Spina Bifida and Hydrocephalus Association of Northern Alberta
Box 35025-10818 Jasper Avenue, Edmonton, AB T5J 0B7
Phone: (780) 451-6921   Email: info@sbhana.org Website: www.sbhana.org

ANNUAL GENERAL MEETING
October 17, 2013
2012/2013 ANNUAL REPORT

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

ADMINISTRATION
Office:
- Kelty Coburn continued to work 30 hours/week as our Program Manager until July 12, 2013. Darlene Cathcart continued as Administrative Assistant for 15 hours/week until she was hired as the new Program Manager as of July 8, 2013. There was one week of overlap. Darlene works 20 hours/week.
- Alexis Millar was hired on July 12, 2013 as the Fund Development and Communications Coordinator. Alexis works 20 hours/week.
- Kiray Jones-Mollerup worked 420 hours over the summer as our Fund Development Coordinator through the Canada Summer Jobs Program through the Federal Government

Membership:
- We now have 251 members on our Membership List
- 117 members renewed their membership during the last fiscal year

Strategic Plan:
- The Board continues to follow the Strategic Plan that was developed in March 2012
- An Adult Focus Group was held on January 26, 2013. Three goals were identified.
    1. Continue to increase awareness with a specific focus on education to the general public on issues that our adult population faces
    2. Connect our adult population through events and programs
    3. Advocate for the complex medical needs of the adult members

Fund Development:
- Successful fundraisers & public awareness events held this year:
  - Hope Classic income $24,323 (Profit approximately $18,252.37)
  - Skate for Spina Bifida income $2323 & Raffle $3190 (Total Event Profit $629.72)
  - School Display income $250 (no expenses)
  - Third party fundraiser - Keegan Benner Charity Golf Tournament for Spina Bifida & Hydrocephalus income $11,113.50 (Profit $6868.87)
- Received the following Grants:
  Community Spirit Grant ($7,507.78)
  Community Investment Operating Grant ($17,500)
  Community Initiatives Program Community Operating Grant ($50,000)
  Canada Summer Jobs Grant ($4,582)
  Royal Alex Employees Charitable Donation Fund ($1,000)
  Muttart Bursary ($300)

- Received $17,000 sponsorship for Camp Freedom from Alberta Association for Insurance Adjusters Northern Chapter

ADVOCACY
- SBHANA is represented at meetings held by the following:
  - Interagency Committee on Recreation for Persons with Special Needs
  - Advisory Board for Persons with Disabilities
  - Royal Alex Celebration of Giving
  - Alberta Disabilities Forum
  - Glenrose Parent Advisory Council Transitions
- Member of the Alberta Disability Forum

RESEARCH
- Communicated information by email to a professor regarding study on disability and sexuality. Answered questions about our membership and shared information about participation in the research study with our members
- Send out phase 2 forms for the SBHAC genetic study

COMMUNITY CONSULTATIONS
- Tirvel Adaptive Bikes – demonstration of their bikes and modifications that can be made
- On Site Placement Services – meetings to share information about SBHANA and our members and for our staff to gain more knowledge about their services

COMMUNITY BUILDING
- Alexis attended Rotarian breakfast meeting as a guest of Doug McEwen
- Manned a display at Bike Day at the Glenrose Rehabilitation Hospital
- Advertised like-minded organizations, programs and services through our updates and opportunity emails and our newsletter
- Had Amy from CPA attend Camp Freedom with adaptive bikes
- International Day for Persons with Disabilities – we donated two Dream Live Inspire silver necklaces for door prizes and Kelty took photos which have been used on their website
- Donated a Dream Live Inspire Video and silver necklace to the Citadel Theatre Volunteer Appreciation Evening

EDUCATION
SB/H Awareness:
- International Day for Persons with Disabilities IDPD – set up and manned our information display
- June Awareness Month 2011:
  - Bridge banners were placed on three overpasses around the city
  - Awareness Displays for SB&H were set up and manned by volunteers at the following locations; Kingsway Garden Mall, Capilano Walwart, Terwillegar Rec Center, Kate Chegwin Junior High School

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- Quality of Life DVD
  - Elaine (past summer student) distributed video to University of Manitoba
- Hope Classic Media
  - Television interview with Global – Cindy Smith
  - On air with 730 CHED – Nicole Stefaniszyn
  - Represented at the Hope Classic - Now Radio (trucksicle) & CHED (booth)
- Skate for Spina Bifida & Hydrocephalus Media
  - Television interview with CBC – Aaron Fotheringham & Wheel Around with Wheelz participants
  - CTV & Global television showed the event on the news
  - Represented at the Skate for SBH – Now Radio (trucksicle)

Educational Assistants Conference:
- The SBHANA participated in the 2013 Educational Assistants Conference on February 22-23, 2013 at MacEwan University again this year, setting up a display and making Education Manuals available.

MEMBER SUPPORT
Newsletter:
- Winter, Summer, and Fall 2013 editions published this year with many member contributions

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

Social Activities:
- Christmas Party held November 24, 2012 with 175 people in attendance
- Summer BBQ held in conjunction with the Hope Classic on August 10th, 2013 with over 200 people in attendance
- Mom's Potluck Dinner hosted by Darlene Cathcart and Monica Sneath in Spring 2013

Camp Freedom:
- 14th annual camp was held on August 1-4th with 25 campers from Western Canada and 18 volunteers

Support Fund:
- Approved 37 different support fund requests with a total value of $18,059.04
- Budget remains at $18,000/year, funding up to $1000 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:
- Elfi Wensel received funding to attend the Alberta Community Living Annual Family Conference

Scholarship:
- Mackenzie Doll and Keighley Schofield are the recipients for the Dr. Peter Bowen Scholarship, with each receiving $1,000 towards post-secondary education

Wheelchair Loaner Program:
- 2 Quickie Kids wheelchairs available for short-term loans
- Both loaned out over the course of the year

New Parent/ New to the City Gift Bags:
- Four new bags were assembled by Sharon Veeneman and distributed through the Spina Bifida Clinic at the Glenrose
- All informational resources are now in an electronic format for easy updating

NoLimits Support Evenings
- Delivered the support evenings 15 times between November 2012 and September 2013 with an attendance rate of 136 members (27 individuals participating total)

Information Referrals & Support
- Numerous calls and visits to the SBHANA office for information and support

SBHAC:
- Renewed our membership with the National association
- Todd Benner is currently a member at large on the SBHAC Board
- Aniquea Thorowsky and Darlene Cathcart participated in the conference call SBHAC AGM as the SBHANA delegate
- Aniquea Thorowsky is on the Education, Fund Development & Communications Committees
- Donated $2500 towards Operating Costs to SBHAC
- Donated $408.15 from the Keegan Benner Charity Golf Tournament
- Donated $3455.16 from the Hope Classic National Fundraiser