

SPINA BIFIDA ASSOCIATION OF ALABAMA NEWS

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January-March 2011

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Letter from the President

By Betsy Hopson

2010 was a truly remarkable year! I was immensely blessed to share many incredible moments and memories with you. We embarked on new territories and were also able to maintain the programs that we have supported for many years. We added over 50 new families to our SBA of AL family, rose over \$40,000 at our bowl-a-thons across the state, and our Adopt-a-ghost program had representation all across Alabama. We also supported young adults attending college through our advanced education scholarship, continued support to our families welcoming a new baby, and provided Spina Bifida and folic acid education to nursing students throughout Alabama. Our calendar of events has historically never been as full as it was in 2010. Between bowl-a-thons, golf tournaments, Adopt-a-Ghost, parties, and conferences, we spent the entire year celebrating one event and immediately planning the next. Thank you all for your support at these events. Your presence makes these events such a success. The sweet faces and smiles from your children provide exactly the right amount of energy to keep us going strong.

Speaking of "going strong," I would like to share with you what the National Spina Bifida Association is saying about us in Alabama. Back in 2007, the SBA of AL began an aggressive plan set out by the National SBA, to become a fully affiliated chapter. We knew that although we had a long way to go, our families in Alabama deserved the very best and most supportive chapter we could possibly be. Over the past 3 years, the National SBA has had many meetings both in person with us and on conference calls to check in on our progress. I am happy to report to you that the National SBA considers us a model chapter. We are achieving national recognition for the families we serve and the programs that we are carrying out. This is truly something to celebrate.

In November, the Board of Directors had our quarterly board meeting to discuss plans for 2011. This discussion will continue at our January board meeting, but beginning January 1st, Lori Turner, who has served as the President of the SBA of AL for the past three years, will move to the position of Past Chair, and I will move into the position of President. Lori has been such a valuable asset to us and has proven to be an incredible leader. The entire process of affiliation growth has come under her leadership. It has been my sincere pleasure to serve as Vice President under her. She leads with honesty, passion, commitment, and dedication. As Past Chair, she will still be very much involved with the SBA of AL. The next major change that will be realized in 2011 is the promotion of Angie Pate from Senior Field Service Coordinator to Executive Director. Angie too leads with great dedication and passion. The Board of Directors believes strongly in her ability to lead us into the next phase of our organization's growth as a fully affiliated chapter of the National Spina Bifida Association. Please join me in welcoming her into this much deserved new role.

Finally, I would just like to thank each of you that attended our Spina Bifida Christmas party. This event was such an awesome blessing. Stacey Courson worked tirelessly on making this event the huge success that it was, THANK YOU, STACEY!! Seeing the children laugh with Santa and their excitement as he entered the party will forever be etched on my heart! I am excited to serve as your President and I look forward to a very busy and exciting year in 2011! Feel free to call or email me with any suggestions, comments or recommendations.

Welcome Stacey Courson!



Meet Stacey Courson. Many of you have already had the opportunity to spend time or talk with her and her sweet family. You probably even saw this same picture a few months ago in

our Huntsville Bowl-a-thon article. That is because Stacey has been involved for a very long time as a volunteer for the SBA of AL. She hosted the 2010 Huntsville bowl-a-thon, has given awareness presentations, such as Nurse First presentations, helped raise awareness across the state through newspaper articles and television interviews, hosted Family Connections in the Huntsville area, and participated in recruiting businesses for our Adopt-a-Ghost Awareness program. She showed an incredible amount of dedication to serving our families and helping us fulfill our mission a long time before she ever joined us as a Field Service Coordinator.

Stacey not only comes to us with many years experience as an R.N. and as an SBA of AL volunteer, but more importantly, she comes with the experience of being a mom of a child affected by Spina Bifida. She is the very lucky mom of two beautiful girls, Jewel and Sophie. Sophie was born with Spina Bifida, so the Courson family understands first-hand about living with the daily challenges associated with this birth defect. Because of this, she has always been and will continue to be a wonderful resource to our families across the state. She is always very willing to share her story and loves having the opportunity to speak with families and give them the support they need.

We are so pleased to have Stacey join us! We have been so blessed to have her as a part of our organization for the last three months and look forward to having her work with us as our permanent Field Service Coordinator!

Strides Toward Transition

By Betsy Hopson

Transitioning into adult care is a very scary time for parents and young adults that have become used to comprehensive, multi-disciplinary care. Adults with Spina Bifida, in addition to the everyday challenges that this birth defect brings, also have “adult-like” issues that are better managed from an adult clinic.

We are very fortunate in Alabama to have Dr. Amie Jackson at Spain Rehab. For the past several years, Dr. Jackson has been managing an adult Spina Bifida program. She treats these patients and their issues in a very holistic, “big picture” type of approach. Many of the patients that have transitioned to Dr. Jackson’s clinic have reported how impressed they were with the head-to-toe assessment and treatment they received. In addition to Dr. Jackson, Dr. Keith Lloyd from Adult Urology is also treating the patients in conjunction with her Spina Bifida clinic.

The most challenging part of the transition process has been neurosurgical care. Adults with hydrocephalus tend to have fewer shunt problems than are seen in the pediatric population but still need ongoing neurological assessment and even surgical treatment at times. In 2010, Dr. Blount from pediatric neurosurgery recognized the need for transitional neurosurgical care. He began working on a process which would allow him to attend the clinic that Dr. Jackson was successfully running. Dr. Blount’s role in the clinic is to evaluate the patient’s needs and assist in the transition to his adult partners. His function in the clinic is ongoing care, while his adult partners will pick up the acute operative needs.

As the clinic coordinator of The Children’s Hospital Spina Bifida Clinic, I have also been attending the Adult Clinic to assist in the transition process. Currently the adult clinic meets on the third Wednesday of every month from 12-4 at Spain Rehab. For more information on the Spain Rehab Adult Spina Bifida clinic, you can contact me at 205-939-5281 (betsy.hopson@chsys.org).





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Adopt-a-Ghost 2010



Alabamians across the state “adopted ghosts” during the month of October on behalf of the Spina Bifida Association of Alabama. Over \$3700 in funds were raised, not to mention awareness of Spina Bifida across the state!

Some participating businesses, such as Moody Monday’s in Huntsville, AL, went beyond just raising funds through Adopt-a-Ghost. Moody Monday’s hosted a Pancake Breakfast on October 23rd and donated all of the proceeds to SBA of AL. Bridgette Gardner and her crew raised over \$1,000 which will go directly to serving our families in Alabama.

Pickens Academy in Carrollton, AL, also worked beyond just selling ghosts, by selling ghost lollipops during their school lunch period, raising over \$600 to donate in honor of their fellow classmate, Owen Johnson. Big thanks to Michele White for coordinating Pickens Academy’s Adopt-a-Ghost campaign!

Thorsby High School in Jemison, AL, holds the title of Top Ghost-Selling Participant with 563 ghosts sold! Thank you to Vanessa Langston for coordinating this hugely successful awareness campaign!

A very special thanks also goes out to Stephanie and Brodie Brazier for coordinating participating businesses in Huntsville and Hazel Green, and to the Oveson Family in Mobile for coordinating participating businesses there.

We should treat every month as Spina Bifida Awareness month, not just October of every year. Speak up, be an advocate for yourself and our community, and let your story be heard year round.

If you know a business or school that would be willing to participate in the Adopt-a-Ghost 2011 Campaign, please contact Stacey Courson at staceymoc@comcast.net or (205)417-5330.

Please be sure to visit our 2010 Adopt-a-Ghost participants and give them a big THANK YOU!

Moody Monday's (Huntsville)
Knight Moves (Hazel Green)
Hillcrest Barbers (Mobile)
Hazel Green Chiropractic (Hazel Green)
Blackwater Hattie's Bar and Grill (Huntsville)
Animal Hospital of North Alabama (Hazel Green)
Popeye's Chicken (Rainbow City and East Gadsden)
Hwy 53 Sports Bar and Grill (Huntsville)

Mellow Mushroom (both Mobile locations)
Sipsey's Grocery (Aliceville)
Paradise Bowling Lanes (Rainbow City)
Mama Goldberg's (Montgomery)
Thorsby High School (Jemison)
Pickens Academy (Carrollton)
Pennington Animal Hospital (Huntsville)
Hillcrest Barbers (Mobile)

Spina Bifida-Staying Healthy and Living Longer

On Friday, October 8th, individuals and families from across the state gathered at The Children's Hospital's of Birmingham Bradley Lecture Center to attend the SBA of AL and The Children's Hospital 2010 Spina Bifida Conference. Whether the attendees were nurses, physicians, individuals affected by Spina Bifida, or their parents, all were there for the singular reason of learning more about living with Spina Bifida and remaining healthy throughout a life span. The impressive line-up of nationally renowned, expert speakers on Spina Bifida was incredible.

Dave Carl, a social worker and author from Washington, opened the conference speaking on overcoming challenges and effective goal-setting and achievement. Living with Spina Bifida himself, Dave has experienced anxiety and depression and uses his life experiences to help others with disabilities. He also helps these individuals gain and retain employment. Through his work, speaking engagements, and seminars, Dave teaches people of all ages, with and without disabilities, the importance of independent living. His children's book, Super Cyclist, also relays this message by chronicling the story of John, a determined kid in a wheelchair who wants to catch criminals when he grows up. Although others discourage him because he has a disability, John decides to follow his heart and overcomes his challenges to achieve his dream. Just like his "Super Cyclist" character, Dave Carl served as an inspirational motivator to all of us at the conference.

Dr. Jeffrey Blount, Pediatric Neurosurgeon at Children's Hospital, tackled the topics of hydrocephalus and shunt health maintenance, as well as the detection of tethered spinal cord. Both of these topics are of great concern to most individuals and families living with Spina Bifida, so it goes without saying that Dr. Blount had a captive audience. So much so, that during the break after his time speaking, he was surrounded by attendees asking more questions about these topics. This just goes to show that Dr. Blount is just as popular as a conference speaker as he is among his patients!

Dr. Timothy Brei, Developmental Pediatrician at Riley Hospital for Children in Indianapolis, spoke on positive parenting and the importance of promoting independence in persons with Spina Bifida. Dr. Brei touched on Non-Verbal Learning Disabilities (NVLD), as well as organizational and social skills strategies. Dr. Brei, a member of the Spina Bifida population himself, is an international speaker on Spina Bifida and currently serves as the Medical Director for the National Spina Bifida Association. Dr. Brei also contributed very candid and helpful information as part of the adult panel during lunch.

Tammy Beasley, a registered, licensed dietician from Huntsville spoke after lunch on obesity, proper nutrition, and the importance of exercise. She lectured extensively on how to "rev up" your metabolism in order to lose weight, reduce food cravings, improve wound healing, and increase your energy. As creator of Rev It Up!, a wellness program taught by registered dietitians across the country, Tammy was able to not only give nutritional guidelines, but also demonstrated simple exercises to do from a wheelchair. Tammy's enthusiastic and encouraging attitude set the tone for the remainder of the conference.

Dr. David Joseph, Chief of Pediatric Urology at Children's Hospital, discussed the topic of renal health maintenance. Renal health is a concern of everyone living with Spina Bifida, therefore, we feel so fortunate that Dr. Joseph agreed to speak on this very important topic. Dr. Joseph touched on urodynamic assessment, how to protect your urinary tract, catheterization and urinary continence, controlling infections, and surgical treatments. He effectively covered each topic across the life span, from newborn to transitioning teenager to adult, giving all the up-to-date medical information needed for urinary health and maintenance.

Joe Thieme from Advantage Medical in St. Cloud, Florida, has been fitting people with their wheelchairs for over 30 years. He has taught proper wheelchair fitting at the National Spina Bifida Association Conference for the past 10 years. Joe discussed mobility and the importance of a thorough and correct seating evaluation. It goes without saying that many attendees were in line to receive Joe's expert recommendations on their chairs. He made himself available for evaluations and adjustments long after most of the crowd had cleared. We wouldn't expect any less from "Joe, the Wheelchair Guy".

We would like to say a very special thank you to Betsy Hopson, President of SBA of AL and Spina Bifida Clinic Coordinator at Children's Hospital, for all of her hard work and dedication in making this annual conference even better with each passing year! We are so fortunate to have such a passionate advocate volunteer her time and talents to our association. Our babies are her babies, and her actions speak this fact very loudly! ***Thanks Betsy!***



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2011 SBA of AL Huntsville Bowl-a-thon Come Join the Fun!



April 30, 2011

2-4 p.m.

Madison Bowling Center

8661 HWY 72 West

Madison, AL 35758

If you are an individual or business that would like to participate, provide a sponsorship for the event, or find out more information, contact Stacey Courson at 205-417-5330 (staceymoc@comcast.net).

Gadsden Bowl-a-thon is a Success!



The Gadsden bowl-a-thon participating teams and businesses did it again! The SBA of AL support in this area is always amazing. Every single year, due to the incredible dedication and hard-work of the families and businesses in the area, they top the awareness and funds raised from the previous year. The October 23rd event was the most successful yet!

Awareness has always been a big focus in this area. Bowling teams go above and beyond helping the SBA of AL educate others about Spina Bifida and its prevention. Articles featuring local families were published in both The Gadsden Times and The Messenger. An on-air interview was conducted on WQSB (105.1) where Spina Bifida Awareness Month and the Gadsden bowl-a-thon were the focus. Teams such as the Kids Care team, a local children's service group, had a car wash where they gave out brochures and spoke to people about this birth defect. Teams, such as Hayley Nelson's and Faith Abernathy's, "pounded the pavement" raising awareness in both Calhoun and Etowah counties, while other teams like the Gitchell Clan raised funds and educated others by having a bake sale and doing face painting during a local event called First Friday.

The funding gained was also astounding! This year the crowd was amazed when the total of \$14,000 raised was announced. This could not have been accomplished without the overwhelming community support. A record twenty-one sponsors signed on to support the bowl-a-thon. We are so thankful to every individual, team, and business who participated in helping us during this event! Because

of you, we are able to support our families more effectively and raise more awareness across our state!

We also want to say a special thanks to Altrusa International, Inc. of Gadsden who for the third year in a row not only supported us through a sponsorship but by also providing volunteers to work the event! We were also very blessed to have Moments by Awdrey volunteer to capture the magic of the day through photography. Enjoy some of these moments on the next page!

Thank you to all our sponsors!



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SBA of AL Christmas Party

By Stacey and Sophie Courson

Note from the Editor:

I would like to say a very special thank you to the SBA of AL Board of Directors for making the First Annual SBA of AL Family Christmas Party possible. Our Board is continually looking for ways to better support our families and provide opportunities for them to make connections with one another. They hit a home run with this one! The party was a huge success and such a blessing to me, the rest of the SBA of AL staff and Board, and to every family that attended. Stacey Courson did an incredible job planning the details of this event, and she and her daughter, Sophie, capture the spirit of the day beautifully in their words below.

From a Mom's heart:

Families from across our state gathered on Sunday, December 5th, to attend the SBA of AL Christmas Party. The Senior Lodge of the Vestavia Hills Recreation Complex proved to be the perfect setting for our family fellowship. The tree was decked, the fire was poppin', and the gifts were a'plenty. Our families dined from several tables of yummy finger foods and desserts, while the children made crafts, colored Christmas pages, and played with their brand new toys courtesy of Toys 4 Tots and the United States Marine Corps. Each child affected by Spina Bifida and their siblings were graciously gifted two gifts each by our US Marines. Cool Reign, including our very own Ryan Hart, provided the background music for the occasion, even playing some of our favorite Christmas carols. Mandy Hubbard of Gallery 26 Photography graciously agreed to capture our party on film. The star of the party was, of course, Santa Claus! After making a grand entrance, he sat and visited with the children and families throughout the remainder of the party.

Looking around the Lodge, one couldn't help but be touched by the families connecting and catching up with one another, children playing together, and new friendships being made. It's times like those when you truly realize that being with others that understand your struggles, makes the celebrations that much sweeter! My only regret is that I didn't have the chance to speak with each and every family member in attendance. Instead of looking at the party as a great ending to 2010, I would rather view it as an awesome beginning to 2011! Happy New Year and God Bless!



SBA of AL Board of Directors (left to right): Cindy Wester, Lori Turner, Betsy Hopson, Martin Nalls, Taron Thorpe. (not pictured Ben Chambliss and Betty Bell)

From a Child's heart:

The Christmas Party was a lot of fun and Christmassy. There was a big tree decorated with beautiful ornaments. The food was very delightful, even though I didn't eat much since I was helping other kids in the craft room. When Santa Claus, came in to our party the band played "Here Comes Santa Claus"! He was so nice and he was warm when I sat in his lap, probably because of the fire beside him. A pretty lady took everyone's picture with Santa. There were three really tall Marines that gave each child 2 gifts. I LOVED my gifts. I got a Moxie Girl and a Liv Doll. They are so pretty and I love to play with them. I was having so much fun. I didn't want to go home. I hope we have another Christmas Party next year.

Some of our SBA of AL Families and Kiddos!



(Pictures cont. next page)



Special Thanks Go To:
GySgt Donald Allen, USMC and
Toys 4 Tots

Tommy Godwin, Santa Claus

Mandy Hubbard, Gallery 26
Photography

TJ Guffey, Buffalo Rock in
Huntsville

Vestavia Hills Recreation Center

Jennifer Brandon, Hallmark

Musicians of Cool Reign
(Ryan Hart, Steve Thomas,
Michael Nelson, Tim Wright,
DeAnne Glass)



Mark Your Calendar

National Folic Acid Awareness Week January 2-8

Be sure to use this week as an opportunity to raise awareness in your area. Contact your local newspapers and radio stations, spreading the message about the daily intake of folic acid's link to the prevention of Spina Bifida and other neural tube defects.

SBA of AL Advanced Education Scholarship Deadline April 30, 2010

Applications can be found on our website at www.sbaofal.org under Programs.

C.A.S.T. for Kids May 7, 2011 Lake Guntersville

A one day fishing event for children with disabilities ages 6-18. Parents are encouraged to attend with their children. Children are matched up with expert anglers from the BASS Federation and/or other fishing organizations who will take them out on boats and teach them fishing, safety, and fishing ethics. To find out more information or to register, visit <http://www.castforkidsalabama.org/>. You can also contact:

Brian Atkins

BAtkins@CASTforKidsAlabama.org.

National Spina Bifida Association 38th Annual Conference Anaheim, California June 26-29

To find out more information, you can visit www.sbaa.org. If you are planning to attend the National Conference, please be sure to contact Angie Pate at 256-617-1414(angie.pate@sbaofal.org) for more information on the **SBA of AL National Conference grant**. The application deadline for this grant is April 30th.

**If you have not been receiving e-mail updates on our events, please e-mail Angie Pate (angie.pate@sbaofal.org) with your updated e-mail address.*

SBA of AL Membership Form

January 1 – December 31, 2011

We firmly believe that every form completed is another "voice" to help gain supporters, grants, and sponsors. There is no fee for membership. Each person who responds can draw more public and political attention to our mission to promote prevention of Spina Bifida through folic acid awareness while enhancing the lives of all currently affected. Please help us make a difference by completing and returning this information.

Your name: _____

Address: _____

City: _____

County: _____ State: _____ Zip: _____

Phone: (Day) _____ - _____ - _____

(Evening) _____ - _____ - _____

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E-mail: _____

Name of person with Spina

Bifida _____

Person with SB is (circle) Male / Female

Please check all items that best describe you.

☐ Parent of a child w/SB (child's name _____ and date of birth _____)

☐ Adult with SB (date of birth _____)

☐ Family member with SB (not parent)

☐ Friend/Supporter

☐ Medical Professional

☐ Other

I am: ☐ White ☐ Black ☐ Asian ☐ Hispanic ☐ Other

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SBA of AL

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