



The Canadian Connection

FAMILIES OF SPINAL
MUSCULAR
ATROPHY CANADA

APRIL 2002

Dear family, friends, and members of FSMAC,

We, at Families of Spinal Muscular Atrophy Canada (FSMAC), would like to welcome all of our new members that have joined our organization in the last year. Our membership is growing with every week that goes by.

As parents of children with SMA, we would like to send a special thank-you to those individuals that have held fundraising events over the last year. We can't say enough about your hard work. It is making a difference!! To all of you that made donations over the last year, thank-you. Your generosity has allowed us to commit \$115,000 towards SMA research for this year.

The past year has been exciting one as we all move forward towards finding a cure for SMA. Research into a treatment or cure is racing forward and we are sure that this year will be full of great news. We have the technology available to us to find a cure, thus making it more important than ever to raise money for research. For those of you who are thinking about holding a fundraising event, now is the time. We all need to pull together and do our part.

Over the past year we have made many new friends. Friends that have become almost like family. We would encourage all of our families to reach out and connect with others. We can all learn from each others experiences.

Darren, Bettylou and Barry
Trustees of Families of SMA Canada

A SPECIAL THANKS!!

We would like to extend a special thanks to Susi Vander Wyk from BC, Tarra Porier from Manitoba, and Aniello Cavallaro from Quebec. These individuals have put in many hours of hard work and have done a tremendous job of raising both awareness of SMA and money to fund research. Thank-you all.

CONFERENCE UPDATE

Hey folks, it's conference time again. Family of SMA's conference is scheduled for June 21st - 23rd, back in the Chicago area.

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

Families also get the opportunity to get to know some of the researchers working towards a cure for SMA. We would encourage everyone to try and attend if possible. It fills up every year, so don't wait to long to register!!

For more information see our website or call our office at (800) 866-0016.

*Individuals wishing they could ,
are certain to be passed by
those thinking they can.*

Family Spotlight

We would like to dedicate a little space in each issue to introduce you to our SMA families across Canada. We will use the first 3 issues to introduce you to the founders of Families of SMA Canada.

My name is Bettylou Ross and my husband Ed and I were delighted to be involved in founding FSMA Canada. We have been members of FSMA in the U.S. since 1990, and have benefited greatly from that support - so we were quite anxious to have the same kind of organization available in Canada. We live in Guelph, Ontario, which is about an hour west of Toronto. Our son, Bernie, who is 5 years old, has SMA type II. We have 2 healthy older kids - Ricki Lee is 19 and Ben is 17. We also lost a son to SMA (Daniel, at 26 months) in 1991. When Daniel was diagnosed, we had difficulty finding anyone who'd heard of SMA, and found out about FSMA - almost by accident - from a book in the library! Now the internet has revolutionized access to parental supports - at least for those of us who are connected. Bernie is much stronger than Daniel was, and we have worked hard to keep him that way. He can stand in long leg braces or his new RGOs (reciprocating gait orthoses) and he uses a manual chair in Kindergarten. We have



Bettylou, Ed and Bernie Ross

just received his first power chair, so that will probably change! Bernie has been pretty healthy, except for a bout of pneumonia which required hospitalization in Feb. 2001. Our favorite form of physiotherapy is swimming in a (not too hot) hot tub, an hour every day. I work part time, while Bernie is in school, as a computer programmer. As well as volunteering for FSMAC, I am the web coordinator for the FSMA U.S. organization. Ed is a pilot with Air Canada. We'd love to hear from any of you - bettylou@fsma.org - or call (519) 822-5184. You can see more pictures of Bernie at - www.ugalumni.uoguelph.ca/~eross

We welcome any suggestions or comments to improve on the quality of our newsletter.

We would love to hear from you. Send us a note about your fundraisers, any special equipment you use or other topics that you feel our readers might enjoy hearing about.

We will do our best to fit your article in to our newsletter as soon as we can.

If you send us a photo, please send us one that we don't need to return.

We would like to send out a special thank-you to all those that participated in our 1st Annual Mailing Campaign this past holiday season. It was a big success!

Many families commented on how this fundraiser allowed them to explain to family and friends what SMA was, and how it has affected their family.

If you would like to get involved and participate in a mailing campaign, please contact our office. It's never too late!

We have several different families who are in the process of planning a 5K run/walk, from across the country for FSMAC. If you would like to get involved by planning one in your city, please contact our office.

ACKNOWLEDGING OUR DONORS!!

Every donation that FSMAC receives is very important to us! Although we do not have the space to acknowledge every donation, we would like to mention a few below.



We would like to acknowledge those donations made by individuals or businesses of \$1000 or more:

Mitch Poirier Plumbing & Heating * Tarra/Mitch Poirier * Marek Wacyk * Theresa Van Fraassen * Minoque Medical Inc * Air Tech * Giovacchino Cavallaro * K G Ruban * Commercial Interior Contractors Inc. * Thomas Cockwell * Patagonia Mercantile Inc * Manitoba Hydro



We would like to acknowledge those donations made by individuals or businesses of \$500 or more:

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We would like to acknowledge those donations made by individuals or businesses of \$100 or more:

Rita/Peter Van Laehoven * Kairn Enterprises Ltd * C.D. Muldrew * Donna Pestell * Sigrid Whelan * Louise Smith * Sveistrup, Barbara * Marg Taylor * Thea Thompson * Candace Pritchard * Adrian Vanfraassen * Darlene Carey * Jack Brown * Ted Cierny * Pumpnickel's - FCP * Cecil Jones * Darrel Nelson * 1425931 Ontario Ltd * Carolyn Rubel * Cecilia McCann * J&F Bevilacqua Enterprises Ltd * Vancouver City Credit Union * United Optical * Regent Fish Ltd * Cioffi's Meat Market and Deli Ltd * McGinn Engineering * John/Marie McNeill * S. Piccolino * Nello Mariani * Elvira Di Lauro * Rosina Foresta * Patricia Tedeschi * Robert Lamarre * Dr Melvin Schloss * Beco Industres Ltd * Medusa Bar & Grill * Boutique Moda Enr * C.M.C. Canada Leather 1989 Inc. * Mario Vocisano * Maurizio Favretto * Societe Administration Lama * Joseph Spingola * Ciot * Sylvia Di Simone * Jean Proulx * Carol Vadnais * Les Labortoires Du St-Laurent E. H. * Jacques Bolduc * Esposito Foods Ltd * Vegas Casino Bar * Giuseppe Cavallaro * Les Systemes Probar Inc * Edward J. Druker * Polyron Packaging Ltd * Canadian Youth Foundation * Peter Trifonopoulos * Les Productions De Concert R.A.M. * Tapis Capital Carpet * Gaetan Bono Inc * Silvia Aquila * ISBA Music Entertainment Inc * 116278 Canada Ltd * Allied Welding Inc * Joe Potenza * James Linton * Susan Long * Schenker of Canada Ltd * Joe Pijuan * Janet McNab * Sharon Stead * Gary Abraham * Scott MacDonald * Janine Hogan * Caroline Scholl * Angus MacInnes * X-Zodiacs Soccer Club * 591454 B.C. Ltd * MSS Engineering Ltd. * Kelowna Lite Kast 1989 * L. Forrest Mechanical Inc. * Draulico Mechanical Services * Roofmart Pacific Ltd. * Rodney Hyslop * Westhill Painting & Decorating * Comren Contracting Ltd. * Acorn Wood Design * Westcoast Cutting & Coring * Ben Leboe * Marilyn Mullan * Jim Murphy * Thomas Fraser * Patrick Pepin * Granum Huterian Brethren * Rami Hamad * Central United Church - Brandon * Leonard/Joyce Schuett * Matthew Ellis * Maryann Nelson * Jenny Chatt * Danica Logan * Susan Pereira * Tera Scott * Hot Springs Holsteins * Kimberley Fines * Winfield Swinging Seniors Line Dance * Susi/Bruce Vander Wyk * Glen Bray * Mario Giobbi * Brian Walsh * Kentonnes * Villa Leitold * Corporation Casa D'Italia Inc * V. Caucci * Autolux Sales and Repairs Inc. * Bugatti Design Inc. * 141800 Canada Inc. * 9072-3529 Quebec, Inc. * Fen-Nelli Fashions Inc. * Canbec Construction Inc. * Gino Olivieri * Brad Entertainment Group * Debracon Equity * Claudia Poirier * Snowline Enterprises Ltd * Premium Canada * Designer Kitchens Interiors * LLC Magic Textiles * Hallis * English-American Import Export Co. * Rivers Elementary School * Stein Fibers, Ltd * Wiebe Vander Wyk * Marc Schuster * La Caisse Populaire De Saint-Boniface * Parcher Enterprises Ltd * J. Sonic Services Inc * Claudia Keats * Karen Guibault * Tina Cavallaro * Dr S. Frenkiel * Leslie Bernstein * John Manoukian * Centre Furmeraire Cote-Des-Neiges 3189 * Dino Mariani * Getracan Inc * Dominic Mariani * Darlene Kastamoulas * Michael Iafigliola * Quapaz Inc * Jepak Inc * Capello-Duval Inc * Les Entrepreneurs Electrique * Les Entrepreneurs Peintre PVA Inc * Reparation Mustang Lift Ent * The Concordian * Katherine Tolnai * Colin Pereira * Rolf/Patricia Soth * Irene Hadley * Andrea Whelan * David Krahn * Tina MacIntyre * Jacqueline Nelson * Mary Nelson * Royal Canadian Legion #57 * Kute Knit * Les Promotions Serma Inc. * Location John Scotti Inc. * Andrew Levinson * Services Administratifs M.F.O. ET A * 3103-3061 Quebec Inc * Nelmar * Alouette Amusement Corp * Eleonor Wiswell * Teacup Holdings * The Treehouse Furniture * Marianne Soth * Valley Plumbing * Haakon Industries * Specialty Overload Services Ltd. * Winn Rentals * Valco Electric Ltd. * Britt Johansson * Senior Scene Inc * Sisters of Charity of the Immaculate * Dwyne Epp * Lisa Giles * Chiara & Associates, Avocats * Ville Marie Suzuki Automobiles Inc * Phyllis Black * Interpaving Ltd * Jose Theodore * Mapei Inc. * Popular Parking Management Inc * Provigo Distribution Inc. * AquaBrass * Zoom Media Inc * Bessner Gallery Kreisman * Diane Crawley * Carol Whapshare * Kidston & Company * Robertson Floors Ltd * Art Huber Archetect * Suzanne Seto * Friendly Forest Preschool * Bray, Carol * Napoletana Pizzeria * Les Excavations Super Inc. * ERA Clothing Inc. * 2531-6928 Quebec Inc Express Inc * Bridge Electric Corp. * Kathleen/John Rink * Dr. Aline Levi * Annunziata Trocchia * Agostino Mariani * Sebastiano Cavallaro * CSG International * D.M.V. Electrique Inc * Randy Kerr * Marianne/Klaus Soth * Double S Hogs * Bacon Hill Farms * J. Hogan, * Shelley Olafson



We deeply apologize for missing any names that should have been mentioned above. Please let us know so that we can acknowledge your donation.

FAMILIES OF SMA CANADA
INCOME STATEMENT
FISCAL YEAR ENDING DECEMBER 31, 2001

Income	
Donations & Fundraisers	135 253
FSMAC Sales	927
Interest Income	234
Membership Dues	<u>600</u>
Total Income	137 014
Expenses	
Bank Service Charges	70
Information Brochures	2 416
Fundraising Expenses	17 390
Office Supplies	316
Postage and Delivery	1 328
Printing and Reproduction	214
Telephone	438
Total Expenses	22 172
Net Income	114 842

We, at FSMAC want you to know that we are working hard to keep operating expenses to a minimum. Our goal is to maximize the dollars committed to funding research. Having a 100% volunteer organization has kept our operating expenses at less than 2% of our gross income.

Your hard work and generous donations has allowed us to commit \$115,000 to research for this year. Thank-you!

Our membership is growing weekly, drawing from families across the country. But it is important, that we keep increasing our membership. Check with family members to see if they would be interested in becoming a member of FSMAC. It is an excellent way for them to learn more about SMA and stay informed of research news. Don't be afraid to give a membership form to your doctor or physiotherapist.

We now have a membership form available online, or you can print and fax us a copy if you wish. If you do not have access to our website you can contact our office and we will send one out to you ASAP!!

**Give more than you're
asked,
and you will receive more
than you can dream!**

FAMILIES OF SMA CANADA
P.O. BOX 22024
BRANDON, MB R7A 6Y9
Ph. (800) 866-0016
Fax (204) 328-7803
www.SMACanada.com
Info@SMACanada.com

TRUSTEES OF FSMAC:
Darren Bray - Manitoba
Darren@SMACanada.com
Bettylou Ross - Ontario
Bettylou@FSMA.org
Barry McGinn - British Columbia
Barry@SMACanada.com