

Spina Bifida Association of Connecticut, Inc.

Volume 3 / December 2001

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THE SPINA BIFIDA ASSOCIATION OF CONNECTICUT, INC.

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A Letter From The Needs Assessment Committee

Dear Members:

One of the goals that came up in our Strategic Planning Meeting in September was the necessity of asking our members what their needs are. With this in mind, we have developed an assessment that is being sent to you in this newsletter. Please take the time to review this assessment and answer the questions to the best of your ability. Utilize the opportunity to comment wherever necessary and add anything that you feel has been omitted from the survey. As a successful growing organization, we are striving to meet the needs and expectations of our membership body. Before we can do that, we have to assess what these needs are. This assessment will be invaluable in our ongoing efforts of fundraising and future grant writing.

Please return the completed survey to the Spina Bifida Association address at the left, no later than **2/1/02**. We certainly hope that we will have everyone's participation. As a little incentive, we will be having a drawing. Each individual who returns the assessment by the due date of 2/1/02 will have his or her name placed in a drawing. The winner of the drawing will be awarded a check for \$200.00.

Thank you for your anticipated cooperation in taking the time to complete this assessment. Once everything is analyzed, we will report the results back to you.

Sincerely,

Spina Bifida Needs Assessment Committee

MEDICAL ALLOCATION DEADLINE

The deadline for the next Medical Allocation is January 31, 2001. Members of the SBAC, can apply for reimbursement of medical expenses not covered by your insurance company. Reimbursement is limited to \$500.00 per family. You must complete and mail the Medical Allocation Form included in this newsletter. Remember – **applications must be postmarked by January 31, 2001.**

ARE YOU A MEMBER OF THE SBAC?

Have you applied for membership to the SBAC? Receipt of the quarterly newsletter does not necessarily mean you are a member of our organization. Membership is **FREE** to individuals with spina bifida or parents/legal guardians of a child with spina bifida. The membership fee for other interested parties is a nominal amount and goes toward supporting our organization and its worthwhile goals.

If you haven't completed and mailed a membership form – would you kindly take a moment to do so now? A membership form is included in this newsletter. Thank you.

NEWSLETTER SCHEDULE – 2002

Please note the following publication schedule for the Newsletter in 2002. Submissions for publication must be received by the date below and can be sent via e-mail to: Newsletter@sbac.org or mailed to: Marybeth Petersen, 25 Lido Road, Unionville, CT 06085.

Newsletter Volume I – Published in March

Submission Deadline: 03/09/02
Approximate In-Home Date: 03/25/02

Newsletter Volume III – Published in September

Submission Deadline: 09/07/02
Approximate In-Home Date: 09/23/02

Newsletter Volume II – Published in June

Submission Deadline: 06/08/02
Approximate In-Home Date: 06/24/02

Newsletter Volume IV – Published in December

Submission Deadline: 12/07/02
Approximate In-Home Date: 12/16/02

The Newsletter is published quarterly by the Spina Bifida Association of Connecticut, Inc. P.O. Box 2545, Hartford, CT 06146-2545. Subscription rate is \$15.00 per year. The Spina Bifida Association of Connecticut, Inc. is a non-profit corporation. Board meetings are held quarterly at the Holiday Inn in Cromwell, CT.

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We welcome comments and suggestions regarding the content or appearance of the Newsletter, as well as commentary on issues related to Spina Bifida. We reserve the right to edit all submissions. Letters must include your name, address and phone number. Mail all correspondence in care of the association. Or, call us anytime with suggestions, questions, impressions, or contributions at: 1-800-574-6274 or on the web at : <http://sbac.org>.

ADDRESS CORRECTIONS

Please check your name and address as it appears on the mailing label of this newsletter for any corrections required.

Should you wish to make any change to how your name or address appears, please send an e-mail to: Newsletter@sbac.org or contact Marybeth Petersen, 25 Lido Road – Unionville, CT 06085-1536 or call (860) 673-4310.

Thank you for your help!

THE SBAC FALL WEEKEND AT CAMP HARKNESS

The SBAC held its annual Fall Weekend and Halloween Party at Camp Harkness on October 12-14. The weather couldn't have been better – a balmy 70+ degrees and turnout by the membership was excellent! Can you believe the kids were playing in the ocean in mid-October?

Special thanks to Janet Lanzetti and Stephanie Beck for all their hard work in planning the kid's party, thanks to Joanne Field who (once again) put her heart and soul into purchasing the food to feed the hungry campers all weekend long, and to Marco Tardiff who served as our Master Chef and was instrumental in K.P. and campfire duties, also to Darlene Bilodeau for growing all the pumpkins for the kids to carve (you did grow them - didn't you, Darlene?!) And a big "Thank You" to all the parents who packed up their little kids and spent a night or two in a cabin with them – getting very little sleep!

It's the hard work on behalf of these individuals that make our weekend get-togethers so much fun for everyone. There is a lot of work to be done in order to pull off these weekend events but if we all chip in a little bit, the work is much easier for everyone. If you would like to join in on the party planning for the Spring or Fall weekend events, please contact Marybeth Petersen at (860) 673-4310. Thanks!

PEOPLE NEWS

Congratulations to Jill and Fred Liguori and "Big Brother Nicholas" on the birth of their son, Matthew William, on November 8th. Matthew has reportedly been the perfect baby – he seldom cries and sleeps a lot! He's also said to be "beautiful", according to the unbiased opinion of his mother! Good luck to the Liguoris with their new bundle of joy!

Hearty congratulations also go to Ann & Brian Thompson on the birth of their daughter, Cassidy. Most of you know Ann from her work with the Cruisers and the Wave at the Hospital for Special Care in New Britain. Good luck to Ann & Brian!

Best wishes for a speedy recovery go out to Chelsea Bilodeau following her recent hospitalization for an appendix rupture and surgery. We hope Chelsea is feeling better really soon!

PARTICIPANTS NEEDED FOR SB STUDY

As youth with spina bifida age into adult hood, there are new challenges and opportunities in their lives. To date, there are few studies which examine the relationships among health status, functional status, and perceived health-related quality of life of youth with spina bifida.

As a doctoral candidate in nursing at New York University and as a nurse with twenty years experience in the care of children and adults with spina bifida, I am conducting a study to identify factors that effect the health-related quality of life in youth with spina bifida, who are 15 to 25 years of age.

As with all doctoral proposals, this study has been reviewed and approved by University Committee Involving Human Subjects Review Board at New York University. If you have any questions at any time or need any further information, please feel free to call me, collect or contact my faculty advisor, Dr. Deborah Sherman at NYU, (212) 998-5316.

Thank you very much for your assistance in this effort.

Most Sincerely,

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Pain-Free Fund Raising with SNET

Gab on the phone and help your favorite charity!

SNET Community Connections is the easiest way for you to help The Spina Bifida Association of Connecticut raise money! SNET Community ConnectionsSM helps the SBAC raise money and gives you a great deal on your own long distance bill at the same time. If you sign up for the Community Connections plan, The Spina Bifida Association of Connecticut gets 5% of every dollar you spend on SNET long distance calling including in-state toll calls, out-of-state and international long distance calls, even calling card calls.

Already a SNET All Distance customer? No problem. Sign up for SNET Community Connections and keep your existing calling plan or check with SNET to see if there's a better plan for your calling needs.

It's easy – you can even sign up over the internet! Visit: <http://www.snet.com/About/0,1847,22,00.html> for more information or to use their simple on-line order form. For more information or to sign up on the telephone, call SNET at 1-800-635-SNET (7638). The Spina Bifida Association of Connecticut's Organization Code is: C2302.