Being diagnosed with ALS came as no shock to Nancy, as she had been experiencing the symptoms for several years: stumbling on uneven surfaces, weakening hands that surgery could not fix, and other changes to her body. Multiple tests later ruled out other diseases and confirmed what she had long suspected, that she had ALS.

Nancy is determined to not let this disease break her. She has created a motto which she lives by every day, “I may have ALS but it doesn’t have me.” She praises her family with giving her the inspiration and support to live her life as she chooses, on her terms. Her daughter Victoria takes her shopping every Sunday and helps her with her laundry and other chores. Her son, Matthew, his wife, and grandchildren Etta and Macy visit her every weekend, something she greatly appreciates.

She is also grateful to ALS Canada and the services it provides, and especially the WALK for ALS which she considers to be extremely important. “Not only is money raised for research but also for equipment,” she said. “They can be very expensive, such as my power wheelchair which they recently funded. These tools may not be available otherwise to those who need them most.”

Nancy Smith is a participant in the Kitchener-Waterloo Walk for ALS and is looking forward to this year’s event on June 1st at the new location of Waterloo Public Square.

She had used a cane for several years but now relies on a walker to get around. The disease has not progressed very rapidly and, although she needs some support to stand, she can still cook and even managed to prepare a delicious Christmas dinner for her family.

She tells others with ALS to “do as much for yourself as you possibly can, as long as you can... and keep smiling!”

Join thousands of others as they WALK to support those living with ALS now, through equipment and support programs, as well as those in the future, through ALS Canada’s national research program.

For a full list of WALK for ALS dates and locations, and to register for a Walk near you, visit www.walkforals.ca
Dear ALS Community,

Many of you are probably wondering what is happening during the Transition in bringing both National and Ontario offices under one roof. I am pleased to let you know that the Transition Board and the staff have achieved significant milestones in merging the organizations. 2012 was a successful year in meeting the needs of clients in Ontario, funding world class ALS research in Canada and restructuring the organization while at the same time reducing our deficit to a level where in 2013 there will be a balanced budget.

The merger of the organization consists of 3 phases – Phase 1 Governance, Phase 2 Merging the Operations Function and Phase 3 Process Improvements. The important part of the Governance Phase is to establish a sound foundation including new Bylaws and Governance Operating Policies in accordance with the New Non-profit Act, formation and recruitment of volunteers for the Research, Federation and Client Service Council. The Federation Council has developed a partnership agreement for all Provinces to partner which will be signed at the May Board meeting. Phase 2 of the transition, related to the Governance issues will be completed prior to the board meeting. The nominating committee is actively recruiting for new board members to manage the new combined organization.

In addition to the Transition activities the Client Service team has realigned its territories to better meet the needs of families living with ALS. The realignment will assist in facilitating services within the community such as CCAC and partnership with the clinics.

In order to ensure we can improve client services and conduct peer reviewed research, it is important for us to increase are fund raising capabilities. Dav Cvitkovic, an experienced fund development expert, has joined the ALS team to lead our fund raising initiatives. Several initiatives are well underway in 2013. If you would like to organize an event or participate in the Walk, please visit our website at www.als.ca or contact our office.

In closing, thank you for your support of our organization. Should you have any questions, suggestions or comments, please feel free to contact me at ld@als.ca or at 905-248-2052 ext. 206.

Warm Regards,
Lindee David
CEO

The ALS Canada Research Program is currently moving in a new strategic direction to identify programs where we can leverage our donated dollars with funds from outside sources, while still maintaining the support of the best peer-reviewed research.

In the past few months, we have actively sought three new potential opportunities; (1) the Canadian Institutes of Health Research funded Strategy for Patient-Oriented Research (SPOR); (2) the Institute of Genetics’ E-Rare-2 grant; and (3) the Canadian Consortium on Neurodegeneration in Aging (CCNA). The goal of SPOR is to ensure that innovations and therapies reach patients effectively and efficiently through better integration between research and the healthcare system. The Canadian ALS community is uniquely positioned to fit this initiative in comparison to other neurodegenerative disorders because of our collaborative approach to ALS. Collaboration occurs between ALS Canada, the sole, nationwide non-profit dedicated to care and research, the CALS network of country-wide ALS clinics, a very cooperative and integrated network of basic scientists and the Canadian Neuromuscular Disease Registry. In addition, the E-Rare-2 focuses funds on projects aimed at solving underfunded disorders with prevalence below 1 in 2000: an unique opportunity for ALS researchers to seek dollars free of competition from larger, well funded disease programs. Finally, the CCNA aims to create a functional gathering of the best minds in neurodegeneration research working together towards the common goal of curing these diseases. Our active solicitation of new funding avenues affirms that our Research Program will continue to provide the best return for your precious donations. Our unique approach positions us well for future success thanks to your continued investment that fuels the work of our network of basic researchers, clinicians, patient groups and a registry. These opportunities represent the first of many new exciting possibilities that will move us closer to our goal of a cure for ALS.
Dr. Pierre Drapeau is a recent recipient of a five year CIHR operating grant for his work entitled “Synaptic targets for therapeutic protection of motor function in a genetic model of ALS.” This represents a significant accomplishment as only the top 17% of over 2300 applications received funding.

Dr. Drapeau started his career as a professor at the Montreal General Hospital where he used the zebrafish as a model to understand embryonic nervous system development. Dr. Drapeau is widely recognized for his contributions to the study of synapse formation (connectivity) between nerve cells during the functional development of the spinal cord. He has been studying the development of the locomotor network in zebrafish by combining cellular neurophysiology and molecular genetics. After collaborating with the famed ALS geneticist Dr. Guy Rouleau to use his expertise and zebrafish to create a new genetic model of the disease, Dr. Drapeau continued by creating zebrafish models of other ALS genes. As a professor and Director of the Department of Pathology and Cell Biology of the Faculty of Medicine at the Université de Montréal, he will now use these models to further understand how ALS occurs and to look for potential new treatments. Dr. Drapeau is also a member of the ALS Canada Research Council.

In what he describes as, “a purely Canadian discovery”, Dr. Michael Strong’s laboratory at Western University have discovered a new gene that causes ALS. Last year, a project led by postdoctoral fellow Dr. Cristian Droppelmann described a protein called rho guanine nucleotide exchange factor (RGNEF) which was identified in clumps (called aggregates or inclusions) that appear inside of sick motor neurons and have long been associated with the disease pathology. Further investigation revealed a mutation in the gene that makes RGNEF (called ARHGEF28) as a previously unknown cause of hereditary ALS.

ALS-causing mutant genes create abnormal proteins that are a scientist’s best tool for understanding the disease process and identifying potential new treatment targets. By examining what happens in a living cell or animal that is designed to make the abnormal protein, researchers can find what processes are affected and look at ways to correct the problem.

The first ALS gene to be discovered was in 1993 (SOD1) and it was the only tool available until another gene was discovered in 2006 (TARDBP – makes TDP-43). Since then, additional ALS genes have been discovered including FUS and C9ORF72, which provide many new avenues for studying how motor neurons get sick and lose their function of helping muscles move. These more recent genes share a common link in that they are involved in what is called RNA metabolism. RNA is a transportable form of genetic information that is critical to the creation of proteins, which perform all of our living functions. RGNEF is important in the regulation of RNA for a particular protein that is involved in neuronal structure (called neurofilament light or NF-L) and is well established to play a role in ALS.

Most of these new genes have been discovered through increasingly sophisticated techniques in reading the DNA of affected individuals. However, Dr. Strong’s study "builds on the old fashioned way of discovering things – look for protein, find it pathological in ALS, and then see if it is mutated.” Further studies will reveal how prominent this mutation is in the 10% of cases that comprise familial ALS. Ultimately, this discovery may prove to be a crucial link in our understanding of ALS and is yet another strong demonstration of how Canada is a world leader in ALS research.

ALS Canada would also like to congratulate Dr. Ian Mackenzie and Dr. Johnny Ngsee for achieving full CIHR operating grants in the most recent competition for their ALS-related work.

Dr. Strong recently worked with ALS Canada to create a video in Understanding Research. Visit www.als.ca to view Dr. Strong, a pioneer in ALS research, describing achievements which wouldn’t be possible without the generous support of our donors.
For the third year, Bombardier will be hosting the Plane Pull for ALS Canada at its testing facilities in Downsview Airport on Sunday, May 26, 2013. The exciting event challenges teams of 10 to pull a Bombardier Q400 NextGen aircraft, weighing approximately 37,000 lbs., a distance of 100 metres in the shortest time possible!

Last year, the Markham Firefighters, who held a Truck Pull two weeks prior to the Plane Pull, won the Emergency Services Division, by pulling the full distance in 33 seconds. Team Tony took home the championship in the main competition. Don’t miss out on this thrilling, fun-filled day. Visit www.alsplanepull.ca to register your team or to put your company name to an event the media loves to cover!

Contact Enzo Raponi er@als.ca 1-800-267-4257 or 905-248-2052 x205.

With a mother and now brother diagnosed with ALS, Mylene Facchini could have been overwhelmed. Instead she put her energies into organizing a Zumbathon in Support of ALS where people from across the GTA met at St. Clair Secondary School in Whitby to move and dance for those who no longer can.

After losing her mother and her husband’s uncle to ALS she wanted to create this event to educate more people about this disease. Her brother has also been recently diagnosed with ALS. Held last December in Whitby, the event was a great success with more 300 people in attendance.

The event raised more than $2,300 which goes towards providing support programs, such as equipment, to those living with ALS in Ontario while supporting world-renowned research programs. Mylene credits the ability to give so much to ALS Canada to her sponsors for donating prizes and even a gift basket for the first 150 people attending the event.

Zumba is a form of fitness involving many different types of dance, such as hip-hop, salsa, and belly-dancing. Mylene herself is a certified Can Fit Pro Fitness Instructor and certified Zumba Instructor. She owns a fitness company, Zoga Fitness. If you have an interest or passion, think about turning it into a fundraiser for those living with ALS now and in the future.

ALS Canada thanks Mylene for her hard work and resulting successes! We are grateful to have many supporters like Mylene who find creative ways to honour their loved ones and raise funds for the cause. Check out ALS Canada’s new events calendar at www.als.ca to find an event in your area.

Thank You for Stretching Yourselves!

This past February, ALS Canada held its second annual ALS Yoga Challenge where participants stretched themselves in various yoga classes in a six-hour challenge. The efforts of these individuals also culminated in more than $22,000 raised for ALS Canada’s support programs, such as equipment, and research into a cure. Thank you to all who participated and supported those involved! Special thank you to Extreme Fitness for donating its facility (267 Richmond St., Toronto) for the six classes of yoga!

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WALK FOR ALS:
27 Walks in Ontario, 85 across Canada

As the Spring season approaches, the WALK for ALS is gearing up for its most successful WALK season yet! With more than 85 WALKs for ALS across the country and 27 in Ontario, find a WALK near you to join in body and spirit – together we will continue to provide care for those living with ALS now and in the future!

Thanks to amazing community support, last year the WALK for ALS raised more than $1.4 million in Ontario and $3.2 million across Canada. This year, we’re aiming to raise $1.6 million through Ontario Walks to continue to support those living with ALS.

This annual fundraiser is the primary revenue generator for ALS Canada and money raised supports programs for those living in Ontario, and research towards a cure.

Last year, ALS Canada loaned more than 2,000 pieces of equipment while Canada led the G8 in peer-reviewed ALS research per capita, twice as much per capita as the U.S., which is the leading research community in the world.

Provincial Sponsors:

2013 ONTARIO WALK FOR ALS LOCATIONS AND DATES

- Alliston: June 1, 2013
- Almonte: June 15, 2013
- Barrie: June 8, 2013
- Belleville/Quinte: TBD
- Cobourg: April 28, 2013
- Cornwall: June 8, 2013
- Durham Region: June 15, 2013
- Georgetown/Acton: June 1, 2013
- Halton Region: May 20, 2013
- Hamilton: June 8, 2013
- Kingston: June 22, 2013
- Kitchener/Waterloo: June 1, 2013
- Niagara Region: May 26, 2013
- Orangeville: June 1, 2013
- Ottawa: June 15, 2013
- Parry Sound: Sept. 21, 2013
- Peel Region: June 8, 2013
- Smiths Falls: Sept. 14, 2013
- Sudbury: June 22, 2013
- Thunder Bay: Sept. 28, 2013
- Timmins: June 8, 2013
- Toronto: June 1, 2013
- Wellington North: June 8, 2013
- Wingham: June 22, 2013
- York Region: June 2, 2013

Walking Virtually Anywhere!

If you can’t find a WALK for ALS near you, you can always do a Virtual WALK for ALS! Go to www.walkforals.ca and register for a virtual WALK for ALS and raise money through online donations. You can then do a walk at your convenience and still support those living with ALS now and in the future.

Last year, Team Schimdt had family members participate in a Virtual WALK across the country and in the United States, and raised more than $1,500!

Get Mobile! Make it simple and download the WALK for ALS app through iTunes and Google Play.
Many years ago, her close friend lost his father to ALS, and by organizing and facilitating this group, she is helping to improve the local situation by providing a place for those affected by ALS to get advice or simply talk about their experiences. The regular meetings help those recently diagnosed transition into their new life, and provide comfort to those who have lost loved ones to the disease. Caregivers and family members are also welcome.

“There were not a lot of resources available,” Denise said. “ALS is a terrible disease and a support community is extremely important for those suffering. After my own experiences, I realized how much London needed a caring support group.”

Her efforts have been well received by the ALS community. Each meeting can draw anywhere from five to 20 people and Denise has received a lot of positive feedback from attendees who find the meetings beneficial. They are grateful for the comfort found in small groups, and Denise continues to organize these meetings because she believes in the value of volunteering as a way to contribute to the community. “I like to help people,” she said.

ALS Canada thanks Denise for her ongoing commitment to client care and all volunteers who support those living with ALS.

For a listing of ALS Canada’s support groups across the province, visit www.als.ca.
NEW SERVICE MODEL TO SERVE ALL CLIENTS IN ONTARIO

ALS Canada - Ontario Client Services continues to be committed to providing services to the approximately 1,100 individuals and their families living with ALS in Ontario by expanding our service coverage.

In an effort to ensure that all clients have equal access to services, ALS Canada rolled out a new service model that re-aligns the service area of our current resources to be in accord with the local Community Care Access Centres (CCAC). This means that there will be a Regional Manager designated for all areas within the province.

The vision for Ontario Client Services is to provide consistent quality programs and services delivered throughout the continuum of the disease to people living with ALS across the province. We are committed to achieving this vision.

The role of the Regional Manager will continue to be:

- To provide information about ALS
- To assist in advocating for timely and appropriate services to meet the needs of clients and families
- To enhance community awareness about ALS

This exciting opportunity will allow us to work with the clients, families, healthcare professionals and community services to ensure every moment matters.

Contact a Regional Manager 1-800-267-4257

Brigitte Labby, N. Central Region, x208, bl@als.ca
Charlene Spector, Thames Valley, x217, cs@als.ca
Joanna Oachis, Toronto West - x 220 jo@als.ca
Laurie Laxer, Greater Toronto Area, x221, ll@als.ca
Lianne Johnston, Champlain Region, x223 lj@als.ca
Nada Loughead, Central East/Durham, x224 nl@als.ca
Sarah McGuire, Simcoe/York Region, x225, sm@als.ca
Sarah Reedman, Central Toronto, x226, sr@als.ca

WHEN THE DOCTOR BECOMES THE PATIENT

By: Dr. Jeff Sutherland

"You are really telling me that I have ALS!"

I can still remember saying to my neurologist colleague who initially diagnosed me. I had already come to that conclusion myself but had been afraid to verbalize it. I did think it would take longer than a 30-minute appointment to prove my fears! After all, I only had symptoms of twitching and left shoulder weakness. I was still active at the gym and thought that, even though I was 41, I was in the best shape of my life.

I think because I was a colleague there was no need to tiptoe around the diagnosis. I think, in retrospect, a little tiptoeing would have been appreciated. I rushed back to the office and put my problems behind me as I listened to everyone else’s problems. This would become one of my crutches to help deal with my growing physical limitations: still being able to help others with their illnesses even though there was no help for my illness.

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The next year carried on pretty much as usual except I gave up my emergency room work. Slowly but surely, over the second year different parts of my practice would be surrendered as my body could not do the skills demanded of it. Like all ALS patients, the mind is so willing but the body stubbornly refuses to comply.

I was lucky I got to work those two years. Normalcy, or the adaptations that one has to go through to make a new normal, is essential to living with this disease. With my crutch disappearing I knew that I had to find more to keep my mind healthy. I would have to start redefining all of my previous self perceptions! During the last few months of my ‘Doctoring Days’, one of my patients, Melanie Franke, approached me with the idea of having a Walk for ALS in Georgetown /Acton. Through her friends and my friends, we ended up forming a Walk Committee that would raise more than $250,000 in our inaugural year. Money that is so needed for equipment, family support and research to end the suffering! More importantly we raised the knowledge of ALS in our community.

Our Walk is in its fifth year now and I know that the $1 million mark is very close. I know that I will be around to celebrate that! I never thought I would have this disease but I am going to make sure I do as much as I can so that in the future there will not have to be anymore Walks for ALS!

Thank you, Dr. Sutherland, for your contribution! To find a WALK for ALS near you, visit www.walkforals.ca
85 WALK LOCATIONS ACROSS CANADA
REGISTER TODAY!

JOIN THOUSANDS OF CANADIANS FROM ACROSS CANADA
FOR FITNESS, FUN AND THE FIGHT AGAINST ALS

HOW YOUR DONATION BENEFITS THE ALS COMMUNITY
EVERY DOLLAR YOU RAISE GOES TO PROVIDE EQUIPMENT, SUPPORT SERVICES, EDUCATION
FOR THE ALS COMMUNITY, AND FUND RESEARCH TO FIND A CURE.

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