

CHIT CHAT

About Your Board of Directors

Your ALS of Michigan Board of Directors is a dedicated and hard-working group of people who, like you, are committed to the fight against ALS. Some Board members serve because a dear relative is now valiantly living, or has sadly lost their battle, with ALS. Others give their time and serve on the Board because they are pALS themselves.

We salute and thank Bryan Lee, whose father Fay had ALS and passed in February 2004, for serving as your ALS of Michigan President from 2000–2001, and as a Board member from 1999–2007. Thank you, Bryan, for all of your hard work and dedication in serving our pALS community!

Also recently resigned from the Board, pALS Joe Rothenberg was a driving force behind our Friends of Wine Tasting and Auction, which raised \$100,000 from 2003–2005. Joe's son, Noah, will be filling out the rest of his father's term. Noah is President of Disability Made Easy, LLC, a new company he founded after his father was diagnosed. We welcome Noah to our group, and gratefully thank Joe for all of his outstanding service!

Always Look for Our Logo

There may be confusion about many organizations asking for your support and donations these days. Rest assured, ALS of Michigan NEVER gives out your address or phone number to any other organization. Look for our ALS of Michigan logo and tagline – “Hope, Help, Here for You™” – to be sure you are supporting the premier group dedicated to helping pALS in Michigan, with the confidence of knowing that your contributions stay in Michigan.

Kids' Coloring Contest

ALS of Michigan is going to sponsor a coloring contest for kids! The theme is “Fun Things I Do With My pALS.” Look for more details in our next newsletter and get your kids coloring creatively. One lucky artist will have their award-winning picture printed on the T-shirts for our *Walk 'n Roll for ALS* in September.

Our Loan Closet “Wish List”

Right now, there are three items we wish we had more of to share through our Loan Closet. We really need manual wheelchairs, portable ramps and voice amplifiers. If you can donate any of these items, please call 800.882.5764. Thank you!

The ALS

Informer

Support Programs and Services for pALS and Their Families

Since our founding in 1978, ALS of Michigan has continued to develop and expand the types of support programs and services we provide to our ALS community. Here is a brief look at all of the benefits available to you through ALS of Michigan.

To take advantage of any of these programs and services, please visit our Web site at www.alsofmichigan.org, or call our office at 800.882.5764. We look forward to serving you!

Augmentative and Alternative Communication (AAC) Center

We provide the only AAC Center in Michigan showcasing some of the latest in speech equipment. pALS can receive a speech evaluation and recommendations for helpful equipment, in addition to ongoing support and training, from a qualified Speech-Language Pathologist. We also have a variety of devices available for loan.

Home Visits

Our professional therapists and social workers are available to meet with you in your home to discuss living with ALS, your needs and our agency's services.

Loan Closet

Our Loan Closet offers useful medical equipment to pALS free of charge – for as long as needed. Some of the items typically available include walkers, wheelchairs, bedside tables, communication devices and more. Our Loan Closet inventory changes every day as items are borrowed or returned, and new items are donated by patients, families or healthcare groups. We gratefully accept clean and usable merchandise to stock and share through the ALS of Michigan Loan Closet.

Respite Care Services

Caregivers have the overwhelming job of caring for a loved one 24/7. Our Respite Care program enables caregivers to take some much-needed time away for themselves — if only to take a nap or go out with friends. Made possible through ongoing generous donations from individuals and corporations, Respite Care services are provided by qualified home healthcare agencies. Our Respite Care program is free of charge and available to any family members caring for a loved one with ALS.

Support Groups

When you have questions about living with ALS, our monthly Support Groups offer important, helpful answers. In a caring and supportive environment, pALS and caregivers come together to discuss their feelings, and topics such as healthcare providers, community resources, respite care, family issues, durable medical equipment and more. Please visit our Web site or call for a list of current Support Group meeting dates and locations.

Workshops and Seminars

ALS of Michigan presents workshops and seminars about living with ALS, research and medical advances. Held throughout the year at a variety of locations throughout the state, these seminars are appropriate for pALS, caregivers, family and friends (children, too), as well as medical and healthcare professionals. Some of our most successful programs include: *Ask the Doctor*, *Managing the Diagnosis* and the *Caregiving With Compassion Conferences*.

The Mission of ALS of Michigan, Inc.

ALS of Michigan is dedicated to helping people with ALS (pALS), their families and caregivers live life as fully as possible. We also support research into the cause, treatment and cure of ALS, more commonly known as “Lou Gehrig's Disease.”

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21311 Civic Center Drive, Suite 200
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“Lou Gehrig's Disease”

Hope • Help • Here for You™



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“Lou Gehrig's Disease”

A Member Agency of
Community Health Charities

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Top 10 Reasons to Walk 'n Roll for ALS

- 10 You'll get some exercise in the fresh air.
- 9 It's our biggest, most important FUNdraiser of the year.
- 8 You can choose from six locations and four dates for one good cause.
- 7 You can win prizes based on how much money you raise.
- 6 Lou Gehrig would be proud of you.
- 5 Your circle of friends, family and coworkers will want to join and support you and your team.
- 4 Can't be at one of the Walks? Become a "Virtual Walker" and collect donations to make a difference.
- 3 Your team can choose a creative name and wear attention-getting apparel, including T-shirts and hats.
- 2 It's easy for you to sign up – see the enclosed Walk brochure or go to www.alsofmichigan.kintera.org.
And the Number One reason why you should Walk 'n Roll for ALS:
- 1 You have the power to help us raise \$300,000 to continue to provide support programs and services for our pALS community in Michigan.

Meet Lisa Bardach Speech-Language Pathologist



Lisa Bardach, MS, CCC-SLP, is a certified Speech-Language Pathologist with over 17 years of experience providing neurogenic rehabilitation to adult and pediatric clients. She is the Speech-Language Pathologist for ALS of Michigan, where she has developed and implemented a regional clinic to provide augmentative and alternative communication (AAC) services for pALS. The AAC clinic is located at ALS of Michigan headquarters in Southfield, and Lisa meets with pALS, by appointment, to evaluate and recommend AAC solutions for pALS' needs.

Lisa is the owner of Communicating Solutions, a private practice in Ann Arbor, specializing in evaluation and treatment for individuals requiring AAC. She also serves as a resource in the state of Michigan for funding issues and documentation in AAC.

Lisa is an adjunct faculty member of the University at Buffalo, where she has presented workshops in the area of alternative access to SGDs. She has authored multiple professional presentations and workshops on AAC on both the local and national levels, in addition to several publications.

Lisa has served as a member of the American Speech and Hearing Association's Health Care Economics Committee Ad Hoc Subcommittee on Medicare Reimbursement, and she is a member of the Medicare Implementation Team, a group of professionals formed under the auspices of the Rehabilitation Engineering Research Center on Communication Enhancement to acquire and facilitate Medicare funding of augmentative communication devices.

If you feel your pALS could benefit from a professional speech evaluation, please contact Lisa Bardach at 800.882.5764 or lisa@alsofmi.org to set up an appointment at ALS of Michigan's AAC center.

Help Raise Money for Patient Services

pALS and their families receive patient services and support as a result of all the fundraising activities we organize and sponsor throughout the year. From wine tastings and auctions to our annual Tiger baseball game and popular *Walk 'n Roll for ALS*, these FUNdraising events provide the needed financial backing to support ALS of Michigan patient services.

Hiller's Markets Cards

Now you can help raise thousands of dollars without spending a dime!

By signing up for a Hiller's Markets Scrip Card, you can help to ensure the continuation of programs and services for the ALS community. For every \$1 you load onto your grocery-shopping card, ALS of Michigan will receive 5% – and you get to spend the entire dollar shopping at any of the fine Hiller's Markets in our area. Activate and load your card for any amount up to \$1,000 at any Hiller's Markets location.

Cards are reusable and ALS of Michigan will continue to receive 5% of all amounts reloaded on your card. Everyone needs groceries. Now you, your family and friends can "shop for a cure!"

Hiller's Markets President Jim Hiller is a tremendous supporter of ALS patient services and research in Michigan. In fact, a new multidisciplinary clinic at the Detroit Medical Center is now the "Hiller ALS Center."

Sign up now!

Don't hesitate! Sign up for your Hiller's Markets cards now, or get more information by calling ALS of Michigan at 800.882.5764, ext. 225. Or visit www.alsofmichigan.org.

ALS Clinics in Michigan

There are many qualified neurologists throughout Michigan who treat pALS on a regular basis. In fact, Michigan is extremely fortunate to have some of the finest ALS physicians and treatment centers anywhere. These centers provide a multidisciplinary approach to caring for pALS, using the latest advancements in the treatment of ALS.

For information about the clinic nearest you, please call us at 800.882.5764.

ASK THE PROFESSIONALS

Q. Over the past few months, my pALS has been having lots of difficulty chewing and swallowing food. Recently, it was recommended that we look into using a PEG tube. What is a PEG tube and how will it benefit my loved one?

A. A PEG tube is a feeding tube that can be an important intervention for pALS who have developed swallowing difficulties (dysphagia), or for those who have lost a lot of weight. The benefit of a PEG feeding tube is best when it's placed before the patient has experienced too much respiratory muscle weakness, thereby lessening the surgical risk, and before the patient has lost too much weight. It's been documented that pALS who have less weight loss experience prolonged survival and improved quality of life.

A PEG tube is approximately 10 inches long. To place the tube, a large endoscope (instrument) is passed through the mouth and down into the stomach. The feeding tube is then threaded down and out through an opening in the abdominal wall. Some physicians use a simple method that doesn't involve an endoscope. One of the strongest advantages of this method is that usually no general anesthesia is needed, only heavy sedation. With a skilled physician, this procedure can be done quickly with few problems. A PEG feeding tube is most often placed as an outpatient procedure, meaning pALS can go home the same day the feeding tube is placed.

It's important that patients and caregivers feel knowledgeable and confident about how the feeding tube works before going home. Often, arrangements can be made for visits by home care nurses until you feel confident. Have your doctor show you a tube before he/she inserts it. Careful routine flushing with water is necessary to keep the tube from clogging.

pALS who get a feeding tube can still have oral intake (if they can safely swallow), and a patient can also stop feedings through the tube at any time if they desire. The PEG feeding tube can be a wonderful solution, not only for giving nutrition, but also for giving medications and hydration, especially for pALS with swallowing difficulties.

(Editor's Note: If you have a question about ALS, or need to know more about how to care for your pALS, ask us! We want to hear from you – and we can help you, too. Contact Simone Bradford, LMSW, patient services director, at 800.882.5764, or email simone@alsofmi.org.)

New Changes to Keep You Informed

ALS of Michigan is taking steps to keep you better informed about news and developments that will help pALS, caregivers and families.

In addition to all the latest news that can be accessed at our Web site (www.alsofmichigan.org) and our bi-annual newsletter, *The ALS Informer*, we now will be publishing a special "Patient Services Edition" of *The ALS Informer* four times a year. This is the first issue.

Using email and the Internet to communicate is quicker and less expensive, freeing up valuable resources for patient services. Please send us your email address, along with your preference for receiving the newsletters.

We want to be helpful to you, not intrusive. So please take a moment to tell us how much information you want to receive. Simply fill in your preferences below and mail the completed form to: ALS of Michigan; 21311 Civic Center Dr., Suite 200; Southfield, Michigan 48076.

- I want to receive **all** ALS of Michigan communications, including print and electronic versions of the newsletters.
- I **only** want to receive *The ALS Informer* twice a year.
- I **only** want to receive *The ALS Informer – Patient Services Edition* four times a year.
- I **only** want to receive electronic versions of the newsletters.

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The ALS Informer

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Our Mission

ALS of Michigan is dedicated to helping people with ALS (pALS), their families and caregivers live life as fully as possible. We also support research into the cause, treatment and cure of ALS, more commonly known as "Lou Gehrig's Disease."

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Medical information provided in The ALS Informer is offered to enlighten readers only, and should always be discussed with your primary physician before any personal action is taken.