



2018/2019 ANNUAL REPORT

Spina Bifida and Hydrocephalus Association of Northern Alberta's Annual General Meeting February 27, 2019



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



ADMINISTRATION

Office:

- Danielle Schmidt worked full-time in the position of Program Coordinator 40 hours/week
- Alexandra Karatairis worked 163 hours and then Geneva Coulter took over as the new summer student for 222 hours over the summer as our Fundraising Event Coordinator 30 hours/week to organize and run the 11th Annual Hope Classic

Membership:

- We have 285 members on our Membership List
- 85 members renewed their membership during the last fiscal year
- The SBHANA is only sending email communications to members who have subscribed and gave consent to continue receiving these e-communications

Strategic Plan:

- The Board re-evaluated what we want to accomplish in the next five years back on February 8, 2017 & set some new goals for which action plans were created
- The Board continues to follow the Strategic Plan that was developed in February 2017

Fund Development:

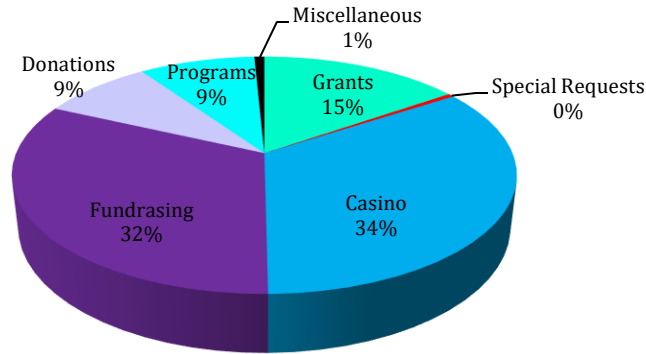
- The SBHANA Casino was held on April 19th & 20th, 2018 at Century Casino with Margaret Miller as the Casino Chairperson
- AGLC Casino money in the amount of \$74,267.37 was received in August 2018
- SBHANA's next Casino will be in the second quarter (April, May or June) of 2020
- Successful fundraisers & public awareness events held this year:
 - Hope Classic income **\$22,450.60** 20% of proceeds excluding corporate donations went to SBHAC (\$2,912.29 to SBHAC); **profit \$19,538.31**
 - Raffle (drawn at our Hope Classic event) income **\$9,950.00**
 - KMS Tools Smokie Sale **\$1,400.00 (June) & \$1,380.00 (November)**
 - Hope Classic Online Auction **\$203.00**
 - Christmas Party Silent Auction **\$520.00**
- Received the following Grants:
 - 1) Royal Alexandra Hospital Employees' Charitable Donations Fund (\$1,500)
 - 2) City of Edmonton: Community Investment Operating Grant (\$13,173)
 - 3) Canada Summer Jobs - Government of Canada (\$3,610)
 - 4) Union 52 Benevolent Society (\$2,000)
 - 5) Edmonton Public Teachers Local Charity Trust (\$3,500)



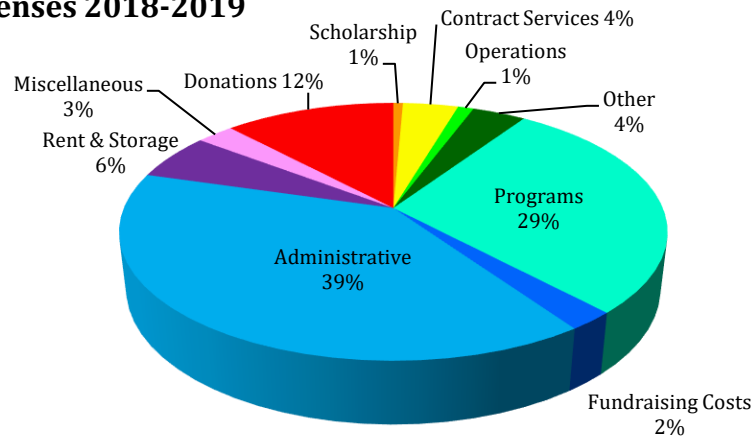


- Special Donation received:
1) Butler Family Foundation (\$500)

Total Income 2018-2019



Total Expenses 2018-2019



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
 - Glenrose Transition Project – Spina Bifida Pathways to Independence Committee
- 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 2018 year



COMMUNITY CONSULTATIONS

- Cindy Smith (President) spoke at the University of Alberta to students in the Occupational Therapy 557 course in the Fall of 2018
- Cindy Smith also attended an OOTH 555 class in December 2018 to participate as a Family Member in a simulated team meeting situation & provided feedback
- Danielle Schmidt did a presentation on December 12th to the Edmonton Civic Employees Charitable Assistance Fund (ECECAF) Board about our organization and the benefits of our support fund. The purpose was to ask them for some funding support for this important program we offer.
- Glenrose Transition Project Focus Groups were put on by Heather Lissel & Kris Mahura from the Glenrose Rehabilitation Hospital and they presented their findings in a Pathways to Independence Webinar along with Danielle Schmidt
- Cindy Smith was a Family Advisor on the Spina Bifida Pathways to Independence Committee & Elfi Wensel participated as the Patient Advisor on this same committee

COMMUNITY BUILDING

- Advertised like-minded organizations, programs and services through our updates and opportunity emails and our newsletter
- Partnered with the Centre for Literacy to offer a 10-week Executive Functioning Workshop for six of our members aged 9 - 14
- Started a partnership with Kids Up Front Edmonton to help create opportunities and life-changing experiences for our members by providing event tickets to an art, cultural, sport or recreation events; distributed 128 tickets to members so far

EDUCATION

SB/H Awareness:

- June Awareness Month 2018: High Level bridge was lit green on June 8th, Bridge banners were placed on three overpasses around the city, Awareness Displays for SB&H was set up and manned by volunteers at the following locations: KMS Tools for 3 days in June & again in November
- Wrote a letter to City of Edmonton Mayor, Don Iveson, in regard to, proclaiming June SB&H Awareness Month
- On June 4th, Alberta Minister of Health, Honourable Sarah Hoffman, invited a group of us to attend an official proclamation at the AB Legislature Building declaring that June is SB&H Awareness month in the province of Alberta
- Hope Classic Media: Geneva Coulter & Jaxon Giesbrecht did an on-television interview with CTV & Geneva Coulter did another interview at the Hope Classic





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 11, 2018 with over 150 people in attendance
- Christmas Party was held on December 1, 2018 with well over 100 members, family members, volunteers and staff who attended
- Chera Giesbrecht hosted the Mom's Tapas Supper on Friday, May 4, 2018 and there were 6 Moms in attendance who all had a great time getting together and catching up

Camp Freedom:

- 2018 Camp Freedom was our 18th annual year
- It was held on July 31st to August 3rd
- There were 25 campers who registered but 3 were unable to attend due to unforeseen circumstances, so there were 22 campers in attendance from all around Western Canada
- 15 volunteers helped make the week of camp possible



Support Fund:

- Approved 53 different support fund requests with a total value of \$27,356.03
- Budget remained at \$30,000/year, funding stayed at \$1,500 per member with spina bifida and/or hydrocephalus for the year
- Health & Wellness component of the support fund was taken out of our support fund criteria

Member Education Fund:

- The member education fund was not accessed in 2018

Scholarship:

- There was one scholarship recipient this year: Gbemiro Adegbuyi was given the Dr. Peter Bowen Scholarship receiving \$1,000 towards his 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:

- 5 New Parent Bags were distributed through the Spina Bifida Clinic at the Glenrose & 3 more bags are made up for distribution when needed



NoLimits Support Evenings

- Coffee nights continued throughout the year on the first Thursday of each month
- NoLimits members helped volunteer with the Raffle, KMS Tools Smokie Sales, Hope Classic and Christmas Party

Adult Retreat

- There was an Adult Social Holiday Party held on December 30, 2018 at the ACT Recreation Centre put on by Monica Sneath & Darlene Cathcart. There were 29 individuals in attendance who all had a great time munching on snacks, playing board games and catching up with old friends for the night.

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 four members this past year at the Misericordia Hospital and University of Alberta Hospital

COMMUNICATION

Newsletter:

- Two electronic editions (Fall 2018, Winter 2019) were created this year, we have continued to send electronic newsletters through Constant Contact

Website:

- Updates to the website have been done throughout the year of 2018; no major changes done

SBHAC:

- Renewed our membership with the National association
- Donated **\$2,000.00** towards Operating Costs to SBHAC
- Donated **\$2,912.29** from the Hope Classic
- Chera Giesbrecht attended the AGM in Winnipeg, MB on September 28, 2018
- Melody Hilman was on the SBHAC Board for 2018 & she has joined the SBHAC Research Committee for the 2018-2019 year