

## Slaying the Dragon: George Goodwin on Voice Recognition Software

I have recently begun using a voice recognition software that I think many could benefit from. To that end I wanted everyone to know about the Technical Access Clinic at Chedoke which is part of Hamilton Health Sciences. There are also similar clinics in Kitchener, Toronto and Ottawa. The service at Chedoke is just fabulous and the equipment that they can outfit you with is quite astounding.

When I went to the clinic the first thing they gave me was a voice amplifier. As my voice is getting a little raspy I find that this amplifier is the real ticket. I can practically whisper into it and it will amplify my voice so that my wife Shirley can hear me in the living room even when I'm in the bedroom.

Now for the best part of the whole story! When my computer was hit by lightning the clinic arranged for me to get a new computer which would include voice recognition software called *Dragon*. The clinic staff really went to bat to get me a computer that would allow me to do the Canadian ALS March of Faces, my web site and all the March of Faces PowerPoint shows - and still leave lots of room to spare.

The whole process for getting the new computer took about two to three months from the time I got the forms and sent them to Dr. Strong who then returned them to the clinic. The clinic told me that there was about a year waiting list at the time but because I had ALS they would move me to the front of the line.

Three weeks later I went to the clinic and started to record and bank my voice, which was then put onto a CD. I can continue to record phrases so that when I lose my voice I will be able to have these phrases in my own voice. One thing that thrills me is that my grandkids will continue to hear my own voice through the computer even when I can no longer speak. In addition to these recordings the staff gave me extensive training on the voice recognition program.

Last week they arrived at my home with a brand new computer set up with Microsoft

Office, a DVD player and burner, a CD player and burner and the Dragon speech recognition program which I am using right now to compose this article. I have had two training sessions at Chedoke and one at home to learn the commands. The technician is coming back twice next week and one more time the following week to get me used to the commands.

The whole system comes from the Assistive Devices Program and is on lease. The added bonus of the lease is that if anything goes wrong with the computer the clinic is on-call to fix it. (There is also the option of going to a laptop if you're unable to use a PC.)

My thanks go out to the ALS Society of Ontario who has graciously picked up the cost of the lease.

I would recommend anyone with ALS, who is having a hard time with their hands, to

see **DRAGON** on page 2



**George GOODWIN**

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*The Ontario Journals is a vehicle for keeping you informed about the latest news with respect to ALS and the ALS Society of Ontario.*

look into these programs. It is not guaranteed that you get a new computer but you will get one that will suit your needs.

To the best of my knowledge if you do have a computer that has the capacity to hold this program you can get it as a stand alone program from one of the Access Clinics listed below.

If you like this idea, I recommend that you talk to your speech pathologist and find out where the nearest clinic is located. Although you may have to wait a few months I guarantee that it is worth the wait!

## ONTARIO COMMUNICATION CLINICS

### OTTAWA

The Rehabilitation Centre  
Technology Access Service  
505 Smyth Road, Ottawa  
(613) 737-7350

### KITCHENER

Grand River Hospital  
Freeport  
Augmentative Communication &  
Technology Service  
3570 King Street West, Kitchener  
(519) 749-4300

### HAMILTON

Hamilton Health Sciences,  
Chedoke Division  
Technology Access Clinic  
Sir William Osler Building, Suite 114  
(905) 521-2100 ext. 77833

### TORONTO

Toronto Rehabilitation Institute  
Augmentative &  
Alternative Communication Clinic  
130 Dunn Street, Toronto  
(416) 597-3028

Sunnybrook Centre  
for Independent Living  
Assistive Technology Clinic  
(This is a fee for service clinic)  
2075 Bayview Avenue  
(416) 480-5756

## Greetings from Susan Graham Walker new Executive Director

Now in my second month as your new Executive Director I have had great fun thinking and seeing things through a new lens – the ALS Society of Ontario lens rather than the ALS Society of Canada lens. But I feel it is a great advantage to be so familiar with the important issues surrounding ALS. I began my new role meeting with my colleague Executive Directors from other Provincial Societies. It will take some time to connect with the long list of key players associated with our work serving those affected by ALS – volunteers, Walk to D’Feet ALS folk, members of the Board of Directors, ALS clinics, and the remarkable ALS Ontario staff.



Susan  
**GRAHAM  
WALKER**

Listening is the task and I have been listening as well through reading as much as I can of files and binders of information to assist in filling in blanks. To increase my knowledge of our far-flung organization I am looking forward to travelling throughout the province to meet in person with Chapter and Support Groups and to attend events where appropriate.

I am eager to hear from you about how we can fulfill our bold challenge to better serve the needs of all those in Ontario who are affected by ALS through:

**A – advocacy and awareness**

**L – leadership and resource development**

**S – services and support**

On a personal note let me tell you a bit more about myself by answering three questions

### What did you want to be when you grew up?

First it was a lawyer. I really admired my uncle because he was sought out by many people for his wisdom as well as his advice. Then it was a librarian because I thought it might be a way of connecting with all the great ideas. After that I was confused, so I studied journalism because I like to ask questions. The story from there to here is much longer.

### So who are you?

I’m not sure who I am; it keeps evolving. I do know that I aspire to be a person who lives what I believe. On a more practical level: I am a partner – with Paul for nearly 24 years. We have two teenagers on the family payroll. I am a volunteer on the Board of Markham Public Libraries and I offer my skills as a facilitator with various groups. With a friend I run ‘gently strenuous’ canoe trips for women.

### What is your motto?

There are two that sit in front of me while I work.

*LOVE is the virtue of the HEART*

*SINCERITY the virtue of the MIND*

*COURAGE the virtue of the SPIRIT*

*DECISION the virtue of the WILL*

The Organic Commandment by Frank Lloyd Wright

*Motivated by love*

*Guided by reason*

Bertrand Russell

I look forward to working with all those in the ALS Ontario network to fulfil our mission. Please don’t hesitate to contact me.

# The President's Corner

In the summer issue, in the context of recognising Karen Ormerod's legacy to the Society, I discussed the 'fine balance' of effort among staff and volunteers. Almost as a given, the article acknowledged the need for paid staff in the Society. That did a disservice to you readers in a couple of ways: firstly, it did not directly deal with the question "Why cannot volunteers do most of the work, saving the Society's precious and hard-earned funds for the direct support of P'ALS and research?" Nor does it give any insight into or reassurance on how we can control the proliferation of paid staff.



**Nigel  
VAN LOAN**

There were a few allusions in the earlier article to the need for staff to ensure "the consistency of the approach" and "the constant overview". But why do we need these and why must the tasks be done by staff? The driving force really is your success in raising awareness of ALS and thereby funding for the Society. In the last five years our revenues have soared tenfold: our 'income' from all sources for 2004 is forecast to be about \$2.3 million. Clearly we have obligations to wisely oversee the expenditure of such large sums: we have a legal obligation to the Government of Canada to stay within the extensive regulations for charitable organizations and — in my mind, the pre-eminent one— we have an obligation to the donors to improve the treatment of and find a cure for ALS.

As a leading example, our 2004 Budget proposes that about \$750,000 be spent on the equipment support programme. This was

at one time a collection of localized, volunteer-run programs spread over several communities, each dealing separately with issues like funding, loan-cupboards, transportation of equipment, maintenance, record keeping and recovery when no longer required. There was not universal availability across the Province. Now it is the exemplar of how our Society works: a small, central staff headed by Ravi Jain, the Director, is from time to time supported by a Volunteer Support Services Committee comprising caregivers and therapists experienced in support of people living with ALS. Together they devise province-wide programs and policies that are fully developed by the staff and ultimately approved

by the Board of Directors, ensuring financial viability. Ravi then works with the Regional staffs and Community volunteers to set up legally-documented, local equipment supplier agreements. The staff and volunteers can then be sure of responsive, affordable and consistent equipment support for all people living with ALS in their areas.

Looking at another case, just over a half million dollars are assigned for "Fund Development". It is here that the efforts associated with the ongoing and diligent oversight of a \$2.3 million budget appear, assuring donors that the Society manages their contributions in an ethical and accountable manner. Moreover, the staff ensure that donors receive tax receipts, reports on how their money is spent and appropriate recognition. This staff team of three also conducts vital planning to develop sustainable funding for our ever-expanding services. They are diversifying streams of revenue with new fundraising initiatives that leverage partnerships with corporations, foundations, government and individual donors. The previous *JournALS* also highlighted

some of the activities of the central staff in the coordination of Volunteer Services. The Coordinator of Volunteer Services develops policy and works with community volunteers and regional staff to ensure that our potential and current volunteers are screened, trained, and recognized for their invaluable contribution to the mission.

These are but three examples of critical roles now fulfilled by the teaming of paid staff, centrally and regionally located, with the volunteers in the communities. To our delight, we are doing all this with an 'administrative overhead' that is only a small percentage of our budget.

How can we ensure that our costs won't grow too large, taking up an unfair proportion of our income? Well, lest I forget — and there are many who almost daily remind me — this is the prime role of the Board of Directors, volunteers all. Let me hasten to assure you that the current Board (and those of the past three years that I have served on or been able to directly observe) take this as the most serious challenge. To a person they display the view that it would be unforgivable to allow spending on staff to consume an undue portion of the budget. This is why the opening of Regional offices will be staged over several years, staying within funding constraints for administrative costs. This is why our September Board meeting in Peterborough will concentrate on considering expert advice we have received recently on the issue of how best to staff our Society.

We know our obligations and we will meet them. In the process, we will need some — but just enough — paid staff.

## Monthly Gifts

Monthly gifts are a terrific way to make your charitable giving more affordable.

The ALS Society of Ontario can help you to set up your monthly gift using your credit card.  
Contact Suzanne at 1-800-267-4257, ext 217 or via email at [dirresdev@alsont.ca](mailto:dirresdev@alsont.ca)

## Recognizing Our Volunteers

In the last issue of the *Ontario JournALS* we took the opportunity to recognize the winners of the 2004 Jack Muirhead and Esmond Butler Volunteer Awards. In this issue, we would like to share the stories of the other nominees for this year's awards, Marvin Streich, Denise Lanteign-Mignault and Paul Muirhead.



**Marvin Streich** was nominated for this year's *Jack Muirhead Award*. To many in the ALS community Marvin is already well known. Marvin's wife passed away from ALS in 1998 and since then he has worked diligently to bring awareness, support and advocacy to ALS in Northern Ontario. He was instrumental in getting the Sudbury Chapter on firm foundation, including involving his fellow masons with setting up a Beef Rib Dinner and the Walk to D'Feet ALS. Marvin has reached out to other communities including supporting the London Walk to D'Feet ALS in its first two years and working with George Goodwin in Hamilton on the ALS website. Marvin's spirit and energy continue to make a difference to those around him.

**Denise Lanteign-Mignault** was nominated for the *Esmond Butler Award*. For the last twelve years Denise has led the London Support Group. She is credited with creating a safe, honest, mutually caring atmosphere for people living with ALS and their families who attend. She leads the support group with unfailing competence and unending care. Denise goes that extra distance during the winter holidays to organize a potluck dinner enjoyed by many over the years. As stated by Eleanor Reynolds, "we are very fortunate in [the] London area to have such a dedicated, well organized [volunteer]."

**Paul Muirhead**, a member of the ALS Ontario Board of Directors for seven years, was also nominated for the *Esmond Butler Award*. He is credited with bringing stability to changing times and for being a source of sage advice and enthusiasm. Among his accomplishments are helping to implement the current Regional Structure of the ALS Society. In her letter of support Deborah Lavender wrote, "I believe that [Paul's] extensive commitment to the ALS Society of Ontario was both a personal and professional commitment and that he came to the Board with a deep sense of purpose in his heart".

To share the accomplishments of a volunteer in your community or to nominate someone for an award, please contact Helen Taylor.



at [www.alsont.ca](http://www.alsont.ca)

Events and Activity Calendar  
The 2003 Annual Report  
New On-line Donation Process  
2003-2004 Volunteer Awards  
Community Pages

# SECOND BIENNIAL NATIONAL ALS SYMPOSIUM "UNMASKING ALS"

## WHAT

The ALS Society of Canada's second biennial ALS Symposium focused on building the capacity of the organization at all levels to better respond to the needs of Canadians affected by ALS.

This three day event will draw together at least 150 volunteers, organizational leaders, people with ALS, caregivers, healthcare providers and ALS clinic personnel for specific training, leadership development, consultation and networking.

## WHEN

Friday, October 29 to Sunday, October 31, 2004

## WHERE

Bank of Montreal Institute for Learning  
3550 Pharmacy Avenue, Scarborough

## COST<sup>1</sup>

There are two packages that participants can choose from.

### Package #1

Registration Fee, Meals and Accommodations - \$400

### Package #2

Registration Fee & Meals only - \$240

<sup>1</sup>Limited symposium subsidies are available through the ALS Society of Ontario. Visit the homepage on our website at [www.alsont.ca](http://www.alsont.ca) to access the subsidy application form. Or call Helen Taylor at 1-800-267-4257, ext. 210 to receive your application form. Subsidies will be provided on a first come, first service basis.

## EVENTS

On Friday, October 29 there will be a National Film Board Reception and a screening of the NFB film *Bearing Witness: Robert Coley Donahue*.

On Saturday there will be a pre-opening exclusive viewing of "The Gee! in Genome" Project and a reception for UNMASKING ALS delegates at the Ontario Science Centre. For more information on "the Gee! in Genome" Project go to <http://www.nature.ca/genome/>

## FURTHERINFO

For further information about the agenda and location you can visit the ALS Society of Canada website at [www.als.ca](http://www.als.ca) or the ALS Society of Ontario website at [www.alsont.ca](http://www.alsont.ca).

# Happenings Around Ontario

Throughout the spring and summer volunteers around the province have been raising awareness about ALS, raising funds for care and cure and having lots of fun in the process.

## SUDBURY

At the Sudbury Walk to D'feet ALS kick off event Merv Lees and Brian Koivu debut "These Shoes Are Made For Walking" sung to that old Nancy Sinatra favourite "These Boots Are Made For Walking." Dora Redman of London wrote the chorus and Merv of Sudbury then wrote three verses. To see the lyrics visit [alsont.ca](http://alsont.ca) and click on the events Walk to D'feet section on the top menu.



**Merv Lees and Brian Koivu debut *These Shoes are Made for Walking***



**Charles Hain (left) and Suzanne McDonald (centre) accept cheque from Dennis Wamsley.**

\$35,537, proceeds from Walk to D'feet ALS.

## BELLEVILLE & QUINTE AREA

The Quinte Chapter is planning their third Walk to D'feet ALS in September 2004. These two walks truly established ALS as a charity to be supported in the minds of people of the Quinte area. To date they have raised more than \$190,000.

This past spring, Betsy Rymes, whose son John has ALS, accepted, two generous donations on behalf of the Quinte chapter from Carole Wilson and Joanne Bailey.

The Trenton Lions Club Val Carswell Volunteer Service Award was presented posthumously to honour the work of Gary Wilson, who lost his life to ALS. On accepting the award, Gary's wife Carol made a donation to the Quinte chapter in celebration of his life's work as a volunteer.

During the Annual Nurse's Week Dinner in Belleville, sponsored by the Registered Nurses Association and the Ontario Nurses Association, Joanne Bailey received the Nurse of the Year Award. This presentation, made by John Scott, President of the Quinte Rotary Sunrise Club, included a monetary award which Ms. Bailey directed to the Quinte ALS chapter.

*HELP SQUASH ALS* was organized and run by Dale Crowley of the Harbour Club in Belleville. Participants enjoyed a fine silent auction thanks to the generosity of the merchants of the Quinte area.

## BRANTFORD

The Warehouse Diner in Brantford wasn't going to hold their annual charity volleyball tournament in 2004 until they met Janice Moulton and Ray and Linda Wrecks! Now Paul Woodnutt, owner and manager Sandy Bennett will keep it going until a cure is found. This year they raised over \$21,000 and still counting! Three hundred and ninety tons of sand were brought in to create the courts!



**Participants in the charity volleyball tournament take a break.**

## OTTAWA & AREA

In the Champlain Region a whole lot of fun has been going on . . .

ALS - Lynx Game Day Dog Days of Summer day at the ball park was held in August! Not to be outdone a Softball Tournament was held at the Long Sault Ball Diamond for ALS.

In June, the Ciena (formerly Akara) Golf Tournament was held.

## KINGSTON

In Kingston, volunteers sold real cornflowers, the symbol of the ALS Society, during ALS Awareness month in June. Kingston raised more than \$10,000 for research through this campaign. Well done team!



**Cornflower Days in Kingston**

## LONDON

Walks in London blazed a trail at the kick off to the 2004 Walk to D'feet ALS campaign singing new words to "These Boots Are Made for Walking".



# YES, I WANT TO HELP PROVIDE SUPPORT FOR PEOPLE WITH ALS!

Please accept my gift of:  \$25  \$50  \$75  \$100  \$250  other \_\_\_\_\_

Please find enclosed my cheque payable to the ALS Society of Ontario

I prefer to charge my gift to my credit card:  VISA  MasterCard  American Express

Card #: \_\_\_\_\_ Expiry Date: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Address: \_\_\_\_\_

City/Town: \_\_\_\_\_ Prov: \_\_\_\_\_ Postal Code: \_\_\_\_\_

Phone: (day) \_\_\_\_\_ (eve) \_\_\_\_\_

I want to find out how I can offer my time to help the ALS Society of Ontario and its people with ALS. I would like more information about:

Memorial Giving  Special Events  Volunteering  Membership \$25

Please enclose your cheque with this form and return to:

ALS Society of Ontario  
265 Yorkland Blvd. Suite 300  
Toronto, Ontario M2J 1S5

All donations are tax creditable and receipts will be issued.

Charitable Registration # 13182 0938 RR0001



**Whatever the gift, it is the circle of connections around those who have lived with or are living with ALS that helps to sustain the work of the Society.**

Thank you.

*[Handwritten signature]*



## WHO ARE YOU WALKING FOR?

This fall 15 Walks to d'Feet ALS will be staged throughout Ontario. The goal is to raise more than \$1 million dollars. The 7 walks held in the spring exceeded their target, raising more than \$300,000. Visit the Community Pages on the website ([www.alsont.ca](http://www.alsont.ca)) for more information about the fall walks.



**September 11, 2004**

Barrie

**September 25, 2004**

Belleville	Orangeville
Cornwall	Ottawa
Hamilton	Sault Ste. Marie
Kingston	Smith Falls
Kitchener/Waterloo	Sudbury
London	Thunder Bay

**October 2, 2004**

Niagara Falls



ALS SOCIETY OF ONTARIO  
265 Yorkland Boulevard, Suite 300  
North York, ON M2J 1S5  
416-497-2267 or 1-800-267-4257  
FAX: 416-497-1256 - [www.alsont.ca](http://www.alsont.ca)

### STAFF DIRECTORY

**Susan Graham Walker - Ext 216**  
Executive Director

**Ravi Jain - Ext 215**  
Director of Support Services

**Suzanne McDonald - Ext 217**  
Director of Resource Development

**Sara Lawson - Ext 222**  
Executive Assistant/Office Manager

**Irene Grecu - Ext 212**  
Accounting Coordinator

**Chris Forty - Ext 211**  
Client Services Coordinator

**Helen Taylor - Ext 210**  
Coordinator of Volunteer Services

**Corina Chevalier - Ext 218**  
Fund Development Coordinator

**Nelly Teitelbaum - Ext 214**  
Finance Manager

**Christine ElChiekh - Ext 213**  
Information Service Coordinator  
(Volunteer Position)

### REGIONAL OFFICES

**Ottawa Regional Office**  
613-820-2267

**Hamilton Regional Office**  
905-540-9746

**Toronto Regional Office**  
416-497-2267

**Northern Regional Office**  
1-888-237-4453

For further contact information please visit our website at [www.alsont.ca](http://www.alsont.ca)