



SOCIÉTÉ DE LA SCLÉROSE LATÉRALE AMYOTROPHIQUE DU QUÉBEC
 AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF QUÉBEC
 LA MALADIE DE LOU GEHRIG'S DISEASE
 www.sla-quebec.ca

The Bulletin

Volume 1, number 1 • Summer 2009

OFFERS services and support for people touched by ALS and their families and caregivers

INFORMS and enlightens people about ALS

FINANCES research, which equals hope

Message from the Executive Director

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To all friends of the ALS Society of Québec,

I am very proud and excited to introduce our new and improved newsletter, *The Bulletin*. Our hope with this newsletter is that it will become your companion throughout your journey with ALS. Much thought will be put into each of our four issues that we will produce throughout the year. To inform, coach and inspire are just a few of our goals we will strive for with *The Bulletin*. As a complement to this, our monthly *Express* newsletter will continue to be produced and starting this year, we will supply an annual report. This report will highlight our achievements from over the year and will acknowledge all of our donors, sponsors and people who have so generously donated their time through volunteering and who have helped us raise awareness and funds for the ALS Society.

I would also like to mention how happy I am to have seen so many of you at our office or at various events over the past year. It is always a pleasure to meet with our growing family of champions of the ALS cause—a cause that is in much need of advocates and supporters. The great news is that the ALS Society is growing.



Claudine Cook, Executive Director

So to best serve our clients' needs across the province of Quebec we are expanding our services. But we can't do this alone. A big thank you to everyone involved in the ALS Society for their support, from our donors, to volunteers, to our spokespeople Allana and Vincent Damphousse and Tony Proudfoot, to our Board of Directors. Together, we have raised awareness, together we will triumph.

A word from the outgoing president



Dear friends,

It is with great sadness that I must inform you that this will be the last time I will address you through The Society's Newsletter.

As President of the Board of Directors of the ALS Society of Quebec for the past 10 years, my dream and goal was to build the Society and its services for our patients and their families in the best way possible. It is a mission that I approached with passion and with all of my heart. Now it is time to pass on the torch to a new group of dedicated volunteers.

Over this past decade, it was a privilege and honour for me to be able to share the joy I experienced in this position as I worked, laughed and sometimes cried alongside you during the various activities organized through the Society.

I would like to thank you from the bottom of my heart for your trust and for your friendship.

My colleagues on the Board of Directors, the staff and volunteers of the ALS Society have all worked with much dedication in achieving and reaching its mission. To all these people who were faithfully present at my side, participating in the planning and maintenance of all services, programs and events—thank you!

Goodbye dear friends. I wish you much luck and hope that you will continue to support the Society as it continues to grow and blossom.

Sincerely,
Lise Deschesnes, Outgoing President

A word from the President of the Board of Directors

Over the years, several cases of Lou Gehrig's Disease are presented to us at the ALS Society of Quebec. Because most of us have had our own personal encounter with ALS it is only natural that we recall our own experiences and bring them to the forefront when making every decision we make.

Most of us can relate first hand to the journey with ALS. In my case, the disease affected my stepfather. I saw how it impacts an individual, a family and caregivers. Our own experiences allow us to empathize with each new person we meet, each new journey we encounter. We know that everything a man or a woman could build family, work, a future—suddenly becomes very small when the battle becomes for one's life. Therefore we can't just sit back, idle. We—by association with the disease—are liable. And by being part of this Board we fully and happily accept this job in the name of every person affected by ALS.

Let me tell you a story that demonstrates a lot about this burdensome disease. The last summer with my stepfather, we would visit him every week. From the special chair he rested in he one day asked my mother to take out his fishing gear to show my children. He ended up giving them his fishing rods and different lures and told them all about his fishing adventures. The entire time he cried. Alec, my 7 year old son at the time, offered to give back his fishing rod when he saw him cry, not knowing that the real reason for the tears was that my stepfather would never again have the chance to indulge in his favourite sport with his grandchildren.



Today, "Nonno" (Grandfather in Italian), may finally see his grandchildren fishing but from a more tranquil place. "Nonno" died May 3, 2006 from ALS.

This is what the new Board members have all experienced in one way or another, with a brother, an uncle, a close relative. All are ready to do their utmost to help everyone affected by ALS. Our goal is to advance research and patient services, while ensuring the sustainability of the ALS Society of Quebec for years to come.

In the name of all of the Board of Director members, thank you for your support,

Eric Poirier
President of the Board of Directors

Lise Deschesnes Volunteer Award

In the name of the ALS Society of Quebec Board of Directors, the staff and volunteers as well as the many families that Lise Deschesnes has helped and supported over the years, in her honour we are happy to announce the creation of the Lise Deschesnes Volunteer Award. This award will be given annually to volunteers in recognition of exemplary leadership and remarkable contribution to the advancement of the mission and objectives of the ALS Society of Quebec.

Members of the ALS Society of Quebec Board of Directors 2009

SPOKESPEOPLE

Allana Damphousse
Vincent Damphousse
Former NHL player

Tony Proudfoot

Former player of the Alouettes
Radio commentator
Diagnosed with ALS in 2007

MEMBERS OF THE BOARD OF DIRECTORS

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District Vice President, Fidelity Investments

Nathalie Beauvais

Occupational Therapist, CSSS West Island

Dr. Monique D'Amour

Neurologist, CHUM, Notre-Dame Hospital
Specialist in treating ALS

Vincent Damphousse

Former NHL player

Béatrice Le Boulengé

Management consultant

Jean Martel

Lawyer
Séguin Racine

Marc Savary

Trustee in Bankruptcy
Litwin Boyadjian

Luc Vilandré

Vice President
Business Development for TELUS Business Solutions

Services offered by the ALS Society of Quebec

Our objective: to improve the quality of life for people living with ALS

With this first edition of *The Bulletin* we would like to take the opportunity to detail the services we offer and to give you a sneak peek at upcoming events

SUPPORT GROUP: The purpose of our support group is to bring together people touched by ALS, including relatives, friends and caregivers. During these meetings we work hard at developing topics that will meet your needs. The goal is to provide you with information and to answer your questions and concerns. These groups usually take place in the evening.

SUPPORT GROUP: At our office from 7 p.m. to 8 p.m.:

1. Wednesday, July 8, 2009 (Getting into a vehicle as a driver or as a passenger with Mme France Duhamel, Occupational Therapist, at the Centre de Réadaptation Lucie Bruneau).
2. Wednesday, August 5, 2009 (The role of the Speech Therapist for people living with ALS with Mme Justine Tremblay-Beauséjour, Speech Therapist at the Centre de Réadaptation Lucie Bruneau).
3. Thursday, September 3, 2009, (Ms. Mia Lanno, Social Worker at the Montreal Neurological Institute), English group.
4. Wednesday, September 9, 2009 (Dr. Monique D'Amour, Neurologist at the CHUM).
5. Wednesday, October 7, 2009 (Life with ALS, adapting to loss and reaching serenity with Ms. Sylvie Champagne and Claudine Trekker, Centre de Réadaptation Lucie Bruneau).
6. Wednesday, November 4, 2009 (Sexuality and ALS with Ms. Mélanie Kogovsek).
7. Wednesday, December 2, 2009 (Ms. Marie-Hélène Ouellet, Communications, Montréal Health).

COFFEE SIT-INS: : We have two groups—one for people touched by ALS and one for their caregivers. There are approximately five to six participants per group. The objective: to allow the participants to engage in discussion, to obtain useful information and to help break isolation.



CONFERENCE CALLS: This is offered in partnership with the Care-Ring Voice network ([visit www.bienvieillir-vitalaging.com/caregivers/index.html](http://www.bienvieillir-vitalaging.com/caregivers/index.html))—a community based, free, confidential and bilingual, Quebec-wide telephone conferencing program for caregivers as a preventive, supportive and informative resource.

EQUIPMENT PROGRAM:

When certain equipment needs for people touched by ALS are not filled by the healthcare system, the ALS Society loans or rents certain essential equipment, such as chair lifts, mobility scooters, and supplies for daily activities. Financial aid for minor adaptations of a residence can also be applied for in certain circumstances.

REGIONS OF QUEBEC

A word from the new Support Services Coordinator Julie Lamarre: It is with great pleasure that I have been appointed the new Support Services Coordinator of the ALS Society of Quebec. My job will be to continue the efforts and work already put into place and to develop a support system for people affected by ALS in this province. I have already had the opportunity to visit some regions and I look forward to visiting more very soon. I am very enthusiastic about building our relations and ties around Quebec. I invite you to tell me your concerns and needs and I will try to address them. I look forward to meeting you!



INTERESTED IN VOLUNTEERING?

The ALS Society of Quebec is always looking for volunteers to help carry out various important tasks. Presently we are seeking volunteers who are skilled in the areas of graphic design to help produce publications and bulletins. If you are interested, please contact us at 1-877-725-7725.

“Suck it up” and get on with life

This article by Tony Proudfoot appeared in the Montreal Gazette on Dec. 20, 2008



One year after my first Gazette article I am still here! Lou Gehrig's disease hasn't completely kicked my butt yet! This time last year, seven months after my initial diagnosis, I was dealing with the early reality of this cruel and insidious disease. My voice was deteriorating, my ability to eat and swallow was already beginning to cause a few issues and the hint of breathing problems was starting to manifest. Initially it didn't seem too much of a worry, as

these issues were not affecting my ability to participate in the activities I have always loved. Canoe trips with my buddy Tom Peters continued to be great, fishing and kayaking on the east coast, including Cape Breton was spectacular and I was looking forward to skiing as the record snowfall of the winter of 2007-08 had begun. Travel plans for Vancouver, Barbados, Hawaii and Melbourne were in full swing. It didn't appear to be a bad life for a seemingly healthy person, albeit one diagnosed with a fatal disease.

Medically I was being well taken care of by Dr. Angela Genge and her team of specialists at the Montreal Neurological Institute. When I say taken care of, I actually mean they were managing my symptoms and my psyche since the medical community has no real treatment or answers for the patients affected by this monster, nor the toll it takes on family. Heck, even the cause of ALS (amyotrophic lateral sclerosis) is a mystery. There are no medications, drugs or even slim hope for those stricken with what may be one of the worst possible paths to death. During the relatively short period of life an ALS patient has (90% of us will die within the first five years) I can expect to face progressively failing muscles throughout my body, in concert with the increasing inability to function without assistance and can therefore chart my demise with, ostensibly, little to look forward to. The character of this disease is one of continued debilitation, without the hope of improvement. It is a downward slope, with more and greater limitations every few months, eventually trapping the patient inside a useless frame waiting for the complete failure of the respiratory system and the thankfulness of death.

I am not looking for sympathy, tears or even prayers. It is extremely important to me that more people understand what this terrible disease is all about and perhaps stimulate increased lobbying to effect how ALS research is funded. So where does Tony Proudfoot sit now? I am still sliding downhill, having more difficulty communicating and maintaining my weight as this disease continues its relentless assault on my body. I am experiencing a lot of frustration from not being able to talk and eat normally, but I am finding ways to make adjustments within my situation. Like Lou Gehrig, I feel lucky to be alive, thankful for past opportunities and working hard to find

ways to remain positive in the days to come. When I look back I have had an absolutely wonderful year and I look forward, with passion, to another one, full of adventures and opportunities.

The slower than normal rate of decline I am currently experiencing has allowed me to stay relatively optimistic and surprisingly buoyant. I am certainly not ignorant of the reality of this disease, and depression is seldom far away, but I choose to view every day from a more positive, if not pragmatic, perspective. You know the old saying; the glass is half full or half empty; well for the first time in my life I know exactly what this means. In fact, my particular wine glass is probably only, full but that makes the drinking all the sweeter since I value what's left all the more. Any of you who know me realize I am not one to wax poetic or even philosophize, but the wine glass analogy seems to me to be crystal clear and bang on.

During Grey Cup week last month my friend and ex-teammate Gabriel Gregoire proffered me a great compliment in his speech at The Legends of the CFL breakfast. He remembered me continually motivating him to struggle through a difficult period with the Alouettes. I was always saying “suck it up Gaby,” and “no whining” as a reflection on the reality of the time. If things are not going your way, if you believe you have been given the short end of the stick or when life just does not seem to be fair, the best option is to dig in, choose a positive goal, pick a path or approach that is upbeat and determined, then work your butt off to get there, to achieve it. Less than three months into my diagnosis I chose to suck it up, to try to live life more fully, reconnect with family and friends, take advantage of every opportunity and seldom saying no to anything. You know what? It has been a very good year and, so far so good. I continually make a point around family and friends to toast the day with a simple but powerful statement: “Thanks for another good day.”



“Suck it up” and get on with life

Cont'd

Many have said how sorry they are for me and everyone has been treating me especially nice. I am far more sensitive and appreciative of the empathy of others than I used to be, and it has become a big part of my positive outlook on life. The University of New Brunswick honoured me with a doctorate degree in celebration of my contribution to the field of physical education throughout my lifetime. The Football Writers of Canada presented me with a lifetime achievement award and Dawson College gave me an excellence in teaching award. Even Marc Trestman presented me with a game ball after the Eastern Final, recognizing my contribution to the team—it left me speechless, literally. These accolades and tributes, at this time in my life, could be construed as tokens to a dying man, but upon reflection I now see them as a testament to who I am and have become, and I cherish every one. I am thankful to be in a position, however tenuous it is, to be able to acknowledge my strengths and to continue to work toward achieving my goals.



Trestman and the Alouette players), the hundreds who walked with me last September are but a few of the players on my team, each of them important to me and all pulling together in this fight. The Tony Proudfoot Fund, started last year to fund research and patient care, has reached \$350,000 and continues to grow. I am both honoured and humbled. I will continue with new initiatives that hopefully will augment awareness of the dreaded disease. With increased awareness, increased support and funding will follow. That, my friends, is the only hope for the thousands of Canadians stricken with ALS and thousands more who will contract it, one or two even as you read this article. To make a contribution right now, please contact: www.sla-quebec.ca, then go to the link for the Tony Proudfoot Fund. Thank you so much.

Goal # 4 – A very personal, positive mantra, and I hope you'll believe in it with me:

Suck it up and get on with life (remember, no whining allowed!) and enjoy every day. What other option do any of us really have?

And what are the goals of a man whose fate is sealed, you ask?

Goal #1 – Support my wife and family and relish in their love and support.

In some ways I wish I had never gone public with my story as now my family has been thrust into public attention as well as having to embrace the sad reality of the situation. It focuses unwanted consideration on them and I am truly sorry for that but I also know, together, we are a very strong, secure family and we will endure.

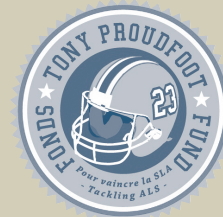
Goal # 2 – Make the relationships I have better, by being responsive to every individual, and each issue.

The direct contact list on my computer is approaching 700 and growing every day. One of the true highlights of these past 18 months are the opportunities and relationships I have embraced, most stemming from those individuals who have reached out to me and others I have renewed. Thank you all for a truly rewarding, growth experience.

Goal # 3 – Make a difference in ALS awareness and improve fundraising efforts.

The ALS Society of Quebec (Claudine Cook et al), the ALS Society of B.C., the ALS Society of Canada, the Montreal Neurological Institute (Dr. Genge), the Montreal Alouettes (Larry Smith, Coach

Tony Proudfoot



Team Proudfoot Campaign

Tony has become an inspiration to those who know him personally; to those who watched him play; heard him on the radio; were taught by him or just heard about his story.

Be inspired too! Visit our website: www.sla-quebec.ca/equipe-proudfoot to take part in a unique fundraising campaign starting July 2nd. See how you can pay tribute to Tony or a loved one, upload pictures, tell your story and help build our **Inspired Mosaic**. Hope to see you there!

Maintaining wellbeing with ALS

The first in a series that we hope will help keep you enlightened through your journey

By Julia Asselstine

I have a friend who was diagnosed with ALS four months ago who told me recently that he feels like he is in the dark. "What do you need or want to help enlighten you," I asked. "I want to read about other peoples' journeys with ALS, from diagnosis on," he said. He wanted to hear how they coped—how they were able to maintain wellbeing through it all. And when approaching others with ALS, I heard similar sentiments. So we begin. This will be the introductory to a series of articles that will profile patients, their families, and their caregivers. It will reveal their secrets of wellbeing. With this series, we hope to help keep you "enlightened" through your journey with ALS.

In this issue, we have teamed up with the ALS Program of the Montreal Neurological Hospital/Institute to come up with some concrete advice that can assist in your efforts in maintaining wellbeing:

- Washing hands frequently and trying to stay away from people with colds is strongly advised.
- Conserve your energy. Overexertion may increase one or some of your symptoms. If you prioritize and plan ahead this will help you conserve energy. Reduce your energy consumption and risk of falls by using the appropriate support, such as canes, walkers, wheelchairs, ankle/foot orthotics. If you have a Handicap parking sticker you should use it as this will allow you to park closer to your destination. If possible sit down when cooking and doing similar activities. The key is to listen to your body and respect its limitations.
- Maintain good oral hygiene. The general public at large should adhere to this piece of advice. Bacteria love the mouth and anywhere you find bacteria there is the potential for infection, which can spread to other parts of the body. With good oral hygiene, which includes regular brushing, flossing and visits to the dentist, you can prevent bacteria "overload."

- Don't become socially isolated. It is important to have a social network to help keep your spirits up so you don't feel alone. Social isolation can contribute to stress, depression and the sense of hopelessness. With ALS you are faced with more physical obstacles than the average person, so ask your friends to visit you, join a chat room, or sign up on Facebook. Email your friends often and ask that they email you. Some CLSCs also provide day centre gatherings. By traveling in good company, it will help make your journey easier.

In the next edition of The Bulletin, we will profile a patient and a caregiver. If you think you would be a good profile candidate for this series, please contact us at 514-725-2653.



RESEARCH – A SOURCE OF HOPE

The ALS Society of Quebec is proud to have contributed more than \$275,000 to research over the three last years

Our research program is carried out in collaboration with the ALS Society of Canada, the Muscular Dystrophy Association of Canada and the Research Institutes in Health of Canada. Thanks to these partnerships, we can finance quality and relevant work in the area of neuromuscular disease. For additional information: www.als.ca/research.

Additionally, our partnership with the Tony Proudfoot Fund has enabled us to give more than \$150,000 for research into ALS at the Montreal Neurological Institute.

Fundraising and Awareness

It gives us much pleasure to inform you that we have been hard at work delivering the services we provide, developing and growing new ones and expanding them across the province. We also continue to raise awareness and to add new fundraising events that will help us fulfill our mission.

We couldn't do it without you, our team members, who include our donors, our event participants and our volunteers. Our hope is that we will continue to build our team—our family—and as we grow, so will our stories...

Upcoming fundraising events - mark your calendars!

We are happy to report that we have a busy schedule of events coming up! Please join us by registering, volunteering or sponsoring a participant. For more details on our events, please visit our website at www.sla-quebec.ca

- **Ride for ALS, September 10th to the 12th:** A three-day cycling event will take place from Montreal to Quebec City. Riders from all levels are welcome!



- **Canpar ALS Golf Classic, August 31, hosted by Vincent Damphousse** at Clublink's Islesmere Golf Club. Please visit www.clublinksignaturevents.com to register! We consider ourselves very fortunate to have Vincent and Allana Damphousse as our spokespeople. In all respects, they share in our vision and our passion with which we strive to make a difference. These are people who are not afraid to roll up their sleeves to help us achieve our goals. In fact, during the first Canpar ALS Golf Classic \$175,000 was raised with Vincent at the helm!



- **Walks for ALS:** Year after year, we walk in an effort to continue the expansion of the ALS Society of Quebec. If you wish to organize a walk in your area, please do not hesitate to join us! The dates are as follows:

September 6: Sherbrooke
September 12: Quebec
September 19: Montreal

September 20: Charlevoix
September: Date TBC

- **Our Website:** Please visit our website at www.sla-quebec.ca on a regular basis for news, updates and photos. The new sleek look supports an easy-to-navigate site packed with new and improved content. Secure donations can also now be made online. And you can use our online fundraising program to help raise funds and awareness for ALS!

A WORD FROM THE EDITOR

Tell us what you think!

As this is the first of many newsletters to come, we want to ensure that we are providing a product that is useful and meaningful. We think this means involving you, the reader. We would like to hear what you would like to read about, what you think of the newsletter overall and how you think we could improve.

By mail or email?

In addition, we would also like to do our part for the environment by giving you the option of receiving *The Bulletin* by email instead of mail. Please let us know how you would like to continue receiving it and if you would like to remain on the mailing list. If you know of others who may benefit from this newsletter, please inform us.

You can tell us your thoughts and send us your mailing/email information via mail, email or fax, found on page 8. Thank you for your time—it is greatly appreciated.



SOCIÉTÉ DE LA SCLÉROSE LATÉRALE AMYOTROPHIQUE DU QUÉBEC
AMYOTROPHIC LATERAL SCLEROSIS SOCIETY OF QUEBEC
LA MALADIE DE LOU GEHRIG'S DISEASE
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**JOIGNEZ-VOUS À NOTRE ÉQUIPE/ JOIN OUR TEAM
AIDEZ-NOUS À VAINCRE LA MALADIE DE LOU GEHRIG
HELP US FIGHT LOU GEHRIG'S DISEASE**

Oui j'aimerais faire un DON / Yes, I would like to make a DONATION :

Nom du contact / Contact Name _____

Adresse/Address: _____ App/Apt: _____

Ville/City: _____ Province: _____

Code postal/ Postal code : _____

Tél./Tel. : _____

Courriel / E-mail : _____

25\$ 50 \$ 100 \$ Autre/Other \$ _____

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Make a secure online donation easily and receive an automatic tax receipt.**

ou/ or

Compléter ce formulaire et le retourner à / Please fill out this form and send it back to :

La Société de la SLA du Québec, 6300, Avenue du Parc, bureau 502,

Montréal (Québec), H2V 4H8,

ou par télécopieur au/ or by fax at : 514-725-6184.

Ci-joint, un chèque libellé au nom de la Société de la SLA du Québec /
Cheque in the name of the ALS Society of Quebec is attached.

VISA MasterCard / Date d'échéance/Expiration date : _____

No de la carte/Credit card Number : _____

Nom sur la carte / Name on Credit Card : _____

Signature : _____

**ALS Society
of Quebec Team**

CLAUDINE COOK
Executive Director

MONIQUE MASSÉ
Psychologist

VÉRONIQUE PIGNATELLI
Group manager
Client Services
Social Worker

JOËLLE SOLIVEAU
Equipment and Volunteer
Program Coordinator
(on maternity leave)

We would also like to
welcome the new members
of our team:

ISABELLE JULIEN
Business Development
and Special Events Coordinator

JULIE LAMARRE
Support Services Coordinator

JULIE CLOUÂTRE
Administrative Assistant
and Special Projects Coordinator

WE ARE MOVING!

On August 1, 2009 we will be
moving to better serve you
(parking is free and we are more
accessible). Our new address is:

5415, rue Paré, bureau 200
Montréal (Québec)
H4P 1P7

Telephone : 514 725-2653
877 725-7725

Fax : 514 725-6184

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