



Spina Bifida and Hydrocephalus Association of Canada

upDate

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2004-2005

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President's Message



Seasons Greetings

My name is Lorelei Hall, and I am the new President of SBHAC. I am a mother of three teenagers, Jennifer 18, Ashley 15, and Tyler 13. Jennifer my oldest daughter has spina bifida and hydrocephalus. This is why I have been involved with the local and national associations for almost 19 years.

I was President of the Saskatchewan South Association for two terms. I have served as a member at large for the past two years on the SBHAC Board. As President, I look forward to supporting SBHAC the best that I can, and learning more about SBHAC and its Member Associations. **Together we can make a difference in the future of individuals with spina bifida and hydrocephalus.**

I recognize the work of our national staff, **Andrea Salmon** and **Mona Rémillard** in helping us achieve our goals. They are currently working on a daisy campaign for 2005, liquor commissions fundraiser, Christmas card campaign, as well as Corporate, and Foundation Appeals, and the Direct Mail campaign.

I would also like to thank every volunteer working to benefit our Associations both locally and nationally. Thank you to **Colleen Talbot** our Past President, whose many hours of hard work and time given to SBHAC are greatly appreciated. I look forward to working closely with her over the next couple of years.

I wish you all a safe, healthy and happy Holiday Season and I look forward to 2005 with great expectations.

Lorelei

Report on the annual general meeting.

Andrea Salmon

SBHAC held its 23rd Annual General Meeting at the bank of Montreal Institute of Learning in Scarborough on September 11, 2004.

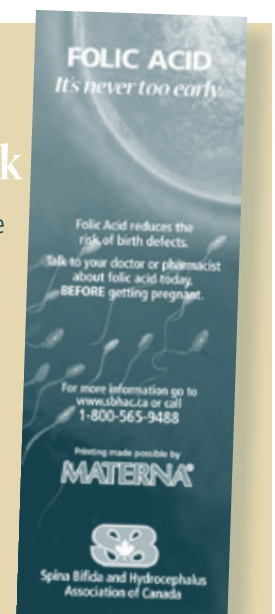
Business included the

- appointment of auditors (BDO Dunwoody) for the fiscal year 2004/5,
- election and appointment of Board of directors (see listing) and
- adoption of by law changes related to the makeup of the SBHAC nominating committee, and to the addition of an Associate Membership under SBHAC Membership categories.

A copy of the AGM Minutes is available from the national office if desired.

NEW Folic Acid bookmark

Please contact the National Office to order.



Bowel Care

The undiscussed issue

Shelley Elder, R.N.

This part of myelomeningocele management is as important as their bladder care. So from the time of infancy it was trial and error. This has been very challenging for Jonathan, our family and health care professionals supporting us.

So we went forth in our efforts to prevent constipation. In infancy, I mixed Jon's rice cereal with prune nectar and unbelievably he never fussed about it. I also introduced 1/2 strength cranberry juice at age 3 months instead of apple juice to help prevent urinary tract infections. He also drank another six ounces of prune nectar daily and this kept his bowel movements soft. He rarely developed a bladder infection. He kept on taking his prune nectar by bottle until he was just under two. Then the constipation developed. His nurse suggested we stimulate and disimpact his bowel and that was it. I found this to be uncomfortable for Jon and this technique really only emptied his rectum if it had anything in it. I could tell by palpating his left side that was bunged up. So the nurse suggested we stimulate his bowel twice a day. Massage his rectum for 15-20 minutes and wait to see if he moves his bowels. After a year of really trying, that was it; I had had it! It was time to try something else, so we introduced a bit of liquid senna or senokot. Pretty harsh and can cramp a bowel. We had some success with getting to an amount that would keep his bowel movements slightly constipated, his rectum would be full at least and disimpaction was easier.

Constipation still was an issue and if we increased the senokot he would have small accidents. We used a teaspoon of senokot when he was age three to age seven. Jon was a trooper and drank a lot of water too. Then I heard about the retrograde enema. At age seven, we tried it and had some success. This was very time consuming. I had to miss my other son's activities so this could be completed in early evening and then finish up with a bath. Sitting on the toilet for one hour was not an easy task for a seven year old. Then we tried Prodiem with Senna and two teaspoons of Milk of Magnesia at bedtime in chocolate ice cream every night. We went back to disimpaction and stimulation and this was the routine for 11 years with moderate success.

Now, Jon has an appendicostomy tube and has 95% success rate and doesn't need anything orally and we can do this care later on in the evening after any social activities. We are very happy with it, even with the few complications that have occurred. He develops about one cold a year and one urinary tract infection a year that will need medication. He also takes a multivitamin, two cranberry extract pills and 500mg of Vitamin C a day, and of course his Unidet which is like Ditropan.

Board Governance Workshop



Twenty six (26) volunteers and one SBHAC staff attended a Board Governance Workshop in Scarborough September 8-11, at the BMO Institute of Learning. Mr. John Dinner facilitated the workshop, and led the participants thought discussions concerning governance models, roles, liabilities, and much more. A list of priority actions was the eventual result of the three and one half day workshop. SBHAC will address these priorities within the next six month, and will report success/failure to the Board of Directors and Member Associations. An evaluation following the workshop indicated that this workshop was extremely informative and helpful to all who attended.

Order your Christmas greeting cards **NOW!** 25 cards for \$24.95

\$10.00 per box will fund the Spina Bifida and Hydrocephalus Association of Canada (SBHAC).

Cards are available online at www.cardshelpingkids.ca/sbhac

Please call our office to find out how you can help us promote this program **1-800-565-9488**



Appendicostomy news follow-up

Shelley Elder, Jon's mom

Well, Jonathan has had his appendicostomy for 12 months now. We have regulated his care and it has gone fairly well. He is done every 48 hours with a whole fleet enema and 500cc of normal saline. We attach a 60cc syringe, which attaches to a tubing that is inserted into his tube. Both are warmed up before doing the job. He sits for about 1 hour following and evacuates very well. His new Panasonic CD player has come into great use.

Jon has had a few problems since the tube was created. Four months following this surgery, unfortunately Jon suffered a small bowel obstruction. The surgeon felt it was from old adhesions, not the appendicostomy. Fortunately Jon didn't require surgery and it cleared on it's own in 10 days in December 2003. Another problem developed and his appendicostomy prolapsed slightly and in the future he may need a revision. The small stoma now tends to secrete a little more mucus. Polysporin is applied around it to prevent skin breakdown and he wears a mepore dressing 10cm x 10cm over the tube. His tube was changed in June and Dr. Miller inserted a Mickey gastrostomy tube. Jon can now open and close the tube; mom locks the attaching tube in place. Jon instills the fluids. He is doing about 50% of his bowel care with one on one supervision and step-by-step instructions. I think he is doing pretty good considering he is also autistic.

God Bless

Websites

www.pwd-online.ca

Persons with Disabilities Online is a site where persons with disabilities, their family members, caregivers and service providers can access a full range of information on disability-related programs and services in Canada. PWD-Online is part of the Government Online initiative, which seeks to provide all government information and services on the Internet by 2005.

www.accesstotravel.gc.ca

This site, spearheaded by Transport Canada in co-operation with 11 provinces and territories, not-for-profit organizations and other federal government departments, provides persons with disabilities with a wealth of information on accessible transportation service providers across Canada.

CORRECTION: Medtronic's Hydrocephalus Therapy Booklet

Toll free number to call is 1-800-268-5346 ext 5259 to order this booklet free of charge.

Communications, Energy and Paperworkers Union of Canada News

National Convention

6th National Convention

Colleen Talbot, SBHAC Past-President, Ken Stickle, SBHAC Board Member and Mona Rémillard, SBHAC National Staff attended the convention in Quebec City from October 17th – 21st, 2004. CEP Local Delegates presented SBHAC with over \$77,000 at the Presentation on October 18th, 2004. Colleen Talbot presented a beautifully framed print by Toni Onley to Brian Payne, President of CEP who accepted this recognition on behalf of all the CEP members across Canada. SBHAC held a raffle draw with over 14 items. Thank you to our sponsors: Local 27, WE Travel, Universal Promotions, Avon Sportswear, Cavan Advertising and also Shannon Feldman of Local 7 who crocheted a beautiful CEP afghan for our raffle. Congratulations to all the winners and a thank you to all the delegates who stopped by our booth. What a week! We recognize the dedication and commitment of CEP members who are instrumental in sustaining SBHAC. We look forward to the 7th Convention which will take place in Vancouver, BC in 2006.



Ken Stickle, Mona Rémillard, Colleen Talbot

CEP delegate presentations



Rain or Shine – CEP Locals Just Do It!

Dryden (CEP) Local 105 Golf Tournament

Everyone who participated in the golf tournament hit the links at Evergreen Golf Course on September 6th, 2004 to raise funds for spina bifida. Well over \$2,000 was raised. SBHAC looks forward to next year's golf tournament.

2nd Annual CEP (Manitoba Area Council) Golf Tournament

Yes – they did it again! Golfers teed up once again this year on September 12, 2004 at Kingswood Golf and Country Club, raising over \$8,900. More than 75 golfers slugged it out through the soggy course to raise funds. SBHAC thanks all of organizers and participants!



Colleen Talbot presented a recognition plaque to Art Crane and Wendy Sol

3rd Annual CEP Ontario Regional Charity Golf Classic

Plans are underway for next year's golf tournament. Well over 200 players will be participating. The set date is scheduled for June 3, 2005 at the beautiful Rolling Meadows Golf & Country Club.

Zellers Community Club Card

To all our members who donate their HBC Rewards Points to SBHAC, we thank you! Our community club card number has now changed – so please go to your Customer Service Department and if you give them your old card, they will provide you with our new number to write on the back of your card. SBHAC was able to purchase a Canon Digital Camera for office use with the points previously collected – **THANK YOU!**



The official book launch of Lucy MacDonald's internationally acclaimed book, **Learn to be an Optimist**: A practical guide for achieving happiness, will take place at Librarie Clio, Pointe Claire Plaza, 245N St. John's, Pointe Claire, Quebec H9R 3J1 on November 27th, 2004. The phone number of the bookstore is 514-695-5557. Lucy MacDonald and Librarie Clio will make a donation to the Spina Bifida and Hydrocephalus Association of Canada. For more information about Lucy's book, please visit her website at www.lucymacdonald.com

“If you want success you should strike out on new paths rather than travel the worn paths of accepted success”

John D. Rockefeller



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SBHAC'S primary source of financial support is through donations from companies, unions, service groups and the general public. If you wish to assist us in providing our services and programs please call 1-800-565-9488.