specialized care is key to improving the quality of life for people living with ALS, and through partnerships with the South Texas Veteran Health Care System, we are able to ensure that veterans with ALS receive the care they need.



# CLINICAL TRIALS

# GIVE HOPE TO TEXANS WITH ALS

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## THE ALS ASSOCIATION OF TEXAS INVESTS IN RESEARCH TO DISCOVER EFFECTIVE TREATMENTS AND A CURE FOR ALS.

One of the ways we support research locally is through clinical trials, which are conducted at our ALS clinics across the state.

Dr. Carlayne Jackson, Medical Director of the ALS Clinic at UT Health San Antonio, first became interested in clinical trials in neuromuscular disease as a medical resident at the clinic. She would be the first to tell you she “fell in love with the patients” she treated during her residency, fellowship and eventually her first two years of leading the clinic’s ALS studies.

Founded in 1996, the clinic is designated as an ALS Association Certified Treatment Center. Dr. Jackson and her staff have used their multidisciplinary approach to offer hope for the future of ALS to their South Texas community and the 250 ALS patients they serve. Through the generosity of the ALS Association and the Glenn Biggs Institute for Alzheimer’s and Neurodegenerative Diseases at UT Health San Antonio, the clinic has recently been able to add neuropsychological testing and the services of a Nurse Research Coordinator to their offerings.

### THE CLINICAL TRIALS PROCESS

The Nurse Research Coordinator meets with patients interested in participating in a clinical trial, sharing helpful information, including the number of visits, what to expect at each visit, potential side effects and treatment effectiveness. Once they have a thorough understanding of the risks and benefits, patients are screened to determine if they meet the criteria defined by the company or group sponsoring the trial. It is important to note that most of the criteria are put in place to protect each patient’s safety. Researchers must quickly determine if an intervention is working or not.

After a particular therapy has gone through Phase I testing on a healthy population, the San Antonio clinic conducts Phase II and Phase III trials on ALS patients accepted into the studies. Phase II trials focus on safety and dosing of the medication. Next comes the pivotal trial – Phase III – which the FDA reviews in order to determine the drug’s approval for patients outside of the trial. Phase II trials typically take six to 12 months, whereas Phase III trials can last 12-18 months.



## Dr. Jackson believes clinical trials are vital.

"We will never be successful in bringing effective therapies to ALS patients without them first being studied in trials. We can't prove what does or doesn't work without a trial," she says. "Through clinical trials at ALS clinics, such as the one at UT Health San Antonio, we are one step closer to finding treatments and a cure for ALS."

### DR. CARLAYNE JACKSON

*Medical Director at the  
University of Texas Health  
in San Antonio*



# ADVANCING RESEARCH

THE ALS ASSOCIATION IS PROUD TO PROVIDE FUNDING FOR THESE EXCITING INNOVATIONS.



## HEALEY CENTER ESTABLISHES FIRST ALS PLATFORM TRIAL

- The ALS Association invested \$3M in Healey ALS platform trial to accelerate drug development. This ground-breaking trial will test multiple therapies for efficacy at the same time, providing time and cost savings and increasing patient access to trials.



## REGULATORY GUIDELINES ADVANCE ALS THERAPEUTIC DEVELOPMENT

- The Association released Principles for Urgent, Patient-Centered ALS Clinical Trials, a series of recommendations to clinical trial sponsors and regulatory bodies worldwide. The principles set out a clear framework for ALS clinical trials that are efficient, impactful, and respectful to people with ALS.
- The Association worked closely with members of the ALS community and the FDA to create a landmark, patient-led guidance initiative that helps drive ALS drug innovation more quickly from the lab to the patient. The Association provided feedback to the FDA by hosting a national workshop and creating a report that informed the final guidance document. The guidance provides regulatory flexibility in trial design and drug approval resulting in direct benefits for people with ALS.



## PUBLICLY AVAILABLE GENETIC DATA PROPELS INNOVATION

- Genomic sequencing is a process to discover ALS new genes. The Association contributed \$3.3M to fund a centralized, cloud-based, genome-sequence database. The first of its kind, it will allow all researchers to share genomic data and conduct standardized analyses, leading to identification of new ALS drug targets.



## ALS FOCUS ESTABLISHED TO DRIVE MISSION STRATEGY

- The Association launched ALS Focus, a survey program that captures the needs and perspectives of people with ALS and their caregivers, placing them at the center of ALS treatment and policy decision-making. All data is open and free to the entire ALS community.



## SIGNIFICANT ADVANCEMENTS FOR ALS CLINICAL TRIALS

- Amylyx Pharmaceuticals, Inc., (funded by the Association) announced that AMX0035 demonstrated statistically significant treatment benefit for people with ALS in the CENTAUR phase 2 trial.
- Biogen announced encouraging positive results for the drug tofersen\* showing reduction of toxic levels of SOD1 protein and slowing disease progression in people with ALS. Phase 3 trial to confirm its efficacy and safety is underway.

*\*The Association funded the drug's underlying technology.*



## COLLABORATIONS MOVE ALS RESEARCH PROGRESS FORWARD

- The Association teamed up with ALS Finding a Cure and the MDA to co-fund Houston Methodist Neurological Institute and Massachusetts General Hospital for a first in-human T-regulatory cell (Treg) clinical trial totaling more than \$2.5M. This trial will test whether patients' own immune Treg cells can be leveraged to treat ALS.
- The Association collaborated with Target ALS to fund the TDP43 Biomarker Initiative with a \$350,000 grant. Mutated TDP43 is a major toxic protein found in ALS. This project will lead to development of a biomarker test to reliably measure TDP43 in human biofluids, tremendously impacting ALS clinical research and drug development.



## INVESTMENT IN INFRASTRUCTURE PROTECTS AND ACCELERATES ALS RESEARCH

- The Association continued support of the Northeast ALS Consortium (NEALS), the largest consortium of ALS clinical researchers in the world. This funding will support new initiatives and ongoing programs to increase the quality and efficiency of ALS clinical trials.
- The Association funded Massachusetts General Hospital and Barrow Neurological Institute with over \$600,000 to improve clinical trial operational infrastructure and support initiatives to enhance clinical trial access and increase trial participant recruitment and retention.



## ADVOCACY CONFERENCE

Every year, a group of ALS Texas staff members, people with ALS, caregivers, and supporters travel to Washington, D.C. to call on our elected officials as part of the National ALS Advocacy Day. Last year, advocates gathered at our nation's capitol to put a human face on this devastating disease and encourage lawmakers to join the fight against ALS.

14

Attendees from Texas

38

Meetings held with  
Texas Senators and  
Representatives

# ADVOCACY & PUBLIC POLICY

The ALS Association is at the forefront of public policy, working alongside people with ALS, caregivers, advocates, and other organizations to advocate for federal investment in ALS research and for patient rights.

## OUR PRIORITIES

### ADVANCING RESEARCH

Thanks to advocacy efforts from the ALS community, we secured 2020 funding in the amounts of:

- \$10 million in appropriations for the ALS Registry at the Centers for Disease Control (CDC)
- \$20 million in appropriations for the ALS Registry at the Centers for Disease Control (CDC), **doubling** the funding level of 2019
- \$41.084 billion in funding for the National Institutes of Health (NIH), a \$2 billion increase over the funding level of 2019 so the NIH can maintain and increase its level of commitment to ALS research

### PATIENT CARE

- Pass the ALS Disability Insurance Access Act to waive the five-month waiting period for patients with ALS before receiving benefits under Social Security Disability Insurance
- Educate and influence congress and administrative officials to remove complex barriers to Medicare home health benefits for people living with ALS
- Opposing competitive bidding for non-invasive ventilators, a critical life support for Medicare beneficiaries with ALS





**Brad has great hope  
for the future.**

*"They're going  
to find a cure.  
I guarantee it,"  
he says.*

*"It's going to be  
in the 3rd or 4th  
quarter, but they  
will find a cure for it.  
And I want to help."*

## **BRAD DUSEK**

*Person with ALS*

# ALS HERO

## BRAD DUSEK

*To Brad Dusek, ALS is just another opponent. But this time the battle isn't on the football field. This enemy is waging war on his body.*

Being a Texan, Brad is no stranger to the game of football; he's been around it his entire life. His dad was a coach, and Brad was a star player at Temple High School, and was later inducted into the Texas High School Hall of Fame in 2018. Brad went on to play at Texas A&M University where he was inducted into the Athletic Hall of Fame in 2014. He was drafted by the New England Patriots in the third round of the NFL draft. During training camp, Brad was traded to the Washington Redskins and was a linebacker for them until he retired from professional football in 1982.

Brad and his family moved back to Texas, where he shared his love of sports with his four children. Little did they know how much the athletic mentality of their family would prepare them for the road that lay ahead. Brad's first indication that something was wrong was in the spring of 2017. He experienced weakness on the left side of his body, and as it progressed, it affected his gait and his ability to get around. He endured multiple surgeries and saw specialists for a year and a half in pursuit of a diagnosis. The family finally took him to Houston's Mayo Clinic (in Rochester, Minnesota) in September 2018, where he was diagnosed with ALS. Brad and his family weren't going to let facts about his diagnosis get them down. We had the attitude that we're going to find a way. And if we don't defeat it, we're going to prolong it. We don't accept losing, because we're way too competitive," says Kimmie.

Shortly after Brad's diagnosis, Kimmie decided to bring their family and friends together and participate in The Walk to Defeat ALS in October 2018. They called their team Linebackers: Tackling ALS, in honor of their dad and his football position. They used the event to announce Brad's diagnosis to his friends, work community and former teammates. Kimmie's goal was \$500. Thanks in part to social media, they were flooded with donations, and in two and a half weeks had raised more than \$11,000.

Brad and Kimmie call the ALS Association of Texas their lifeline. When they have questions, it's the one place they can turn to. Soon after Brad's diagnosis, Kimmie knew her dad and Marta would be coming regularly to Houston, where she lives. "I realized he wouldn't be able to even get in my house or go to the bathroom, so I reached out to the ALS Association of Texas. They met me with a portable ramp and a shower and toilet chair that we still have." Marta adds, "They came out to the house not long after Brad's diagnosis, did an evaluation and made suggestions to make our home more accessible."



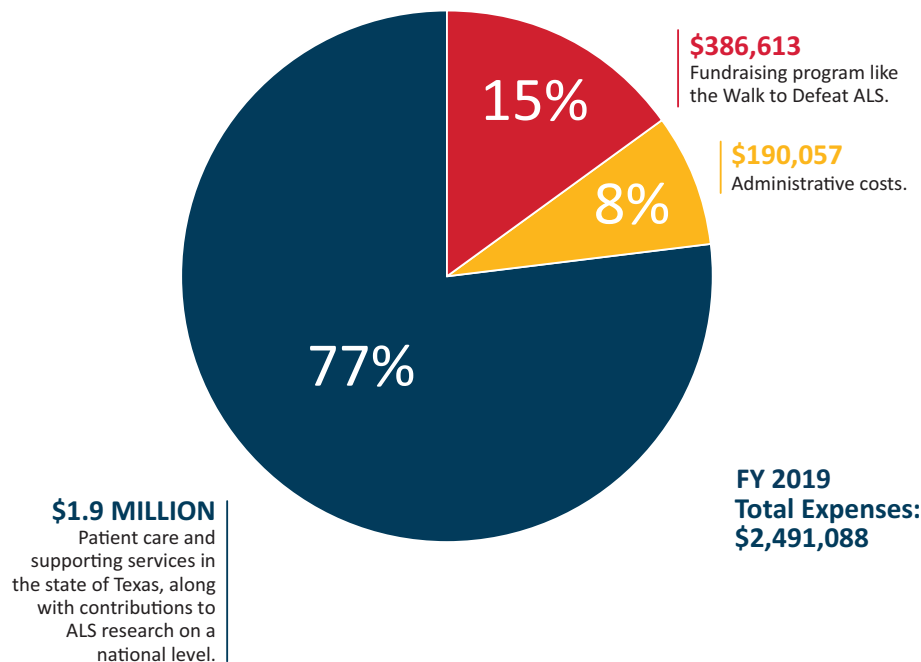


## BOTTOM LINE

Everything we do, from providing crucial patient care at our clinics to advocating for public policy changes, relies on the donations of our generous supporters. Your donation to the ALS Association of Texas provides services for Texans with ALS and helps fund our global network of researchers who are searching every day for a cure.

As an organization, we are committed to transparency and efficiency, and we use every dollar donated to maximize our impact on the community.

# ALS TEXAS FINANCIALS







# OUR SUPPORTERS

**RUBY** \$75,000+



Anonymous

**DIAMOND** \$50,000+

**HALLIBURTON**  
CHARITABLE FOUNDATION

Joe and Cathy Cleary  
In Honor of Debbie Glauser

**EMERALD** \$25,000+



Nichols Family Foundation  
Arizona Community Foundation  
Spiros Fore A Cure Inc.



**PLATINUM** \$15,000+

Kiewit Companies Foundation  
Barbara Ildebrando Fund  
Respiratory Quality Services (RQS)  
George and Mary Josephine Hamman Foundation  
McDonough Elevators  
Lynn Parker Memorial Golf Tournament  
MLN Company  
William Burton  
Mrs. Sherry Russo  
Laredo Area Community Foundation  
Travis Medical





# TOP FUNDRAISING WALK TEAMS

Team John Lay, Sally Allen, Austin

Harvey Builders, Patricia Jaloway, Houston

Team Crowder, Holly Crowder, Dallas

Craig's Crusaders, Lori Spink, Houston

The Wright Team, Jacqueline Wright, Houston

Sherry's Legion of Support, Chad Smith, Austin

Team Coale, Mary Murphy, The Woodlands

Team Laura BTHO ALS, Laura Weiss, Austin

Steps for Sheps, Shepherd Family, Austin

PQ's Crew, Andrea Clark, Houston

ARC, Mary Beth Ziegler, San Antonio

Darci's Defenders, Darci Garcia, Houston

Judy's Joggers, Russ Weaver, San Antonio

Team Tom, Thomas Fruge, Fort Worth

Houston Poly Bag, William Sumner, The Woodlands

Linebackers: Tackling ALS, Kimmie Longstreet, Houston

Pat's Angels, Patricia Hamilton, The Woodlands

Tobin's SeALS, Diane Tobin, The Woodlands

Team Judy, Shelley Bender, Dallas

Kevin's Krusaders, Linda Licarione, Houston

Wind Warriors, Priscilla Caballero, San Antonio



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