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

Annual General Meeting
At the Annual General Meeting (AGM), we will be electing a board of directors for the 2016/2017 year and presenting the annual report. There will be some baked treats and hot beverages (tea and coffee) to eat and drink.

Date: Wednesday February 24, 2016
Time of AGM: 7:00-8:00 pm (1 hour)
Location: Conference Room B
Glenrose Rehabilitation Hospital
10230 111th Avenue  Edmonton, AB
RSVP: Email info@sbhana.org or call 780-451-6921 by February 17, 2016

SBHANA’s Annual Family Christmas Party was held on November 28th.
Story on pages 11 and 12.
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: Danielle Schmidt
Program Manager: Megan Gergatz
Newsletter Editors: Danielle Schmidt & 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:

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 presented based on their own circumstances and medical needs. No treatment should be started without first consulting your doctor.

President’s Message 3
Mark Your Calendar 4
Office Updates & Volunteer Opportunities 5-6
Medical News & Member Information 7-8
Updates & Opportunities 9-10
Christmas Party 11-12
Adult Cruise & Fundraisers 13-14
IDPD 15
Support Fund in Action 16
How to Get Your Driver’s License: Steps & Experiences 17-18
Easter Seals Services 19
Technology 20
Diving In 21
Donations & Grants 22-23
Membership Form 24
President's Message

With more than one of my children having complicated medical needs, my life can be... well, complicated. Nathan's skiing and Daniel's basketball practice have fallen on the same night and as much as I would like to, I cannot be in two places at once. Juggling our family schedule is especially tricky on nights when my husband is working. Getting a ride for Nathan or Daniel means asking someone else to not just transport them, but to also take some responsibility for their medical needs. I cannot tell you how much it meant to me when a dear friend said these words after I gave her a brief run-down of Daniel's insulin needs: "I'm not afraid." She was willing to step up and give it a try, and I was willing to let her.

Fear can be paralyzing. It's often tempting to avoid any risk and play it safe. I've learned that in order for my family to be actively involved in this craziness we call life, it means risking the mess, mistakes, and even some epic fails. There are many, many moments in my life where I think, "I'm not sure that I can do this." There are many mornings when I need to tell myself "I can face this day" because I would rather stay in bed, hiding under the covers. Somehow, by forcing myself to carry on even when life seems hard, by continuing to move, even through fears, I find myself surprised by what is accomplished and experienced.

The other night, we wanted to take our family to see the Ice Castle in Hawrelak Park. I was tempted to let Nathan stay home with Grandpa, since he wasn’t particularly interested in going out and would be quite happy to stay and play on his computer. I wasn’t sure how accessible the ice castle would be for him and bringing Nathan along would require more effort. But I really wanted to do this together as a family, so I rallied. We decided to gamble on there being SOME way of involving Nathan once we were there. We got there and discovered that although it was a challenge for Nathan to push himself around through the packed and bumpy snow, I could push him without too much difficulty. And Nathan absolutely LOVED it! He delighted in the lights dancing through the ice to the music. He marveled at the ice formations. He chatted with the staff, asking all sorts of questions. He imagined and enjoyed and experienced. I was so glad I didn’t choose the easier, more certain option for him.

There are times when I do choose the easiest, safest route. Sometimes I do hide in bed. However, I find that when I put one foot ahead of the other or keep pushing those wheels forward, I am surprised and even delighted by what transpires.

“Inaction breeds doubt and fear. Action breeds confidence and courage. If you want to conquer fear, do not sit and think about it. Go out and get busy.” - Dale Carnegie

“Are you feeling a bit shaken, maybe stirred, maybe fearful and doubtful and completely utterly, wildly terrified? Good. Keep going.” - Victoria Erickson

“Courage doesn’t always roar. Sometimes courage is the quiet voice at the end of the day saying, ‘I will try again tomorrow’” - Mary Anne Radmacher

Much Love,

Cindy
### Calendar

**February 24, 2016**  
**Wednesday**  
**AGM**  
Annual General Meeting  
Location: Conference Room B at Glenrose Rehabilitation Hospital  
Time: 7:00-8:00 pm  
*Baked goods and hot beverages provided*

**February 28, 2016**  
**Sunday**  
**“Comedy for a Cause” SBHANA Fundraiser**  
Location: Rick Bronson’s The Comic Strip @ WEM  
Time: Doors open 6pm, Show starts 7pm  
Silent Auction & 50/50; Comedian Sarah Tiana

**June 9, 10 & 11, 2016**  
**Thursday-Saturday**  
**Spina Bifida & Hydrocephalus Awareness Month**  
**Skokie Sale**  
KMS Tools NEW LOCATION: 10406 184 Street

**June 25th OR 26th, 2016**  
**Saturday OR Sunday**  
**Skate for Spina Bifida & Hydrocephalus**  
Location: Castle Downs Skatepark  
More information to come

**July 28-31, 2016**  
**Thursday-Sunday**  
**Camp Freedom 2016**  
Camp for teens with spina bifida (age 12-18 years)  
Location: Lake Isle (1 hour west of Edmonton)  
Registration packages will be emailed in February

**August 13, 2016**  
**Saturday**  
**Hope Classic 2016 & Summer BBQ**  
Location: Rundle Park (113 Ave. and 29 Street)  
Time: Registration 9:00 am; Run/Walk/Wheel: 10:30 am  
Summer BBQ: 11:30 am—2:30 pm

**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
Office Update

NEW STAFF: Danielle Schmidt—Program Manager

I have now spent a few months learning the ropes of the Program Manager position working for the Spina Bifida and Hydrocephalus Association of Northern Alberta (SBHANA). Darlene provided me with two weeks of training, after which she officially resigned from her administrative position with the SBHANA where she spent five years. I’m sure that the members will miss Darlene’s cheerful presence and all of the hard work that she did for this organization! Megan and I are now sharing the role of Program Manager and I think that we are making a pretty great team. I look forward to meeting and getting to know more and more of you as the year progresses.

I thought that I would take the time to tell you all a little bit about myself, so here it goes… A few of the things that I value with great importance in my life are family, education, volunteering and staying active.

I went home to spend some quality time with my family in BC over the holidays and I ended up having a lovely visit. Most of my time was spent with my Mom, my sister and my two nephews, Nicholas and Thomas, who I just adore. Nicholas, who turned two back in November, got to go skating for his first time, and it was such a cute experience watching him figure out how to properly coordinate his feet to move on the ice. A few falls were had and some tears were shed but he definitely had a big proud smile on his face when he moved around (on his own) on the ice. “Love you Auntie” were the words my nephew said to me as I got ready to return to Edmonton. I definitely have a lot to be thankful for in my life and my family is one thing that brings me a lot of joy and happiness.

I finished my Bachelor of Science Degree from MacEwan University where I majored in biological sciences. While working on my degree, I had the opportunity to do an independent research class working with frozen tick embryos… I know… sounds gross, but it was so much fun!! One thing that will stay with me forever from my research experience is that making mistakes is not a bad thing; making mistakes can actually be one of the best ways to learn something new that you did not fully understand before.

While I was going to school I volunteered for several different organizations, and it was also how I received my introduction into the disability world. Volunteering with my family was something that we always did together when I was growing up, and every experience that I have gained has been so rewarding for me.

I would say that staying active is an important part of my life, but I do enjoy just relaxing and reading a good book or watching a movie. Hockey is my first love and it has been such a wonderful experience challenging myself to learn how to play sledge hockey these past two years. I spend my Tuesday nights coaching a Junior Sledge Hockey team for the Paralympic Sports Association, and it has been such a pleasure being able to mentor the young children that have played on my team these past three years.

I really love seeing all of the colours of Fall, and it means that my birthday is just around the corner, but Winter is probably my favourite season. Snow on the ground means that snowmen can be built, winter adventures on skates, skis or running shoes can be had, and maybe a snow ball fight or two gets waged… pure bliss!
Megan Gergatz-McMorran– Program Manager

I hope everyone enjoyed the holiday season and had a very happy new year! The last few months have been filled with a lot of change: new name, position and a new office mate. Change brings a lot of new things with it and new can be a positive thing.

One exciting new opportunity that has come together for our adult members is an Alaskan cruise. I absolutely love traveling myself so I’m excited to hear about their experience in the great white north. My favourite thing about going on a trip is experiencing something new every day. There are so many different cultures and landscapes across this beautiful planet, that I find it difficult to not want to discover every single one. After going to Europe and South East Asia I found it fed my curiosity and built my confidence to be able to travel more in the future. I gained the ability to strike up a conversation with strangers, and became very comfortable navigating the unknown streets and transportation systems. I feel that the group that goes on the upcoming Alaskan adventure will gain so much more then the opportunity to see gorgeous ocean and mountain views, but also come back with everlasting memories and in some way grow from the experience.

Volunteer Opportunities for 2016

We have various events throughout the year and wouldn’t be able to do it without our countless volunteers. We are more than appreciative that we have such a great group of volunteers who give their time and efforts to ensure we are able to run our events, services and programs so smoothly.

KMS Smokie Sale

Through out the year KMS Tools distributes smokies to its customers. Each week a lucky charity receives the donations from the smokies. This year we will require volunteers on June 9, 10 and 11 to assist with the barbecuing, serving, donation collection and selling of raffle tickets. The proceeds will got towards SBHANA.

Hope Classic 2016

On Saturday, August 6 we will be hosting our annual Hope Classic Run/Walk/ Wheel event. The Hope Classic is a very large fundraiser for SBHANA and there are many volunteer opportunities such as: race course marshals, information table, registration, race bag stuffing and distribution, barbecue, photography, games for children, set-up, take down, and pledge collection. It is a very fun event to volunteer at and we enjoy coordinating it every year! We will be sending out emails regarding these volunteer opportunities and will keep you posted!
CALL FOR BRITS TO FORTIFY FOOD GROWS LOUDER
(Reprinted with permission from SBHAC Newsclips Dec. 8, 2015)

Studies in Britain are showing that, despite proving that folic acid supplements reduce neural tube defects, less than one in three women take them prior to pregnancy. The result is that the rate of neural tube defects has not fallen in the UK, but the rate of abortion due to neural tube defects has risen in England and Wales.

The British Medical Journal (BMJ) reported that researchers announced that voluntary measures are failing and issued a call that mandatory fortification of food with folic acid be considered. While 80 countries, including Canada and the US, have had fortification policies for 20 years, Europe has failed to implement an effective policy for prevention of neural tube defects by folic acid. Each year, about 5,000 pregnancies in Europe are effected by neural tube defects.

Although termination of pregnancy for fetal anomalies has reduced the live birth prevalence of these anomalies, it is not an optimal solution for a birth defect that is highly preventable with readily available and low-cost folic acid supplementation or food fortification.

“Food fortification will reach women most at risk due to poor dietary habits or socio-economic status as well as those women who may not have planned their pregnancy,” said Prof. Alan Cameron of the Royal College of Obstetricians and Gynecologists. Opponents to the plan point out that high doses of folic acid may make it difficult to spot vitamin B12 deficiencies, which can lead to anemia and even brain damage. Some link higher levels of folic acid and cancer, although the evidence is mixed. However, no harmful effects have been observed since folic acid fortification was enforced in the US in 1998.

A UK Department of Health spokeswoman said it was considering the new evidence and would make a decision on folic acid imminently.

SECOND TRIMESTER SCREENING STILL NECESSARY
(Reprinted with permission from SBHAC Newsclips Oct. 7, 2015)

A report from researchers at the Baylor College of Medicine, located in the Texas Medical Center in Houston, indicates that pregnant women may not be receiving screening for spina bifida in the second trimester of their pregnancies.

The study showed that nine out of twelve cases of prenatally-missed spina bifida were not screened by a blood test that identifies levels of a chemical called maternal serum alpha-fetoprotein. A high level of alpha-fetoprotein is indicative of a neural tube defect. The study showed that patients were forgoing blood tests in the second trimester quad screen. Blood screenings done earlier would not identify maternal serum alpha-fetoprotein because it is too early to draw protein levels during the first trimester screening. Ultrasounds may not always detect neural tube defects, so the alpha-fetoprotein levels provide an added layer of detection. Drawing blood for the screening test also allows physicians to determine whether the problem can be repaired while the baby is still in the uterus.
NEW SB TREATMENT USING 3D PRINTING IN UTERO RECEIVES €50K GRANT
(Reprinted with permission from SBHAC Newsclips Nov. 18, 2015)

Researchers from Leiden University in the Netherlands received a €50K grant to further develop their 3D printing techniques to correct gaps in the backs of fetuses affected by spina bifida. This procedure is less invasive and can be done earlier in the pregnancy, and the patch will stretch as the baby grows to provide a watertight seal. The procedure is not seen as a cure, but rather as a less risky method for the mother and reduces further damage to the baby’s spinal cord and nervous system.

Membership Renewal

It is that time of year! A friendly reminder that it is time to renew your SBHANA membership. The memberships are for a period of one year, from February 1st to January 31st. The membership form can be found on the last page of the newsletter. The membership fee continues to be $10.00 per member.

As a member you will receive the SBHANA Newsletter and have access to resources 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.

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

Volunteers NEEDED: SBHANA Casino 2016

The SBHANA Casino will be held in the third quarter of this year. We haven’t received our information package with the exact date yet, but it will be in July, August or September. This means that we will be looking for volunteers in the upcoming months. You need to be at least 18 years old with a picture ID to volunteer at a casino. Invite a friend or relative to help out and you will end up having some time to visit with one another, and everyone who volunteers gets a complimentary meal at the casino for volunteering their time. Please look out for updates on when the exact date for our casino will be. Thanks.

To put things into perspective, a casino brings in roughly $80,000 for organizations who work them, so if you crunch the numbers it means for each volunteer shift that is required to be worked you are helping raise close to $2,000 for our organization. This sounds pretty good, doesn’t it? I hope many of you will be able to help out.
Updates & Opportunities

Gateway Association: Still Room & Time to Register!

Visioning for Families with Young Children (Ages 0-14)

How do I dream for the future again when my world has been shaken by my child’s diagnosis of disability?
In this workshop we will explore many possibilities for the future including post-secondary, employment, and independent living in adulthood. We will discuss how having a vision is necessary to guide the choices we make every day to help to build toward a future that has meaning. When: Wednesday, Feb. 10th, 6 to 9 p.m.

Navigating the Systems for Young Families (Ages 0-11)

When our child is diagnosed with a disability we are suddenly required to access a variety of services we may not have even heard of before. We are put in the position of making difficult choices that most parents never face. In this workshop, we will discuss: navigating the school system; medical system; and financial supports from Disability Services (formerly FSCD). We’ll focus on how to approach difficult conversations to get what your child needs while maintaining those necessary relationships. When: Saturday, March 19, 9 a.m. to noon.

Transition Planning for Adulthood “Planning Positive Futures” (Just Opened for Registration)

Is your teen with a disability preparing to transition to adulthood?
Learn how to assist your teen to experience a fulfilled and authentic life – a life where he or she is respected, and can contribute meaningfully to community. Join us for a four-part series of workshops where we explore a variety of topics designed to help remove the uncertainties you may be feeling, including: Engaging your teen in creating a vision statement to help drive future planning and decision making. What is a meaningful day? Striving toward an active, engaged, and purposeful adult life for your teen? Explore inclusive post-secondary, employment, building relationships, rights, and valued roles. Determining how staff fit into achieving your vision, tips for finding and retaining good staff, empowering job descriptions/ads, and executing goals. What systems and services are available? An introduction to PDD, AISH and other supports.
When: Wednesdays, March 23, April 6, April 20, May 4 Sessions are designed as a progressive, connected series and are not independent workshops. Registration is for the series in entirety. Time: 6 to 9 p.m.

To register, visit www.eventbrite.ca. Search “Gateway Association.” Families only please. All of our workshops are free and take place at Gateway Association’s office, in our Learning Centre. Questions? Call 780.454.0701 ext. 125

Cerebral Palsy Association in Alberta (CPAA)

Computability Program

The computability program offered by the Cerebral Palsy Association in Alberta allows participants to learn basic skills in computer usage. Basic skills in computers can be applicable to today’s everyday life settings and awards participants with improved confidence in technology. Each level will consist of a 4-6 week session. Age Group: Adults
Times: Each person will have a permanent scheduled day and 1 hour time slot each week.

To register for this program please contact Kim Henye at 1-888-477-8030 or kim@cpalberta.com. Also, you can go to their website for information on other programs: http://www.cpalberta.com/programs-services/programs/
SBHAC Looking for Committee Members

At the most recent SBHAC board meeting, President, Susana Scott shared her vision in moving SBHAC forward in achieving its ongoing mission to assist those living with spina bifida and/or hydrocephalus and their families. She stressed that success is only reached when everyone works together. We know that there are members of regional associations with an interest and/or skill that would assist SBHAC to improve and expand on the services and programs that are offered to individuals and their families.

You are invited to become a part of the committees that provide direction and support to SBHAC’s programs and services.

The list of committees is as follows:

Education
Fund Development
Research
Policy and Governance
Communication & Awareness
Human Resources
Finance and Audit
Nominating
Advocacy

If you are interested in joining a committee, then please contact:
Bonnie Hidlebaugh
Spina Bifida & Hydrocephalus Association of Canada
National Manager, Communication & Development Coordinator
bonnie.hidlebaugh@sbhac.ca
Tel. 204 925-3650
Toll Free. 800-565-9488

Parks Canada to waive entrance fees in 2017 to celebrate Canada’s 150th

Here is some really exciting news!!

Are you an outdoorsy person who likes to go exploring Canada’s National Parks in the spring/summer/fall/winter? Well then this is right up your alley. The Liberal Government has decided to make park access free for the entire year of 2017. Help celebrate Canada’s 150th birthday by purchasing a park pass that will be good until 2018, or you can go to the parks as much as you like in 2017 without cost. "Make admission for all visitors to National Parks free in 2017, the 150th anniversary of Confederation," reads the letter. "Beginning in 2018, ensure that admission for children under 18 is free, and provide any adult who has become a Canadian citizen in the previous 12 months one year’s free admission."
SBHANA’s Annual Family Christmas Party

On November 28, 2015 the annual SBHANA Christmas Party was held at the newly renovated Kensington Community League Hall. 150 SBHANA members and their families attended the holiday event. The children had an opportunity to visit with Santa and receive a gift. We were very grateful that Santa was able to make a special appearance once again. Photos of Santa, children, dinner and dance were done by the talented Ryan Cathcart. For the first year, temporary tattoo artists from Giggles N Glitter dressed up as elves and joined us to put glitter tattoos on our members and their families. Various art and craft activities were enjoyed by everyone. Grace Fisher, Sadie Ramage, and Maddie Appleton were extremely helpful in the craft room and as Santa’s helpers. Two lucky winners took home jars of candy for correctly guessing the number of candies in the jar. A silent auction of 7 items ranging from ski day passes, to tickets, to plays were put up for auction. Three lucky recipients also took home door prizes which included a $25 Gift Card to Scholar’s Choice, Whirley Pop Stove Top Popcorn Popper, and a gift basket with a blanket, hot chocolate and Cineplex Gift card. The evening capped off with dancing and music done by returning crowd favorite, Jay Cathcart.

A very special thank you to Cindy Smith for coordinating such a great event. A big thank you to Cindy, Janine Fisher, Jackie Gibb, Shanna Ramage, and Amy Appleton for the delicious meal. The brownies were especially a hit with the candy cane ice cream.

We would also like to thank Natalie Buchsdruecker, Chris Minchau, Chris McMorran, Lisa Bennett, Curt Coupal, Ben Calihoo, Meighan Jones, Alexandria Karatairis, Dale Abrahams, Brandon Cathcart and Heidi Johnson for helping out at the Christmas Party.

Alyson Rodger made beautiful bracelets and necklaces that were sold to benefit the upcoming 2016 Adult Cruise. Please see page 13 for more information on purchasing the jewelry.

Thank you to the following places who donated to the silent auction and door prizes:

- Festival Place
- Citadel Theatre
- Rabbit Hill Snow Resort
- Snow Valley Edmonton
- Edmonton Symphony Orchestra
- Rick Bronson’s The Comic Strip
- Scholar’s Choice West
- Dandy Salon and Spa
Adult Cruise Fundraisers

Purchase your Tickets: SBHANA “Comedy for a Cause” Fundraiser

When: Sunday, February 28th. Doors open at 6pm. Show starts at 7pm.

Where: Rick Bronson’s The Comic Strip in West Edmonton Mall

What: There will be a silent auction and 50/50 tickets sold before the show. Headliner for the evening is comedian Sarah Tiana from Los Angeles. Sarah’s credit include Reno 911, The Burn, We Love you Mrs. Bevins, The Soup, Chelsea Lately, Comedy Central, Just for Laughs Festival, and the Late Late Show with Crag Ferguson.

Cost: $20 per ticket

SBHANA Jewelry Fundraiser

Alyson Rodger has made beautiful bracelets and necklaces that are being sold and the benefits are going towards the Adult Cruise. They are $15.00 for a bracelet and $10 for a necklace. Please contact the office at 780-451-6921 or megan@sbhana.org if you are interested in making a purchase.
Winds of Change

I have had the pleasure of being a part of Camp Freedom for the past 16 years. From inception and co-directing with Darlene Cathcart for many years, to working with Cindy Smith and Kiray Jones-Mollerup these past two summers, it has been a huge part of my life. Planning camp each year starts in January and wraps up in August. My children have grown up stuffing welcome bags and coming out to camp as nursing babies, my sisters have helped out at camp several times and my husband has supported me the whole time in various tasks that I’ve asked of him. I have witnessed the generosity of our community in their donations of time and money towards Camp Freedom. It has brought much joy to my life!

This summer I will be passing on this role to Cindy Smith. Cindy has joined us at camp for the last two summers as a co-director and has so many great ideas and enthusiasm to share with our teens! She will do an amazing job taking over Camp Freedom and continuing to provide a fantastic summer camp experience for our teens with spina bifida. I absolutely adore the teens and counselors that I have met over the years through camp! It has been a privilege to watch them grow up, some of them even returning to mentor our younger teens at camp. It is mixed with sadness too, as a few campers have left us way too early and will always be in our memories. I feel that with my oldest daughter Kailyn, now moving into adulthood that my interests need to move along with her as well.

The fastest growing area of our membership within the SBHANA is our adult population. I really think that this is what I need to focus my future attention on. Summer camp is a great opportunity when you are a teen, but the next natural transition into adulthood is being able to take a holiday.

A couple of the barriers our members face in regards to travel are: needing assistance – this can range from full care, to just needing help to carry a suitcase or a transfer into bed at night. The second one is not having someone to travel with or being nervous to travel independently. These two together can severely limit how you can travel on your own.

One of our Camp Freedom nurses, Meighan Jones and I, want to organize a trip for our adult members that will hopefully overcome these barriers. Our trip is for people who want to join a group of like-minded individuals and share an adventure. It is for people who may need a little bit of extra help to be able to travel. It is for people who want the security of travelling with a group.

On August 20th, 20 of us from BC, AB and SK will be cruising aboard Holland America to Alaska for a week! We are actively fundraising as a group to try to bring costs down for our travellers and are looking forward to our new adventure!

My dream for the future is to be able to offer a local retreat and an escorted group trip, in alternating years, to our adults living with spina bifida. Creating memories together creates social bonds; those friendships are what gets us through the tough times and are there to share the joys of life together.

“We travel not to escape life, but for life not to escape us.” – Anonymous

All my best, Monica Sneath
Megan and I both had the opportunity to attend IDPD on December 3rd at the Ramada Edmonton Hotel and Conference Centre. We set up our display and chatted with people from the community about the services we offer as they walked by our table and asked questions.

International Day of Persons with Disabilities is on December 3rd each year, and this day aims to promote an understanding of disability issues and mobilize support for the dignity, rights and well-being of persons with disabilities. The emcee for the day was Quinn Ohler from Global TV and she did a great job. I thought that the Pecha Kucha Ability presentations were very well done this year with lots of humor, great pictures and some interesting topics. For those of you who are unfamiliar with Pecha Kucha, it is a presentation style where the presenter prepares 20 images and they get 20 seconds on each image to talk on their topic. It was very heartwarming to see Joey Moss accept the Marlin Styner Achievement Award. They have decided to do Pecha Kucha again next year, so mark your calendars for December 3, 2016 if you are interested in attending this event.
SBHANA’s Support Fund in Action

Nicole Stefaniszyn: New Scooter

Back in October, Nicole applied for the Support fund to help her pay for a new scooter. A few weeks later, after getting approval for funding from the Board, Nicole received the new scooter and she was really excited to take it out for a spin.

Nicole selected a Pride Go-Go LX 4 wheel scooter in red with a cell phone holder, a lap belt, a rear view mirror and a safety flag. After Nicole received the scooter, she shared a picture with us at the office and expressed her appreciation to SBHANA for helping her get the new scooter.

Nicole told me that she “loves it very much!”

Tyson Rietveld: Hand controls and spinner knob

Thank you so much for helping pay for the hand controls and spinner knob in Tyson’s vehicle. It has given Tyson the opportunity to practice driving with us since he’s had his learners license. He’s really looking forward to getting his license this summer and being able to drive himself to school and sledge hockey as well of course to visit his friends. As everyone knows a child with special needs always comes with added cost to adapt things for them. Your support is always greatly appreciated. Thanks again from Tyson and our family.

Sincerely,
Jason & Kristine,
Tyson, Troy, Janaye Rietveld
Steps on How to Get Your Driver’s License

Interested in getting your learners and/or drivers license in the future? Here is the step by step process taken by Morgan Cathcart that will assist you in knowing the process!

1) First your learners can be written at any Alberta registry office. The cost to write the test approximately $31.45. Once Morgan had passed her test she spoke with an agent who called Alberta Transportation (ABT) and informed her she needed to have a medical form completed by her doctor.

2) Leo De Lion was contacted at Spina Bifida Clinic and Morgan’s name was put on the wait list for an assessment at the Glenrose Rehabilitation Hospital.

3) Once the medical form was completed by Morgan’s doctor it was taken to the registry office and they send it off to ABT. You then wait for a letter to come in the mail. Once the letter came, it stated that Morgan’s license is restricted to Code B condition which states “valid for Glenrose Driver Evaluation and Training Only”.

4) Morgan did her first assessment at the Glenrose Occupational Therapy Department, done at a cost of $250 and the assessment was sent to ABT. The Glenrose staff requested a more thorough eye exam from an optometrist.

5) Morgan received a letter from ABT that advised her to not to drive until the following conditions are met: undergo 18 hours of in-class driver education course (Morgan does this at AMA at a reduce fee of $189 because in car lessons are not done with AMA), 10 hours of driving lessons at the Glenrose and a vision referral report.

6) Copies of the vision report (stating she does not need glasses for driving) and the AMA course completion letter were sent to ABT and Glenrose.

7) Morgan took 12 one hour on road lessons from Darko at the Glenrose at a cost of $75/lesson.

8) During the fall of 2014, Morgan was still not ready to drive with her parents and as winter was approaching Darko suggested simulation driving to be taken at the Glenrose.

9) Simulation driving is excellent! Morgan attended once every two weeks for the winter and then once a week for a couple months in the spring. An OT worked with her for 1.5 hours at a time. The simulation driving built Morgan’s driving skills and confidence. These lessons are free!

10) During the spring of 2015, Morgan took 4 one hour on road lessons at a cost of $75/lesson and improvements in her driving ability were seen. Darko sent a letter to ABT stating that Morgan was ready to drive with her parents.

11) ABT sent a letter in the spring of 2015, stating that Morgan can get her new licence with the following Codes: A (glasses) B (right spinner knob) L (hand controls). The new license was $22.75 and purchased at the registry.

12) Morgan practiced all summer and took her final on road test through the AB registry office in her own vehicle with hand controls. She passed the test! Morgan received her temporary licence at the office and then the final one in the mail. The cost is approximately $130 for the road test and new license.

13) Morgan’s new licence comes with the spinner knob and hand control restrictions, but also with a requirement for eye glasses to be worn (this was supposed to be removed). Morgan went back to the registry office and they needed to do a third eye exam at their office (ABT will not accept the more thorough optometrist exam). Morgan waited while results are faxed to ABT and the glasses restriction is removed. Morgan was not charged for the change as it was their mistake.

14) Morgan’s final license came in the mail with all the correct information!
Learning to drive is a rite of passage for most people. You get your Learners in your mid-teens, and by the time you’re 16, you could have your license and pull into your high school parking lot with your first car (much to the envy of your peers!).

Driving can open a lot of doors to independence, and who doesn’t like jumping into their vehicle and going wherever they want, whenever they want, instead of waiting on DATS, City Transit, or begging for a ride from someone else?

I learned to drive a little later than many of my same age peers, in part because we didn’t know where to find the resources needed, such as vehicle adaptations and insurance concerns. Plus, being the youngest of four children, I pretty much had to wait my turn for the bank of “Mom and Dad” to help pay for my first vehicle!

My process to getting a Drivers License was a bit complicated, but well worth it. The first step, was getting my Learners, which is basically an academic step; study the book on driving, write and pass the test – which fortunately I did on the first try! After passing my Learners, I also took a general defensive driving classroom course (which I was told could lower my “new driver” insurance rates!).

After passing my Learners, we looked into driver training. Most mainstream driving schools didn’t have cars equipped with hand controls, so I went through the Driver Training Program offered through the Glenrose Rehabilitation Hospital. I needed a Doctor’s letter to confirm I had no other impairments to driving (seizures, vision, or insufficient physical ability in my arms/upper torso). I think I took one driving lesson per week, for about eight weeks. Upon completing my lessons, I took my Drivers License test (I didn’t have my own equipped vehicle, so I took my test in the same vehicle I had my lessons).

An advantage of going through assessment at the Glenrose, is they are aware of some of the cognitive challenges some of us with Spina Bifida/Hydrocephalus face. Many of us have, to varying degrees, issues like Non-Verbal Learning Disabilities and deficits in Executive Functioning. These are vital considerations if you are interested in driving, as they impact your ability to concentrate, memory, planning, organizing, and quick decision making. There is a cost to the assessment, but remember, driving is a Privilege and not a Right!

Some of the major considerations people fail to plan for are the expenses related to driving; believe it or not, acquiring simple adaptations like hand controls, spinner knobs, and booster seats are fairly easy to acquire. New vehicle dealerships will often have programs available to cover vehicle adaptations, and under SBHANA’s Support Fund, equipment requests of up to $1000 are also considered. Other important new drivers need to plan for are things like fluctuation gas prices (eg: a fill up of 50 Litres at say $1.10/L is $55; fill up at least twice a month = $110.00/month), regular maintenance, oil changes, WINTER TIRES, and insurance costs. Without a steady income, driving, from a financial perspective, is out of reach for many.
Easter Seals Services

#1. Disability Travel Card
(Information taken from the Easter Seals Alberta website www.easterseals.ab.ca)

One of our members, Dale Abraham, brought to my attention what I thought was an interesting service offered by Easter Seals. It is called a Disability Travel Card. This card provides FREE travel for support persons accompanying someone with a disability via Rail, Greyhound Bus, or Red Arrow. The person with the disability will pay full price for their ticket but their support person will travel for free. I had a phone conversation with Theresa De Waal from Easter Seals AB about the travel card and we also talked about flights. West Jet doesn’t require the travel card, but they offer a discounted price for the attendant on flights within Canada. I suggest that you contact West Jet for further details on this service.

Terms and Conditions:

1. The person with a **permanent disability** and the **adult attendant** must **travel together the entire trip**.

2. The adult attendant must be **capable of assisting** the person with a permanent disability.

3. The person with a disability **fills out and application** supplied by Easter Seals Alberta.

4. The **form is signed** by a **health care professional** verifying the need for a travel attendant. (See Section B: Health Care Provider information on the application).
   * Applicants must be a client/patient of the authorizing health care provider.

A person with a permanent disability may apply for the card to help cover the cost of a travel attendant that is required. Services that the attendant would do include assisting the person with eating, medication and washroom needs.

**Link to Application Form:**
http://www.easterseals.ab.ca/Files/Travel%20Card%20Application-AB.pdf

#2. ACCESS 2 Entertainment Card
(Information taken from the Easter Seals Canada website http://easterseals.ca/english/)

You may have already heard about this card that Easter Seals offers, but for those of you who haven’t… The Access 2 Entertainment card allows a person with a permanent disability to utilize and participate in recreational activities with their personal attendant, without having to pay admission for both. The attendant or support person’s entrance fee or ticket price is free (or a significant discount) and the person with the disability just pays for their own admission. Some of the places that you can access around Edmonton include movie theatres and City of Edmonton attractions (Cineplex, Landmark Cinemas, Art Gallery of AB, Edmonton Valley Zoo, Fort Edmonton Park, John Janzen Nature Centre, Muttart Conservatory, TELUS World of Science, and the Ukrainian Cultural Heritage Village). Please note that there is a cost for the card and you have two options: a $20 (3 year expiry date) or a $30 (5 year expiry date) fee.

**Link to Application Form:**
http://www.access2card.ca/application/
Technology

We Belong App
(information was gained from webelong.ca website)

The We Belong App was launched in February 2015. The App was launched by the Edmonton based Gateway Association to promote inclusive employment initiatives.

The way the App works is consumers are able to nominate businesses that hire inclusively and look up other inclusive businesses that they may want to purchase goods and services from. The user is able to answer a few simple questions on the App to put the nomination forward. In order for the business to be considered inclusive they must have a direct employment contract with the employee, provide a workspace where the employee works alongside the other employees, the employee is at least paid minimum wage, and provide an environment where the employee is able to engage in the culture.

To find a suitable business that will fulfill their needs, the App user is able to search by name, location, and category (restaurant, pets, services, etc.). There is now also a Version 2.0 with added functionality which includes a search-by-city option. The app can be downloaded for free on an android or iPhone.

NEW APP PROMISES IMPROVED SELF-MANAGEMENT SKILLS
(Reprinted from SBHAC Newsclips Oct. 28, 2015)

A new smartphone app “iMHere” (interactive Mobile Health & Rehabilitation), developed by the University of Pittsburgh Medical Center, could provide assistance to adolescents and young adults with spina bifida and improve their daily self-management skills.

The app was part of a pilot study with patients aged 18 to 40 who have myelomeningocele. It features reminders and messaging with healthcare providers, combining a suite of smartphone modules and a web-based portal for healthcare providers, linked by a two-way communication system. The modules were tailored to include information on medications, reminders to perform important daily self-care activities, and monitoring mood and depression symptoms.

After one year, the patients in the trial met or exceeded expected levels of use of the iMHere system and users were more likely to communicate new information or symptoms to a wellness coordinator by secure message, survey or photograph, the study showed. The higher use of reminders did not decrease the rate of events requiring medical attention, but those using the app gained new independence in certain spina bifida self-management skills.

The system holds promise for use in many diverse chronic care models to support and increase self-management skills.
Diving In

My name is Morgan and I am 17 years old. I have been a competitive swimmer for 7 years. I swam on an able-bodied team for 5 years but I have been swimming with the Steadward Bears Para Swim Team for the last 2 years. This swim program is for people with physical and/or sensory impairments.

On December 8th, I travelled to Bismarck, North Dakota along with my swim coach Nathan Kindrachuk, my parents, and 5 of my teammates to compete in the 5 day, Can Am Open Para-swimming competition. This was my first ever national level competition and one of my biggest swimming goals, since I had started competitive swimming. The day that we got there, there were so many people with various disabilities from all over the world in the airport, and staying in our hotel. We grabbed our luggage and set out to the hotel, then later to the pool. Because this was my first national competition, I had to get nationally classified. This I got done the next day. This process included a physical out of water physical/medical examination as well as an in water assessment. After my classification was complete I spent some time with the Swimming Canada Para-swimming Development coach, Janet Dunn and Nathan. Janet had me working in the water and gave me tips on how to improve my swimming technique and even gave me a new diving technique which allows a coach to support me on the block to improve my balance. Keeping Janet’s critiques in mind, I competed for the next 3 days, swimming one event each day. There was such a positive and encouraging vibe being on the pool deck, and although it was a little intimidating at first, the nerves faded quickly. I competed in the 400 metre freestyle, the 100 metre breaststroke (which I was required to swim as part of my classification process), and the 50 metre freestyle. I shaved off 27 seconds in both the 400 free and 100 breast! The entire time I was in Bismarck, both on and off the pool deck, I met so many extraordinary athletes and coaches. I found at this meet, that there was a huge social aspect about it. Everyone constantly wanted to get to know everyone else. What was different for me from regular swim meets was that people wouldn’t ask many questions about my disability, to them it didn’t matter much, we were all here for one reason, to swim. I got to see how other athletes adapt their techniques and the strategies they used in order to compete in a way that works for them. I loved exchanging stories with other athletes from all over Canada and the United States who understood the struggles of being an athlete with a disability. This allowed me to open up and see that I was not the only one who has had to go through the stress of being a student, a medically complicated teen, and an athlete who trains 4 days a week. I am so incredibly fortunate to have been able to have had this experience with my family, teammates, and coach. I made so many memories and shared so many laughs on my trip and I would not change for this experience for the world. I have gained a whole new perspective and respect for this sport and I would encourage anyone and everyone with a disability to join. You won’t regret it!
A HUGE THANK-YOU TO OUR DONORS FOR THE 2015-2016 FISCAL YEAR

General Donations

Alison Martens, Robert Podmoroff, Donald Waddell, Theodore and Brenda Carter, Robert and Kimberley Martinew, Christina Colenutt, Derek MacDonald, Eldon Campbell, Cint Heath, Susan Neufeld, Jeff Cathcart, Starbucks Coffee Company, Chivers Carpenter Lawyers, Mark Bradshaw, The Home Depot Foundation, ATCO Electric, Valley of Edmonton, Darnelda Volkman, Mary and Ben Rietveld, El Shaddai Dairies Inc., Curtis and Donna Treen, Rhonda Altmiks, Leonard Jacobs, Tom Semmens, Select Communications Inc., Alisha Brown, QSP, Canadian Association for Disabled Skiing—Alberta, Congdon’s Aids To Daily Living Ltd. (Skate for SBH), Buttler Family Foundation (Camp Freedom), Al Shamal Temple (Camp Freedom), Commercial Lodge No. 81 A.F. & A.M. G.R.A. (Camp Freedom)

Hope Classic 2015

In Memory and In Honour:

In memory of Cheryll Jonstone- Gwyneth White, Ian Chown, NAIT Academic Staff Association, Valerie Billey, Marjorie Kuziw, Heather Johnstone, Marlene and Clare Stinson, Melody Stewart,

In memory of Bradley Reid- Liz Bertolli, Rick Scott

In memory of M. MacCrimmon- Margaret Miller

In memory of Dr. Lawrence Mix- Darlene Stefaniszyn, Nicole Stefaniszyn

In memory of Ronald Barnes- Vince & Alice Meyer

In honour of Emma Befus- Darlene Cathcart, Taralynn Semmens

In honour of Nathan Smith- Elizabeth Koch

In memory of Faith Lamoureux- Nicole Stefaniszyn

Grants and Special Requests:

TELUS Edmonton Community Board Donation

Canada Post Community Foundation Grant

Quality of Life Grant

Community Investment Operating Grant

Edmonton Public Teachers Charity Trust Fund

Canada Student Jobs Grant
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**

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

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 __ Anyon模仿

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

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