

JOIN THE ALS SOCIETY MARCH OF FACES

Add your portrait to an ALS Society of Canada **March of Faces** banner - with photos of people with ALS, past and present. See the **March of Faces** Web Gallery at www.als.ca/march-of-faces

March of Faces is a tool for local awareness activities and a 25th anniversary project of the ALS Society of Canada. If you reside in Canada and are living with ALS or had a family member or friend with ALS, we invite you to add a portrait to our project. The ALS Society units will receive banners containing 20 portraits and make them available for ALS Society awareness and fundraising events.

HOW TO PARTICIPATE IN THE ALS SOCIETY MARCH OF FACES

With two easy steps you can participate:

ONE - THE PHOTO

Mail a colour or black & white photo (any photo will do) to:

George Goodwin,
20 Congress Crescent,
Apartment 401,
Hamilton, Ontario L8K 5H7

or email a .jpg or .tif version of a photo to:
george.goodwin@sympatico.ca

TWO - THE PERMISSION PHOTO SUBMISSION:

Name (person in portrait):

Address:

City:

Province:

Postal Code:

Contact name:

Email:

Year of birth or lifespan (i.e., 1941-2002):

Date of diagnosis:

PERMISSION WAIVER REQUIRED

By my own personal authority or power of attorney, I give permission to use the photograph of

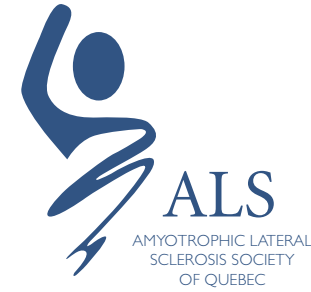
submitted The ALS Society of Canada, to be printed on an ALS **March of Faces** Banner and on the **March of Faces** area of the ALS Society website for the purposes of awareness, advocacy and fundraising and at events that benefit people with ALS.

Signature

- Photos are reproduced in portrait orientation. Photos submitted in landscape orientation may be cropped.
- Photos will be returned if a self-addressed stamped envelope is included.

MAIL TO:

ALS Society of Canada
March of Faces
c/o George Goodwin,
20 Congress Crescent,
Apartment 401
Hamilton, Ontario L8K 5H7



LOU GEHRIG'S DISEASE

WINTER 2005



THE ALS SOCIETY OF QUEBEC

SUPPORTS people affected by ALS to serve immediate needs
RAISES funds for research
PROVIDES information to build awareness

peripheral

the information path



RESEARCH UPDATE

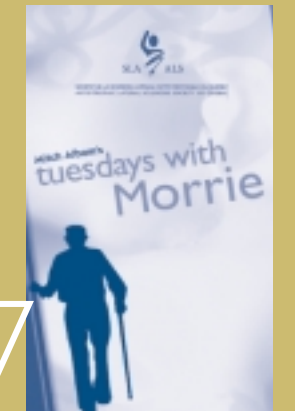
BY JEAN-PIERRE JULIEN, PH.D

CHRISTMAS PARTY 2004

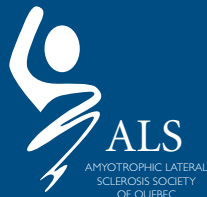


5

UPCOMING EVENTS



7



FOR FURTHER INFORMATION,
CONTACT THE ALS SOCIETY
OF QUEBEC

6300, Park Avenue, Suite 502
Montreal, Quebec H2V 4H8

Phone: (514) 725-2653
Toll-free: 1 877 725-7725
Fax: (514) 725-6184

info@als-quebec.ca
www.sla-quebec.ca



A WORD FROM OUR PRESIDENT

I am pleased to report that the Society's positive momentum has continued throughout the winter months.



- On December 6th, we had a very memorable Christmas party. It was a joy to see our members with their family and friends join us for some holiday spirit. Our party would not have been possible without some very important contributions. First, I would like to thank **Monique Durocher** from the Lisette Dupras Rehabilitation Centre for allowing us to use their facility and for helping us throughout the evening. Our guests enjoyed some hors d'œuvres from **Saputo**, a delicious meal thanks to the **Au Vieux Duluth Restaurant** and were treated with stockings filled with gifts thanks to **DOLLARAMA**. Santa was busy in his workshop as everyone received great presents from various donors. A special thanks to **ADT Apparel** for donating the wonderful pyjamas!
- Our support groups continue to be well attended and very informative. We are pleased to be planning new interesting themes with new guest speakers. Please contact our social worker, **Véronique** if you would like to learn more about them.
- Looking ahead: I am pleased to announce that The ALS Society of Quebec will be hosting a benefit performance of Mitch Albom's Tuesdays with Morrie on May 2nd. Anyone who read the book agrees that it is truly a wonderful and inspirational story regardless of the life challenges one might be facing. I would like to thank the **Edward Bronfman Family Foundation** for their support of this event.

Spring is just around the corner and we will continue to update you on The Society's news and activities.

All the best,

Lise Deschesnes

ALS SOCIETY OF CANADA LAUNCHES BILINGUAL PSA CAMPAIGN:

"WHAT WOULD YOU DO, IF YOU STILL COULD?"

The ALS Society of Canada launched a new public service advertising campaign to raise awareness about ALS and the ALS Society's efforts to support research towards a cure for the disease.

The nature and progression of ALS leads many of those living with the disease to consider how they will use the time they have left. This campaign asks consumers to consider a similar scenario with the question -- What would you do, if you still could?

Created by BBDO Canada on a pro bono basis, the campaign includes two, 30-second television public service announcements (PSAs), "Running" and "Hugging". Sixty-second PSAs for cinema will be available later this year along with print and interior transit PSAs based on the same theme. "We wanted to help people understand how ALS changes the lives of people living with the disease and those around them," said Stephanie Nerlich, Senior Vice President, Group Account

Director, BBDO Canada. "That led us to think about simple tasks that we take for granted, tasks that people living with ALS are forced to consider every day."

Both ads are available in French and English for airing as public service announcements and can be viewed online at www.als.ca.

(Source : ALS Canada)

COMMENTS AND SUGGESTIONS:

We appreciate all your comments and suggestions. Keep them coming! We will continue to do our best to accommodate them. info@sla-quebec.ca.

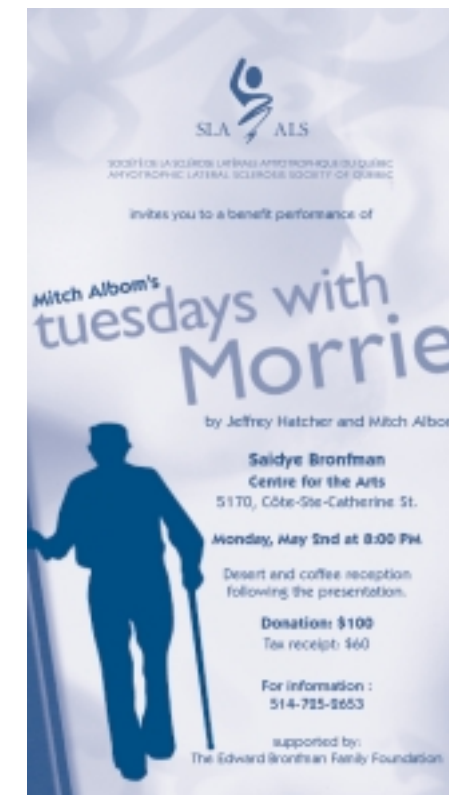
UPCOMING EVENTS:

Mitch Albom's Tuesdays with Morrie

From May 2-22, 2005, The Saidye Bronfman Centre for the Arts will be presenting the play, based on the New York Best Seller, Tuesdays with Morrie. It is the heartwarming true-life story of a relationship between renowned American sports journalist, Mitch Albom, and his college mentor, Morrie Schwartz, with whom Albom reconnects after 16 years after finding out that Morrie has ALS.

The story is based on a series of weekly visits, rekindling their loving relationship while tackling the subject of "The Meaning of Life". Topics are covered such as love, work, aging, family, community, forgiveness and death.

If you would like to purchase tickets or for more information, please call or email us at the office. Tickets and seating will be on a first come first serve basis.



VERNISSAGE JOHN ARCARO

Montrealer **John Arcaro** is an 18 year old, up and coming artist. While pursuing his studies and his love for painting, John 's beautiful artwork has helped various charities , including the ALS Society of Quebec, raise funds.

John Arcaro's third solo show will be held at the Leonardo da Vinci



John Arcaro and Micheal Schumacher

Centre on Thursday May 26 to Sunday May 29 2005. The Center is located at 8370 Boul. Lacordaire in St.Leonard. The ALS Society will be co-benefactor of his show. His artwork can be viewed at www.johnarcaro.com

ALS AWARENESS MONTH

We are in the midst of planning events and activities for ALS Awareness Month in June. Please contact the office if you would like to take part by selling cornflowers in your community, hosting a fundraising event or being a volunteer with some of the activities that we are planning. Details to follow!

ALS WALKS 2005

Mark your calendar! The ALS Walk in Montreal and La Malbaie in Charlevoix, will be held on **Sunday, September 25th**. We are still hoping to add a couple of regions and will keep you posted. Please contact us if you like to be part of a 2005 walk team in your region!





PEOPLE WHO MAKE A DIFFERENCE

We would like to thank all those who have taken the initiative to organize events in support of The ALS Society of Quebec. We truly appreciate your dedication and passion for helping us raise funds and awareness. To all the volunteers, participants and donors of these events, thank you for making them special and for helping us with our mission.

"SNOWMAN JOE"

Louise Boucher-Arnott's dad died of ALS on November 9, 2000. Days after his death, her family looked outside and decided to build a snowman remembering how her dad once built a 7-foot one. They named him "Snowman Joe" and he became famous being the first snowman of the season. Whether there was snow on the ground or whether they had to collect snow from the local arena, the Boucher-Arnott family, friends, children and grand-children have built "Snowman Joe" for the last 4 years with the goal of raising awareness and funds for ALS. Louise also sells "Snowman Joe" gift cards and notepads in support of the Society.



BOWL-A-THON IN BEAUPORT QC.

A year and a half ago, Marjolaine Mercier-Paquin's mother's friend, Hélène Blouin, was diagnosed with ALS. Her mother grew up with Mrs. Blouin and like everyone around her, was devastated upon hearing the news. When she had the opportunity to make a difference and raise awareness about the disease, she did. She and her high school classmate, Véronique Maheux organized a Bowl-a-Thon on January 29th for the ALS Society of Quebec as part of a school project. The event was a big success, raising a total of \$2170! If we were grading their project, we would give them an A+. Great job girls!



DO YOU WANT TO HELP RAISE FUNDS AND AWARENESS IN SUPPORT OF THE ALS SOCIETY OF QUEBEC?

Do you want to organize a fundraiser in your community, at your school, with your colleagues, at your church or at your local mall, for example, but don't know where to start? Does your company or social club organize fundraising events whereby the Society could qualify to be a recipient of the funds? Please contact the office and we would be glad to help you get started and guide you.

ATTENTION GOLFERS!

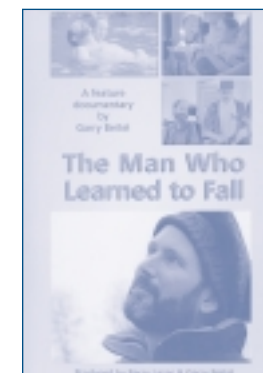
The 5th edition of the CAN-US Golf Tournament will take place on August 13th at the Dorval Golf Course. Tickets for foursomes are 600\$ and include golf, brunch, carts, dinner and a great silent auction while supporting the ALS Society. If interested, please call the office. Space is limited!

CROSS-COUNTRY SKI MARATHON

The ALS Society of Quebec would like to congratulate Gilles Lacourse for completing a 160 Km cross-country ski marathon, the longest in the world which took place on February 12 & 13 from Lachute, QC to Gatineau. Over the last two years, Gilles has raised \$3052 for the Society and looks forward to adding over \$1000 again this year. Gilles' sister, who has ALS, is his inspiration to challenge himself in this gruelling marathon and raise funds and awareness for ALS.



NEWS FROM CLIENT SERVICES



PUBLIC MEETING

On Thursday, Feb. 17th, 2005, twenty three volunteers and staff from the CLSC NDG/MTL-O took part in an evening of exchange on ALS. A discussion led by our social worker Véronique Pignatelli followed the showing of the film "The Man Who Learned To Fall". This is an unforgettable movie with Philip Simmons, an English professor and writer who was stricken with ALS at 35 years of age. Produced by Gary Beitel with tenderness and humour, this movie is generous, sincere and positive. For more information, refer to the web site www.learningtofall.com/Film.htm

VOLUNTEERING

The ALS Society wishes to expand its volunteer program in order to provide more services to its members. Examples of volunteering activities: home visits, office work (telephone calls, mailings, translation), welcoming of participants at events, help in organizing ALS Walks, etc. If you have time to spare, please call us!

There will be a free screening of the documentary "The Man Who Learned to Fall" open to the public on Thursday, May 5th at 1:00 PM at The Leonor and Alvin Segal Theatre of The Saidye Bronfman Centre for the Arts (5170 Côte-Ste-Catherine Rd.)

Wheelchair access by Westbury Street. Come meet Gary Beitel, Sunday May 8th at 11:00 AM, when he talks about his film as part of "88.5 CBC Radio One Presents Sunday-@-the Saidye".

COFFEE GET-TOGETHERS

The ALS society is organizing its third coffee get-together for caregivers on Tuesday, March 22 from 1:30 to 3:30 PM. These get-togethers allow the participants to discuss among themselves, to obtain information on a whole range of subjects and also helps break the isolation caregivers often feel they're in. Topics of discussion center around daily situations experienced by caregivers and their families. Do not hesitate to let us know your areas of interest and suggestions.

NEW! At the request of quite a few members, persons stricken with ALS are invited to get together as well in order to get to know each other, share the joys as well as the more frustrating moments of their lives with ALS. This meeting will also be held on Tuesday, March 22nd, from 1:30 to 3:30 PM in the Society's offices on Park Avenue.



IN MEMORIAM

Léopold Babin
Denise Belzile
Claude Couture
Arleen Dionne
Pauline Dubois
Simon Dubé
Fernande Foisy Filiatreault
Gaétane Frère
Benoît Gaudreau
Marthe Lacasse
Catherine Larochelle
Doline Malette Larivière

Huguette Martel
Pierre-Paul Martin
Martine Perreault
Robert Plante
Francine Portelance
Paul-Yvon Proulx
Colette Roy
Lucie St-Jean
Fleuriette Touchette
Charles-Auguste Trottier
Berthe Turcotte

UPCOMING SUPPORT GROUPS - MARK YOUR AGENDA!

All the support group meetings are held in our offices located at 6300, avenue du Parc, office 502, from 7:00 to 9:00 PM

Monday, April 11th
Technical and technological help devices

Monday, May 16th
Nutrition and Difficulties with Swallowing

BRIEFLY NOTED: ALS AND THE FIRST STEPS FOR THE FAMILY

- Obtain as much information as you can
- Plan ahead
- Accept the fact that you are going through a highly emotional period
- Create a help network
- Ask for help
- Recognize the progressive nature of the disease
- Be aware that caregiving can be extremely demanding
- Never forget the person with ALS
- Remember that the Society is here to help you. You are not alone. If you need information or help, you have one number to dial: 1 877 725 7725

(source : ALS Canada)



RESEARCH UPDATE - PART II OF III

BY JEAN-PIERRE JULIEN, PH.D, PROFESSOR
CANADIAN RESEARCH CHAIR IN NEURODEGENERATION DEPARTMENT
OF ANATOMY AND PHYSIOLOGY,
LAVAL UNIVERSITY

Genetic Therapy and Stem Cells

There is a lot of talk concerning genetic therapy and stem cells for the treatment of ALS and other neurodegenerative diseases like Alzheimer's disease and Parkinson. We must realize that these approaches are still at the experimental stage on animals. Nonetheless, these novel approaches raise much hope and preliminary results on ALS-model mice are promising. Two research teams, one in California and the other in Belgium, have recently demonstrated the feasibility and the beneficial effects of genetic therapy on an ALS-model mouse. In these studies, the approach was based on the intramuscular injection of a genetically modified virus to produce factors favoring the survival of motoneurons such as the IGF-1, BDNF or VEGF factors. The scenario called for the viral particles to enter by the nervous endings on the muscle and make their way to the motoneurons of the spinal chord. This genetic therapy approach will probably be tested within a year or two on a small number of patients stricken with ALS. Certainly, there are risks in introducing viruses and the costs will be high. However, if the preliminary results on humans turn out positive, this could open the way to a strategy of injection of viral particles with the objective of reducing the production of mutant SOD proteins on patients having the hereditary type of ALS.

The approaches for stem cells are promising but still very experimental. For ALS, the strategy would consist, not in replacing the lost motoneurons, which would be very difficult, but rather of replacing the (glial) cells so as to create an environment more conducive to the survival of still functional motoneurons in the nervous system. Before proceeding with tests on humans, we will need to determine which is the best source of stem cells (embryos, bone marrow, or skin cells?) and also know how to better control the processes of proliferation and differentiation of these cells.

At the CHUL research center in Québec, we have put together a new group of researchers from Laval University (Rivard, Vallières, Julien, Kriz, Lacroix) to evaluate the potential of cells derived from bone marrow, the macrophages, as vehicles to bring factors of survival to the central nervous system. Indeed, these cells have the particularity of being capable of crossing the hemato-encephalic barrier. This new research program, which

will be expanded over the next few years, was recently approved at the first competition on nonmedicine of the Canadian Health Research Institutes.

Discovering Other Genes Responsible for ALS

Mutations of SOD are responsible for approximately 2% of all the ALS cases. It is therefore only the tip of the iceberg. Plenty of resources are presently dedicated to research on other genes responsible for ALS because that will open up new pathways to understand the mechanisms and develop treatment options. To look for mutations is like looking for a needle in a haystack. A collaborative project of our laboratory with doctor Guy Rouleau and François Gros-Louis recently led to the discovery, in a sporadic case, of a very rare mutation in a gene affecting the well-being of the cytoskeleton of nervous cells. Furthermore, other groups have identified, in a few cases of ALS, mutations in the coding genes for proteins involved in intracellular transport. We can expect discovery of other genetic mutations in the years to come which could lead to new therapeutic targets.

The Exercise is Beneficial for ALS

For the longest time, there has been controversy on whether or not physical exercise is beneficial for patients stricken with ALS. We know that athletes can develop this disease. We can recall the famous ballplayer, Lou Gehrig, and more recently certain players of an Italian soccer team who have contacted ALS. Is physical exercise harmful?

Recently, some American researchers have tackled this question experimentally by having ALS-model mice run in a regular and moderate fashion. In this experiment, the model mice are placed in a wheel which forces them to run. Lo and behold, these mice lived longer by doing exercise! Exercise even acted synergistically with an experimental genetic therapy treatment for the IGF-1 factor. If we rely on the model animal, physical exercise would therefore be beneficial. Hence we encourage patients stricken with ALS to carry out physical exercise as much as possible. It's good news, but careful! We're talking here of moderate physical exercise and not of extreme sports.

HOPE & HUMOUR

As a grade school teacher born on October 31st, Halloween has always been a very special day for me. Retired since June 2004, I knew that several of my former students would come to visit me on Halloween. Wheelchair-bound, I decided to disguise myself in order to make them smile. With the help of my close friend Lorraine, we created "Hélène on Wheels", "Rapid transport Canada-USA". My costume was a big hit and it generated much laughter among the young and the not-so young. Next year, I plan on adding a lighting system to my vehicle. For those who may be interested, I fulfill small delivery contracts.

Hope and humor breathe life.

**Hélène Blouin, diagnosed with ALS in 2003
Ile d'Orléan**



CHRISTMAS 2004

T'WAS A PARTY TO REMEMBER!



Guests enjoyed a delicious meal courtesy of **Au Vieux Duluth Restaurants**



Some Salsa dancing tips from the pros!



Congratulations **Germain Rheault** for winning the hand knit blanket by volunteer, **Lucette Deschesnes**



Congratulations to **Nathalie Quesnel** and her family for winning the Special Edition "Celine Dion" CD box that included every single one of her smash hit recordings!



Santa was a popular man!



Herman Jacob



Treasurer **Rejean Moreau** and son **Louis-Philippe**



Paul Tartre and his brother **Normand**



André Pépin