



24359 Northwestern Hwy. • Suite 100 • Southfield, Michigan • 48075
phone 800.882.5764 • email alsofmi@alsofmi.org • website www.alsofmi.org

January 1, 2012

ALS of Michigan is pleased to be able to provide you with our ***ALS Patient and Caregiver Resource Manual***. We have done our very best to provide you with the most comprehensive set of local and national resources available in the ALS community.

Our mission is to help our pALS (person with ALS) and their families live life as fully as possible. To that end, we believe that this resource manual is an instrumental document for you to keep as a reference, and just one of the many ways that we strive to make living with ALS easier.

ALS of Michigan wants you to know that you are not alone in your fight against ALS, and that we are here to provide assistance to you, your loved ones, and your healthcare professionals. If you have any questions about the manual, local or national resources, or our programs or services please feel free to call or email us. We are here to help you and to provide support.

With warmest regards,

Sue Burstein-Kahn
Executive Director



Disclaimer/Copyright Notice

Information contained in the ALS of Michigan, Inc. Resource Manual is for informational and educational purposes only. ALS of Michigan (i) makes no express or implied warranties or representations of any kind regarding any of the information contained in the ALS of Michigan, Inc. Resource Manual, (ii) assumes no liability of any kind for the content of any information transmitted to or received by any individual/entity in connection with such individual/entity's use of the ALS of Michigan, Inc. Resource Manual, and (iii) does not endorse or recommend in any way any such information.

In consideration of your accessing the ALS of Michigan, Inc. Resource Manual, you agree that (i) under no circumstances shall ALS of Michigan, Inc. be liable for any damages whatsoever in connection with, arising out of or resulting from your use of the ALS of Michigan, Inc. Resource Manual or any information contained in the ALS of Michigan, Inc. Resource Manual and (ii) you will defend, indemnify, save and hold harmless ALS of Michigan, Inc. from and against all suits, claims, demands, causes of action, judgments, damages, losses, liabilities and expenses arising out of or resulting from your use of the ALS of Michigan, Inc. Resource Manual or any information contained therein.

Any hypertext link contained in the ALS of Michigan, Inc. Resource Manual is provided for convenience only. The ALS of Michigan, Inc. Resource Manual (i) possesses no control whatsoever over such links or any sites linked thereby, (ii) makes no express or implied warranties, representations or endorsements of any kind regarding any linked site, and (iii) assumes no liability of any kind for any information contained in any linked site.

ALS of Michigan, Inc. may modify this Disclaimer, or any other information contained in the ALS of Michigan, Inc. Resource Manual, at any time without notice, and it is your responsibility to apprise yourself of the most current disclaimer/information.

No part of the ALS of Michigan, Inc. Resource Manual should be reproduced, copied, or transmitted in any form without written permission from ALS of Michigan, Inc.



Table of Contents

<u>About ALS of Michigan</u>	5
ALS of Michigan Programs and Services	6
Making Financial Donations	8
Equipment Donations.....	9
Employer Programs	9
Volunteer Opportunities	10
<u>ALS Information and Research</u>	12
Common Questions about ALS.....	13
Recommended Steps after Diagnosis	16
ALS Functional Rating Scale (ALSFRS).....	17
Clinical Trials	20
Research Internet Sites	28
<u>ALS Treatment</u>	29
ALS Medical Team	30
Medication.....	33
Managing Neck Muscle Weakness	34
Range of Motion Exercises	40
Managing Saliva.....	49
Swallowing Problems (Dysphagia)	52
Strategies for Safer Swallowing	55
About Feeding Tubes	58
Breathing Problems/Ventilation	66



<u>Adaptive Equipment</u>	72
Adaptive Equipment Overview	73
Mobility	74
Transfers	78
Environment	80
Eating	82
Hygiene	84
Sleeping	87
Swelling (Edema)	88
Augmentative and Alternative Communication	89
Breathing	91
<u>Legal and Financial</u>	93
Insurance Questions	94
Elder Law: The Basics	96
Advance Directives	100
Medicare Basics	103
Medicaid	107
Veterans	109
Social Security Disability	110
Employment	115
MI Child of Michigan	117
<u>Support Services</u>	118
Support Groups	119
Online Support	122
Loaner and Used Equipment	123
Caregiver Information	123
Family Caregiving-Why Respite?	124
Respite Care Assistance Program	126
MI Choice Waiver Program	127
Hospice Information	128
Grief/Bereavement	130
<u>Local Resources</u>	131
Local Michigan Resources	132
Local Government and Non-profit Organizations	138
Who Was Lou Gehrig?	146



24359 Northwestern Hwy. • Suite 100 • Southfield, Michigan • 48075
phone 800.882.5764 • *email* alsofmi@alsofmi.org • *website* www.alsofmi.org

About ALS of Michigan

ALS of Michigan Programs and Services - 6

Making Financial Donations – 8

Equipment Donations - 9

Employer Programs - 9

Volunteer Opportunities - 10



ALS of Michigan Programs and Services

Workshops & Seminars

ALS of Michigan offers workshops and seminars for PALS (persons with ALS), caregivers and health professionals. These seminars include our ALS Agency and Caregiver conference that is offered several times and held in various locations in order to serve the ALS community and health professionals. We offer several seminars presented by neurologists and health care professionals who specialize in the field of ALS. Our research conference is held annually to discuss local, national and international research. In addition, many workshops are held on a variety of additional topics such as augmentative communication, children who have a loved one with ALS, newly diagnosed, respiratory symptom management and many other topics that are of interest to PALS and their loved ones.

Augmentative Communication

ALS of Michigan offers speech evaluations to PALS by a speech pathologist that specializes in communication issues for PALS. Speech evaluations are recommended as soon as a person is aware of changes in their speech. An evaluation is completed at ALS of Michigan or at home. Recommendations are made on what form of augmentative communication would be most appropriate. An augmentative communication loan closet is also available to PALS.

Equipment Loan Closet

A loan closet of durable medical equipment is available free of charge to PALS. Most items in the closet have been donated by patients and families and include wheelchairs, lifts, and walkers, to name a few. If you need an item, please contact our office with your request, and we will do our best to fill it from the items available. We can also help individuals obtain equipment that is not available through our loan closet by working with other local agencies that have loan closets.

Support Groups

PALS and their caregivers (CALS) often have a multitude of questions about living with ALS. Support groups offer an opportunity to discuss topics such as health care providers, community resources, respite care, family issues, durable medical equipment, and to talk with other families living with ALS. For a list of our current support groups, please visit our website or contact our office.

Information, Referrals, & Resource Guides

ALS of Michigan has a variety of resource guides available to help you find community and national services. Additionally, our trained staff is available to answer your questions or refer you to an appropriate source.



24359 Northwestern Hwy. • Suite 100 • Southfield, Michigan • 48075
phone 800.882.5764 • *email* alsofmi@alsofmi.org • *website* www.alsofmi.org

Respite Care Services

Caregivers have the overwhelming job of caring for a loved one 24-hours-a-day/seven-days-a-week. Our respite care program enables caregivers to take some time away for themselves. For program information please contact our office.

Home Visits

Our professional staff is available to meet with you at your home to discuss living with ALS, your needs, and to coordinate services. We recommend meeting with a patient services staff person soon after diagnosis. To schedule an appointment to meet with one of our professionals, please contact us to schedule a home visit.

Research

At ALS of Michigan we support research focused on the cause and the cure for ALS. ALS of Michigan, Inc. supports research through our own grant making initiatives.

ALS Neurologists

There are many qualified neurologists throughout Michigan that treat our PALS. In addition, Michigan has many neurologists and clinics that specialize in ALS. Some of these neurologists provide a multidisciplinary approach to caring for pALS and are up-to-date on the latest advancements in the treatment of ALS.

Volunteers

The general public is one of the greatest allies in the fight against ALS. Through our public awareness and education activities we reach out to our community to join in our battle. By volunteering for any of our programs or learning more about ALS, you can help spread our message.



24359 Northwestern Hwy. • Suite 100 • Southfield, Michigan • 48075
phone 800.882.5764 • *email* alsofmi@alsofmi.org • *website* www.alsofmi.org

Financial Donations

ALS of Michigan, Inc. receives no government or insurance funding and relies totally on the generosity of individuals, corporations, trusts and foundations for its support. ALS of Michigan, Inc. is a registered nonprofit organization. As a qualified 501(c)(3) tax exempt organization, all contributions to ALS of Michigan, Inc. are tax deductible.

Remembrance Program

A donation to the Remembrance Program allows you to support the programs and services provided by ALS of Michigan. while, at the same time, remember a special family member, friend, colleague, or special occasion. When you contribute through the ALS of Michigan, Inc. In Memory Program, a memorial card is sent to the family of the deceased, acknowledging your gift. A contribution through the ALS of Michigan's In Honor Program allows you to make a gift in recognition of important occasions such as weddings, anniversaries, birthdays and graduations. A card is sent to the person(s) you wish to honor acknowledging the occasion and your gift. Under all circumstances, the amount of the gift remains confidential.

When making either an *In Memory or In Honor gift*, we need to know your name and address, the name of the person being memorialized or honored, and the name and address of the family to whom the card will be sent.

Call us to make an In Memory or In Honor gift or to learn more about the ALS of Michigan, Inc. Remembrance Program.

ALS of Michigan, Inc.

24359 Northwestern Hwy. Suite 100
Southfield, MI 48075

To donate online visit: <http://www.alsofmichigan.org/>



Medical and Assistive Technology Equipment Donations

ALS of Michigan offers a variety of used medical and assistive technology equipment on a loaner basis. If you have something that you no longer need please contact ALS of Michigan, Inc. to arrange a donation. We accept items that are in clean and working condition. An acknowledgment letter will be provided confirming your gift. Your donation will not only provide you with a tax deduction but will help provide needed equipment to someone who may be able to use it. Examples of equipment which is needed are as follows:

Bath Benches	Shower Wheelchairs	Hoyer Lifts
Manual Wheelchairs	Power Wheelchairs	Recliner Lift Chairs
Walkers	Nutritional Supplements	Augmentative equipment
Scooters	Bed Tables	Raised Toilet Seats
Transport Chairs	Voice Amplifiers	Wheelchair Cushions
Transfer Boards	Portable Ramps	Commodes

Employer Programs

Employer Matching Gift Programs

If your employer has a Matching Gifts Program for charitable organizations, your contributions to ALS of Michigan, Inc. can grow! By simply checking with your Personnel or Employee Benefits department, ALS of Michigan, Inc. may be an eligible organization under your company's policy. Several donors have utilized their employer's Matching Gifts Program, allowing their personal gift to double.

Charitable Employee Campaign Programs

Support ALS of Michigan, Inc. the easy way...through workplace giving campaigns. Check with your employers Personnel or Employee Benefits department to see if your company has a Charitable Employee Campaigns program. These programs give donors an ongoing opportunity to give all year long in a no hassle process that allows you to automatically have a donation deducted from your paycheck. All the paperwork is done by the campaign; no checks to write...no envelopes to address. All you have to do is fill out a campaign pledge card with a designated amount of money to be deducted per pay period and name a specific charity you want to donate to.



24359 Northwestern Hwy. • Suite 100 • Southfield, Michigan • 48075
phone 800.882.5764 • *email* alsofmi@alsofmi.org • *website* www.alsofmi.org

Volunteer Opportunities

ALS of Michigan relies heavily on volunteers to respond to the critical needs of people with ALS and to give support to the family and friends who care for ALS patients. This small but dedicated group has been of immeasurable value to ALS patients, caregivers, families and friends. With the help of additional volunteers, we can greatly increase the number of ALS patients we serve. Any amount of time that you can give in the following areas will make such a difference in the life of an ALS patient!

Administrative Support

Help with mailings, answering the phones, talking with volunteers, families, and patients. Provide much-needed support to the on-going operations of ALS of Michigan, Inc. If you are skillful in talking to people, recording information, and have good attention to detail, then this volunteer work is for you!

Event Planning

Join the fun with others to create awareness and raise funds for ALS through events such as the ALS Walk and Roll, Lou Gehrig Day at Comerica Park, Bootlegger's Bash, awards dinners, and much more!

Create Your Own Event!

Whether it is a “**jean day at work**” or “**spaghetti dinner**”. Our families and friends put on their own events to support the efforts of ALS of Michigan. Of these events some support their walk teams and some go directly to supporting programs and services for our ALS families. For assistance in creating your event call 800.882.5764.

Advocacy We need our PALS and caregivers to tell their story. We need our legislators to be educated about ALS and how it impacts an individual and their family. It's so very important for us to get the word out about ALS and how many people in Michigan are living with ALS. Please contact ALS of Michigan if you would like to help with advocating for our PALS and their caregivers.