

ALS[®]

ASSOCIATION

Wisconsin Chapter

**ANNUAL REPORT
YEAR ENDING JANUARY 31, 2020**

The ALS Association Wisconsin Chapter
3333 North Mayfair Road, Suite 104
Wauwatosa, WI 53222
Phone: (414) 763-2220
Fax: (414) 231-9100
www.alsawi.org



A MESSAGE FROM THE CHAPTER PRESIDENT

Dear Chapter Members and Friends:

This annual report covers the fiscal year February 1, 2019 to January 31, 2020, and developments since the end of the fiscal year. For obvious reasons, this letter focuses on those developments and how the Chapter has responded.

The Chapter is Wisconsin's only organization dedicated to providing care, services, support and advocacy to nearly 600 people living with ALS and their families in the State of Wisconsin. In January 2020, I was honored to be asked to extend my second term as President of the Chapter, led by individuals dedicated to this cause, including our volunteer Board of Directors, volunteer Leadership Team and incredibly hardworking staff.

Little did I know that, six weeks into that term, I would be facing the most challenging year I can remember in my 23 years as a member of the Chapter Board. My thanks to everyone involved in supporting the Chapter during these unprecedented times, and especially our staff. Every member of our staff, from usually part-time employees to those who regularly work nights and weekends, has stepped up in this time of crisis. It is through their generosity and dedication that we have been able to continue providing excellent services to individuals in Wisconsin living with ALS and their families, to provide public awareness and advocacy, and to fund cutting-edge ALS research.

I also never imagined that six months after we welcomed Angela Pereira, RN, BSN, as Care Services Director, that she would be converting in-person programs to virtual programs, including an ALS Care and Research Symposium website that will be released in November 2020. She was tasked with overseeing the staff and collaborating with ALS clinics, providers and community resources on a remote basis, and the continuation of care has been nothing but stellar. The Chapter is indeed fortunate for Angie's leadership as she administers existing Care Services programs and creates new ways to serve our constituents. In addition to Angie, the team members who have done extraordinary work last year, but especially over the last six months, are: Care Services Coordinators Robin Stanczyk, RN, and Mary DeFrain Jones, CSW, in the Milwaukee area, Carolynne Younk, MS, in Green Bay, and Diane Fergot, CSW, in Oshkosh; Program Support Assistant, Janet Gauger, and Equipment Loan Coordinator, David Ferrie.

The Chapter's Care Services Coordinators work directly with people living with ALS and their families, providing virtual, phone and in-person consultations to deliver information, support and resources. Programs throughout the state include monthly Support Groups in Milwaukee, Oshkosh, Manitowoc/Two Rivers, Green Bay, Wisconsin Rapids, La Crosse and Madison. These have been converted to virtual groups with the addition of a state-wide support group that has enabled many people living with ALS to attend, when they otherwise could not attend in person due to their physical and geographical limitations. Thanks to Facilitators Meg Posorske in Wisconsin Rapids and Connie Troyanek and Carolyn Herman in La Crosse for their leadership, and to the families who banded together to form these groups. Caregiver support groups are offered in the Milwaukee and Fox Valley areas and were converted to statewide virtual groups in May. As noted, these support groups converted to Zoom meetings in March and we look forward to resuming in-person meetings in the future.

The Chapter's Augmentative Communication and Equipment Loan Programs continue to grow exponentially due to the increase in need to communicate remotely. My thanks to David Ferrie,

our Equipment Program Coordinator, who, despite the pandemic, continued to fill the equipment needs of people living with ALS in Wisconsin from sites in Milwaukee, Appleton and Eau Claire. The Brian Trinastic Memorial Grant Program also continued to provide grants to individuals living with ALS for transportation, home modifications, communication devices and other needed equipment. Since its inception in 2009, hundreds of grants have been awarded to hundreds of people living with ALS in Wisconsin.

Fundraising during a pandemic, especially when the market was on a roller coaster and people's employment was uncertain, is a herculean task. Fortunately for the Chapter, our fundraising and development team met the challenge head on, reinventing existing fundraisers like the Walks (more on that below), creating new online fundraisers, and dedicating substantial effort to grant writing. Thank you to the Chapter's Executive Director Melanie Roach-Bekos and Development Manager Susie Reed for their stellar efforts. Susie and Cheryl Brooks, our Outreach Community Coordinator, took the lead, and very successfully increased the Chapter's grant writing efforts, especially in Northeast Wisconsin. Taylor Skorik kept the Chapter in the forefront of social media including the Chapter's website, www.alsawi.org, Facebook, Twitter and Instagram. The Fundraising and Development Team also created billboard campaigns and participated in television and radio interviews.

Like many non-profits, the Chapter saw the cancellation of Chapter and family/community events due to the COVID-19 pandemic. After initially moving the *Evening of Hope*, our gala dedicated to funding research, from March 13 to July 31, we ultimately decided to cancel the event as it simply was not safe to host an event attended by nearly 700 people, including many people at high risk. Despite the cancellation, many, many generous supporters told us to keep their payment for *Evening of Hope* attendance as a donation or to roll it over to 2021. We are most grateful for their generosity.

The Chapter's signature events, the Walks to Defeat ALS, will be different in 2020. Instead of a gathering of thousands of people in different locations across the state this fall, smaller groups of families and friends will participate in MINI-WALKS – spreading awareness and raising money in their neighborhoods and dressed as “ALS Super Heroes.”

I also wish to thank the Chapter's Leadership Team, a group of professionals dedicated to supporting the Chapter's work, who have provided substantial financial support through both in-kind contribution of services and facilitating the creation of partnerships with Wisconsin's business community. Thanks, also, to the ALS Ambassadors, a group of people primarily in their 20s and early 30s who have expressed an interest in supporting the cause. Group members are asked to attend at least two events, invite their friends to join them, and to spread the word about the Chapter's work and services by word of mouth and social media.

Special thanks to former Board Members Ben Becker and Laura Hinrichsen, as well as Melanie Roach-Bekos and Lori Banker-Horner, for serving on the national level in the last fiscal year. Ben was the Vice Chair of the Chapter Relations Committee, he and Laura served on the Board of Representatives, Lori served on the Care Services Committee, and Melanie served on The ALS Association's Research Committee. Because it is vital to present the Wisconsin perspective to the ALS Association, Board Member Carl Bahneman joined the Board of Representatives, Meg Posorske became a member of the Strategic Planning Committee and Melanie remains on the Research Committee.

I have been remiss in past letters for not specifically mentioning the Chapter's Finance Manager, Kathleen Huevler. Kathleen's responsibilities go far beyond finance as she fills the roles to manage our database, human resources, information technology, insurance and much more. Kathleen has expertise in providing detailed financial reports necessary for the Board and staff to make day-to-day and long-term decisions, to apply for grant funding and to fill the reporting needs of the ALS National Headquarters. In the last six months, Kathleen has done all of that, is working diligently to keep the Chapter's finances in the forefront and, at the same time, is leading a conversion of the Chapter's software required by the national organization.

The Chapter Board of Directors, staff members and volunteers are dedicated and committed to the Chapter's mission. I thank all of them, and all of the Chapter's supporters for their efforts.

Sincerely,

Kathryn A. Keppel

Kathryn A. Keppel, President, Board of Directors

PROGRAMS AND SERVICES

The ALS Association Wisconsin Chapter is very pleased to provide a variety of services to people living with ALS and their families and caregivers across the state. Those programs include:

Care Services Staff

The Chapter's Care Services Staff provides services to people living with ALS, their families and their caregivers, helping them learn about the disease, locate resources in the community and cope with the changes occurring in their lives. During the year ending January 31, 2020, the Chapter served nearly 600 Wisconsin residents living with ALS who were registered with the Chapter. Care Services programs and services listed below are available to assist individuals and families to meet the daily challenges of ALS.

ALS Support Groups

The Chapter reaches out to people living with ALS, their families and their caregivers through support groups in Milwaukee, Oshkosh, Manitowoc/Two Rivers, Wisconsin Rapids, La Crosse, Green Bay and Madison. Support group meetings are upbeat gatherings that focus on coping with ALS and its challenges in the best way possible. Speakers discuss topics such as nutrition, insurance, communication devices, legal and financial issues, and breathing and swallowing problems with coping strategies. The meetings provide a supportive environment where tears, smiles and laughter are all part of the sharing experience.

Separate caregiver groups meet in Milwaukee, Appleton and Green Bay. The caregiver group is an informal dinner gathering for individuals in a caregiving role, providing an opportunity to learn from, share with, and give and receive support from others who understand. In addition, caregivers in Milwaukee whose loved ones have passed away have formed a Next Chapter group. This group meets socially, participates in Chapter events and spends time together as they focus on the next chapter of their life without their loved one.

As mentioned in my opening remarks, these groups have transitioned to virtual forums starting in March 2020.

Wisconsin ALS Certified Treatment Centers of Excellence

The ALS Clinic at Froedtert Hospital/Medical College of Wisconsin and The Clement J. Zablocki Milwaukee VA Medical Center ALS Clinic are recognized as Certified Treatment Centers of Excellence by The ALS Association. Thank you to Dr. Paul Barkhaus, Dr. Dominic Fee, Angela Pereira, Lori Banker-Horner and Robin Stanczyk for their dedication and persistence in making this recognition possible.

The two Certified Treatment Centers of Excellence provide neurological diagnostics and imaging, as well as access to the services of a team of highly trained health care professionals specializing in ALS. Under the medical direction of Dr. Paul Barkhaus and Dr. Dominic Fee, the Clinic team consists of a Nurse Coordinator, Social Worker, Dietitian, Speech/Swallow Therapist/Augmentative Communication Specialist, Physical Therapist, Occupational Therapist, Respiratory Therapist, Chaplain, Child Life Specialist, Research Coordinator, Pharmacist and Wisconsin Chapter Care Services Representative.

Approximately 30 patients are seen at the Froedtert ALS Clinic and 15-20 patients are seen at the VA Clinic on a monthly basis.

In recent years, the Chapter provided expanded services at University Hospital & Clinics MDA ALS Clinic in Madison. Under the direction of Dr. Stephanie Gardon and Dr. Andrew Waclawik, the clinic is seeking to become a Recognized Treatment Center by The ALS Association, offering a high-quality approach to multidisciplinary care. The Chapter provides a member of the Care Services staff at each clinic to meet with patients and families to offer support and resources. Approximately 25 patients are seen at the clinic on a monthly basis.

The Chapter also supports a developing ALS Multidisciplinary clinic in the Neurosciences Center at Gundersen Health System in La Crosse, by providing a member of the Care Services staff at each clinic. This clinic is under the medical direction of Dr. Michael Leone and meets one to two times per month. Approximately 30 patients are currently being seen through this clinic.

Equipment Loan Program

The Chapter has an inventory of gently used durable medical equipment and assistive devices for loan at three sites in Wisconsin, thanks to the generous support and partnership with NuMotion, a statewide medical equipment company. The inventory includes wheelchairs, scooters, canes, walkers, grab bars, toilet seat risers, special utensils and other supplies and devices. The Equipment Loan Program has locations in the Milwaukee area, Appleton and Eau Claire. During the year ending January 31, 2020, nearly 800 pieces of equipment were on loan to people living with ALS throughout Wisconsin. The Equipment Loan Program is one of the most highly utilized programs offered by the Chapter.

Augmentative Communication Program

The Chapter maintains an inventory of gently used augmentative communication devices for loan for individuals with no or limited insurance coverage to obtain such devices if available. Devices range from low- to high-tech devices, based on individual need. The Chapter networks with and can provide resources for speech therapists, who are able to assess specific needs with respect to communication and communication aids. During the year ending January 31, 2020, nearly 160 pieces of equipment were on loan to people living with ALS in Wisconsin.

Brian Trinastic Grant Program

The Chapter is pleased to provide transportation and flex grants through the Brian Trinastic Memorial Grant Program. These grants provide some financial relief from costs associated with ALS for individuals living in Wisconsin who are registered Chapter members. Two different reimbursement-type grants are offered under this program to help offset some of the high costs associated with an ALS diagnosis. Transportation grants help with the costs of travel and lodging associated with medical visits and Chapter events. Flex grants provide reimbursement for some out-of-pocket costs for medical equipment, home modifications, communication devices, ramps and other needs. For the year ending January 31, 2020, 51 people living with ALS received transportation grants totaling \$15,385 and 88 people living with ALS received flex grants totaling \$50,525.

Symposium and Youth Day

The Chapter's ALS Care and Research Symposium has been held annually in the Milwaukee area for 15 years. The Symposium's speakers include scientists conducting cutting-edge ALS research, Chapter board members, staff and supporters who provide updates on matters such as advocacy, fundraising, and volunteerism, and families who discuss living with ALS, the choices they have made along their journeys and the reasons for their choices. In 2016, the Chapter formally added "Youth Day" to the event, recognizing the important role youth in the home play in providing support for their loved one and our responsibility to in turn educate and support them.

Over 135 attendees and 20 exhibitors participated in the Symposium held on May 18, 2019, in Brookfield, Wisconsin. The keynote speaker was Dr. Richard Bedlack, Professor of Neurology at Duke University and Director of the Duke ALS Clinic. Dr. Dominic Fee, Neurologist at the Froedtert/Medical College of Wisconsin provided an update on local ALS research. The Symposium wrapped up with an engaging "Ask the Experts" panel discussion including the following presenters: Dr. Andreea Anton, Pulmonologist, VA Medical Center; Dr. Paul Barkhaus and Dr. Dominic Fee, Neurologists, Froedtert/Medical College of Wisconsin; Dr. Richard Bedlack, Neurologist, Duke University and Duke ALS Clinic; and Mr. Herman Green, ALS Research Ambassador for the ALS Association Wisconsin Chapter.

The Symposium included a Youth Day program facilitated by Melinda Kavanaugh, PhD, LCSW, with the Helen Bader School of Social Work at the University of Wisconsin-Milwaukee. Dr. Kavanaugh received assistance from the following specialists to educate and support the young caregivers: Suzi Bloedel, SLP; Elizabeth Kelley, SLP; Mallory Riggs, SLP; Deb Romoren, OTR; Christina Wipperman, PT. The program provided children an opportunity to learn about communication devices, power wheelchairs and breathing devices. More importantly, the program

gave the children an opportunity to make connections with other children dealing with similar circumstances.

The 2020 Symposium was postponed due to COVID-19; however, we are pleased to announce that our 16th Annual ALS Care and Research Symposium and Youth Day will be featured on a website and will premiere on November 7, 2020. Our virtual Symposium will continue to feature valuable information and resources with the goal of providing education, guidance, services and support to ALS patients, their families and their caregivers. It will also promote public awareness, support the ALS Association Certified Centers and affiliated ALS Multidisciplinary Clinics throughout Wisconsin, and encourage the development of ALS specialty care to ensure the highest level of care is available to individuals living with ALS in Wisconsin. Our new virtual format will also benefit others outside of the Wisconsin community as it will be a live website and available to anyone online.

The Symposium website will include: two presentations by expert physicians in the field of ALS; a page dedicated to Froedtert and the Medical College of Wisconsin's ALS Clinic and Research Programs; and a patient panel that consists of a group of individuals with ALS and the people that support them. The individuals' comments will be prerecorded and they will present their special journey, including obstacles they have encountered and insights they have gained along the way.

There will also be a section on the website dedicated to a special ALS Youth Program for children and teens ages 8-18 curated by: Melinda Kavanaugh PhD, MSW, LCSW Associate Professor, Helen Bader School of Social Welfare, University of Wisconsin-Milwaukee.

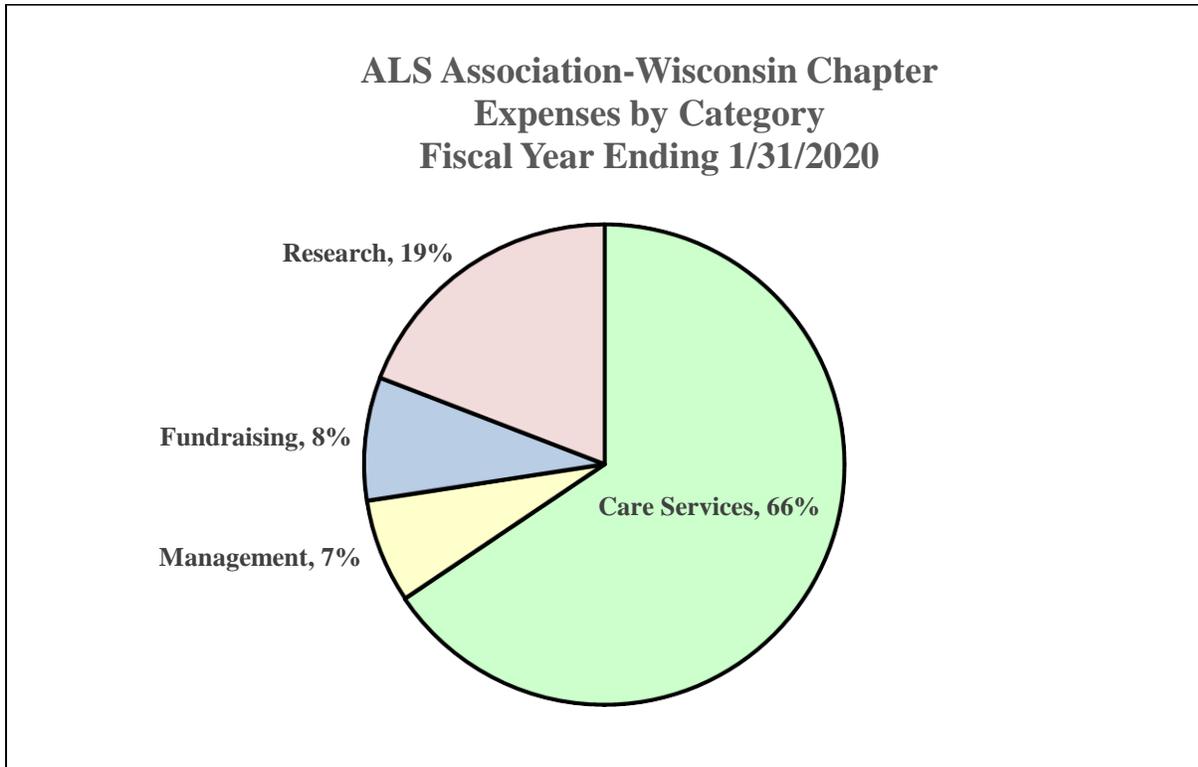
The website also will feature local and national companies whose mission is to provide care, services, equipment and supplies to our ALS community.

FINANCIAL REPORT
Year Ending January 31, 2020

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|-------------------------------------|--------------------|
| REVENUES | |
| Fundraising Events | \$647,753 |
| Contributions, gifts, grants | 595,014 |
| Advocacy Events | 237,643 |
| Research Special Events | 175,670 |
| Federated Campaigns | 33,525 |
| Interest Income | 1,364 |
| Total Revenue | <u>\$1,690,969</u> |
| EXPENSES | |
| Care Services / Programs | \$1,040,033 |
| Research Expenses | 303,406 |
| Salaries & Related Expenses | 168,885 |
| Office & IT Expense | 20,048 |
| Professional Services | 16,310 |
| Insurance | 8,484 |
| Office Rent | 8,063 |
| Other | 21,124 |
| Total Expenses | <u>\$1,586,353</u> |
| Net Assets - Beginning of Year | \$1,069,863 |
| Non-Cash Loss on Equipment Disposal | (150,286) |
| Change in Net Assets | <u>104,616</u> |
| Net Assets - End of Year | \$1,024,193 |

HOW THE CHAPTER USES ITS FUNDS

As explained in Board President Kathryn A. Keppel's letter, the Chapter's primary revenue source is donations from individuals and entities. The Chapter Board of Directors is committed to utilizing all specifically designated funds in accord with the donors' wishes and utilizing all non-designated funds in the manner the Board believes best serves the people in Wisconsin living with ALS and their families.



BOARD OF DIRECTORS

February 1, 2019 – January 31, 2020

Kathryn A. Keppel
President
Partner at Gimbel, Reilly, Guerin & Brown LLP
(FYE2018-FYE2020)

Mary Beth Schlecht
Treasurer
Community Volunteer
(FYE2018-FYE2020)

Carl Bahneman
Director-Product Line Manager at FIS
(FYE2020-FYE2022)

Holly Blake
Community Volunteer
(FYE2019-FYE2021)

Lauren Domnick
Senior Director Data Science
at Northwestern Mutual
(FYE2020-FYE2022)

Joel Hess
Principal at LeaseCrunch
(FYE2020-FYE2022)

Terri McKenzie
Underwriting Consultant at IBU, Inc.
(FYE2019-2021)
resigned July 11, 2019

Mary Brennan Druml
Vice President
Community Volunteer
(FYE2018-FYE2020)

Laura Hinrichsen
Secretary
Media Director at STIR Advertising &
Integrated Messaging
(FYE2018-FYE2020)
resigned November 13, 2019

Ben Becker
Senior Vice President & Manager
of Business Banking at First Citizens Bank
(FYE2018-FYE2020)
Resigned December 31, 2019

Meg Posorske
Community Volunteer
(FYE2019-2021)

Thomas D. Kettler
Community Volunteer
(FYE2020-FYE2022)

Manis Mullarkey
Securities Specialist at US Bank NA
(FYE2020-FYE2022)

CHAPTER STAFF

Melanie Roach-Bekos
Executive Director

Lori Banker-Horner, BA, LPN
Care Services Director
(through August 2019)

Angie Pereira, RN
Care Services Director
(beginning September 2019)

Development/Public Awareness Team

Susie Reed
Development Manager

Taylor Skorik
Marketing/Fundraising Coordinator

Cheryl Brooks
Outreach Community Coordinator

Administration

Kathleen Huevler
Finance Manager

Care Services Team

Robyn Stanczyk, RN
Care Services Coordinator
Southeast Wisconsin

Mary DeFrain Jones, CSW
Care Services Coordinator
Southeast Wisconsin

Diane Fergot, CSW
Care Services Coordinator/
Support Group Facilitator
Oshkosh/Fox Valley

Carolynne Younk, MS
Care Services Coordinator/
Support Group Facilitator
Green Bay and Northeast Wisconsin

Shannan Morgan
Care Services Coordinator
Madison

Janet Gauger
Care Services Assistant

David Ferrie
Equipment Program Coordinator

Meg Posorske
Support Group Facilitators
Wisconsin Rapids

Connie Troyanek & Carolyn Herman
Support Group Facilitator
La Crosse

2019-20 MEETINGS OF THE BOARD OF DIRECTORS

*Thursday, March 19, 2020**

5:30-7:00 p.m.

*Thursday, May 14, 2020**

5:30-7:00 p.m.

*Thursday, July 9, 2020**

5:30-7:00 p.m.

*Thursday, September 9, 2020**

5:30-7:00 p.m.

Thursday, November 12, 2020

5:30-7:00 p.m.

Thursday, January 14, 2021

5:30-7:00 p.m.

Meetings generally are held at The Forum Conference Room
3333 North Mayfair Road
Wauwatosa, WI 53222

* Meetings held via Zoom