SBCAN
Annual Report
2022

Spina Bifida Families of Canada
We've got your backs.

Spina Bifida Families of Canada

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Who Are We?

We are a grassroots volunteer collective of parents of children with spina bifida. We help connect members of the community and provide information and resources to spina bifida families.

Vision

People with spina bifida can do anything. Because of us, children with spina bifida will grow up in a supportive, understanding, and accepting community. These brave and resilient kids will grow into strong and confident adults who will achieve their goals, chase their wildest dreams and explore all of life's possibilities. We, as a spina bifida family, will foster an environment for greatness to happen for people with spina bifida all across Canada.

www.sbcan.ca

Mission and Purpose

We believe those living with SB CAN

We provide love and understanding

We are a safe space to ask questions and share experiences

We are a bridge to medical research

We are proud ambassadors for the community

Core Values

We are SB families, for SB families

We believe that anything is possible

We know life with spina bifida is beautiful

We are relationship-driven - open, frank, and supportive of all

We are positive, optimistic and forward-thinking – SB CAN!

We educate and improve Canadians' perception of spina bifida

We are a family, here to support each other in good times and in bad

Message From The President

"It's the friends we meet along the way that help us appreciate the journey" - unknown

Every year when I reflect back to see how far we have come, I am so touched to see how many open hearts and open hands helped move our organization along the way. To help us go a little bit further than we were at least year. The wonderful volunteers who have so selflessly poured their time, energy, experience into finding ways to make the future better for all spina bifida families. Our friends in the medical field who have helped teach us more about spina bifida and help us get things right for everyone else. I see all our generous donors and fundraisers who rally behind the families we serve. And I see our community. A community who has gone through many incredibly difficult days and sleepless nights still manage to be a beacon of hope for the rest of the community.

I am in awe of the strength and resilience of so many of our community members no matter what age. Your stories that you share are used to light a path for everyone else following in your footsteps. The paths we are creating are less dark than they used to be. The paths are filled with so many amazing friends.

We are so excited to be finding ways to support Canadian families. We are constantly looking for existing resources and bringing them back to our community and finding the gaps that need to be filled and working to make tomorrow better than today.

Cheers to year three and many more to come!

Romeila Son

Romeila Son
President
Spina Bifida Families of Canada

Spina Bifida Families of Canada
We've got your backs.

SBCAN Launches
The Medical Travel Support Fund

TRAVELLING FOR CARE IN CANADA JUST GOT A HELPING HAND

Having to travel to receive care is not new for many members for our community in Canada. Specialists appointments, clinics, surgeries and hospital stays far from home can cause financial burdens on man many families and people living with spina bifida. With many families needing resources to help with these expenses, we have launched the SBCAN Medical Travel Support Fund in 2022.

The program was launched in late October of 2022 to the community and was also communicated to the Ontario Fetal Centre and various hospitals and clinics across the country. We are happy to say that we have received 5 applications in 2022 and that we were able to give away $1,930.64 back to the community.

We are hoping to widen our reach within the medical community and in the spina bifida community to get more help in the hands of more families.

Affordable Accommodations with StayWell

In an effort to help find ways to make travelling for medical care of spina bifida for families in Canada easier, SBCAN has reached out and connected with our friends at StayWell to provide affordable short-term and long-term stays near medical centres across Canada.

Members of the community can now access the Staywell website and mention SBCAN and get discounted accommodations.

When you have to travel away from home for medical care, accommodation affordability is the last thing you want to worry about. SBCAN and Staywell have got your backs!

Spina Bifida Families of Canada
We've got your backs.

X

staywell.

Holiday Cheer For SB Families

The holidays can be a little tough for many families. This year, the community nominated families who could use a little holiday cheer. We were able to help spread a little Christmas cheer and gave away $100 Amazon Gift Cards to eleven amazing families.

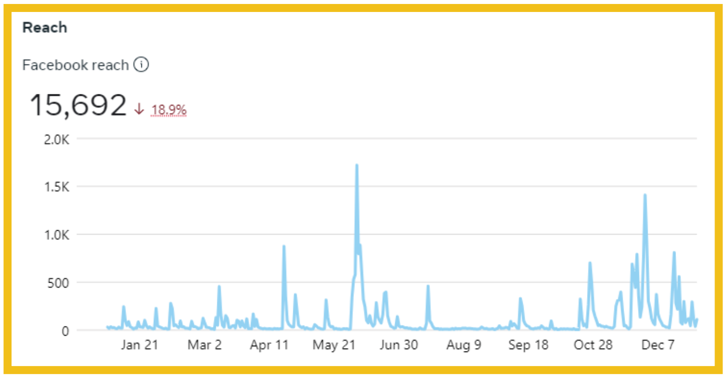
Social Media

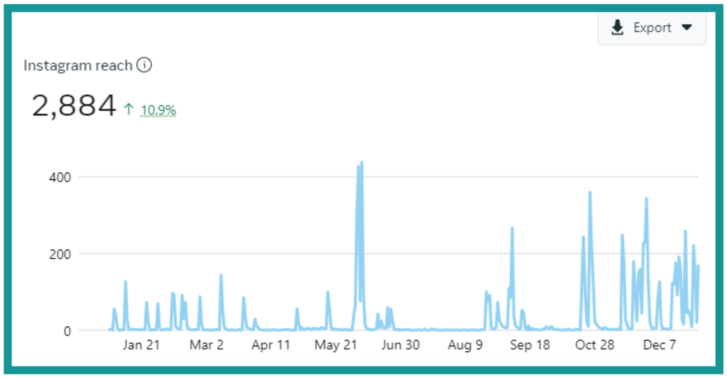
In 2022, our Facebook posts reached 15,6921 views, with our most popular post being one about " What Is Spina Bifida?" Which reached over 2000 accounts.

The second top performing posts were the launch of the Medical Travel Fund with over 1300 views, announcement of Dr. Paige Church's departure with over 1300 views and a series of posts during the Giving Tuesday campaign, each over 1000 views.

As of June 2023, our Facebook page has 612 likes, and 695 followers. Our Instagram page has 409 followers, which is an increase of 50% from the previous year.

Our private Facebook group continues to grow and be a source of connection and information sharing for the community.





Virtual Gatherings

Lockdowns are over but we still love our easy and convenient virtual gatherings. In 2021, we held 2 virtual Coffee Houses plus a special farewell to an even more special doctor.

We discussed travelling with spina bifida. We shared ideas and experiences and put together an article with a checklist to share with the community.

We gathered as a community in June to say thank you and farewell to Dr. Paige Church. Someone who has been so instrumental in our organization and in the lives of every patient she touches. Members of the community send in heartfelt messages and photos and shared wonderful memories of Dr. Church. This beautiful tribute to Dr. Church is on our Youtube Channel.

We are grateful for every opportunity we have to connect with our Canadian SB community.

What Do You Wish Others Knew About Spina Bifida?

We asked our community: What do you wish others knew about spina bifida?

Here are some of their responses.

That spina bifida is just one part of who you are.

@artemis_0778

That we have feelings too, and that we can have kids.

@kimia.ommani

Doctors can be wrong.

@Emily Anderson

I wish people knew how much we can do, despite the limitations we are dealing with on a day to day basis.

@_bible_reading_with_kelly

So many things.

@matt.hartshorn

I wish people knew there's so much love and so much strength in everyone.

@joycelins

That SB affects each of us in so many ways.

@mmgaynor

That SB (and disability in general is not always visible.

@mitch_pritch

That 'quality of life' is not determined by medical professionals. Just because someone can't walking they use the bathroom differently from others does not mean they have poor quality of life.

@Katrina Keating


Blue LIGHT
BLUE LIGHT
Blue
Blue
MONSTER

Fundraising Campaigns & Activities

Our second year with our registered charitable status, we are so grateful for the community champions who have led some great fundraisers and all the donors, participants and volunteers who have helped Canadian families in spina bifida community.

We are so thankful to receive a total of **$24,471** in donations in 2022. As we are a volunteer led organization, every penny we have received is going back towards the supporting the community and creating awareness.

A big THANK YOU to our very generous donors and those who have supported our campaigns and our work in 2022. We could not do what we do without your help and support.

Pedal 4 Purpose Charity Bike Ride For SBCAN

September 3rd, 2022, **Pinoy Pedal Pushers** aka PPP partnered along with the **RCC - Romeo Chadley Crisostomo Real Estate Group** organized the second annual Pedal 4 Purpose bike ride. **Over 70 cyclists rode over 100KM from Burlington to Niagara Falls to raise awareness and have raised $4680 to help Spina Bifida Families of Canada.**

A huge thank you to Pinoy Pedal Pushers and the RCC - Romeo Chadley Crisostomo Real Estate Group for putting this event together for the second year in a row. Thank you to all the cyclists who peddled their hearts out and donated their time, energy and peddles through the leg cramps to fundraise and support our community. It was great to see everyone out there.

We are so grateful for everyone who donated, posted, shared and supported this event and out community.

SBCAN's Second
Giving Tuesday Campaign

Giving Tuesday is an annual global philanthropy event where charities around the world come together for one big fundraising and awareness push. Giving Tuesday follows Black Friday and Cyber Monday as a celebration of giving back. The first Giving Tuesday in Canada was in 2013.

In 2022, we were so touched to have so many donors generously contribute to our campaign. Our Giving Tuesday total was a wonderful **$6,092.68** . We are so grateful to our community, family and friends for their support.

Thank You For Your Support

A special thanks to our generous supporters for your time, talent expertise and donations. Your contributions have helped us to provide the Canadian spina bifida community with much needed support during the pandemic. Our community is so fortunate to be surrounded by such amazing and generous people like yourselves.

Ontario Fetal Centre

Dr. Paige Church

Dr. Tim Van Meighem

Dr. Greg Ryan

Dr. James Drake

Dr. Abhaya Kulkarni

Shauna Beaudoin

MAVEN
COMMERCIAL REAL ESTATE

FARIS TEAM
REAL ESTATE BROKERAGE

Ryan Lesperance
Realtor

PINOY PEDAL PUSHERS

Oakville
BLUEPRINTING

RC GROUP
REAL ESTATE

Robertson Family

Geady Family

Thank You For Your Generous Donations

GEADY FAMILY
FRANCES MAIZEN
MILAGROSA SON
GWENDA BARTLEY
ANGELES RASCO
RICHARD GEADY
ALFREDO FERIA
KEN & KRISTA BURKE
EDDY VAN HOOYDONK
LARRY PRITCHARD
TEILO MOORE
SANDRA MOORE
DOUG STRYPE
KEATING FAMILY
ROBERT SANDLES
RORY USSELMAN
DAVID PHILLIPS
MARIA DI CARLO
MARIE RIDDING
LARISSA HANBIDGE
MARK RAMIREZ
THOMAS MCDERMOTT
ARNOLD VALLON
WALTER PILICARPIO
GILBERT BERMUDEZ
MARIA LUISA DIAZ
PHILIP DAVID QUIZEO
CHRISTINA KADRI
MARIA CRISTINA GALVAN
ROBERT CHERYL PAMPLONA
BERNARD YOONG
CHONA HILARIO

AND 3 GENEROUS ANONYMOUS DONORS

Jamieson | Mullin
Chartered Professional Accountants

Professional Strength
Personal Services
Practical Solutions

COMPILATION ENGAGEMENT REPORT

To the Directors of Spina Bifida Families of Canada

On the basis of information provided by management, we have compiled the statement of financial position of Spina Bifida Families of Canada as at December 31, 2022, the statement of operations and changes in net assets for the year then ended, and note 2, which describes the basis of accounting applied in the preparation of the compiled financial information ("financial information").

Management is responsible for the accompanying financial information, including the accuracy and completeness of the underlying information used to compile it and the selection of the basis of accounting.

We performed this engagement in accordance with Canadian Standard on Related Services (CSRS) 4200, Compilation Engagements, which requires us to comply with relevant ethical requirements. Our responsibility is to assist management in the preparation of the financial information.

We did not perform an audit engagement or a review engagement, nor were we required to perform procedures to verify the accuracy or completeness of the information provided by management. Accordingly, we do not express an audit opinion or a review conclusion, or provide any form of assurance on the financial information.

Readers are cautioned that the financial information may not be appropriate for their purposes.

Jamieson Mullin Chartered Professional Accountants Inc.

Quispamsis, NB
June 29, 2023

Spina Bifida Families of Canada
Statement of Operations and Changes in Net Assets
For the year ended December 31, 2022 (With comparative figures for 2021)

	2022	2021
Revenues		
Donations	**$ 24,471**	$ 29,607
Fundraising	**-**	2,096
	24,471	31,703
Expenditures		
Advertising and promotion	**3,977**	-
Travel	**1,931**	-
Accounting and legal	**531**	1,065
Office	**108**	-
Interest and bank charges	**67**	426
	6,614	1,491
Excess of revenues over expenditures	**17,857**	30,212
Net Assets - beginning of year	**28,034**	(2,178)
Net Assets - end of year	**$ 45,891**	$ 28,034

Spina Bifida Families of Canada
Statement of Financial Position
As at December 31, 2022 (With comparative figures for 2021)

	2022	2021
Assets		
Current		
Cash	**$ 50,777**	$ 29,247
Accounts receivable	**-**	1,000
Total Assets	**$ 50,777**	$ 30,247
Liability		
Current		
Accounts payable and accrued liabilities	**$ 4,886**	$ 2,213
Net Assets		
Unrestricted	**45,891**	28,034
Total Liabilities and Net Assets	**$ 50,777**	$ 30,247

1. General Information

Spina Bifida Families of Canada was incorporated under the Canada Not-For-Profit Corporations Act on February, 28, 2019. The Organiztion received registered charity status effective January 1, 2021 and is exempt for income taxes. The Organization provides support to people with Spina Bifida and thier families across Canada..

2. Basis of Accounting

The basis of accounting applied in the preparation of the statement of financial position of Spina Bifida Families of Canada as at December 31, 2022, and the statement of operations and changes in net assets for the year then ended, is the historical cost basis and reflects cash transactions with the addition of the following:

accounts receivable less an allowance for doubtful accounts
accounts payable and accrued liabilities

SBCAN Board Of Directors

Romeila Son, President
Romeila works as a Real Estate Broker at Harvey Kalles in Toronto where she leads a high-performing sales team. Romeila enjoys giving back to the community and has previously served on the Board at KMC and volunteer Advisor with Junior Achievement teaching business to youth. Romeila is a mom of five wonderful kids with the youngest, Eiko being the family spina bifida warrior. Eiko was the first spina bifida in-utero repair in Canada in June 2017. Romeila and Eiko share their stories so that future diagnosed families can see what their spina bifida babies are capable of.

Chris Gready, Vice-President
Chris has spent his entire career to date working at, and consulting with nonprofits in Canada. He brings many years of fundraising and information management governance expertise to his role as Vice President of the Board of Spina Bifida Families of Canada. Chris lives in Burlington, Ontario and is a father of a child with spina bifida.

Andrea Lesperance, Vice-President (till Sept 2022) Secretary (Sept -Dec 2022)
Andrea brings a background in kinesiology and research to SBCAN. She holds a B.Sc.in Human Kinetics from the University of Ottawa and a M.Sc. in Rehabilitation Sciences from the UofT/ Bloorview Research Institute (BRI). At BRI, she conducted gait analysis for paediatric orthopaedic research. She went on to work as a project coordinator for a global health research funding agency. Andrea left the work force to raise her two daughters, the youngest of which has spina bifida. ****Resigned Dec 2022****

Katrina Keating, Treasurer
Katrina has been in the accounting field since 2011. Prior to the birth of her daughter Jacqueline, she had no prior medical vocabulary. Since diagnosis day in 2017, she has learned more than she ever thought possible. She takes great pride in supporting newly diagnosed families navigate through the process and, helping make it a bit easier at a time when things are at their worst. She lives in New Brunswick with her daughter, and husband, Jeff.

Amanda Ridding, Director of Medical Education
Amanda has been a perinatal nurse since 2004 and a spina bifida mom since 2009. She brings together her knowledge of nursing with her passion for helping spina bifida families. She was an avid blogger of her family's life with spina bifida from 2009-2016 and created an educational blog with the knowledge she learned through her journey. Amanda is the founder and administrator of the Our Lives, with spina bifida Facebook group, that brings families in Canada together. She strives to help families better understand the medical side of spina bifida and wade through difficult names and unfamiliar territory.

Michelle Pritchard, Director of Programs
Michelle received a B.A. in Psychology before starting a career with the Ontario government focusing on employment and training services. She brings a strong background in policy and communications to the organization, along with her passion for helping others. Michelle hopes to give back to the spina bifida community after receiving so much love and support during her family's journey, starting with her son's diagnosis in February 2018.

Alana Robertson, Director of Community Relations
Alana and her family live in a small town east of Peterborough Ontario. She has been a social service worker since 2013, specializing in mental health and youth work. Alana became involved with Spina Bifida Families of Canada after undergoing fetal surgery in 2017. Alana is passionate about advocating and creating community through the elimination of barriers. She joined this group so she can pay it forward.

Meredith Sandles, Secretary
Meredith brings many years of human resources and policy experience to her role as Secretary of the Board of Spina Bifida Families of Canada. After many years working in Human Resources, Meredith switched gears to be a stay-at-home mom. She now works part-time as a personal trainer and fitness coach.
She loves to travel with her family. She's always thinking about their next adventure, big or small.
She lives in Burlington, Ontario with her husband, two daughters and a couple of cats. ****Resigned September 2022****

Help Our Community Grow

Join The Conversation

Connect with us and participate in our online communities and our virtual get-togethers. Share your experiences, swap stories as we learn and grow together as a community.

Follow, Like & Share

Help us spread awareness by following us on social media, liking and sharing our posts and help us spread the word. Help us show Canada what life with spina bifida is like and what spina bifida is all about.

f **@Spina Bifida Families of Canada**
@spinabifidacanada

Donate

We want to continue to create and improve resources available to the Canadian spina bifida community. This would not be possible without the generous donations of our amazing community supporters. Visit us online at **www.sbcan.ca**

Volunteer

We will be opening up more opportunities in 2023 to volunteer with SBCAN and work with the community. For more information on becoming a volunteer, email us at **hello@sbcan.ca**

... On To Year Four

In early January 2023 the Board held a strategic planning session. We brainstormed ideas and talked about how we can create spina bifida awareness in the school setting.

By fall of 2023, we hope to launch the first phase of Spina Bifida In The Classroom programs throughout Canada. We are looking at ways for primary teachers to explain in simple terms what spina bifida is and how it affects our friends with spina bifida. We hope it creates open conversation and learning about spina bifida in the classrooms and at home.

By the fall of 2023 we also hope to establish an endowment fund that will be able to provide care financial support for future programs to launch in 2024 so we can provide more support to more families.

We are excited to move forward into 2023 along with you.

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