



Barth Syndrome  
Foundation of Canada

# Canadian Newsletter

www.barthsyndrome.ca

March 2009

*Dear Readers,*

*Thank you for your support. Your feedback has indicated that we should include more articles from our Barth boys and men and their interests and progress through life. Be sure to keep this in mind when reading this issue of the newsletter. And, don't forget we appreciate and welcome your creative feedback.*

*-Les Morris and Marjorie Bridger*

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## In our next issue:

- **Poinsettia Fundraiser**
- **Creative Donation Ideas**
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# Living with Barth Syndrome

*By Robert Hope*

I was asked to write an article on what it is like for an affected individual to live with Barth Syndrome. This disorder affects everyone differently at various stages of their life. In order to get a cross section of outlooks and attitudes I asked some of my closest friends that I met through the BSF organization. Sadly the response was a booming silence---Barth Syndrome is something that we live with everyday and asking us to describe what it is like to live with it is like asking a person what it is like to write with their right hand. We face it and deal with it in our own way.

Here are some of the responses I received:

'Having Barth means that I have to be aware of what my limits are and not over exert myself while working. Yet I do not let it control my life, I control it.'

-22 year old Barth Individual

'Living with Barth Syndrome has given me an opportunity to share my unique experience with others, including those studying to be doctors.'

-20 year old Barth Individual

'Well in my opinion Barth syndrome is a nasty piece of work. It makes me really, really tired and also really hungry all the time.'

-10 year old Barth Individual



Courtesy of BSF ~2008



Courtesy of BSF ~2000

Hopefully, these statements will provide insight into the lives of those boys and men that live with this disorder and its challenges every day, and yet face those challenges with all of their courage.

# Reflections

## Reflections from the President



By Lynn Elwood

For this report we agreed to focus on the scientific and medical grants Barth Syndrome Foundation of Canada has funded. This year marks the 4<sup>th</sup> grant that we have been involved in funding. Since this is a significant portion of our expenditures and a very exciting part of our program, we wanted to provide a little more background.

Barth Syndrome Foundation of Canada participates in the Barth Syndrome Foundation grant program. Full information on the grant timeframes and application process, as well as the full set of grant recipients is available on the BSF website [www.barthsyndrome.org](http://www.barthsyndrome.org). We are fortunate to be able to participate in this program because it is administered by our Scientific Director, Matt Toth and all applications through this program are looked at by independent reviewers and recommendations are made by the Scientific and Medical Advisory Board. Once we have heard reviews of all of the grant applications, the Canadian board of directors votes on which of the eligible grants (if any) we will participate in and what amount we will fund. (In addition to the scientific criteria, there is a specific list of agencies Canadian charities are permitted to fund for research).

Here is a summary of the grants we have been involved in funding to date.

The **2008** grant cycle (awarded February 2009):

**Miriam L. Greenberg, Ph.D.**

Professor and Associate Dean for Research  
Biological Sciences  
Wayne State University

**"The role of tafazzin in mitochondrial protein import—Implications for Barth syndrome"**

Award — US \$40,000 over 1-year period

*Funding provided by the Barth Syndrome Foundation, Inc. and the Barth Syndrome Foundation of Canada*

The **2007** grant cycle (awarded early 2008):

**Richard Epand, PhD**

Professor  
McMaster University  
Hamilton, ON

**"Consequences of the alteration of cardiolipin structure on the properties of the mitochondrial membranes"**

Award — US \$38,900 over 1-year period

*Funding provided by the Barth Syndrome Foundation of Canada*

*Research currently underway*

**Christopher R. McMaster, PhD**

Professor  
Dalhousie University  
Halifax, Nova Scotia

**"Synthetic genetics towards understanding Barth syndrome cell biology"**

Award — US \$36,712 over 1-year period

*Funding provided by the Barth Syndrome Foundation, Inc. and the Barth Syndrome Foundation of Canada*

*Research currently underway*

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For the **2005** grant cycle (awarded early 2006):

**Grant M. Hatch, Ph.D.**

Professor, Pharmacology and Therapeutics  
Acting Associate Dean of Medicine for Research  
University of Manitoba  
Winnipeg, Manitoba

**"Cholesterol Metabolism in Barth Syndrome"**

Award: US \$40,000 over 2-year period

*Funding provided by The Barth Syndrome Foundation, Inc. and the Barth Syndrome Foundation of Canada*  
Associated Publications To Date:

Hauff KD, Hatch, GM. **Cardiolipin metabolism and Barth Syndrome.** [Prog Lipid Res. 2006 Mar;45\(2\):91-101. Epub 2006 Jan 18. \(PubMed Abstract\)](#)

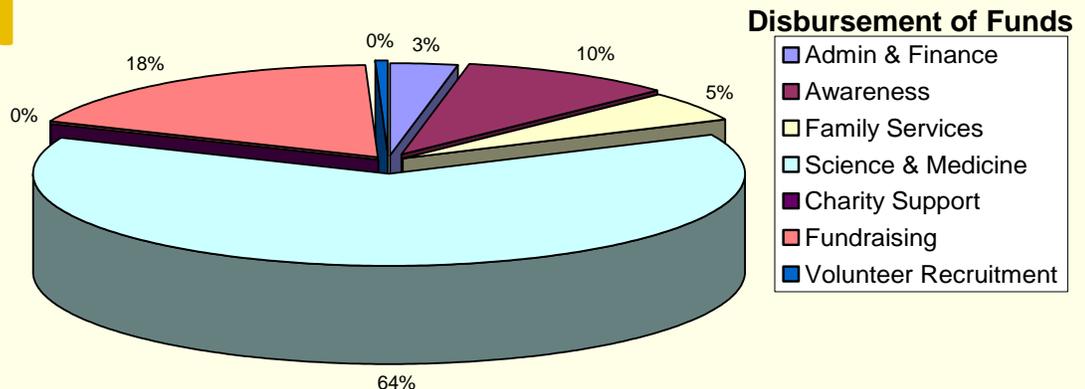
There have been some terrific advances in understanding Barth syndrome through these and other Barth Syndrome Foundation grants. We are happy to be able to participate in funding of some of these and expect to continue funding appropriate grants to qualifying agencies in future years.

One of our goals in the 2009 year is to promote the grant process to a greater number of Canadian groups so that we have a growing number of Canadian researchers applying for grants to assist in aspects of Barth syndrome discovery.

If you would like more information on the grant process please feel free to contact us at [inquiries@barthsyndrome.ca](mailto:inquiries@barthsyndrome.ca).

# Financial Update 2008

By Christine Hope



Last year was a triumphant year in more ways than one for the Barth Syndrome Foundation of Canada. We are very proud to be able to report that we spent money! While this may sound a little unusual, the bottom line is that we fundraise in order to use the income to further our goals and objectives. In the past while our fundraising has been successful we did not have the manpower, or the capacity to use those funds to the highest potential. Instead we planned for the future and invested what monies we could to maximize our income. Highlights of expenditures in 2008 include participation in two separate research grants, both to Canadian researchers, we sent awareness literature across the country, we assisted in funding with the Barth Syndrome International Conference, financed two Canadian medical participants to attend the conference, and we sent a resource manual to all of our families living with an individual affected by Barth syndrome.

The only reason we were able to achieve all of these accomplishments this past year, was due to successful fundraising, and most importantly generous donors. Every year the BSF Ca board and executive carefully plans out an ambitious set of goals and objectives, keeping in mind that we are always accountable to our donors, and constituents (in many cases family members). Therefore, while we are ecstatic with the funds we have disbursed this year, we did not spend them unwisely. We made sure that every dollar was maximized. We are obviously aware of the current financial climate, and took that into consideration and planned accordingly for 2009. We believe that we have a manageable budget, and feel that we will be able to continue with all of our programs.

# Fourth Annual Barth Syndrome Charity Golf Classic

## Tangle Creek Golf Club September 8, 2008

By Lois Galbraith

Even a steady, half-hour downpour of rain did not dampen the spirits of our loyal golfers. Our 2008 Barth Syndrome Foundation of Canada (BSFCa) golf classic was another fabulous success thanks to our golfers and our very wonderful volunteers.

All of our foursome and individual prizes, as well as our silent auction items, were donated by very generous folks who believe in this day and our cause.

Our corporate sponsor (Hope Aero), our cart sponsor (IQI – Ian Morris) and our luncheon sponsor (Buss Megg Society) made a huge difference.

We had a great day of golf at challenging Tangle Creek Golf Club where we saw great shots, rain, long drives and tricky putts. The day was also filled with silent auction bidding, wonder camaraderie, prize selecting, presentations and great food.

Jan Kugelmann, Sharon Olson and Joanie Weaver from Florida golfed with us this year and made it an international event.

We raised **\$24,300** for our programs and sincerely thank all of our hard working volunteers, our dedicated sponsors and all those great people who golfed and who donated the myriad of prize items.

**Our 5<sup>th</sup> Annual Golf Classic will again be held at Tangle Creek on Monday September 14, 2009.**

**See you there!!**





By Christine Hope

After having attended the first official Barth Syndrome Foundation international conference, it was decided that to better help Canadians affected by the disorder a Canadian organization needed to be created.

While the goals of this affiliate are similar to those of the non-profit corporation in the States, we focus on the special and unique needs of Canadians. To do this, and to ensure that work is not duplicated, we are in close contact with the US group at all times. While continuing to work on Canadian endeavours, many of our executive members participate in International activities, such as the international website, the Barth Syndrome Medical Database and Biorepository, Research and Family Services programs, and the International conference. Those accomplishments are in addition to our Canadian specific ones.



Decided to form a Canadian BSF affiliate

Received not-for-profit status nationwide

Held 1<sup>st</sup> Family Outreach in Lindsay, ON

Article in newspaper Toronto Family Outreach Invited to CIHR round table 1<sup>st</sup> golf tournament

Awareness ads netting results Presented at Neurology conference Established research program

Attended medical conference in Quebec City Visited hospitals Mail campaign to geneticists Nation wide public awareness created by several members

Major involvement with the International BSF conference providing both substantial financial and volunteer commitment

# Looking back at our



Started running letter awareness campaigns to doctors

Attended medical conference in Ottawa

Acquired Registered Charitable Status Started running ads which are printed at no cost to us in *The Medical Post* Worked major international endeavours

Held 2<sup>nd</sup> AGM Expanded executive Helped finance International BSF conference

Partially funded multi-condition haematology conference Presentation performed by Barth individual Partially funded research grant Attended Paediatric medical conference in Toronto Full page article on Barth in *The Medical Post* Held 1<sup>st</sup> volunteer workshop

Created and sent resource binder to families Agreed to fund 1 ½ research grants Added 3 advisors to the Board Began Canadian newsletter

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# Ready to Tackle 2009

## Executive Planning

*By Cathy Ritter*

A cold snowy weekend in November saw the Barth Syndrome Foundation of Canada (BSFCa) executive gather at the lakeside homes of Lois Galbraith and Carol Wilks for our annual strategic planning weekend. After an initial reflection of both the successes and the things we had learned in the previous year, the focus changed to the coming year.

Plans were proposed to further program goals while we concurrently created a manageable budget. During this process fundraising plans and goals were set in order to be able to facilitate the running of our programs. It was an intense, work-packed weekend, but better prepared the organization for the coming year.

Once again, Les Morris provided both his culinary and clean-up skills so the executive could stay focused and maintain their hard-at-work rhythm! We were also able to enjoy a visit on Sunday afternoon from Susan Hone's in-laws Barbara and Jack.

## Volunteer Planning

*By Lois Galbraith*

On January 24<sup>th</sup> our fabulous volunteers gathered to hear about the Barth Syndrome Foundation of Canada's program plans for 2009 and to roll up their sleeves and begin planning of their own. The room was abuzz with new ideas, opinions, suggestions, plans and enthusiasm.

In attendance were Carol Wilks, Jan Humphries, Audrey Hintze, Lindsay Sisson, Paula Sisson, Robert Hope, Lynn Elwood, Maureen Pitkethly, Celia McGuinness, Christine Hope and Lois Galbraith.

The business, fundraising and activities of the Barth Syndrome Foundation of Canada are all conducted by volunteers and we are very fortunate to have terrific and active folks with us. Our volunteers at the meeting on Saturday helped to formulate plans for physician and community awareness. They also came up with ideas for newsletter articles and fundraising. One young lady, Lindsay, explained her awareness project on Barth Syndrome.

We came away enthused and buoyed by the spirit of our volunteers and ready to tackle 2009 with new ideas and plans.



**Thank you to all our  
VIP Volunteers!!**



# From The Heart



*By Wayne and Dianne Bridger*

The first time Dianne and I heard about Barth Syndrome was about 10 years ago. We were at Les and Lois's home on Lake Kassabog, and the subject of Barth Syndrome came up. It was then that we found out about this genetic disorder and how it affects boys by being passed on by their mothers. It was that weekend that we first met Adam, Les and Lois' grandson, who had Barth Syndrome. On our trip home to Scarborough we talked quite a bit about what we had learned that weekend and decided to become more involved with the Barth Syndrome Foundation.



At first, we only supported the Foundation with monetary donations, as it was the easiest way for us to help. However, we soon learned that there were many other ways to help out. We have both participated in the annual golf tournament in Barrie. I have attended a few volunteer workshops and tried to help in any way that I can, such as, stuffing envelopes with other volunteers at the lake and cutting string for the golf tournament. Dianne, through Novopharm, has sponsored a hole for the golf tournament, as well as donating gifts for the prize table. A recent pet project of ours is "Bottles for Barth", where bottles are returned to the Beer Store for cash. We find this is a great way to raise money and encourage others to participate in this easy fundraiser. On a more personal note, I feel privileged to have been invited to Adam's birthday breakfast for the last 3 years. As this was a "grandparents only" breakfast, I felt honoured to be included.

The satisfaction that we have received for the small amount that we have done for Barth Syndrome is amazing! Our lives have been enriched through our involvement with The Barth Syndrome Foundation of Canada.



## Awareness at Work

*By Cathy Ritter*

Awareness of Barth syndrome is an ongoing program for the Barth Syndrome Foundation of Canada (BSFCa). On a number of occasions we have assisted high school, college and university students in research projects they have chosen to do on Barth syndrome or on our organization. Recently, we were approached by an Ajax student, Lindsay, who needed to do a project on a local charity.

It was great news that she and her group found BSFCa in their research of Canadian charities and chose us for their project. Over the span of a few weeks, they did considerable research on Barth Syndrome and the BSFCa. They created a sample brochure on the condition and the organization and a presentation to accompany it. The questions they asked during this research were interesting and insightful.

This talented group received a very high mark on their presentation and may be invited to present to a higher level in the Youth and Philanthropy Initiative competition, where the chosen charity group wins \$5,000 towards their charity's programs. Whether they win the contest or not, this project has raised

# Did You Know...



Adam Elwood has been growing his hair for several years. It was straight and blonde...hair to envy! Even though people suggested cutting it for all sorts of reasons, the family soon grew to accept Adam's hair. Last spring, Adam announced that he would be cutting his hair to donate to cancer patients. In January, just before going off to college in Lindsay he had about 10 inches cut from his hair. This is just another example of our Barth boys and men giving back and helping others where they can.

**Congratulations, Adam!**

Blaine Shaw, the President of The Mississauga Classic Car Club made a special donation to the Barth Syndrome Foundation of Canada. He is seen here presenting the cheque to Carol Wilks.



## Our Wishlist

The Barth Syndrome Foundation of Canada was started by a group of parents and family members who wanted to help improve the lives of those affected by the disorder. Using only volunteer work, this dynamic group remains totally focused on the overall goals of the organizations which is to save lives, and find a cure for Barth syndrome. While we feel that we are starting to make progress, we know that there is much more to be done. Unfortunately, we do not have the experience nor the time needed to fulfill all of the tasks we have set out to do. For that reason, we have created a 'wish list' in the hopes that we can encourage more volunteers to come forward with their abilities and know-how. Right now we are looking for:

- People to help us find ways to contact and gain access to teaching institutions so that we can make a presentations on Barth syndrome.
- People to do internet and background research on organizations that we could hook up with, such as Imagine Canada, or the Canadian Organization of Rare Disorders.
- People to research for corporations or groups that would give us donations.
- Fundraisers
- French and Chinese translators
- Proofreaders
- People with contacts in the news media to help us gain access to newspapers, magazines and newsletters (both medical and general) in order to get awareness articles or stories published.
- Legal advice regarding charities
- Contacts for service clubs or organizations that would assist families to attend the international conference

If you feel that you are able to help us with any of these items, or know someone who is, **please contact us.**