

# ALS Community News

## The Newsletter of ALS Ontario



### Power of Creativity

Volume 6, Issue 1

Spring 2012



Mario's creativity is an inspiration to many as is his positive attitude; left, Mario with his wife Maria, right, his 3D art.

#### Inside this issue:

Greeting from ALS Ontario	2
Making Moments Matter	3
Snapshot Events	4
Equipment Survey	6
Caregivers Series	7
Giving Back	9
A Lending Hand	10

#### Other Features

- Equipment Statistics and Services
- Client Story: Eddy LeFrançois—Let's Roll
- Power of Family: Paradis Family WALK Story



### Painting a Pretty Picture with Positivity

Mario Fabiano has always been a creative person, pulling from life's beauty to create paintings and other forms of art over the years. He has painted from memory (especially landscapes of his hometown in Italy) and inspiration, even creating 3D paintings; he has crafted bird houses and is now working on a doll house with details down to tiled floors. His mind is always thinking of his next creative project despite being diagnosed with ALS in 2003.

"I've always been positive," said Mario. "I have pain in my hands when I paint but I keep going because it's good to keep your mind going, away from suffering. It would be worse to do nothing."

Mario has always worked with his hands, immigrating to Canada from Italy in the 60s, where he set to work as a barber. With his wife, Maria, he brought up his daughter Stefanie who is now a teacher in the Toronto area.

Now Mario keeps his mind active despite his physical restrictions from ALS.

"I won't say I feel bad," said Mario. "The main thing is to be positive. If I get pain in my hands so I can't hold a paint brush, I try something else. At least to try it. It's like poking at a sore tooth; if you keep touching the tooth with your tongue, the pain will be there all the time. I don't touch it, I don't think it."

Mario is now completing a large doll house with tiled floors, stairs and balconies with banisters, curtains, and a white picket fence to complete it.

"I picture how I want things to look then try to re-create it. It keeps my brain working and alive."

His family, friends and neighbours have pulled together to support Mario. The family is grateful to neighbours who help out by shoveling, mowing the lawn and driving him to his doctor appointments.

"Even if something bothers him, he tries to handle it in his own way," said Maria. "Our family and friends have been amazing which

means a lot. Stefanie, our daughter, is the best medicine for him."

Stefanie participates in the Toronto WALK for ALS each year in support of her dad, under the team name, Mario's March.

"My dad is the most positive and inspiring person I know," said Stefanie. "I became involved with the Toronto WALK for ALS two years ago and we tripled the number of people walking from the first year to the second and our support in donations has been great. ALS Ontario has provided things for my father to make his day-to-day life a little bit more comfortable. This is why I've chosen to donate to ALS Ontario as my guest favours for my upcoming wedding."

With the support and power of his own desire to keep active despite living with ALS, Mario continues to enjoy daily

*Continued on page 2*

## Message from Bob

I have been actively engaged with the Board of Directors of ALS Ontario for almost six years, and for the last six months as interim President and CEO; my involvement as a volunteer dates back to 1997. In all that time the singular and overwhelming motivation for me has been the stories of our clients and the desire, indeed the need, to help them along their path. And I know that motivation drives our staff, our volunteers and our donors as well. And the client stories keep coming, and the need to help them on their path continues.

So, as we find ourselves in 2012, it is time to renew our efforts to support those living with ALS. There are many ways in which you can get involved. ALS Ontario has a number of exciting events such as the second annual ALS Ontario Plane Pull and WALK for ALS.

These events are part of our mission to make every moment matter for those living with ALS. ALS Ontario's new Moments Matter campaign aims to change this and you can help.

Join us to give the Gift of Voice. You can equip our clients with the latest communication technology to express their thoughts. You can provide access to virtual peer support groups and peer mentors.

By supporting our volunteer program, you can give the Gift of Connection. Our volunteers visit homes, facilitate support groups and assist caregivers when needed.

Our equipment loan program gives flexibility to clients at little to no cost, removing a major financial burden. Giving the Gift of Movement will help expand and improve the equipment loan pool. This enables clients to live with dignity in their own homes.

Lastly, you can give the Gift of Peace. When one breadwinner is diagnosed with ALS, the other will often leave their job to become a fulltime caregiver. Almost 40 per cent of Ontario families coping with this disease find themselves in financial crisis.

These gifts will help ensure that every moment of each precious life is lived to the fullest.

With your generous help, we can make moments matter.



**Robert Webster**  
Interim President & CEO  
ALS Ontario

## Behind the Scenes



The new ALS Ontario website is live (it can be found through [alsont.ca](http://alsont.ca), [alsontario.ca](http://alsontario.ca) or [alsontario.com](http://alsontario.com)). The new website holds information on ALS, ALS Ontario, services, information for clients and families, and for healthcare professionals, news, volunteer job postings, and a new blog.

Also available is a Virtual Scrapbook so you can post your pictures and memories to share with family and friends online.

If you want to remember a loved one virtually, the Memorial section allows you to pay tribute to that loved one.

ALS Ontario's social media, such as Facebook, Twitter and

YouTube feeds, are integrated into the home page of the new web site.

The ALS Ontario Plane Pull has its own micro site through the new web site where you can register your teams online and donate to the event.

Visit the new website and participate in the online ALS community through Scrapbooking, Memorials or the MyALS section where you create your own account to keep your virtual presence in one easy-to-use place.

Join in on our virtual ALS community to hear the latest news, meet others going through similar experiences and hear advice from experts.

## Power of Creativity—Continued from Page 1

activities such as walking around the neighbourhood using his cane and walker.

“When people ask how I’m doing, I say I’m 102 per cent so then the next day I can say 103 per cent,” said Mario. “I’ll keep walking until I no longer can. I plan to walk my daughter down the aisle at her wedding.”

Stephanie is getting married this July and her guest gifts are donations to ALS Ontario.

“It’s good to keep the mind going, away from suffering. It’s worse to do nothing,” said Mario.

“He chooses to stay positive and not allow the illness to affect his moral spirit,” added Stefanie. “Even if he doesn’t feel good, he will put a

positive spin on it. Positivity is a great piece of medicine that I think more people should have in their lives. When I have a bad day, I think of my dad and what he suffers through daily and realize my day is not so bad after all.”

*Pictured below are pictures of Mario’s doll house, including the kitchen with individual tiles.*



## ALS Ontario Co-Presents Hot Docs’ Jason Becker: Not Dead Yet

ALS Ontario is pleased to co-present another Hot Docs film which highlights guitarist Jason Becker’s inspirational story in living with ALS.

According to Hot Docs: Jason Becker should have been a household name. A guitar prodigy from a young age, Jason burst onto the scene with his band Cacophony, garnering notice from the major industry players. In 1991 Becker was hired as lead guitarist in David Lee Roth’s band, the most coveted guitar gig at the time, but Jason never made it on tour. Shortly after recording the album, he was diagnosed with ALS and given five years to live. Archival footage of Jason’s rise to almost-stardom is given the exposure it deserves with this inspiring rock doc. More than 20 years

later, Jason is still living strong and making music by communicating with his eyes. A true testament to the strength and possibility of the human spirit.

The Toronto Hot Docs screenings are April 28, 29 and May 6—[www.hotdocs.ca/film/title/jason\\_becker\\_not\\_dead\\_yet](http://www.hotdocs.ca/film/title/jason_becker_not_dead_yet)



## SNAPSHOT: Making Moments Matter

### 2011 Equipment Review

#### New clients registered in 2011:

301

#### Total number of equipment requests 2011:

2415

#### Number of hospital beds in use:

135

#### Number of lifting devices (ceiling and Hoyer) in use:

119

#### Number of lift chairs in use:

199

#### Number of leased communication devices in use:

137

#### Number of tilt commodes in use:

57

#### Number of manual wheelchairs in use:

210

#### Number of power wheelchairs in use:

131

You can help the growing needs of our client base by giving the Gift of Movement.

The Moments Matter campaign aims to raise funds for key areas within ALS Ontario, including the Gift of Connection, Gift of Peace and Gift of Voice. The Gift of Movement supports the equipment loan program that most our clients rely on as the disease progresses. Help us help others!

Thank you to those who participated in the **ALS Ontario Equipment Satisfaction Survey!** Results are now available (contact Eleanor, VP Support Services). See a snapshot of results on page 6.



### EDDY LEFRANÇOIS: Let's Roll!

By Joseph Ho

Eddy Lefrançois is no stranger to adversity. When he was nine-years-old, his mother was diagnosed with cancer, which she fought courageously until she succumbed to a brain tumour five years later. Over these tough formative years, Lefrançois learned to appreciate the good things in life, an important lesson with practical applications, considering how he would later be diagnosed with ALS. It was an illness that he knew by its common name, "Lou Gehrig's disease," and only tangentially as the neurological disease that caused muscular atrophy.

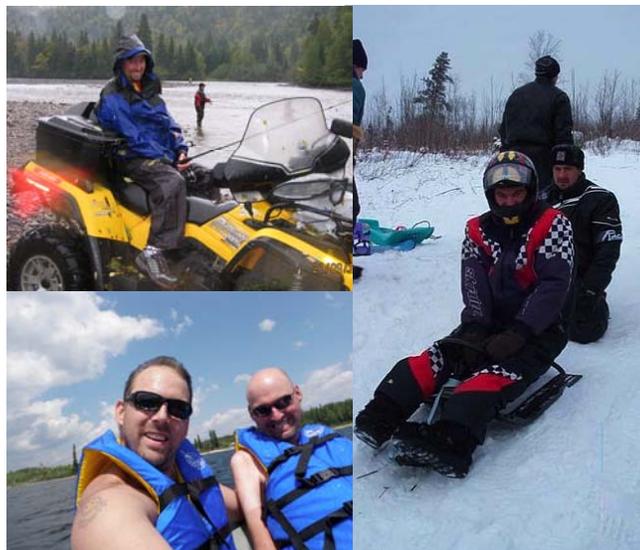
"Now that I'm living with a deadly disease, I have to show my mother that her fight taught me how to fight," he said. "I'm often referred to as stubborn. I like to think that I know what I want instead."

So just what does Lefrançois want? Perhaps it is to be miraculously cured of this terminal illness. Certainly, an understandable request for which no one would hold against him. But what he really wants is to live a rich life regardless of the obstacles he encounters.

**"ALS can't take your smile away, you use less muscles to smile than to frown. Also, ALS can't take away the fact that you always have a choice."**

Lefrançois' attitude can be found on his website ([www.lets-roll.ca](http://www.lets-roll.ca)). It provides an overview of ALS, his wrist-watch collection, but most importantly, his philosophy. Apart from getting adequate rest and keeping a healthy diet, he ignores things that lie beyond his control.

"I can't control what others say or do. People often forget that life is a gift, it's beautiful, why complicate it, keep it simple," he said. "I block the negatives around me, if others choose to be negative, I don't have to be subjected to that."



*Lefrançois participating in various recreational activities.*

Lefrançois believes his positive outlook on life has helped in his 20-year journey with ALS. Since his diagnosis almost two full decades ago, he is now 42.

"I was diagnosed in April 1992. As I like to say, since 'my expiry date' was April 1997, I've long exceeded my expiry date. This is all bonus for me," he said. "Gotta [sic] enjoy life. I do what I can with what I have."

What he has, among other things, is the support of ALS Ontario through the provision of equipment and services designed for his needs.

**"ALS Ontario has been a great help to me with the loan and purchases of wheelchairs, ramp, computer chair, or any questions I may have had. The financial help I've received is appreciated," Lefrançois said.**

But living with ALS is more than simply getting through each day. He also has family and friends who enable him to experience the thrills of a healthy person such as sledding and riding ATVs.

"Who says living with ALS has to be boring? My sister, brother and my friend, Eric, make sure I stay active. I do what healthy people do. We just do it differently, that's all," he said. "We hunt, fish, four-wheeler ride, ski-doo, sliding on a GT. You name it, we probably did it, or would try it as long as we felt safe."

Continued on page 11

## SNAPSHOT: EVENTS TO EDUCATE AND BUILD AWARENESS

### Help Make Moments Matter at the 2012 WALK for ALS!

The most cost-efficient way is to register online at [www.walkforals.ca/ontario](http://www.walkforals.ca/ontario).

Create your own webpage where friends, family and colleagues can read your story and make a secure donation to your WALK campaign.

#### Top seven advantages to registering and raising funds online:

1. Shorter lines at registration (no one wants to stand in line...)
  2. Reduced administrative costs for ALS Ontario – your data entry is done, all your online donors receive their tax receipt automatically by email and our reporting process is simplified. What a great way to be part of the solution to lower administrative costs.
  3. Statistics show that people give more with their credit card than those who donate cash in person.
  4. You can create a personal webpage that tells why you are passionate about helping those with ALS. You can post a few pictures and put links to videos on YouTube.
  5. From your webpage you can send an email to friends, family and colleagues with a link that takes them directly back to your page where they can make their secure online donation.
  6. Your webpage will track your donations, showing progress towards your goal.
  7. Step-by-step instructions for the website are available at the top of the home page – click on “Website How-to-Tips” for a .pdf document that will guide you through the process.
- Having problems registering online – give us a call – we’d be happy to help! 1-866-611-8545 x218

### Virtual WALK for ALS Now Available! If there is no WALK for ALS in your area or you can't make it on the day of your local walk, take part in the Virtual WALK for ALS!

Here's how you can participate:

- Go to [walkforals.ca/ontario](http://walkforals.ca/ontario).
- Click on the sign up button to register.
- Choose “Virtual Walk” from the list of WALK locations.
- Set up your personal page.\*
- Raise funds online—you can send emails from the website to others who will direct them to your personal webpage.
- Do your “Walk around the

block” before September 30, 2012.

\*For instructions on how to use the website, click on the “How-to-Tips” link at the top of the home



page at [walkforals.ca/ontario](http://walkforals.ca/ontario).

#### Please note:

All virtual walkers must register and raise funds **online by credit card only**.

Virtual walkers are also eligible for contests and fundraising rewards (incentives) – we will mail them to you in October, 2012.

Questions? Call Christine Kirby, Manager, Events at 1-866-611-8545 ext 218.

## 2012 WALK DATES

Acton/Georgetown - June 2  
 Alliston - June 2, 2012  
 Almonte - June 16  
 Barrie- June 9  
 Belleville - September 22  
 Brampton - see Peel Region  
 Cobourg - June 16  
 Cornwall - June 9  
 Durham Region - June 23  
 Halton Region - May 21  
 Hamilton - June 2  
 Huntsville - to be determined  
 Kingston - June 23  
 Kitchener-Waterloo - June 9  
 London - September 29  
 Mississauga - See Peel Region  
 Niagara Region - May 27  
 Orangeville - June 2  
 Ottawa - June 16  
 Peel Region - June 9  
 Smith Falls - September 22  
 Stratford - merging with Kitchener-Waterloo  
 Sudbury - June 23  
 Thunder Bay - September 29  
 Timmins - June 9  
 Toronto - June 2  
 Wellington North - June 9  
 Wingham - June 23  
 York Region - June 3  
 Virtual Walk March - Sept 30

Register at [www.walkforals.ca/ontario](http://www.walkforals.ca/ontario)

## One Rope, One Plane, One Great Cause: ALS Ontario PLANE PULL Presented By Bombardier



exciting event! Last year, the Toronto Firefighters took first place and the Markham Firefighters (who did a Fire Truck Pull in advance of last year's Plane Pull) placed second, pictured left.

Last year's ALS Ontario Plane Pull was such a huge success that all organizing bodies (ALS Ontario, Bombardier and The Marketing Store) are well underway in the plans for the second annual ALS Ontario Plane Pull on May 27th! Get your company or friends & family team together so you don't miss out on this year's fun,

This year, on Sunday May 27th, you and nine co-workers or friends can pull a plane to support ALS Ontario, which provides equipment and support programs for those living with ALS.



This incredible event is a great team-building exercise for your company and excellent sponsorship opportunities exist to add value to your pull.

Any corporate or association team that registers to pull the plane (Bombardier's Q400 airplane) will automatically get a Silver Sponsorship level and some great recognition as our way of thanking you for your support.

Visit [www.alsont.ca/alsplanepull](http://www.alsont.ca/alsplanepull) for more information. Like us on Facebook

([Facebook.com/ALSOntario](https://www.facebook.com/ALSOntario)) to see pictures and videos from last year's event. For more information, contact [brian@alsont.ca](mailto:brian@alsont.ca)

Pull a plane for ALS Ontario!



## Power of FAMILY: the Paradis Family WALK for ALS Story

By Joseph Ho

When the weather warms and spring comes rolling in, the season of WALK for ALS kicks off. These Walks are organized by dedicated ALS Ontario volunteers aiming to raise awareness and funds for ALS Ontario client care and support as well as research for a cure.

Hundreds of participants, crossing generations, take part in each of these events. They walk and traverse in motorized wheelchairs while decked in their purple WALK for ALS t-shirts. For former ALS Ontario client, André Paradis, who passed a few months ago, the annual event showed what can be accomplished when families, volunteers and community supporters walk together.

The Paradis family began participating in the WALK for ALS in 2002 when two of André's siblings were diagnosed with ALS. André committed to raising thousands through the WALK for ALS, under a campaign he called \$25,000 for 25 km, and asked his friends to help meet his goals to support his siblings' diagnosis. He ended up surpassing this goal.

Then André himself was diagnosed with ALS. On retirement, his plans were simple: to play golf and spend time with his grandchildren, enjoying the fruits after 30 years of labour. After returning from a trip to Vietnam, where his daughter and son-in-law adopted twin daughters, he decided to play a



The Paradis family participating in the WALK in 2010, top right; 2008, top left; 2007, bottom left; 2004, bottom right.

round of golf to help him re-adapt after his jet lag.

"But I played the worst game of golf I've ever played," André had said. "I thought I was really jet-lagged but it was when I couldn't turn on my bedside lamp that I thought something was wrong."

Two of André's siblings succumbed to ALS, leading him to deduce that this was the disease he was experiencing.

In 2010, André participated in the WALK for ALS in Ottawa, travelling a few hundred metres in the event. His son Charles and his wife Erica were also there. It was an inspiring feat, his son Charles wrote in a letter to ALS Ontario.

"It was a strong reminder of who we do this walk for," Charles wrote. "[It's] for those who can't."

Last year, André was unable to participate on the pavement, but saw many of the WALK's participants through an iPhone video-call.

André's contingent of supporters was nick-named "André's Army." Their original fundraising target was \$1000. By the day of the WALK, they had exceeded their goal by raising \$3356.

It was an achievement that touched André. In Charles' letter, he included his father's thoughts, transcribed through special voice-

recognition software.

"How marvelous it would be if anyone everywhere affected by ALS was blessed with as many friends and supporters as I seem to be," he said.

"Overwhelmed, grateful, appreciative, thankful are just a few of many words that I could use to express my appreciation for your support this year and in past years. None of them however, can do justice to the depth of feeling that I have for all of you at this moment. My wife Charline and I are at a loss for appropriate words to express our gratitude."

André passed away last December, six months later, but in Charles' letter he called for greater ALS awareness. He said that the majority of people still do not know about the disease and its effects but with enough public education, he hopes that finding a cure would become a government priority.

"After approximately 140 years of knowing about this disease, it's high time that the community of citizens, political leaders and research [and] medical leaders resolve this most terrible of diseases that appears to be affecting increasingly more people," André had said.

Those who walk might do it for the journey; but, they have every intention to reach this destination.

### UPCOMING EVENTS

#### April 13th

ExtraORDinary Tribute Event—KickOff Reception of the Doug Ord Memorial Fund 7-10 p.m., Toronto Police Association Hall 180 Yorkland Blvd., Toronto  
Ticket: \$40—reserve with [maisie@alsont.ca](mailto:maisie@alsont.ca)

#### April 29th

Cornwall Fundraising Breakfast Knights of Columbus (2nd & Amelia St.) 9 a.m.—1 p.m., \$5 (\$2.50 for kids) at door  
Contact [lianne@alsont.ca](mailto:lianne@alsont.ca)

#### May 12th

"Make Change Happen" Spaghetti Dinner & Dance, Mifo Orleans 6600 Carriere Street, Orleans  
Tickets are \$15, contact Julie at 613-355-8553

#### June 9th

2nd Annual ALS Fundraiser Wild Wing 80 Courtney Park Drive East, Mississauga

#### London Bingo

April 29th, 5-10 p.m.  
May 8th, 5-10 p.m.  
June 2nd, 5-10 p.m.  
July 1st, 5-10 p.m.  
August 1st, 5-10 p.m.  
Held at Lucky Days Bingo in London. Contact Sandra at [sandranunn@rogers.com](mailto:sandranunn@rogers.com) to volunteer!

#### Toronto Marathon

ALS Ontario and our partner GoodLife Fitness invite you to run for those who can't!



The GoodLife Fitness Toronto Marathon

takes place on Sunday May 6th, 2012.

There are several race options from which to choose whether you are a marathoner or someone

who thinks a 5 km race is just perfect!

We need as many runners as possible to show support for ALS clients and their families in Ontario.

Consider getting your neighbours, running club, work colleagues and family members involved! Runners of all abilities are welcome! Contact Brian Dunphy, Manager Business Development for more information and to get fundraising!

Go to [www.torontomarathon.com](http://www.torontomarathon.com)

# ALS ONTARIO CARE COMMUNITY

## A Caregiver-turned-Volunteer Perspective

By Kate Payne

When Donna Fitzgerald's husband was diagnosed with ALS, her life changed forever. She became a support system and caregiver for her husband, but also for her community.

Often caregivers forget to take time for themselves, feeling guilty that they are being selfish if they do. Caregiver burnout, for those caring for loved ones battling ALS, is very high. The caregiver has to adjust to changes in the whole dynamic of the family structure. Whether it is giving up a job, care giving full-time, raising children, or household financials, daily routines can be overwhelming at times.

Donna knows first-hand what it feels like to try and do everything for your loved one and maintain strong ALS support in her community. She is a strong supporter for a Respite and Education centre for those living with ALS and their loved ones in the Kingston area. There are currently two rooms set up at St. Mary's of the Lake Hospital, but these rooms are not always available for ALS patients. Donna hopes to raise money through her marathon running, wearing her Mind and Muscle running shirt to raise money towards a respite room in the new proposed Providence Care Hospital in Kingston. Clients with ALS need these types of rooms as a result of a crisis, whether it is medical or their caregiver is burnt out and needs rest.

Donna is extremely committed to caregiver support and care. She is advocating for the importance of support groups as caregivers



need a safe environment where they can speak and feel heard. Hope for the disease is in education and understanding. She feels that if she can offer information and personal experience, answering a few questions for new patients and their family, then she has succeeded in making a difference even in small way. The ALS manual and ALS Ontario are great resources for those diagnosed with ALS. Doctors can also be a great resource and the Neuromuscular Clinic in Kingston offers wonderful resources and a caring and knowledgeable staff.

Her advice to current and future caregivers? **“Always accept as much help as possible, whether it is from health care professionals, family friends or coworkers. You never know how long your journey is going to be and you need all the help you can get.”** Donna also suggests educating yourself about the stages of the disease so that you can be prepared. Knowing that your life is being turned upside down can get frustrating and

make you angry, and it is normal to have these emotions.

Visit Donna's website at [SurviveALS.ca](http://SurviveALS.ca) and read our Caregivers Series on page 7.

### Swallowed by ALS Tsunami

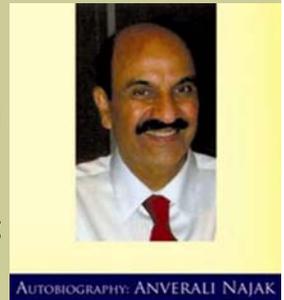
*Swallowed by ALS Tsunami* is Anverali Najak's autobiography. It is the story of one person with an extraordinary vision to lift his community and his fight against ALS.

Anver lives with ALS, losing the function of his feet, hands and legs. In October 2011, he decided to write this book to leave a written legacy for his grandson, family and more than 3,000 ALS patients in Canada.

While Anver enjoys writing, he had help putting this volume together. His personal care worker typed his story while another friend helped with editing. ALS Ontario volunteer Josh Willms helped with proofreading.

He hopes proceeds from the book's royalties will go towards supporting ALS care and research. To order *Swallowed by ALS Tsunami* online, visit: [trafford.com](http://trafford.com), [amazon.com](http://amazon.com) and Barnes and Nobel websites.

Thank you, Anver, for sharing your story!



## ALS Ontario Equipment Satisfaction Survey Results

In an effort to ensure that the Support Services provided by ALS Ontario are valued by and meet the needs of people living with ALS in Ontario, a client satisfaction survey was taken in 2011.

The survey was developed to garner feedback on the quality, professionalism, responsiveness and value of information and services provided. Clients were also asked to rate the importance of services such as home visits and contacts by Regional Managers, equipment program and group activities.

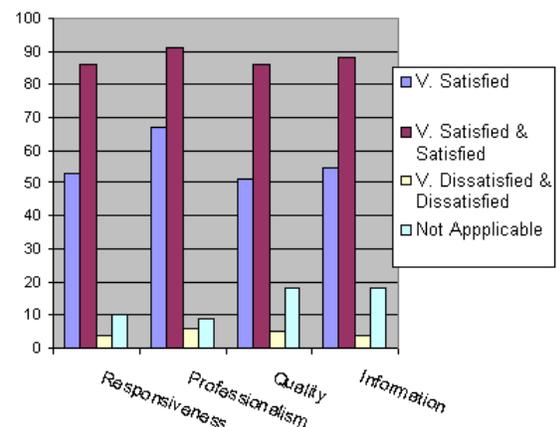
More than 700 surveys were mailed to registered clients and a return rate of approximately 35 per cent was

realized. The graphs indicates more than 80 per cent of respondents rated each of professionalism, responsiveness, quality and information provided as "very satisfied" and "satisfied."

Equipment loan and funding assistance were the top most valued services with each receiving "very important" and "important ratings" of over 90 per cent. Support Services received an overall rating of 83 per cent of "excellent" and "good."

For full survey results, contact Eleanor, VP Support Services.

Client Satisfaction Survey 2012  
Satisfaction with Services Provided



## Caregiver Series: You Cannot Give Care If You Do Not Take Care

*The Caregivers Series is an opportunity for caregivers to share their experiences and tips in living with ALS.*

*ALS Ontario routinely sees the efforts of the caregiver and aims to assist this position. Beyond support groups, ALS Ontario offers caregiver training, mentorship programs as well as volunteers to help caregivers 'regenerate their batteries'. Through this Gift of Connection, no one is alone in living with ALS.*

*Reach out to ALS Ontario to see how you can be supported or if you would like to share your experiences.*

*This Caregivers Series is brought to you by Beth Martin whose husband has ALS.*

From a very young age, my parents provided me with a gift, by introducing me to swimming, an activity and sport, in which I have found comfort, balance and solace. From that time on, I was magnetically drawn to this wonderful new universe, not only learning to swim, but also doing my best to excel, competing in both distance and sprints through high school, university and since. The water challenges my physical being and simultaneously I find myself in a milieu that always allows me to balance my emotions and psyche, exhausting me physically in a very satisfying way. It has been a gift, which has continued to serve me throughout life. In water and by swimming, I can always relieve myself of stress, increase my strength, become balanced and ready myself for life's next challenge.

I have since been faced with one of my greatest challenges when my husband, John, was diagnosed with ALS after several years of concern, worry and recognition that something was wrong. When we finally had our second visit to the Sunnybrook ALS Clinic, we were relieved to finally to put a name to this progressively deteriorating problem that we had been dealing with for years. The diagnosis was not what we hoped for or wanted, but at least we knew what we were dealing with and could begin to fight back.

We were welcomed to the "Clinic of Last Resort." Although it sounds harsh, we appreciated the honesty, and began to understand the magnitude of the battle that lay ahead. For me the question now became how I dealt with the progression of the illness, as well as the ultimate premature loss of my partner, best friend, love, handy man, gardener, plumber, electrician, helper, clown and general trouble-maker.

As we travel on this journey together, I have found that ALS is a slow, sometimes funny, sometimes sad and often a very painful journey. With each day, we experience little changes, progressive loss of strength and loss of his abilities to do things he was able to do the day prior. With each loss of an ability, no matter how minute, I mourn. His body is fading, and I mourn every loss.

**"If we are not able to keep ourselves healthy in all aspects of our being, it is difficult to take care of our loved ones, and maintain a positive environment with a positive attitude."**

So daily, I must prepare for the inevitable – prepare physically, cherish our time together and share in laughter, balance my psyche, physique and emotions, particularly since at this point in time, given it is primarily just the two of us meeting the daily struggles. Once again, as always, I depend on my swimming to give me the physical strength as well as emotional and psychological balance to work through daily changes in our ALS journey.

Given my training is that of a distance and competitive swimmer, the extensive 2.5 kilometres in water, several times weekly, provides me with the alone time needed

to accomplish this balance. This time is necessary in order to be able to continue the journey bestowed upon John and me and to have the energy, fortitude and stamina to fight it. When possible, we savour our time together and look for the humour every day in every situation. No matter the situation or predicament confronting me prior to the workout, the physical activity and aloneness in the water allows me to gain the physical, emotional and psychological strength to once again confront our challenges. It regenerates my batteries!

**Based upon my experiences in this journey with John, it is critical for the caregivers, to take care of themselves in all senses of care – emotionally, physically and psychologically. If we are not able to keep ourselves healthy in all aspects of our being, it is difficult to take care of our loved ones, and maintain a positive environment with a positive attitude.**

Finding an outlet, whatever suits your abilities, whether it's walking, yoga, Chi Kung, meditation, jogging, cooking, or dancing, if it provides a change in environment where one can remove themselves from immediate struggles and exercise your body, mind and spirit, it will serve you and your loved one. As much as possible we caregivers and our loved ones should take care of one another, enjoy the precious little time we have to share with each other, make memories, and laugh as much as we can.

ALS can be a long and debilitating journey, and, we, the caregivers are a critical component to providing dignity and joy through the journey. Caretakers: "To Thine Own Self Be True." Take care of yourselves!

# ALS ONTARIO CARE COMMUNITY

## Home Visiting Volunteer: Margaret Gianna

By Joseph Ho

Margaret Gianna is a Home Visiting Volunteer for ALS Ontario and has been on the job for a year-and-a-half now. Her job is to provide clients with companionship, assistance with tasks such as phone calls and housekeeping, and to give caregivers a much-needed break. After visiting clients, volunteers like Margaret submit reports to ALS Ontario detailing what takes place. She acts as the "eyes and ears" of ALS Ontario, notifying Regional Managers of problems that are not always easily identified.

Home Visiting Volunteers do this by providing feedback to ALS Ontario Regional Managers on client status in the form of log reports.

Like many who help the ALS cause, Margaret has a family connection to the disease that served as the impetus to get involved.

"I chose to get involved with ALS [Ontario] because I discovered that my cousin, who lives in the UK, had been diagnosed with the disease and since I couldn't be of service to her, I wanted to help others in the same situation," she said. "I chose to be a Home Visiting Volunteer because I thought I could do that best."

But volunteering didn't come without its challenges. Margaret found it difficult to take the first step and reach out to ALS Ontario. However, despite her initial reservations, the thought of her cousin drove her to help. "I am a shy person and putting myself out there was difficult for me," she said. "However, I couldn't stop thinking about my cousin with ALS and I wanted to help -- if not her, then others in the same situation."

Margaret now looks forward to visiting her client each week. She said that giving her time to people who appreciated and needed it was rewarding.

"The people I help are most appreciative of having company and somebody who understands and can relate to their condition and its ramifications," she said. "The most rewarding part of volunteering is the good feeling from having been able to help someone who is gradually becoming helpless, getting to know and understand them, and becoming friends."

### Thank you, Margaret!

ALS Ontario thanks all its volunteers who help out with various tasks from events and fundraising to administrative and support programs. Due to your generosity, more and more clients know they are not alone.

If you are a client looking for support, let us know what you need by contacting your Regional Manager or Manager, Volunteers (contact info to right).

*Did you know* there are people who will help you with housekeeping, cooking or yard clean up? The generosity of our volunteers inspires us daily; they could be an inspirational support to you and your loved ones too!

## Gift of Connection

You too can give the Gift of Connection by volunteering for ALS Ontario.

Home Visiting Volunteers, such as Margaret in the story to the left, are trained through ALS Ontario and those connections help alleviate caregiver efforts while providing a relationship to those living with ALS.

ALS Ontario is incredibly grateful to its volunteers who help organize and plan events, including the WALK for ALS.

There are volunteers who donate their time to help create and edit video, administer the new web site, or even spend a few hours in the office to help with daily activities.

No effort is too small and each volunteer helps in his or her own way to support those living with ALS in Ontario.

If you are interested in becoming a Volunteer at ALS Ontario, contact Kelly Entwistle, Manager, Volunteers at ext. 344 or [kelly@alsont.ca](mailto:kelly@alsont.ca)



## Cherishing Our Friends

Gary Addison	Abdul Chaudhry	Jack Gilligan	Attila Kollar	Monty O'Brien
Margaret Airth	Dorothy Clarke	Donald Gow	Krzysztof Kulesza	Bogdanka Okameme
Brenda Aldersey	Ivan Clow	David Grant	Michael Kuzmich	Robert Oloman
Gordon Augustus	Gary Corcoran	James Gray	Vincenzo La Grutta	Doug Ord
Jacqueline Baldwin	Jill Cumming	Leo Guertin	Jospeh Laviolet	Andre Paradis
Chang Ban	Ludwik Cyfracki	David Halton	Helen List	Edward Rose
Penny Banner	Diana Dale	Wayne Hardison	Sylvia Maharaj	Robert Rowe
Bette Bedard	William Daniels	Vibert Henry	John McFarlane	Frank Schmied
Marvin Bernstein	Ronald Dekker	Barbara Hernandez	Jacqueline McGuinty	Trudy Seibert
Karim Bhojani	Gino Diorio	Nancy Ho	Doug McMillan	Yvette Serrurier
Ronald Bisbee	Terese Dolan	Peter Ho	Gerald McNaughton	Eileen Simeon
Laurine Bosancich	Robert Ethier	Earl Johnston	Allyson Melanson	Clifford Smith
Karen Brockwell	Luigi Ferrante	Margaret Kimpton	Mary Montero-Clayton	Sid Svendsen
Myrtle Brooks	Eleutherio Fraidakis	Joseph Kingsley	Maria Moo	Gertie Terry
Colleen Brown	Hazel Gentry-Hacker	Vicki Knox	Rasiah Murugesu	Kathleen Zambrick

## GIVING BACK

### Thank You to our Donors for Supporting ALS Ontario!



#### Algonquin Dinner for ALS

Thank you again to Allen Holtz and his group of professional chefs for putting on another elegant and successful dinner at Algonquin College for Culinary Stars. The event, held annually in January, raised \$5744.72. Pictured: ALS Ontario board member Cathy Cummings with Allen Holtz, centre, and Rick Morgan.



#### CGI Breakfast for ALS Ontario

Thank you to CGI who held a fundraising breakfast last December. Pictured is Lianne Johnston receiving \$1000 raised at the event from Ken Taylor, Vice President, Consulting Services, CGI Canada.



#### Thank you Russell Public School

ALS Ontario appreciates the support received from Russell Public School in Champlain Region. The school organized an event which included drumming in support of teacher Siobhan Rock, who is living with ALS. Pictured is Lianne Johnston receiving the proceeds of the event from organizer Kelly LeBlanc.



#### District 61—Ontario Councils

Thank you to the Knights of Columbus—Ontario Council for donating \$1500 to ALS Ontario. Pictured are Charlene Spector and District Warden (61-Ontario) Jim Houston. Thank you for your donation which goes towards ALS Ontario's equipment loan program.



#### SWOMP Rats

The South Western Ontario Motorcycle Pack donated \$500 (received by Charlene Spector, pictured) to ALS Ontario. SWOMP Rats are longtime supporters of ALS and ALS Ontario thanks the group for its continued support.



#### Oakville Civitan Club

Thank you to the Oakville Civitan Club for donating \$2,600 towards the purchase of equipment for local clients. Pictured (left to right) are Robert McConnell, Chris Smith, Nada Loughead (ALS Ontario), Doug Guthrie, George Horhota, and James McConnell.

#### Algonquin Scholarship: Food for Thought

For the past several years, Allen Holtz and the guest chefs of the Ottawa Region along with students of the Culinary Program have hosted a gourmet meal, *An Evening with the Culinarian Stars*, each January with proceeds benefiting ALS Ontario.

Now in an effort to raise more awareness, Allen, Natali Dyck and Algonquin College are partnering to dedicate a scholarship in honour of a former ALS Ontario client, Brian Dyck.

The Brian Dyck Scholarship will go to a student in the new bachelor degree program for Hospitality and Tourism Management. This student maintains a B average or better and is involved in the community.

Thank you to Allen and Natali Dyck for submitting this proposal and to Algonquin College for creating a scholarship in Brian's name.

### ALS Ontario Thanks United Way of Greater Simcoe County for its Continued Support!



The United Way of Greater Simcoe County has granted funds in support of Simcoe County support services for a second year, in the amount of \$46,000 (last year \$32,000 was awarded to ALS Ontario).

UWGSC awarded Regional Manager, Sarah McGuire with the Outstanding Speakers Bureau Participant Award at its celebration event. Sarah was involved in multiple speaking engagements as part of their Employee Campaign. ALS Ontario client Bernard Schoutsen and his family were also featured in UWGSC material and participated in local speaking engagements. Bernie passed away earlier this month

"Bernie passed away just after we received notice that UWGSC would be funding ALS Ontario again this year, and I have no doubt we were successful in this endeavour in part due to Bernie and his family's efforts to support UWGSC," said Sarah McGuire.

### Remembering Grandpa

"My name is Alison Orr. My grandpa, Howard Orr, died in 2006 from ALS. My friend Audrey and I are on Student Council at Park Manor Senior Public School in Elmira, Ont. We organize dances at our school and it costs each student a toonie (\$2) to get into the dance. We thought it would be a good idea to give the entrance fee for the dance to an organization and we chose ALS Ontario in honour of my grandpa. We ended up raising \$200 for ALS Ontario just from our toonies!! Park Manor would like to challenge other schools out there to also raise money for ALS Ontario!"



Thanks to Alison Orr, right, for her innovation in organizing school dance fundraisers for ALS Ontario!

# A LENDING HAND

## Share your thoughts and experiences at one of our support groups

### Belleville/Quinte

**Location:**

Calvary Temple

Corner of Wallbridge-Loyalist and Hwy 2, Belleville

**Date/Time:**

Second Tuesday of the month at 7 p.m.

**Contact:**

Lou Scanlan at 613-962-4835

### Brampton

Brampton support groups will be combined with the Mississauga Support Groups.

**Contact:**

Laurie Laxer at 905-616-8675

### Durham

**Location:**

The Court at Pringle Creek

Retirement Residence

3975 Anderson St, Whitby

**Date/Time:**

Last Tuesday of the month at 7 p.m.

**Contact:**

Eleanor Leggat at 1-866-611-8545 ext. 215

### East Toronto (Scarborough)

**Location:**

The Hub—Caregiver Wellness Center, 2660 Eglinton Ave. East (north-west corner of Eglinton and Brimley)

**Date/Time:**

Second Wednesday of the month at 6:30 p.m.

**Contact:**

Oana Istoc at 647-899-0305

### Hamilton

**Contact:**

Nada Baranow-Loughead at 1-877-643-7870

### Norfolk-Haldiman-Brant Region

**Contact:**

Nada Loughead at 905-643-7870 or nada@alsont.ca

### Kingston

**Location:**

For more information, contact Eleanor Leggat, VP Support Services, ALS Ontario at 1-866-611-8545 ext. 215

### Kitchener

**Location:**

Motion Specialty, 1362 Victoria Street North

**Date/Time:**

Second Tuesday of the month at 6 p.m.

**Contact:**

Ann Larkin at a\_larkin@rogers.com

### London

**Location:**

Loblaws Community Room, (upstairs - elevator available), Masonville

**Date/Time:**

Usually fourth Monday of the month at 7 p.m. (except December)

**Contact:**

Denise Lanteigne-Mignault at 519-435-0404

### Mississauga

**Location:**

Erin Mills Sunrise Retirement Centre (4046 Erin Mills Parkway)

**Date/Time:**

First Wednesday of the month, 7 p.m.

**Contact:**

Laurie Laxer at 905-616-8675

### Niagara

**Contact:**

Nada Baranow-Loughead at 1-877-643-7870

### Ottawa

**Location:**

Carlingwood

CCAC 14-2121 Carling Ave.

**Date/Time:**

Last Tuesday of the month at 2 p.m.

**Contact:**

Tracey Cummings or Lianne Johnston at 613-820-2267

### Pembroke

**Location:**

Pembroke CCAC, 1100 Pembroke St. E.

**Date/Time:**

On hold until further notice

### Peterborough

**Location:**

Murray St. Baptist Church 175 Murray St.

**Date/Time:**

Third Monday of the month at 3 p.m.

**Contact:**

Dale Soble at 705-745-5376

### Sault Ste. Marie

**Location:**

Common Room, Senior's Residence,

55 Chapple St. This group meets informally on an occasional basis.

**Contact:**

Evelyn Kuchma at 705-942-1338

### Simcoe County

**Location:**

Woods Park Care Centre (basement), 110 Lillian Cres., Barrie

**Date/Time:**

Second Monday of the month at 7 p.m.

**Contact:**

Sarah McGuire at 1-888-719-7667

### Sudbury

**Contact:**

Brigitte Labby at 1-888-249-6115

### Thunder Bay

This group meets informally on an occasional basis.

**Contact:**

Barb Scanlan at 807-767-4921

### Toronto

**Location:**

124 St. Regis Cres. South

**Date/Time:**

Second Monday of the month at 7 p.m.

**Contact:**

Laurie Laxer at 905-616-8675

### York Region

**Location:**

Sunrise of Aurora Senior Living (4th Floor), 3 Golf Links Dr., Aurora

**Date/Time:**

First Wednesday of the month, 7 p.m.

**Contact:**

Sarah McGuire at 1-888-719-7667

## STAFF DIRECTORY

Interim President & CEO	Robert Webster	robert@alsont.ca	x216
Vice-President, Support Services	Eleanor Leggat	eleanor@alsont.ca	x215
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Data Entry Specialist	Nisha Manickam	nisha@alsont.ca	x345
Support Services Admin Asst	Cheryl Leung	cheryl@alsont.ca	x300

### Regional Managers:

Central West	Nada Baranow-Loughead	nada@alsont.ca	1-877-643-7870
Champlain Region	Tracey Cummings	tracey@alsont.ca	1-866-858-4226
	Lianne Johnston	lianne@alsont.ca	1-866-858-4226
Durham Region	Nada Baranow-Loughead	nada@alsont.ca	1-877-246-8612
Greater Toronto Area	Laurie Laxer	laurie@alsont.ca	1-800-351-8676
East Toronto	Oana Istoc	oana@alsont.ca	1-866-611-8545
North East	Kendra LaCarte	kendra@alsont.ca	1-888-672-2836
North Central	Brigitte Labby	brigitte@alsont.ca	1-888-237-4453
Simcoe-York	Sarah McGuire	sarah@alsont.ca	1-888-719-7667
Thames Valley	Charlene Spector	charlene@alsont.ca	1-877-414-1518
Thunder Bay	Jon Hansen	jon@alsont.ca	

ALS Ontario, 402-3100 Steeles Ave E., Markham ON L3R 8T3

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Call us at  
1-866-611-8545 or  
905-248-2101 and visit our  
web site: [www.alsont.ca](http://www.alsont.ca)

View videos at  
[www.youtube.com/alsontario](http://www.youtube.com/alsontario)

Join us on Facebook,  
Twitter and YouTube to  
help spread ALS  
awareness!

### Let's Roll! —STORY CONTINUED FROM PAGE 3

Surprisingly, Lefrançois said that the biggest challenge he had to overcome in his life was not ALS. Instead, it was the separation from his wife 10 years ago. However, he had family and friends there to help him cope. Likewise, community is what helps him live with ALS. His family and friends keep him active and meet any special needs. Dubreuilville, ON., the town where he resides, made places wheelchair-accessible and held fundraisers in his honour.

"I'm treated just like any other healthy person," he said. "After a while, people don't see the wheelchair. They see you as you."

All too often, people both ill and healthy, can succumb to self-pity when they face adversity. They become needy and forfeit power over their lives. But Lefrançois is adamant in his commitment not to let ALS define his life. On his website, he writes, "I may have ALS, but it doesn't have me...yet!"

"The biggest challenge I had to overcome isn't ALS and many find it surprising when I answer that. I never accepted having ALS and never will, but from the day I was told I had ALS, I learned to live with it," he said. "Yes it may be a terrible disease to live with, but life can still be good if you let it."

His words resound with defiance and fight, as they should. After all, it runs in the family.

**"The biggest challenge I had to overcome isn't ALS and many find it surprising when I answer that...it's a terrible disease to live with but life can still be good if you let it."**

# I Want To Support People Living with ALS!

Remember using **ALS Ontario's secure online donation (www.alsont.ca/donate)** helps reduce administrative costs and you'll receive an immediate electronic tax receipt!

- I would like to join ALS Ontario's Monthly Giving Program
- I authorize ALS Ontario to withdraw my monthly donation of \$ \_\_\_\_\_ from my bank account at the **middle** of each month. (Please provide a blank cheque marked "VOID")
- I authorize ALS Ontario to charge my monthly donation of \$ \_\_\_\_\_ to my credit card at the **middle** of each month. (Please complete credit card information below)

**Date:** \_\_\_\_\_ **Authorizing Signature** \_\_\_\_\_

- I am enclosing a one-time donation of (circle one): \$25 \$50 \$100 \$250 Other: \$ \_\_\_\_\_
- Enclosed is a cheque payable to: ALS Ontario
- Please charge the above amount to my credit card (Please complete credit card information below)

### Please send my income tax receipt to:

Surname: \_\_\_\_\_ First Name: \_\_\_\_\_  
Address: \_\_\_\_\_ Suite/Apt # \_\_\_\_\_  
City/Town: \_\_\_\_\_ Province: \_\_\_\_\_ Postal Code: \_\_\_\_\_  
Phone: \_\_\_\_\_ Email: \_\_\_\_\_

### Credit Card Information:

Select: Visa MasterCard American Express Card Number \_\_\_\_\_ Expiry Date \_\_\_\_\_  
Name on card: \_\_\_\_\_ Signature: \_\_\_\_\_

### I would like to learn more about how I can help ALS Ontario. Please send me more information on:

Monthly Giving Leaving a gift in my will Special Events Volunteering Membership

**Please return completed form to:** ALS Ontario, 402-3100 Steeles Ave. E., Markham, ON, L3R 8T3

**Thank you! Your gift will help those with ALS live with independence, dignity, hope and choice.**

Privacy Statement: Your personal information will never be abused, sold or shared without your express knowledge and consent. For more information on how we protect your information, please visit [www.alsontario.ca](http://www.alsontario.ca) or contact the office. **Code: NLSPI2**

**Tax Receipts:** Unless otherwise requested, tax receipts are only issued for donations of \$20 or more. Charitable # 131820938RR0001



### ALS Ontario

3100 Steeles Avenue E. Suite 402  
Markham, ON  
L3R 8T3

[www.alsontario.ca](http://www.alsontario.ca)

**ALS Ontario is moving to electronic newsletters to continue to reduce costs.**

If you would like to receive this newsletter electronically, please notify Kathryn at 1-866-611-8545 ext. 213 or [kathryn@alsont.ca](mailto:kathryn@alsont.ca)

### Recipient

123 Street Name  
Town, Province  
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Thank you for helping to Make Moments Matter for those living with ALS.