



2020 **IMPACT** REPORT





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BECAUSE OF YOU

WE'RE SERVING MORE TEXANS WITH ALS AND THEIR FAMILIES THAN EVER BEFORE

This year our ALS community has come together in new ways, connecting from afar and working together, even when we are physically apart. In the midst of a pandemic, your support never ceased. And **because of you**, we are now serving more Texans with ALS and their families than ever before.

Because of you, family caregivers are receiving the support and resources they need. Medical equipment is being loaned to people in need and alleviating their financial burden. Youth are sharing their voices and finding strength through shared experiences. ALS clinics are continuing to deliver specialized care and conducting clinical trials. New treatments are on the horizon.

Because of you, our Texas Chapter Events continue to raise crucial funds while moving to socially distanced and virtual fundraisers. And our Walk to Defeat ALS at Home brought Texans together from across the state, allowing us to celebrate even from afar.

As we look beyond this crisis, virtual programming will continue to be a critical part of our work, enabling us to reach Texans with ALS and their families in all corners of the state. Even when we can safely resume in-person gatherings, we'll continue to provide a place to virtually connect, learn, and share.

In the face of the pandemic, you made this crucial work possible. Thank you.



Tanner Hockensmith
Executive Director



Trent Parten
Board President





2020 BY THE NUMBERS



1,272

PATIENTS ASSISTED



11

MULTIDISCIPLINARY
CLINICS IN TEXAS



653

PATIENT VISITS AT OUR
MULTIDISCIPLINARY CLINICS



18

CLINICAL RESEARCH
TRIALS IN TEXAS



2,313

PATIENT
INTERACTIONS



\$1.4M

WORTH OF
EQUIPMENT LOANED
TO PATIENTS



1,633

PEOPLE
ATTENDED

160

VIRTUAL WORKSHOPS,
PRESENTATIONS, AND
SUPPORT GROUPS FOR
PATIENTS & FAMILIES



SERVING THE NEEDS OF THE COMMUNITY

We listened closely to our ALS community to discover where additional resources are needed. Two big needs emerged: greater support for caregivers and programs for youth and children.

Caregiver, Youth and Children Programs

In 2020, we created new programs for families and their children, including interactive workshops, support groups, and more.

Staying Connected, Even from Afar

Gathering in-person was not an option for our ALS community during the pandemic. To stay connected, we moved quickly to virtual platforms, enabling our support groups to continue meeting monthly. As time progressed, we realized how these virtual support groups were not only keeping our regular attendees connected, but also enabling other people with ALS and their families to join from more remote areas of the state. After the initial success of these groups, and in response to a growing need, we started bereavement support groups and a Veterans support group.

We worked with partners across the state to develop an educational series of presentations and interactive workshops. This included a clinical series, focused on different aspects of the ALS clinic, a series to equip caregivers with the tools to manage stress and promote self-care, and a Navigating ALS series to guide newly diagnosed Texans with ALS.

The exploration of virtual programs broke down barriers to access, enabling us to continue serving Texans with ALS and their families in a way that will continue beyond the pandemic.

11

Clinics
in Texas

653

Patient visits
at our clinics

18

Active clinical
trials in Texas

BREAKING DOWN BARRIERS

ALS CLINICS

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. 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.

In the early days of the pandemic, many of our ALS Multidisciplinary Clinics had to cancel regular clinic days. As time has progressed, each clinic has modified their operations to best serve the safety of their community. Most have now resumed normal operations or offer a combination of in-person and virtual visits. We've been working closely with our clinic partners to help keep our ALS community safe and ensure our presence as a resource for Texans with ALS and their families.



THE ALS CLINIC AT TEXAS NEUROLOGY

DR. DARAGH HEITZMAN

The ALS Clinic at Texas Neurology has served the ALS community for 20 years. Dr. Heitzman opened this clinic after coming to Dallas in the nineties to open a private practice. He'd previously worked with ALS patients at the Cleveland Clinic, and thus had grown a passion for serving that community.

"If You Build It, They Will Come"

At first, clinics were held every three months, with six patients served each month. Today, they are held twice a month, with 30-35 patients per month at the clinics and an estimated 220-230 people with ALS under their care.

"We know patients live longer when they attend clinic. It also saves them from having to visit multiple healthcare providers. If you can consolidate that, it makes it easier on the patients and the caregivers. Coming to a clinic allows you to get it all-in-one, and to get help from people experienced with ALS."

Telemedicine: Breaking Down Barriers to Access

Telemedicine isn't new, but prior to the COVID-19 pandemic, healthcare providers struggled to use telemedicine because of virtual platform restrictions and insurance barriers. When the lockdown started, most ALS clinics in Texas closed temporarily. The ALS community, the ALS Association, the American Academy of Neurology, among others advocated for a telemedicine expansion, resulting in new guidelines that removed these barriers. The ALS Clinic at Texas Neurology began to offer telemedicine to patients, and ALS patients across Texas jumped at the opportunity to continue their care from the safety of home.

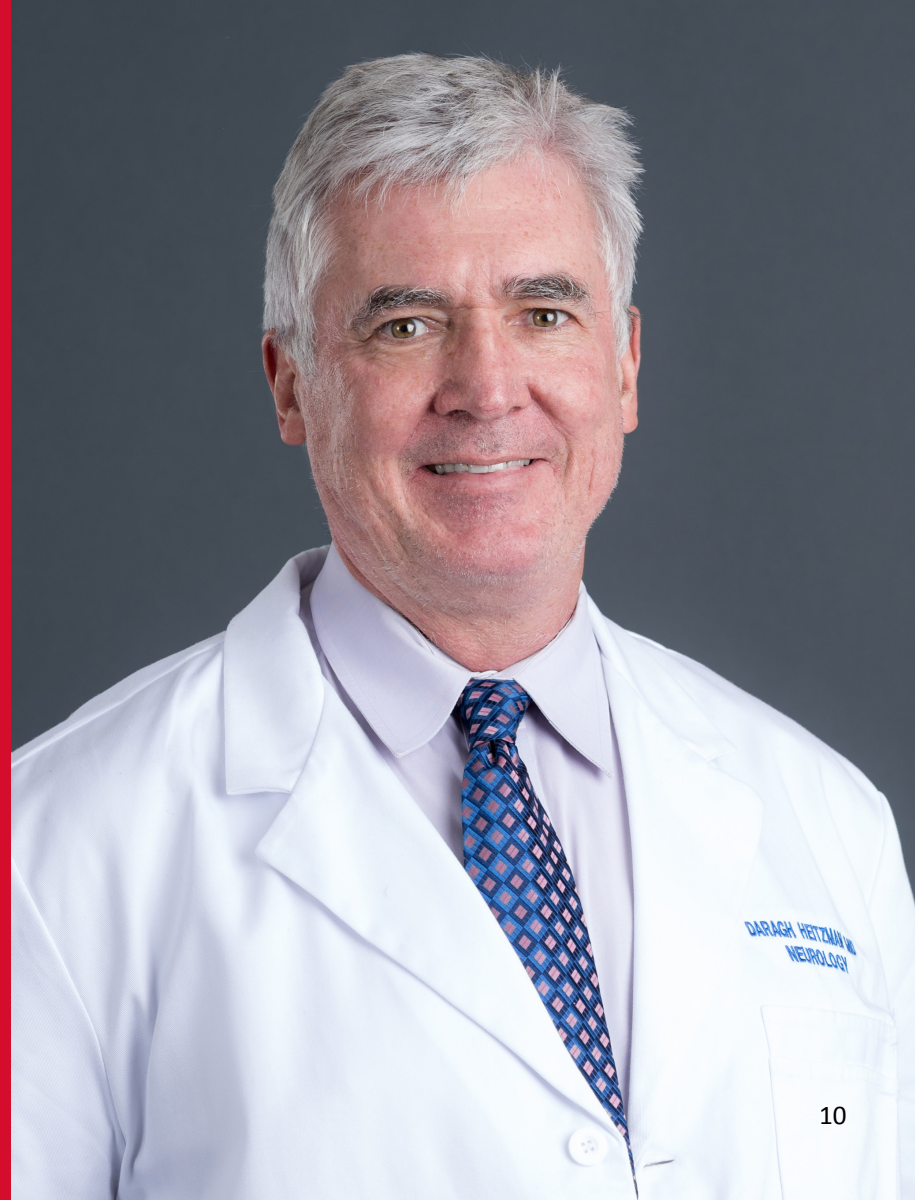
Dr. Heitzman and his team see the advantage of providing a telemedicine option to patients long-term. "We need to see them initially to make the diagnosis, but thereafter from the physician perspective, with the exception of doing PFT's (pulmonary function tests), we can do this all through telemedicine," Dr. Heitzman states. "But I think we can get to the point where we may be able to send them a kit that they can do at home and then send to the pulmonologist. It just makes it a lot easier on the patient." Telemedicine still does not replace the one-on-one visits with the ALS multidisciplinary team.

There are still challenges to overcome with telemedicine, such as lack of internet access for those in under-resourced communities, and that the guidelines enabling broader use of telemedicine are only temporary. But with partners like ALS Clinic at Texas Neurology, we are working to overcome these challenges and advocate for Texans with ALS to continue to have access to telemedicine to continue the crucial care they need to improve their quality of life.

Dr. Heitzman has seen firsthand the positive impact of telemedicine for Texans with ALS.

"We need to see them initially to make the diagnosis, but thereafter, with the exception of doing PFT's, we can do this all through telemedicine."

- Dr. Daragh Heitzman



ADVANCING RESEARCH

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



HEALEY CENTER ESTABLISHES FIRST ALS PLATFORM TRIAL

\$3M Helped support the HEALEY Platform Trial to speed up drug development by **reducing the cost of research by 30%** and **decreasing the trial time by 50%**.



STARTING A NEW EFFORT TO STOP ALS AS SOON AS POSSIBLE

Starting a new effort to stop ALS even before people get sick by funding the **first ever development of genetic testing and counseling guidelines** for ALS to help with ALS and their families identify and **manage their genetic risk** and **guide treatment decisions** on emerging gene-based therapies. We are also partnering with CDC on a workshop to problemsolve and translate research about ALS causes into preventive approaches and treatments to **reduce risk of ALS**.



PUBLICLY AVAILABLE GENETIC DATA PROPELS INNOVATION

By committing over **\$5.4M of funding for 24 new projects** spanning diverse areas of research such as biology, therapeutics, biomarkers, infrastructure, and clinical trials. The Association managed **over 162 active projects** with a **multiyear commitment of over \$55M**.



BRINGING EFFECTIVE TREATMENTS CLOSER TO APPROVAL

Including AMX0035 from Amylyx Pharmaceuticals that was **shown to extend life and slow disease progression**, and continued progress on Tofersen, a genetic therapy for SOD1-ALS in late phase trials, along with progress on biomarker research.



INVESTING IN INGRASTRUCTURE AND DATA ACCESS ACCELERATES ALS RESEARCH

With over **\$1.2M** for the PRO-ACT (Pooled Resource Open-Access ALS Clinical Trials) database which is the **world's largest ALS clinical data repository**. Since its launch in 2012, over 900 researchers from 68 countries in both for-profit and non-profit sectors, have obtained access and analyzed these datasets resulting in 32 scientific publications.



FINDING OUT WHAT'S MOST IMPORTANT TO PEOPLE WITH ALS AND THEIR FAMILIES

Since launching, over **1,450 people have participated in the ALS Focus**. These surveys bring the perspectives and needs of people with ALS and caregivers to the forefront of program and policy decision making. To join, visit: www.als.org/research/als-focus.



ADVANCING RESEARCH

THE HEALEY ALS PLATFORM TRIAL

In 2020, the ALS Association, in partnership with Massachusetts General Hospital, launched an innovative approach to research, the HEALEY ALS Platform Trial. In most clinical trials, a single drug is tested, and participants cannot be enrolled in more than one trial at a time. The HEALEY ALS Platform Trial enables us to test three proposed drug treatments at once. This is a model that has been successful in cancer research, among other diseases. It will accelerate our search for effective treatments for people living with ALS by allowing investigators to test more drugs, increase patient access to trials, and reduce costs by quickly and efficiently evaluating the effectiveness of multiple therapies. There are now 54 test sites nationwide, three of which are in Texas.

Texas Neurology was one of the first five initial sites for utilizing this new model. “This is big. I’ve been doing trials since the early nineties. The average trial takes 8 years. Going through platform methodology shortens the duration of the trial to 2-3 years,” states Dr. Daragh Heitzman, clinical director at Texas Neurology. Dr. Heitzman was recently appointed to the HEALEY ALS Platform Trial Executive Committee, as the first physician investigator to join an elite group of scientists.

“What’s different about this trial is that the placebo group is being shared for all five drugs, such that the number of participants who actually get a drug is dramatically increased. So, it’s a lot quicker to get to an answer, more patients are getting drugs, and less are getting a placebo.”

Trial participants will have the option to continue treatment for at least a year, and if the drug shows promise during the six-month trial, the FDA could potentially fast-track its approval, getting a crucial treatment to people living with ALS.

Texas HEALEY ALS Platform Trial Sites

The ALS Clinic at Texas
Neurology in Dallas

Houston Methodist ALS Clinic

The ALS Clinic at UT Health
San Antonio



ADVOCACY & PUBLIC POLICY

OUR PRIORITIES

ADVANCING RESEARCH

Accelerate development, approval, and access to effective new treatments by re-introducing and passing the Accelerating Access to Critical Therapies (ACT) for ALS Act and the Promising Pathway Act, so the FDA is fully equipped to speed ALS trials and drug approvals.

Increase funding for ALS research programs, including:

- At least \$130 million at the National Institute of Health (NIH).
- At least \$60 million for the ALS Research Program (ALSRP) through the Department of Defense.
- At least \$50 million for ALS research to the Orphan Products Grant Program (OPGP) through the FDA.
- At least \$10 million to continue the National ALS Registry and Biorepository.
- At least \$1 million for the National Academy of Sciences, Engineering, and Medicine study to develop a plan and policy recommendations for what can be done by the government and all stakeholders to end ALS.

PATIENT NEEDS

Permanently extend access to telehealth for people with ALS to ensure they continue to have access to high-quality care from their home.

Provide high-quality, affordable, and accessible health care, including protections for pre-existing conditions, reducing costs for Medicare coverage, durable medical equipment, and all medications needed by people with ALS.

Increase veteran's benefits for people with ALS and their families. Veterans from all branches of the United States Armed Forces are twice more likely to develop ALS than civilians.

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. **Learn more at alstexas.org/advocate**

ADVOCACY BIG WINS

Every year, the ALS Association of Texas, people with ALS, caregivers and supporters meet with our elected officials, sign petitions, and call on lawmakers to join the fight against ALS. Because of the efforts of our ALS community, this year we saw two big victories:

- The ALS Disability Insurance Access Act was passed to waive the five-month waiting period for every person living with ALS, enabling them to receive benefits under Social Security Disability Insurance immediately.
- Funding was increased to \$40M for the Department of Defense ALS Research Program in 2020, which is double the previous year's amount.

*Due to the COVID-19 pandemic, the 2020 Fly-In and the 2020 Advocacy Conference were virtual. Pictured right is a group of ALS advocates from Texas at the Advocacy Conference in Washington D.C. in 2019.



ALS HERO

NORMAN JONES

Faith guided Norman Jones his whole life. Even in the face of an uncertain ALS journey, it hasn't wavered.

Norman described the beginning of his ALS journey as an emotional rollercoaster. He went from the highs of retirement and having more time to spend with his family, to the lows of an ALS diagnosis. "But my faith has kept me strong," Norman shared.

Even from a young age, Norman's grandmother instilled in him the importance of faith. It kept him strong when he moved to the U.S. from Jamaica as a child, and it led him to become a Chaplain in the Army. Norman served in the army for 32 years, 24 of those being as Chaplain, before retiring in 2016.

After two years in retirement, Norman noticed symptoms such as his left foot dragging while he walked and slurred speech. Through a series of tests and doctor's appointments, he was formally diagnosed with ALS in May 2018.

Today, Norman and Dee, his wife of 41 years, live in San Antonio. They have two daughters—one who lives with them at home and the second who recently got married and is teaching in Korea.

Just two years into their ALS journey, Norman and Dee had to also adjust to the challenges of the COVID-19 pandemic. In-person clinics and support groups came to a halt for the safety of Texans with ALS and their families.

During this time, virtual support groups kept the Jones family connected with the ALS community. "You're able to express your emotion and your struggle. And then you get advice from others how they handle their struggles," Norman shared.

Hearing the stories of other ALS families and swapping notes has been incredibly helpful to Dee as a caregiver. "For me, it's a lifeline," Dee shared. She recalled that many times, she has heard experiences from other wives and caregivers that are like her own. "Some of us are going through the same issues and same journey. I try to embrace it."

"Reach out and connect with family, friends, and organizations, because you get your strength and support from others."

NORMAN JONES

Person with ALS



TEAM JONES
WALK FOR
NORMAN
Stomp out ALS



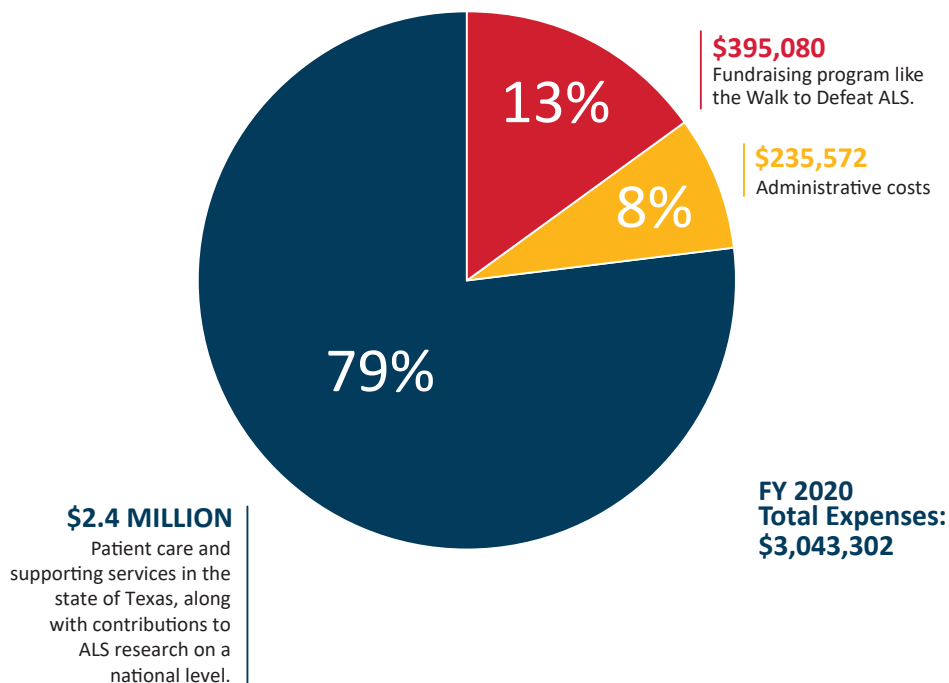
TEAM JONES
WALK FOR
NORMAN
Stomp out ALS

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+

Mr. Thomas Coale
Anonymous Family Foundation
Charlotte and Kelly Hall
Cathy and Joseph Cleary Jr.

DIAMOND \$50,000+



Whalley
Foundation

EMERALD \$25,000+

Mr. Philip J.
Russel



Mr. Louis
Scantland



Mr. Thomas
King

PLATINUM \$15,000+

McDonough Corporation
Mr. Guido Costantini
Barbara Ildebrando Fund
Helping Our Heroes
George and Mary Josephine Hamman Foundation
Harvey Builders
The Gordon Hartman Family Foundation
The Quaid Group



TOP FUNDRAISING WALK TEAMS

Team Coale, Mary Murphy, The Woodlands

Katie's Warriors, Ronald Lenss, San Antonio

Team Dallas, Leigh Ann Dallas, Houston

Team Kathy, Stephanie Tucker, Houston

Rich for the Cure, Kristin Sedate, San Antonio

The Wright Team, Jacqueline Looney Wright, Houston

Team John Lay, Sally Allen, Austin

ARC, Mary Beth Ziegler, San Antonio

Team Brian, Nicole Brown, Dallas

Friends of Rupesh: Join the Fight, Rupesh Kotiya, Dallas

#AttackLifeSloan, Shanda Sloan, Dallas

ALS Can Kiss My A\$\$, Jessica Bardin, Houston

TEAM LAURA BTHO ALS, Laura Weiss, Austin

Pat's Angels, Patricia Hamilton, The Woodlands

Houston Poly Bag, William Summer, The Woodlands

WALK WITH ROY, Lydia Joseph, Houston

Old Town Road Family, Toshene Fletcher, San Antonio

Steps for Sheps, Shepherd Family, Austin

Helping Our Heroes, Sherry Russo, Rio Grande Valley

Judy's Joggers, Russell Weaver, San Antonio

Kevin's Crusaders, Linda Licarione, Houston



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