ALS ASSOCIATION

Florida Chapter

2021 Southwest Florida

May 15th

WALK TO DEFEAT ALS THE ALS ASSOCIATION

TO OUR WALK TO DEFEAT ALS® SPONSORS

NATIONAL SPONSORS

numotion Foundation

permobil FOUNDATION

Mitsubishi Tanabe Pharma America

STATEWIDE SPONSORS

Venture Construction Group OF FLORIDA

ABILITY MEDICAL

AMYLYX Rooted in Connection

Trulieve

maxim healthcare services

THANK YOU

AGENDA

9:30 AM	**Opening Ceremony - Unlock ALS Ceremony**
10:00AM	**Walk Your Way! Post Pics on Facebook!**
10:45AM	**Closing Ceremony**

ALS ASSOCIATION FLORIDA RADIO – CLICK TO CONNECT

SPREADING THE WORD

Our supporters know the impact spreading the word can have for research. Today, we encourage you to spread the word about your participation in The ALS Association Florida Chapter's Walk Your Way - benefiting the Walk to Defeat ALS.

HASHTAGS

#SWFLWalktoDefeatALS
#SWFLWalkYourWay
#WalktoDefeatALS
#ALSInThisTogether
#WeCantWait
#ALSFlorida

SOCIAL MEDIA

Tagging The ALS Association Florida Chapter and The ALS Association's social media channels is a great way to increase awareness of today's event. Below is a list of "tags."

TWITTER	FACEBOOK	INSTAGRAM
@ALSFlorida	**@ALSFlorida**	**@ALSFlorida**
@alsassociation	**@alsassociation**	**@ALS**

WHAT IS ALS?

Amyotrophic lateral sclerosis (ALS) is a progressive neurodegenerative disease that affects nerve cells in the brain and spinal cord.

ALS slowly robs people of their ability to move, speak, and eventually breathe.

5,000+ *people are diagnosed with ALS each year*

2-5 YEARS *is the average life expectancy of a person with ALS*

$250,000 *is the estimated out-of-pocket cost of caring for a person with ALS*

90% *of cases occur without family history*

Military veterans are more likely to be diagnosed and die from ALS.

There is **NO CURE** *for ALS*

WHAT THE ALS ASSOCIATION DOES:

CARE SERVICES

We help families manage the staggering emotional, physical and financial burden of ALS.

ADVOCACY

Advocating for changes in laws and polices affecting people with ALS and their families.

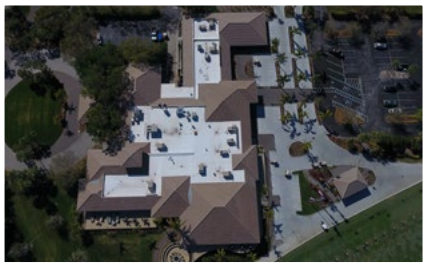
RESEARCH

We are the largest private funder of ALS research worldwide.

WHAT YOU CAN DO:

ALS ASSOCIATION

Every moment matters to people with ALS and their families.
Visit **als.org** and learn more about how you can give help and hope.



AWARD-WINNING CONSTRUCTION & RESTORATION EXPERTS

Residential & Commercial General Contractor

Call Today For a Free Consultation!
866-459-8351

HAIL Damage

HURRICANE Damage

WIND Damage

FIRE Damage

Commercial Expertise

- Hotels/Resorts
- Retail/Malls
- Hospitals
- Schools
- Businesses
- Government Complexes
- Multi-Family Unit Complexes
- Condominium Boards
- Homeowner Associations (HOA)
- Property Management Associations

Venture Construction Group
OF FLORIDA

State Licensed General Contractor FL.CGC.1517893
State Licensed Roofing Contractor FL.CCC.1328055
www.VCGFL.com

MISSION

MISSION INTEGRATION AND SYNERGY

Care Services

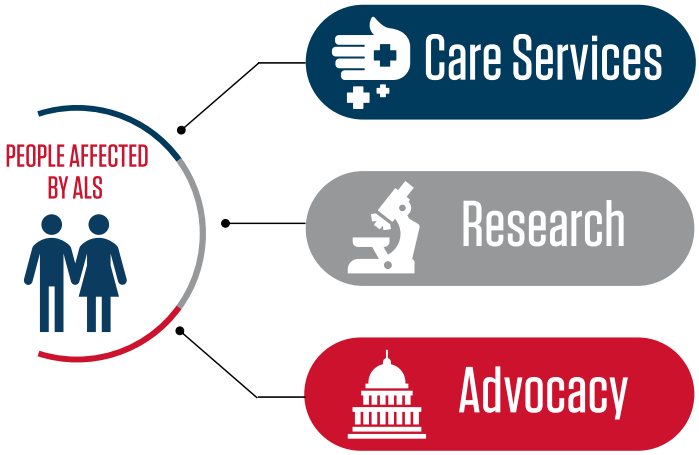
- Local access to clinical trials
- Service needs and surveys drives advocacy

Research

- Can change the course of treatment
- Data to drive benefit and insurance decisions

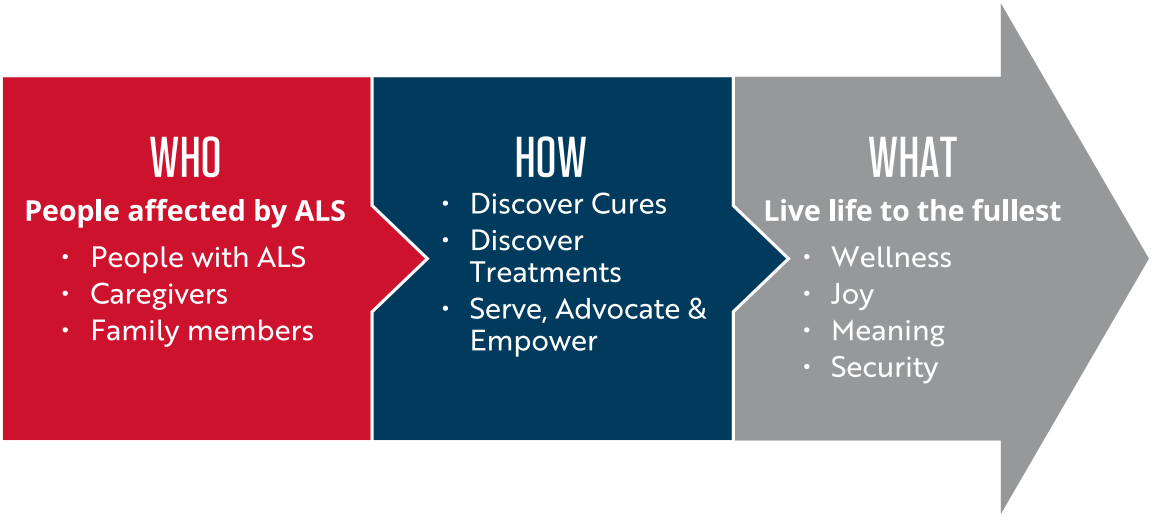
Advocacy

- Generates government support for research and clinical services
- Protects rights of families with ALS, despite genetic advances



A COMPREHENSIVE 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



SUPPORT GROUPS

We understand that dealing with ALS is physically, emotionally and financially devastating for the person diagnosed and their family. ALS Resource Connections groups provide a caring, supportive, open environment for people to gather, connect, and talk with one another. These groups are open to persons living with ALS, their families, caregivers and friends, and are located around the state to provide opportunities to learn more about living with the disease from others who understand the challenges, and to help establish a network of valuable resources and sustained support. A Chapter Regional Program Manager facilitates each meeting and will have speakers on relevant topics combined with time for attendees to discuss and share information and provide feedback to one another.
If you are attending a group for the first time, please RSVP to the facilitator. *PLEASE NOTE: Times and locations occasionally change so please check our website prior to each meeting.

We realize that COVID-19 is creating a "new normal" for the time being - but ALS doesn't stop and neither do we. The ALS Association Florida Chapter has postponed in-person attendance of support groups until further notice. HOWEVER, we still want to support and see you and are now offering virtual support groups. Please see below for instructions and a schedule based on your region.

VIRTUAL CHAPTER MEETING INSTRUCTIONS

1. You do not need your own username of password to sign in to the meeting, simply use the link provided to you in the email from your Regional Program Manager. You will receive an email reminder several days before your region's scheduled support group meeting with the link to participate. If you have not received a link, please email or call your Regional Program Manager in advance to receive the appropriate link.
2. If using a phone/mobile device, you may be prompted to download the application through your app store. Please consider downloading the app a day or 2 before the meeting.
3. When joining the meeting on a mobile device or computer, you may be asked to follow these prompts - "join using computer camera" and "join using computer sound". It is helpful to test the computer sound prior to the meeting. You may need to identify yourself when you join the meeting.
4. For better connectivity, consider limiting the number of other applications running in the background, limit the number of devices connected to wi-fi, or if possible connect directly to your modem.
5. Staff will be available prior to the start of the meeting to assist with technical difficulties. Please email the Regional Program Manager in your region to assist.

For further information on using RingCentral, please click images below regarding downloading app, and signing in and joining a meeting.

Downloading RingCentral App

Signing in and Joining A RingCentral Meeting

SUPPORT GROUPS

VIRTUAL CHAPTER MEETINGS

North Florida

Jacksonville
2nd Fri., 11:00am - 12:00pm
Melissa Fehrenkamp

Volusia/Flagler
2nd Wed., 1:00 - 2:00pm
Marixa Salgado

Central Florida

Orlando
1st Wed., 1:00 - 2:00pm
Marixa Salgado

Brevard
3rd Wed., 1:00 - 2:00pm
Marixa Salgado

The Villages
4th Wed., 1:00 - 2:00pm
Marixa Salgado

Tampa
4th Fri., 2:00 - 3:00pm
Heran Sisay

Pinellas
4th Mon., 1:30 - 2:30pm
Heran Sisay

Southwest Florida

Sarasota/Bradenton
2nd Wed., 1:00 pm – 2:00 pm
Patti Stanco

North Port
4th Weds., 1:00 - 2:00pm
Patti Stanco

Fort Myers
3rd Wed., 1:00 - 2:00pm
Patti Stanco

Naples
1st Weds., 1:00 - 2:00pm
Patti Stanco

South Florida

Martin
1st Mon., 1:00 - 2:00pm
Tina Duane

Palm Beach
3rd Tues., 1:00 - 2:00pm
Tina Duane

Broward
2nd Mon., 1:00 - 2:00 pm
Tina Duane

TELEPHONE GROUPS

PLEASE NOTE: Our telephone ALS Resource Connections meetings have limited capacity. Please reach out to the Regional Program Manager running the group for information prior to each meeting.)

Statewide - 3rd Tues., 2:00pm ET, 1:00pm CT | "Caregiver Connections" Phone Group
Judie Benwick | jbenwick@alsafl.org | 813.637.9000 x112

Statewide - 2nd Wednesday, 2:00pm ET, 1:00pm CT | "For Veterans and their Family Caregivers" Phone Group
Judie Benwick | jbenwick@alsafl.org | 813.637.9000 x112

Panhandle - 2nd Tues., 12:00pm ET, 11:00am CT | Phone Group
Judie Benwick | jbenwick@alsafl.org | 813.637.9000 x112

Spanish (Statewide) - 3rd Thurs., 1:00pm ET | Spanish Speaking Phone Group
Camila Arizaga | carizaga@alsafl.org | 813.637.9000 x116

Serves SW Florida

LIVE A BETTER LIFE

Amyotrophic lateral sclerosis (ALS) is a devastating disease. But Lee Health's ALS clinic uses proven treatment methods, certified therapists and new technology to help patients in Southwest Florida.

Our compassionate team delivers individualized care plans in a family oriented atmosphere.

Serving Lee, Charlotte, Collier, DeSoto, Glades, Hardee, Hendry, Highlands, Monroe and Okeechobee counties.

LEE HEALTH

©2020 Lee Health • 4050.28 7/20

ADVANCES IN ALS RESEARCH

A significant number of research innovations, advancements in drug development and clinical trials, new collaborations, and more, all aimed at finding treatments and a cure for ALS, accelerated the pace of discovery.

We're excited to share some of our most newsworthy research headlines that gave us and people living with ALS hope this year!

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 TPD43 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.

USF Health

ADVANCING ALS TREATMENT

With the Power of Academic Medicine

USF Health Amyotrophic Lateral Sclerosis (ALS) Clinic in Tampa offers the latest treatment, clinical research opportunities, supportive care and educational resources to help patients, their families and caregivers manage the effects of ALS. Our clinic has been recognized by The ALS Association as a **Certified Center of Excellence**. Our multidisciplinary team of experts provides the highest level of ALS-specialized care while creating a compassionate community of support to improve the daily lives of our patients and their caregivers.

As part of the **only academic medical center** on the west coast of Florida, we join other universities across the country to conduct clinical trials and discover new breakthroughs, benefiting patients with a better quality of life, pharmacologic therapies and advanced palliative care.

Contact Us 813-974-9273 or alsclinic@usf.edu

health.usf.edu/medicine/neurology/als

WHAT WILL YOUR LEGACY BE?

CURING ALS IS YOUR MISSION | NOW MAKE IT YOUR LEGACY

als.plannedgiving.org

ALS ASSOCIATION

ALS ASSOCIATION ADVOCACY IMPACT

With the support of over 20,000 ALS Advocates, we secure resources to support treatment and research for the entire ALS community. Our nationwide network of 39 chapters and two service areas are essential to our efforts at the federal, state and local levels in advancing our 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.

Here are recent successes in ALS advocacy!

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.

Continued to play a key role in **ensuring people with ALS have access to wheelchairs, speech-generating devices, and other complex technology** through legislative and regulatory pressure.

Joined with other leading patient organizations in the fight to **preserve protections for pre-existing conditions for people with ALS** under all insurance plans, including Medicare, Medicaid, and private insurance.

690+ MEETINGS

11 ACTION ALERTS

Supported over **690 meetings with Members of Congress** at the 2019 Advocacy Fly-In and National ALS Advocacy Conference. **Empowered more than 20,000 ALS Advocates** with eleven action alerts — resulting in nearly **73,000 advocacy messages** to Congress.

Spearheaded the effort to pass the bipartisan ALS Disability Insurance Access Act to waive the 5-month wait for people living with ALS. As of December 2019, 220 Representatives and 50 Senators support the bill.

$20 MILLION

Initiated and led the campaign to increase funding for the ALS Research Program at the Department of Defense (DOD) **to $20 million in fiscal year 2020 — a $10 million increase over the funding levels in previous years.**

$10M NATIONAL ALS REGISTRY

Fought for $10 million in funding for fiscal year 2020 for the National ALS Registry at the Centers for Disease Control and Prevention to identify genetic and environmental factors for ALS, provide support to researchers to find treatments and a cure, and promote access to clinical trials.

$41.7B NIH

Joined with other leading patient organizations to secure for $41.7 billion in fiscal year 2020 funding for the **National Institutes of Health (NIH)**. In fiscal year 2018, NIH invested $83 million on ALS research.

HOW TO BECOME AN ADVOCATE

OUR MISSION

The ALS Association is leading the fight 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.

ALS ADVOCATES

Our goals are ambitious, and ALS Advocates help us achieve them. Advocates are empowered with the information and tools to make a difference in the lives of those living with ALS. Our Advocates:

- Share their passion and stories with elected officials and their staff to advance the Association's legislative priorities
- Step out of their comfort zone to effect real change
- Amplify our voice on Capitol Hill and in state capitols across the country

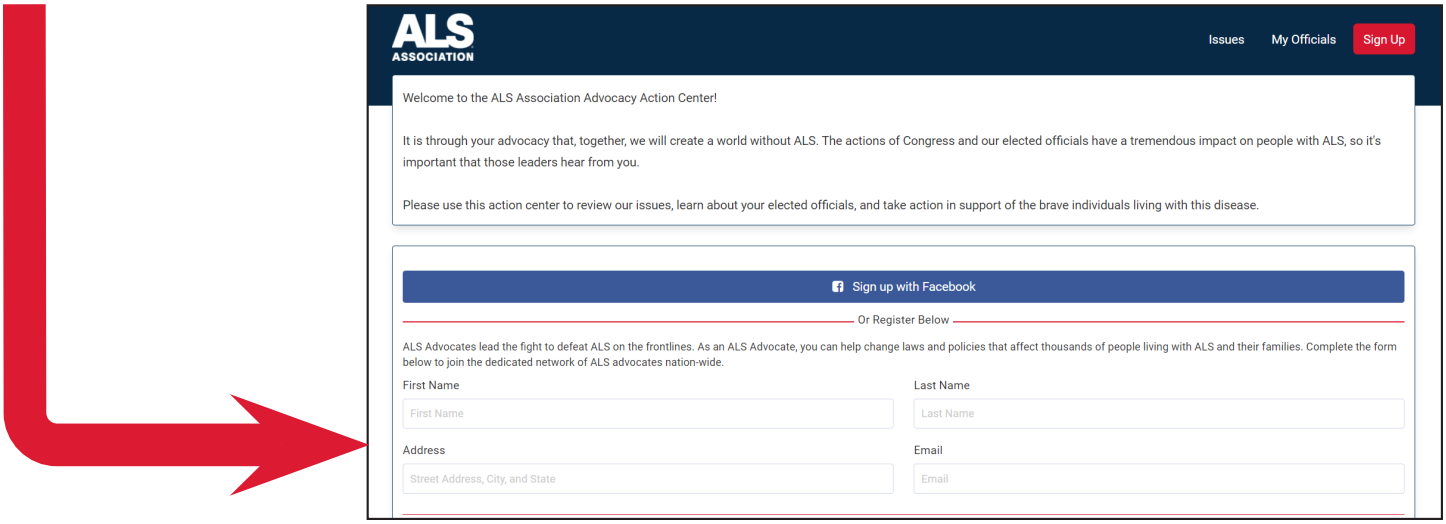
JOIN US

We need your help. As an ALS Advocate you will:

- Educate decision-makers on the latest research and needs of people with ALS
- Develop relationships and educate your members of Congress
- Participate in legislative action alerts via email, among other advocacy-related activities

SIGN UP

- Becoming an ALS Advocate is easy! Simply visit www.als.org/advocacy and click on "Action Center" to complete the ALS Advocate sign up illustrated below:



facebook.com/alsassociation twitter.com/alsassociation www.instagram.com/als

The ALS Association • 1300 Wilson Boulevard • Suite 600 • Arlington, VA 22209 • www.als.org

09/08/20

Maxim Healthcare Services

Caring. Serving. Enriching Lives.

We have been making a difference in patients' lives across the nation for more than 30 years. Our team of nurses, therapists, and home health aides help patients of all ages maintain the highest quality of life in the comforts of the home. We offer skilled nursing, physical rehabilitation, companion care, respite care, and behavioral care for individuals with chronic and acute illnesses and disabilities. Our commitment to compassionate care and excellent service makes us an established provider wherever healthcare is needed.

OUR SERVICES INCLUDE

- Home healthcare
- Private duty nursing
- Ventilator and tracheostomy care
- G-tube care and management
- Medication management
- Personal care and companion services

maxim® healthcare services

Contact me today for more information!

Tallahassee, FL 850-422-1111
The Villages, FL 352-360-7291
Miami, FL 305-316-8253

THE ALS ASSOCIATION CHAPTER NETWORK AND CLINICAL PARTNERS (AS OF JUNE 2020)

CERTIFIED TREATMENT CENTERS OF EXCELLENCE

To find a Certified Treatment Center in your area, visit http://www.als.org/community/centers-clinics/

Clinic Name	ST
The ALS Care Clinic at Crestwood Medical Center	AL
Arizona Mayo Clinic	AZ
Barrow	AZ
Phoenix Neurological	AZ
Cedars-Sinai	CA
Forbes Norris	CA
Keck Medicine of USC ALS Clinic	CA
UC Davis	CA
UC Irvine	CA
UC San Diego	CA
UC San Francisco	CA
Loma Linda University	CA
Hospital for Special Care	CT
VA Connecticut	CT
George Washington University Hospital	DC
Jacksonville Mayo Clinic	FL
Phil Smith Neuroscience Institute at Holy Cross Hospital ALS Clinic	FL
U of Miami	FL
U of South Florida	FL
U of Florida Jacksonville ALS Clinic	FL
Augusta University ALS Clinic	GA
Emory ALS Center	GA
U of Chicago	IL
U of Illinois	IL
Indiana University ALS Clinic at IU Health	IN
U of Kansas	KS
U of Kentucky	KY
Ochsner ALS Clinic	LA
U of Maryland	MD
Curt and Shonda Schilling ALS Clinic at Lahey Clinic	MA
Henry Ford	MI
Mercy Health	MI
University of Michigan	MI
Spectrum Health ALS Multidisciplinary Clinic	MI
The ALS Center of Excellence at Hennepin County Medical Center	MN
Mayo Clinic Rochester ALS Clinic	MN

Clinic Name	ST
M Health Fairview ALS Clinic	MN
Minneapolis VA Health Care System	MN
U Missouri Healthcare ALS Treatment Center	MO
SLUCare ALS Clinic	MO
Atrium Health ALS Center	NC
Duke University ALS Center	NC
Wake Forest	NC
U of Nebraska	NE
Dartmouth-Hitchcock Medical ALS Center	NH
University of New Mexico	NM
Rutgers – Robert Wood Johnson	NJ
Hospital for Special Surgery	NY
Mount Sinai	NY
Stony Brook	NY
ALS Association Program at Columbia University	NY
SUNY Upstate	NY
OhioHealth ALS Clinic	OH
Cleveland Clinic	OH
Louis Stokes – Cleveland VA Clinic	OH
Portland – VA Clinic	OR
Providence	OR
Oregon Health & Science University	OR
ALS Center at Allegheny Health Network	PA
Penn State – Hershey	PA
Jefferson Weinberg ALS Center	PA
Medical University of South Carolina (MUSC)	SC
Baylor	TX
Houston Methodist	TX
U of Texas – San Antonio	TX
U of Utah	UT
Richard R. Dart ALS Clinic (University of Virginia)	VA
U of Vermont	VT
ALS Center at the Swedish Neuroscience Institute	WA
Puget Sound – VA Clinic	WA
Virginia Mason	WA
Froedtert Hospital ALS Center	WI
Clement Zablocki Milwaukee VA Medical Center	WI

AMYLYX®

PARTNERS. PATHWAYS. PROGRESS.

WHO ARE WE?

Amylyx Pharmaceuticals is a company dedicated to the development of therapeutics for the treatment of neurodegenerative disorders. Our mission is to one day end the suffering of people living with these diseases as well as their loved ones. How? By working together and by preserving motor neurons with AMX0035.

WHAT IS THE CENTAUR TRIAL?

- The CENTAUR trial studied AMX0035 as an investigational therapy designed to tackle dysfunction in both the mitochondria and endoplasmic reticulum. It's made to protect neurons with the goal of ultimately slowing the rate of progression in amyotrophic lateral sclerosis (ALS)
- The CENTAUR trial is a 24-week, randomized, double-blind, placebo-controlled phase 2 clinical trial
- Amylyx collaborated with patients, patient organizations, and investigators at ALS medical centers throughout the Northeast ALS (NEALS) Consortium to design a trial with minimal disruption to patient lives
- AMX0035 demonstrated statistically significant results in slowing the rate of functional decline for people with ALS, based on the ALS Functional Rating Scale-Revised (ALSFRS-R), and was generally well tolerated
- Most participants in the CENTAUR trial were also being treated with riluzole and/or edaravone (Radicava)
- AMX0035 is an investigational product and its safety and effectiveness have not been established by the US Food and Drug Administration (FDA)

WHAT IS THE ALSFRS-R?

- ALSFRS-R, also known as the functional scale, measures functional ability in people living with ALS
- It measures 4 categories using a point-based scale: gross motor function (eg, climbing the stairs), fine motor function (eg, handwriting), bulbar function (eg, speaking), and respiratory function (eg, breathing)
- Loss of a single point can reflect a big change in a person's daily activities, such as no longer being able to dress independently

To find out more about the CENTAUR trial data, visit **AMYLYX.COM**.
Follow us on social media for the latest information.

© Copyright 2020 Amylyx Pharmaceuticals, Inc.
All Rights Reserved. AMX-2020-1196-v1 11/20

ALS FOCUS

BRINGING THE PERSPECTIVES OF PEOPLE WITH ALS AND THEIR CAREGIVERS TO THE FOREFRONT OF RESEARCH, CARE, AND ADVOCACY.

WHAT IS ALS FOCUS?

ALS Focus is a patient and caregiver-led survey program that asks people impacted by ALS about their needs and burdens. The goal is to learn about individual experiences throughout the disease journey so that the entire ALS community can benefit.

The survey data we collect is:

- Open and free to the entire ALS community
- Protected – All data and findings are de-identified using a unique code called a global unique identifier (GUID)
- Combined with other ALS research studies that use a GUID, such as the National ALS Registry and clinical trials, to broaden the impact of your participation
- **Actionable!** Data will be used to inform decisions and strengthen programs and policies around:
  - ✓ Drug development
  - ✓ Clinical trial design
  - ✓ Regulatory review
  - ✓ Drug payment and reimbursement
  - ✓ Clinical care
  - ✓ Home health, and more

Every step of the survey development process is informed and reviewed by a committee of people with ALS and caregivers.

WHO CAN PARTICIPATE?

- People living with ALS
- Current or past caregivers of people with ALS. Spring 2021 survey is for current and past caregivers only.

**Participants must be at least 18 years old and reside in the United States. Survey instructions and questions are presented in English.*

HOW LONG WILL IT TAKE?

Registering for Focus and completing the surveys will take approximately 15-25 minutes.

WHERE?

Access the survey at als.org/als-focus or use the QR code on this page.

SPRING 2021 TOPIC: CAREGIVER NEEDS:

Past and current caregivers, please share your experiences with us.

JOIN US — YOUR VOICE MAKES AN IMPACT

The ALS Association is recruiting people with ALS and their caregivers for the ALS Focus survey program to capture their needs, preferences, and experiences as they meet the challenges of ALS.

Participate in research in addition to clinical trials. Know how your experiences and opinions compare to the rest of the ALS community.

ALS ASSOCIATION

For more information, please contact ALSFocus@alsa-national.org

01/25/21

Mitsubishi Tanabe Pharma America
One scientific breakthrough can change countless lives
By taking on seemingly insurmountable challenges, we give ourselves the opportunity to achieve remarkable things and make a real difference in the lives of people struggling with debilitating diseases.
To learn more, scan the QR code or visit
mt-pharma-america.com
CNP-MTPA-0186 10/19

ALS ASSOCIATION
The ALS Medicare Resource Line

Providing Compassionate, Effective Support

AT NO COST TO YOU, OUR CASE MANAGERS ARE HERE TO HELP ADDRESS ANY ROADBLOCKS TO ACCESS AND AFFORDABILITY:

Reduce Financial Burden

- Find local, regional and national resources for financial support and for practical needs such as housing, utilities, transportation, and food
- Educational and emotional support resources
- Guide patients through eligible workplace protections such as FMLA and ADA
- Give assistance engaging, applying and appealing workplace benefits including short-term and long-term disability

Enroll into Appropriate Programs

- Provide eligibility, enrollment and appeal navigation into Medicare
- Evaluate eligibility and facilitate application to charity care and discount programs

Case management services provide hands-on navigation of the reimbursement system, ensuring access to prescribed and emerging therapies and treatment and the practical financial support needs and often addressing the holistic needs of the patient, recognizing that everyday barriers often impact access and compliance. Education, research, and representation across a wide spectrum of services are provided for uninsured, underinsured, and insured patients.

Who is Eligible?

- **A U.S. Citizen or Permanent Resident of the U.S.**
- **Diagnosis or screening of ALS**
- **Currently receiving treatment at a facility in the United States or one of its territories**

Contact Us

Request help at
https://als.pafcareline.org
24 hours a day

Call Toll-free at
(844) 244-1306

Hours of operation
8:30 am – 5:00 pm Monday - Thursday;
8:30 am – 4:00 pm Friday EST

ALS.PAFCARELINE.ORG • (844) 244-1306

ALS ASSOCIATION
The ALS Medicare Resource Line

PAF Patient Advocate Foundation

11/07/19

mayoclinic.org

You are changing the world.

MAYO CLINIC

© 2021 Mayo Clinic

ALS FOCUS

The ALS Association is recruiting people with ALS and their caregivers for the ALS Focus survey program to capture their needs, preferences and experiences as they meet the challenges of ALS.

REMEMBER:

Sharing your experience will make a difference!

Completing the National ALS Registry surveys helps researchers uncover the risk factors for ALS while completing the ALS Focus surveys helps identify the burdens of living with the disease.

Bringing the perspectives of people with ALS and their caregivers to the forefront of research, care, and advocacy.

WHAT IS ALS FOCUS?

ALS Focus is a patient and caregiver-led survey program that asks people impacted by ALS about their needs and burdens. The goal is to learn about individual experiences throughout the disease journey so that the entire ALS community can benefit.

JOIN US - YOUR VOICE MAKES AN IMPACT

Participate in research in addition to clinical trials.

See your survey responses compared to the rest of the ALS community.

The survey data we collect is:

- Open and free to the entire ALS community
- Protected – All data and findings are de-identified using a unique code called a global unique identifier (GUID)
- Combined with other ALS research studies that use a GUID, such as the National ALS Registry and clinical trials, to broaden the impact of your participation
- **Actionable!** Data will be used to inform decisions and strengthen programs and policies around:
  - ✓ Drug development
  - ✓ Clinical trial design
  - ✓ Regulatory review
  - ✓ Drug payment and reimbursement
  - ✓ Clinical care
  - ✓ Home health, and more

Every step of the survey development process is informed and reviewed by a committee of people with ALS and caregivers.

WHO CAN PARTICIPATE?

- People living with ALS
- Current or past caregivers of people with ALS

**Participants must be at least 18 years old and reside in the United States.*
Survey instructions and questions are presented in English.

HOW LONG WILL IT TAKE?

Once registered, each secure online survey can be completed in approximately 15-25 minutes.

WHERE?

CLICK HERE to register for ALS FOCUS & complete your demographic information!

ALS ASSOCIATION

For more information, please contact ALSFocus@alsa-national.org

UFHealth

Neurology– Jacksonville - ALS Association Certified Center of Excellence

580 W. 8th St. Tower 1, 9th Floor Jacksonville, FL 32209 –904.383.1022—UFHealthJax.org/neurology

UF Health is a proud supporter of the

ALS Association Florida Chapter

UFHealth
UNIVERSITY OF FLORIDA HEALTH

Visit UFHealth.org to learn more.

numotion® ALS Expedite Program

Numotion, the nation's largest and most trusted provider of Complex Rehab Technology (CRT), **has developed a program specifically to provide ALS patients with faster access to a mobility solution.**

By streamlining document processing time, and leveraging our partnerships with top wheelchair manufacturers, **we have created a program to equip ALS patients covered by Medicare, with customized equipment that allows them to maintain their independence, minimize safety risks and maximize independence.**

The Numotion ALS Expedite Program timeline is 14 – 21 days.

Mobility evaluation conducted & signed paperwork completed in clinic.

1 day

Medicare funding approval process begins using streamlined paperwork & submission process.

2 – 4 days

Equipment ordered & shipped from manufacturer.

5 –14 days

Patient receives copay info from Numotion.

6 – 10 days

Final assembly completed & chair delivered.

14 –21 days

Learn more at www.numotion.com

When Someone Asks:

"WHAT CAN I DO TO HELP?"

Tell them:

"ALS CARE CONNECTION"

ALS Care Connection is a private online calendar that can be used to support to the entire family – by organizing volunteers to take care of some of those tasks families describe as "falling through the cracks." It is a simple online tool that helps organize the community of people who want to help and coordinates their efforts to more efficiently support families living with ALS.

To learn more about this tool and its features, visit
www.alsa.org/als-care/caregivers/care-connection.html

ALS ASSOCIATION CARE CONNECTION

THE **NEUROLOGIST** IS IN.

Neurology telehealth appointments are now available.

Don't let COVID-19 and social distancing keep you from receiving the care you deserve. With a telehealth appointment from Holy Cross Hospital, our board-certified neurologists can see you from the comfort of home. From migraines and numbness to stroke recovery and spine issues, we're proficient at making virtual visits work for our patients. For a telehealth appointment, please call the Phil Smith Neuroscience Institute at 954-414-9750.

HolyCrossNeuro.com

Holy Cross Hospital
Phil Smith Neuroscience Institute

ALS ASSOCIATION
CERTIFIED TREATMENT CENTER OF EXCELLENCE

ABILITY MEDICAL

For All Your Mobility Needs

At Ability Medical, we understand the everyday challenges faced by those battling ALS; this helps us meet the individualized needs of all our clients and is why we are one of Florida's leaders in providing cutting-edge equipment for the ALS community. Ability Medical not only provides clients with the most specialized equipment needed for comfort, mobility and independence,. We are a proud sponsor and supporter of the ALS Association Florida Chapter and home to one of it's largest loan closets. You can always find us at any of the statewide Walk to Defeat ALS events or at many of the ALS support groups throughout Florida. Better yet, call us at 1-888-572-7603.

We want to help. Let us know what we can do for you.

Assistive Technology Professionals

Our Assistive Technology Professionals are certified and trained to analyze your needs and assist you in the selection of the appropriate technology.

Power Mobility Customization

Rehab power wheelchairs to help you conserve energy and moving with less effort. Mobility challenges require mobility solutions.

Rehab Equipment Customization

Our trained staff is here for you every step of the way. We will guide you and work tirelessly to help you get the equipment you require. We will be there when you need service.

Customization and Repairs

Our highly trained technicians will keep your equipment operating at peak performance with routine maintenance and repairs.

CALL NOW ! 888-572-7603

1923 W Copans Rd
Pompano Beach, FL 33064

abilitymedical.net
info@abilitymedical.net

CONTACT US

Relief is possible, *naturally*.

Caring for yourself is a full-time undertaking. We are learning from ALS patients that it is possible to improve the quality of your life with the benefits of cannabis medicine.

While there have only been few clinical studies* proving medical cannabis' efficacy for people with ALS, there is anecdotal patient evidence to establish symptomatic benefits, both physical and emotional.

How you consume is up to your particular preferences. And because cannabis is a personal experience, your choices at Trulieve will range from oral tinctures, concentrated oils, ingestible oils, infused lotions, capsules, and nasal spray, in addition to flower. Many of our patients with ALS have reported both physical relief and a positive emotional and mental impact, hopefully allowing you to improve your quality of life.

Trulieve welcomes new patients. Once you have your Florida Medical Card, come into any of our 50+ dispensaries to speak to a Patient Consultant to get your treatment started!

Trulieve®

New Patient and Veteran Discounts Available

*The American Journal of Hospice & Palliative Care

ALS ASSOCIATION Florida Chapter

The ALS Association Florida Chapter believes that the use of medical marijuana in the treatment of amyotrophic lateral sclerosis is a decision that should be made by the person with ALS in consultation with a physician and family.

844.878.5438 | info@trulieve.com | **Trulieve.com** | @trulieve_fl | @trulieve | @trulieve

permobil
FOUNDATION

Our mission

The Permobil Foundation is dedicated to enhancing the quality of life by empowering strength and independence through community support, employee engagement and grant funding. We work in partnership with non-profit organizations and agencies to provide support and services so individuals can live a life without limitations.

ALS Center
UNIVERSITY OF MIAMI

Hope • Care • Cure

Serving the South Florida ALS patient community
Combining world-class multidisciplinary patient care
and cutting-edge research

Located in the heart of the Miami Health District:
1150 NW 14th Street, Suite 609, Miami FL, 33136

www.ALS-Miami.org
305-243-7400 (Patient Care)
888-413-9315 (Research)

UHealth
UNIVERSITY OF MIAMI HEALTH SYSTEM

DEPARTMENT OF
NEUROLOGY

ALS ASSOCIATION
CERTIFIED TREATMENT
CENTER OF EXCELLENCE

ADD MORE IMPACT

MATCHING GIFTS

If your company has an employee matching gift program, you could double the impact of your gift to The ALS Association Florida Chapter. Check with your human resources or community relations department and ask for the proper form to request that your company match your gift. Some companies match gifts made by retirees and/or spouses. If your company is eligible, visit the Matching Gifts database for detailed steps to request a company match for your donation.

AMAZONSMILE

Shop online and The ALS Association Florida Chapter will receive a portion of your purchase amount.
All you need to do is:

- Visit smile.amazon.com
- Sign up or log in using your Amazon account
- Search for The ALS Association Florida Chapter and select it as your designated organization
- Shop for what you need!
- Make sure you are shopping through smile.amazon. com instead of www.amazon.com in order to support us through your purchases

UF Health is a proud supporter of the ALS Association Florida Chapter.

UFHealth
UNIVERSITY OF FLORIDA HEALTH

Visit UFHealth.org to learn more.

OUR MISSION

To discover treatments and a cure for ALS, and to serve, advocate for and empower people living with ALS to live their lives to the fullest.

OUR VISION

Create a world without ALS

ALS Association Florida Chapter

3242 Parkside Center Blvd
Tampa, FL 33619 | 813.637.9000
| ALS.org/Florida