



SBHANA

SPINA BIFIDA & HYDROCEPHALUS
ASSOCIATION OF NORTHERN ALBERTA

2024 ANNUAL GENERAL MEETING



Spina Bifida and Hydrocephalus
Association of Northern Alberta
Annual General Meeting
April 24, 2024, at 7:00 PM
Zoom Meeting

AGENDA

- Welcome
- Quorum
- Approval of the Agenda
- Approval of the Minutes from April 26, 2023 AGM
- President's Report
- Treasurer's Report
- Appointment of Auditors
- Election of the 2024 Board of Directors
- Election of the Executive Board
- Future Plans
- Adjournment





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Message from the President of SBHANA

Dear Members of SBHANA,

It is with great pleasure that I present the President's Report for the past year, highlighting our achievements, challenges, and vision for the future at the Annual General Meeting (AGM) of SBHANA.

- **Achievements:** We connected with new families at the Glenrose Spina Bifida clinic and developed a new website for updated resources and services. The Support Fund provided over \$30,000 to our members, a vital element for our organization's sustainability.
- **Advocacy and Awareness:** We're actively engaged in advocacy discussions to improve continuity of care for transition to adult care, ensuring our community isn't left behind.
- **Research and Education:** Our research partnerships and educational programs empower individuals, promoting independence and self-advocacy.
- **Challenges:** Funding remains a challenge, but our dedicated staff actively seek funding opportunities to sustain our vital support.
- **Vision for the Future:** We aim to expand support services, enhance advocacy efforts, foster more research partnerships, and increase community engagement through capacity building and transition enhancement initiatives.

In conclusion, we have had many successes but there is still much to do moving forward. I would like to express my gratitude to our dedicated board members, volunteers, staff, and supporters who have contributed to SBHANA's success and continue showing up for the members and the organization. Together, we will continue making a positive impact and creating a brighter future for individuals living with spina bifida and hydrocephalus.

Danielle Lysak
SBHANA, President

Highlight In 2023

ACHIEVEMENTS



We have had the opportunity to connect with many new families at the Glenrose Spina Bifida clinic by having our own table there. We were able to fund development of our new website to provide updated information, resources and services for our membership. This new website will provide a key online presence for our organization.

Support Services



Throughout the year, SBHANA has continued to provide crucial support services to individuals living with spina bifida and hydrocephalus, as well as their families. The Support Fund provided over \$30,000 to the SBHANA membership last year which assisted many individuals and families. Our support fund is a foundational element to our organization. We continue to explore ways to provide financial support to as many families as we can in an equitable and sustainable manner.



Advocacy and Awareness

Advocacy has been highlighted as a key issue to tackle among discussion with our membership. We are actively in communication with health care professionals in the Spina Bifida and Hydrocephalus community to improve continuity of care for transition to adult care. By remaining a part of these key conversations, our community will not be left behind.

Highlight In 2023

Research and Education

SBHANA's research partnerships in the past have been valuable and we are eager to continue seeking opportunities to participate and contribute to research within SB and H. Our educational programs have promoted independence and self-advocacy among individuals, empowering them to lead fulfilling lives.



Community Outreach

We have expanded our community outreach initiatives to ensure that all those living with SB & H are reached through attending the SB Clinic. Creating connections at the clinic provides visibility of our organization and a connection point to ensure any family new to the clinic can meet with Kim or Monica and ask any questions they may have. Being at the clinic allows us to connect with members regularly.

Vision for the Future



- Looking ahead, SBHANA remains committed to enhancing the quality of life for individuals with spina bifida and hydrocephalus. Our vision for the future includes:
- Increased Advocacy: We will continue to contribute our voice in advocating for policy changes and improved healthcare coverage to ensure that our community receives the support and resources they deserve.
- Enhanced Research and Education: SBHANA will foster more research partnerships and educational programs to advance knowledge, improve treatments, and promote independence among individuals with these conditions.

Stronger Community engagement

- Enhancing Community Involvement: We are dedicated to enhancing our community engagement initiatives, promoting inclusivity, embracing diversity, and empowering all members.
- Capacity Building Initiative: We aim to increase SBHANA's capacity through the implementation of a Capacity Building Initiative. This includes initiatives such as hiring a fundraising developer to assist in expanding our financial resources.
- Transition Enhancement: We are committed to developing a transition enhancement program to support individuals in navigating transitions effectively and ensuring continuity of care and support.



Treasurers Report

In 2023, SBHANA generated revenue through various income sources, contributing to the financial stability and sustainability of the organization. Here's a breakdown of how SBHANA made money during the year. Here are the key highlights from the Treasurer's Report:

- **Membership Dues:** SBHANA received income from membership dues paid by our members. This source of revenue reflects the ongoing support and engagement of our members, who contribute directly to the organization's financial resources.
- **Donations and Grants:** The organization secured donations and grants from various sources, including individuals, corporations, foundations, and government agencies. These donations and grants significantly contributed to our financial sustainability, allowing us to fund our programs, services, and initiatives effectively.



Fundraising Events 2023

In the past year, SBHANA organized successful fundraising events including the Walk & Roll Alberta event, WestJet Raffle, Birdie for Kids 50/50 Matching program, and the KMS Smokies initiative, all contributing significantly to both funding and community engagement for spina bifida and hydrocephalus awareness. The Walk & Roll Alberta event held in 2023 achieved remarkable success, attracting a wide range of participants, supporters, and volunteers who not only promoted physical activity and inclusivity but also raised funds for SBHANA's programs. Key highlights of the event included substantial participation, strong community support from businesses and donors, and its role in increasing awareness and advocacy.

The financial impact was notable, providing crucial support to SBHANA's programs and initiatives. Furthermore, the collaboration with KMS Smokies bolstered fundraising and outreach endeavors, leading to positive feedback and contributions that directly advanced SBHANA's mission.

Treasurer, Brook Bateman



Grants

These grants are a testament to our collective efforts and the invaluable support of our generous donors and funding organizations. With these grants, we are empowered to continue our mission of supporting individuals and families affected by spina bifida and hydrocephalus. Here is a summary of the grants obtained:

1. Community Initiatives Program (CIP) Operating Grant: \$72,000
2. City of Edmonton Community Investment Operating Grant: \$7,681
3. Universidad Grant: \$4,905
4. ParticipACTION Grant: \$5,000
5. TELUS Friendly Future Grant: \$10,000
6. Canada Summer Jobs Grant: \$4,703

These grants play a pivotal role in funding our various programs, services, and initiatives, ensuring that we can provide essential support, advocacy, and education to our community. Each grant represents a vote of confidence in our organization's impact and the meaningful difference we make in the lives of those we serve.

Treasurer, Brook Bateman

