ALS ASSOCIATION
Greater Sacramento Chapter
FY 21
ANNUAL IMPACT REPORT
Creating a World Without ALS
ALS ASSOCIATION
Greater Sacramento Chapter
Friends,

If there is one thing that 2020 revealed, it is that our world is much smaller than most of us probably ever imagined. The rapid pace in which COVID-19 spread around the globe serves as a reminder that, as people, our connectivity to one another binds us regardless of where we live. Good or bad, we are one, and each of us play a vital role in creating safe, healthy, and vibrant communities, starting with our own.

As a leader in the fight to end ALS, the philosophy of accountability to one another and our community is embraced by the chapter as culture. As a result, when the pandemic hit in California, our team was prepared to roll-up their sleeves to ensure that the needs of the ALS community continued to be safely met. It certainly wasn’t easy. Hundreds of thousands of dollars in funding was lost due to the pandemic, but we never lost sight of our vision of a world without ALS. We continued to push on, serve, advocate for, and empower people living with ALS to live their best lives despite the limitations that COVID-19 placed on all of us.

With the ALS space rapidly changing, I’ve never had more hope that an effective treatment is around the corner. In this Annual Report, you’ll hear about the advancements we’ve made toward a cure, along with the cool things we were able to do despite the challenges of 2020.

You’ll hear from families who are redefining what it looks like to live with ALS and the front-line staff who serve them.

You’ll learn about our new ALS Allies initiative that is designed to sustain our core programs and services into the future, while shining a light on the personal stories of people impacted by ALS.

Before signing off, I want to extend my sincere gratitude to our donors who have faithfully supported our efforts to create an inclusive community for people living with ALS. With your help, we can continue to serve, support, and help people navigate the complexities of ALS while we search for a cure, so the next generation doesn’t have to.

Together, we’ve got this.

Amy Sugimoto

**Mission:** To discover treatments and a cure for ALS, and to serve, advocate for, and empower people affected by ALS to live their lives to the fullest.

**Vision:** Create a world without ALS
FINANCIALS

FY20 Support & Revenue

- **Contributions & Special Events**
  - $822,085
  - 69%
- **Grants**
  - $299,104
  - 25%
- **In Kind**
  - $73,266
  - 6%

FY20 Functional Expenses

- **Programs & Services**
  - $715,105
  - 78%
- **Fund Development**
  - $145,411
  - 16%
- **Mgmt & General Expenses**
  - $56,255
  - 6%

ALS Association Greater Sacramento Chapter Board of Directors

- **James Morgan, President**
  - Department of Development Services
  - Finance Project Manager
- **Sheila Lamb Carroll, Vice President**
  - Carroll & Associates
  - Senior Attorney/CEO
- **Tony Sertich, Treasurer**
  - California Housing Finance Agency
  - Director of Enterprise Risk and Compliance
- **Jeff Rosenblum, Secretary**
  - Law Office of Jeffrey Rosenblum
  - Attorney
- **Jennifer Porter**
  - Hill-Rom Respiratory Care
  - Account Executive
- **Heinz Ludke**
  - Charter Communications
  - Retired, Regional Director
- **Shelly Hoover, PhD.**
  - Author
- **Martin McGartland**
  - Red River Technology LLC
  - Retired, President RRCS
- **Dr. Nanette Joyce, DO**
  - UC Davis Medical Center
  - Co-Director, Multidisciplinary ALS Clinic
- **Candace Bonney**
  - Bonney Heating, Plumbing, & Air
  - Co-Founder
- **Cherie Felsch**
  - UC Davis School of Veterinary Medicine
  - Retired, Personnel Manager
- **Dara Bellino**
  - Cordially Yours Travel
  - Travel Consultant
- **Claire Rogers**
  - SMUD
  - Manager, Audit Services

“I have made it my mission to honor my father and to eradicate this atrocious disease by giving back to the incredible Greater Sacramento Chapter who supported me and my family through our ALS journey.” - James Morgan, Board President, Greater Sacramento Chapter
While much of the world paused to quarantine during the first half of the year, ALS did not stop for COVID-19. Neither did The ALS Association’s Global Research program. Our commitment to building a world without ALS only intensified as the needs of the community we serve became more pressing in the face of a global pandemic.

As the largest private funder of ALS research worldwide, our work has led to some of the most promising and significant advances in ALS research to date and we simply cannot stop now. As of this moment, we are funding 171 research projects across 15 countries in an effort to end ALS.

Every project we fund supports our mission of finding treatments and a cure for ALS, which is why it is so critical to fund outstanding ALS research. From harnessing innovative ideas, to translating concepts to therapies, to advancing treatments for people living with ALS – The ALS Association’s collaborative and global approach to funding research continues to lead to significant discoveries by top ALS scientists.

Your generous support enables The ALS Association to fund millions of dollars in research every year, in locations across the globe. From individual projects to global collaborations, we provide funding to experts in a variety of scientific focus areas critical to advancing the search for treatments and a cure for ALS.

Our association funds a wide breadth of specific fields of study that are critical to advancing ALS research:

- Assistive Technology
- Biomarkers
- Clinical Studies
- Cognitive Studies
- Disease Mechanisms
- Disease Models
- Genetics
- Nanotechnology
- Natural History Studies
- Drug Development
- Stem Cells
- Environmental Factors

Here are a few highlights of advancements made in 2020:

- Our research funding includes a $3 million commitment to help set up the first-ever ALS platform trial at the Sean M. Healey & AMG Center for ALS.

- We launched a partnership with I AM ALS to fund research into biomarkers utilizing BrainStorm’s ongoing phase 3 clinical trial of its NurOwn treatment.

- Our partner, Biogen, recently published promising results from its phase 1–2 Trial of Antisense Oligonucleotide Tofersen for SOD1 ALS and is now actively enrolling participants for their Phase 3 Valor study. It also announced that there is an open-label extension available in the study.

- Since January 1, The ALS Association has committed over $13 million to fund 44 research projects around the world.
The ALS Association is a leader in working to improve the lives of people with ALS and their loved ones through public policy that educates and mobilizes Congress to work on behalf of the ALS community. Each year, hundreds of ALS advocates from across the country work with their representatives in a nonpartisan manner on issues and legislation that put ALS at the forefront of federal policy.

This year, because of the pandemic, we couldn’t meet on Capitol Hill, but that didn’t stop us from advocating for legislation designed to improve the quality of life of people living with ALS. Our ALS Advocacy supported over 630 meetings with members of Congress and over 500 calls to Congress during the Virtual Advocacy Fly-In and National ALS Virtual Advocacy Conference. Over 39,000 ALS advocates generated over 62,000 messages to Congress.

Our work scored us some big achievements in 2020, including:

- **ALS Disability Insurance Access Act (S. 578/H.R. 1407):** Spearheaded the effort to pass this bipartisan legislation to waive the SSDI five-month wait for people living with ALS. Increased support to 68 senators and 301 representatives.

- **Noninvasive Ventilators:** Protected access to life-support devices by successfully removing noninvasive ventilators (NIV) from being competitively bid, ensuring Medicare beneficiaries with ALS can continue to access these critical devices at home.

- **FDA/Amylyx Petition:** Engaged the ALS community in a campaign to bring AMX0035 to market as quickly as possible by collecting over 51,000 signatures on our petition to FDA and Amylyx.

- **ACT for ALS Act (S. 4867/H.R. 8662):** Led the effort to strengthen this legislation that will accelerate the fight against ALS by authorizing $100 million for ALS research, increase access to experimental therapies, and create the first federal entity explicitly charged with accelerating the development and approval of effective new treatments for neurodegenerative diseases.

- **DOD ALS Research Program:** Secured $20 million in FY2020 for the Department of Defense ALS Research Program – a $10 million increase over the funding levels in previous years.

- **National ALS Registry and Biorepository:** Secured $10 million in FY2020 for the National ALS Registry at the CDC to identify genetic and environmental factors for ALS, provide support to researchers to find treatments and a cure, and promote access to clinical trials.

- **NIH:** Joined other leading patient organizations to secure for $41.7 billion in FY2020 for the National Institutes of Health.

“Federal support for ALS-focused legislation and funding for ALS research at the Department of Defense, CDC, & NIH continues to grow thanks to our public policy work. We will remain staunch advocates for aggressive research funding to find treatments and a cure to help everyone living with ALS.”  
-Heinz Ludke, Board Member & Living With ALS
Mark Tannenbaum was formally diagnosed with ALS in December 2015 at the age of 54. Adored for his outgoing personality and cherished for his authentic character, Mark’s friends and family wanted to rally in support of him and others impacted by ALS.

In October 2016, “Team Tannenbaum” was officially born and partnered with The ALS Association in Mark’s hometown of Sacramento, California to establish the PALS 4 Life program. Their mission was ambitious—they wanted to address the most critical needs of people living with ALS and their families.

Since then, “Team Tannenbaum” has raised over $350,000 to help families living with ALS with in-home caregiving, transportation, durable medical equipment, and augmentative speech communication devices. Their commitment to help pALS remain safe in their home with access to the equipment and transportation needed to live their best life serves as a beacon of hope for others following in Mark’s footsteps.

As 2020 continues to challenge all of us, we have never been more grateful to Team Tannenbaum for stepping up to help those who are battling ALS during this difficult time. For more information, or to make a gift to the PALS 4 Life program, please contact Julia Marsili at (916) 979-9265 or jmarsili@alssac.org.

The PALS 4 Life program was initiated in 2016 by the Tannenbaum family with the goal of helping people living with ALS remain safe and independent in their homes, while reducing the financial burden of managing the disease.
The keystone of my work at the local chapter has always been to provide pALS and cALS with the resources and support needed to improve quality of life. Our team has over 30 years of cumulative experience to draw upon and to help people living with ALS save precious time and money as they navigate the disease—this truly is a life calling and I’m grateful to have the opportunity to serve alongside our dedicated team.

2020 brought many unexpected challenges to the families we serve and to our chapter. We know how difficult a diagnosis of ALS is, and recognize the added challenges of navigating this disease along with the many restrictions, dangers and isolation that a pandemic creates. We quickly identified the needs, reassessed our modes of delivering support and didn’t skip a beat in the continuation of services and programs, while adding elements to address the new needs that COVID-19 has introduced into the lives of our ALS families. Whatever the situation, we are here to make sure all pALS and their families feel that there is a place where they can turn for support.

In gratitude,

Nancy Wakefield

Our team provided information, vital resources, & support to people living with ALS 6,193 times this year.

We provided 153 loans of durable medical equipment to ensure safety & independence.

We loaned 57 augmentative speech generating devices so people could continue to communicate beyond the loss of speech.

Our ALS multidisciplinary clinics provided 314 visits to support the health & well-being of people living with ALS.

Our care services team conducted 159 care consultations & visits to families coping with ALS.

Over $47,000 in grants were provided in support of in-home health, transportation, & medical equipment.

The Greater Sacramento Chapter held 61 Support Group Meetings for people impacted by ALS.

The period represented is October 2019-October 2020
ALS multidisciplinary clinics provide people living with ALS access to multiple healthcare professionals in one visit. This collaborative approach provides integrated care and guidance along a person’s ALS journey. The ALS Association Greater Sacramento Chapter provides funding and staffing support to three ALS multidisciplinary clinics in Northern California, drastically reducing out-of-pocket costs for families.

The Clinic Compass

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The Chapter Supports Three Multidisciplinary ALS Clinics
(in FY21, 224 people received care & support through our clinic programs)
Fundraising

2020 Greater Sacramento Walk To Defeat ALS®

$290,000 Raised  |  313 Participants  |  31 Walk Your Way Events

Top Teams
1. Nate the Great
2. Team Kelly-Walk and Not Grow Weary
3. Keith’s Brew Krew
4. Time for a Cat Walk
5. Cross/Novo/Moreno Fans
6. Team Tyack
7. Marty’s Marchers: A 10 Year Memorial
8. Standean Against ALS
9. Team CalHFA
10. James Tops Morgan Team

Ways to get involved and support our vision of a world without ALS

ALS ALLIES

ALS Allies is a new community comprised of donors, families, and supporters who work collectively to create a world without ALS. Their sole purpose and vision is to unite the ALS community and collectively impact our global efforts toward a cure, while also supporting innovative, local programming for people living with ALS in Northern California. ALS Allies are given the opportunity to share their remarkable story and recognize their loved one online, while leaving a lasting legacy that will have a lifelong impact on how people live with ALS. To learn more about the ALS Allies program and giving levels, visit www.alsallies.com or contact Julia Marsili at (916) 979-9265 or jmarsili@alssac.org.

MAKE A SUSTAINING GIFT

Help us combat ALS and support people living with ALS by making a monthly pledge. For as little as $20 a month, you can make a lasting impact on the fight to #endALS. Every dollar adds up to support localized care, global ALS research, and local, state, and federal advocacy. To help combat ALS, please call (916) 979-9265 or visit www.alssac.org to schedule your monthly pledge today.

HOST A THIRD PARTY FUNDRAISER

You can help us end ALS by hosting a third party fundraiser in support of the mission-critical programs and services that are designed to improve quality of life for people living with ALS while we search for a cure. Create a Facebook fundraising event, organize a golf tournament, run a marathon, or dine and donate at your favorite restaurant—the sky’s the limit. However you choose to fundraise, keep it FUN and know that you’re supporting the ALS community. To begin planning your event, please call Stefanie Daniels at (916) 979-9265 or email sdaniels@alssac.org.
In the summer of 2016, if you'd have asked 32 year-old Nate Arnold how long he'd live, he probably would've said well into his nineties. After all, he comes from “good stock”, and with no major genetic health issues in his family, his relatives frequently live that long.

But by then, he'd already been dying for months. He just didn't know it yet.

Though most of life was going well, he did have that odd spasm in his left hand that had started as an imperceptible twitch in his pinky. But that was just due to the stress of the busy season at work...right? Finally, nearly a year since symptoms had started, he decided to seek medical advice.

After seeing a few doctors, he had more of an idea of what he could be facing. Going into a series of MRIs, he was hoping and praying for a benign brain or spinal tumor. Something serviceable. Anything, as long as it wasn't neurological.

But the MRIs came back clean. Next up was a bunch of tests at the neurologist. Those didn't come back clean, and the following day he was diagnosed with ALS.

Despite his diagnosis, ALS was not stopping Nate. Instead, Nate and his family became warriors in the battle against ALS, building an army of friends and family who rose to the challenge of creating a world without ALS. His Walk to Defeat ALS team, Nate the Great, quickly became one of the western region’s top fundraising teams, raising an astounding $137,000 since they began walking in 2017.

Nate embodies what it means to live everyday to the fullest (the quote in his Facebook profile is Oscar Wilde’s “Life’s too short to be taken seriously”). Since his diagnosis, Nate has checked off some incredible adventures, including packing up two RVs with 24 of his closest friends and visiting 23 breweries across the Pacific Northwest.

Nate's family, friends, and faith are an integral part of his fight, alongside a healthy dose of self-deprecating humor.

“Perspective. Is. Imperative.”
-Nate the Great
The stakes have never been higher for local non-profits seeking to sustain their operations and fund mission-critical programs and services beyond 2020. So, when Piedmont Moving Systems in Silicon Valley stepped up with a $25,000 donation in support of people living with ALS, it was a met with joy from the team who serve on the front lines helping families navigate the disease.

“A new partner like Piedmont Moving Systems offers so much hope to people living with ALS. Their strategic investment into local services will have a lasting impact on the chapter’s ability to operate and execute wide-ranging programming moving forward.

The company has served the Silicon Valley with comprehensive moving services tailored to the unique needs of local businesses for 39 years. Their values of providing the highest degree of customer service to their clients echos the commitment our team makes daily to people living with ALS, making this a synergistic partnership.”

—Amy Sugimoto, Executive Director

We are grateful to the following 2020 corporate partners who have also stepped up their commitment to sustain mission-critical services for the ALS community:
Chapter Services

Care Consultations & Support:
The Chapter’s professional care service team provides expertise and guidance to people living with ALS and their caregivers throughout their journey with the disease, offering information and resources to improve quality of life.

Support Group Meetings:
Support groups are offered throughout the Chapter’s 24 county service area. These professionally facilitated meetings provide people with ALS and their caregivers with emotional support, valuable insights, and interaction with others who understand ALS.

Durable Medical Equipment Loan Program:
The loan program provides safety and independence to people living with ALS and their caregivers by offering loaned durable medical equipment for all stages of ALS progression, including: wheelchairs, shower chairs, lifts, transfer boards, walkers, and more.

Augmentative Communication Device Program:
This program helps people living with ALS to communicate their needs to caregivers, while also maintaining relationships and interaction with family, friends, and their medical team through a variety of speech device loans, from low-tech boogie boards to high-tech eye gaze computers.

Multidisciplinary ALS Clinics:
Each of the three regional ALS clinics offered at UC Davis, Forbes Norris, and Kaiser provide the highest level of medical care, support, and expertise to people impacted by ALS.

Get Smart Equipment Loan Program:
This program helps people living with ALS control their home environment through their smartphone or speech device, using smart home hubs like Amazon Echo Dot and Google Nest, as well as extensions such as Bluetooth-enabled plugs, locks, lights, thermostats, cameras, and entertainment devices.

PALS 4 Life:
The PALS 4 Life program seeks to holistically support those affected by ALS by providing direct financial support through a responsive grant program intended to address (1) in-home care, (2) transportation needs, and (3) subsidizing DME and augmentative speech device loans.

Community Outreach & Education:
We conduct regular outreach and awareness activities throughout Northern California to bring awareness to ALS and to ensure people newly diagnosed with ALS know where to turn for help designed to improve their quality of life, as well as support their families and caregivers throughout their journey with ALS.

ALS Association Greater Sacramento Chapter Team

Amy Sugimoto
Executive Director

Nancy Wakefield
Director of Care Services

Nancy Ferguson
Care Services Coordinator

Julia Marsili
Director of Development

Stefanie Daniels
Community Outreach Manager

Nicole Wilson
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