



# 2021 ANNUAL REPORT

**ALS** Minnesota  
North Dakota  
South Dakota  
ASSOCIATION Chapter



# DEAR FRIENDS,

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.

PHILIP ALBERT  
CHAIR, BOARD OF DIRECTORS

JENNIFER HJELLE  
EXECUTIVE DIRECTOR

# CONTENTS

## PAGE 4-5

OUR SERVICES

## PAGE 8-9

FUNDING OUR MISSION

## PAGE 6

ADVOCACY

## PAGE 10-11

FINANCIAL STATEMENTS

## PAGE 7

RESEARCH

## PAGE 12

CONTACT US

# BOARD OF DIRECTORS

**PHILIP ALBERT, PRESIDENT**  
Medtronic, Inc.

**CLAY AHRENS, VICE PRESIDENT**  
*Living with ALS*  
Retired, Allina Health

**JOHN ORNER, TREASURER**  
Highmark Health

**JORDAN SING, SECRETARY**  
United States Department of Justice

**KRISTI WAITE,  
BOARD OF REPRESENTATIVES**  
Retired, Rasmussen College

**NANA AHWOI**  
Ernst & Young

**KEN BALTES, PhD**  
*Living with ALS*  
Retired

**AMY BRACHIO**  
Ernst & Young

**MARY JONES**  
Avera McKennan

**PETE KLINKHAMMER**  
*Living with ALS*  
Retired, MN Brain Injury Alliance  
& MN Stroke Association

**MORGANA KOLENDA**  
Northwood Children's Services

**STEVE KRAUS**  
Thomson Reuters

**DAVID LAMM**  
Independent Consultant

**GRANT LANDER**  
Dell Technologies

**MARY ELLEN LEARY**  
The MEL Group, LLC

**TINA LINNE**  
Reading & Math, Inc.

**JAN NELSON**  
BNC National Bank

**BRENDA OLSON**  
Avera Queen of Peace Hospital

**JEREMY RICE**  
Abbot Downing

**SUSAN SCHUSTER**  
Blue Cross Blue Shield

**DR. NATHAN STAFF, MD**  
Mayo Clinic

**DR. EZGI TIRYAKI, MD**  
Minneapolis VA Health System

**DR. DAVID WALK, MD**  
University of Minnesota Medical  
Center

# OUR SERVICES



## HRBEK-SING COMMUNICATION & ASSISTIVE DEVICE PROGRAM

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**



## DURABLE MEDICAL EQUIPMENT LOAN POOL

The Chapter's largest program, the Durable Medical Equipment Loan Pool provides medical equipment to assist with challenges people living with ALS face throughout disease progression. Equipment includes items like bathroom equipment, hospital beds and adaptive utensils, all of which help the person living with ALS and their caregiver. Housed at several sites throughout our service area, equipment is loaned to individuals and families at no cost, filling a need in instances when insurance coverage isn't possible. New sanitation protocols were adopted in light of the pandemic with limited disruption to distribution.

Number of Individuals and Families Served in 2020: **393**  
 Pieces of Equipment Distributed in 2020: **3,052**  
 Adaptive Items Distributed in 2020: **250**



## JACK NORTON FAMILY RESPITE PROGRAM

Through the Jack Norton Family Respite Program, we are able to provide much-needed respite to full-time family caregivers, bringing certified home care personnel into the home for up to 18 hours per month. The program instills confidence in the caregiver that their loved one is in expert care while they pursue their own interests outside the home. The program has been fully operational under new safety guidelines and is anticipated to return to pre-pandemic usage levels in 2021.

Number of Individuals and Families Served in 2020: **94**  
 Number of Respite Hours Provided in 2020: **8,752**



## SUPPORT GROUPS

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.



## FAMILY ASSISTANCE PROGRAM

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, prepping 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.



## HOME SAFETY PROGRAM

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**



## CLINIC SERVICES

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.

A crucial victory on the advocacy front in 2020 was the passage of the **ALS Disability Insurance Access Act**, a bill that ensures people living with ALS and their families no longer have to wait the previously established five-month waiting period to secure the Social Security Disability Insurance (SSDI) that will help them. Introduced in 2016 with a single sponsor, the resilience of the ALS community over the course of four years added 370 cosponsors until the bill became law, demonstrating the true power of advocacy.

To learn more or become an ALS Advocate, visit [als.org/advocate](https://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 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.

## FUNDING OUR MISSION

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.

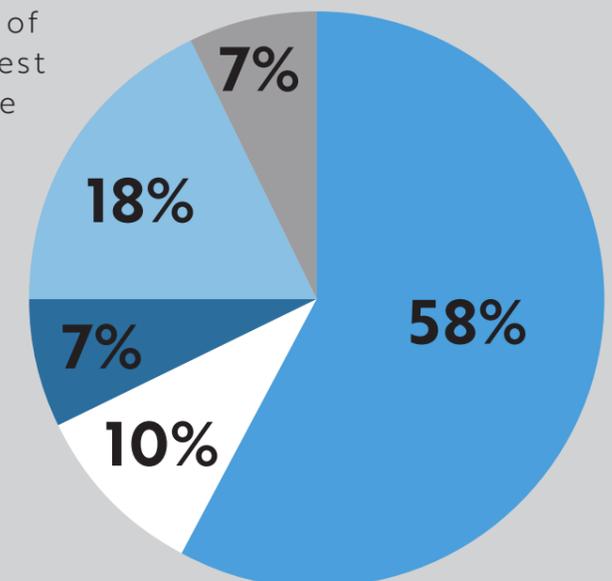


The 26th Annual Larry Sing Memorial ALS Golf Classic raised more than \$50,000 for individuals and families in our region.

## 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%**



# STATEMENT OF ACTIVITIES

YEAR ENDED JANUARY 31, 2021

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

	Without Donor Restrictions	With Donor Restrictions	Total
<b>Support and Revenue</b>			
Support and contributions	\$ 871,638	1,279,861	\$ 2,151,499
Donated equipment	624,385	-	624,385
Special events, net of \$11,869 in direct benefits to donors	1,063,423	-	1,063,423
Interest and dividend income	37,724	-	37,724
Unrealized and realized gain on investments	142,996	-	142,996
Paycheck Protection Program forgiveness income	326,616	-	326,616
Total support and revenue before net assets released from restrictions	3,066,782	1,279,861	4,346,643
Net assets released from restrictions	1,180,936	(1,180,936)	-
Total support and revenue	4,247,718	98,925	4,346,643
<b>Expenses</b>			
Program services			
Care services	2,241,209	-	2,241,209
Advocacy	407,425	-	407,425
Research	266,974	-	266,974
Total program services	2,915,608	-	2,915,608
Supporting services			
Fundraising	685,055	-	685,055
Administration	287,890	-	287,890
Total supporting services	972,945	-	972,945
Total expenses	3,888,553	-	3,888,553
<b>Change in Net Assets</b>	359,165	98,925	458,090
<b>Net Assets - Beginning of Year</b>	4,040,196	263,145	4,303,341
<b>Net Assets - End of Year</b>	\$ 4,399,361	\$ 362,070	\$ 4,761,431

# STATEMENT OF FINANCIAL POSITION

YEAR ENDED JANUARY 31, 2021

ASSETS	January 31	
	2021	2020
<b>Current Assets</b>		
Cash and cash equivalents	\$ 866,496	\$ 480,709
Investments, short-term	621,431	408,146
Current maturities of pledges receivable	1,080	3,081
Other current assets	40,052	36,018
Total current assets	1,529,059	927,954
<b>Investments, long-term</b>	2,472,514	2,606,174
<b>Property and Equipment</b>		
Medical equipment loan pool	1,993,137	1,729,053
Hrbek-Sing program equipment	687,430	635,557
Office furniture and equipment	215,398	215,398
Leasehold improvements	490,367	490,367
Total property and equipment	3,386,332	3,070,375
Less accumulated depreciation	1,861,940	1,509,890
Net property and equipment	1,524,392	1,560,485
<b>Other Assets</b>	19,518	19,518
<b>Total Assets</b>	\$ 5,545,483	\$ 5,114,131
LIABILITIES AND NET ASSETS		
January 31		
2021		
2020		
<b>Current Liabilities</b>		
Accounts payable	\$ 112,232	\$ 45,797
Accrued liabilities	69,574	81,293
Current maturities of capital lease obligations	1,855	1,773
Due to ALS National	106,014	145,586
Deferred rent	43,289	40,109
Total current liabilities	332,964	314,558
<b>Deferred Rent, net of current portion</b>	449,314	492,603
<b>Capital Lease Obligations, net of current maturities</b>	1,774	3,629
<b>Commitments and Contingencies</b>		
<b>Net Assets</b>		
Without donor restrictions	4,399,361	4,040,196
With donor restrictions	362,070	263,145
Total net assets	4,761,431	4,303,341
<b>Total Liabilities and Net Assets</b>	\$ 5,545,483	\$ 5,114,131



ALSMN.ORG | 612-672-0484

1919 UNIVERSITY AVE W SUITE 175 | SAINT PAUL, MN 55104

**ALS** Minnesota  
North Dakota  
South Dakota  
ASSOCIATION Chapter

