

Offering **HOPE**
to those afflicted with ALS
and **HELP** to their families ... **ALSSO**



The ALS Service Organization provides this guide. It was originally put together by a Spokane PALS (Patient with ALS) and has been recently revised.

What is ALS?

ALS is defined as amyotrophic lateral sclerosis, which is commonly referred to as “Lou Gehrig’s Disease”. It is a neuromuscular disease that attacks nerve cells and pathways in the brain and spinal cord. There is no known cause or cure.

Where do I find more information and help in NE WA and N Idaho?

ALSSO - ALS SERVICE ORGANIZATION
ALS ASSOCIATION – Spokane & Inland Empire Region
MDA-ALS DIVISION (Multiple Dystrophy Assoc.)
MATT’S PLACE FOUNDATION
CATHOLIC CHARITIES OF SPOKANE
DISABLED AMERICAN VETS (DAV) & PVA
HOSPICE OF SPOKANE PALLIATIVE CARE

ALSSO – ALS SERVICE ORGANIZATION

A group of volunteers – relatives and friends of people who have had ALS plus current patients and caregivers; mission is to befriend patients and caregivers, and to share resources and ideas through our monthly meetings. We can provide PALS (People with ALS) and their caregivers and loved ones (CALs) with contact information, ideas, resources, information and small amounts of funding

if possible and appropriate for needs specific to each situation. We have wheelchair platform lifts available on loan; please ask if you think you could use one.

Contact: Debbie King
(509) 467-8761
E-mail: info@alssso.org

Website: www.alssso.org.

Monthly meetings: 1st Wed. of the month, usually at the Millwood Community Presbyterian Church, 3223 N. Marguerite Rd., Spokane at 5:30 p.m. (Please call to confirm.)

ALS ASSOCIATION – Spokane and Greater Inland Empire Region

Patient Care Coordinator (PCC) makes home visits to bring resources and equipment. The Association has grant money available for speech equipment and money available for respite care (Caregiver Respite Grant). Sponsor and put on events to educate and to increase awareness about ALS, and to do ALS specific research. They are connected to the Virginia Mason ALS Clinic in Seattle and with Dr. Carlson/Rockwood's ALS Clinic in Spokane. They have a large Loan Locker.

Contact: Nathan Ziegler, Care Services Coordinator
Nathan@alsa-ec.org
(509)725-1002

Good websites with information about ALS and many good links - www.alsa.org and www.alsa-ec.org.

Monthly Support Group Meeting: 2nd Tuesday of each month at Heart of the City Church, 772 W. Kathleen Ave., Coeur d'Alene, ID in the Vertical Room, 5:30 p.m.

***MDA-ALS DIVISION (MUSCULAR DYSTROPHY ASSN.)**

Contracts with Vivian Moise, MD, through St. Luke's Rehabilitation Center in Spokane, WA; with Donald Dicken, MD, through Physicians Health Center in Pasco, WA; and with Sharon Genung, MD and James Reggin, MD, through Shriners' Hospital for Children in Spokane. MDA provides office consults and other medical services for registered patients at these clinics with no cost to the patient. MDA also provides equipment loans and \$500 grants toward the repair or modification of equipment each calendar year for registered MDA clients. (Not for new equipment purchase or vehicle modifications.)

*Contact: Brooke Lively, Health Care Services Coordinator
blively@mdausa.org
(509) 325 3747 or 800-577-6716

Very good information on the website at www.mda.org.

Outreach Groups are held the third Wednesday of each month @ 6:00 p.m. at St. Luke's Rehab, Room 200. Please note that these meetings are open to all the folks with MDA diseases, not just ALS.

DISABLED AMERICAN VETS (DAV) or PARALYZED VETERANS OF AMERICA

If you have ever served in any branch of the military, including the Coast Guard, contact the Disabled American Vets (DAV) or PVA. There is a very large package of benefits you will qualify for as the diagnosis of ALS gives you an automatic service-related disability.

The DAV contact is John Erp, (509) 434 7746. The PALS who are connected to him speak highly of him.

The PVA contact is Duane Hughes @ (206)220-6175. He is located in Seattle, but the PALS who have used him speak highly of him and of his ability to help and speed things up.

MATT'S PLACE FOUNDATION

Started by local veteran with ALS, the mission is to help local PALS acquire ramps and to help fund remodeling projects. They are currently in the process of building an ALS House in North Idaho. They have been known to help fund vans and other equipment, but their focus now is on ramps and remodeling funds. You will find application for funds at their website under the Contact Us tab. That address is www.mattsplacefoundation.com.

Contact: Matt or Theresa Wild
matt@mattsplacefoundation.com
(509)995-9103

CATHOLIC CHARITIES OF SPOKANE

CC of Spokane is the administrator of Team Gleason funds for our region's PALS. They will help with remodeling, funding vans, domestic expenses, temporary caregiving funding, etc. on a case by case basis. They will want to know what you and your family AND other organizations are going to be contributing towards the need, so you will be asked to coordinate your request with ALSSO and possibly with Matt's Place (and VA) as well.

Contact: Tom Carroll
tcarroll@ccspokane.org
(509) 459-6175

HOSPICE OF SPOKANE PALLIATIVE CARE

Spokane Palliative Care is a service of Hospice of Spokane which provides PRE-Hospice level services which would be appropriate for anyone living with ALS who is not on a ventilator or who is receiving therapies or treatments which are considered aggressive. A person does not have to have a prognosis of six months or less to be in this program. The services include a nurse practitioner, a doctor, a social worker and a chaplain. It is intended to help coordinate resources, manage symptoms and provide emotional support.

**Contact: Trisha Fitzhugh, Palliative Care Coordinator
(509) 458-0359
tfitzhugh@spokanepalliativecare.org
www.spokanepalliativecare.org**

NOTES:

— **Both MDA & ALSA have very good written and DVD/CD information available, along with very good websites.**

Many Spokane area patients work with Dr. Scott Carlson and his ALS Clinic AND/OR with Dr. Vivian Moise at MDA.

There is also good ALS help at the University of Washington Neurology Clinic in Seattle with Dr. Weiss and with their pulmonologist, Dr. Josh Benditt.

If you would like names of other specialists and therapists whom and companies which our group members recommend, please ask.