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## Reflections from the President



Looking back on the accomplishments of 2011 and early 2012, a lot has been done within Canada. We have held a number of successful fundraisers including the Golf Tournament as well as individual events such as Boogie for Barth, a 50<sup>th</sup> Birthday bash and a Poinsettia sale. We have received a number of donations and expanded the amount of grant money we received, partially through ties with the United States BSF organization. Coupled with prudent expense

management by our Board and Executive has resulted in a strong financial position for 2012.

The Scientific and Medical Grant funded by BSF of Canada last year was "A screen for drug leads for the treatment of Barth syndrome" submitted by Christopher R. McMaster, Ph.D., Professor of Pediatrics and Biochemistry, Dalhousie University, Halifax, Canada. This year, we have once again been able to fund a

*(Continued on page 11)*

### Summary of Financials

#### Statement of Operations (Year Ending Dec 31, 2011)

|  |                 |
|--|-----------------|
| Revenue  | \$66,854        |
| Expenses   | \$26,759        |
| Excess of Revenue over Expenses before Grant Funding | \$40,095        |
| Research Grant Funding                               | \$38,234        |
| Excess of Revenue over Expenses & Funding            | <b>\$ 1,861</b> |

#### Statement of Changes in Fund Balances (Year Ending Dec 31, 2011)

|   |          |
|---|----------|
| Opening Balance                           | \$89,448 |
| Excess of Revenue over expenses & funding | \$ 1,861 |
| Closing Balance                           | \$91,309 |

**From the Heart!** By Harry and Helen Hope

As grandparents of Barth grandsons, we have seen the first hand effects of this genetic anomaly in our family. Everyday living, while becoming a challenge for the affected individual and siblings, is met with courage and tenacity by our involved family, just as every Barth family must.

Harry's involvement with Rotary has enabled us to visit areas that the ordinary tourist does not normally go. As well, we have met many people that one would not ordinarily meet. We have spoken to people professionally involved in medicine and tried to explain what this disease is and how it affects our grandson. Our Barth shoulder travel bag has become an item of interest, easily drawing fellow travellers into a conversation which we hope will be of great interest to them and that they might recall later and pass on to others.

Our travels with Rotary International allowed Helen to visit the B.M. Birla Heart Research Centre in Kolkata, India and meet with paediatric surgeons to tell them about Barth. Perhaps in searching out candidates for their life giving surgery at their Healing Little Hearts project, they may meet a boy with Barth like symptoms and know what it is. As we all know, Barth knows no economic or cultural boundaries.

After attending the annual general meetings of Barth and seeing the dedication of those attending, we cannot help but think of them when an opportunity arises to carry on their enthusiasm. The Barth Golf Tournament is an example of well executed planning and dedication.

By getting the word out and informing as many people as possible, one never knows who it may touch. It just might be another (Barth) parent with an obviously sick little boy, who is not getting any answers. We will do our best to be as informative as possible and pass on all information to anyone who is interested and will listen.



## Implications of Barth from a Six year old – Talk with Abby

In the past, we have interviewed siblings of those affected by Barth Syndrome for international publication. Now in our Canadian newsletter, we are privileged to hear the point of view of a six year old niece.

Name: **Abby Wright, 6**

Where do you live?: **Regina, SK**

Who in your family has Barth syndrome?:  
**Uncle Jared has Barth syndrome.**

How does Barth syndrome affect your family?: **It means we have to take care of Jared (Jared is 18 and also has cerebral palsy).**

What do you like to do with your uncle?:  
**Read books to him.**

What Barth syndrome event have you been to?: **The conference in Florida.**

What did you learn about Barth syndrome?: **That people with Barth syndrome can eat and drink by themselves.**

What would you say to someone you met



Jared and Abby

with Barth syndrome?: **My uncle has Barth syndrome, too.**

What would you say to people about Barth syndrome?: **Accept the people who have it and try to get rid of it, but nobody can.**

What would you ask the Barth syndrome doctors?: **What kind of cures do you know for Barth syndrome to get rid of it?**



Jared sailing the seas at the conference in Florida 2012



Lynn presenting Lois with her recognition plaque

“The person who says it cannot be done should not interrupt the person doing it.”

--Chinese Proverb

**AGM** By Chris Hope and Susan Hone

The Barth Syndrome Foundation of Canada’s Annual General Meeting (AGM) was held on April 21<sup>st</sup> for all members. With the aim of giving everyone a chance to take part, members have the option of attending this meeting either by phone, or in person, in Toronto, Ontario at the ideal office facilities arranged for us by Ian Morris.

This yearly meeting allows the board and executive to give members an assessment of the previous year’s activities, to review the financial statements, and to give an overview of the current year’s plans and events, as well as a projected budget.

This year, we had five individuals with Barth syndrome in attendance—Jared and his family once

again made the trek from Regina, Saskatchewan to Toronto. Due to being temporarily non-ambulatory, our newsletter editor, Les Morris, was unable to attend in person, but he continued to give his valuable input via phone—it just wouldn’t be a BSFCa AGM without Les’ contributions!

This once-a-year event is a great occasion to reflect on the work that has been accomplished and to acknowledge the volunteer hours and effort that everyone has contributed to ensure that our programs run smoothly. Special plaques were presented this year to Lois Galbraith and Cathy Ritter for their exceptional hard work and dedication. They are both essential to the function of our Foundation.

After the business portion of the day, it was social time. After a bit of catching-up and friendly chit chat, while munching on some goodies, it was on to the bowling alley. Everyone was eager to show their stuff and balls quickly started flying in all directions. A fun time was had by all and we are looking forward to next year!





## The Greatness in Golf! By Lois Galbraith

We at the Barth Syndrome Foundation of Canada (BSFCa) are proud of our fundraising work, particularly our annual golf tournament. We love this event because of our wonderful friends and supporters who make it not only a GREAT day but a memorable and profitable day as well.

Monday, September 10<sup>th</sup> 2012 will see us on the pristine course of Woodington Lake Golf Club in Tottenham again ([www.woodingtonlake.com](http://www.woodingtonlake.com)). Our team of volunteers (Bob, Susan, Jeannine, Phyllis, Bruce, Carol, Cathy, Penny and the BSFCa Executive) will be smiling and ready to implement plans for a FANTASTIC day of golf.

Generous donations of silent auction and foursome prizes will be beautifully arranged. Our BBQ and Myrtle Beach Condo raffles will also be displayed. Everything will be in place – our volunteers all primed and ready. Now, the INCREDIBLE part starts... We get to meet and greet the real heroes of the day... four or five of the Canadian guys affected by Barth; our brave Floridian ladies (Sharon, Jan and Joanie) who trek to Canada every September AND our special golfers, both new and returning. We appreciate each and every golfer, many who have golfed in all eight of our tournaments!



**Joanie, Jan, Sharon and Lois**

The day offers HUGE rewards. Jamie Sheppard, Director of Golf, will be sure that the course is in great shape for us. The club will organize the patio BBQ for lunch and a fine evening meal at the end of the lovely day.

The BSFCa will be working hard to ensure a fantastic day; prizes for all, camaraderie and GREAT golf!

We thank our guys, our volunteers and our families and friends who participate in our annual golf day and who make the day so very special and memorable!



**Steve, Ryan, Jim, and Chris**



**Adam, Travis, Robert, and Chris**

## Raising Green Through Grassroots Fundraising By Cathy Ritter

Like many other charitable organizations, the Barth Syndrome Foundation of Canada (BSFCa) relies on grassroots fundraising to raise money to further its programs, goals, and mission. The past year provided a bumper crop of events including our annual poinsettia sale.

**Thank you** to all of the wonderful volunteers and supporters who helped plan, promote or support one of these events. You not only “raised some green”, but you also increased awareness about Barth syndrome while spreading the word about BSFCa. Feel free to contact us about any fundraising event you wish to do. Here’s to another successful year in 2013!



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## **BOOGIE FOR BARTH!** By Bob McIannett

**Boogie For Barth 3.0**

**Dance & Silent Auction**

**September 29, 2012**

**Toronto Humber Yacht Club**

**Start time: 7:30 PM**

**Tickets \$25.00**

Tickets are available from Lois Galbraith, 705.877.3159, [lois.galbraith@sympatico.ca](mailto:lois.galbraith@sympatico.ca), Bob McJannett [bmcj@sympatico.ca](mailto:bmcj@sympatico.ca) and at the bar at the yacht club.

**Seating is limited**, so don't wait till the last minute to get yours.

We promise a fun evening and a deserving charity to support!

## Volunteer Corner By Lois Galbraith

We would like to thank all our volunteers and recognize a few in this issue. **Celia McGuinness'** Barth teddy bears were a selling sensation at the conference in Florida this June. AnnMarie Daley and the nurses in the Heart Cath Lab of Peterborough Regional Health Centre donated \$100.00 to the BSFCa in return for caps sewn for them by **Lois Galbraith**. As well, **Natalie Sisson** spent numerous hours preparing "golfer envelopes" for our September 10<sup>th</sup> golf tournament. Kudos to **Lynn Elwood** for her work on the BSFCa website [www.barthsyndrome.ca](http://www.barthsyndrome.ca). **Les Morris** made us fifty-five Canadian scissor caddies that we distributed to Barth families at

our June conference.

The talents and generosity of all of our volunteers are welcome and truly appreciated.

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](mailto:lois.galbraith@sympatico.ca)



## Friends of Barth

|   |                                      |                             |                                    |
|---|--------------------------------------|-----------------------------|------------------------------------|
| Adair, Jamie  | Christie, Steve & Jill               | Gilmour, John & Christine   | Lyall, Diane & Doug                |
| Adams, Lynda & Phillip                                      | Clelland, Bill                       | Gilmour, Paul               | Lyall, Judy                        |
| Adams, Terry  | Conway, Beth                         | ~ Precision Aero            | Lyall, Susan                       |
| Alblas, Henk  | Cooper, Cindy & Rick                 | Ginou, Jonathan             | MacDonald, Carol & Fred            |
| Allison, Vickie   | Coulson, Steve                       | Gordon, Karen & David       | Madigan, Jim                       |
| AME Association of<br>Ontario                               | Country Meat Cuts                    | Gordon, Travis              | Malfara, Frank                     |
| Anderson, Allanna   | Cowper, Margaret                     | Gordon, Ann                 | Malick, Mel & Suzanna              |
| Anderson Dickie, Galen                                      | Cox, Patty & Gerald                  | Gregorio, John              | Magennis, Lyem                     |
| Arsenault, Bill   | Cummings, Marie & Jim                | ~ Strictly Excavations Inc. | Magennis, Jasmine                  |
| Allen, Jim  | Daly, Annamarie                      | Haggett, John & Judy        | Magennis, Debra                    |
| Atkinson, Jim   | Daley, Jin & Arnold                  | Halifax, Carol & Guy        | Mandar, Scott                      |
| Aitken, Stewart   | Davidson, Alex & Bonnie              | Hamilton, Reg               | Mann, Ruth & James                 |
| Barrett, Lawrence &<br>Marilyn                              | Davies, Barbara                      | Hill, John                  | Marccuci, Gabe                     |
| Blacklaws, Matthew  | Davies, Diane                        | Hill, Richard               | Marchesin, Elvy                    |
| Blaka, Alex   | Davison, Marilyn & John              | Hill, Robert                | Masterson, Moira                   |
| Basilio, Paul & Anita                                       | Deforest, Wilmer & Ina               | Hintze, Audrey              | McDowell, Joan & Bill              |
| Baxter, Katherine & Ralph<br>Smith                          | Deligiannis, Dino                    | Hocevar, Helen & Frank      | ~ J & B Customs Brokers<br>Ltd.    |
| Baxter, Russ & Arthur                                       | Demick, Diane                        | Hone, Barbara               | McGarrity, David                   |
| Bentley, Thomas   | Dickson, Bel                         | Hone, Chris & Susan         | McGill, Steve                      |
| Bereczky, AJ  | DiDiodato, Giulio                    | Hone, Josh                  | McGlaughlin, Jackie                |
| Best, Cathy & Rance   | Dilland, Darren                      | Hope, Harry & Helen         | McGlaughlin, Larry &<br>Jackie     |
| Best, Jennifer  | Doherty, Jerry                       | Hope, Michael & Christine   | McGuinness, Celia                  |
| Bill, Paul  | Dolenc, Julia                        | Hope, Robert                | McJannett, Susan & Bob             |
| Bingham, Joan   | Dolenc, Marko                        | Hope, Terry & Ruth          | McKee, Jim                         |
| Bond, Brett   | Douse, Dave                          | Hope Aero,                  | Meehan, Louis                      |
| Bond, Darryl  | Dove, Judy & Randy                   | Howard, Sharon              | ~ Sunnyside Capital<br>Canada Inc. |
| Bonneau, Rodger & Lynda<br>~ Bonneau Mechanical<br>Services | Downard, Jason                       | Hubner, Malca               | Megelink, Jasper & Mary            |
| Bridger, Marj   | Duclos, Bev                          | Hughes, Ron & Cathy         | Melen, Pat                         |
| Bridger, Wayne & Dianne                                     | Dvorkin, Gary                        | Humphries, Jack & Jan       | Mill, Dawn & Marvin                |
| Browman, Elaine   | ~ Peel Scrap Metal<br>Recycling Ltd. | Irwin, Kevin                | Millar, Ronald & Margaret          |
| Boyle, John   | Ebata, Lyle                          | Jardine, Ward               | Miller, Nancy                      |
| Butler, Gayle   | Ebata, Jim                           | Jarvis, Peggy               | Miller, Pickard Law                |
| Campbell, Josh  | Ellsworth, David &<br>Elizabeth      | Jayavendra, Paul            | Milne, Peter                       |
| Cameron, Pat & Ken  | Elton, David                         | Jeffery, Elaine             | Miloff, Maury                      |
| Cardarelli, Paul  | ~ Max Bell Foundation                | Kadoguchi, Lilly            | Moore, Nigel                       |
| Carter, Paul  | Elwood, Adam                         | Kahn, Stephen               | Morenz, Caitlyn & Dave             |
| ~ Adapt Aviation  | Elwood, Bryan & Susan                | Kahn, Vera & Dave           | Morenz, Sharon & Terry             |
| Chai, Patrick   | Elwood, Lynn & Rick                  | Kemp, Bill                  | Morris, Erik                       |
| Chalmers, Mark  | Ernst, Gabriele & Kevin              | Kolli, Tom                  | Morris, Elsie                      |
| Chalmers, Stephanie &<br>Shawn                              | Farrow, Russ                         | Kralvic, Andrew             | Morris, Ian                        |
| Chambers, Ronald  | Francis, Mark                        | Kritschgau, Rick            | ~ Jones Deslauriers                |
| Chen, Chee  | Fink, Penny                          | ~ Vision 2000               | Moss, Don                          |
| Cherniak, Andy  | Flanagan, Mae                        | Krueger, Rudy               | Nagel, Siegfried & Erna            |
| Cherniak, Miriam  | Fraser, Wendy                        | Kugelmann, Jan              | Nagel, Thomas                      |
| Cherniak, Morris & Evelyn                                   | Freeland, Dagmar                     | Labelcraft Products Ltd.    | Newfeld, Jeff & Beth               |
| Chili-Chew, Yu  | Galbraith, Lois & Les<br>Morris      | Lamorie, Bruce & Sharon     | Noddle, Bev & Norm                 |
| Christie, John & Garnrel                                    | Gallacher, Betty                     | Weller                      | Olson, Sharon                      |
|   | Garment, Linda & Philip              | Lacroix, Guy                | Paczkowski, John & Vicki           |
|   | Gilles, Larry & Shirley              | Lawson, Alexander S.        | Perkins                            |
|   | Gilman, Jeanette                     | Leighton, Keith & Jeannine  |                                    |
|   |                                      | Lindsay, Sue                |                                    |
|   |                                      | Lister, Verna               |                                    |
|   |                                      | Loos, David & Ann           |                                    |

*(Continued on page 10)*

## *Friends of Barth*

*(Continued from page 9)*

Paul, Bill  
 Patrick, Barbara  
 Pearce, William & Bev  
 Perkins, Phyllis  
 Pickup, Jacob  
 Pitkethly, Maureen  
 Poitras, Mike & Sandi  
 Primus, Christopher  
 Prodan, Magda  
 Quackenbush, Earl & Carolyn  
 Raymond, David & Lila  
 RBC Foundation  
 Ritter, Ryan  
 Ritter, Cathy & Chris  
 Roberts, Marlowe, Jackson, Jackson & Assoc.  
 Robinson, Jim  
 Rodgers, James & Tina  
 Ross, Barbara  
 Sawh, Harold & Ruby  
 Schillaci, Paul

Schuller, Dana  
 Schuller, Dennis  
 ~ Aviall Canada Ltd.  
 Scott, Bob  
 ~ Mx Aerospace Services Inc.  
 Segal, Joseph  
 Selkirk, Kim  
 Sharkey, Derrick  
 Sheridan, John  
 ~ ScotiaMcLeod  
 Sisson, Paula  
 Smith, Glenn  
 Smith, Ted  
 Smolic, Alex  
 Smolic, Joe  
 Soberman, Johnathan  
 Stevens, Mike  
 Stitt, Barbara  
 Storey, Dick & Janis  
 Swinimer, Bill  
 Street Classics Cruise  
 Sturup, Penny  
 Sunlife  
 Tate, Bill

Teva  
 Thomas, Brian  
 Timleck, Barry  
 Tjart, Gwen & Richard  
 Trueman, Carole  
 Tsilikas, George & Alana  
 Tyers, Byron  
 Tyers, Rob  
 van Dam, John & Marian  
 Vanderwater, Barbara  
 Vautour, Crystal  
 ~ Nova Scotia Community College  
 Vella, Betty  
 Vento, Betty Ann  
 Vilneff, Bill & Rita  
 Walker, Chris  
 Wallace, Mike  
 Warden, Keith  
 Warden, Patrick  
 Warden, Steve  
 Warren, Jerry & Janet  
 Warus, John  
 Weaver, Joan  
 Webb, Lindsay

~ Lindsay Webb  
 Financial Inc.  
 Weeks, Ken & Jane  
 Whitmore, Connie  
 Wild, Andy  
 Wilks, Carol & Bruce  
 Wilks, Dennis  
 Wilks, Helen  
 Willis, Dave  
 Wood, Gale & Peter  
 Woodcock, Sharon & Roy  
 Worsley, Dorothy  
 Wright, Jessica & Cameron  
 Wuthrich, Grace  
 Young, Ron & Lenora  
 Zavitz, Peter



BSF 2012 Conference Group Shot—Florida (photo courtesy of Amanda Clark 2012)

*(Continued from page 1) Reflections from the President*

complete grant: "MLCL AT-1 elevates cardiolipin and mitochondrial function in cardiac myocytes of *taz* knockdown mice" by Grant Hatch, PhD, Professor, University of Manitoba, Winnipeg, Manitoba, Canada. We are pleased to be able to fund grants recommended by the Scientific & Medical Advisory Board for these Canadian researchers and very much appreciate the closer working relationship that is developing between them and the Canadian organization.

We have had some good success in our Family Services program this year, with members of our board being in touch with and having the opportunity to meet with almost all of our boys and men affected by Barth syndrome. In April, we brought five of them together in a family outreach event that accompanied our Annual General Meeting. A number of the men affected with Barth syndrome and their siblings are now official voting members of BSF of Canada and it is a pleasure to have more of them participating in the AGM meeting itself.

We continue to publish Canadian newsletters (now with the new team of Les Morris and Paula Sisson) which are well received by our family and donor population. Another significant project this year was the trip out east where awareness and Family Outreach events took place. Opportunities like we had in Halifax with Dr. McMaster and several medical doctors are most beneficial since we are able to meet with a larger number of physicians and scientists.

This year, the biennial Family, Scientific and Medical conference was held in Florida in late June. It was a great conference! Despite hurricane Debbie's attempts, we had 388 people at the conference, including seven new families and 44 Barth affected individuals. This event was a slightly different conference than in past years, with greater emphasis on ensuring the boys and men with Barth had extra time together and that there were more options for people to attend a variety of sessions, both family and research focused. There were medical consultations, and for the affected boys and men, there were fewer traditional "clinics" involving challenging and often exhausting tests.

The sessions during the conference provided considerable flexibility. They were arranged so that Scientific and Medical sessions that might be of interest to families were held at times when people could attend and all participants were encouraged to do so. It was extremely inspiring to watch as clinical doctors shared information with researchers—the full group of medical and scientific people talked about what findings could mean and openly discussed options for next steps in research. We had a number of discussions with researchers from around the world, shared their poster session and enjoyed social time with them.

The family sessions contained additional opportunity for newer families to share concerns and questions with longer term families as well as providing questions for presenters. In both the family and scientific sessions, there was strong participation from the older Barth affected individuals. A number of them presented to the physicians and doctors, provided introductions in the family sessions or shared their experiences and issues with the families. This direct involvement from so many of them really added a powerful incentive to all of the discussions and research and, as always, ensured that our individuals with Barth are at the center of all that we do. They made a tremendous impact on the audiences!

Barth Syndrome Foundation of Canada was once again prominent at the conference in the provision of volunteers who helped in clinics, registration, organization and several other areas. We were also a key contributor to the conference, sponsoring the Scientific Poster session and some of the programs for the affected individuals.

As always, our volunteers and our supporters make all of our work possible. We remain a completely volunteer organization and we continue to do great things that rival charities larger than

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



Barth Syndrome  
Foundation of Canada

## Barth Syndrome Foundation of Canada

*(Continued from page 11) Reflections from the President*

ourselves. We are very lucky to have such a strong and committed Board, Executive and larger set of volunteers that apply their tremendous and varied talents to all of the things we do, bring great new ideas, and inspire us with their enthusiasm and dedication.

Our donor list continues to grow. We appreciate each new supporter and the continued contributions from our repeat supporters. Every dollar and every in-kind donation helps and makes a true difference to the work that we can do over the year. Especially now, we need all the help we can get and thank each of you who support us. We have already seen many accomplishments this year and it is thanks to all of you. Please continue to support us as we move through the rest of the programs this year and in coming years.

### IN OUR NEXT ISSUE:

- Highlights of 2012
- Golf Results 2012
- Planning 2013



## 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](http://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](mailto:info@barthsyndrome.ca)