

2018



IMPACT REPORT





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SPARK HOPE

Spark. At first glance, the word spark may seem small. After all, it's only five letters. However, this word's meaning is anything but small. It is both a thing and an action. The word spark means "to set off in a burst of activity" and "to respond with enthusiasm." We can think of no better way to describe 2018 at the ALS Association of Texas.

This year, because of the generosity of our donors, volunteers, and families, we have accomplished more than we ever thought possible. We've seen an **energy** sparked in our community, through our clinic expansion into El Paso and our advocacy work, which impacts the lives of ALS patients here in Texas and beyond. New **breakthroughs** in research show promise for future treatments and, ultimately, a cure for ALS. We continue to spark **innovation** through a project that helps patients keep their voices, even after they lose the ability to speak.

But most of all, we've seen our community spark **hope**.

We need to instill this hope for the future in our community, but we can't do this alone. We need your help to fulfill our mission of providing quality care, advocating for patient rights, and investing in essential research. Together, we can take this hope and create a world without ALS.



Tanner Hockensmith
Executive Director



Trent Parten
Board President



"Advocating for my fellow ALS soldiers has sparked a fire in me that will never go out."

SUNNY BROUS ERASMUS

Person with ALS

BOARD LEADERSHIP

Trent Parten
PRESIDENT

Rebecca Moss
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TREASURER

Bob Ballou

Jeff Duncum, DDS

John Fleming

Kelly Hall

Sterling Hillman

Mary Klenke

Kris Knapstein

Randy O'Hare

Philip Russell

Alison Talarcek



2018 BY THE NUMBERS



1,125

PATIENTS ASSISTED



\$25,000

IN FINANCIAL ASSISTANCE GRANTS TO
COVER DISEASE-RELATED EXPENSES



1,156

PATIENT VISITS AT OUR
MULTI-DISCIPLINARY CLINICS



11

MULTI-DISCIPLINARY
ALS CLINICS IN TEXAS



56

CLINICAL RESEARCH
TRIALS IN TEXAS



414

PATIENT
HOME VISITS



387

EQUIPMENT LOANS
TO PATIENTS



1,545

PEOPLE
ATTENDED

144

SUPPORT
GROUPS



Photo provided by Texas Tech University Health Sciences Center El Paso

"The ALS Association staff and volunteers have dedicated their lives to ensure that those living with ALS today can continue to live life and make memories."

COLLIN HADLEY

Person with ALS

SPARK HOPE

PATIENT STORY

I HAVE ALS, BUT IT DOESN'T HAVE ME

Collin Hadley was diagnosed with ALS in October of 2014. He resides in Fort Worth with his wife Emily, two children, and their dog.

After being diagnosed with ALS, Collin Hadley gave himself one day to be frustrated, only one, before declaring "I have ALS, but it doesn't have me."

Since that day, Collin and his family have set out to make as many memories as possible, including 25 family trips, fundraising for ALS, finishing the Cowtown half-marathon (in a neon pink stroller), and more. Although Collin strives to be positive, he recognizes that not every day is easy. He says, "Though not visible on a daily basis, every month for the rest of your life is a little more difficult than the one before."

Even in the face of ALS, Collin has continued to grab life by the horns with the help of the ALS Association of Texas. "When I had my first falls with this disease, they got a hooyer lift in my home immediately. When it was no longer safe for me to stand up in the shower, they had a shower chair sent to me that day. When I could no longer get in the swimming pool with my kids, they found me a pool lift." He went on to describe how an ALS Association representative made a 4.5 hour drive to deliver a power wheelchair to his hotel room when he was on vacation. "The ALS Association staff and volunteers have dedicated their lives to ensure that those living with ALS today can continue to live life and make memories."

Collin stressed the importance of having a community of heroes to help people with ALS navigate through life: "This terrible disease takes a village, and, thankfully, the one many of you have built for me and my family is rock-solid."



SPARK BREAKTHROUGHS

ADVANCING RESEARCH

"Our goal is to give a patient hope for the future. We may not cure a patient's disease, but we can make a difference."

DR. STANLEY APPEL

*Co-director of the Houston Methodist
Hospital Neurology Institute*

IMMUNOTHERAPY TREATMENT STOPS ALS PROGRESSION

Dr. Stanley Appel, neurologist and co-director of the Houston Methodist Hospital Neurology Institute, has been leading the ALS Clinic at Houston Methodist Hospital since its founding in 1982. This was the first multi-disciplinary clinic dedicated to the treatment of and research on ALS. More than 35 years later, he continues to innovate in the field.

His latest research focuses on an immunotherapy treatment that could stop the progression of ALS in its tracks.

After years of research and studies related to the immune system, Dr. Appel and his team discovered a key component accelerating ALS progression, regulatory T cells. Also known as Tregs, regulatory T cells are immune cells that help protect the body from harmful inflammation that accelerates the progression of ALS.

"We found that many of our ALS patients not only had low levels of Tregs, but also that their Tregs were not

functioning properly," said Appel. "We believed that improving the number and function of Tregs in these patients would affect how their disease progressed."

The research team discovered that after removing blood from patients, the Tregs returned to normal once outside the body. The phase 1 study included three patients who underwent a process called leukapheresis, a procedure in which blood is removed, and white blood cells are separated from red blood cells to increase the number of each patient's own Tregs before administering the red blood cells intravenously back into the patients.

The phase 1 study, funded in part by the ALS Association, has shown to stop the progression of ALS in patients, a tremendous feat for a disease with only a few treatments available to slow progression. Phase 2 trials will further evaluate the safety and effectiveness of the treatment, and, hopefully, turn this research into an off-the-shelf cellular therapy for ALS patients.

Photo provided by Texas Medical Center / Cody Duty



2018 ADVANCES IN ALS RESEARCH



KIF5A ALS GENE DISCOVERED

A large collaborative effort involving more than 250 researchers, led by Dr. John Landers (UMass Medical School) and Dr. Bryan Traynor (NIH), came together to achieve this exciting gene discovery, including organizations supported by the Association - Project MinE, Genomic Translation for ALS Care, Answer ALS, the Target ALS Postmortem Tissue Core, the New York Genome Center (NYGC) ALS Consortium, the CReATe Consortium, the NIH, and others.



ANTISENSE DRUGS ACHIEVED SIGNIFICANT PROGRESS

- Biogen announced encouraging results of SOD1 (BIIB067) phase I trial and is moving to the next clinical phase with urgency.
- Biogen also initiated the C9orf72 (BIIB078) phase I trial this fall and the first patients were dosed.



ASSISTIVE TECHNOLOGY ADVANCED AT RAPID PACE

- Pison Technology, winner of our ALS Assistive Technology Challenge, is growing. Our \$100,000 investment leveraged more than \$1.7 million in outside funding and their wearable muscle sensor technology is moving fast toward the market.
- Project Revoice was launched to help encourage people with ALS to voice bank and make it easier to use their synthesized voice.
- Telemedicine is on the rise to help people with ALS connect with the company's care teams, especially in rural areas, through the hard work of our chapter network and funded researchers.



DRUG DEVELOPMENT MOVED COMPOUNDS TOWARDS THE CLINIC

- A viral gene therapy targeting the ALS SOD1 gene was safe and effective in nonhuman primates, which paved the way for a human clinical trial.
- Anelixis Therapeutics moved its compound AT-1501 into clinical trials and dosed its first patient.
- Karyopharm Therapeutics announced that Biogen acquired compound KPT-350, with plans to advance it into clinical trials in the near future.



FDA DRUG APPROVED FOR ALS

ITF Pharma, Inc. announced that Tiglutik*, the first and only thickened liquid form of riluzole, was approved by the FDA to treat ALS. This formulation should help individuals with swallowing difficulties.



RESEARCH AIMED AT HELPING PEOPLE WITH ALS

- Respiratory strength training showed safety and feasibility in an ALS case study and moves forward with hope to strengthen inspiratory and expiratory muscle function.
- Research to improve noninvasive ventilation for people with ALS is underway through the use of custom-printed 3D masks.



SIGNIFICANT PROGRESS FOR ALS CLINICAL TRIALS

- Amylyx Pharmaceuticals is close to finishing enrollment in its phase II AMX0035 trial and announced an open-label extension study.
- Origent Data Sciences made headway in clinical trial patient stratification using its unique computer algorithms.
- The mexiletine phase II trial showed positive results in reducing muscle cramping.
- The phase II ezogabine trial completed, meeting its primary goal to measure a reduction in motor neuron excitability in people with ALS following treatment.



STATE-OF-THE-ART TECHNOLOGY REACHED EXCITING RESEARCH MILESTONES

- An organ-on-a-chip was developed to recreate human biology (blood vessels connected to motor neurons) on a microchip to uncover novel ALS biomarkers and therapeutic targets.
- Artificial intelligence was used to microscopically examine and analyze cells involved in ALS to better understand their disease characteristics.
- Specially engineered cells transplanted into the brain's motor cortex protected motor neurons and delayed disease in animal models.



Photo provided by Houston Methodist Hospital

FEATURED CLINIC

Texas Tech University Health Sciences Center El Paso ALS Association Affiliated Clinic

The geography of Texas and accessibility of care are challenges for people with ALS. With the state's sprawling cities, growing suburbs and vast rural areas, the nearest ALS clinic may be several hours away. El Paso is a large community with a heavy veteran population, and, until recently, people with ALS needed to travel four to eight hours to visit an ALS clinic. Last year, in partnership with the ALS Association of New Mexico and the Texas Tech University Health Sciences in El Paso, we funded and opened an ALS clinic in El Paso to bring much-needed ALS patient care services to the community.

"We have an amazing team that is committed to our ALS community.

Having the presence, guidance and support of two ALS Chapters, Texas and New Mexico, is unique to this border town. Patients and families do not have to go alone on this difficult journey"

LOURDES MARTINEZ

*Social Worker, Texas Tech University
Health Sciences Center El Paso*

SPARK ENERGY

ALS CLINICS: CONTINUED INVESTMENT

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 multi-disciplinary approach is scientifically proven to extend patients' 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 seven clinics across the state, watching them grow and serve more patients than ever before. We also formed new relationships with an additional three clinics. 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.

11

CLINICS
THROUGHOUT
TEXAS

1,156

PATIENT VISITS
AT OUR CLINICS

56

CLINICAL TRIALS
CONDUCTED THROUGH
OUR CLINICS

Photo provided by Texas Tech University Health Sciences Center El Paso



Upper Limb Spasticity (U.L.S.): Common Postures and BOTOX® Treatment



Muscle	Range of Motion (ROM) for BOTOX® Treatment
Biceps Brachii	100% to 100% (100% to 100%)
Flexor Digitorum Profundus (FDP)	100% to 100% (100% to 100%)
Flexor Carpi Radialis (FCR)	100% to 100% (100% to 100%)
Flexor Carpi Ulnaris (FCU)	100% to 100% (100% to 100%)
Flexor Digitorum Superficialis (FDS)	100% to 100% (100% to 100%)
Flexor Pollicis Longus (FPL)	100% to 100% (100% to 100%)

Notes: Flexion and extension also should be noted in the treatment of each subsequent treatment session to determine optimal outcomes.

Botox
onabotulinumtoxinA

SPARK INNOVATION

PROJECT REVOICE

What does it mean to lose your voice? For many, the loss of vocal communication means losing a piece of what makes them feel human. As ALS progresses, it robs people of their ability to speak, leaving them to talk to loved ones through devices with clunky, computerized voices. Pat Quinn, creator of the famous Ice Bucket Challenge, spoke to the ALS Association about the pain of losing your voice, saying, “It is crushing when you have so much to say, but you are almost forced to keep it in.”

We understand the pain patients endure as they feel their voices slipping away, and we set out to do something about it. In 2018, the ALS Association launched Project Revoice, an initiative aimed at returning the voices stolen by ALS. Thanks to technology created by Canadian-based tech company Lyrebird, ALS patients will be able to recreate high-quality, natural-sounding voices with only a few hours of voice banking.

It’s through Project Revoice that Pat was once again able to hear his own voice. “It truly feels like a piece of me that ALS took away has returned,” he said in his own voice. He continued, expressing how this new development gave him the push he needed to keep going: “This has lit a fire inside me to continue fighting with everything I have.”

“For patients to know that they can still speak
in their own voice after ALS takes it away will
transform the way people live with this disease.”

PAT QUINN

*Person with ALS and co-founder
of the Ice Bucket Challenge*

PROJECT
REVOICE



"If there is one lesson I have learned in my life, it's that you can never give up. And even though ALS is trying to beat me, I am going to keep pushing to be the best example I can be to my family, friends and students. It's what I've always been called to do."

ERIC MARTINEZ

Person with ALS

SPARK HOPE PATIENT STORY

BE A STEWARD FOR CHANGE

Eric Martinez was diagnosed with ALS in 2017. He is a proud father of two children and resides in Midland, TX.

Texas-born Eric Martinez would describe himself as a father, educator, doctor, mentor and friend. But, in 2018, he added ALS patient to that list. "Nobody ever wants to be labeled as an ALS patient, but I believe that through this terminal diagnosis, God is giving me a second chance at life," said Eric.

Eric's goal has always been to inspire and prepare children of limited economic resources to succeed in school and lead in their communities. He said, "There is no greater gift than seeing a young student with few resources achieve their full potential." Eric taught his students to work hard and persevere because, after working tirelessly to earn his PhD, he knows what is possible. "My ALS diagnosis has only helped me further model that example. I do not let the challenges ALS presents to me stand in the way of my life's work." Today, he mentors student teachers and interns at University of Texas Permian Basin and hopes to instill in them the same values he's learned throughout his career.

Speaking to the kindness of the ALS community, Eric went on to explain how a man, who'd recently lost his wife to ALS, had donated all of her medical equipment and accessible van to him in her honor. "His gifts have allowed for me to be independent, still work, and be a member of my community. I will never forget his kindness and will continue to pay it forward."

Eric ended by sharing an important life lesson: "If there is one lesson I have learned in my life, it's that you can never give up. And even though ALS is trying to beat me, I am going to keep pushing to be the best example I can be to my family, friends, and students. It's what I've always been called to do."



SPARK ENERGY ADVOCACY & PUBLIC POLICY

The ALS Association is at the forefront of public policy, working to improve the lives of people living with ALS and their caregivers. Below were the biggest priorities in ALS advocacy in 2018:

ADVANCING RESEARCH

- Ensure at least \$10 million in appropriations for the ALS Registry at the Centers for Disease Control (CDC)
- Ensure at least \$10 million in funding for the Department of Defense's (DOD) ALS Research Program
- Support increased funding for the National Institutes of Health (NIH) in FY2019, especially in the National Institute of Neurological Disorders and Stroke (NINDS)

PATIENT NEEDS

- Pass the ALS Disability Insurance Access Act (S.379/H.R.1171) 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

ADVOCACY CONFERENCE

Every year, a group of ALS Texas staff members, ALS patients, caregivers, and supporters travels 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 capital to put a human face on this devastating disease and encourage lawmakers to join the fight against ALS.

22 Attendees
from Texas

20 Meetings held with
Texas Senators and
Representatives



"As long as I am able, I will raise my voice in the fight for those that no longer can."

SUNNY BROUS ERASMUS

Person with ALS

SPARK HOPE

PATIENT STORY

RAISE YOUR VOICE

Sunny Brous Erasmus was diagnosed with ALS in 2015. She resides in Fort Worth with her husband Kenneth, their dog, and two cats.

Since being diagnosed with ALS right before her 28th birthday, Sunny Erasmus has become a warrior for others with the devastating disease. "There are many things that ALS has taken away from me," she said, "but my voice is loud and persistent in the fight to end this disease."

In May of 2018, she was one of 570 ALS advocates who made their way to Washington, D.C. for the National ALS Advocacy Conference. There, people with ALS, their friends, and their families were able to make their voices heard and speak up for those who no longer can.

At the conference, advocates like Sunny learned about the latest ALS research, care service programs, and advocacy efforts to prepare them for meetings with Texas Senators and Representatives. During those meetings, advocates fought for public policy initiatives that would improve the lives of people with ALS.

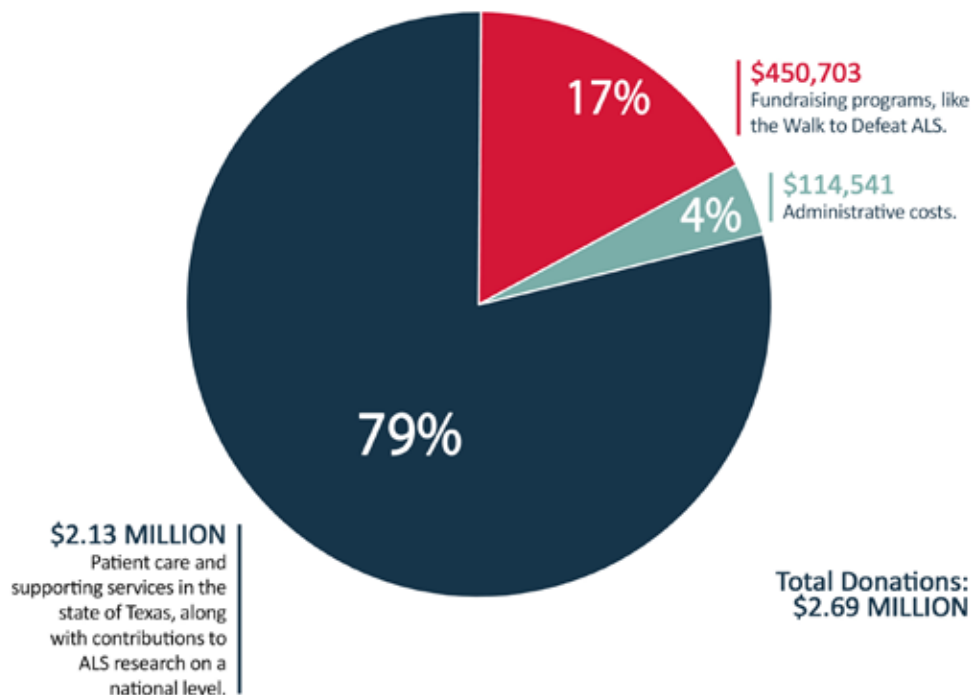
Sunny called the conference "one of the most impactful experiences" of her life, where she learned about what it means to be an advocate, what to advocate for, and the progress that's being made by other ALS advocates along the way. "Keeping up energy and focus is hard," she said, "but advocating for my fellow ALS soldiers has sparked a fire in me that will never go out."

"As long as I am able, I will raise my voice in the fight for those that no longer can."





ALS TEXAS FINANCIALS



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.

TOP FUNDRAISING WALK TEAMS

Harvey Builders, Patricia Jaloway, Houston

Team Crowder, Holly Crowder, Dallas

Team Tom, Emily Fruge, Fort Worth

Steps for Sheps, Shepherd Family, Austin

#TeamAyeez, Ayeez Lalji, Houston

PQ's Crew, Andrea Clark, Houston

Houston Poly Bag, Bill Sumner, The Woodlands

Worth Fighting, Ernie Worth, The Woodlands

Team Brian, Brian Patelski, Dallas

Friends of Frank, Douglas Robinson, Dallas

Greg's Herd, Caroline Wood, Houston

Craft's Crusaders, Trace Craft, Fort Worth

Kenworthy, Jeff Kenworthy, The Woodlands

Carol's Crew, Lisa Avila, San Antonio

Team Laura BTHO ALS, Laura Weiss, Austin

Flamingo OLE', Caron Scruggs, Fort Worth

ARC, Mary Beth Ziegler, San Antonio

Judy's Joggers, Russ Weaver, San Antonio

Linebackers: Tackling ALS, Kimmie Longstreet, Houston

Mikey's Magic Marchers, Michael Christian, Austin

Billy Rudd Team, Sterling Hillman, Dallas

Pat's Angels, Patricia Hamilton, The Woodlands

Chandler's Champs, Hailie Cormier, Dallas

Team Judy, Shelly Bender and Dawn Baucom, Dallas

Mike's Defenders, Amy Smith, Austin



THANK YOU

RUBY \$75,000+



DIAMOND \$50,000+

**Goldman
Sachs**

Gives

Mr. Frank J. Ildebrando

EMERALD \$25,000+



George & Mary Josephine Hamman
Foundation Charlotte W. & Kelly Hall
Andrew J. Kaiser
Anonymous



PLATINUM \$15,000+

Cathy & Joseph A. Cleary
Mr. Thomas Dowling
Mr. Eric S. Lane
Ms. Barbara Loeb
Wells Fargo Advisors
Mr. & Mrs. Thomas York, Jr.
Mr. Philip J. Russell
The Gordon Hartman Family Foundation
Kiewit Companies Foundation
HP Austin Charity Group
Silver Eagle Distributors Charitable Fund
Lynn Parker Memorial Golf Tournament
Original Terlingua International Chili Cookoff
Nancy & Tom Fruge



ALS Association of Texas
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alstexas.org