



Barth Syndrome
Foundation of Canada

Canadian Newsletter

www.barthsyndrome.ca

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Reflections from the President



Whenever I sit down to do one of these semi-annual reports, I am reminded just how much work gets done by this organization. We are very lucky to have such a dedicated and efficient group of volunteers working on behalf of all individuals affected by Barth syndrome. We cannot thank them enough for all their hard work.

In our last newsletter, we mentioned that we were having a Needs Assessment done in order to have an impartial view of the true needs of our men and boys affected by Barth syndrome. We have been very fortunate to have BJ Develle, MSW work with affected individuals and their families. Since we were so anxious to have the complete report, we asked BJ to join us at our Annual General Meeting and family outreach session in April, 2011. Thankfully, he made the trip up to the cold north, shared time with the group and was able to complete his report.

The Annual General Meeting

itself went well and an afternoon of bowling was a resounding success. The Barth affected boys and men thanked us for listening to their requests and asked that we do something similar for future outreach sessions.

This type of request is an example of the information we discovered from the Needs Assessment. We believe several findings apply to the larger Barth population and we will share a summary of these results with the International organization. For the areas that are specific to our population, we are acting on delivering them through our programs. We really have shifted our focus as an organization to the new mission "Enhancing the lives and outcomes of Canadian individuals and families affected by Barth" and our members have been vocal in their appreciation.

Other gatherings over the last six months included our annual golf tournament. This year, we were at a new

venue and were fortunate to have four young men with Barth syndrome and some of our Barth friends from the US join us for the day. As you will see from the article later in this edition, the day was a resounding success in awareness, outreach and also in raising much needed funds.

The most recent outreach took place in Eastern Canada. Two of our board members and one affected young man travelled to Halifax to meet with doctors, researchers and one of our young men, Lyem, and his family. This session has been one of our strongest awareness events this year and is a powerful example of our Barth men taking part in significant ways within the organization.

A few weeks ago, Lindsay Graff joined BSF, Inc. as its new Executive Director. Lindsay is based in Philadelphia and has strong experience in being both an advocate for her own child with a rare condition and in leading

(Continued on page 8)

From the Heart—The Two Jans! By Jan W. and Jan H

The heart of a volunteer is not measured in size, but by the depth of the commitment to make a difference in the lives of others

DeAnn Hollis

Friends refer to us as the two Jans and we have been close neighbours in Scarborough for thirty years. When Les Morris was principal at a local school, he also worked with our Block Parent and Community Associations. Friendships developed and we became acquainted with each other's families as well. We met Lynn Elwood and her family while visiting at the lake. At that time, they were learning more about Barth syndrome and how to live with young Adam's symptoms.

With his proud grandparents, we have cheered Adam's growth since he was a youngster racing over to Grandpa's for some extra bacon (very) early in the morning. We have applauded new achievements like his tractor riding, then driving, wood working, mastering the outboard and every other glorious machine he came into contact with. His family's quest to learn more about Barth syndrome and their ambition to educate others about it always impressed us.

Since then, we have invited the annual volunteer think tank sessions to take place in our homes. It has provided us with opportunities to meet and hear from other BSFCa family members and supporters. As ideas are proposed for additional educational and medical materials, projects come to fruition due to the brainstorming, networking, and enthusiasm of these sessions

The annual golf tournament, silent auctions, coin drives, dances and other fundraisers have become part of our lives. It is exciting to hear the latest achievements and success stories of the medical teams working for BSF and how the funding is helping the gentlemen and families living with this disorder—this is what keeps us coming back.



An Extremely Positive Look at Handling Life with Barth Syndrome

(Results of My friendship and conversations with Robert) By Les Morris

Attending Barth syndrome functions for seven years has allowed me the great pleasure of meeting these young Canadian men and sharing their progress from childhood to adulthood.

Robert is now twenty-five years old and employed full time in a job which is like any position - not without challenges.

"I am often required to lift and stack heavy material and, although I am sometimes tired at the end of the day or the end of the week, it's great to be working. I find that initially some work is difficult, but I gradually become better conditioned and therefore successful."

Robert says his schooling was relatively normal through elementary, high school and college, sometimes receiving extra help but always with great family support.

"I did have some special interest in History, but after a number of years of working it is difficult to think about going back to school. If I do go back, I think I would like to be a teacher."

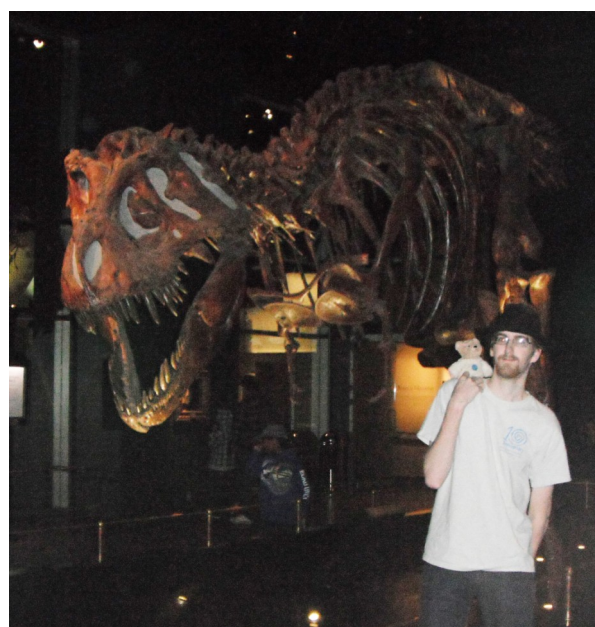
Personally, I think Robert has already done a lot of teaching. He has made presentations to groups explaining Barth syndrome, has represented our Canadian Foundation at conferences and he has taken part in many annual general meetings before and after the age of eighteen when he could officially vote on resolutions.

Robert still lives at home with Mom, Dad and brother Andrew, which is conveniently near his workplace. A favourite hobby of Robert is strategy

games.

In summing things up Robert says, "If and when we find a cure for Barth syndrome it will be wonderful but I'm leading a good life. I have a driving license and I am looking forward to even more independence in the future."

My congratulations to you, Robert. You are a wonderful role model for all the Barth families.



Robert at Royal Tyrell Museum,
Drumheller, Alberta



Dr. Christopher McMaster

Toward the end of October, with the encouragement and help of Dr. Christopher McMaster, PhD, we participated in a grand rounds meeting at the IWK Children's Health Centre in Halifax, Nova Scotia. Ryan and Cathy Ritter gave a joint presentation to a room full of doctors and other medical professionals.

Canadian Doctor: Champion of BSFCa By Chris Hope and Cathy Ritter

The enthusiasm of Dr. McMaster and his colleagues was outstanding as they learned about Barth syndrome, a disorder many knew little or nothing about.

Ryan covered their family history dealing with Barth syndrome, as well as some of his own problems and successes. He was followed by Cathy who gave an in-depth explanation of what Barth syndrome is, how it can present in affected individuals along with current treatments, and, most importantly, how to diagnose the disorder. Dr. McMaster then gave a brief overview of his ongoing BSFCa supported research into finding a drug to help combat Barth syndrome. His presentation was fol-

lowed by a question and answer period.

All presentations were very well received and we are heartened by the interest shown. Participating in grand rounds is a huge accomplishment and the contacts and awareness generated will benefit us in the months and years to come.

We were also able to meet up with Dr. McMaster and a couple of co-researchers in a more informal setting at which time he was able to tell us that the research grant we funded lead to further major funding from Genome Canada for research in "orphan diseases" including Barth syndrome.

While in Nova Scotia, we

took the opportunity to meet up with Lyem, a Barth syndrome affected individual, his mother, and grandmother. It was great to be able to re-connect and share recent events and future plans with them. We enjoyed some down-home eastern friendliness while catching up with our east coast family.

A big thank you goes to Ryan, Cathy, and Chris Hope for taking the time to make this dream possible. As well, thank you for being such ideal ambassadors for the Foundation!



Financial Update by Chris Hope

We maintain a continuous and careful eye on our expenses and revenues and as the end of the year approaches, we continue to be very careful in our spending habits and start to look a little more attentively at the figures to see how we have fared financially in the last few months.

We are happy to report that we have been able to follow through money-wise with all of our program plans for the year.

We remain a small but powerful organization made up entirely of volunteers, consequently, all of the donations and funds we receive go directly into our programs. With successful fundraisers such as the annual golf tournament and direct mail appeals as well as fantastic profits from fundraisers held on our behalf, we are able to continue to look forward and make plans to carry out our mission and goals without having to cut back.

This year, in addition to the fundraisers mentioned in this newsletter, we are the happy recipients of a generous contribution from the Max Bell Foundation. This grant-awarding organization has a mission with emphasis on health and wellness. We are very grateful to Ken Marra, a father of a young girl who is a carrier of the Barth gene, for being instrumental in getting the donation for us.

What a pleasure it is to have such great support and be able to remain positive in a difficult economy.

Thanks to all!

Terrific Golf Tournament 2011!!

By Lois Galbraith

Golfers, Good People, Great Course, Gorgeous Day..... Let's Golf!!

Where can a person find great fall weather, good friends, fantastic raffles and unique silent auction items? Add to this four fantastic ambassadors for Barth syndrome (Robert, Adam, Ryan and Travis), a new and beautiful golf course, and scrumptious meals over a few drinks? Yes...you are at the BSFCa annual golf tournament!

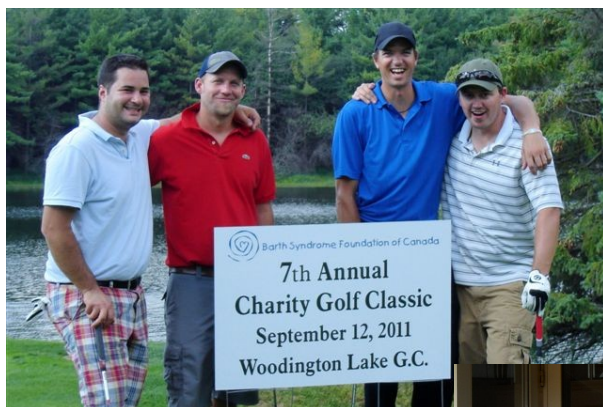
Monday September 12, 2011 did not disappoint any of us. We enjoyed the new venue at Woodington Lake Golf Club (WLGC) and experienced tough but pristine golf holes. We shared the day with dedicated, hard-working volunteers and we raised **\$21,000.00!!**

Our thanks go out to a record number of golfers who attended our seventh annual golf day. Once again this year, our friends Sharon, Jan and Joanie made the trip all the way from Florida and we helped golfer Lynda celebrate her 50th birthday!!

We would like to thank all of the prize donators, the hole sponsors, the numerous volunteers, the loyal golfers, and our hardworking Executive. In addition, we would like to especially thank our Corporate Sponsor, Hope Aero and our luncheon sponsor, the Buss Megg Society. Finally, we would like to give a big thanks to Jamie, Director of Golf, WLGC, for his generous donation of free golf foursomes for our early bird draw and prize table.

Please keep Monday September 10, 2012 free for another great day of golf and camaraderie!!

Contacts: Lois Galbraith 705.877.3159 lois.galbraith@sympatico.ca Cathy Ritter 705.424.4684 critter@xplornet.com



**Golf Tournament
Foursome**



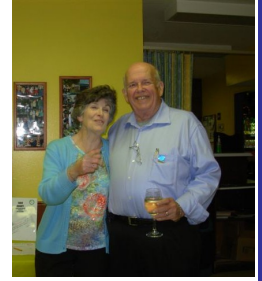
Enjoying the golf day!



**Lois and the Men: Travis,
Robert, Adam, and Ryan**

Raising Green Through Grassroots Fundraising By Cathy Ritter

Like many other charitable organizations, BSFCa relies on grassroots fundraising to raise money to further its programs, goals, and mission. **Thank you** to all of the wonderful volunteers and supporters who help plan, promote or support these events. You not only "raise some green", but you also increase awareness about Barth syndrome and our foundation. Feel free to contact us about any fundraising event you wish to do. Here is to another successful year in 2012!



BOOGIE FOR BARTH! A REPEATED FUNDRAISING SUCCESS

By Bob McJannett

Saturday, October 1st was the chosen date for Susan and Bob McJannett's Boogie for Barth dance which was held again at the Toronto Humber Yacht Club on the scenic Humber River. This year, the date was changed from August to October to accommodate the cottagers who had been unable to attend the first one.

There was a wide selection of interesting items in the silent auction (45 in all) that brought some spirited bidding. No matter where your interest lay, there was something to catch your eye. Restaurant certificates, hand made furniture, books signed by the author and unusual chachkies were all up for grabs.

We were treated to George Olliver and his full band "Gangbuster". This year George was supported by a bass guitar, drums and keyboards. This backup allowed him to get out and mingle more with the crowd. Again he brought his "A" game and the dance floor was jumping.

There was one unusual event during the evening!! One of Bob's friends, Lou Meehan, told him he would pay \$1,000.00 if Bob would sing. "For \$1,000.00 for Barth, I am willing to make a fool of myself," said Bob. So during the first set, Bob got up and sang the Big Bopper's song "Chantilly Lace". "You know, it proves that four great musicians can make anyone sound good," quibbled Bob. Lou showed up

with his cheque the next day!

Again this year, George had the ladies up singing "Mustang Sally". It appeared to us that everyone had a good time and, after the dust had settled, we had raised in excess of \$5,500.00 plus we had loads of fun!!

Hats off to Bob and Susan, Les Morris and Lois Galbraith, Bruce and Carol Wilks plus Frank Malgara and Linda Upshall who showed their dedication to BSFCa by helping with the set up, rounding up auction



Rick Elwood's 50th Party/Fundraiser By Lynn Elwood

The big day was coming up. Rick was turning 50!! We wondered what we could do to mark the day. We realized that what Rick really wanted most was to spend time with good friends. An idea was born ---- why not have a party and fundraiser together!

Consequently, this past June, we had one of the best nights of fun with friends and family that we've had in a long time. At the same time, we raised funds for the charity so near to our hearts – Barth syndrome.

We gathered at Grizzly's in Pickering, shared some food and time with friends and danced the night away to the outstanding "Just Us" classic

rock band. It was amazing to see so many people from Rick's work, family, lots of dojo people, friends from hockey and other sports and friends from way back.

Special thanks to Cheryl, Jeannine, and Lois who organized the draws and making sure everyone was invited to participate. Also, to Steve for making the beautiful bowl for the draw and to Sensei Jardine for donating his draw winnings. Fittingly, he won the bowl! As well, thanks to Adam, our son with Barth syndrome, who joined the party for part of the evening and acted as the designated driver to get several of us home safely.

Rick's party was very special – the type of warm, friendly and fun night he so richly deserves.

It was a terrific night and raised over \$1,000 for a great cause. Thank you to everyone who joined us!!



Poinsettia Fundraiser By Chris Hope

We have one more fundraiser planned for the end of the year—selling poinsettias. This is the first fundraiser we ever tried and we were thrilled with the response. Now typically as November approaches, friends and family start asking us when we are going to be taking orders and when will the plants arrive. Year after year, people buy these cheerful plants to cele-

brate both the season and our charity. We are very grateful for everyone's continued support with this fundraiser as they fill their homes with these beautiful flowers. The success of this event helps us face the new year with renewed drive and energy as we start the planning process for another ambitious year.



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(Continued from page 1) Reflections from the President

organizations such as ours. One of her first acts was to reach out to the International organizations and learn more about what we do and where we focus. We welcome Lindsay and look forward to working closely with her in our shared global Barth syndrome goals.

Of course, our continued financial health is critical to the delivery of our programs. As you will see from the financial summary in the newsletter, we continue to be in a strong financial position. The conservative budgeting and the close watch on expenditures by the board and executive have been key to this success. Of course, the contributions of all of our Friends of Barth, through donations and participation in fundraisers make this success possible. Thank you to all of you for your continued support, in whatever form that takes.

IN OUR NEXT ISSUE:

- Year-end Update
- AGM/ Outreach Update
- 2012 Planning Session results



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 our editors: Les Morris at les.morris@sympatico.ca or Marjorie Bridger at mbridger@rogers.com