



2017/2018 ANNUAL REPORT

Spina Bifida and Hydrocephalus Association of Northern Alberta's
Annual General Meeting February 21, 2018



**Spina Bifida and
Hydrocephalus**
Association of Northern Alberta



Our Mission Statement: To improve the quality of life for people affected by spina bifida and hydrocephalus through advocacy, education, and support.



ADMINISTRATION

Office:

- Megan Gergatz-McMorran worked as the Program Manager for 20 hours/week until April 22, 2017 when she resigned from the SBHANA
- Danielle Schmidt shared the position of Program Manager with Megan and worked 20 hours/week and transitioned into 40 hours/week on May 8, 2017
- Julianne De Gara worked for 378 hours over the summer as our Fundraising Event Coordinator to organize and run the 10th Annual Hope Classic

Membership:

- We have 277 members on our Membership List
- 99 members renewed their membership during the last fiscal year
- Canada's Anti-Spam Legislation (CASL): Came into effect July 2017. The SBHANA is only sending email communications to members who have subscribed and gave consent to continue receiving these e-communications.

Strategic Plan:

- A meeting to reevaluate the Strategic Plan was held on February 8, 2017
- The Board re-evaluated what we want to accomplish in the next five years and set some new goals for which action plans were created. Copies will be available through the Office upon request.



Fund Development:

- The next SBHANA Casino will be held on Thursday, April 19 & Friday, April 20th, 2018 at Century Casino
- Successful fundraisers & public awareness events held this year:
 - Hope Classic income **\$18,450.75** 20% of proceeds excluding corporate donations went to SBHAC (\$3,094.70 to SBHAC); **profit \$15,356.05**
 - Hope Classic Online Auction brought in **\$755.00**
 - Silent Auction from the Paint for the Skate **\$977.00**
 - Skate for Spina Bifida & Hydrocephalus income **\$2,858.00**
 - Raffle (drawn at skate event) income **\$5,250.00**
 - KMS Tools Smokie Sale **\$1,244.00**
 - Christmas Party Silent Auction **\$613.00**



- Received the following Grants:
 - 1) Royal Alexandra Hospital Employees' Charitable Donations Fund (\$1,000)
 - 2) City of Edmonton: Community Investment Operating Grant (\$13,941)
 - 3) Community Board Donation – TELUS (\$1,500)
 - 4) Canada Summer Jobs - Government of Canada (\$3,674)
 - 5) Union 52 Benevolent Society (\$3,000)



- Special Donation received:
 - 1) Butler Family Foundation (\$500)

ADVOCACY

- SBHANA is represented at meetings held by the following:
 - Interagency Committee on Recreation for Persons with Special Needs
 - Alberta Disabilities Forum
 - Royal Alexandra Hospital Celebration of Giving
- Members of Edmonton Chamber of Voluntary Organizations, and Voice of Albertans with Disabilities (Alberta Disabilities Forum)

RESEARCH

- Did not receive any donations for research in the 2017 year

COMMUNITY CONSULTATIONS

- Cindy Smith (president) spoke at the University of Alberta to students in the Occupational Therapy 557 course on September 6, 2017

COMMUNITY BUILDING

- Advertised like-minded organizations, programs and services through our updates and opportunity emails and our newsletter
- Wrote a letter to City of Edmonton Mayor, Don Iveson, in regard to proclaiming June SB&H month
- International Day for Persons with Disabilities – we donated Cineplex Admission Passes as a door prize and Danielle Schmidt manned a display at the event which was held at the Steadward Centre



EDUCATION

SB/H Awareness:

- The SBHANA participated in the 2017 Educational Assistants Conference on February 24, 2017 at MacEwan University, set up a display and handed out Education Manuals
 - Quality of Life DVD & Educator Manual – 5 were handed out
- June Awareness Month 2017: High Level bridge was lit green on June 1st, New Bridge banners were purchased & placed on three overpasses around the city, Awareness Displays for SB&H were set up and manned by volunteers at the following locations: Skate for SB&H, we held a Paint for the Skate event at On the Rocks on June 12th, and KMS Tools for 3 days in July.
- Trish Mupedziswa, a student from the University of Alberta finisher her 20-hour Community Service Learning placement with SBHANA working on social media in April 2017
- Skate for SB&H 2017 Media: Several radio stations around the city advertised our event. Global News featured information on the Skate the morning of the event. Jacob Bos from The Boss Vlogs put together a video titled Aaron “Wheelz” Fotheringham ft YEG REALHEROS in EDMONTON on the Skate.
- Hope Classic Media: Julianne de Gara, Tammy & Rose McKenzie did an on-television interview with CTV & Julianne de Gara did another interview at the Hope Classic for CTV
 - Represented at the Hope Classic - Now Radio (trucksicle)
- International Day for Persons with Disabilities IDPD – Danielle Schmidt set up and manned our information display at the Steadward Centre



MEMBER SUPPORT

Information Updates:

- Regular emails sent out to membership with Information in Updates and Opportunities and website kept up to date with current information

Social Activities:

- Summer BBQ held in conjunction with the Hope Classic on August 19, 2017 with over 150 people in attendance.
- Christmas Party was held on December 2, 2017 with 123 members, family members, volunteers and staff who attended.



- Melody Hilman hosted the Mom's Potluck Dinner on Friday, May 12, 2017 and there were 10 Moms in attendance who all had a great night getting together and catching up.

Camp Freedom:

- 2017 Camp Freedom would have been the 18th annual year, but it was cancelled by the venue (Camp He Ho Ha) due to unforeseen circumstances.

Support Fund:

- Approved 40 different support fund requests with a total value of \$27,740.24
- Budget was increased to at \$30,000/year, funding was increased to \$1,500 per member with spina bifida and/or hydrocephalus per year
- Health & Wellness component of the support fund continues to fund up to \$500 towards medical/wellness expenses on a one-time or trial basis

Member Education Fund:

- The member education fund was accessed by Betty Ann Thibodeau this past year in the amount of \$1,296.29. She attended the 3rd World Congress on Spina Bifida Research and Care which was held on March 16 -19, 2017 in San Diego, California.

Scholarship:

- There were two scholarship recipients this year: Morgan Cathcart and Gbemiro Adegubuyi were given the Dr. Peter Bowen Scholarship receiving \$1,000 each towards their post-secondary education

Wheelchair Loaner Program:

- 2 Quickie Kids wheelchairs available for short-term loans
- Both are still loaned out over the course of the year; no new requests for the wheelchairs have been made

New Parent Bags:

- 8 new parent bags were assembled by Sharon Veeneman this past year
- The bags are distributed through the Spina Bifida Clinic at the Glenrose
- The Board has been reviewing and updating information content in these packages this past year.

NoLimits Support Evenings

- Coffee nights continued throughout the year on the first Thursday of each month
- Social and educational support evenings were delivered monthly. The group attended an RDSP info session, took a Taekwondo Self Defense Class and did a group dinner at Chiantis to name some of the activities.
- NoLimits members helped volunteer with the Raffle, KMS Smokie Sale, Hope Classic and Christmas Party



Adult Retreat

- There was an Adult Retreat this past Fall on September 30, 2017 at the Parkdale-Cromdale Community Hall where we had 24 adult members living with spina bifida come out to attend the Dinner Party. The group learned how to prepare a handful of salads, desserts, biscuits & chicken pot pie. After food preparations and eating there was time for socializing and games. It was a great event.



Information Referrals & Support

- Numerous calls and visits to the SBHANA office for information and support
- Several adults living with SB&H calling & visiting for support
- Hospital visits were made to five adult members this past year at the Royal Alexandra Hospital and University of Alberta Hospital

COMMUNICATION

Newsletter:

- Three electronic editions (Spring 2017, Fall 2017, Winter 2018) were created this year with several member contributions: article ideas, articles, member spotlights and support fund thank you articles. We have switched to sending electronic newsletters through Constant Contact.

Website:

- Updates to the website have been done throughout the year of 2017; no major changes done

SBHAC:

- Renewed our membership with the National association
- Donated \$2000 towards Operating Costs to SBHAC
- Donated **\$3,094.70** from the Hope Classic
- Danielle Schmidt & Melody Hilman attended the AGM teleconference on September 28, 2017
- Melody Hilman joined the SBHAC Board November 22, 2017