

CHIT CHAT

Welcome!

We welcome Stephanie Kline, BS, our new Coordinator of Patient Services. Stephanie holds a Bachelor of Science in Social Work from Rochester College and is currently pursuing her Master's in Social Work at Wayne State University. Stephanie shares life with her husband Craig, who is a surgery resident at Detroit Medical Center, and their new puppy, Radar.

Right @ Home

Many local agencies are part of national organizations, and are required to send a portion of their revenues outside of Michigan to support their national organization's overhead. ALS of Michigan is a LOCAL, independent organization that uses ALL donations to help our pALS right here at home in Michigan. Always look for the teal-green ALS of Michigan logo and our tagline – Hope, Help, Here for You™ – to be sure you are supporting the premier charity organization dedicated to helping pALS right here at home in Michigan.

Thank You!

We wish all the best to Brian Roth, who recently resigned from our Board of Directors. Brian's father, Sanford Roth, was one of our pALS, and Brian provided many years of service to ALS of Michigan, for which we are extremely grateful. Thank you, Brian!

Home Healthcare Agency

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- 11 What are the agency's financial procedures? Does it provide written statements that explain all the costs and payment options?
- 12 What procedures are in place to handle emergencies? Are the agency's caregivers available 24/7?
- 13 Does the agency have an infectious disease control policy in place?
- 14 How does the provider ensure patient confidentiality?
- 15 Has the agency treated cases similar to yours and your loved one's?
- 16 If you are unhappy with the caregiver they provide, will the agency make a sincere effort to find a more appropriate match?

It's all about relationships...

The home healthcare business is really all about relationships. Asking questions will help you better understand the home healthcare agencies' services and the types of people who will be providing them for you.

Also, a good home healthcare company should ask you a lot of questions about your loved one's medical, physical and mental status – this means the agency is thorough, and chances are the caregiver match they provide will be better.

If you are interested in home healthcare services provided through ALS of Michigan, you will need to complete a Patient Application form and secure a Physician Statement. Please contact our Coordinator of Patient Services Judi Fortuna at 800.882.5764, ext. 224, or email Judi@alsofmichigan.org.

The
ALS

Fall 2007

Informer

Update: ALS Registry Passes House

The U.S. House of Representatives recently passed the ALS Registry Act and a companion bill is now up for vote in the Senate. If approved, the ALS Registry will provide centralized data and vital information that researchers can use as they work to find viable treatments and, eventually, a cure for ALS.

Please contact Senator Carl Levin and urge him to sign on as a co-sponsor of Senate bill S. 1382.

Tell him why the ALS Registry is important to you and your family, and the impact that ALS has had on your lives. Let's make the ALS Registry a reality for our pALS!

How to Choose a Home Healthcare Agency

It's a proven fact: home healthcare improves quality of life for pALS. It keeps families together, preserves independence and postpones or prevents a move to a healthcare facility. Home healthcare provides freedom for the patient – and the caregiver.

But, how do you know when it's time to get home healthcare? And how do you go about finding the right agency to assist you and your loved one?

ALS of Michigan coordinates home healthcare services for our pALS community. Here are some things we suggest you consider when considering home healthcare.

What is home healthcare?

Home healthcare encompasses a wide range of health and social services that are delivered at home to people who need medical, nursing, social or therapeutic treatments and/or assistance with the essential activities of daily living. It is recommended for people who:

- need assistance to live independently due to illness or disability
- want to spend their remaining time in dignity and in the comfort of their own home

Who provides home healthcare?

Home healthcare services generally are provided by three main groups: home care agencies, home care aide organizations and hospices. Home healthcare typically requires a team effort, depending on your needs. A specific plan of treatment should be designed by your physician, in cooperation with the people who will provide the care, including:

- physicians
- social workers
- registered nurses (RNs) or licensed vocational nurses (LVNs)
- therapy specialists (physical, occupational and speech)
- dietitians
- pharmacists
- home care aides
- chore workers, companions, family members and/or volunteers

For medical procedures, a nurse is a necessity. However, a professional caregiver can perform many non-medical tasks, such as hands-on personal care, cooking, light housekeeping, shopping or transportation. The cost of a non-medical caregiver is much lower than that of a nurse.

Who pays for home healthcare services?

Private insurance programs typically cover services for short-term needs, but benefits for long-term services vary from plan to plan. Also, ALS of Michigan will pay agencies up to \$15 an hour to provide up to 24 hours a month of home healthcare services for our pALS. Public third-party payors may include Medicare, Medicaid or the Social Services Block Grant programs.

Home healthcare can also be paid for directly by the patient and his or her family. Prior to providing services, the best agencies will screen your insurance plan and confirm your level of coverage with you.

How do I find home healthcare services?

ALS of Michigan will help you. You can also ask your doctor for a referral or contact Michigan's departments of health and social services to get a list of their licensed agencies. Home care agencies are also listed in the Yellow Pages under "home care" or "home healthcare."

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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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Save the Date!

NOVEMBER 2007

Annual ALS Recognition Event

Tuesday, Nov. 27
6:30 p.m.

Shield's Restaurant, Southfield

DECEMBER 2007

Jackson & Lansing Area Walk Recognition Dinner

Tuesday, Dec. 4
6:30 p.m.

Marinos Pizza, Jackson

FEBRUARY 2008

The Bootleggers' Bash - A Roaring Good Time!

Saturday, Feb. 23
7:00 p.m.

American Polish Cultural Center, Troy

MARCH 2008

Ann Arbor Walk 'n Roll for ALS

Presented by Phi Delta Theta
Details to be announced

JUNE 2008

3rd Annual Lou Gehrig Day at Comerica Park

Saturday, June 28
Detroit Tigers vs. Colorado Rockies
Comerica Park, Detroit

SEPTEMBER 2008

Metro Detroit Walk 'n Roll for ALS

Sunday, Sept. 14
Kensington Metropark, Milford
Stony Creek Metropark, Shelby Twp.

Jackson Walk 'n Roll for ALS

Saturday, Sept. 20
Cascade Falls Park, Jackson

Lansing Walk 'n Roll for ALS

Saturday, Sept. 27
Hawk Island Park, Lansing

Downriver Walk 'n Roll for ALS

Sunday, Sept. 28
Lake Erie Metropark, Brownstown

Meet Simone Bradford

Director of Patient Services



Simone Bradford, LMSW, is Director of Patient Services for ALS of Michigan. She has worked in the human services field for over 10 years and we are lucky that six of those years have been with us.

Perhaps Simone's most important contribution is that she works directly with our patients and families to assist them in their daily needs of living with ALS. She helps pALS apply for disability and works with their health insurance carriers as needed. She also helps patients obtain the necessary medical equipment and connects them with other local resources to meet their needs.

Another way Simone helps our pALS community is by coordinating our local Support Group Meetings and working with the Support Group leaders. These meetings are held every month in a variety of convenient locations throughout southeastern Michigan.

Simone has been providing social work services at the Harry J. Hoenselaar ALS Clinic at Henry Ford Hospital for the past five years where she works with Dr. Daniel Newman and his staff.

She received her Bachelor's degree from Oakland University and her Master's of Social Work degree from Wayne State University. Simone lives in Commerce Township with her husband Chris and son Christopher.

If you feel you or your pALS could benefit from any of the professional services Simone Bradford, LMSW, provides, please contact her at 800.882.5764, ext. 223, or email Simone@alsofmichigan.org to set up an appointment.

ASK THE PROFESSIONALS

Q. My husband was recently diagnosed with ALS and I've been looking into different types of resources that might help us treat and manage the disease in the months ahead. I've learned that there are several "multidisciplinary clinics" in the Metro Detroit area. What are these clinics all about, and how might they be able to help us?

A. Michigan is extremely fortunate to have some of the finest ALS physicians and treatment centers anywhere. Some of these centers provide a "multidisciplinary approach" to caring for pALS, using the latest advancements in the treatment of ALS.

Recent research published in the *Journal of Neurology, Neurosurgery and Psychiatry* shows that pALS who received their care at a multidisciplinary clinic had a better prognosis than patients attending a general neurology clinic. The data suggest that active and aggressive management enhances survival, particularly among pALS with bulbar dysfunction.

The multidisciplinary clinics in our area are associated with major hospitals, so if your loved one needs further testing, it can be accomplished within the system. Also, because these clinics take a holistic approach in treating patients, it means they will help you with more than just prescriptions.

Two multidisciplinary clinics in our area are:

- The new Hiller ALS Center at Wayne State University School of Medicine, 313.745.4275
- The Harry J. Hoenselaar ALS Clinic at Henry Ford Hospital, 313.916.2835

If you'd like more information about the clinic nearest you, please call ALS of Michigan at 800.882.5764.

(Editor's Note: If you have a question about ALS, or need to know more about how to care for your pALS, ask us! Contact Simone Bradford, LMSW, patient services director, at 800.882.5764, ext. 223, or email simone@alsofmichigan.org.)

BY THE NUMBERS

\$750,000

Direct payments ALS of Michigan has made to home healthcare providers – to help care for our pALS and allow primary caregivers some time to themselves – since we started our Respite Care program in 2000.

Over 1,000

Patients, family members, friends and healthcare professionals we provide services to every year.

400

Support groups, workshops and conferences ALS of Michigan has presented to help our local pALS community throughout the State of Michigan since 2000.

287

Durable medical equipment items available at any one time from our Loan Closet. These items are free for you to use, and include: manual and electric wheelchairs, scooters, lifts, ramps, walkers, commodes, speech-generating devices and much more. Currently, 150 items are being used by our pALS and their families.

100

Evaluations and trainings for speech/communication devices that have been conducted at our AAC Center in Southfield and around Michigan to help our pALS stay connected with family, friends and their healthcare providers.

7

Walk 'n Roll for ALS events held throughout Michigan this year alone! Thanks to everyone who helped make our most important fundraising events a huge success! Since 2001, \$1,241,000 has been raised in Walks to support our pALS. Watch the next issue of *The ALS Informer* for complete Walk updates and 2007 Walk Team totals.

1

All it takes to make a difference in the lives of our pALS by donating or volunteering.

Home Healthcare Agency *continued from page 1*

How do I select the right agency?

ALS of Michigan maintains a list of home healthcare agencies and we can give you recommendations. If you are looking into home healthcare on your own, here are some questions to ask that will help you determine which agency is best for you and your loved one.

- 1 How long has the agency been serving the community?
- 2 Is the agency certified by Medicare?
- 3 Is the agency licensed or unlicensed?
- 4 Is the agency accredited? (Accreditation is a voluntary process that signifies whether the agency has met national industry standards.)
- 5 Does the agency provide literature explaining its services, eligibility requirements, fees and funding sources?
- 6 How does the agency select and train its employees?
- 7 Are the agency's nurses or therapists required to evaluate the patient's home care needs?
- 8 Is the patient's course of treatment documented, detailing the specific tasks to be carried out by each professional caregiver? Is a copy of this plan given to the patient and family members, and updated as changes occur?
- 9 Does the agency assign supervisors to oversee the quality of care patients are receiving in their homes? How are problems followed up and resolved?
- 10 Does the agency take time to educate family members on the type of care being provided?

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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.