



**S
B
H
A
N
A**

www.sbhana.org

Spina Bifida and Hydrocephalus Association of Northern Alberta Fall Newsletter 2015

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



Hope Classic Run/ Walk/ Wheel 2015

The annual run/walk/wheel was held at Rundle Park in Edmonton, Alberta on August 8, 2015. The beautiful location, warm weather and energetic participants made for another successful year. The Hope Classic was followed by the Summer Barbecue, games, face painting and prize giveaways. To read more about this event and look at some great pictures, please see pages 10 and 11.

**FALL
2015**



**S
B
H
A
N
A**

www.sbhana.org

BOARD OF DIRECTORS

The Spina Bifida and Hydrocephalus Association of Northern Alberta is governed by a volunteer Board of Directors. The Directors' commitment and leadership provide direction for fulfilling our mission statement.

Executive

President: Cindy Smith
Vice President: Chris Minchau
Treasurer: Rebecca Moss
Secretary: Katherine Bateman

Program Manager: Darlene Cathcart
Assistant Program Manager: Megan Gergatz
Fundraising Event Coordinator: Kyra Cusveller
Newsletter Editors: Darlene Cathcart & Megan Gergatz
Design, Layout, and Publishing: Camrose Morning News
This newsletter is published by SBHANA. Please address any correspondence for the Association or the newsletter to:

Board Members

Marisha Milette
Ken Godbeer
Frances Miller
Lise Johnston
Lilianne Gosselin
Sean Bouffard
Lisa Bennett
Betty Ann Thibodeau
Curt Coupal

SBHANA Contact Information

P.O. Box 35025 – 10818 Jasper Avenue
Edmonton, AB T5J 0B7
780-451-6921 info@sbhana.org
Fax: 1-888-881-7172

SBHANA Office Address

#305—11010 101 Street (Hys Centre)
Edmonton, AB T5H 4B9

WE WANT YOUR INPUT!

We would love to hear from you and will incorporate suggestions, personal stories, questions, tips, and feedback into the newsletter. We'd also love to share what different members are up to! Contact us through e-mail info@sbhana.org or by phone 780-451-6921. Our website is sbhana.org.

CONTENTS

The views and ideas expressed in some of the articles in this issue do not necessarily reflect the views and ideas of the Board of Directors or the Association. Articles are provided for the reader's information and everyone has to determine the validity of the concepts

President's Message	3
Office Update & Fundraising	4,5&6
Mark Your Calendar	7
Updates & Opportunities	8
Scholarship	9
Hope Classic & Barbecue	10&11
Skate for Spina Bifida and Hydrocephalus	12&13
Camp Freedom	14&15
Thank you to our Supporters	16&17
Raffle & Melting Pot	18
Volunteer Spotlight	19
Vitalize Conference	20&21
Medical News	22
Membership Benefits	23
Membership Form	24

President's Message

This summer I drove with my kids and dad to Yellowstone. It was a wonderful trip and we were able to “camp” in a cabin at the KOA. My husband isn't a fan of camping (“Why pretend to be homeless?”) but my kids and I love the campfires, sleeping in a sleeping bag, and everything else that goes along with it. I decided last year that my back wouldn't be able to handle lifting Nathan through a tent in a crouched position, on and off the ground any longer. I was thrilled to discover that many KOA's have camping cabins! It's worth the extra expense (still cheaper than a hotel) to save my back and allow for us to keep camping.



I was determined to make it back in time for the Hope Classic, so we planned a twelve-hour drive back home the day before. The long drive turned out to be a blessing, as I was able to clearly observe something alarming with my nine-year-old son, Daniel. We were having to pull over every half hour to let him pee! I knew this was not normal and we headed to the Stollery Emergency immediately after arriving back in Edmonton. We were up all night as Daniel's blood was analyzed and he was given IV fluid. Daniel was very sick and admitted to the Stollery for the weekend, being diagnosed with Type One Diabetes. We never did make it to the Hope Classic.



"Some believe it is only great power that can hold [hardship] in check. But that is not what I have found. I have found that it is the small everyday deeds of ordinary folks that keep the darkness at bay. Small acts of kindness and love." - Gandalf

I love this quote! My life has become significantly harder, and as I navigate through these choppy waters, I find strength and buoyancy in even the smallest act of kindness.

In the words of Plato: “Be kind, for everyone you meet is fighting a hard battle!”

Much love to you all,



Cindy Smith
President



S
B
H
A
N
A

Office Update

Kyra Cusveller—Fundraising Events Coordinator

Several people who have visited the SBHANA office over the past four months have commented on my ‘interesting’ choice of interior decor – namely, sticky notes. The door against which my desk sits is papered with dozens of notes; topics ranging from to-do lists, to interview dates, to contact information, to my personal favourite: a big yellow one that simply states “NO BALLOONS.” As I slowly begin to clean up my personal disaster area, I’ve had a chance to reflect on the mountain of information I’ve learned this summer. For instance, I no longer need to reference the business card with the office phone number highlighted – I’ve left enough voicemails this summer to have that memorized – but the one that tells me to “THANK VOLUNTEERS” still serves as a daily reminder.

This summer has been indescribable, but I think the term “whirlwind” comes close. It’s hard to imagine, but as I write this it was just over four months ago that I was on the phone with Darlene, desperately trying to convince her to grant me a phone interview before I left to go to China the next day. I am so thankful that Darlene, Megan, and the board decided to take a chance on me, and that the position was still available to me three weeks later when I returned to Edmonton. I can’t imagine this summer without this experience.

The past few days have been bittersweet, as I unfortunately will not be a student next summer, and will thus be unable to return to the Fundraising Events Coordinator position.

By this time next year I hope to have completed my degree in International Business and Business Law, and hope to be exploring what that world has to offer. I’m excited, and a little terrified, and fairly sad to say goodbye to the incredible people I have met since taking on this position. Each and every staff member, board member, volunteer, and SBHANA member has inspired my work for today and my goals for the future, and for that I cannot thank you enough.



Kyra and her brother at the Hope Classic



SBHANA



SBHANA

www.sbhana.org

Darlene Cathcart– Program Manager

Life is Journey Not a Destination”, this is one of my favourite quotes. The SBHANA has been a big part of my journey for 17 years. This fall I made the difficult decision to resign from my position as Program Manager. I will miss working with awesome staff and members. As I look back on my journey I



thought it would be interesting to reflect on the ways I have been involved with the SBHANA. It all started when our daughter, Morgan, was born in the summer of 1998. I had grown up in a family where volunteering was part of what you do, you made time for others. So, when Morgan was three months I joined the board of directors (my husband, Jay and I shared one position on the board for the first year). I stayed on that board of directors for 10 years with three of those years dedicated to the position of president. The first few years I spent most of my time planning social events. This is how I met Monica Sneath. We decided to plan the Family Christmas Party and Summer Barbeque together. We worked really well together and a friendship was born. Monica and I saw a need for the teens with spina bifida to be connected and to have independence away from their parents. We made the decision to start Camp Freedom, a four day overnight camp for teens with spina bifida in August of 2000. I am proud to say that Camp Freedom is still going strong. During those early years I enjoyed the connections I had with other parents. Monica started a pre-school playgroup and I was her trusty side kick in planning monthly events. After the playgroup ended when our children went to school we continued to host dinners for the moms so that we would stay connected. I still enjoy these dinners even though my daughter is now 17. Over the years with the SBHANA I have manned our display at countless community events and have had the privilege of educating others about spina bifida, hydrocephalus and the SBHANA. This includes presentations to medical students, education students, nursing students, human ecology students, private company sponsors and service clubs. Morgan now joins me on several of these presentations sharing her story about living with spina bifida and hydrocephalus. For the 2006 and 2011 national conferences held in Edmonton I was able to take on key roles on the steering committee and see the benefits of bringing people from all over Canada together to share our experiences and learn from each other. I have also had the privilege of attending conferences in various provinces as a delegate for the SBHANA and learning about the associations across Canada. I began working in the office as an employee of the association in 2010. I held the roles of Administrative Assistance and Program Manager for the past five years. Supporting others in their challenges has brought me great support and information as well. My connection to the SBHANA is strong. I have shared stories with expectant mothers, new parents, families, teens and adults, offering encouragement or sometimes just providing a listening ear in times of challenges. The personal benefits I have received from being involved over the past 17 years is priceless! I did jump in with two feet and little knowledge but it has been so worth the efforts for me and my family. I have gain strong friendships and have been fully supported by others who can share my challenges and rewards of parenting a child with medical needs. My favourite part of the SBHANA is the generous, amazing people I have met who volunteer their time and talents and expect nothing in return. These are the people who have become part of my life and made my journey with the SBHANA so meaningful. I plan to stay connected to this great community of people and look forward to what the future brings the SBHANA with new staff, new volunteers and new ideas. Thank you all for being a part of my journey!



**S
B
H
A
N
A**

www.sbhana.org

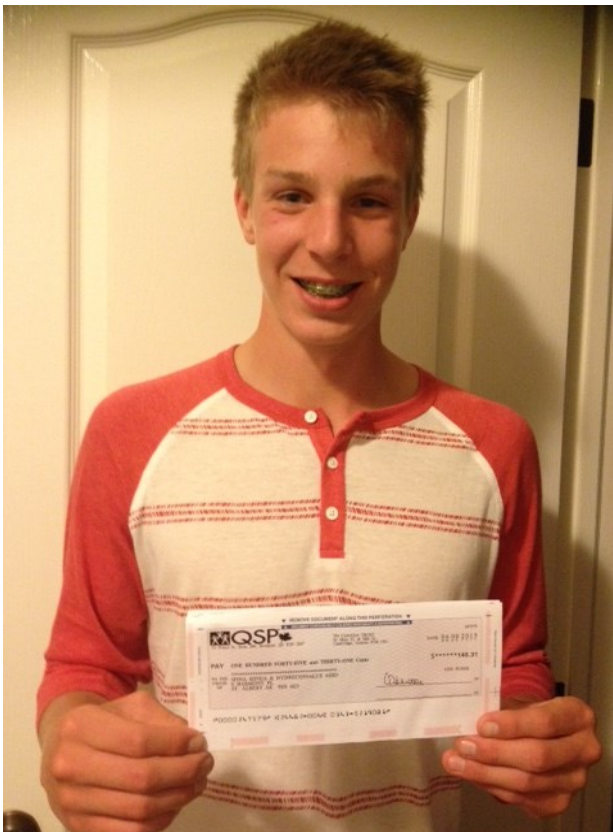
Megan Gergatz– Assistant Program Manager

I can't believe it is already the Fall! As beautiful as the fall leaves are, it sadly means that all the fun summer events are over. It was my first time attending a skateboard competition at the Skate for Spina Bifida and Hydrocephalus. I was very impressed on what a great event Kelty had planned and executed. I will never forget the smiles on the faces of the kids, teens and yes adults, as we threw skateboard merchandise into the bowl. It was my favourite part of the day by far.



I cannot show enough appreciation to all of the volunteers, the Board of Directors, and Darlene for all of their contributions to the Hope Classic. Kyra did an amazing job as her first time as a Race Director. She is extremely hardworking and put a lot of effort and thought into making it the successful event it was. I also wanted to personally thank all of the participants in the run/walk/wheel, we couldn't have done it without you.

I have only worked with Darlene for a short period of time but during the many hours of grant writing, event planning, financial tracking, etc. we have had great conversation and lots of laughs. Although I know we will still see her around, she will definitely be missed and I wish her the best of luck in her next chapter!



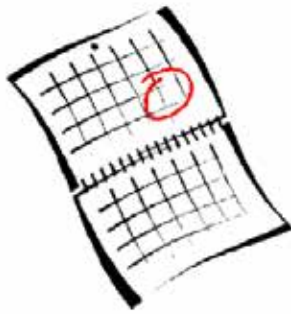
Fundraising for SBHANA

My name is Jeremie. I decided to fundraise for the SBHANA because I had an opportunity to raise money through QSP magazine sales. I chose this organization because my 7-year old brother has spina bifida and I know that when he gets support, the right equipment, and encouragement, he can be so independent. He's always excited to show us the new skills he learns, from scooting around to climbing stairs using his upper body strength. I wanted to help others get what they need as well.



**S
B
H
A
N
A**

www.sbhana.org



MARK YOUR CALENDAR!

**October 24, 2015
Saturday**

NoLimits Peer Support Halloween Party
Location: TBA
Time: 1:00pm– 4:00pm

**October 26, 2015
Monday**

**Canadian Association of Disabled Skiing
Student Registration Evening**
Location: Snow Valley Ski Resort
Time: 6:00pm-8:00pm

**November 28, 2015
Saturday**

SBHANA Christmas Party
Location: Kensington Community Hall
(12130– 134 St NW Edmonton, AB)
Time: 5:00pm – 9:00pm

**December 3, 2015
Thursday**

International Day of Persons with Disabilities
Location: Ramada Edmonton Hotel
(11834 Kingsway Ave)
Time: 10:00am - 2:00pm

**February 17, 2016
Wednesday**

SBHANA AGM
Location: Glenrose Rehabilitation Hospital
Time: 6:00pm-8:00pm

**July 28-31, 2016
Thursday-Sunday**

Camp Freedom
Camp for teens with spina bifida (age 12-18 years)
Location: Lake Isle (1 hour west of Edmonton)

NoLimits Peer Support

Stay up-to-date on NoLimits Peer Support group by joining the NoLimits group on Facebook and watching for details in our Updates & Opportunities member emails.



SBHANA's newsletter layout and printing is provided by the Camrose Morning News. The Maschke Family, owners and operators of the Camrose Morning News, are proud members of the SBHANA



S

B

H

A

N

A

www.sbhana.org

Updates & Opportunities

CADS Edmonton Program

Become a student and learn to ski or snowboard with CADS Edmonton or volunteer as a ski or snowboard instructor.



*Canadian Association
for Disabled Skiing*

Edmonton

Registration Evening: Monday, October 26th from 6:00pm – 8:00pm @ Snow Valley
Student Lessons: Mondays from 7:00pm – 9:00pm
Starting January 11th, 2016 – March 6th, 2016 @ Rabbit Hill
Checkout our new website: www.cadsedmonton.ca
Contact: Program Coordinator Sharon Veeneman at coordinator@cadsedmonton.ca

Challenged Athletes Foundation—2016 Grant Applications is now OPEN

It is the mission of the Challenged Athletes Foundation to provide opportunities and support to people with physical challenges so they can pursue active lifestyles through physical fitness and competitive athletics. The Challenged Athletes Foundation believes that involvement in sports at any level increases self-esteem, encourages independence and enhances quality of life.

To be eligible for a grant through Access for Athletes, an athlete's physical disability must be recognized within the International Paralympic Committee (IPC) classifications. For more information, please visit the IPC website. CAF does not discriminate based on age, gender, level of ability or sport, but does require applicants to demonstrate a clear financial need for their grant request. For more information check out <http://www.challengedathletes.org/>
Application deadline is December 4, 2015 at 5:00pm

A Guide For Educators—Educational Resources Available free of Charge

A Guide for Educators is an invaluable resource manual for teachers, educational assistant and school administrators working with a student with spina bifida and/or hydrocephalus.

This manual includes detailed information about the following topics:

- Spina Bifida –what is it, the causes and treatments
- Hydrocephalus- what is it, the causes and treatments
- Medical conditions associated with SB&H (seizures, latex allergies, incontinence)
- Accessibility
- Social Development
- Physical Education
- Learning disabilities
- Resources

If you have a school age child living with spina bifida and/or hydrocephalus this is the resources your child's school needs. Contact our office for a free copy to mailed to you. Email info@sbhana.org or call 780-451-6921.



SBHANA

www.sbhana.org

Scholarship

The SBHANA offers two post-secondary scholarships each year to students with spina bifida and/or hydrocephalus. This year Yuan Zuo was the individual who received the \$1000 scholarship.

Yuan is currently taking her first year of Business Administration at the Northern Alberta Institute of Technology (NAIT). She would like to major in Management for her second year and then hopefully do another year concentrating on Human Resources. Yuan really enjoys working with people and she took some time after high school to explore her options, and felt that Management and Human Resources would be a good personal fit. She is currently working at a Real Estate office as a receptionist., and would one day like to work in management.

Yuan's favourite part of school is the group activities and leadership opportunities such as student council. She has applied to be apart of Student Council at NAIT and is very much looking forward to her upcoming Management classes.

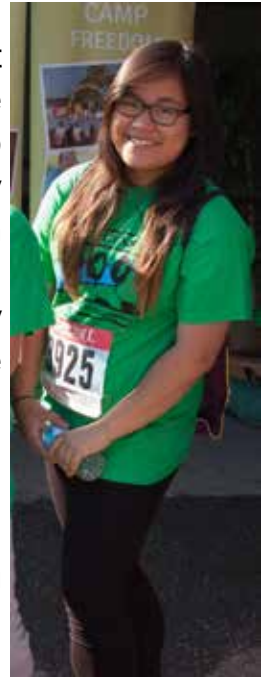
Between a busy school and work schedule, Yuan enjoys reading in her spare time. She feels it doesn't hurt to be more educated. Yuan has also volunteered with the Hope Classic Run/ Walk/ Wheel for multiple years. She has pinned the ribbons, helped put together race bags, distributed race bibs, assisted with set-up and take and down, amongst other tasks during the annual event.

Advice that Yuan has for other members who are pursuing a post secondary program is to take your time. Explore, go on adventures and have fun before settling down. She stated that when you are more certain you tend to be more motivated.



For those members who aren't certain, she empathizes with as at first she didn't think should would pursue post secondary schooling. But she advises you to push yourselves, and to not be afraid.

Good luck Yuan with the Business Administrative program at NAIT! With your positive and pleasant personality we know you will do great!





**S
B
H
A
N
A**

www.sbhana.org

Hope Classic Run/ Walk/ Wheel



The eighth annual Hope Classic Run, Walk, and Wheel took place on August 8th, 2015, and was a rousing success! Nearly 150 people ran, walked, wheeled, or cycled the 5K and 8K routes through Rundle Park, and together we raised over \$21,000 for the SBHANA! Our deepest thanks go out to everyone who donated to, volunteered for, or attended the Hope Classic this year. We are deeply grateful for your support, and cannot wait to see you again next year.

A big thank you goes out to all our volunteers at the event; Chris M., the Bateman family, Ian, Doug, Steph P. Betty Ann, Zac, Kailyn, Chris, Jasmine, Miryam, Lise, Chris G. Catherine, Alyson, Ashley, Charlie, Angie, James, Jacki, Becky, Bobbi, Sarah, Alexandra, Sunny, Stephanie L., Steph L., Ben, and Dale.

Additional thanks must be given to our sponsors, without whom such an event would not have been possible.



The barbecue meal and activities were sponsored by: Save On Foods, Superstore, Costco, the Toy Hutch, Joyful Face Painting, M&M Meat Shops, and the City of Edmonton Recreation Services.



Prizes were donated by: Booster Juice, City of Edmonton Community Services, BMO Lynnwood, McDonald's, London Drugs, West Edmonton Mall, Famoso, Home Depot, the Running Room, and Earls on Campus. The Hope Classic was supported by: The Ribbon Factory, Pure Water Connection, COBS Bread, Concordia University of Edmonton, Tim Hortons, the Steckly family, the Cusveller family, the Bateman family, the Turenne family, and the Running Room.

Special thanks go out to Brooklyn Marie Photography, for the stunning pictures of the event, and to DJ Kris Gallinger, for the donation of his DJ skills and upbeat music.



SBHANA

www.sbhana.org

Summer 2015 Barbecue

Using the brand new gazebo at Site #6 in Rundle Park was a highlight of the day, as it provided us with reprieve from what was a very sunny, hot, and beautiful summer day. Just under 200 race participants, volunteers, members, and friends attended the SBHANA's annual summer barbecue, and a great time was had by all. Over the course of the afternoon, attendees were treated to a delicious barbecue lunch, music by Kris



Gallinger, an inflatable bouncy castle, games like Giant Jenga, door prizes, face painting by Val Martens of Joyful Face, and even a visit from the NOW 102.3 Trucksicle! Thank you to everyone who took part in this summer get-together! If you haven't had a chance to view the event photos yet, you can see the entire album on our Facebook page.



Tyson Burgsma received the most pledges for an individual.

Team Nicole received the most pledges for a team.

Skate for Spina Bifida and Hydrocephalus



**S
B
H
A
N
A**



June 27, 2015 was a very hot and sunny day at the Castle Downs Skate Park in Edmonton, Alberta. More than 60 skaters of all ages, participated in the Skate for Spina Bifida and Hydrocephalus event. The event coordinator, Kely Coburn and committee members Chad, Andrew, Corey, Kiray, Jordyn, Taylor, and Vinnie, ensured the event was run flawlessly and the competitors thoroughly enjoyed themselves and were very well rewarded for their efforts. Competitors were able to win great prizes in different competitions and levels, and almost everyone received some merchandise during the long awaited product toss. The product toss was done at the end of the day. All of the competitors

stood in the middle of the bowl while the planning committee, volunteers and SBHANA staff had the joy of throwing skateboards, wheels, t-shirts, shoes and other fantastic prizes into the group below. With the registration fees and sales of the fun and very popular reverse tie-dyed t-shirts, the event was able to raise over \$1000 for SBHANA as well as continue to build awareness of spina bifida and hydrocephalus.



Lovely SBHANA volunteers, Ken, Chris and Sean also sold raffle tickets at the event. At the end of the event, 3 raffle ticket winners were drawn. You can find out who received all 3 prizes on page 18.



SBHANA

www.sbhana.org



We would like to thank the following sponsors: Riot, Rumor Skate and Snow, Swerve, Four Wheels, Olive, Hollow Point, Local 124, Ultimate Distribution, Platinum Distribution, Supra Distribution, WestJet, The Pole, Easy Rider, United Cycle, Black & Whyte Screenprinting, Etnies, Timebomb Trading, Pro-tech, Peeler Boards, Carbon Steel Building, Congdon's Aids to Daily Living Ltd., Photo Junkies, Globe, Blind, Almost, Vulcan Bolts, Edge Photography, Lush Body and Hair, Rob Trudeau Photography, Vagrant Skateboards, Castle Downs Coffee Krew, Rockstar, Toy Machine, Warco Skateboards, and last but not least, Bogue Brigade!





**S
B
H
A
N
A**

www.sbhana.org

Camp Freedom 2015 By Monica Sneath



The SBHANA hosted Camp Freedom on August 13-16th. This year we had 19 teens from all over Alberta and Saskatchewan come out and enjoy a fantastic four days at camp. We participated in many activities over the weekend; a cooking class, a painting class, swimming, canoeing, mini-golf, basketball, campfires, crafts, games, roller sledges, the Superhero challenge, and our social event of the weekend; the dance, with our awesome DJ Jay Cathcart and his lovely assistant Darlene Cathcart.

A huge thank you to our fabulous group of counselors, we couldn't do it without you: Ben Callihoo, Tabitha Colenutt, Mathieu Figeys, Elizabeth Hawkins, Meighan Jones, Kiray Jones-Mollerup, Candice LaBerge, Brandon Novak, Rajdeep Pandher, Alyson Rodger, Julian Rosario-Ng, Kris Slov-Rackette, Cindy Smith, and Betty Ann Thibodeau. Your enthusiasm and dedication makes camp a great place to be for everyone involved!

Thank you to Katy Agnew from Silver Stag photography for coming out and taking some great photographs of our day on Friday! She captured both the fun the campers were having and the beauty of the location.

Next summer Camp Freedom will be held on July 28-31, 2016. Applications forms will be available on line February 1st. Please contact our office if you wish to be added to our email list. Camp Freedom is open to



teens (12-18years) who have Spina Bifida, living in Western Canada. We promote personal independence, in a safe, social, teen focused atmosphere.



Fees for Camp Freedom have been kept very inexpensive, with an early registration cost of \$200. We also fund campers fully, if their family is unable to pay these costs. We have maintained these low fees, to keep it affordable for families, despite the fact that our rental and meal expenses have almost doubled since we started camp in 2000. We have a budget of \$16,000 (over \$700 per camper) and use all volunteers to plan and run Camp Freedom. We are currently looking for donations, sponsorships and fundraisers for Camp Freedom, to keep our camp operating. Please contact us if you are interested in supporting this valuable experience for our teens!



SBHANA

www.sbhana.org





SBHANA

www.sbhana.org

Thank You to our Supporters!

Telus Community Board Donation

Words can not express our appreciation for the generous donation from TELUS in support of Camp Freedom. We would like to thank TELUS for the donation of \$16,000 to cover the full cost of Camp Freedom 2015. This program would not be possible without the financial assistance of this very caring group. Thanks to Bonnie for coming to the office with the wonderful surprise of a donation cheque.



The Masonic Foundation of Alberta

On May 23, 2015 Monica Sneath and Darlene Cathcart had the privilege of doing a presentation on Camp Freedom to the board members of The Masonic Foundation of Alberta. At the end of the presentation we were excited to receive a generous donation of \$2000 which will ensure Camp Freedom can continue for the next summer.



Commercial Lodge No. 81

Thank you Commercial Lodge No. 81 for your kind donation of \$750. It is because of the support we have received that we are able to continue providing important programs to our youth living with spina bifida. Meeting others experiencing similar life challenges and sharing our support for each other is what keeps each of us strong.

Duncan Craig Laurel Awards

On September 16, 2015 Monica Sneath and Cindy Smith, our Camp Freedom Directors, attended the Laurel Awards luncheon at The Westin Edmonton. The Laurel Awards recognize the innovation & creativity of Not-For-Profit Organizations.





**S
B
H
A
N
A**

www.sbhana.org

Thank you to the Valley of Edmonton A & ASR

The Valley of Edmonton A & ASR has provided the SBHANA with a generous donation of **\$500** to fund general operations. Without funding from societies such as the Valley of Edmonton, we would not be able to run all our programs, which allow us to fulfill our mission of improving the quality of life for people affected by spina bifida and/or hydrocephalus. This donation is greatly appreciated and will be of great benefit to assist with SBHANA expenses.



Thank you to the Government of Canada Summer Jobs Grant



Government of Canada

The Canada Summer Jobs Grant is an extremely important grant for the SBHANA. This grant is specifically allocated to pay the salary of our summer student that is hired each year. The summer student takes on the role as the Event Coordinator for the Hope Classic Run/Walk/Wheel. It is a very busy position and is a tremendous help to our office staff. This year we are pleased to have received **\$4794**.

Thank you Edmonton Public Teachers Charity Trust Fund

It is because of the generosity of others that the SBHANA is able to continue our programs and support people effected by spina bifida and hydrocephalus. This year we are grateful for receiving a donation for **\$5000** from the Edmonton Public teachers Local #37 of the Alberta Teacher's Association.



Thank you Christopher & Dana Reeves Foundation



It is very exciting to have received a Quality of Life Grant from the Christopher and Dana Reeves Foundation. The grant for the amount of **\$800** is allocated to assist in covering expenses for the NoLimits Peer Support Program. This program was created for an by and adults living with spina bifida and/or hydrocephalus. Each month they get together to support each other and enjoy a social or educational event.

Thanks to the City of Edmonton

Each year the SBHANA applies for financial support through the City of Edmonton. We are pleased to announce that they have once again have shown us that they value or programs and services with the approval of the Community Investment Operating Grant Award for the amount of **\$17,000**. This financials assistance will go a long way in contributing to the success of the SBHANA and future programs.



Thank you Al Shamal Temple

Camp Freedom will continue providing our teens living with spina bifida with the opportunity for independence and social interactions because of the support received from Al Shamal Temple and other donors. We are grateful for the generous donation for **\$2500**. This will go a long way in making our program successful and enabling our camp directors to focus on facilitating the best experiences for our teens.



**S
B
H
A
N
A**

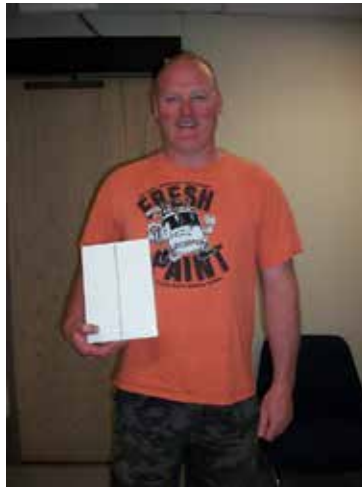
www.sbhana.org

Raffle

As part of June Spine Bifida and Hydrocephalus Awareness Month, a raffle was held to raise funds for SBHANA programs. We received wonderful donations from WestJet, Carbon Steel Buildings and Edge Photography. The raffle was drawn at the Skate for Spina Bifida and Hydrocephalus event on June 27, 2015 and raised over \$4000.



3rd Prize Gloria Adams
Portrait Package



2nd prize Mike Gray
I Pad Air 2



1st Prize R.V.J. Westgard
Flight Voucher for Two

Melting Pot Fundraiser

On Sunday, June 7th Camp Freedom directors, Monica Sneath, Cindy Smith and Kiray Jones-Mollerup hosted a fundraising dinner at the Melting Pot. The evening included a delicious four course fondue dinner with beverages and a presentation on Camp Freedom that was held in a small private room with 40 guests. The evening raised over \$3700 through dinner tickets, a silent auction, raffle ticket sales, fundraising games and sponsorships. Thanks to Tabitha Colenutt for sharing her personal story with the guests. Thanks to the generous donation from the Melting Pot of all the meals and the private dinning room this was a very successful event.



Volunteer Spotlight

Lisa Bennett has been apart of the SBHANA for as long as she can remember. Her mom became a member of the association after Lisa was born. Her first memories of being involved with SBHANA is participating in youth activities on the weekends. Lisa also went to Camp Freedom, which is a four day overnight camp for teens with spina bifida, located at Camp He Ho Ha on Lake Isle.

Growing up in a small town and being the only individual with spina bifida, has motivated Lisa to volunteer with the SBHANA. Lisa felt like an outsider when she was younger and that no one understood, especially her peers when she was a teenager. She also felt the transition from a teenager to a young adult was difficult. Lisa has taken her personal experiences and wants to try and help provide support for others making this transition. She has become the NoLimits Peer Support Group Coordinator. NoLimits is group of adults who have spina bifida and/ or hydrocephalus who meet once to twice a month for coffee nights and other social and educational evenings. Lisa coordinates each event with the assistance of the NoLimits administrative team. She shared with us that her favourite part of volunteering with SBHANA is the coffee nights. It is a great time to relax and catch up with adult members each month. There are a lot of laughs and she enjoys that there isn't a set structure.



Lisa has also volunteered with fundraising for NoLimits, KMS Smokie Sale, Christmas Party, June Awareness displays, selling raffle tickets, International Day of Disabled Persons, and is an active member of the Board of Directors.

When Lisa isn't busy volunteering for SBHANA, she likes to go to movies, shop, hang out with friends and go dancing.

Lisa shared that SBHANA has been like a second family for her. She has been able to make unique connections that she doesn't have outside of it. We are extremely fortunate to have Lisa as a member and avid volunteer for SBHANA! We appreciate all of your effort and hard work that you have put towards the association.



SBHANA

www.sbhana.org

Vitalize 2015 By Sean Bouffard

In July Kyra, Megan and I attended the Vitalize 2015 conference. I enjoyed this experience. I liked most of the talks that were given. If I have the opportunity to attend this conference in the future it is something I would strongly consider doing. I originally planned on going to the leadership talks but space had already filled up and so I had to choose other talks. There were other talks that I was interested in as well that I did not have time for. Fortunately there are PDF's for talks that I could not attend or missed (on the second day I did not realize that the bus schedules on Saturday was different than on weekdays so I missed the first talk of the day.)

The follow is information on three sessions I attended: Generations, Communicate to Captivate and Ignite Your Evolution.

Generations

This talk by Merge Gupta-Sunderji was about the differences between people of different generations and the kinds of things that motivate them. The four generations in this talk were: Traditionalists (Born before 1946), Baby Boomers (Born Between 1946 and the mid-1960's), Generation X (born between the mid-1960's and 1979) and finally Millennials (Born between 1980 and 1994). The first thing Merge Gupta-Sunderji spoke about was the word that could be used to best describe each group in a nutshell: Traditionalists are loyal, Baby Boomers are Optimistic, Gen Xer's are skeptical and pragmatic, Millennials are realistic.

Some Key Things From This Talk:

Careers

Traditionalists

What they want: to build and leave a legacy

Why they stay: loyalty to their employer and their customers and clients, an enjoyable schedule with reasonable hours

Why they leave: Physical reasons (health and mobility), Inconsistent enforcement of policies and procedures

Boomers

What they want: To have a stellar career

Why they stay: Because they feel that they are making a difference

Why They Leave: Stress and burnout, they don't feel that they can make a contribution

Gen X

What they want: To have a portable career (skills that they can take from one organization to the next)

Why they stay: Autonomy, a good schedule with time off as needed

Why they leave: Inability to get ahead without becoming managers, opportunities with other organizations, particularly those that help build their resumes

Millennials

What they want: To have a parallel career (doing different things in different aspects of their lives)

What makes them stay: Professional growth, personal satisfaction

What makes them leave: Job not meeting expectations, repetition or boring work, no challenges and opportunities for development

Work Style

Traditionalists are chain of command

Boomers are egalitarian (so chain of command, but flatten the organizational chart)

Gen X is independent and entrepreneurial

Millennials are collaborative (don't command)



**S
B
H
A
N
A**

www.sbhana.org



**S
B
H
A
N
A**

www.sbhana.org

Environment

Traditionalists want a stable, secure, respectful environment with clearly-defined goals and clear direction.

Boomers want opportunities for advancement, recognition. They are team-oriented, want a vision and mission that are clearly identified. They are non-hierarchical.

Gen X: Flexible, results-oriented, efficient, informal and fun, opportunities for development.

Millennials want a positive, collaborative, flexible, respectful and achievement oriented.

Messages to motivate

Traditionalists: Your experience is respected here, It's valuable to the rest of us to hear what has and has not worked in the past, your perseverance is valued and will be rewarded.

Boomers: You're important to our success, you're valued here, Your contribution is unique and important, We need you, I approve of you, you are worthy.

Gen X: Do it your way, we've got the newest hardware and software, There aren't a lot of rules here, we're not very "corporate"

Millennials: You'll be working with other bright, creative people, your boss is in their sixties, you and your coworkers can help turn this company around, you can be a hero here.

Communicate to Captivate

Presented by Lorraine Behnan

Here are some of the key points from this presentation on the best ways to communicate.

- Efficient organization of content and effective delivery of content are solutions to the challenges of the limited attention and retention abilities of people.
- Body language, voice quality and content/messages all work together for effective communication.
- Body language points: demonstrate confidence, connect with eyes, engage through animation (hand gestures)
- Vocal quality points: Tone establishes mood and intent, articulation gives clarity to speech, pace enhances understanding, pitch adds variety for better engagement. Proper breathing (diaphragm breathing) is important for vocal quality.
- For creating compelling content: determine relevant information, repeat key messages, use simple language, generate emotion, tell true personal stories.
- Assertive Behavior: speaks firmly and definitively, quick to compliment and acknowledge another point of view, makes comfortable engaging eye contact, uses open and receptive gestures, invites feedback.

Ignite Your Evolution

Presented by Lorraine Behnan

Here are some key points from this presentation on excelling through change.

- Act with agility: look for the middle ground between perfectionism and procrastination. (you will not be able to get stuff done if you don't.)
- Continually review processes
- Be an opportunity seeker (If opportunity doesn't knock, build a door)
- Investigate before judging
- Expand experiences, initiate, don't wait
- Practice tenacity and optimism

Thank You KMS Tools

Thanks to KMS Tools, who for the second year allowed us to be one of the charities they support through their customer appreciation smokie events. KMS customers were served delicious smokies and drinks by SBHANA and they in return donated to the SBHANA. Many raffle tickets were also sold in the store over the three days. Thanks to our dedicated volunteers: Doug McEwan, Sharon Veeneman, Ryan Cathcart, Lisa Bennett, Sean Bouffard, Brooke Bateman, Roxanne Ulanicki, Chris Minchau, Cam Befus and Emma Befus.



HYDROCEPHALUS VIRTUAL LAB IN DEVELOPMENT

Reprinted with permission from SBHAC Newsclips August 26, 2015

The U.S. based Hydrocephalus Association (HA) will partner with scientists worldwide through an innovative virtual lab with a focus on research aimed at finding a cure for hydrocephalus.

HA will attempt to raise \$500,000 at its Vision Dinner in October to support its HA Network for Discovery Science (HANDS) concept that will centralize the field of research. The HA will also provide access to grants to kick-start and test potential research leads. It is expected that the virtual lab will accelerate the development and implementation of cure-focused ideas by providing researchers with access to the tools, specimens and the expertise of scientists and clinicians around the globe.

HANDS will support and promote basic scientific efforts to understand the causes, consequences and complications of hydrocephalus as well as to identify mechanisms that lead to its prevention or cure. By sharing resources, researchers will be able to test their hypotheses at an accelerated pace.

SCIENTISTS TO BUILD NEW SHUNT PROTOTYPE FOR HYDROCEPHALUS

Reprinted with permission from SBHAC Newsclips August 5, 2015

BioNews: A joint team of researchers from the University of Texas at Arlington are working on assembling a prototype for an implantable in-line shunt flow monitoring system that can monitor hydrocephalus on an on-demand and continuous basis.

Researchers were awarded \$100,000 from the Texas Medical Research Collaborative. This product could prove especially beneficial to infants and children who comprise a significant portion of the number of shunt operations each year. There remains a relatively high rate of complications with shunt placement for years following the original surgery.

The new shunt prototype is expected to prevent these complications through its improved proactive monitoring of the flow of fluids and catheter malfunctions. It could also enable neurosurgeons to better trace the source of complications.

The new shunt system will also feature an ability to give a real-time diagnosis in a hospital, outpatient or home setting, and can potentially provide research platforms for other biomedical applications, such as in cardiovascular disease and designing artificial organs.

The hydrocephalus community will be watching the results of the project. Any opportunity to reduce the amount of failures of a shunt, and lengthen the life of the performance of the shunt is welcomed. A better shunt and less brain surgeries will give a much better outcome to those living with hydrocephalus.

TO CORRECT EFFECTS OF HYDROCEPHALUS

Reprinted with permission from SBHAC Newsclips August 5, 2015

A 3-year-old girl in China is recovering after receiving the world's first full skull reconstruction surgery utilizing 3D printing technology. The child's head had grown to 4 times its normal size due to hydrocephalus, which was diagnosed when she was 6 months old. The procedure involved a full 3D reconstruction and 3D printing of a titanium skull to reposition her brain.

Doctors first had to remove several litres of fluid from the brain and treat an infection by inserting a shunt. The pressure of the excess fluid on the brain made her head weigh more than half her body weight. Surgeons were able to use 3D data and a CT scanner to create models for 3D printing three titanium mesh skull implants that would replace the girl's entire top portion of her skull.

The 17 hour operation was successfully completed when the patient opened her eyes and was breathing before being transferred to ICU for recovery. As she grows, the titanium implants will become surrounded by her own bone. She is expected to make a full recovery.

Membership Benefits

The Spina Bifida and Hydrocephalus Association of Northern Alberta's mission is to improve the quality of life for people affected by spina bifida and hydrocephalus through advocacy, research, education and support. Membership renewal date is February 1. Becoming a member of the SBHANA provides you with the following benefits:

Support Fund—SBHANA offers a support fund of up to \$1000 each year for individuals with spina bifida and/or hydrocephalus. The support fund is designed to assist with the cost of specialized leisure and recreational equipment, medical equipment, services such as specialized lessons or camps, and emergency personal expenses.

NoLimits Peer Support Evenings—Monthly peer support evenings for individuals with spina bifida and/or hydrocephalus to come together to discuss special topics, guest speaker, or attend events for each meeting.

Toddler Wheelchair Lending Program—Toddler sized wheelchairs are available to lend out to families who are in the process of getting their child a wheelchair.

Scholarship—Two scholarships \$1000 are available each year for students with spina bifida and/or hydrocephalus who are pursuing post secondary education.

Camp Freedom—SBHANA organizes and holds a 4 day camp for teens aged 12-18 at Camp He Ho Ha. Some of the great activities that are included are swimming, crafts, basketball, dance, games, campfire, mini golf, canoes, and paddle boats!

Newsletters—Three times per year, the SBHANA writes a newsletter full of information about upcoming events, volunteer requests, member accomplishments, opportunities, stories, photos from social events, and other useful information.

Social Events—Each year, SBHANA invites all members to attend a summer BBQ and a Christmas party. Attending these social events is a great way to get support from others who have had similar experiences, meet new individuals with spina bifida and/or hydrocephalus, and have a fun time!

Educator's Manuals—An informative resource binder for your child's school is available for members for free.

Member Education Fund—A fund to provide members of the SBHANA with the opportunity to further their education and understanding of spina bifida and hydrocephalus through the attendance of national and international conferences.

Informative Resources—The SBHANA has a small resource library with books, binders, information sheets, videos, and brochures.

For information about current and upcoming events, as well as application forms for any of our services, please check our website at www.sbhana.org.



**S
B
H
A
N
A**

www.sbhana.org



SBHANA MEMBERSHIP FORM



S
B
H
A
N
A

www.sbhana.org

To join or renew your membership, please complete this form and mail to SBHANA with your payment. Our mailing address is: P.O. Box 35025 - 10818 Jasper Avenue Edmonton Alberta T5J 0B7

Membership Fee: \$10.00

Memberships are for a period of one year, from February 1st to January 31th.

As a member you will receive the SBHANA Newsletter and have access to resource and educational materials. Members in good standing with SBHANA will have access to the association's funding programs and scholarship program. You will also automatically become a member of the national association (SBHAC) and receive information about relevant opportunities.

Date: _____

_____ I am making a payment of \$10 to renew my membership or join the association

_____ I would like to pay \$10 per year for _____ years (i.e. 2 or more), for a total of: \$ _____

_____ I would like to join/ renew but am not able to pay the membership fee

_____ Enclosed is a general donation in the amount of \$ _____

Please Print:

Name (s) _____

Address _____

City _____ Province _____ Postal Code _____

Telephone _____ Cell _____

Email _____

Type of Membership (please check one)

_____ Parent of child with Spina Bifida and/or Hydrocephalus

Name of Child: _____ Gender: M F Date of Birth (m/d/y): _____

_____ Individual with Spina Bifida and/or Hydrocephalus Date of Birth (m/d/y): _____

_____ Support person (relative, friend)

_____ Professional Caregiver (medical, social worker, educator, etc.)

I can volunteer to help the association and other families:

_____ Board of Directors _____ Fundraising _____ Phoning

_____ Special Events _____ Newsletter

I would prefer not to be contacted by volunteer program coordinators regarding SBHANA programs

I would like to keep up-to-date on the latest SBHANA updates, programs, and social events by consenting to receive SBHANA e-communications.

I would prefer to receive my newsletter: ___ Electronic ___ Colour ___ B&W

I am willing to be a contact for: ___ New Parents ___ Adults with SB/H ___ Anyone

I am willing to speak with others about my surgeries (please specify): _____

This form can also be found on our website at: www.sbhana.org