

SBA Newsletter

Issue #33, Fall 2007

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SPINA BIFIDA ASSOCIATION OF ALBANY/CAPITAL DISTRICT IS GROWING WITH YOU!

By Karen Wentworth

Over the past few years, and especially the last few months, our chapter has gone through major growth and change. After working out of our homes for 14 years, it was time to move in to an official office. This decision was driven by many factors not limited to the need to become more visible to the public in order to better serve the Spina Bifida community and growing out of the space available in our homes. We are now settled in and encourage you to visit. Office hours are 9 -1 Monday through Thursday, or by appointment. I encourage you to call ahead. Since there is only one of me, it is sometimes necessary for me to be out during office hours for appointments.

Our office space is not the only way in which we have grown. Our fundraising and awareness efforts have also been stepped up to another level. Many of you attended

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Executive Committee Co-Presidents

Kevin Chamberlain
Vanessa Chamberlain

Vice President

Christine Darby-King

Treasurer

Margaret Langelier

Secretary

Hali Holmes

Executive Director

Karen Wentworth

SBA NATIONAL CONFERENCE EXPERIENCES

By Barbara Devore

With the support of our local chapter, this year I attended the 34th Annual SBA conference in Louisville, Kentucky. The conference was entitled "Expanding Our Horizons" and for me, it certainly did live up to its title! While I have lived with Spina Bifida for many decades, this was the first time I attended the conference. It was wonderful. It provided me with the opportunity to hear from national experts, to meet people living with spina bifida and their families, to hear from other chapters about their programming, to view state of the art equipment and supplies, and to better understand the

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SBA NATIONAL CONFERENCE EXPERIENCES

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focus of our national organization. I also had the chance to spend time with many of the folks who serve on the board of our local chapter, SBA of Albany/Capital District and together we discussed the challenges of guiding our organization as we grow to meet the needs of those we serve as well as increase our efforts at education of the community about both prevention of neural tube defects and living successful lives with Spina Bifida.

Because I am an adult living with Spina Bifida, I chose workshops that addressed issues of Spina Bifida in adults, and there were many. The workshop on establishing a successful adult clinic, "The Art of the 3 Cs,

Cooperation, Collaboration, Compromise", was particularly informative. Karen Rauen, the speaker,

"...THE SPEAKER STRESSED THE IMPORTANCE OF YOUNG PEOPLE WITH SB BEING INVOLVED IN THE MANAGEMENT OF THEIR MEDICAL CARE FROM A YOUNG AGE..."

stressed the importance of young people with Spina Bifida being involved in the management of their medical care from a young age, assuming greater and greater control as they age. She noted the significant

differences in models of pediatric vs. adult SB clinics; while pediatric clinics often dealt with neurological and orthopedic concerns of young children, adult clinics needed to focus more on prevention of secondary conditions, encouraging healthy lifestyles, teaching

self management, and addressing mental health issues.

Ms. Rauen also described creative ways to establish the clinic. She emphasized the need to get buy in from a provider who could champion the cause and bring on other specialties. She also explained that given the small numbers of adults in some areas of the country, a full time clinic is not always financially feasible, and suggested success can be obtained by creating a part time clinic, piggybacking with another clinic (for example, an adult spinal cord injury clinic), with slots designated for individuals with Spina Bifida.

Finally, Ms. Rauen discussed the transition process that involved education of the young person with Spina Bifida about what to expect at the new clinic site, followed by a site visit and introductions to the new staff.

All helped make for a smooth transition. This presentation was particularly pertinent to our chapter, as we have been discussing the lack of coordinated care since the closure many years ago of the Albany Medical Center Spina Bifida clinic. Several of us will continue to discuss the feasibility of this model in our community.

I strongly encourage families to attend

"I STRONGLY ENCOURAGE FAMILIES TO ATTEND ONE OF THE NATIONAL SB CONFERENCES."

one of the national SBA conferences. The medical experts were available and eager to answer questions from parents and persons living with Spina Bifida,

the workshops were filled with exciting, ground breaking information, and the participants were giving of their time. It was both an enlightening and fun time.

NEW GOALS FOR THE SPINA BIFIDA ASSOCIATION

BY MARGARET LANGELIER, CHAPTER TREASURER

As your long time treasurer and more recently as your delegate to the national conference of the Spina Bifida Association in Louisville, Kentucky in June of this year, I've been asked to communicate some of the features of the conference. A few paragraphs are much too short to provide even a synopsis of the workshops and seminars that your representatives attended. We were fortunate to have two official delegates to conference and to also have 10 other people representing our chapter, SBA of Albany Capital District. Among us all, we covered most of the territory!

Not only was I your delegate to the official business meetings of the organization but I was also selected to attend a two day Leadership Conference that preceded the other conference activities. It is this experience on which I'd like to focus in this article. I will be sure to share some of the programmatic and medical agenda with you in other newsletters during the year.

Most of you are not aware that the national Spina Bifida Association is undergoing major change in an effort to reach more of its constituents and to become more publicly recognized. The national organization has just completed a visioning and planning process for its future (and ours) and is beginning to implement many of the recommendations that resulted from that process. The leadership institute focused heavily on the objectives for constituent organizations like ours over the next five years.

At conference, the national association detailed requirements for local chapters to maintain their current affiliation with national. The goals are demanding and will require planning and hard work on the part of our group in order to meet the specifications. As many of you know, we have already grown substantially from a parent support group begun in 1993 to a full-fledged chapter with employees, education and social programs, and advocacy resources. However, we still have giant steps to take to reach the new national goals. There is one area, fundraising, where we especially need your help. Your board has always embraced the vision /philosophy that this is an inclusive organization that must be accessible to all without attention to financial capability. It is for this reason that many of you have no idea how or who supports our activities. However, it is becoming necessary to ask for your help in this regard.

First, though, let me tell you that many of the requirements that national SBA has established are already in place or in planning for your local association. Your Board of Directors is currently reviewing the bylaws to make the board composition more compliant with the guidelines suggested by the national SBA. Our chapter has recently opened an accessible office (come and visit when you can) at Socha Plaza on Route 50 in Scotia, New York. We now have two part-time paid staff, Karen Wentworth and Jackie Citriniti. Our financial house is in order with regular outside audits and completion of all federal and state filings on a timely basis.

And now to the heart of this matter! The national association has established a requirement that all affiliate chapters must raise (and spend) \$50,000

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NEW GOALS *Continued from Page 3*

annually. This is an ambitious goal for SBA of Albany/Capital District since our annual budget is not currently at that level. As you can imagine, this will require that all members and interested constituents engage with our fundraising process on an ongoing basis. We are not asking you today for money. Rather

THERE ARE MANY PAINLESS WAYS IN WHICH THIS MONEY CAN BE RAISED THAT WILL ALSO CONTRIBUTE TO AWARENESS OF SPINA BIFIDA...

We recently received a donation of \$60 from P.J. Gallagher, the five-year-old brother of a younger sister with Spina Bifida who raised this money at a summer lemonade stand. He was aware of the need of the organization and the good things that can happen when a group of people come together to learn and advocate for those with Spina Bifida. This is an example of what we are asking of you.

In your daily lives there are many opportunities to think of the Spina Bifida Association. At birthdays, anniversaries, and retirements, at the death of a loved one, people often look for appropriate remembrances or memorials. SBA of Albany/Capital District would appreciate being the beneficiary of those moments. Remind your family and friends of the important work that we do. For your information, much of our operating capital currently came from a bequest from Helen Mertens. She remembered a

this is an article to ask for your awareness and your advocacy. There are many painless ways in which this money can be raised that will also contribute to awareness of Spina Bifida and to the growth of our organization.

family member with SB and at her death, left part of her estate in honor of that person. At work, many of you participate in United Way campaigns, Community Health Charities, or the Federal and/or State campaigns for annual giving.

Are you aware that you can designate your donation to be sent to the Spina Bifida Association of Albany/Capital District rather than to the general United Way, Federal, or State funds for distribution to organizations of their choice? We have several family members that currently designate their annual United Way gifts and those checks help to pay our rent and utilities. Might you ask your friends at work through an email or personally to think about making this designation during the annual fund raising campaigns? People do like to have a personal connection to their charitable donations and you are the link to that connection.

Also, many of you belong to church or fraternal organizations, business groups, and volunteer organizations that hold events and are looking for beneficiaries of the monies that are raised. Won't you speak up for SBA of Albany/Capital District? In the past year, a Moose Lodge donated almost \$600 from a pot luck dinner and raffle held on our behalf. School groups and groups of young

AT BIRTHDAYS, ANNIVERSARIES, AND RETIREMENTS, AT THE DEATH OF A LOVED ONE, PEOPLE OFTEN LOOK FOR APPROPRIATE REMEMBRANCES OR MEMORIALS. SBA OF A/CD WOULD APPRECIATE BEING THE BENEFICIARY OF THOSE MOMENTS.

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NEW GOALS

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people often look for beneficiaries of their energy and good will and we'd like to be at the front of the line when they are thinking about what to do. Your communities are quite willing to help our community

YOUR COMMUNITIES ARE QUITE WILLING TO HELP OUR COMMUNITY WHEN THEY ARE AWARE OF THE NEED AND WHEN THEY ARE ASKED.

when they are aware of the need and when they are asked.

Finally, we will have a number of fundraising events over

the coming months. We value your time as much as your treasure so if you could help in organizing for those events we would welcome your participation. The recent awareness and fundraising event at the Saratoga Racetrack was a wonderful testament to the hard work of our fundraising committee.

Our fundraising committee is already working to plan what our next event will be with several ideas being considered. If you are interested in working on the next event, we welcome your participation. You'll hear of the planning meetings through the newsletter or you can contact Karen directly at the office (399-9151 or SBAAlbany@verizon.net) to get involved.

In the meantime we are asking you to be aware of our common goals. SBA of Albany/Capital District needs help from all our constituents to meet these ambitious financial goals. Please do what you can, when you can. We value what we have built and hope to secure its future for all those with Spina Bifida through creating a strong financial foundation for the organization. We hope

that in doing this that we will expand awareness of Spina Bifida and continue to extend our support to those who might need our resources.

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SBA OF A/CD GROWS...

By Karen Wentworth

our event at Saratoga Thoroughbred Racetrack on August 12th. Others noted all of the publicity that occurred around that date. Many others now on our chapter list found us as a result of those efforts. Thank you, thank you, thank you to all whose efforts made that event such a success that not only raised funds that will support chapter events and expenses, but raised awareness about Spina Bifida!

Our growth was also evidenced by the number of people from our chapter who attended the national conference of Spina Bifida Association in Louisville. We not only had 2 delegates and their families, but several other families who attended as well. Please note the articles inside from Barbara Devore & Margie Langelier sharing some of what they learned from the experience. As you read, you will want to consider putting the dates for next year's conference on your calendar. It is a valuable experience for individuals who have Spina Bifida and their families. Finally, perhaps you have noted another sign of growth – our newsletter has a new look! This is in response to new requirements from our national organization to help with name recognition for Spina Bifida and for the organization as well. I hope that you enjoy reading all of the information cover-to-cover!

Fundraising Activities

JOIN IN THE GOOD SEARCH!

www.GoodSearch.com

Good Search is an internet search engine powered by Yahoo that allows you to search the internet like you always have but this one pays SBA of Albany/Capital District 1 cent for every search you perform. Help our chapter while searching the internet. *You can download a free Yahoo! Search bar that allows you to retain the home page you have now, all while earning a penny a search.* It's free and easy to set-up. With over 100 families on our list who use the internet, we can all work together helping the chapter by doing something that we do every day. Please join the Good Search

right now!



GIVING TIME OF THE YEAR

Many people make donations to their favorite charities around Thanksgiving and at the end of the year. Please consider making a gift to SBA of Albany/Capital District. If your employer offers a matching gift program, remember to register your gift through your employer and double your money donated! Thank you!

EMPLOYEE GIVING PROGRAMS

Very soon, many of you will be seeing programs through your jobs for employee giving sponsored by United Way & Community Health Charities. SEFA (State Employees Federated Appeal) and CFC campaigns will be occurring. SBA of Albany/Capital District is registered with all of these giving programs. Please consider your SBA chapter when you make decisions for your workplace giving program. Encourage family and friends to support us as well.

We will be at the SEFA fair on October 10 at the Empire State Plaza. Stop in and see us! Thank you!

SBA OF A/CD

GOES TO THE RACES

On August 12th, our fundraising committee, chaired by Jim and Jennifer Gallagher, spearheaded a fundraising and SB awareness raising day at Saratoga Thoroughbred Racetrack. The day proved to be both fun and profitable. Your SBA chapter had a table with brochures and t-shirts. Many people stopped to tell of someone they knew with SB or to pick up information about folic acid supplementation. Over 200 people gathered under tents to share lunch and

A RACE WAS NAMED FOR OUR CHAPTER AND MANY OF THE YOUNG PEOPLE WITH SB IN ATTENDANCE WERE ESCORTED BY NYRA PERSONNEL TO THE WINNERS CIRCLE...

conversation and betting advice! A race was named for our chapter and many of the young people with SB in attendance were escorted by NYRA personnel to the winners circle to watch the race and be present at the award ceremony.

Appropriately for us, "Wish Me Success" was the winning horse! The horse's owner immediately pledged a donation to our chapter. Figures are not yet final but we have raised in excess of \$13,500 from this single event.

Other fundraising events are being considered. Please call or email to see how you might get involved to help with the next event!

HELEN R. MERTENS SCHOLARSHIP AWARDS FOR 2007

This year, our chapter was fortunate to present awards to 2 very deserving scholarship winners. The purpose of the scholarship is to award financial assistance to persons who have Spina Bifida and are pursuing higher education, technical training, or driver's education. This year's scholarship recipients are Jabraya Tanksley of Albany and Lyndsi Holmes of Niskayuna. They were presented with their scholarship awards at their high school award ceremonies in June. Congratulations Jabraya & Lyndsi. Best wishes as you pursue your educational goals!

SBA NATIONAL CONFERENCE GRANT

June 2007 was a first for our chapter with grant offerings. In an effort to encourage first time attendance at our national conference for SBA, a grant was offered to reimburse for specific conference related expenses. Barbara Devore was awarded this grant, and hopefully you have already read her first report back to the chapter on earlier pages of this newsletter! Her report is a testament to the value of conference attendance.

NEWSLETTERS BY EMAIL

Did you know we offer our newsletter by email? If you use email and would prefer to receive the newsletter in that format, please email SBAAlbany@verizon.net. Indicate "newsletter" in the subject line.

WEEKEND RETREAT AT DOUBLE H RANCH

We are busy planning our activities for our annual weekend at Double H Hole in the Woods.

Details are enclosed along with a reservation form. Please complete these and return them as soon as possible. It helps us to know who is attending so that we can plan events accordingly.

PARENT SUPPORT GROUP

We have heard from many parents that there is a need for a parent support group for those whose children are teens and adults. In response to this, we are arranging for a these parents to have an opportunity to meet and talk together about their particular concerns; transitions in work and living situations, resources for adults with disabilities, estate planning, respite services, and concerns about what will happen to an adult child after a parent is gone are a few of the topics that are frequently heard. If you have a child who is a teen or older, this group may be for you.

The first group will meet on Saturday, October 6, from 3:15 – 4:15. The location is yet to be determined, but will be somewhere in Schenectady. Please call or email if you are interested and we will put you on the announcement list for details.

T-SHIRTS FOR SALE

SBA of A/CD is selling SB awareness t-shirts. Be prepared for Spina Bifida Awareness Month! See the attached order form for details.

Chapter Calendar

SEPTEMBER

Saturdays 3 – 4:30 pm

Accessible Tennis Lessons, Central Park, Schenectady
(Please call ahead to register.)

Saturday, 9/15

Teen Support Group Outing

OCTOBER

Saturday October 6

3:15 – 4:15 pm

Parent Support Group

Saturdays 3 – 4:30 pm

Accessible Tennis Lessons, Central Park, Schenectady
(Sportime – previously Schenectady Racquet as of 10/20/07)

To Be Announced

Teen Support Group

Saturday, 10/13

Chapter Board Retreat

October 26 – 28

Double H Camping Weekend

NOVEMBER

Saturdays 3 – 4:30 pm

Accessible Tennis Lessons, Sportime, Schenectady

Saturday 3:15 – 4:15 pm

Parent Support Group

Saturday, November 17

Preschool Family Program
