



Barth Syndrome  
Foundation of Canada

# Canadian Newsletter

www.barthsyndrome.ca

September 2014



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



## A Decade of Golf Fun and Funding: by Lois Galbraith

TEN Barth Syndrome Foundation of Canada (BSFCa) golf tournaments have allowed us to further research and give hope and encouragement to our special young men world-wide.

This past summer, the BSFCa contributed in significant ways to the 7<sup>th</sup> International BSF Science & Medicine/Family Conference in Clearwater Beach, FL. Five of our Canadian men attended, took part in research and participated in educational sessions and social events. Be sure to read their first-hand thoughts and impressions about this important event.

Congratulate yourselves!! You as golfers, volunteers and donors have ***"made a difference"***!

We love our golf days and the fun and excitement we can bring to all attendees while raising awareness and funds for this important cause!

This year we thank and honour our new sponsors as well as our 'dyed-in-the-wool' annual sponsors. Our twenty-five plus hole sponsors, our Condo and BBQ sponsors, and our luncheon sponsors all make us proud to be involved with Barth syndrome.

Enjoy this golf day. We planned every detail to make you happy and to thank you for ***"making a difference with us"***! Thank you, thank you!!



## President's Report *by Lynn Elwood*



As this has been a Barth Syndrome Foundation (BSF) conference year, I will focus much of my report on that important week. Barth Syndrome Foundation of Canada (BSFCa) was once again very involved in the conference. Lois was part of the steering committee, coordinated the travel and accommodations and logistics for the Science and Medicine presenters and worked at the registration desk. Devoted volunteers knitted sweaters for the Barth bears, mittens and scarves which were for sale at the conference with proceeds going to BSFCa. Silent auction items and contributions to the family gift bags were also provided by BSFCa.

We funded travel and accommodations for two Canadian scientists to present their research findings at the conference, sponsored the very well attended poster research session, a breakfast for all attendees and the popular photo booth at the evening social event. It was truly an inspirational week and we were delighted to help make it happen.

Chris, Susan and others have been working hard at getting our new website up and running. It is in the testing stage now and you will soon see the modern, easy to use look of our new site.



I would like to close on a personal note. My son Adam (now 24) and I were privileged to attend the conference again this year. We have attended every conference since the first one and will do everything we can to get to them all. This trip we do together every second year continues to be very special to both of us, and is the best gift we can give each other. I have never seen Adam as comfortable as he is during this week. He is among friends and family from all over the world. The week lets him be himself, to learn and grow, enjoy the laughter and face the fears among people who accept and understand. The same

is true for me. Not only do I get a week of time away and bonding with my son, I also get the chance to be among friends and my Barth family who understand what I am facing, accept me and help me through the challenges. Whether I meet the families for the first time or have known them for years, the bond and the support from this group is incredible. It doesn't stop at the families either. I had some great discussions with scientists and physicians. I am truly inspired and very excited about the work they are doing. It seems like the rate of progress is accelerating and we are getting close to recommendations and treatments that can really help in the daily lives of our affected guys. Together, the conference gives us a chance to learn, laugh, dance, help advance the research and enjoy the time with our Barth affected guys. It was an outstanding week that renewed my inspiration and touched my heart.



### **From the Heart!** *by Carol and Bruce Wilks*



We are very long time friends of Les and Lois and have been a part of their family circle so have had firsthand knowledge of Barth syndrome through their grandson Adam. Our first involvement with the Foundation was helping Lois with little tasks preparing for the golf tournament. Before we knew it, Bruce and I were at the golf tournament, and not being golfers, were put to work. Bruce was stationed at the Hole in One and I was handed a camera to take foursome pictures. We are now in our tenth year at the tournament. It turns out that my quiet husband is very good at building awareness. He spends the day talking with folks and informing them about Barth syndrome.

A few years ago, Lois mentioned that the Foundation was in need of help with bookkeeping, and the next thing I knew, I was a member of the executive and their bookkeeper. Funny how that happens when Lois is a friend! Les and Lois's dedication and passion somehow just rubs off on a person!

Now that I am a member of the executive, Bruce is pulled into all of our fundraising endeavours. He grins and bears dances with loud music as well as everything else we drag him into for Barth syndrome. We are both happy to be part of such a great group of people with the common goal of enhancing the lives of these boys and young men.

### **Gifts of Love** *By Christine Hope*

The Barth Syndrome Foundation of Canada wishes to gratefully acknowledge the support of our donors' collective donations. It is only with the help of the many generous individuals and companies that we are able to continue to function. While we have a variety of fundraisers, we have also been blessed with donations made in honour and in memory of individuals. We would like to acknowledge these special people who are a great inspiration to us.

#### **IN HONOUR**

Dianne Bridger

Marg & Brian Bridger

Bonnie Davidson

Rick Elwood

Lois Galbraith

Dina Godinho

Audrey Hintze

Jared Hone

Barbara Hone

Michael Hope

Andrew Hope

Robert Hope

Lyem Magennis

Bob McJannett

Les Morris

Norm & Bev Noddle

Heather Segal

#### **IN MEMORIAL**

Maggs Barrett

Jay Bonneau

Michael Bowen

Margaret Burns

Skip Casson

John Christie

Connie Churchill

Nan Cooper

Margaret Cowper

Bruce Davidson

Paul Dickie

Galen Dickie

Linda Farrell

Mary Findlay

Bob Hammond

James Hope

John Humphries

Jeff Jeffery

Bruce Lamorie

Doug Lockhart

Dorianne Martin

Moira Masterson

Nancy McGill

Al Miller

Elsie Morris

Mrs. Nunes

Tony Patterson

Norm Perkins

George Schnell

Pat Scott

Shelley Sills

Brian Simms

Wanda Sutton

Michael Telles

Ben Thorpe

Danny Tomlinson

### **Illuminating the Skies to Honour Our Guys!** *by Susan Hone*

I was talking with Shelley Bowen from BSF prior to the BSF International Conference and asked if there was anything I could take off her plate. She mentioned she needed someone to use an exacto knife to cut out over 300 dragonfly and starfish shapes on paper bags for a luminary project she had in mind. After laughing at her and asking if she was serious and did she know what was involved in doing this, she said she was quite serious.



Okay Shelley... I have it covered, I will make your vision a reality. Next was to convince my daughter Jessica that this would be a good project for her to do on her electronic die cutter I got her for Christmas. With her on board, I purchased the supplies, dropped off 500 white bags at her house and thanked her. Once we saw the finished project, I started imagining how good it would look on the beach at night, and of course, they would be placed to look like the BSF logo.

I never realized the impact this one project was going to have on members of our Barth family or myself. The dragonfly has become our symbol to represent those who have died due to Barth syndrome and we had one dragonfly bag for each person we knew who had died. The starfish represented those currently living with Barth syndrome. We had 160 dragonflies and 180 starfish. I was overwhelmed by the numbers. I started thinking about all the boys and men I had met over the last 14 years. I had to get this task right.

They looked amazing! Seeing everyone follow the bagpiper and drummer around the logo in the sand on the beach and placing the lights in the luminary bags was an image I will not forget for a long time. The emotions of the group, the smiles, the tears, the flashing of cameras told me that Shelley's idea



was one of her best and I am so pleased to have had a part in making it a reality.

Thank you to the numerous people who helped me with the set-up and clean-up, I couldn't have done it without you. Special thanks to my daughter Jessica who I nagged every day until she had the bags cut out. She was able to see all her work at her first conference ever. We have her hooked, she will be back again.

## **Bear Lays Bare the International Conference** *By Barthur Bear, now of Hampshire, England*

I was reading the latest BSF Journal when the thought occurred, everyone loves the conference, but there is no word from any bear attendee. I attended the 2012 conference and can give you some first paw impressions.

I'm not a tropical bear and so the weather was quite a shock! You think you've got problems, I've got fur and lots of it! Then there was Tropical Storm Debby, the violence of the storm was terrifying and it caused a power blackout at the hotel. Somehow, I and the other bears survived without air-conditioning although it was uncomfortable, but the hotel staff and people from the Barth syndrome community did all they could to provide us with the bear necessities.

The facilities at the hotel were superb; so bear-friendly, comfortable and relaxing. Just what the (bear) doctor ordered. There were lots of bears just like me at the conference. I got on really well with everyone and made friends; friendships that I am sure will last a lifetime. I loved the bear breakout sessions or just chilling together.

The people at the conference deserve special mention. Families, physicians, scientists and most of all the affected guys were so compassionate, generous, committed, and friendly – a real community providing awesome inspiration and I'm proud to have been a part of it. They all get on so well together – something a bear would notice.

I'm really excited at the chance to attend another conference. It will enable me to meet old friends, make new ones, get up to speed on the latest research, and perhaps, inspire or stimulate new directions for further research. It causes the fur on my back to rise up when I think of the last wonderful conference and the future, a world without Barth syndrome. I have a nose for these things and can smell out success long before any human can. One day there will be a cure and the conference does much to help make that day arrive sooner – please come!

*Editor's Note: A Canadian Barth Bear made its way to the UK after the 2012 Conference and its owner Nigel Moore, wrote the preceding article for your amusement. (At right, you see Barthur helping to edit the BSF Journal).*



## Barth Guys Speak Out—First Hand Impressions of the Conference

### Adam:



The fact that just outside the hotel there was so much, so close was great. It was like a sense of freedom. I appreciated the fact that the clinics were set up nicely and that I was able to get everything done in one day. Dr. Kelley’s session “Men of Barth” was excellent. He was very encouraging to us older guys.

### Travis:

I find the week of the conference involves so much and it is so great to meet new friends (Ollie, Morgan & Josh) and to visit with old friends again. This is like a family reunion to me.



### Jared:



I am unable to properly convey my feelings and thoughts. Even though I am not able to participate in many of the activities, the Barth conference is extremely important to me. I have friends that I look forward to meeting every two years, and also, since my cerebral palsy is so much more obvious than the Barth syndrome, the conference serves to remind everyone who takes care of me, that I’m doubly special, and not to get complacent about this dangerous component to my health.

### Robert:

For me, the best part of the conference, aside from seeing old friends and meeting new ones was the amount of information willingly offered to the families and affected individuals by the doctors and scientists attending alongside. The fact that the information about the research being done was presented in such a way that could be understood by the families really helped prevent any non-alcohol related headaches. Also, I appreciated the fact that the doctors made themselves available after the sessions so that if we did not understand or if we had questions about things we wanted elaborated on.



### Ryan:



I was nervous about making a presentation to the Science & Medicine panel on the first day, but I did enjoy the talks and compliments from the scientists and researchers later during the conference. For me, attending the Clearwater Beach conference this summer was like coming home to family!!

## AGM - Eating the expenses instead of the profits! *By Christine Hope*

Our annual general meeting (AGM) was held in early May this year. Once again, we would like to thank Ian Morris and Jones DesLaurier Insurance for letting us use their office space. As usual, the business portion of the meeting covered the activities and finances of the previous year, and the plans and budget for the current one. As the various board members gave their reports, members asked questions and made comments along the way, keeping everyone involved in the discussion. For variety and ease of understanding, the finances were represented using jelly beans, instead of paper graphs. This way, we could actually eat our expenses!

A good portion of the meeting was employed to describe and explain the New Canada Not-for-Profit Act which will come into effect October 2014. All Canadian charities must get a continuance to comply with this Act by that time or they will be dissolved. BSFCa has been diligently working with a lawyer to ensure that we will meet all of the new requirements. One of the major items in this process was to overhaul our by-laws. At the meeting, President Lynn Elwood explained the changes in the by-laws and the reasons for them. They were then approved by the members, and we are now well on our way to completing the process and getting this rather tedious job done.

As we hope you know, the BSFCa remains proud to function entirely by volunteers (including the board and executive). We are very grateful for all of the time and energy people have exerted to help us to achieve our vision. For the last couple of years, we have taken the opportunity at our AGM to thank and honour some special volunteers for their

dedication and hard work. This year, we chose the trio of Paula, Lindsay, and Natalie Sisson. We are very thankful to have the three of them on our team to help with this newsletter, creating awareness and various other jobs that they can be counted on at all times.

After the meeting and some social time, the fun part of the day began. This year, as an activity, we chose *in-door glow-in-the-dark mini golf*. Instantly, little coloured glowing balls went flying everywhere, occasionally even into the holes they were destined for. The day was rounded off with a delicious meal at a nearby restaurant. Once again, it was wonderful to see everyone, and to do some catch up.

### SUMMARY OF FINANCIALS FOR THE YEAR ENDED DECEMBER 31, 2013

Revenue	\$57,888
Operating Expenses	\$44,379
Research Grant Funding	\$9,648
Net Revenue	\$3,861



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## HOW YOU CAN 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 BSFCc. Or create an event—”Fress down day, Fifty/fifty draw, Bottle drive, Garage sale.

#### IN-KIND GIFTS

BSFCa welcomes items to be used for prizes, raffles and awards at our events—TV, iPod, Camera, Jewellery, Gift Certificates.



#### SPONSOR A SPECIAL EVENT!!

- Ⓢ AGM & Family Outreach.....\$700.00
- Ⓢ BSFCa Annual Planning SessionⓈ\$300.00
- Ⓢ Volunteer Recognition AwardⓈ\$50.00
- Ⓢ Physician Awareness & OutreachⓈ\$1,000.00

Tax receipts provided for all contributions according to Canadian laws

## What is Barth Syndrome?

Barth syndrome (BTHS; OMIM #302060) is a rare, life threatening genetic disorder primarily affecting males around the world. It is caused by a mutation in the *tafazzin* gene (*TAZ*, also called G4.5), resulting in an inborn error of lipid metabolism.

Though not always present, cardinal characteristics of this multi-system disorder often include combinations and varying degrees of cardiomyopathy, neutropenia, underdeveloped skeletal musculature and muscle weakness, growth delay, exercise intolerance, cardiolipin abnormalities, and 3-methylglutaconic aciduria.

*Taken from “Do You Know About Barth Syndrome?” Healthcare Professional Brochure October 2013*

#### Going Green!

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