

ALSNB QUARTERLY



Volume 1 Issue 1

2009 has been a very exciting year for the ALS Society of New Brunswick and it seems only fitting to start the first edition of our NEW newsletter by sharing some of the news with you.

As you may know, last Fall, the Society hired its first Executive Director. This new position marked a turning point and has allowed the Society to advance client services and programming, as well as respond to the ever-changing fund development environment.

Early in 2009, the Board participated in a strategic planning session that has helped us direct our upcoming initiatives and ensure that we continue to be responsive to you, our client.

In fact, we are working on a number of new initiatives, including this newsletter, that might interest you. They include:

- ◆ A revised and regularly updated website
- ◆ A volunteer management program
- ◆ A corporate sponsorship program for the provincial Walk for ALS
- ◆ A new corporate recognition program
- ◆ A formal third-party event program and guidelines
- ◆ A new awareness program featuring personal stories, told by our clients
- ◆ An "ALSNB FRIENDS" planned giving/donation program
- ◆ A new 'equipment-sharing' partnership with ALSBC
- ◆ A new funding program offering up to \$1500 for all ALSNB clients
- ◆ And funding for a new provincial care map coordinator

As an organization we are also committed to providing a greater number of programs and services in both official languages, including general correspondence, forms and of course, this newsletter. We will also be looking for a sponsor in 2010 to support the translation of our website.

On behalf of the board, I wish you well.

Carol Cottrill
Executive Director

The ALS Society of New Brunswick is a non-profit organization consisting of dedicated volunteers across the province.

Our goal is to have a presence in every geographic area in New Brunswick so we can fully support people living with ALS.

Our Mission is to develop the best quality of life available to each and every ALS patient in New Brunswick by exceeding their expectations and contributing directly to their hope for a cure.

We will achieve this by providing timely, accurate and professional service at every contact and by making annual donations to support research.

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THIS ISSUE:

Welcome
Equipment Sharing Program
Benevolent Fund
Support for Champions
Provincial Care Map
Volunteer Opportunities
My ALS Story
Walk for ALS

ALSNB.CA

Have you checked out ALSNB.CA lately?

You should because we have made some exciting changes to the site.

We hope these changes make the website more valuable to you, by providing up to date information, tips, facts and stories.

My ALS Story

We need your voice to help spread the word about ALS.

Your story will rally people across Canada and around the world to recognize the importance of finding treatments and a cure for ALS.

Please sign-up and share your personal ALS story.

This is your space. Whether you are living with ALS, have a loved one, friend or family member with ALS, or want to honour the memory of someone with ALS, this is your place to share your ALS Story.

Your voice has power. Please share your story and together we will create a chorus, united towards ending ALS.

www.myalsstory.ca

*Sign up today on
WWW.ALSNB.CA to receive
your newsletter electronically.*

*And don't forget to check out WWW.ALSNB.CA
for news and information all the time!*

ALSNB BENEVOLENT FUND GUIDELINES

The objective of the ALS Society of New Brunswick (ALSNB) is to support people living with ALS, their families, and caregivers. Our board has looked at new and innovative ways to make sure we are responding to your needs.

To do this we offer all registered clients of ALSNB the opportunity for funding through our Benevolent Fund. The Benevolent Fund was created for requests that do not meet requirements of the equipment funding or the Support for Champions Fund.

Any registered client of ALSNB can request up to \$1,500.00 annually to support them in achieving or living a better quality of life.

All requests will be considered on a first come, first serve basis, and is offered only as funds are available. The maximum funding available through the Benevolent Fund's is \$1,500 annually. If you have an idea but are not sure whether or not it would qualify, please call or e-mail for more information.

VOLUNTEERS The Heart of ALSNB

ALSNB is committed to supporting and nurturing volunteerism by providing guidance, resources and recognition to all volunteers in a mutually beneficial relationship.

Each year volunteers across the province provide invaluable support to persons with ALS and their families and raise funds through special events within their community to support programs and services.

Some of the volunteer opportunities currently available include:

Walk for ALS Coordinators and team members
Graphic Design Assistant
French Translation Coordinator
Client Service Volunteer
Marketing Assistant
Board Treasurer

Whether it is important to you to solve a community problem, advance a worthy cause or to develop as a person, volunteering offers many benefits in appreciation for the gift of your time and expertise.

For more information on these opportunities, please contact carol@alsnb.ca today.

MOVING DAY: SHARING EQUIPMENT COAST TO COAST

It will come as no surprise, the equipment that may be needed for an individual living with ALS is expensive. It is estimated that it costs approximately \$140,000 to supply the medical equipment required during the course of the disease.

Our inventory of equipment (available through Easter Seals New Brunswick) is limited, but we found an innovative way to supplement those needs last year. In a discussion with ALS British Columbia, we discovered they had excess equipment, some of the very equipment that we needed. And a partnership was born!

With the help of ALS Supporters and moving experts Jim Williams and Randy Hoyt, 29 pieces of equipment, including walkers, hospital beds, and wheelchairs, made the 6,000 km journey from the West coast.

Most of this equipment is already in use in our clients' homes, and we are forever grateful to ALS BC for providing us with this support.

To our delight, this support was not a one-time proposition. ALSNB and ALSBC will be looking again at our equipment needs and surplus this Fall and seeing what may be Eastbound in the new year.

SUPPORT FOR CHAMPIONS

The devastations of Amyotrophic Lateral Sclerosis (ALS) or Lou Gehrig's Disease on the family unit are well documented, as no member is immune to the perils of such a devastating illness.

Gilles LeBlanc was diagnosed with ALS at the age of 36. At the time, his sons were seven and four years of age. His foremost wish was for both of them to enjoy a non-interrupted journey through childhood, despite his devastating illness.

"The emotional scars of a sick parent are enough to bear, without having them sacrifice their very own childhood" says Gilles.

As a result, he created a special fund in conjunction with the ALS Society of New Brunswick to give a helping hand to every child of families touched by this terrible illness.

His family and friends vow to build upon his dream of seeing every child of ALS sufferers in Canada, flourish through childhood.

Support for Champions is there to help with scholarships to a recognized educational institution, or with expenditures for the cultural development of the child through the participation in extra-curricular pursuits, especially sports.

Applications are available online or by calling the ALSNB office.

FUNDING APPROVED!

ALSNB Gets Funding to Develop 'Provincial Care Map'

In February 2009, the ALS Society of New Brunswick undertook a strategic planning session. One of the key goals arising from this was our desire to provide a 'navigation system' which helps ALS patients and their families to access the care and supports they need, and to resolve issues which may prevent them from timely access to this care.

This directly supported our client survey results, in which 40% of respondents said they had difficulty navigating NB's health care system.

To that end, ALSNB successfully applied to ALS Canada for a Seed Grant. This funding will allow us to hire a part-time researcher who will, over the next year, develop a comprehensive 'map' that leads a client from their initial diagnosis, through specialists, social services, financial and spiritual counselling, equipment management, end of life planning, etc.

This project would also help us to identify disparity of available care and services in the various regions of the province, and enable us to advocate for improved coverage.

Our goal is for ALSNB to be the access point for people with ALS to enter and navigate the health care system. Our goal is to develop a useful resource for you and your family.



The Walk for ALS took place in five cities across the province in June 2009.

BATHURST - FREDERICTON - MIRAMICHI - MONCTON - SAINT JOHN

We raised nearly \$70,000 for ALS research and provincial programs and services.



Want to know more about
volunteering for,
or starting a walk in
your city?

E-mail carol@alsnb.ca

Thank you to everyone who participated in this year's Walk for ALS. The energy and support from our walkers, volunteers, and sponsors made this year a great success. Please watch for the November 2009 Issue of ALSNB Quarterly for an in-depth review of this year's events, as well as information on the 2010 Walk for ALS.