

Northern Directions



FAMILIES OF SMA

Balancing Life's Tough Times™

Volunteer Needed

FSMAC needs a volunteer to apply to foundations and corporations for donations and grants, on a continual basis.

Individual would need to have internet access, good PC skills, and strong organizational and communication skills.

Working with our office, the individual would be responsible for seeking out foundation, filling out and mailing applications, and applying for grants.

For more information, contact Darren at (800) 866-0016.

Families of Spinal Muscular Atrophy Canada

1-800-866-0016

www.SMACanada.com

Gene Therapy—A Treatment for SMA?

Progress towards SMN gene therapy as a possible treatment for SMA by Christine DiDonato, Robin Parks and Rashmi Kothary

The muscle weakness and paralysis that SMA patients experience is due to reduced amounts of a protein that is absolutely required for the proper function and maintenance of muscle and nerve. This crucial protein is synthesized from a gene called

survival motor neuron (SMN).

Because of a recent event in the evolution of the human race, people have two nearly identical survival motor neuron genes (SMN1 and SMN2). SMN1 produces primarily one RNA transcript that can be used to make abundant amounts of SMN protein. In contrast, SMN2 produces two RNA species: small amounts of a large RNA transcript (that is the same as that produced from SMN1) and

abundant quantities of a smaller RNA transcript.

All SMA patients lack a functional copy of SMN1 but retain at least one copy of SMN2 that is capable of producing a small amount of SMN protein. This small amount of protein appears to be sufficient for all cell types except motor neuron cells within the spinal cord; hence the nerves controlling voluntary movement degenerate and

(Continued on page 4)

Screen Time by Cristina Campbell

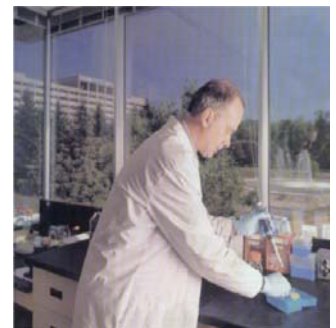
This article was first printed in Report on Business, October 2002. Used by permission.

"I'm a pediatrician with a problem" is how Dr Alex MacKenzie of the children's Hospital of Eastern Ontario in Ottawa describes himself.

He says he's close to finding a drug treatment for spinal muscular atrophy (SMA), a genetic disorder that can paralyze and kill infants by the time they are 18 months old. MacKenzie's problem is the lack of interest from major pharmaceutical companies in developing a drug treatment. Big Pharma's first question, he says, is how frequent is this disorder? "And you

say, 'Well, although it's the most common inherited form of infant mortality, it really is only 1,000 births a year in North America.' And they say, 'That's interesting, but not to us from a financial point of view.'"

A discouraging response, to put it mildly. But MacKenzie says he may now have the money and the tools he needs. He's received a \$1.5-million grant from Genome Canada. He will combine that with what he describes as some "transformative" technology in the final stages of development at Virtek, a small and struggling laser systems company in Waterloo.



Dr Alex MacKenzie

MacKenzie says everyone carries a "copy" gene that can replace the one deleted in the SMA mutation. He's trying to figure out how to "switch it on." That entails hurling as many as hundreds of thousands of different drugs at test tubes containing nerve cells to see which

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Vimy Samplonius Walsh
August 18–November 1, 2001

Editor's Insights

A changeover has occurred here at Northern Directions. Darren Bray has handed off the editorial/publishing position to myself, Sarah Samplonius. Although some would say that looking after a group home of six rambunctious foster kids (all boys) with my husband is enough for anyone, I wanted more.

It all started on August 18th, 2001 with the birth of our gorgeous son, Vimy. He was a floppy baby (said with much fondness), and required oxygen-assisted breathing. Just under

two weeks later he was diagnosed with SMA Type I (the genetic testing done by none other than Dr Alex MacKenzie at CHEO, to whom we are forever grateful and who is featured in an article on the first page of this issue and who is funded by FSMAC).

Vimy died, at home sleeping in bed between us, on the morning of Nov. 1st, 2001.

His life was short, but his impact was and remains huge. He lives on as a 'mascot' for CHEO's tissue and organ donation program and he's inspired

his mom to maintain her contact with SMA through this newsletter and the organization of the Vimy's Angel Run For SMA (see pg. 7 "Newmarket event kicks off with a bang").

Let's keep all our children's memories alive, by helping out with fundraising events, such as Susi Vander Wyk's highlighted on pg. 1 or by creating your own. Or simply sending in your membership renewal forms.

You can contact me at sarah@SMACanada.com. I look forward to hearing from you.

Fundraising Families: Christina & Terry McDonald, for Natalie (SMA Type 2/3), age 3

Source of Inspiration: "If 400 people raised \$2,500 each we would be \$1,000,000 closer to a cure." Spring 2002 Direction and Natalie McDonald.

\$2,500 to Christina McDonald from Mt Forest, Ontario seemed 'do-able'. She decided to get together friends and family members for a dinner and dance. She imagined something like a wedding. Small, informal, friendly. But then things changed...

The plant manager at the factory where Christina worked donated the hall rental and gave time at shift meetings for Christina to do a presentation on the event.

With two live bands, a DJ, and a trip giveaway (who wouldn't want to go to Vegas?) it wasn't a hard sell. But with 1200 tickets, Christina needed all the support she could get.

Christina had a small goal—she wanted people to help. And they did. 11 people offered to shave their heads, beards, chests, moustaches, and legs for \$5,000.

A local business changed their golf charity tournament to the time of the dance. Donations of services, food, and



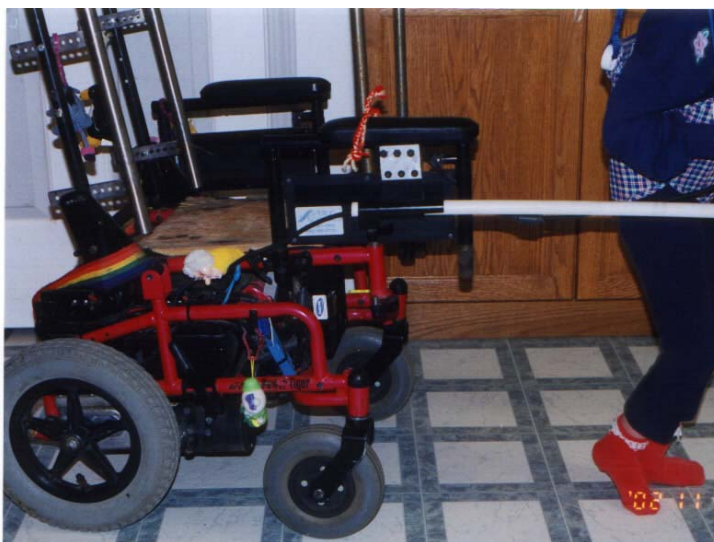
Christina & Terry McDonald at Fundraiser

prizes poured in.

Christina thought small, \$2,500 was her goal. She raised \$26,000. Think what you could do.

*Moved?
Take a moment.
Send in your
address changes and
help minimize
mailing costs and
maximize money
for research!*

Mechanical Marvels



Walking

Q: How many people does it take to modify a wheelchair?

A: Four men and a mom

Everyday we are amazed by the feats of our children and our family members who are affected by SMA.

Their strength and resilience often inspire those of us who can only watch their daily strug-

gles to greater feats. We learn to adapt, we cope, and sometimes, we build.

Holli Vander Wyk is one such girl. Holli is 6 years old with Type 2 SMA. She wanted to go to dance classes. And why not?

At home, her family had a jolly jumper suspended from a solid ceiling beam in their living room that allowed Holli freedom of movement.

So, all they had to do was sus-

pend her, like this, at dance class. While the ceiling was out, they figured they could wire some sort of A-frame support system on wheels. That was easy. But how to give it power to increase her freedom of movement?

Holli's Dad had an idea. He'd rig the A-frame to the wheelchair to take the wheelchair's power for the dance support system.

The idea was born and four men and one mom sat down one night to join a jolly jumper and a wheelchair.

They removed her foot rest hangers, exchanged her control bar into a long pvc pipe so the controls could slide forward, and after an hour of welding and work, a wheelchair modification was built that takes merely a minute to install.

The wheelchair wasn't carrying much more weight, so safety concerns about tipping were a non-issue. But to be sure, they tested it, figuring if a grown man could stand on the posts without tipping it, it was safe.

It works like a dream and one

happy little girl now goes to dance class. She can do foot movements, dance across the floor, do some tap, a little ballet and walks to the parking lot on her own. Her pride in herself and her joy is indescribable.

As Mom describes it: "She also has figured out that if she puts herself into a sping, she can make her own little tilt a whirl, round and round, practically horizontal, but that's another story..."



Holli at Dance Class

Screen Time, cont'd.

(Continued from page 1)
drugs will work on the copy genes. The process is called high-throughput screening.

Given the small potential financial payoff, MacKenzie could not afford to pursue the search with current DNA chip reading technology. Virtek's fibre-optic nucleic acid (FONA) biosensor

could slash costs for analyzing DNA and RNA samples. The small container filled with very thin fibre-optic strands reduces the job of screening for the gene from hours to seconds. It can also be used repeatedly. A process that costs up to \$1,000 a try could soon cost a few dollars. This also would make it

practical to test all pregnant women and newborns for SMA and other rare genetic diseases, another objective of the Genome Canada project.

FONA was invented by Dr Ulrich Krull, a professor of biochemistry at the University of Toronto and Dr Paul Piunnot. It has been in development for a dec-

ade. The Genome Canada grant, to be shared by MacKenzie and Virtek (Virtek will also match it), supports the first test of the technology against a specific disease.

Editor's Note: Dr MacKenzie is a FSMAC grant recipient.

International SMA

A world wide alliance to find a cure for SMA has begun with these members:

- Families of SMA (USA)
- The Jennifer Trust for SMA (U.K.)
- Research and Therapy for SMA (Germany)
- Families of SMA (Italy)
- Families of SMA (Canada)
- Families of SMA Charitable Trust Hong Kong

Canadian Grants

We are very fortunate to have some amazing individuals working with us to find a treatment or cure for SMA. Your hard work and generous donations will be funding the work of the following Canadian Researchers in 2003:

Investigation of SMN protein function

Dr Louise Simard—Investigation of SMN's neural specific function in P19 cells

Dr Alex MacKenzie—Pre-clinical protein and RNA profiling in a mild SMA mouse model

Modifying splicing in animal models

Dr Rashmi Kothary—"Modulation of SMN2 exon7 alternative splicing in transgenic mice"

Animal Models

Dr Louise Simard—"Creation of conditional and hypomorphic alleles of the murine survival motor neuron gene as models of SMA"

Dr Christine DiDonato—"Functional Analysis of SIP1 in transgenic mice", "Creation of an allelic series of SMN mutant mice"

Gene Therapy, cont'd

(Continued from page 1)

die. Previous genotype/phenotype correlation studies of SMN2 and genetic complementation in SMN deficient mice have shown that SMA disease severity is tempered by the level of endogenous SMN. Thus, methods aimed at increasing intracellular levels of SMN are potential treatment strategies for SMA.

As a means to increase intracellular levels of SMN, we are investigating the potential of SMN gene replacement therapy. Our paper, DiDonato et al. (2003), that appears in the January 20th issue of Human Gene Therapy is the first step in this process.

Although motor neurons are the ultimate target for therapy, we tested the overall feasibility of SMN gene replacement in skin cells (fibroblasts) derived from severe type I SMA patients. We chose these cells because they are relatively easy to grow, have low levels of SMN and lack a structure in the nucleus that we call "gems".

These nuclear "gems" are rich in SMN and other RNA processing proteins. When SMN is present at higher levels within the cell, gem structures are able to form. Normal skin cells contain gems (indicated by white arrows below), but

cells from type I SMA patients have a greatly reduced number of gems or none at all.

We used this distinguishing feature to assess the potential of SMN gene delivery to skin cells of SMA patients. Our results demonstrate that SMN can be efficiently expressed from a viral vector and that the resulting recombinant SMN protein can interact with other intracellular proteins.

When we transduced patient cells with our adenoviral vector containing SMN, we were able to increase intracellular levels of SMN and restore gems to SMA type I patient cells. In addition, when SMN relocated to gems, it caused other SMN associated proteins to relocate to these structures as well.

From our results, we believe that a therapeutic treatment strategy based on SMN gene transfer could be effective. However, we have only begun the process of determining the potential of this treatment strategy. Our next step is to move to an in vivo situation.

In this instance, we will deliver our adenoviral construct containing SMN to mouse models of SMA. In doing so, we will address whether delivery of SMN can correct the

pathological defects that result from low intracellular levels of SMN, i.e. can motor neurons and skeletal muscle be rescued. We also realize that life-long expression of SMN will be required to treat SMA patients.

To deal with this issue, we are trying to develop an adenovirus that is devoid of all viral coding sequences and contains the entire SMN1 genomic locus. Similar types of vectors have been shown to provide life-long transgene expression and ameliorate disease pathology in other mouse models of human disease.

Overall, the work presented by DiDonato et al. (2003) in Human Gene Therapy shows the feasibility of SMN gene transfer. We welcome other investigators to join in and use other methods to deliver SMN (either viral or non-viral) to animal models of SMA.

In doing so, a broad base of knowledge will be gained which will allow us to move forward and put forth the best possible gene therapy treatment for SMA patients.

This is very important since an overall treatment strategy for SMA may require both pharmacological and genetic intervention.

Editor's Note: Dr DiDonato and Dr Kothary are FSMAC grant recipients.

FSMA Launches Landmark Effort to Develop Effective Treatment for SMA

We are very pleased to inform you of an agreement signed by Families of SMA (US) and deCODE genetics.

deCODE genetics and Families of Spinal Muscular Atrophy (FSMA) have signed an agreement aimed at developing a new therapeutic compound for SMA. **Using promising compounds identified through previous FSMA-funded gene- and drug-discovery work, deCODE's Chicago-based pharmaceuticals group will identify the most promising lead compounds,**

optimize these compounds, and conduct the medicinal chemistry and scale-up work to develop a potentially effective new drug ready for clinical trials.

The three-year agreement is potentially worth \$5.2 million, including milestones for the successful development of a compound approved for clinical trials.

FSMA will retain all rights to drugs developed under the alliance for use in treating SMA as well as royalties on sales for their use in other indications.

FSMA-sponsored research has contributed not only to the identification of the SMN1 gene, but also to the identification of another gene located nearby called SMN2. In most SMA patients the SMN2 gene contains a mutation that leads to a reduction in the amount of SMN protein produced by the gene and to a defect in the protein that is produced.

Previous FSMA-sponsored drug discovery work has identified a series of compounds that may correct the transcription error in

the production of SMN protein and/or increase the amount of protein produced. If a compound can be found that can do this safely and effectively, it may be possible to restore the proper amount of SMN protein in the body and slow or reverse the disease process.

deCODE's work will focus on identifying and developing such a compound.

For more information see www.fsma.org

An Executive Moment

Dear Family, Friends, and Members of FSMAC,

Another year has passed and the New Year is starting with some exciting news. FSMAC would like to thank all our supporters for making the past year a big success.

Your generosity and hard work has made it possible for FSMAC to commit \$200,000 towards SMA research in 2003.

Preparing for Clinical Trials— Seeking Patients

As a preparation for clinical trials, FSMAC is very excited to inform you of an upcoming clinical study we will be funding. Project CURE SMA is a clinical study whose objective is to validate different measurements of SMA as potential "outcome measures" in the event of a therapeutic trial. Some of the measurements that will be tested include muscle strength, motor response, pulmonary function and SMN RNA.

100 type II SMA patients, 20 at the Montreal site, between the ages of 2 to 12 years will be recruited. They will be seen three different times over a 1 year period. We will be looking at how these measures vary with time within each patient as well as the variability between patients.

The question that is being asked is "what do we measure if we want to test whether a drug or treatment is having a positive or negative effect when given to a child with SMA". This study will help set up the framework for future therapeutic trials.

Gene Therapy Research in Canada

We are also very excited to inform you about a gene therapy paper being released by Christine DiDonato, Robin Parks and Rashmi Kothary. FSMAC sponsored work of DiDonato and Kothary in 2002.

Using adenovirus-mediated

gene delivery, they showed that SMN can be efficiently expressed in patient fibroblasts (skin cells), and leads to restoration of nuclear gems, which are thought to be important for the functional rescue of the SMA phenotype.

Overall, this work is the first demonstration of the feasibility of virus-based delivery of the SMN-coding gene to restore the normal SMN expression pattern in SMA patient-derived cells, and holds promise for gene therapy of SMA, as a potential long-term therapy for this disease.

A more detailed description can be found in this newsletter or by checking out our website at www.SMACanada.com.

The International Alliance

FSMAC and the members of the International Alliance of SMA (IASMA) have only been able to fund all this research because of the hard work and commitment of all those that

support our organizations. We are dedicated to finding a cure for SMA and we will do all we can to make a cure a reality. It is important that we all do our part and donate what we can.

Money is Always the Key

If you can, please make a commitment to hold a fund-raising event this summer. The more money raised, the more research we can fund, the sooner we will have a cure!!

As you can see, the progress towards finding a treatment or cure for SMA is moving ahead very quickly. Excitement is building, as we begin to realize that a cure for SMA may be in the near future.

Thank you all,

Darren, Bettylou, Aniello and Susi

Families of SMA Canada



Rebecca's Angel Run for SMA

Newmarket, Ontario Event Kicks Off with a Bang

Still beaming from the success of the 2002 race, co-race directors Louise Smith and Doug van Fraassen held a kick-off party for the 2003 race committee for Rebecca's Angel Run for SMA to be held on July 12th.

What's new? For one, starting at the opposite end of Fairy Lake there'll be more parking, with space for a reserved handicapped lot. In addition the 5km route will be a double loop—giving ample time for fans to cheer on their favorite runners.

With one corporation commit-

ted, we are pleased to announce the addition of a Corporate Challenge. This is an excellent way for companies to build staff morale and give back to the community for their continued support.

By far and wide, the most exciting element is that the event will be dedicated in the honour of first year participant, Liam Zajdlik, an incredibly beautiful boy who lost the battle with SMA in the fall.

All in all, things will be bigger and better without losing the

'family' atmosphere. SMA families are encouraged to check www.town.newmarket.on.ca for more information on where to stay, where to eat, and what else there is to do in Newmarket. Come on out and make it a weekend affair.

Best of luck to the other cities (Vancouver and Ottawa) that are planning their own Angel Run for SMA in 2003.

For more details contact Louise Smith at: Louise@SMACanada.com

Membership Drive

*Remember:
Memberships are a
tax-deductible
donation! Please
help us reduce costs
and mail in your
membership form
today!*

As we move forward and explore other means to raise money, it is also important that our membership numbers grow.

Your memberships are important to us. We use them to help recover costs to print and mail out newsletters on a regular basis and to send info packs to newly diagnosed families, and to offset our operating costs. And, as always, to continue to

fund important Canadian Research in the ongoing search for a cure to SMA.

In the next couple of months FSMAC will be sending out membership renewals to all those with outstanding membership dues.

We have many families on our mailing lists who have not joined FSMAC or have not renewed their memberships.

Please, take this moment to undergo your own personal membership drive on behalf of FSMAC.

Give it as a gift to family members to keep them informed or pass along the membership form at your doctor's office, your dentist's, or just your neighborhood arena or dance class.

Please join!

CoughAssist Training CD



CoughAssist: a device that helps patients who can not cough for themselves.

The J.H. Emerson Co. is pleased to announce the release of their new Introduction and Training CD for the CoughAssist, a noninvasive airway clearance device.

This interactive disc includes complete step-by-step instructions as well as a comprehensive clinical tips section.

To receive a free CD please con-

tact the J.H. Emerson Co. by phone at 1-800-252-1414 or by email at rob@jhemerson.com.

The CoughAssist, a device that helps patients who can not cough for themselves, enhances or replaces a patient's natural removal of bronchial secretions.

The noninvasive device simu-

lates a natural coughing process and reduces the risk of airway damage and respiratory complications associated with more invasive procedures.

You can check out the CoughAssist device at:

www.jhemerson.com.

A Simple Request

FMSA gets many requests for pictures of people affected with SMA for the many fundraisers. We have decided to make a compilation of pictures for the purpose of the much needed awareness and to raise funds. What we need now is pictures and a brief bio.

Please help us by sending a picture of your child or you, along with a date of birth, type

of SMA, date of passing (if applicable), and something about them personally (e.g. likes).

Thank you for taking the time, you can say as much or as little as you like. We know that when people see the faces, they are more apt to donate help.

Please forward them to Susi Vander Wyk at the FSMAC's office or by email to Susi@SMACanada.com.

SMA Takes the Hill

We would like to remind everyone of FMSA's conference scheduled for June 20-22, 2003 in Washington, D.C.

You can be sure it will be an informational weekend, giving families the opportunity to network with other families from across North America and the world.

Families also get a chance to meet some of the researchers



that work very hard on a daily basis to find a cure for SMA.

For more information see www.SMACanada.com. Don't wait too long to register or you may not get in.

FSMAC Thanks You!

We would like to take a little space and recognize the following individuals and businesses for their generous donations made during the period of July 1/02 to Dec. 31/02.

\$1000 or More

Darren Bray * Vanhof and Blokker Ltd * Hanna Pestell * Continental Cabinet Company Ltd * Velan * Tracey Manerikar * Rotary Club of Aurora * Bell Canada * Johnny K Sports * Manitoba Hydro * Mastec Canada

\$500 or More

Rosalyn Properties Inc * Paul Shavings * Birmingham Lodge (1995) Ltd * Jean Bray * Mail-O-Matic Services Ltd * Shelley Wolsey * Karla Pesula * Dave Zajdlik * Lee/Joanne Chapman * A. Vecchiarino Financial Services Inc * Sean Whelan * Raspa Benoit

\$100 or More

Harper Collins Canada Ltd * Brenda Leigh * Dazmo Musique Inc. * Leonard/Joyce Schuett * Video Assist * Video Mtl * Bruce Jensen * Darlene Carey * David Macarios * Defelice

Domenico * Ed O'Hara * Heluva Good Cheese * John De Sousa * John Long * Lori Heron * Lynden Hernessy * Sylvia MacIntyre * Mary Ellen Stanley * Mike Green * Nidan Holdings Inc * Night-Hawk Janitorial Services * Sigrid Whelan * Cedarwell Excavating Ltd * Graphic Innovations Inc * Greg Buchholz * Justin De Vries * Brendon Rothwell * Karen Schell * Welbeck Sawmill Ltd * Julie Insley * Gloria & Daniel Evenson * Famous Players * Nick Schnidrig * David Dedman * Henry Proulx * Hilda Zajdlik * Carl Legrow * Dianne Wolstenholme * Erliss Stobbe * Ioana Mistreanu * Wayne Campbell * Granum Huterian Brethren * Terry Houle * Adrian Vanfraassen * Anne Champion * Robert Oppermann * Stuart Main * Michael Wildschut * Eden of York * Jason Cawley * Sue Lang * Robert Motz * Gerard Flanigan * Brenda Porter * The Estate of Irene Bray * Leslie James * Morley Doan * John & Barbara Sltgraaf *

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Every donation that FSMAC receives is very important to us and we regret that we can not mention every donor.

Families of Spinal Muscular Atrophy Canada

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Our Mission

To fund the best possible Canadian research in search of a treatment or cure for the SMA diseases.

To support families and individuals affected by SMA.

INCOME STATEMENT

FISCAL YEAR ENDING DECEMBER 31, 2002

Income		
Donations	204,374	
FSMA Sales	173	
Interest Income	3,547	
Membership Dues	463	
Total Income		\$208,557

Expense		
Fundraising Expenses	10,813	
Office Supplies	887	
Postage and Delivery	1,497	
Printing and Reproduction	2,032	
PST Expenses	1,065	
Telephone	602	
Travel Expenses	998	
Miscellaneous	171	
Total Expense		18,064

Net Income \$190,493

Thanks to your continued support, FSMAC has had another very successful year. FSMAC has made a commitment to fund \$200,000 towards SMA research in 2003.

Together we will find a cure!

Name: _____
 E-mail Address: _____
 Street Address: _____
 City: _____ Province: _____
 Postal Code: _____ Country: _____
 Business Phone: _____
 Home Phone: _____

Membership Form—FSMA Canada

To join Families of SMA Canada fill out this form and mail it to us with payment. Please make cheques payable to "Families of SMA Canada"

I am/have/had a family member or friend affected with:

- SMA Type I (Werdnig-Hoffmann Disease)
- SMA Type II (Chronic)
- SMA Type III (Kugelberg-Welander Disease)
- SMA Type IV (Adult Onset)
- Adult Onset X-Linked (Kennedy's Syndrome)
- Don't know

Name: _____ Sex: [] Male [] Female
 Birth date: _____ Diagnosis Date: _____
 Father's name: _____ Mother's Name: _____
 Current Status: _____ Relationship: _____
 Date of Death (if applicable): _____

(If you have additional family members diagnosed with SMA, please provide the same information for each one on an attached sheet of paper.)

I am including my annual dues, as follows—

- Family/Affected/Friend \$25.00 Cdn
- Professional \$30.00 Cdn
- International (outside Canada) \$40.00 US

This is a: Renewal New Membership

I am including an additional contribution of \$_____.

Have you received your initial information package? Yes No

I authorize Families of SMA Canada to release my name, address, and phone number to other SMA families.

I authorize Families of SMA Canada to release my name and address to researchers investigating SMA.

Office use— IS _____ Date _____