



Research Highlights

Dignity and Distress – A research study

Dr. Wendy Johnston, ALS Clinic Director at the University of Alberta and Principle Investigator, Dr. Harvey Max Chochinov, announced a new research study. The purpose of this study is to investigate the areas influencing a person's sense of dignity – both a person living with ALS and the major caregiver or family member. The results will incorporate valuable information on maintaining dignity of persons toward and at the end of life. For more information, please contact Shelley Wrona RN, at (780) 492-0393 or wrona@ualberta.ca.

Lithium trial update

In February 2008 a pilot study was started in Italy to test the effects of lithium combined with riluzole as a way to slow the progression of ALS. This study showed a largely positive effect and was therefore picked up by Canadian and American researchers. The study was commenced in North America and an interim analysis was compiled after the 84th subject was enrolled. Based on the interim analysis the trial was stopped for futility. The study did not show the same beneficial effect of lithium on the progression of ALS as the prior pilot study conducted in Italy. While the outcome was extremely disappointing, as a result an incorporation of ALS clinicians from 15 centres across the country formed a Canadian consortium for ALS clinical research and trials, the Canadian ALS Clinical trials and Research Network (CALN).

ALS Society of Alberta Mission Statement

"The Amyotrophic Lateral Sclerosis Society of Alberta is dedicated to making everyday the best possible day for people with ALS by providing support, facilitating the provision of care, promoting awareness and helping find a cure and advocating for change."

Contact us:

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Toll Free: 1 (888) 309-1111
Email: info@alsab.ca

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Edmonton, Alberta T5K 0M1
Phone: (780) 487-0754
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Toll Free: 1 (866) 447-0754

Thank you

To all of our volunteers, clients, families, partners and donors, thank you for supporting us in making each day the best possible day for people living with ALS. Even in this difficult economic environment, we have managed to continue to meet the every increasing demands on our supports and services. We are committed to providing the best possible service across the province and we greatly appreciate your support. We could not do our work without you.



Tips and Tricks

Difficult Reading the Time?

Is the clock on the wrong side of the bed? Are you having trouble rolling over to see the time? There is a clock made by Electrohome that you can buy at Canadian Tire that projects the time onto the ceiling and walls – problem solved!

Travel and Entertainment Cards

Easter Seals Canada (www.easterseals.com) have two programs that might be of interest –an Access 2 Entertainment card allows an attendant free access into some movie theatres as long as they are accompanying a person with a disability. The Disability Travel card allows an adult attendant free travel as long as accompanying someone with a permanent disability.

Cold Hands?

Mittens to use with power chairs: Take some fleece material, cut out and sew together the shape and size of your hand. Then cut a hole in the centre of the mitten so you can continue to use your joystick while your hands stay warm.



Electric Toothbrush

It is easier to manipulate than a regular toothbrush.

Satin Sheets

Satin Sheets or sheets made with polyester wedding gown fabric can make it easier to move around in bed.

Wheelchair Accessible Vans!

Looking for a wheelchair accessible van? Try the following:

www.canparaplegic.org and click on Swap and Shop

www.danielmaclellan.com

We have also seen them for sale in the Auto Trader and listed on vendor bulletin boards. Also, if you have a van for sale, let us know and we can send out a quick note via e-mail to everyone.



In home esthetics

Toe nail cutting is very important for those who are immobile.

Some Podiatrists will provide in-home services. Look in the Yellow Pages under Podiatrists for services in your area or ask your Home Care coordinator for a recommendation.

Esthetic Services – In your home (recommended by a current user)

First Class Mobile Hair and Esthetics - hair do's, manicure, pedicure and waxing.

Contact (780) 964-0145 in Edmonton and contact Jane (403) 228-3857 in Calgary.

Canada Revenue Agency - Tax Time!

Possible Credits to discuss with your advisor:

Disability Tax Credit; Medical Expenses (Attendant Care, travel of 40k+ to and from doctor);

Caregiver Amount; Infirm Dependent; Eligible Dependent



Helpful Websites

www.alsindependence.com

www.patientslikeme.com - this is a great site for pals

www.alsforums.com/forum/index.php - more Canadians on this forum

Kids of ALS - Canada

A Facebook group has been created for Kids of ALS. Search for “Kids of ALS - Canada” when you log onto Facebook!

More Tips and Tricks

Communication Boards

Occasionally, our clients end up in a situation where the communication method they have been using doesn't work. This alphabet board, in this format, with the vowels on the left can make the difference between being able to communicate or not.

How to use the letterboard

Letters are arranged alphabetically with vowels at the beginning of each row.

Manual Method:

1. Face ALS client, Bill, for example and hold the alphabet board towards him and then point to the first letter in each row always starting with the vowel. Bill will indicate (for example by blinking or by sound) when you reach the row containing the correct letter.
 2. Bill will indicate if the first letter in the row is the correct one.
 3. If not, go across the row, pointing at each letter in the row and saying the letters while pointing. Bill will indicate which letter is correct.
 4. Write down the letter and confirm with Bill. (Very important)
 5. Repeat steps 1 to 4 to get the next letter, etc.
- OR the board can be printed off and the person can point to the letters.

A	B	C	D	NEW WORD										
E	F	G	H	YES	NO									
I	J	K	L	M	N									
O	P	Q	R	S	T									
U	V	W	X	Y	Z									
00	01	2	3	4	5	6	7	8	9	10	11	12	AM	PM

You can print this board off in any size – and then have it made larger or smaller on a photocopier according to your needs.

If you would like to have a larger one to print and put away, we would be happy to e-mail or send it to you – please contact Jane at jane@alsab.ca or (403) 714-8211.

Computer Accessibility Options

Computers are such a wonderful tool for everyone to use; yet often, as ALS progresses, it can become quite a challenge to use them. Fortunately, Windows and Vista have an accessibility option installed into their programs. All you have to do is click on the control panel and under programs you will see (depending on which version you have) either an 'ease of access center', or an 'accessibility' option to click on. By using this option, you will have access to the following:

1. An on screen keyboard- this allows you to type with your mouse.
2. A magnifier- while ALS doesn't affect eyesight, the use of wheelchairs can make it tough to get close enough to the computer screen to see clearly. The magnifier allows you to see, even if you are seated further back.
3. Narrator- this option will read, out loud, the text that appears on the screen.

Outside of the accessibility option is another feature called "speech recognition". This is also found in the control panel. With the use of a separate microphone or more preferably, a Bluetooth earpiece, this program can be thought of like a 'verbal mouse'. It will listen to your commands and open up programs, compose documents, and emails. The program also comes with a tutorial, which has been described as easy to use.

Even if you don't use Windows or Vista, it is worth checking to see if your system has something similar.

A huge thanks to the 2 gentlemen who brought this to our attention.

For more information, you can email either Jane - jane@alsab.ca or Megan - megan@alsab.ca, and also check out the following website: <http://www.microsoft.com/ENABLE/>.

Resources

Edmonton

Pilgrims Hospice

Pilgrims Hospice Society exists to provide a voluntary free-standing Hospice that offers supportive care to enhance the quality and dignity of life for those diagnosed with a progressive life-limiting illness. They offer support to those who are ill, their families, caregivers, and others until natural death occurs. The Pilgrims Hospice has an extensive list of programs and is an excellent resource. Among the vast programs that they provide, there are 2 programs that people living with ALS have readily accessed (The Adult Day Respite Program & The Home Hospice Volunteer Support). For more information, visit to www.pilgramshospice.ca.

Camrose

The Healthy Living Centre

A local point of access for information, services and referrals. Health disciplines include Kinesiology, Nursing, Occupational and Physical Therapists, Dietician, Rehab Assistants, Respiratory Therapists, and Speech Language Pathologist. For more information in your area, visit www.healthlinkalberta.ca.

Tel: (780) 60- 8683

#3, Edgeworth Centre, 4512 – 53 Street, Camrose T4V 4E3

Upcoming Support Groups and Information Sessions

2010 ALS Support Groups - Calgary

Saturdays, Jan 9, Feb 6, Mar 6, Apr 10, May 1, June 5
1:30 - 3:00 p.m.

ALS Society of Alberta office, Suite 400, 320 - 23 Avenue SW
Please contact Jane for more information - (403) 714-8211

2010 PLS Support Groups - Calgary

Jan 14, Mar 4 - 1-3 p.m.

Renaissance at North Hill Mall Condominium Complex
1718 - 14th Avenue NW

Please contact Jane for more information - (403) 714-8211

2010 ALS Support Groups - Red Deer

Saturdays, Jan 16, Feb 20, Mar 27, Apr 24 - 1:30 - 3 p.m.

MS Society Office, 105, 4807 - 50th Ave, Red Deer

Please contact Jane for more information - (403) 714-8211

2010 ALS Support Groups & Information Sessions - Edmonton

Facilitator – Susan Patenaude

Dates TBA - Third Tuesday's of the month 1-3 p.m.

Edmonton ALS Office, # 410, 11456 Jasper Ave.

Please contact Patricia for more information - (780) 487-0754

Condolences

Our sincerest condolences go out to the families of the following people who recently passed away from
September 9, 2009 to December 14, 2009

Linda Baker
Fred Belcourt
Ray Burroughs
John (Barry) Cowie
Thelma Christensen
Debra Egan
Mary Ann Ellenwood
Tom Gandolfo

Vivien Gaudin
William (Bill) Gordon
Robert Graham
Bonnie Holtsbaum
Barry Lewis
John Lyzaniwski
Rea Malcolm
Giuseppe Marinaro

James Orr
Ken Robinson
Pierre Rondeau
Henry Rozsa
Mary Serna
Ken Stephen
Catherine White
Herman VanRee

A special thanks goes out to those who kindly sent donations to the ALS Society of Alberta in memory of friends and loved ones affected by ALS. Your thoughtfulness is greatly appreciated.

Third Party Fundraisers

Thank you to our incredible third party fundraisers!

Bonanza Dinner - Brian Eaglesham and his friends once again organized a fantastic dinner and silent auction at Bonanza in Edmonton to raise funds and awareness for The ALS Society of Alberta. The event raised over \$3,000!

From the Heart - Linda McMurray held her annual silent auction and dance this year in October. The night was a great success and people danced until late in the night! The event raised over \$12,000!

Deal for Denny - Lisa Coles and friends organized a poker tournament in support of the ALS Society of Alberta. The tournament was a huge success and a great deal of fun and raised \$2,085!

Tin Man Open - Abal Building Products held a great golf tournament in memory of Dennis Paulson. The event drew a huge crowd and over \$2,000 was raised!

The Garage First Annual Golf Tournament - This first annual golf tournament was a huge success! Hosted by the Garage Sports Bar, the day was filled with great food and golf!



Deal for Denny



Jason and Tracy, organizers of the Garage Golf Tournament with Jane Rivest.

Upcoming Events

The ALS Society of Alberta is thrilled to announce that we have been chosen as one of the two recipient charities at the **Vehicles and Violins Gala** on March 9, 2010 in Calgary. The Gala is a preview evening of the CMDA Calgary Truck and Auto Show. The evening includes food, beverages and music arranged by the Calgary Philharmonic Orchestra. Proceeds from the evening will be split between the Alberta Cancer Foundation and the ALS Society of Alberta. This premiere event is generously hosted by the Calgary Motor Dealers Association (CMDA).

Jim Gillespie, Executive Director of the CMDA says *“The ALS Society of Alberta was chosen as one of our 2 charities benefitting from the Vehicles and Violins Gala because the CMDA felt that the incredible exposure the Gala provides would be very beneficial to the Society, in addition to the donation itself. The ALS Society of Alberta is locally run and all funds raised will be benefitting Calgarians that are affected in some way by this terrible disease.”*

The ALS Society is very excited about the event and awareness it will bring to the disease.

If you would like to buy tickets to the event, volunteer or donate a silent or live auction item, please contact Rahael at (403) 228-3857 or rahael@alsab.ca.



Congratulations Gerrish Family!

The Gerrish Family was just awarded the Generosity of Spirit Award for Outstanding Philanthropic Family! This is a wonderful honour, as the award is only given to one family a year and is awarded by the Association of Fundraising Professionals.

In May 2005, Holly Gerrish's husband, Mark, a cancer survivor, was diagnosed with ALS. The family's hopelessness quickly turned to determination as Holly and their four children, Lindsay, Laura, Carly and Duncan decided to raise money for ALS. In 2006 they hosted a party to celebrate Mark's birthday with the goal of raising funds to support ALS client services through Betty's Run. This turned into a yearly fundraiser in which every member of the family was involved. When Mark passed away in 2008, one month shy of his 47th birthday, the family decided to continue to honour Mark's life by helping others get through the difficult journey of ALS.

"Sometimes it's the most difficult times in life that bring out the gifts in people." - Holly Gerrish



The Gerrish Family

ALS Society of Alberta Board of Directors

CHAIR - Cathy Martin
VICE CHAIR - Tara Mackay Pentney
TREASURER - Shelley Engstrom
SECRETARY - Olga Maciejewski
DIRECTORS
Jan Desrosiers
Judy Collins
Scott Klassen
Norm Pollock
Dave Williams

And finally...

Calling all casino volunteers!

The ALS Society Calgary Casino will be held on March 6&7 at the Stampede Casino. If you are able to volunteer, please contact Yulia at (403) 228-3857 or yulia@alsab.ca. No experience required!

Tax Receipts

If you have not received your 2009 tax receipts, please contact the office at (403) 228-3857 and we will be happy to help!

E-Mail address?

Do you have an e-mail address? In the past few years, many people have now acquired an e-mail address – if you could provide it to us, we can make sure that we keep you more informed as to what is going on at the ALS Society. Send your email address to info@alsab.ca.

Equipment

If you have any equipment not in use, please contact our equipment coordinator Jeremy for return at (403) 228-3857 or jeremy@alsab.ca.

