January 18, 2009

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.

ALS of Michigan relies on the generosity of our donors and supporters. We are fully funded by private donations and receive no governmental or insurance funding or payments. As a qualified 501(c) 3 - tax exempt non profit organization – all contributions and equipment donations are tax-deductible to the fullest extent of the law.

With warmest regards,

Sue Burstein-Kahn
Executive Director
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Table of Contents

About ALS of Michigan .......................................................... 5
ALS of Michigan Programs and Services ............................... 6
ALS of Michigan, Inc. Staff Members ................................. 8
Making Financial Donations .............................................. 9
Employer Programs ........................................................... 10
Volunteer Opportunities .................................................... 11
ALS Advocacy ................................................................. 12

ALS Information and Statistics ......................................... 13
Common Questions about ALS .......................................... 14
Who was Lou Gehrig? ...................................................... 17
Recommended Steps after Diagnosis ............................... 19

ALS Research .................................................................... 20
ALS Functional Rating Scale (ALSFRS) .............................. 21
Clinical Trials .................................................................. 24
Research Internet Sites .................................................... 31

ALS Treatment ................................................................. 32
Description of ALS Medical Team Specialists .................... 33
Drugs and Supplements .................................................... 36
Managing Depression in ALS ......................................... 38
Muscle Spasms ................................................................. 40
Constipation .................................................................. 43
Managing Neck Muscle Weakness ................................... 46
Range of Motion Exercises .............................................. 52
Managing Saliva ............................................................... 61
Swallowing Problems (Dysphagia) ..................................... 64
Strategies for Safer Swallowing ....................................... 67
About Feeding Tubes ...................................................... 70
BiPap/Ventilation ............................................................ 78
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adaptive Equipment</td>
<td>88</td>
</tr>
<tr>
<td>Adaptive Equipment Overview</td>
<td>89</td>
</tr>
<tr>
<td>Mobility</td>
<td>90</td>
</tr>
<tr>
<td>Transfers</td>
<td>95</td>
</tr>
<tr>
<td>Environment</td>
<td>97</td>
</tr>
<tr>
<td>Eating</td>
<td>99</td>
</tr>
<tr>
<td>Hygiene</td>
<td>101</td>
</tr>
<tr>
<td>Sleeping</td>
<td>104</td>
</tr>
<tr>
<td>Swelling (Edema)</td>
<td>105</td>
</tr>
<tr>
<td>Augmentative and Alternative Communication</td>
<td>106</td>
</tr>
<tr>
<td>Breathing</td>
<td>108</td>
</tr>
<tr>
<td>Legal and Financial</td>
<td>110</td>
</tr>
<tr>
<td>Insurance Questions</td>
<td>111</td>
</tr>
<tr>
<td>Insurance Problems</td>
<td>113</td>
</tr>
<tr>
<td>Elder Law: The Basics</td>
<td>118</td>
</tr>
<tr>
<td>Advance Directives</td>
<td>122</td>
</tr>
<tr>
<td>Medicare Basics</td>
<td>125</td>
</tr>
<tr>
<td>Medicaid</td>
<td>129</td>
</tr>
<tr>
<td>Social Security Disability</td>
<td>132</td>
</tr>
<tr>
<td>Employment</td>
<td>138</td>
</tr>
<tr>
<td>MI Child of Michigan</td>
<td>140</td>
</tr>
<tr>
<td>Support Services</td>
<td>141</td>
</tr>
<tr>
<td>Support Groups</td>
<td>142</td>
</tr>
<tr>
<td>Online Support</td>
<td>145</td>
</tr>
<tr>
<td>Loaner and Used Equipment</td>
<td>146</td>
</tr>
<tr>
<td>Recommended Books and Videos</td>
<td>147</td>
</tr>
<tr>
<td>Caregiver Information</td>
<td>155</td>
</tr>
<tr>
<td>Family Caregiving—Why Respite?</td>
<td>157</td>
</tr>
<tr>
<td>Respite Care Assistance Program</td>
<td>159</td>
</tr>
<tr>
<td>MI Choice Waiver Program</td>
<td>161</td>
</tr>
<tr>
<td>Hospice Information</td>
<td>162</td>
</tr>
<tr>
<td>Grief/Bereavement</td>
<td>164</td>
</tr>
<tr>
<td>Local Resources</td>
<td>165</td>
</tr>
<tr>
<td>Local Michigan Resources</td>
<td>166</td>
</tr>
<tr>
<td>Local Government and Non-profit Organizations</td>
<td>173</td>
</tr>
<tr>
<td>ALS Organizations</td>
<td>180</td>
</tr>
<tr>
<td>ALS Internet Websites</td>
<td>182</td>
</tr>
</tbody>
</table>
About ALS of Michigan

ALS of Michigan Programs and Services ....................... 6
ALS of Michigan Staff Members .............................. 8
Making Financial Donations ................................ 9
Employer Programs ............................................ 10
Volunteer Opportunities ..................................... 11
ALS Advocacy .................................................. 12
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 Respite Conference** that is offered several times and held in various locations in order to serve the ALS community and health professionals. The **Ask the Doctor Conference** and **Managing the Diagnosis** are held annually and are presented by neurologists and health care professionals who specialize in the field of ALS. The **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, caregivers, and their families and friends. We encourage all health professionals, PALS and their family to attend any of these conferences.

Augmentative Communication Room
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 sometimes at home. Recommendations are made on what form of augmentative communication would be most appropriate. Insurance coverage is taken into consideration and an augmentative 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.

Peer Counseling
For those people who cannot attend support group meetings or prefer talking one-on-one, we have individuals available to assist. The volunteers have had experience with ALS, and are available to lend a friendly ear.
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. Also available is *The ALS informer*, our news magazine, which offers information and education of interest to PALS, their families, friends and caregivers.

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 more information 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 local research through our own grant making initiatives.

ALS Neurologists

There are many qualified neurologists throughout Michigan that treat PALS on a regular basis. 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.
## ALS of Michigan, Inc. Staff Members

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
</tr>
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<tbody>
<tr>
<td>Susan Burstein Kahn</td>
<td>Executive Director</td>
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<td>Joanne Berry</td>
<td>Director of Development</td>
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<td>Simone Bradford, LMSW</td>
<td>Director of Patient Services</td>
</tr>
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<td>Judi Fortuna</td>
<td>Patient Services Coordinator</td>
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<tr>
<td>Stephanie Kline, LLMSW</td>
<td>Patient Services Coordinator</td>
</tr>
<tr>
<td>Lisa Bardach, MS CCC-SLP</td>
<td>Augmentative Communication Specialist</td>
</tr>
</tbody>
</table>
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 to the fullest extent of the law. Tax-deductible donations can be made by sending a check, made payable to ALS of Michigan, Inc., to the following address:

ALS of Michigan, Inc.
24359 Northwestern Hwy. Suite 100
Southfield, MI  48075

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
(800) 882-5764 or (248) 354-6100
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. Please consider using this added benefit to assist the ALS of Michigan, Inc. to continue its important work.

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.

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
- Manual Wheelchairs
- Walkers
- Scooters
- Transport Chairs
- Transfer Boards
- Shower Wheelchairs
- Power Wheelchairs
- Nutritional Supplements
- Bed Tables
- Voice Amplifiers
- Portable Ramps
- Hoyer Lifts
- Recliner Lift Chairs
- Augmentative equipment
- Raised Toilet Seats
- Wheelchair Cushions
- Commodes
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. But we would like to do much more! 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! Please think about your available time, your interests, and your skills. ALS of Michigan, Inc. is ready to help you help others!

**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 any of our ALS Walk and Roll’s throughout the state, Lou Gehrig Day at Comerica Park, Bootlegger’s Bash, Wine Auction, and awards dinners.

**Public Awareness**

Help to educate the public about ALS through flyers, newsletters, promotional materials, Public Service Announcements, presentations, health fairs, volunteer recruitment, and much more! Volunteers who are creative and enthusiastic about making a difference in the lives of others enjoy this kind of assistance.

**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. Some support their Walk teams and some directly support programs and services for our ALS families. For assistance in creating your event call 800.882.5764.

Call ALS of Michigan to find out more on how you can help!
ADVOCACY

BECOME AN ADVOCATE! 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. This could be at the state level or by attending Advocacy Day in Washington D.C. We are looking for the ALS community to meet with our state representatives and by writing letters on behalf of our PALS. Call ALS of Michigan, Inc. for more information on how to become an advocate.