



Barth Syndrome  
Foundation of Canada



# Canadian Newsletter

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

November 2022

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President's Report	1,8	I hope this newsletter finds everyone well and getting back to their previous lifestyles before the global pandemic. Although the pandemic is not yet over, the world is adjusting to living with it and the fear is not as heightened as it was last year at this time. We still need to be cautious as Barth syndrome can cause individuals to be immunocompromised at times and those are the individuals who are most susceptible to the corona virus.	President's Report by Susan Hone
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Brotherly Love	4	We continue to reach out and connect with our Canadian Barth families old and new. BSFCA hosted an outreach this summer in Calgary, AB. It was part of the 'Barth Syndrome Stronger Together World Tour' being held this year to reconnect with old friends and welcome new families. Read more about the Canadian tour stop on page 5. Additional stops happened in the US, the Netherlands, and the UK, with one more being planned for France.	BSFCA's Outreach 2022. Photo submitted by Susan Hone
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BSFCA's portion of the 'Barth Syndrome Stronger Together World Tour'. Photo submitted by Susan Hone

We are once again sharing the funding of a research project with Barth Syndrome UK.

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

## Farewell to a Good Friend of Barth! by Lynn Elwood



Adam and Bob.  
Photo submitted by Lynn Elwood

In June of this year, we bid a fond, final farewell to a good friend of BSFCa, Bob McJannett. For many years, we have been blessed with Bob's caring, laughter, and both advisory and funding support. Bob, his late wife Susan, and their BuzzMeg group have held a special place in our hearts and have been amazing supporters of our charity for many years.

When we organized the BSFCa golf tournament, Bob, Susan, and the BuzzMeds were "all in". They golfed, volunteered, supported financially, and Bob was the Master of Ceremony for several years. They not only made the day more fun, but were also instrumental in the fundraising success over the ten-year span the tournaments ran.

When we no longer ran the golf tournaments, Bob and Susan turned Bob's birthday party into a great event that brought in donations from many people. The live band and food were provided by Bob and Susan, and the event was an annual highlight for friends, car enthusiasts, and neighbours.

Bob joined the BSFCa annual meetings and became a Board Advisor, sharing wisdom and advice with us. We will miss Bob's smiling face, his ready jokes, and his sage advice. Thank you to Bob and his family for all their caring and support over the years. You have helped make the lives of the Canadian boys and men who live with Barth syndrome, and their families better.



Famous McJannett Parties!  
Photo submitted by Lynn Elwood

## 2021 Financial Overview by Christiane Hope

As with all charities, the Barth Syndrome Foundation of Canada has had to take a hard look at fundraisers and fundraising. We are extremely grateful to all our long-time supporters, many who have been with us now for 19 years, and heartily welcome our newer friends. It is because of their dedication that we can say that the Foundation's finances remain healthy.

We continue to be very careful with our funds to ensure that our spending goes, as much as possible, towards helping those with Barth syndrome, whether it is research, awareness, or support.

We started 2021 with	\$104,912
Our revenue for the year:	\$ 53,995
Program expenses:	\$ 15,982
Research grant:	\$ 42,565

And ended the year with \$100,360, leaving us in a good position to look to the future.

## An Amazing Volunteer Retires! by Lynn Elwood

Carol Wilks (Aunt Carol to me) is one of those quiet people who does everything she can to help, and seems to effortlessly do what others can't. When we started this organization, there were so many things we didn't know. We did our best in those early days and learned a lot – including the fact that we needed someone who could manage our books and ensure we were handling our finances correctly. Aunt Carol was right there to help. For many years, Carol has been our bookkeeper - managing the books, filing GST reimbursement forms, getting ready for the annual audit, and ensuring we put processes in place that would grow with us. It is impossible to count the many hours she has spent with our Treasurer, Christiane, working through receipts, dealing with accounting software, balancing the books, and reporting on our finances.

In addition to being our trusted bookkeeper, Aunt Carol has sold poinsettias, bought raffle tickets, volunteered at the annual golf tournaments, and made quilts that we sold in silent auctions to raise funds (I enjoy the one on my bedroom wall every day). She was also a part of our Executive for several years and we have fond memories of sitting in her living room as we did our annual planning.

Thank you so very much for all the work you've done with and for us over the years, Aunt Carol. You have been an important part of our success and we will miss working with you. Much love from the BSFCa Board of Directors and Executive.



Carol and Christiane at a planning session  
Photo submitted by Lynn Elwood



Carol and Les drawing winners.  
Photo submitted by Lois Galbraith



Cathy, Susan, Lynn, Chris, Carol, Lois – at one of our annual Golf Tournaments. Photo submitted by Lynn Elwood



Carol and the late Bruce Wilks  
Photo submitted by the Wilks

## Brotherly Love by Jasmine Champagne



Jordan is an eight-year-old boy whose little brother, Caleb, has Barth syndrome. Caleb has gone through his five years of life in heart failure, immunocompromised, battling low muscle tone/muscle weakness, and extreme fatigue, but Jordan has always been at his side, helping, soothing, and advocating for him.

Jasmine, the boys' mom, started volunteering for the BSFCa four years ago and in that time has helped plan and host an annual fundraiser, a virtual 5K race, that raised not only funds but also awareness for Barth syndrome. Both Jordan and Caleb have participated in these events and were always with their mom when she made video announcements for it. This past May, the most recent 5K race made Jordan decide that he too wanted to do a fundraiser for BSFCa.

Every summer Jordan has done tie dye projects with his mom, he loves the bright colours. Jordan decided he wanted to make and sell tie dyed t-shirts with the Barth logo on them as a fundraiser for BSFCa. With the help of his mom and his parents' friends who own DesignX Promotions, a custom apparel printing company, Jordan set out to raise money for his little brother. His mom posted the idea on Facebook and took orders for two weeks. What they thought would be 20-30 orders quickly took off, and they ended up selling 120 shirts including some international orders from other Barth families.

After 130 hours of folding, twisting, dyeing, rinsing, washing, and putting logos on them, Jordan's designs are complete! When we ask him why he did this his answer is always the same, to raise awareness about Barth syndrome, to raise money for his brother Caleb and the other people with Barth so that they can find a cure, and because he loves tie dye!

Jordan's final total that he'll be donating to the BSFCa is \$2000! Awesome job, Jordan!



All pictures courtesy of Jasmine Champagne

## Barth Syndrome ‘Stronger Together World Tour’ by Susan Hone

The BSFCa ‘Stronger Together World Tour’ Outreach took place in Calgary, AB from August 19 – 21st.

Four families, including a set of grandparents, and Dr. Hilary Vernon, Barth specialist from Maryland, got together at a restaurant Friday evening, meeting one family for the first time in person. After a great meal, we met back at the host hotel and chatted with each other for hours. Our thanks to Marilyn for providing snacks while we chatted.

Saturday’s activities started with a buffet breakfast at the hotel, followed by a two-hour presentation and question and answer session on everything Barth. Dr Vernon gave an excellent presentation and audience participation was great. We had the pleasure of having a paediatric cardiologist and paediatric haematologist from Calgary Children’s Hospital join us. After a very filling buffet lunch, we headed out to Heritage Park to see how people lived in the west in the late 1800’s. Our afternoon went by too quickly, and we were among the few groups that stayed until closing time. Our next stop was for supper at a delicious cheesecake restaurant. Although everyone was so full after the main course, some people managed to try the signature desserts which were absolutely fantastic.



Sunday morning, after a group breakfast, we said our good-byes to Dr. Vernon and then visited the Airport Hangar Museum. There was so much to look at and the children got a chance to take the controls in one of the vintage planes. I learned a few history lessons too! That concluded the scheduled weekend. Most of us did not want to say good-bye quite yet, so we headed over to the grandparents’ house for lunch and an afternoon of more chatting about Barth syndrome. That evening, we went out for supper and afterwards, those staying at the hotel chatted only briefly since everyone was very tired from the busy weekend.

Monday morning, the Board chair, treasurer, and the mom of the family who resides in Calgary, went to the Calgary Children’s Hospital, and met with the haematologist who attended the Saturday presentation. We discussed many issues related to being an ultra-rare disease in Canada. She gave us advice on how to make our voice stronger in the rare disease community and who to approach to advocate for us in the medical field.

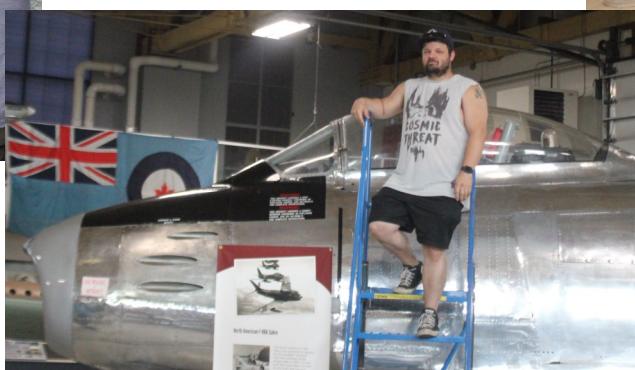
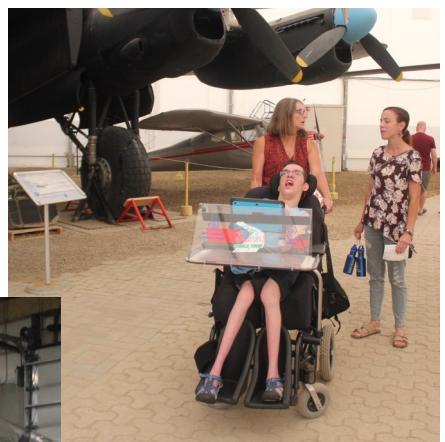


Although the Outreach was officially over, a couple of families remained in Calgary for a few days and went to see the Rocky Mountains in Canmore, a short drive from Calgary. It was the perfect ending to a great weekend with old and new friends!

All pictures courtesy of Susan Hone



## Pictures of the Outreach and the Virtual 5K Run



*Photos submitted by Jasmine Champagne, Lynn Elwood, Susan Hone, Christiane and Robert Hope, and Laurel Pridgen*

## **Running for Barth Syndrome by Jasmine Champagne**

When you are affected by a rare disease that is essentially invisible to the outside world but is anything but invisible to those living with it or with someone who is affected by it, you NEED to lean into those around you at times. THIS is what happens when you have a community of thoughtful, kind, loving people who want to help make a difference!

Over the month of May, 81 women, men, and children chose to take part in our 3rd annual Barth Syndrome Virtual 5K race.

Some completed their 5K inside, some walked, some ran, some hiked mountains, some split up their distance throughout the month, all with the common goal – to raise money for the Barth Syndrome Foundation of Canada. Even though we were spread out across the globe, social connection was felt because we were all working towards a cause that is bigger than ourselves.

Together, we raised \$5,424!!! These funds will specifically be used by BSFCA for: supporting families affected by this devastating disease, funding research for a possible cure/treatment, and educating and bringing awareness to more people.

Thank you to all those that donated, registered, or shared our posts. We have SO MUCH GRATITUDE to each and every one of you who took part. These funds will make SUCH an impact!

**Advanced Notice!  
Reserve the date now!  
July 29—August 3, 2024.**

BSF has announced that after a long hiatus due to COVID, they are returning to the even-year schedule of hosting families, researchers, healthcare providers, and advocates from around the world.



## President's Report by Susan Hone

(Continued from page 1)

This year's recipient is Borko Amulic, PhD, Lecturer (Assistant Professor), University of Bristol, Bristol, UK. His research is on neutrophil dysfunction in Barth syndrome. Funding this grant opens up additional funding which will double the total grant. This research is particularly important as many individuals with Barth do not have an adequate neutrophil count to fight infection which makes them especially prone to illness and infections. The result of this research should pave the way for therapeutic interventions.

Fundraising is a challenge for non-profit organizations at the best of times and with our current economy, it is going to be a bigger challenge this year. We did have a successful Virtual 5K Run again this year and a t-shirt fundraiser by an incredibly determined young man (see articles in this newsletter) as well as personal fundraisers to celebrate individuals' birthdays. If you have an idea for a fundraiser or would like to hold a

fundraiser on BSFCA's behalf, please reach out to us and we will assist with the logistics of conducting a fundraiser.



Although repetitive, it is very important that we thank all our donors and volunteers. Without your support we would not be able to exist as a foundation and help those affected by Barth syndrome. Having an ultra-rare condition means there are not many people aware of the condition and not many people working to find a cure/treatment. With your help, awareness of Barth syndrome is spreading, and we can continue research into this much overlooked disease. Thank you for your devotion to our cause.



Jordan and one of his fundraiser t-shirts.

*Photo submitted by Jasmine Champagne*

For donations, please visit [www.bartsyndrome.ca/donate](http://www.bartsyndrome.ca/donate)

### What is Barth Syndrome?

Barth syndrome is a rare, genetic disorder primarily affecting males around the world. It is caused by a mutation in the *tafazzin* gene which results in an inborn error of lipid metabolism. This error causes, in various combinations and varying degrees: cardiomyopathy (disease of the heart muscle), neutropenia (an abnormally low count of a type of white blood cell that helps fight off infections), underdeveloped skeletal musculature and muscle weakness, and severe growth delay and exercise intolerance.

While much progress has been made in treating Barth syndrome, unfortunately, it still remains all too often a fatal disorder.

### Going Green!

If you have any concerns or are interested in receiving our newsletter via email, please contact us at  
[info@bartsyndrome.ca](mailto:info@bartsyndrome.ca)