The Spina Bifida Association
of Western New York

SBAWNY

Spring 2011

Adult & Parent/Child Groups:

Check out what's happening for the Adult group as well as a new group working with our younger kids.

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2010 SBAA Conference Highlights: By Liz Keicher
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2011 Membership: Membership form is included in this newsletter. **Page 5**

Check us out on Facebook!

We are now on Facebook.

Search for "Spina Bifida Association of Western New York"

If you're already on Facebook then please join the group and tell your friends and family as well. With social networking being the new thing it's a great way to get information out to everyone.

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From the President of SBAWNY

Greetings to all:

Winter is still here but it will soon be Spring. I hope you had an enjoyable and healthy holiday season. It won't be long and the nice weather will be here once again.

I would like to remind you to send in your SBAWNY membership. Your membership lets us know who we are serving. It also helps us to keep our database up-to-date for mailings, email, etc.

I also want to remind you that we are always looking for individuals who have energy, ideas and want to get involved with either serving on our board or assisting with activities.

With everything going to the electronic world these days we'd really like for you to provide us with your email address so that we can get a database put together. We would like to use that so we can email upcoming events out to you instead of having to rely on the Post Office and the time delay it takes it getting the information printed up and sent out. Please send an email to Pam Morris at pmorris@sbawny.org and she will add you to the list.

We are anticipating that Variety Club will once again sponsor the Bison's baseball game in July. Karen Savanyu is putting together an outing to a Buffalo Bandits game for the Adult group and Liz Keicher is working on a group with parents, infants, and toddlers. Contact information for both of these individuals is included in the newsletter.

I hope you will be able to attend some or all of these events. We are always looking for ideas from our membership as well as to events/activities you would like to see offered.

Have a happy healthy summer.
Cynthia Carlson President SBAWNY

Wild Game Dinner

Unfortunately there will be no Wild Game Dinner this year sponsored by John Hutchins. He had some health issues last fall and was unable to go out on his many hunting expeditions. John has been an avid supporter of our group doing this in memory of his sister who also had Spina Bifida.

He is now the owner of the Rapids Theater in Niagara Falls and is looking to possibly put together some kind of fundraiser for us. Once we know more we will post it to the website and send an email out to those whom we have email addresses for.

Wheelchair Accessories

The mother of a special needs child has decided created her own little business making wheelchair capes, bags, foot plate covers, and whatever you may need! You can check out her website at: www.wheelchairflair.com or give her a call at 716-534-5805 (Heather).

ADULT NETWORK EVENTS

Buffalo Bandits: Karen is working on getting tickets to a Buffalo Bandits game sometime in April. If you are interested please contact her at 585-457-9867 or via email: kes484@aol.com or Cory at his email: prince1217@aol.com. Tickets will be on a first come basis. Older teens can also contact her if your are interested.

Sabres Game: The group attended a Sabres game in December and had a great time.

Spring Raffle: Karen is getting donations together for the annual spring raffle. If you would like to sell or purchase tickets please contact her at the phone number or email above.

PARENT/CHILD PLAY GROUPS:

The youngest members of our association have been gathering for play dates and we'd love to see you at one! It's a great time for babies/toddlers/kids to play and have fun, and the perfect opportunities for moms and/or dads to chat, share, and support each other.

Please contact Liz Keicher at 716-685-0684 or email her at lizkeicher@yahoo.com if you are interested. We try to meet once a month. Once the warmer weather comes we are planning on meeting at various parks and fun places in and around Buffalo.

CHRISTMAS PARTY:

We had a great turn-out for our Christmas party. We had about 50 people. The event took place at Dave and Busters at the Eastern Hills Mall. We had a nice buffet lunch and the food was great. Everyone had a great time playing the games. We will be planning for this again at the end of Nov 2011.

SPINA BIFIDA ASSOCIATION OF AMERICA ANNUAL CONFERENCE:

This year's conference theme is "Today's Magic/Tomorrow's Vision. This is the 38th National conference which will be held in Anaheim, CA from June 26th thru June 29th. For more information you can go to their website at: www.spinabifidaassociation.org and click on the banner. This will give you all the details as to location, cost, etc.

INDEPENDENCE FOUNDATION EVENTS:

Chris Mueller and her group are holding a Young Adult Valentine's Party at the Riley Street Station in East Aurora, NY on Sunday, February 20th. Cost is $15 which includes snacks, pop, and dinner. For more information contact Chris at: 716-685-3976

2010 National Spina Bifida Association Conference Overview:

The 37th SBA National Conference was held June 27-30 2010 in Cincinnati, Ohio. This 4 day comprehensive conference offered something for everyone. Over the course of four days there were a multitude of sessions with various topics. As first time attendees, and the parents of a then 1-year old daughter with Spina Bifida, my husband and I came home more knowledgeable, empowered, and with many new friends.

Everything started with Pre-Conference Programs. This included a Health Care Professionals Day, with the topic "Leading the Way to the Future – Translating Research into Clinical Practice", and an Adult Day, with the topic "Planning for the Future". This particular topic had an emphasis on employment, and session topics included "Disability and Employment", "Work Incentives for Social Security Beneficiaries", "First Impressions: Resumes and Interviews", "Don't use Your Disability to Disable Yourself", and "the benefits of Exercise and Adapted Sports for Healthy Living".

The next three days had over 40 session options. Highlights included an opening Plenary Session with the topic "Spina Bifida: The Past and the Future". This session included a history of Spina Bifida in the medical field, given by Dr. Sonia Oppenheimer (who had recently retired as Director of the Division of Development and Behaviorial Pediatrics, and Director of the University Affiliated Cincinnati Center for Developmental Disorders). It was eye-opening to learn, for example, that the first modern shunt was used in 1952; that prior to the 1960's less than 10% of individuals with Spina Bifida made it to adulthood; that carbon-dated skeletons of adults and infants found in caves in Morocco demonstrated the existence of people who survived with Spina Bifida; that the use of catheters can be traced back to the 7th Century BC; and that as early as the 1600's they were attempting lesion closures. While medical advances have been made, it has really only been since the 1980's that comprehensive treatment of Spina Bifida has been evident in the medical community. It was a reminder that while we have come far, there is still a long way to go with many aspects of Spina Bifida.

Other key sessions over the next three days included a "Parent Chat" for ages ranging from newborn – 5, 6-11, and 12 – 19. This was a chance to be among peers facing similar questions and concerns. They also held "Ask the Doctor" sessions, on Urology, Neurosurgery, and Orthopedics. This was a wonderful opportunity to seek second opinions, and learn about other treatments and approaches. Additional session topics were: "Latex Allergy: 2010 Update", "Medical Management of the Neurogenic Bladder" with separate sessions for late childhood-adulthood, and newborn-10 years old, "Social Skills for Children with Spina Bifida", "Health Issues Affecting Men with Spina Bifida" and "Health Issues Affecting Women with Spina Bifida" (for both of these, the second half of the session was open to individuals with Spina Bifida only, in order to discuss health and sexuality), "Chiari and Hydrocephalus" "Proper Seating and Wheelchair Fittings for Persons with Spina Bifida", "Ten Tips to Guarantee College Success" and one entitled "Brothers and Sisters Speak Out", a panel discussion consisting of siblings of individuals with spins bifida.

With a wide range of topics and the ability to ask questions throughout and after each session, I really walked away with that sense of individual attention even though there were hundreds of people there. What I also enjoyed was how the conference is set up for both parents and individuals with Spina Bifida. There were many conferences where I was able to hear questions/concerns right from adults with Spina Bifida, and make new friends as well. This glimpse into the future for our daughter was very appreciated.

They also had a Kids Camp offered in groups from Birth – age 3, ages 4-6, ages 7-12; and a teen program ages 13-19. While our daughter didn't attend, I did speak with several parents whose kids attended and they had a blast – there were even nurses at the camps to take care of cathing needs while parents attended the conferences. They also have a Brother's and Sisters Program for ages 13-19, for siblings of kids with Spina Bifida.

And it wasn't all business: there were activities like a Teen Night and a trip to the ballpark (with all accessible transportation and so on taken care of), and in general it was a great atmosphere to socialize, or take in the sites of the city.

In addition to the sessions, at Exhibition Hall they had many medical corporations and sponsors…lots of free samples!

This year's conference is being held June 26-29th at the Disneyland Hotel in Anaheim, California. You can visit http://www.spinabifidaconference.org/ for all the information and to register. Hope to see you there!

- Elizabeth Keicher

SBAWNY 2011 Membership Form

Individual/Family Memberships:

First and Last Name (Household Family)	Ages (Children only)	Check if this is person has SB or Hydro	Birth Date Children Only	Email Address: (This will allow dissemination of information quicker)

Street Address: ______________________________

City, State, Zip: ______________________________

County: ______________ **Phone Number(s):** ______________

Membership dues are on a sliding scale to enable you to give as much as you can for our programs and services. We value your membership and financial support. Please circle one of the following dollar amounts and mail a check or money order for that amount to the address shown below.

$15, $20, $25, $30, or $35: Local Chapter family/individual membership

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Professional Memberships:

Contact Name: ______________ **Organization:** ______________

Title of Contact: ______________ **Relationship to SBAWNY:** ______________

Street Address: ______________________________

City, State, Zip: ______________________________

County: ______________ **Phone Number(s):** ______________

We value your membership and your financial support. Please choose your organization's membership level.

____ **Gold ($500)** ____ **Silver ($250)** ____ **Bronze ($150)** ____ **Professional ($50)**

Please make checks payable to SBAWNY and mail with this form to:

SBAWNY, 137 Warner Avenue, North Tonawanda, NY 14120

Spina Bifida Association of Western New York
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North Tonawanda, NY 14120

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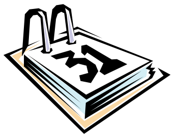

MARK YOUR CALENDARS

Feb 20th - Young Adults Valentine’s Party

Jun 26 thru 29th - SBAA National Conference

July 2011 - Bison’s Baseball Game

Please make a note of our correct mailing address located on the front of this newsletter. The mailing address associated with the phone number is not correct. We have not had any success with getting it changed or removed.