Gratitude is a sentiment that we can’t express nearly enough. 2020 was a year unlike any other, but your unwavering commitment to the fight against ALS continues to inspire. That commitment shines through in the following pages of this report and improved the lives of the 608 families we served throughout our region last year.

For more than 27 years, our mission has been to discover treatments and a cure for ALS, while serving, advocating for, and empowering people affected by ALS to live their lives to the fullest. You bring that mission to life. With a goal of supporting every individual living with ALS and their families across Minnesota, North Dakota and South Dakota, our work continues to be guided by the needs of those we serve. Our programs and services promote continued engagement with family, friends, and neighbors through improved mobility, communication, and independence. By focusing on providing the highest quality care possible, we strive toward our ultimate goal of bringing an end to this disease.

The pandemic has been a challenging time for the ALS community as the threat of respiratory illness has forced many to take significant measures to reduce the risk of exposure. Understanding that people living with ALS and their families come first, as a Chapter, we moved to a remote work environment and made the necessary adjustments to our service delivery to ensure our operations remained strong. We also emphasized connection so we could identify emerging needs and develop practical solutions.

Advocacy and research efforts continue to push forward. The diligence of the ALS community has led to meaningful policy changes and significant increases in federal funding for research. As more potential treatments enter the research pipeline, we are prioritizing how these potential treatments can get to individuals living with ALS as quickly as possible.

The response from our incredible network of supporters in 2020 is beyond anything we could have imagined. We hope you’ll reflect on the following pages with the knowledge that you have made a positive difference in the lives of individuals and families. Your involvement in our mission, along with your tremendous generosity, underscores your commitment to further the fight against this disease no matter the circumstances and we are grateful.

**608 FAMILIES SERVED IN 2020**

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**DEAR FRIENDS,**
The Hrbek-Sing Program provides assistive or augmentative communication equipment and smart-home technology to individuals who have lost their ability to verbally communicate. The program provides electronic aids such as speech amplifiers, environmental controls, smart home technology and eye-gaze devices so that individuals with ALS can maintain their independence as their disease progresses. In addition to the traditional equipment that was deployed through this program, in 2020 the Chapter focused on sending out additional technology, such as iPads, so that individuals could stay connected with their friends and family, as well as the Chapter, during the pandemic.

Number of Individuals and Families Served in 2020: 334
Augmentative/Communication Equipment Distributed in 2020: 1,448
Supportive Equipment Distributed in 2020: 200

The Chapter sponsors several support groups within our service area, which offer people with ALS and their loved ones a place to receive education and support. During the pandemic, the Chapter has moved all support groups to virtual meetings. 143 participated in a support group in 2020.

Through the Family Assistance Program, a volunteer is connected to an individual or family affected by ALS to support them by completing everyday tasks and providing companionship. Volunteers can assist with anything outside of daily living, medical care and transportation, including cleaning, organizing, preparing meals, mowing, gardening, yard work, pet care, errands, grocery shopping, basic technology setup and hobbies. The program engaged 40 volunteers to serve 38 individuals and families in 2020. In addition, 15 families received grants to help cover house cleaning or yard work.

Our Home Safety Program covers the cost of evaluations by an occupational or physical therapist in someone’s home. The evaluations provide families with ideas on home modifications, which equipment will work best based on their floor plan and tips for how families can help individuals stay safe in their homes as their needs change. During the pandemic, the Chapter has conducted a number of these assessments via video conferencing, ensuring necessary modifications are identified while maintaining safety for those we serve.

Number of Individuals and Families Served in 2020: 39

Partnerships with local health care systems are key to serving the ALS community. The Chapter certifies and provides funding to ALS Certified and Recognized Centers of Excellence, which provide multidisciplinary care to ensure that all of an individual’s needs are met in one place. Chapter staff are a part of the care teams at these clinics to identify needed support on an individual basis. Many clinics moved to telehealth visits during the pandemic, with Chapter staff coordinating virtually to ensure needs from clinic visits were addressed.
ADVOCACY

Every year, The ALS Association’s Advocacy Conference brings together ALS advocates from across the country to discuss legislation that impacts people living with ALS. Due to the pandemic, the 2020 conference was held virtually, but representation remained strong. Association-wide, more than 600 virtual meetings took place with members of Congress. Our Chapter held 16 meetings with our congressional offices, advocating for 5 bills and 3 appropriations requests. The sharing of personal stories, as well as follow-up emails, letters and phone calls from these amazing advocates, helped demonstrate the need for legislative action and increased research funding for ALS.

To learn more or become an ALS Advocate, visit als.org/advocate.

LEGISLATIVE PRIORITIES

- **Accelerate Development, Approval and Access to Effective New Treatments**
- **Increase Federal Funding for ALS Research**
- **Permanently Extend Access to Telehealth for People Living with ALS**
- **Provide High-Quality, Affordable, and Accessible Health Care**
- **Increase Veterans Benefits for People with ALS and Their Families**

RESEARCH

The ALS Association funds more ALS research than any other organization and is recognized for the program's scope and diversity. Thanks to your support, the Association funded more than 171 projects in 15 countries around the world in 2020. Projects are milestone-driven, meaning dollars are directed when the science demonstrates that one approach is more promising than another. The Association's collaborative and global approach to funding research continues to lead to significant discoveries by top ALS scientists around the world.

Investments in the first-ever HEALEY ALS Platform Trial by The ALS Association seek to speed up the research process by allowing scientists to test multiple ALS drugs at the same time. The approach reduces costs and time while increasing participation. In our region, M Health Fairview and Mayo Clinic have been named HEALEY ALS Platform Trial sites. Innovative approaches like this, coupled with the Association's investments in 13 scientific focus areas, push us closer to the discovery of new treatments that can help us find a cure.

SCIENTIFIC FOCUS AREAS

- **Assistive Technology**
- **Biomarkers**
- **Clinical Studies**
- **Drug Development**
- **Disease Models**
- **Cognitive Studies**
- **Natural History Studies**
- **Environmental Factors**
- **Precision Medicine**
- **Disease Mechanisms**
- **Nanotechnology**
- **Genetics**
- **Stem Cells**
The resilience and flexibility of our community were on full display in fundraising this past year. Amidst great uncertainty, individuals, corporations and foundations demonstrated why our region is one of the most generous in the country. The pandemic forced us to rethink our fundraising strategies and present them in a different form. Most Chapter events moved to a virtual format, but people engaged with us in ways that were comfortable for them. In the summer of 2020, we launched In This Together, a fundraising campaign to connect our fantastic support network as we navigated the pandemic. Through event dollars, individual contributions, community fundraisers, grants and planned gifts, we were able to raise critical dollars and, ultimately, meet the resource needs to fulfill our mission. As we move forward, we will lean on the innovation, creativity and inspiration that so many demonstrated in such a challenging time to continue our momentum in the fight against ALS.

The Walk to Defeat ALS raised more than $740,000 for the ALS community. The 26th Annual Larry Sing Memorial ALS Golf Classic raised more than $50,000 for individuals and families in our region. The Light the Journey Gala at Home supported our mission with more than $211,000 raised. Heroes everywhere helped raised over $110,000 through the ALS SuperHero Dash.

**Financial Snapshot**

Our finances are a direct reflection of our commitment to providing the best possible care and support to anyone living with ALS in Minnesota, North Dakota, and South Dakota.

- **Programs & Services 58%**
- **Public Awareness 10%**
- **Research 7%**
- **Fundraising 18%**
- **Operations 7%**
This is the Statement of Activities and Statement of Financial Position for the year ending January 31, 2021. An annual audit is conducted by a professional independent certified public accounting firm that provides an opinion on the fairness of our financial statements in accordance with accounting principles generally accepted in the United States of America. The ALS Association, Minnesota, North Dakota, South Dakota Chapter is committed to operating with the highest financial integrity and serving the community in the most effective way possible.

If you would like more information on our audited financial statements, please contact us at 612-672-0484.

The ALS Association, Minnesota, North Dakota, South Dakota Chapter, d.b.a. ALS Association, MN/ND/SD Chapter