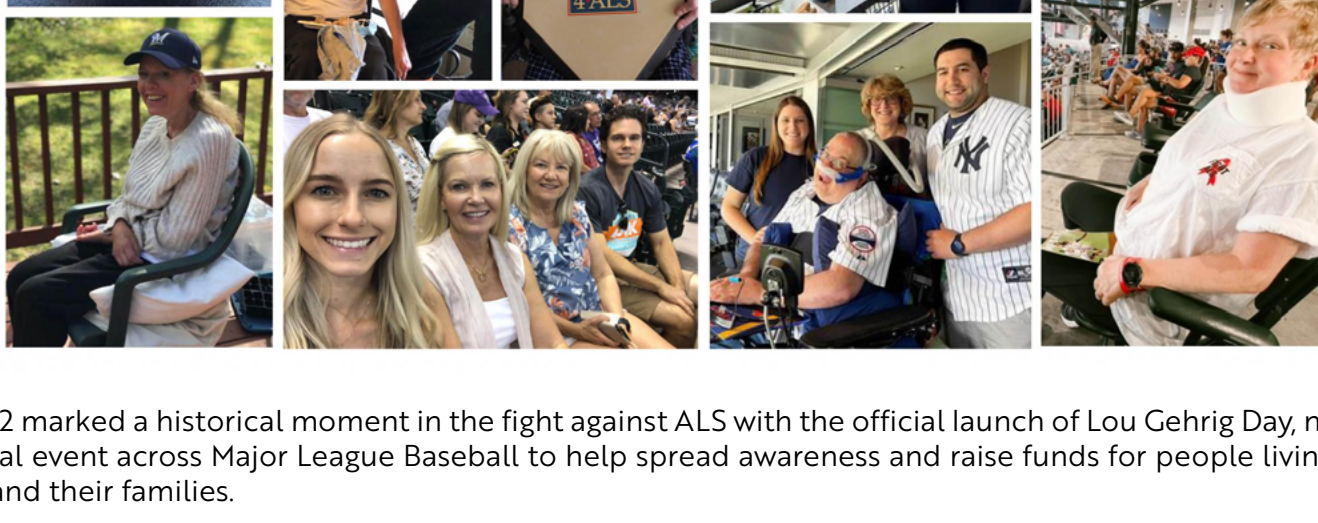


### Our Response to the FDA's Latest Letter and What We're Doing to Keep Up the Pressure

Following our We Can't Wait Action Meeting with the FDA, we sent a letter to the agency asking it to reaffirm its commitment to the 2019 ALS Guidance and provide us with a detailed report showing how it has implemented the guidance. Last week, The ALS Association received a response from Dr. Patrizia Cavazzoni, Director of the Center for Drug Evaluation and Research.

[Continue Reading](#)

### Lou Gehrig Day: An Amazing Day of Awareness for the ALS Community



June 2 marked a historical moment in the fight against ALS with the official launch of Lou Gehrig Day, now an annual event across Major League Baseball to help spread awareness and raise funds for people living with ALS and their families.

[Continue Reading](#)



### It's Camp Season!

It's camp season and kids with a family member with ALS are invited.

[Hope Loves Company](#) is a camp specifically for children and young adults with a parent or grandparent with ALS. Of the 30,000 Americans diagnosed with ALS each year, 85% of them have a child or grandchild. Hope Loves Company provides traditional camp activities - s'mores, crafts, hikes, tie-dyeing and more. Locations are around the country and include virtual camp July 16-18.



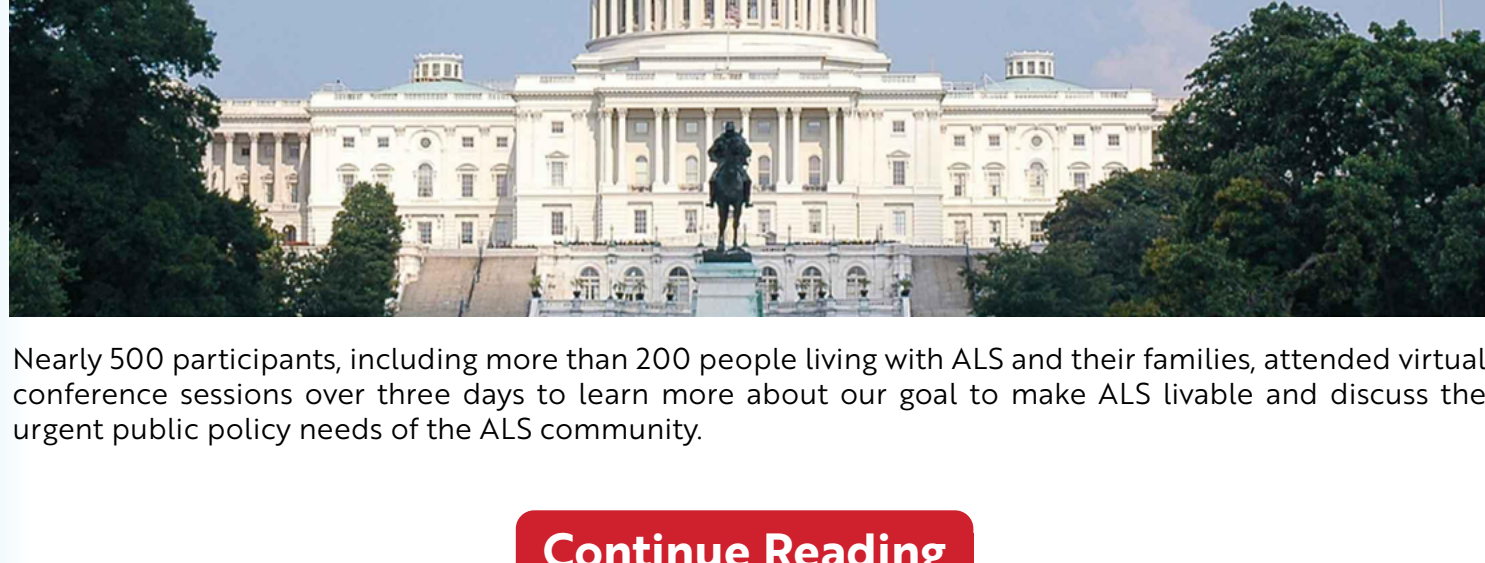
### To Spark Your Interest!

A study from Purdue University, "Efficacy of Expiratory Muscle Strength Training to Improve Communication in ALS," aims to provide knowledge regarding the efficacy of expiratory muscle strength training on communication, cough, and psychosocial functions for people with ALS when implemented through telehealth.



For more information [click here](#) or contact Bri Kiefer via e-mail at [Kiefer4@purdue.edu](mailto:Kiefer4@purdue.edu) or phone at (765) 494-3796.

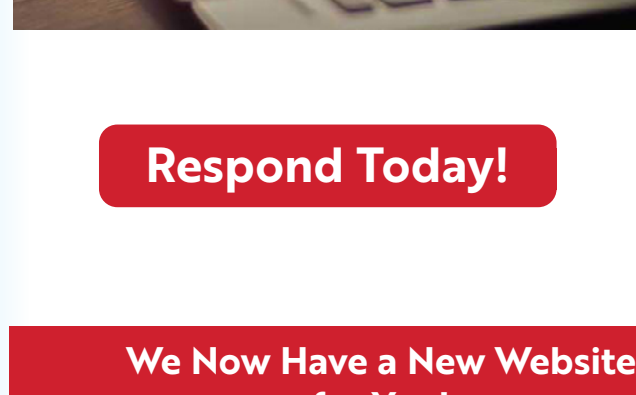
### ALS Association Wraps Up Virtual Advocacy Conference with Calls on Congress to Act



Nearly 500 participants, including more than 200 people living with ALS and their families, attended virtual conference sessions over three days to learn more about our goal to make ALS livable and discuss the urgent public policy needs of the ALS community.

[Continue Reading](#)

### Share Your Perspective in the New ALS Focus Survey

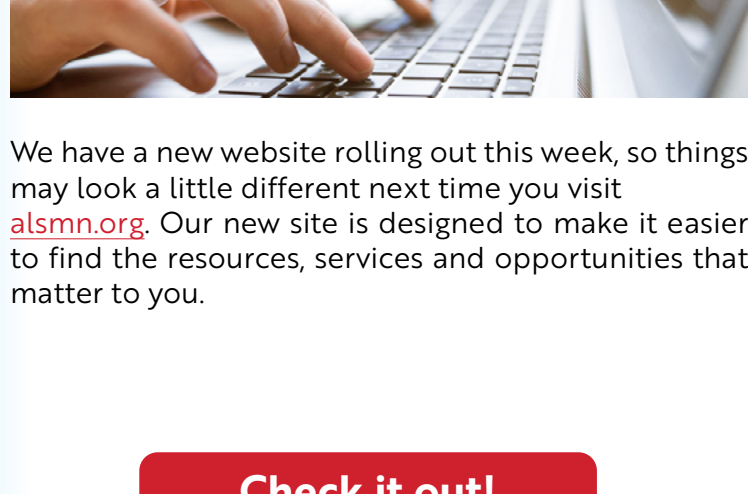


Calling all people living with ALS and caregivers: your perspectives are urgently needed! Your responses on the ALS Focus survey create action and influence ALS program and policy decisions.

ALS Focus is a survey platform that brings the perspectives of people with ALS and their caregivers to the forefront of research, care and advocacy. It only takes 10 minutes to participate after registering and all data collected will be open and free to the entire ALS community. The current survey focuses on your experiences with telehealth.

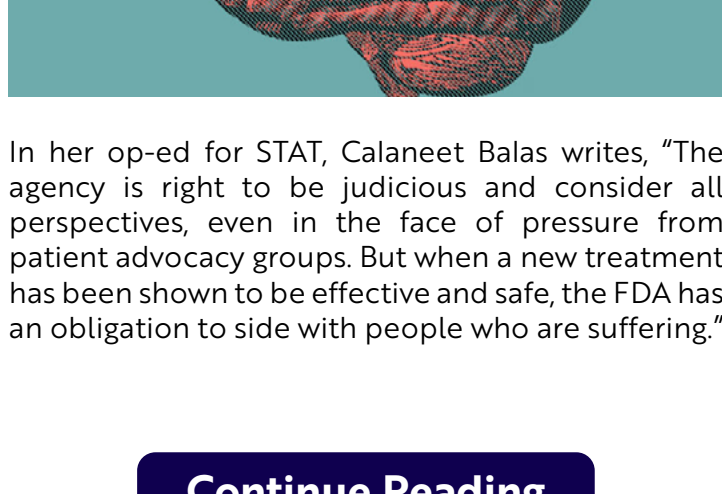
[Respond Today!](#)

### We Now Have a New Website for You!



We have a new website rolling out this week, so things may look a little different next time you visit [alsmn.org](http://alsmn.org). Our new site is designed to make it easier to find the resources, services and opportunities that matter to you.

### FDA Should Lead the Way on New ALS Treatments, not Canada and Europe



In her op-ed for STAT, Calaneet Balas writes, "The agency is right to be judicious and consider all perspectives, even in the face of pressure from patient advocacy groups. But when a new treatment has been shown to be effective and safe, the FDA has an obligation to side with people who are suffering."

[Check it out!](#)

[Continue Reading](#)

### Upcoming Care Services Programs

July 8	<b>Northern MN Support Group (Virtual Meeting)</b>	July 21	<b>Family Caregiver Support Group (Virtual Meeting)</b>
July 8	<b>Family Caregiver Support Group (Virtual Meeting)</b>	July 27	<b>SD and Southern MN Support Group (Virtual Meeting)</b>
July 20	<b>ND and Central MN Support Group (Virtual Meeting)</b>	August 4	<b>Minneapolis/St. Paul Metro Area Support Group (Virtual Meeting)</b>
July 20	<b>Young Adult Hangout (Virtual Meeting)</b>		

**Midweek Meditation - Every Wednesday at 11:00 AM (CT)**



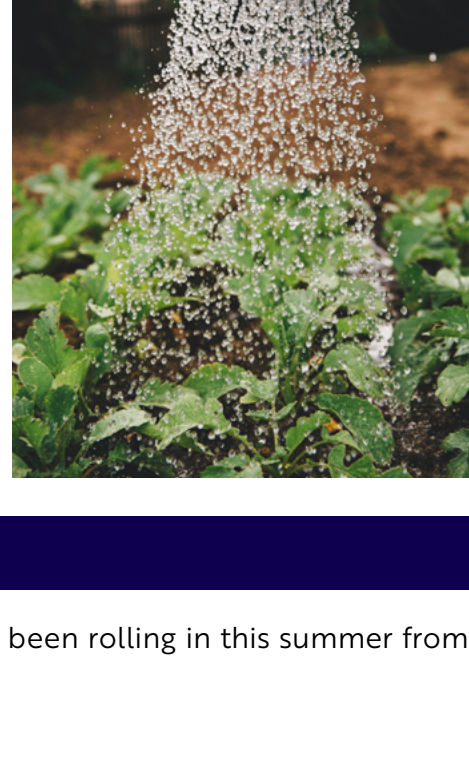
### Want to Connect Directly with Someone? Become a Family Assistance Volunteer

Through this program, volunteers are connected with families affected by ALS to help with everyday tasks or provide companionship.

With assistance, families report that their stress level is lowered knowing certain tasks will get done on a regular basis. The person living with ALS may not be able to physically complete the tasks and their caregiver may not have the time or energy. Additionally, most volunteers and families develop close relationships as time progresses.

The requests for assistance vary by task, frequency, and length and you can choose what works best based on your interests and availability. The Family Assistance Program has now reopened to both indoor and outdoor activities, with COVID-19 safety protocols in place.

**If you have any questions about volunteering, the volunteer positions available, or the application process, please call 612-455-6052 or email [jenna@alsmn.org](mailto:jenna@alsmn.org).**

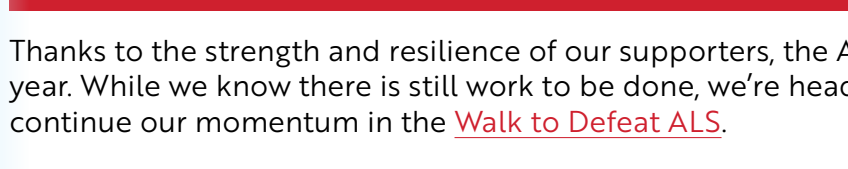


### Help Wanted!

Calling all service-minded Minnesotans! Family assistance requests have been rolling in this summer from across the state. Current needs by city include:

- Austin: vacuuming, dusting, cleaning
- Bloomington: help using computer/phone, cleaning
- Brooklyn Park: odd jobs, unpacking
- Duluth: cleaning
- Edina: weeding
- Lake City: companionship
- Princeton: gardening, shopping, meal prep, cleaning
- Rochester: laundry, housekeeping
- Spring Grove: cleaning
- Sunfish Lake: window washing (one time)

If you live in or near any of these cities, we'd love to chat with you about how you can make a difference. Please contact Jenna at (612) 455-6052 or [jenna@alsmn.org](mailto:jenna@alsmn.org) for more information.



### Upcoming Events

July 31	<b>North Dakota Walk to Defeat ALS</b>	August 23	<b>Larry Sing Memorial ALS Golf Classic</b>
August 21	<b>South Dakota Walk to Defeat ALS</b>		

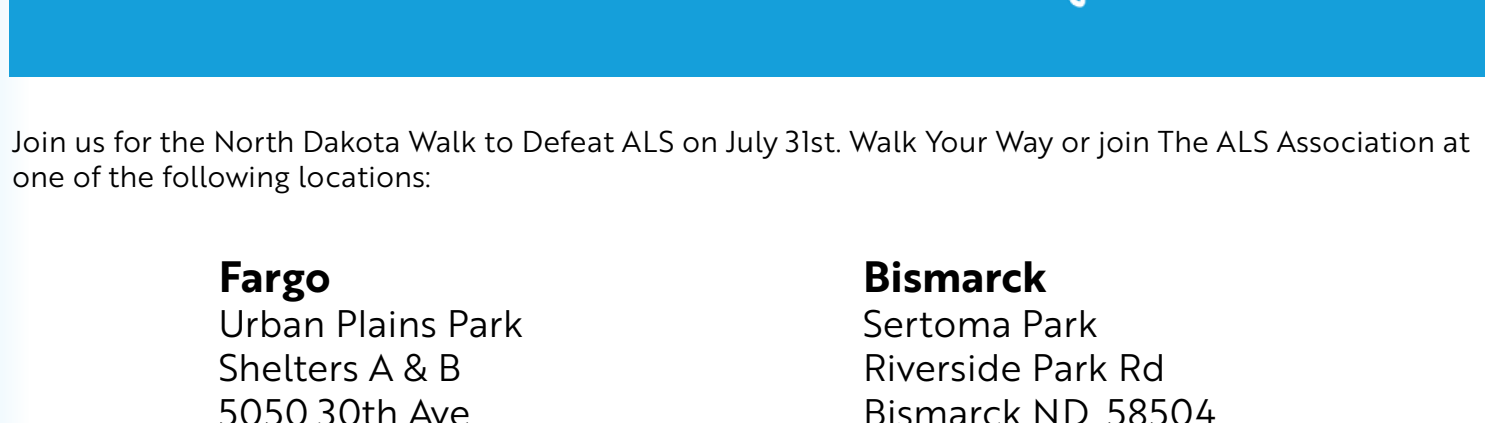
### You Can Now Join Us In Person for the 2021 Walk to Defeat ALS!

Thanks to the strength and resilience of our supporters, the ALS community has come a long way this past year. While we know there is still work to be done, we're heading in the right direction and we want to continue our momentum in the [Walk to Defeat ALS](#).

That's why we're excited to host in-person Walks as an option for our Walk Teams on Walk Day!

We encourage you to Walk Your Way however is best for you. No matter your location, we will all be walking together as one!

Learn more and get started: [web.alsa.org/mnndsdwalk](http://web.alsa.org/mnndsdwalk)



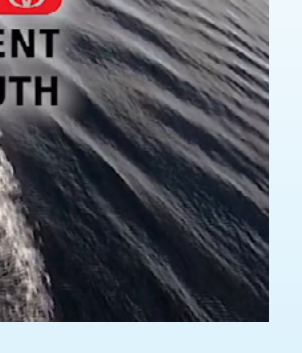
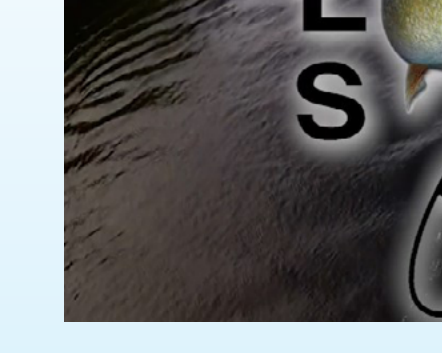
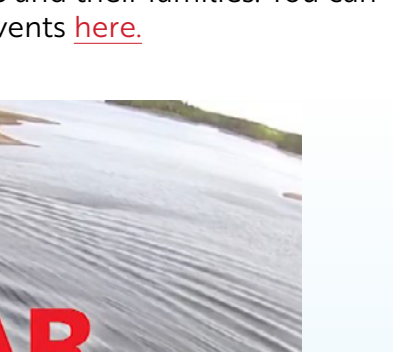
Join us for the North Dakota Walk to Defeat ALS on July 31st. Walk Your Way or join The ALS Association at one of the following locations:

**Fargo**  
Urban Plains Park  
Shelters A & B  
5050 30th Ave  
Fargo, ND 58104

**Bismarck**  
Sertoma Park  
Riverside Park Rd  
Bismarck ND, 58504

### Walk Sponsor Thanks

Thank you to our Walk to Defeat ALS Voice Sponsors. Your support helps spread the word about the Walk to Defeat ALS while raising important ALS awareness.



### Kolar Toyota ALS Fishing Tournament Casts for a Cause

Congratulations to the Kolar Toyota ALS Fishing Tournament for a successful 2021 event. This year, anglers fished Island Lake in Duluth, as well as virtually from any body of water, while raising funds for the fight against ALS. Over \$200,000 was raised to benefit individuals living with ALS and their families. You can learn more about this year's event and how you can be involved in future events [here](#).

