



Barth Syndrome
Foundation of Canada

Canadian Newsletter

www.barthsyndrome.ca

September 2013



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"Enhancing the lives and outcomes of Canadian individuals and families affected by Barth syndrome."



Ten Years in the Making

by Lynn Elwood & Chris Hope

At times, it is hard to believe that the Barth Syndrome Foundation of Canada (BSFCa) has been operating for ten years. Knowing that it would not be an easy job, several Canadian families joined together during the 2002 Barth Syndrome International conference and decided to form a Canadian affiliate. We learned a considerable amount during those first few years as we worked through incorporating the business, ensuring governance was in place and achieving our charitable status. We worked closely with the US BSF group and set up programs focused on awareness, family services, science & medicine and charitable support as well as fundraising.



In the early years, much of our efforts went toward raising awareness within Canada. We created material that explained Barth syndrome and shared it broadly. We attended conferences, contacted hospitals, did outreach to key types of physicians and shared information on Barth syndrome and the organization with

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From the Heart! By Bob and Susan McJannett

Les Morris asked me to explain how Susan and I became involved with the Barth Syndrome Foundation of Canada.

First you need to know that Susan and I are two of the luckiest people in the world! We have never faced serious illness, have two sons that make our chests swell with pride, a successful small business and one of the greatest groups of friends a couple could ever ask for.

Two of our best friends are Bruce and Carol Wilks, in fact a friendship that extends over 50 years. Through Bruce and Carol, we met and became friends with Les Morris and Lois Galbraith, and as they say the rest is history.

Somehow we were press ganged into playing in the Barth golf tournament. Those who know us know we are not golfers; in fact we did so poorly we embarrassed our playing partner by winning the "most honest golfer" trophy. Once we had proven our ineptitude at that silly game Lois promoted us to golf tournament helpers.

It was during that time while working with other volunteers we learned about Barth Syndrome and its effects. We met Barth Boys who soon became Barth Men. We also met their families and became more aware of the trials and tribulations each faced dealing with this relatively unknown disease. At the same time we became aware of how little funding was available for research and the huge efforts our friends and the other Barth families were putting in to raise desperately needed cash.

It seemed like something where we could make a difference. We liked the idea that all the funds raised were going to benefit the foundation, no one was taking any salary and expenses were being kept to a bare minimum.

We started by coercing our friends in the BussMegg society to sponsor the lunch at the golf tournament, have been able to run a couple of silent auctions at one of the car shows and operated two Boogie for Barth dances. These were all labours of love and semi successful. This year we are looking for something different. If anyone has any ideas we are interested in hearing them. It is imperative that we keep the funds coming in.



One of my concerns for the future is the age of the hard core workers; no one is getting any younger. Who will be the next generation of fund raisers? It is time to recruit the next group to step up to the plate.

Now Les asked for about 350 words so that is what I have written. But I could have put the whole adventure into a single sentence. "It was the right thing to do and Lois Galbraith is tenacious."

We are always looking for ways to improve, and in order to be more efficient in handling the mail that we receive, we decided to move our primary mailing address. To ensure that no mail addressed to us gets lost, we are retaining our original mail box for a year, until we are sure that no mail is directed there any longer. Our new mailing address is:

162 Guelph St. Suite 115
Georgetown, ON L7G 5X7

We now also have a second address, which we hope will encourage families and

doctors to contact us from the western part of the country.

20 Mayfair Cr.
Regina, SK S4S 4H5

Our phone number has been changed to 905.873.2391, and our general email address is info@barthsyndrome.ca.

As always, our website which is getting a new look is www.barthsyndrome.ca, and we encourage you to check it out frequently for updates and event information.

Grant Hatch....Friend and Advocate of the BSFCa:



It has been just over a decade ago when I received the phone call from Dr. Richard Kelley from John Hopkins University in Baltimore inviting me to come to a meeting in Baltimore focussed on cardioliipin and Barth Syndrome. I

was on sabbatical at the University of Minnesota when I read with interest the paper by Dr. Peter Vreken from Dr. Peter Barth's group in Holland which showed that defective cardioliipin remodelling could be involved in the pathology of Barth syndrome. Since I had just begun work on cardioliipin remodelling a couple of years back I was excited and very enthusiastic to visit Baltimore and meet the scientists involved in this rare but intriguing disease.

I quickly realized that this was a serious condition which impacts not only the young boys that are diagnosed with the disease but also their families. The International Scientific, Family & Medical Conferences were then developed through the Barth Syndrome Foundation to not only bring together doctors and scientists to discuss and collaborate in the understanding and treatment of the disease but to also bring together families to share information and provide their stories.

The meetings are truly unique from any other scientific conferences I attend as basic scientists, such as me, can meet front line clinicians involved directly in patient care and the individuals with the disease and their families. My experience at these meetings has been an inspiration to what I now do and how I approach my work. I have received several grants over the years from the Barth Syndrome Foundation and the Barth Syndrome Foundation of Canada. Based upon the foundation of these grants I have published several papers on Barth syndrome that I hope have led to a greater understanding of the disease. I was subsequently successful in obtaining a five year grant from the Canadian Institutes of Health Research to continue with my studies. The Barth Syndrome Foundation of Canada has been instrumental in all of my efforts.

Grant M. Hatch, Ph.D., Professor, Dept. of Pharmacology & Therapeutics, University of Manitoba, J. Buhler Research Centre, Faculty of Medicine

Editor's Note: Grant is a Canadian Researcher, University of Manitoba, who has attended several of our BSF Conferences and he serves on the Scientific and Medical Advisory Board of the BSF. He is an inspiration to us here in Canada. He is a great supporter of the BSFCa and is helping to promote awareness of this unique disease.

Thank you, Dr. Hatch!!

AGM - Business and Falling on Ice By Robert Hope, affected individual

On 6 April, 2013, members of the Barth Syndrome Foundation of Canada descended on the Annandale Golf and Country Club for our Annual General Meeting (AGM), an afternoon of business and fun. The first part of the afternoon was spent reviewing the accomplishments of the BSF Canada in the past year, voting in board members, and hearing about the plans for this coming year. As always, attendees asked various questions during the meeting for any clarification and added their thoughts and comments. Near the end of the meeting, Wayne and Dianne Bridger, two of our dedicated volunteers were presented with an award for their support and fundraisers for BSF Canada.

Once the meeting had adjourned, almost everyone moved to an adjacent curling hall where we tried, and mostly failed, to throw rocks into a bulls-eye on a sheet of ice. Thankfully, we had secured a pro to give us some pointers, but even with Nikki's tutoring, balancing on one foot, with your weight

partially on a heavy rock and partially on a broom, caused more than one person to fall.

My personal curling career ended early on when I fell while stepping off the ice.

Among the multitude of falls and rocks not going the distance was Susan Hone's double takeout, securing victory for her rink.

Overall, it was an enjoyable day, despite the pain from falling on the ice. I am looking forward to seeing everyone at this year's Golf Tournament in September.



Wayne, Dianne, and Lynn



Sheldon getting ready to slide



Nicki, Travis, Adam, Lynn

Spotlight on Families: Introducing Ryan - Affected Individual

Ryan has successfully completed his first year of the two year Culinary Management Diploma at Georgian College of Applied Arts and Technology. His full time studies included courses such as Food Theory, Kitchen Management, and of course, many hours spent in the kitchen preparing, baking, grilling, sautéing and all the other skills required of a chef. He is currently honing his skills while working as a Porter in the kitchen at a local Golf Club. September will see him start his second year. His parents do wonder however when he will start making supper for them at home!



Ryan the Chef! (above)

Oops! Careful, Travis! (left)



My Tattoo by Josh

I wanted to do something to remember my brother and also raise awareness for Barth syndrome.

I decided a tattoo would serve both purposes. Jordan was my older brother who died in 1991 and Jared is my younger brother who is living with Barth syndrome.



THE MANY WAYS TO HELP THE BARTH SYNDROME FOUNDATION OF CANADA



TWICE THE FUN!

Make your next event —Birthday, Anniversary, Tea, Wedding, BBQ—even more special by raising funds for the BSFCA. Or create an event—Dress down day, Fifty/fifty draw, Bottle drive, Raffle, Garage sale.



IN-KIND GIFTS

BSFCA welcomes items to be used for prizes and awards at our events—TV, iPod, Camera, Jewellery, Gift Certificates. Income tax receipts provided according to Canadian government laws.



TRIBUTE/IN MEMORY

Honour someone's life, or special day—Graduation, Anniversary, Memorial by making a donation in their name. We will send them a card and you a tax receipt.



SERVICE CLUB DONATIONS

Do you belong to a service club? Donations from service clubs are greatly appreciated! We would be happy to provide a guest speaker for your meeting.

SPONSORSHIPS!! SPONSORSHIPS!! SPONSORSHIPS!!

.....SPECIAL EVENTS!!

Ⓜ Annual General Meeting/Outreach	\$ 700.00
Ⓜ BSFCA Annual Planning Session:	\$ 300.00
Ⓜ Volunteer Recognition Award:	\$ 50.00
Ⓜ Doctor Awareness and Outreach:	\$1,000.00

.....SWING INTO GOLF!!

 Title Sponsor:	\$5,000.00
 Dinner Sponsor (2)	\$2,000.00
 Lunch Sponsor	\$1,500.00
 Golf Ball Sponsor	\$ 500.00
 Foursome Prizes	\$ 50.00

For Information please call 905.873.2391 or
 Contact: Lois Galbraith: lois.galbraith@sympatico.ca
 Christine Hope: chope62@cogeco.ca



www.barthsyndrome.ca

Registered Canadian Charity Number: 86102 2002 RR0001

Our Congratulations and Gratitude to our Golfers & Volunteers

By Lois Galbraith

September 9, 2013 marks our ninth annual golf tournament!! These golf days have all been very exciting and filled with good fun, much laughter and great friendship.

We want to thank the golfers and volunteers from all of our tournament days for their continued support and dedication to the BSF of Canada. To date, we have raised \$150,000 for BSFCa plans, activities, research and family support. We are very proud to be fulfilling the vision of ***Enhancing the lives and outcomes of Canadian individuals and families affected by Barth syndrome.***

To succeed takes determination, organization, drive, fundraising and a strong desire to beat this disorder. We owe much of our success to people like you who have believed in the BSFCa and encouraged and supported us in many ways.

If you would like to join us / pitch in / offer your talents or skills, please contact me directly at 705.877.3159 or lois.galbraith@sympatico.ca





8th Annual Golf Classics - Sept 2012

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everyone we could reach. The result of this continuing program is a strong and growing set of physicians and researchers, families and friends that are aware of and support Barth syndrome research, affected individuals and the organization in countless ways.

Fundraising has been very important throughout our 10 years and grows in significance as we strive to expand our programs to provide more family services, further research and support for affected individuals. We started with projects like letter appeals, selling poinsettias and collecting change. Soon, it became clear that if we could raise more funds we could expand our efforts. We held our first golf tournament in 2005 and have raised over \$150,000 to date in this annual event. Throughout our history, grassroots fundraising has played a key role, bringing both funds and awareness with activities like sales, draws, parties and events put together by families, friends and volunteers.

Our Science & Medicine program has been a goal from the beginning and really grew when we started to fund research grants in 2007. We participate in the BSF grant process which utilizes the International Scientific and Medical Advisory Board, Science Director and several outside researchers who review and prioritize grants from around the world that further research into all aspects of Barth syndrome. We have contributed over \$220,000 in funding to eight research grants from Canadian and International researchers. This is a very exciting aspect of the work that we do, as research has greatly increased the worldwide understanding of the disorder and allowed us to get closer to recommended treatment options.

Throughout our ten years, there has been a program that directly focuses on families and individuals affected by Barth syndrome. Through this program, we work directly to educate and support families and to help individuals affected by the condition. This support has involved everything from being at the end of the phone or mail to help with concerns; providing educational material; advocating within the healthcare system; and bringing families together so that they can share experiences, fun and laughter. As we closed our fifth year, we spent time reviewing the organization and our path forward. At that juncture, we agreed to refocus the organization with a mission that more tightly focuses on the Canadian individuals and the things they need to have for better short and long term outcomes. We did a needs assessment with the affected individuals and have changed our programs and mission to more closely respond to their needs.

Our revised mission is:

Enhancing the lives and outcomes of Canadian individuals and families affected by Barth syndrome.

We are grateful for the many hours put in by our growing set of volunteers. We remain a completely volunteer organization and none of what we do could be accomplished without the countless hours from so many devoted people. We now have a program that focuses on finding, engaging and sharing information with

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Friends of Barth

Adair, Jamie	Chalmers, Cathy	Ellsworth, David & Elizabeth	Hone, Chris & Susan
Adams, Lynda & Phillip	Chalmers, Mark	Elton, David ~	Hone, Josh
Adams, Terry	Chalmers, Stephanie & Shawn	Max Bell Foundation	Hone-Best, Jennifer
Aikens, Steward	Chen, Chee	Elwood, Adam	Hope Aero
Alblas, Henk	Chili-Chew, Yu	Elwood, Bryan & Susan	Hope, Harry & Helen
Allen, James	Christie, Garnrel	Elwood, Lynn & Rick	Hope, Michael & Christine
Allison, Vickie	Christie, Steve & Jill	Ernst, Gabriele & Kevin	Hope, Robert
Anderson, Allanna	Chung, Ann	Farley, Iris	Hope, Terry & Ruth
Anonymous	Cipriani, Josie	Finch, Glenn	How, Jimmy
Antler, Casey	Clark, Pat	Fitzgerald, Mary	Howard, Sharon
Arsenault, Bill	Clark, Steve	Flanagan, Mae	Hu, Ian
Asbury, Fred & Renée	Clelland, Bill	Fogh, Pam	Hubble, Larry
Bajor, Linda	Colaris, A	Forbes, Lyn	Hucaluk, Adrienne
Barrett, Lawrence & Marilyn	Connell, Margaret	Forster, Sharon	Hughes, Ron & Cathy
Basilio, Anita	Conway, Beth	Fraser, Wendy	Humphries, Jack & Jan
Basilio, Paul	Cook, Bob	Freeland, Dagmar	Husar, Vandra
Bereczky, AJ	Corneilius, John	Fuller, George & Jane	Ian, Hu
Best, Cathy & Rance	Cornthwaite, Hazel & Mike	Gallacher, Betty	James, Jennifer
Bingham, Joan	Coulson, Steve	Garment, Linda & Philip	Jardine, Ward
Blacklaws, Mathew	Country Meat Cuts	Gilles, Larry & Shirley	Jeffery, Elaine
Blaka, Alex & Bonnie	Cowper, Margaret	Gilmour, John & Christine	Jones, Ernie
Bond, Brett	Cox, Patty & Gerald	Ginou, Jonathan	Jones, Marilyn
Bond, Darryl	Cummings, Marie & Jim	Godin, Cheryl	Kehoe, Joan
Bonneau, Rodger & Lynda ~ Bonneau	Curkan, Sharon & Gary	Godinho, Dina	Kemp, Bill
Mechanical Services	Dave, Cornelius	Gooch, Sylvia	Kennington, Paul
Boyle, John	Dave, Hassell ~	Gordon, Karen & Dave	Kofsky, Liz
Breen, Carol	Hassell's Automotive Ltd.	Graham, Ruth	Kostal, Jerry
Brennan, Cameron	Davidson, Alex & Bonnie	Gregorio, John ~	Kritschgau, Rick ~
Bridger, Marj	Davies, Barbara	Strictly Excavations Inc.	Vision 2000
Bridger, Wayne & Dianne	Davies, Diane	Haggett, David & Sharla	Krueger, Rudy
Briggs, Paul	Davison, Marilyn & John	Haggett, John & Judy	Kugelmann, Jan
Burmania, Owen & Sharon ~ Sunsational	DeForest, Warren	Hall, Arthur	Lacey, Mary
Landscapes Inc.	DeForest, Wilmer & Ina	Hamilton, Reg & Anna	Lacroix, Guy
BussMegg Society	Deligiannis, Dino	Marie Daly	Laing, Sherril
Butler, Gayle	Demick, Diane	Hamilton, Wayne	Lamb, Doug ~
Byers, Cal	Dickson, Bel	Hammond, Jean	Exceltec Auto Services Ltd.
Caffrey, Rita	DiDiodato, Giulio	Harrison, Georgia	LaVigne, Carol
Campbell, Josh	Doherty, Jerry	Hassell, Dave	Leighton, Blair
Campbell, Karen & Glen	Douse, Dave	Helliwell, Kelly	Leighton, Keith & Jeannine
Cardarelli, Paul	Dove, Judy & Randy	Herner, Brian and Barbara	Leslie, Wayne & Carol
Carruthers, Elizabeth	Downard, Jason	Higley, Hazel	Lindsay, Sue
Carter, Don	Duclos, Bev & Roger	Hill, John	Loos, David & Ann
Carter, Nic	Dvorkin, Gary ~	Hintze, Audrey	Ludlow, Stephen
Cave, Doreen	Peel Scrap Metal Recycling Ltd.	Hocevar, Helen & Frank	Lyall, Dianne & Doug
	Ebata, Lyle	Hone, Barbara	

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Friends of Barth

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MacDonald, Carol & Fred	Murphy, Tony	Scothorn, Pam	Vella, Betty
Madigan, Jim	Musgrave, Bruce	Scott, Bob ~	Vilneff, Bill & Rita
Magennis, Debra	Nagel, Siegfried & Erna	Mx Aerospace Services Inc.	Walker, Chris
Magennis, Jasmine	Nagel, Thomas	Segal, Joseph	Walker, Shirley
Maier, Charles & Carol	Naraine, Chris	Selkirk, Kim	Wallace, Mike
Malick, Mel & Suzanna	Newfeld, Jeff & Beth	Sharky, Derrick	Warden, Keith
Mallais, Mary & Raymond	Nixon, Jane	Sharpe, Andy	Warden, Patrick
Mann, Ruth & James	Noddle, Bev & Norm	Sheridan, John ~	Warden, Steve
Marchesin, Elvy	Nunes, Maureen	ScotiaMcLeod	Warren, Jerry & Janet
Marcucci, Gabe	O'Connell, Don	Siebenga, Thom	Warus, John
Markham, Wanda	Olson, Sharon	Simms, Anne	Weatherall, Cathy
Martin, Dave	Paczkowski, John & Vicki Perkins	Simms, David	Weaver, Joan
Martin, Margaret	Patrick, Barbara	Simms, Marie	Webb, Lindsay ~
Masterton, Moira	Pearce, William & Bev	Simsons, Joyce	Lindsay Webb Financial Inc.
McClory, Brigid	Perkins, Phyllis	Sisson, Paula	Weeks, Ken & Jane
McCrodden, Jack	Pickup, Jacob	Smith, Glenn	Wegman, Gelja
McDonald, Carol	Pitkethly, Maureen	Smith, Karen	Weller, Sharon
McDowell, Joan & Bill ~	Poitras, Mike & Sandi	Smith, Ralph & Katherine Baxter	White, Susie
J & B Customs Brokers Ltd.	Poitras, Sandy	Smith, Ted	Wilks, Carol & Bruce
McGarrity, David	Post, Belvia	Sone, Marlene	Wilks, Dennis
McGill, Steve	Post, Michael	Soummer, Inna	Wilks, Helen
McGlaughlin, Larry & Jackie	Preece, Brian	Spall, Robert	Willis, Dave & Penny
McGregor, Don	Prodan, Magda	Steele, Carl	Windrim, Brenda
McJannett, Susan & Bob	Pudsey, George	Stevens, Mike	Wiwcharyk, Lubow
McKay, Cathy	Quackenbush, Earl & Carolyn	Stitt, Barbara	Wood, Gale
Megelink, Jasper & Mary	Raymond, David & Lila	Storey, Andy	Woodcock, Roy
Merrill, Deb	RBC Foundation	Storey, Dick & Janis	Worsley, Dorothy
Millar, Ronald & Margaret	Ritter, Andrew	Storey, Jan	Wright, Jessica & Cameron
Miller, Pickard Law	Ritter, Cathy & Chris	Sturup, Penny	Wu, Jin & Arnold Daley
Miller, Romaine	Ritter, Ryan	Tailor, Adarsh	Wuthrich, Grace
Milne, Peter	Roberts, Marlowe,	Teva	Young, Joan
Miloff, Michael	Jackson, Jackson & Assoc.	Thomas, Brian	Young, Ron & Lenora
Mintzas, John	Robertson, Mary	Thomas, Val	Zavitz, Peter
Moore, Nigel	Robinson, Jim	Thompson, Diane	
Moore, Walt	Robinson, Val	Timleck, Barry	
Morris, Elsie	Rodgers, Jim	Tjart, Gwen & Richard	
Morris, Erik	Rosatoni, Vico	Trueman, Carole	
Morris, Ian ~	Ross, Barbara	Tuccitto, Mary	
JonesDeslauriers	Sawaie, Marie	Turner, Cathy and Dave	
Morris, Les & Lois	Schertzl, Dawn	Tweed, Scott	
Galbraith	Schillaci, Paul	Tyers, Byron	
Moss, Don	Schmid, Corinne	Tyers, Robert ~	
Muller, Dea	Schuller, Dana	Wellington Consulting Inc.	
	Schuller, Dennis ~	Vallejo, Joe	
	Aviall Canada Ltd.	van Dam, John & Marian	
	Scollick, Charlie	Vanderwater, Barbara	



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Barth Syndrome
Foundation of Canada

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volunteers. Working with this amazing group of people has become one of the most rewarding parts of the organization.

It is with a great deal of satisfaction that we are able to look at the boys who have become young men in the past ten years. When we started, the ages of the individuals we work for ranged mainly from six years old to the early teens. We now have several men in their late teens and upward who play a vital role



in helping to raise awareness and in informing us of their needs.

As we close our first 10 years and look towards the next decade, we realize that we have learned, grown and accomplished a great deal. We welcome input and ideas to help us grow to the next level and sustain the organization in the spirit it has enjoyed during our first decade. Thank you to all of you for your part in this amazing group. We are making a difference in the lives of Canadians and others around the world who are in some way affected by Barth syndrome .

What is Barth Syndrome?

Barth syndrome is a life-threatening, complex, genetic disorder that primarily affects males. It is passed from mother to son. Barth syndrome was named after Dr. Peter Barth who first described the syndrome and did extensive research on the condition in the Netherlands. Death is more likely to occur when it is not recognized or misdiagnosed. Early awareness and diagnosis has already saved many lives; however, there are still many people who do not know about Barth syndrome, including medical professionals. Some of the main symptoms are cardiomyopathy, neutropenia, muscle weakness and growth delay.

taken from the Barth Syndrome Foundation community brochure (October 2005) and www.barthsyndrome.ca

Going Green!

If you have any concerns or are interested in receiving our newsletter via email, please contact Lois Galbraith at info@barthsyndrome.ca