Spina Bifida Association of Mississippi

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THE ENABLER

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Inside this issue:

"A resource for people in Mississippi living with Spina Bifida."

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Dr. James Keeton—Retires with Praises From All!

Compiled by Amy Wilkinson

Drs. James Keeton & Mark Barraza

News that Dr. Keeton is retiring is met with mixed emotions by his patients and co-workers. While we realize he deserves a much needed break, we will miss the tremendous care he has given to his patients over his many years of practice. In his new position, he will be overseeing the Surgical Unit at UMC.

Throughout his practice he has taken care of an untold number of patients with Spina Bifida, being the primary care provider urologically, for the majority of the children ages 0-21 for the entire state of Mississippi. He has "passed the baton" to Dr. Mark Barraza.

We especially thank Dr. Keeton's wife, Jona, for providing these priceless pictures. Who wouldn't love a doctor who would allow himself to be painted, or one who dressed up as Santa?

There are numerous stories – some funny, some sweet – to tell about Dr. Keeton. A few of his patients and co-workers shared their thoughts.

"I knew this day would come sooner or later (I would have preferred much later). This was the day I had dreaded for so long. The man who got me through so many tough times wasn't going to be there anymore.

Dr. Keeton always encouraged his patients' independence. He was always very eager to hear the next step I had taken in achieving my independence. At last year's SBA Christmas party I told him that I had recently moved into my own apartment. He jokingly told my mother, "I'm glad she finally got rid of you."

Dr. Keeton's constant encouragement is, in large part, why I am who I am today - a young adult with SB who is living independently and holding down a full-time job. Thank you, Dr. Keeton, for the care and concern you have shown your patients and their families over the years."

Amy Wilkinson

Dr. Keeton fishing with his Uncle, James Keeton.

Dr. Keeton's godchildren, on the eve of their father's funeral.

"Dr. Keeton to me - one of the most giving and caring men I've ever known and worked with. Besides being a great boss, he gave 100% in taking care of 'all' his children.

The last few years before Dr. Barraza came, Dr. Keeton was stretched to the max with an office practice and Spina Bifida/UMC patients. He recruited Dr. Barraza to insure these special kids wouldn't suffer an interruption in their urological care. He could leave private practice and feel these patients and future patients would continue to have the best of care. Need I say more? That's the kind of man he is."

Joyce Splain, R.N.

The EnABLEr is published quarterly by the SBA of Miss, 1511 Tracewood Drive, Jackson, MS 39211. Susan Branson, Editor. Permission to reproduce items may be obtained by calling (601) 957-2410. Please send a copy of the re-printed material to the above address. Although every effort is made to ensure information is accurate at the time of publication, our readership is advised that the field of spina bifida is growing rapidly. The reader is advised to consult qualified medical professionals in his field. Views and opinions expressed are not necessarily those of the SBA of Miss.

Chapter Updates

Our members attended a Bowling Party at Paradise Lanes in Jackson. The event was made possible by donations raised at the Enterprise Rent-A-Car Charity Golf Tournament. Thank you, Enterprise!

Abigail Branson helps deliver the toys collected at our Christmas Party. The toys and gifts were received by Jennifer Drews, Child Life Specialist at Blair E. Batson Children's Hospital in Jackson.

Our Board members have been busy the past few months planning meetings and events. We would love to report everything was well attended, but this was not the case.

Our First Aid and CPR Class in Philadelphia and "Achieving Independence" talk in Jackson prepared by our members Hope Ratcliff and Amy Wilkinson were cancelled because no one signed up. Only three families from our Association attended the Pajama Party at Borders and four families were present at the Panhellenic Tennis Tournament. We would like to see greater participation in our Chapter events. We can also raise more awareness when a larger number of families participate.

We would like your input in deciding which programs to host for the remainder of the year. Our Association is made up of over 180 families with spina bifida. Together we can support each other and make a huge difference!

Webmaster and Treasurer Needed

Our chapter needs a new Webmaster and a Treasurer!

Justin Ratcliff, the designer of our web page will be taking a leave of absence for the next two years while he completes mission work for his church. He has done an incredible job with our site. It was recognized as the #1 SBAA Chapter website in the country during it's debut year.

Justin has completed two years of study at Ole Miss and plans to study aerospace engineering. Thank you Justin for establishing our site and for all of your innovative ideas! We wish you luck!

If you would like to pass on a message of thanks to Justin, write to our chapter's email address: sbamiss@hotmail.com. Take a minute to let him know how much we appreciate his efforts!

Our chapter is also in need of a member to volunteer to as Treasurer. It would be helpful if this person lived in Jackson and had a computer. Please call our office if you can help!

Member Birthdays

May Birthdays

Courtney Fortune	5/10/90
Gabriel Roth	5/20/96
Rebecca Heath	5/27/84

June Birthdays

Dazeon Bail	6/4/94
Haley Wilson	6/4/94
Hannah Fitzhugh	6/14/93
John Word	6/14/99
Chazmine Haynes	6/14/00
Angel McCain	6/18/78
Sarah Tagert	6/18/82
Kacie Hall Baughman	6/21/90
Steven McBride	6/25/82
Emily Turner	6/26/94
Tommie Lee	6/30/99

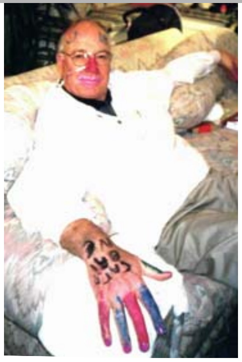
July Birthdays

Maggie Long	7/98
Chassity Bradshaw	7/7/93
Dustin Moak	7/7/79
Angel Montgomery	7/14/98
Courtney Hudspeath	7/15/86
Zena Taylor	

If you are not listed, we do not have a record of your birthday. Send in your information today!

Dr. Keeton's Praises Continued

DR KEETON



Dr. Keeton smiles after being fixed up with nail polish and face paint. Lovely!!

"The thought of the way Dr. Keeton has cared for Amy over the years brings a smile to my face. He treated patients as though each one was his only concern – (a smile). With just a little "sharing" about Amy, Dr. Keeton knew who she was and what his plans were for her -- (another smile). Dr. Keeton has consistently sought the most current procedures for all his patients with spina bifida in order that their lives would have the highest quality possible.

On one occasion, Dr. Keeton had arranged for Amy to have surgery. After Amy was taken back to the operating room, I saw Dr. Keeton coming toward me. He looked anxious and advised us he had decided not to perform the surgery at that time. He was not certain about how this surgery would affect the long-term care for Amy and wanted to "think" on this a bit longer – (another smile!).

There has never been a doubt about his dedication and commitment to our children. He has afforded parents to "breathe a little easier" by winning their confidence through his tenderness and gentleness – (another smile). Thank you Dr. Keeton for the "smiles" you have given to our family."

Carolyn Wilkinson

"For nineteen years, I have looked forward each week to the day that I worked with Jimmy Keeton. I have been giving anesthesia to his patients for that long, and it has, indeed, been an honor to be associated with him.

His operations were not the simplest procedures,... but [his patients] needed surgery and Jimmy Keeton was happy to help them. He wanted them to have the quality of life that they deserved.

And his enthusiasm was contagious. You could not help but be excited about a successful outcome for each patient. To Jimmy Keeton, each patient was so important. He was genuinely concerned about every one of them. For him, their well being was what it was all about.

If I had the chance to pick any surgeon I know to work with, it would be Jimmy Keeton. Why? Because he is technically excellent and his bedside manner is unsurpassable. He cares about his patients. Bottom line...he cares."

Camille J. Jeffcoat, M. D.

Dr. Keeton with his dog "Bear."

Dr. Keeton with his 90 year old father.

"My son and I moved from Atlanta to Jackson 7 years ago and Dr. Keeton was our first experience with a Mississippi doctor. I have to say he has been a blessing. He always treats his patients like he was treating his own child. We are really going to miss you, Dr. Keeton."

Sandra Temple and Derek Middlebrook

"Dr. Keeton has been my urologist since my birth almost 23 years ago. Anytime my mom thought I might have a UTI all she had to do was call. Dr. Keeton always joked that I was "weird" because I NEVER responded to treatments, medications, etc. as most of his patients did. My family and I knew this day would come and dreaded it. I appreciate and will sincerely miss the special rapport we enjoyed as doctor and patient. May God continue to use you to bless others as you have blessed my life, Dr. Keeton."

"The Weird" Dustin T. Moak

Dr. Keeton as "Santa."

"I have been going to you for as long as I can remember. I am so sad that you are not going to be our doctor anymore. I want to thank you though for all that you have done for us through the years. We were more then just patients to you. We were your friends. Thanks for being so nice to us.

The memory I remember about you is when I came to you for a visit and you did an ultrasound. After you read it you told me that I had the quietest little kidney's you ever did see... I was so proud that you said that about me! Thanks Dr. Keeton! I love you so much. You are more then my doctor...you are my friend!!"

Rebecca Heath

"Dr. Keeton introduced himself within hours of Abigail's arrival to the NICU. He told us our relationship with him would last a life-time; or at least until he retired. He appeared too young to retire, so we took comfort. I guess we were wrong, but we are thankful Abigail had four years under his care!

We appreciate how supportive he has been of the SBA of Mississippi.

Dr. Keeton riding an elephant!

Now he will have more time to enjoy fishing, spending time with family, playing dress-up and riding elephants! "

Susan Branson

ACE PROCEDURE

ACE Procedure Has Changed Our Lives!

By Susan Branson

As part of editing this newsletter, I receive newsletters from other SBA chapters throughout the country. Last year I received a newsletter from the SBA of Massachusetts, and read with great interest an article written by a 15 yr. old boy who had recently had surgery to help control his incontinence. I knew Dr. Mark Barraza was performing a similar procedure, the ACE Procedure, on patients in Mississippi. After much research and discussion with Dr. Barraza, we decided to have this surgery for Abigail, our 4-year-old daughter born with spina bifida. It has changed our lives, and I feel compelled to share her experience with you.

> "Although this surgery does not change her paralyzed bowels, it does give us the predictability of knowing when she will use the bathroom..."

Not much past the age where it is unusual to find a child still in diapers, Abigail was beginning to be aware of the restrictions associated with bowel incontinence. Up until this time we had controlled her paralyzed bowels by administering laxatives every 3 days, which would help her to completely empty her bowels. This "system" worked well for us, except that it meant bowel movements for up to 10 hours, and sometimes at inconvenient times. This uncertainty would dictate when she could be away from home and playing at friend's houses, when she could swim, and when she could wear her braces. It was our desire for her to have freedom in all of these areas, despite complications related to spina bifida.

We scheduled an appointment to discuss the ACE Procedure surgery with Dr. Barraza to see whether it would be an option for Abigail. He took the time to explain that ACE meant Antegrade (moving or extending forward) Continence Enema. He told us how he would make a small incision in the abdomen to locate the appendix; or if the appendix is not available, part of the bowel itself could be used. He could perform this laproscopically or in conjunction with another surgery on the abdomen. He would bring the appendix to the surface of the abdominal wall and create a stoma (a small opening). To complete the operation he would stitch a flexible catheter in place, which remains for six weeks while the skin surrounding the stoma heals. The patient would later be able to insert a catheter in the stoma and into the bowel to help empty the bowels.

He was very patient with us, as we had many questions. He discussed how he would perform the surgery with Dr. John Gosche. We decided to schedule the operation.

It has been two and one half months since the surgery, and we have been very pleased with the results. We wanted to share our experience, and we encourage all families living with spina bifida or bowel incontinence to see whether this procedure would be the right option for you.

Pre-Operation

Prior to the operation, Abigail was required to completely clean out her bowels. Not unlike her normal laxative regimen, but even more thorough. She drank a bottle of Magnesium Citrate to finish the clean out. We also completed pre-admission certification the day before surgery. During this time, I was careful to let all hospital personnel know about Abigail's latex allergies. I found the pre-admission nurses were unfamiliar about which items contained latex. The nurse completing the blood work knew not to wear latex gloves, but was going to use a latex tourniquet, and apply a latex band-aid. She was receptive to my suggestions, but I would caution all patients and parents to become their child's "latex police" in any hospital environment. (Our office has a detailed handout identifying items found in the hospital and home environments contain latex, and a suitable alternative for each product. Please call us to request a copy—it could save your child's life!)

Getting Ready to Begin

Shortly after arriving at the hospital, Abigail was given a sedative and taken down to the pro-op holding area. Again, we were given the opportunity to ask questions and to meet all of the physicians and nurses who would be in the operating room. We brought our list of products containing latex, (put on our "latex police" hats) and hospital staff seemed to appreciate the information. After all questions were answered, and Abigail was promised a new Barbie doll, she was taken off to surgery. We were told to wait in her hospital room and the nurse would call us during the surgery.

The Operation

We were called and updated during the surgery and after about 45 minutes told to come down to the surgical waiting area. After another short wait, I was allowed to see her. She was still under sedation, but her first question was if I had remembered the Barbie doll! I was able to hold her if I kept her reclined. We were back in our room within an hour.

Recovery

Dr. Barraza explained how he had performed the procedure. He was pleased with how he had been able to bring her appendix up to the area below her belly button to create a stoma. After a nap back in the room, Abigail woke up and had questions as to why she had bandages on her stomach and an IV. She felt most comfortable in a reclined position. I asked about her need for pain medication, but she did not seem in any real discomfort. Dr. Barraza had told us because of the lack of sensation in her lower half of her body, she may not be able to feel much pain. This was the

Abigail, one week after ACE Procedure. Incision site on lower left is where laproscope was inserted.

ACE Procedure continued

ACE PROCEDURE

case for Abigail. She seemed more agitated about her throat being sore from the anesthesia tube. I was relieved, because I knew her sore throat would pass quickly.

I was very pleased how Dr. Barraza and Dr. Gosche's teams made numerous visits to our room. Dr. Barraza explained in a very appropriate way for a four year old, how he actually placed a tube in her "stomach." She was very proud of her new tube, and made sure all visitors saw her latest feature!

Discharge

Her hospital stay lasted from Tuesday morning to Thursday morning. The main reason for the hospital stay was to administer antibiotics. Brief training on how to use the stoma and administer the enema was given. An appointment for a follow up visit was scheduled with Dr. Barraza.

Actual Enema Process

At home, on Friday evening, we administered the first enema. A bag that was hung on a hook above the toilet was filled with one half of an adult enema solution. This bag had a tube for the enema to drain out and into the tube held in place in her stoma. Gravity helped the liquid to flow into her appendix and in turn into the beginning of her large intestine. Following the enema, we poured 2 cups of saline solution into the bag. This drained into her appendix as well.

The results were almost immediate. We heard bowel sounds when the enema was draining into the stoma. Shortly after the saline began, she was having her bowel movement. It took about 30 minutes for the saline to completely drain in. After about 1 hour total, her bowels appeared to be completely emptied, and mostly clear liquid was draining into the toilet. She did not seem uncomfortable with the process. As she learns to "bear down" to assist with the process, I believe the length of time for the procedure will decrease.

Two Months Later

We have made a few slight adjustments in this process over the last few months. We now use regular tap water and not saline, and alternate the enema solution with the tap water. We have also found completing the procedure every two days seems to work best for Abigail. The complete procedure takes about 45 minutes to one hour.

Pleased with Results

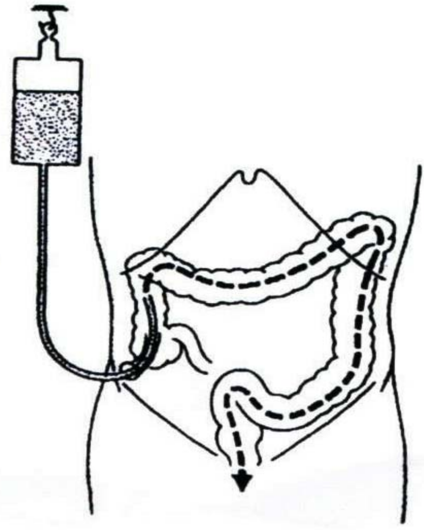
We have been very pleased with the results of the surgery. Abigail has been able to wear her braces every day, unlike her previous schedule of 2 days with her walking braces, and one day off to allow time for her many diaper changes. She also now has the freedom to swim whenever she chooses; and for those who know our family, we swim very often!! If she chooses, she will now be able to participate with her brothers and sister on swim team.

The biggest difference has been in the predictability of when her bowel movements will occur. Although this surgery does not change her bowels, it does give us the predictability of knowing when she will use the bathroom, and for a shorter amount of time. She has the freedom to play at her friend's houses any day, knowing she will not have an "accident." She is able to wear regular underwear, and no longer needs diapers, which thrills her.

Two months after the surgery. The actual stoma opening is the size of an 8 French catheter and is located just below her belly button.

We feel as though she has a new lease on life! One of the most difficult aspects of living with spina bifida was the uncertainty related to bowel movements and the social implications of incontinence. This difficulty has now been turned into something manageable and we are so happy for Abigail. I am thankful for having read the SBA of Massachusetts newsletter and how it prompted us to inquire further about this surgery. Sharing information can be powerful!

Approximately 2 cups of saline solution (salt water) or a phosphate enema is placed in a bag hung just over a yard above the floor while the patient is sitting on the toilet. The solution and the contents of the bowel empty into the toilet.



For More Information

If you are wondering if this procedure would benefit you or someone who has difficulty with constipation, please contact your Urologist. I would also be glad to share more about our experience and you may contact me at spbranson@juno.com or by phone at (601) 957-2410.

MEDICAL

ACE Procedure Study

ACE Procedure
Study on Physical and Emotional Benefits

A paper written by a team of doctors in Norway reported some of the physical and emotional benefits of the ACE procedure for their patients. A group of patients (age 6-17) was tested before and after the ACE procedure for physical issues (fecal leaking, constipation, etc.) and emotional issues (self-esteem, independence, etc.). This group was also compared to a similar group that did not have the procedure.

The ACE recipients showed significant physical improvement after having the procedure in terms of independence, fecal incontinence, and constipation. Six of the patients did require some revision to the ACE procedure afterward – all of these revisions were successful. One patient did eventually have a colostomy procedure 10 months after the ACE procedure.

	Pre-ACE	Post-ACE
Independence with fecal washout procedure:		
No assistance required	1	8
Some assistance required	-	8
Major assistance required	15	3
Not applicable	3	-
Fecal Incontinence:		
Never/Rarely	4	16
1-4 times per month	7	3
Several times per week	8	0
Constipation:		
No problems	9	16
Minor problems	3	2
Major problems	7	1

In terms of mental health and self-esteem, there were significant improvements within the group as measured by survey results from the participants and their parents.

	Pre-ACE	Post-ACE
Mental Health and Self-Esteem:		
No problems	0	11
Minor problems	2	6
Moderate problems	4	2
Considerable problems	14	1

The doctors concluded that the ACE procedure was a relatively simple procedure that had a high likelihood of improving a patient's ability to become independent in toilet matters and avoiding problems of fecal leaking or constipation. The improvement in the patient's ability to manage his/her toilet matters independently removed a significant source of social isolation and resulted in improved mental health and self-confidence.

Best Prescription-Avoid Latex!

Latex allergy is an important problem for an increasing number of people. The general population has roughly a 3% sensitivity rate, while people who have spina bifida have 30% to 70% sensitivity rate.

Due to the high probability of latex allergy, avoiding latex is the best management. Educating families and providing a list of products containing latex and latex substitutes is essential. Medical procedures on children who have spina bifida always should be carried out in a latex-free environment.

An article found in <u>Pediatrics in Review</u> magazine wrote "Patients who have latex sensitivity should be instructed to obtain Medic-Alert bracelets and carry self-injectable epinephrine." (January 1999, Volume 20, Issue No. 1)

Through the Jackson Panhellenic Association's recent Tennis Tournament, funds were donated to pay for all members to order Medic-Alert bracelets. Please call our office to request an order form.

Many products found in the home and school environment contain latex such as: pencil erasers, chewing gum, tires, door stops, carpet backing, bathing suits, remote control buttons, band aids, shoes, sandals, diapers, incontinence pads, newsprint, coupons, lottery tickets, fabric paint, glue, and many more items. The good news is for most of these products, there are suitable alternatives!

Please call our office for a *Latex in the Home* and *Latex in the Hospital* flyer printed by the Spina Bifida Association of America which was updated in Spring of 2001.

Create a Local Spina Bifida Awareness Campaign

Adrienne Griffen of the Spina Bifida Association of America wrote to our chapter about an upcoming Spina Bifida Awareness Campaign. With members spread all across Mississippi we have a potential to really increase awareness in many different communities. Please call our office to obtain the materials listed, or to brainstorm about how you can spread the word in your area!

We're mothers. We're fathers. We're sisters. We're brothers. We all have one thing in common…somehow we all live with spina bifida. Either we have a child with spina bifida, we care for someone who has spina bifida or we have spina bifida ourselves.

But not many people outside our spina bifida community know exactly what spina bifida is. Not many people know how to say it let alone what it's like to live with it.

This year between Mother's Day and Father's Day, the Spina Bifida Association of America is launching an awareness campaign in partnership with group members. We would like the Spina Bifida Association of Mississippi to participate in this effort.

So, what's in this for you?? Use this opportunity to build relationships with other community groups, increase fellowship among your members, and catch the eye of a potential funder or two! When you're out in the community display a sign for your organization that says that you're a non-profit and donations are tax-deductible.

We are providing suggested materials and community education activity ideas. Feel free to be creative and do something new and different or a project that you know will work well for your membership in your area. We just ask that you do some focused media and community outreach over the five-week period between Mother's Day and Father's Day. Together we can make a difference. Together we can help people begin to understand what spina bifida is.

1.) CHILDREN'S STORY HOUR

Local libraries are a great way to reach families. Ask your local library if you could host a "children's story hour." Offer to read a children's story about spina bifida, like "Rolling Along with Goldilocks and the Three Bears," or "Princess Pooh." (Both are available through SBA of Miss. office (601) 957-2410 or SBAA's I&R 1-800-621-3141.) You may want to approach the library with an offer to man a table with information on spina bifida.

2.) AWARENESS POSTER DISPLAY IN GROCERY STORE

Approach local grocery stores and ask if they will display a spina bifida awareness poster for the duration of the campaign. Why grocery stores? Women who are at increased risk for having a child with spina bifida say this is the best place to communicate with them. Spina bifida awareness posters are available from SBAA's I&R Service 1-800-621-3141. Add your local contact information and ask your local grocery store to hang one up!

3.) SPINA BIFIDA TAG LINE ON LOCAL BUSINESS FAXES/EMAILS

(An example fax sheet is available.)

Ask local businesses and individuals to add a line of text to their fax cover letters that gives information on spina bifida. Then this information is passed along to other individuals and businesses when they send out a fax. You could also ask local businesses to add this text to the signature blocks of their emails for the duration of the campaign. Just think of all the people you could reach!

4.) PRESS RELEASE

(A sample press release is available.)

Let the local media know that you are participating in the spina bifida awareness campaign and let them know what community activities you will hold. The press release is the quickest, most succinct way to do this. Follow up with a quick phone call.

5.) BUILD A "FRIENDS OF OUR SBA" LIST

Whenever you're in the community for an awareness activity, ask your attendees to sign in. You can use this list to approximate the number of people you are reaching with your activity and you can provide them with updates on your future activities.

Thrift Home Care

Thrift Home Care of Brookhaven, MS provides durable medical equipment in southwest Mississippi. They are Joint Commission credited and serve the counties of Pike, Amite, Walthall, Franklin, Lincoln and Amite.

Thrift Home Care is open five days a week in Brookhaven and six days a week in McComb and can be reached at (601) 684-2871. They strive to provide the best equipment available and service possible by continuous training and education of all employees. A respiratory therapist handles all types of oxygen and other respiratory services. Their Advanced Nursing Program provides private duty nursing services.

THRIFT HOME CARE
119 West Presley Blvd., Ste C
McComb, MS 39648
(601) 684-2871

They would be glad to help with the above named services as well as wound care products, ostomy supplies, diabetic supplies, and other related items.

Making My Mark

By Hope Ratcliff

Hope Ratcliff is a recent graduate of Miss. College & Board Member of the SBA of Miss.

My mom said something to me that really revealed to me my nature as a disabled person that I would like to elaborate on in this article. It was about a year ago when I first decided to move out on my own. My grandmother bought a new trailer and asked me to take residence in her older one. It was beautiful and looked like it was just bought and so I eagerly accepted. But, because it had been so well taken care of over the years and looked like new, my mom was concerned that my wheelchair would be too damaging to the interior walls and floors and that my grandmother may regret giving me the opportunity to live there once I moved out and returned ownership to her.

So, my mother went to my grandmother, who lived in Texas for most of my young life and didn't fully identify with everything that my being in a chair meant, and proceeded to explain to her what my living there would do to the trailer. She said to her, "Hope lives in her chair. She is going to hit things and dent and scar walls and mark up the floor, because that is how she gets around and gets things done." When my mom told me she said that to my grandmother, she opened up to me a reality that I had not even considered until that moment.

When she said, "Hope lives in her chair," she didn't mean that I dwelled on the fact that I was in a chair. Actually, it was just the opposite. She meant that I lived normally despite that very fact. She meant that I didn't let it stop me from living. She knew that I would have to scar up the walls and mark up the floors in order to do the things one has to do on a daily basis, especially when living alone, because the term 'user friendly' didn't apply to me. She made no excuses and had no complaints about that reality, because she knew that in an able-bodied world, a disabled person has to make due if they want to succeed. She knew that some walls needed to be knocked down and I had been doing that all my life and would continue to do so with a vengeance.

My grandmother, without hesitation, agreed to allow me to live in her trailer for as long as I wanted, and I will celebrate one successful year of living on my own in June of this year. And now, when I look around and see the dents in the walls and the scuffs on the floor, I just nod my head and laugh and say that I'm just making my mark.

We Will Miss Mark Smith

Mark Smith, longtime executive director of the Coalition for Citizens with Disabilities, died on Monday, February 25, 2002, of cancer complications. Smith was a tireless advocate for the disabled from lobbying lawmakers for disability rights to coaching Challenger League baseball.

"He believed everyone should be treated equally," said Christy Dunaway, project director of Living Independence for Everyone, an organization founded by Smith.

Mark Smith spent his life to better the lives of others. He did not have a disability or close family members with a disability, but saw a need and did his best to help.

Smith was a National Truth Team Coordinator for Justice for All, an advocacy group, being awarded the national "Justice For All Disability Rights Award," during the 11th anniversary of the Americans With Disabilities Act. "Mark was a very compassionate individual," said Senate President Pro Tempore Travis Little, of Corinth.

The Spina Bifida Association of Mississippi will miss Mark and the leadership he provided for our members. A donation of $100 was made on behalf of the SBA of Miss. to the Coalition for Citizens with Disabilities.

Special Needs Planning Kit

The Special Needs Planning Kit is an easy to use, step-by-step guide to making sure that all the needs of your loved one, regardless of age or disability, are met if you are unable to care for that person.

Barton Y. Stevens, ChLAP, founder of Life Planning Services, developed the Special Needs Planning Kit, designing it to include every possible issue faced by families - from legal planning to making sure your loved one's favorite snacks are in the fridge.

Included are detailed instructions for recording information for Wills, the Special Needs Trust and other legal documents. You'll create a monthly budget for your loved one; calculate the effects of income on SSI cash benefits; and specify how your estate should be distributed. A legal planning section includes instructions for your attorney on coordination of the Special Needs Trust kit with other legal documents.

The kit contains the Letter of Intent forms to include all the information future care providers will need to continue the level of care previously provided. Also included is a section on government benefits and guardianship information. A disk is provided which includes all the forms in the kit.

The costs for this planning can easily exceed $2,000. This kit is available now for only $240 including shipping and handling. A donation will be made to SBA of MS for 15% ($36) of the sales price of each kit purchased.

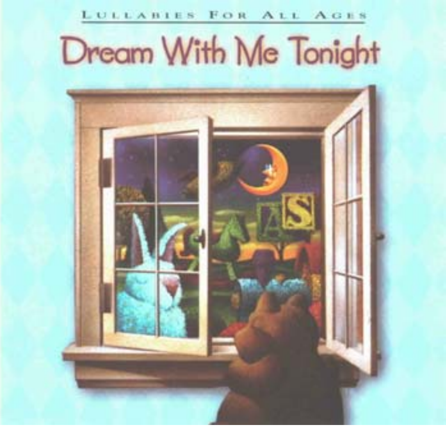
To order, call 888-222-8441 or visit: www.specialneedsplanningkit.com.

Dream With Me Tonight Raises Funds and Awareness

The Spina Bifida Association of America is pleased to announce a new partnership that is music to our ears!

The producers of the award-winning lullaby CD, *Dream With Me Tonight*, have committed to donating 10% of the proceeds from the CD sales to SBAA! Each *Dream With Me Tonight* CD will also carry an insert about spina bifida to raise awareness of spina bifida and SBAA's many resources.

Lanny Sherwin, President of Sandman Records and producer of the CD, approached SBAA last fall when he was looking for an active and growing non-profit to receive a portion of the proceeds. "We were looking for a unique group that matched our own goals with high energy, high quality and a meaningful mission. SBAA seemed a perfect fit - a newly energized organization with chapters throughout the country."



"This is a wonderful opportunity for the Association, not only to raise much needed funds, but to educate the public about spina bifida," said Cindy Brownstein, SBAA's CEO. "*Dream With Me Tonight* is one of the best lullaby CDs we've heard - it is quality from start to finish and we are very pleased to be able to work with Sandman Records."

Dream With Me Tonight was voted "Best Toddler CD" in 2001 by the Children's Music Web. The Children's Music Web Awards are the world's first internet-based music awards for children, where the awards are decided by kids. *Dream With Me Tonight* recently received the prestigious Parent's Choice Foundation Award. The Parents' Choice Award's seal of approval is awarded to products that meet and exceed standards set by educators, scientists, performing artists, librarians, parents, and kids themselves.

"If each of our members bought one CD and encouraged their friends to purchase a copy, this campaign would be off to a great start. Word of mouth is a very effective tool for advertising children's music, and the more we talk the more money we raise," said Brownstein.

Visit www.dreamwithmetonight.com to purchase your copy, listen to tracks from the CD and to learn more about the making of the CD. *Dream With Me Tonight* can also be purchased at most music and bookstores nationwide.

Dream With Me Tonight is licensed by Scream Marketing in Nashville, TN, and distributed nationally by Navarre Distribution.

Pajama Party at Borders Bookstore

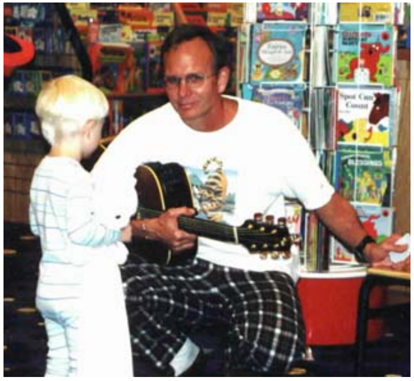
Singer Susan Haynes with songwriter Lanny Sherwin captivate the children with stories and music.

Children enjoyed reading to themselves before being serenaded by lullabies.

Over 50 people from the community attended the Pajama Party as part of the Grand Opening Festivities at the new Border's Bookstore in Dogwood Festival Market.

While the children were munching on milk and cookies we introduced our members in attendance and shared information about Spina Bifida and folic acid. This was a great opportunity to raise awareness! We thank Lanny Sherwin and the Border's Bookstore staff for their work on promotion efforts.

Our chapter will be selling the *Dream With Me Tonight* CD as a fundraiser during the next 6 months. (Price $13) Call our office today to place your order.



Lanny visits with a toddler in his PJ's.

DREAM WITH ME TONIGHT

National Spina Bifida Conference in Orlando, Florida

June 24-26, 2002

Walt Disney World Resort

Spina Bifida Association of America (SBAA), the national support center for Spina Bifida chapters, will be holding their annual conference in Orlando. The Spina Bifida Association of Florida is working with the SBAA to make this year's conference the best ever!

Two thousand people from across the country are expected to attend this educational conference including parents, children and adults with Spina Bifida, physicians, nurses, educators, and social workers. There will be a special session for Nursing and Health Care Professionals.

Conference Registration Fees:

$240 per person with current SBAA membership (adult, child, parent or physician), **$320 for nurses** with current SBAA membership (Additional fees for non-members and applications received after 4/15 Early-bird deadline).

A recent IRS ruling allows parents to deduct registration fees and travel expenses to medical conferences on their child's disability. Hotel and food expenses are not deductible.

Workshops will include:

Medical Updates: Neurosurgery, Orthopedics, Urology, Genetics, Fertility, Folic Acid, Latex Allergies, Secondary Conditions, Psychosocial Development, and Research

Educational Issues: IEP's, Due Process, Learning Disabilities, Driving, Assistive Technology in Schools

Related Issues: Siblings, Employment, Housing, Independence, Agent Orange, Depression, Americans w/ Disabilities Act

Special Issues: Insurance Systems, Home Modification, Community Support

Children's Programs:

Daily activities and outings will be run by a professional staff, meeting children's medical and social needs (also latex safe). For the older children there will be seminars to learn about Spina Bifida and mastering life skills. Programs will be available as follows: Infants and Toddlers (0-2), Preschool (3-6), Youth (7-12), Teens (with Spina Bifida), and Brothers and Sisters (ages 13—19 without Spina Bifida).

How can I find out more?

Call our office at (601) 957-2410.

Enterprise
rent-a-car

Enterprise Rent-A-Car's successful Golf Tournament and the Enterprise Foundation's generous grant will be funding camp scholarships for 2 young people this summer.

Also, 11 people will be attending SBAA Conference in Orlando. They will be receiving scholarship funds for conference registration, hotels and a portion of their travel fees.

Look for attendees reports from camp and the conference in the next issue of The Enabler.

We sincerely thank Enterprise for providing the funds to make these scholarships possible!

Dr. Karin Muraszko Inspires Her Patients

It's not often that a young person with spina bifida sees their doctor walk in the exam room with leg braces on and knows that their doctor truly knows how they feel and what they go through. Dr. Karin Muraszko does. Dr. Muraszko was born 46 years ago with spina bifida leaving one leg shorter and weaker than the other.

She knows she is lucky. At birth her doctors gave her a very small chance of a "normal" life. She was walking at age two, to the amazement of her doctors, but they felt that this ability would be short-lived. It wasn't.

Dr. Muraszko knew what career path she would take. After years of intensive training, Dr. Muraszko is now chief of pediatric neurosurgery at C.S. Mott Children's Hospital in Ann Arbor, Michigan. In the year 2001 she performed approximately 400 neurosurgeries, most on patients born with spina bifida. One of Dr. Muraszko's main goals is to teach women the importance of taking folic acid before conception. Taking 400 mcg of folic acid daily can decrease the chances of the child developing spina bifida by 75% and she takes this message to women around the world. She goes to Guatemala annually with colleagues to speak about this and related issues and to perform surgery at no charge on children with neurological disorders.

She admits that dealing with a brace can be complicated. She realizes, however, that seeing her with the brace can instill confidence in her young patients. "It's easier to do things for them than to see them struggle. That's the great thing about my job: I get to spend time helping parents and children do what's necessary so the kids grow into independent people."

Dr. Muraszko and her architect husband, whom she met on a blind date, look anxiously to the time they can experience parenthood for themselves. They plan to adopt a child soon to add to the thousands of children she has that she sees every year in her practice. She is their inspiration.

This inspiring article was found in Good Housekeeping Magazine, January 2002. Our chapter summarized it due to space constraints.

Membership Info

Your membership fees to the SBA of Miss. will enable us to continue providing programs and educational materials to over 200 families in Mississippi living with Spina Bifida. As always, membership dues are optional.

Membership Levels:

$10	SBA of Miss. Member
$30	SBA of Miss & SBAA member ($20 to Nat'l SBAA)
$50	Professional Member & SBAA ($40 to Nat'l SBAA)
$250	Sponsoring Member* ($20 or $40 to SBAA for membership)

*Sponsoring Members will appear in The Enabler for one year.

Valuable Services Available to Members:

1. Quarterly newsletter, The Enabler
2. Invitations to chapter meetings; both educational and social
3. Referrals to area service providers within their geographic region
4. Web site posting current conferences, clinic information, facts about SB, email and contact information
5. "Goodie Bags" delivered to hospital when in the Jackson area
6. Free books and SB related materials
7. Contact with other families in the SB community.

New Members and Renewals February-April

Mrs. Amy Allen*
Mr. & Mrs. Alan Branson*
Dr. & Mrs. Donald G. Branson*
Mr. Larry Chisholm
Mr. Jamy Dickson
Ms. Margaret Dowdall
Ms. April Farmer*
Mrs. Amy Freeny*
Mr. & Mrs. Eddie Fuente
Mrs. Valerie Garriga
Dr. & Mrs. Michael Gleason
Dr. Marilyn Graves*
Dr. Virginia Green*
Ms. Roxanne Harville
Mrs. Alice Heath*
Dr. Anita Henderson*
Mr. & Mrs. Robert Hess*
Ms. Stacey Ishee*
Mrs. Barbara Kasper
Ms. Michelle King
Mr. & Mrs. Stevie Lovelace*
Pat and Jan Mahaffey*
Mrs. Barbara McBride*
Peggy and Shelton McKay*
Dr. & Mrs. Drew Middleton
Miss. Band of Choctaw Indians*
Mr. & Mrs. J. Moak*
Mr. & Mrs. Gordon Montgomery
Murphy Family*
Dr. & Mrs. Howard Nichols
Dr. Andrew Parent*
Dr. Kenneth G. Perry, Jr.*
Sr. Marie Louise Pohlman
Mrs. Diane Preuss, RN
Dr. John Purvis*
Ms. Hope Ratcliff*
Mr. & Mrs. Mark Roth*
Mr. & Mrs. David Setzer
Mrs. Charlotte Shaw*
Ms. Allison Shelton*
Mr. Lanny Sherwin*
Mr. & Mrs. Scott Sides*
Mrs. Pam Stanfield
Ms. Cheryl Steve*
Ms. Sarah Swanner/MS Band of Choctaws*
Kyla & Perilia Taylor*
Mrs. Karin VanderVelde
Dr. Glen C. Warren
Mr. And Mrs. Tremon Watson*
Ms. Amy Wilkinson*
Mr. & Mrs. Richard Wilkinson
Mrs. Julie Williams*
Ms. Jan Wilson*
Mr. & Mrs. Jerome Wojnicki*
*Indicates National SBAA Member

Contributors (above Membership dues)

Ms. Margaret Dowdall
Mrs. Valerie Garriga
Mrs. Linda Hickey
Elda and Ross Roth
Dr. & Mrs. Boyd Shaw
Mrs. Susan Sneed
Mrs. Karin VanderVelde
Mr. & Mrs. Richard Wilkinson

Sponsoring Members

(Each donating at least $250 within the last 12 months)

Jackson Brace and Limb
Enterprise Rent-A-Car Foundation
Enterprise Rent-A-Car
Telepak, Inc./Cellular South
Pediatric Orthopedic Specialists of MS
Scoots of Petal, MS
Duraline Medical
MS Band of Choctaw Indians
Friends of Abigail Branson
Mentor Urology
Dr. and Mrs. Corcoran Sneed
Co-Lin Comm. College Nursing Students
Dr. Glen C. Warren
Dr. & Mrs. Donald G. Branson
Anonymous Contributor
Mr. & Mrs. Jerome Wojnicki
Jackson Area Alumni Panhellenic Assoc.

CONTRIBUTORS

SPINA BIFIDA ASSOCIATION OF MISSISSIPPI

1511 Tracewood Drive
Jackson, Mississippi 39211

ADDRESS SERVICE REQUESTED

Look inside for a special pullout chart listing state and federal agencies providing services to our families.

Panhellenic Tennis Tournament is a Grand Slam!

The Jackson Area Alumnae Panhellenic Association held their 12th Annual Ladies Doubles Tennis Tournament on April 6th and it proved to be their most successful tournament ever. This may be attributed to the masterful leadership provided by Emily Berg, event Chairman, or to the amazing support of the Alumnae members, or because of all of the terrific publicity surrounding the event. The Panhellenic Association selected our Association to receive a large portion of the proceeds from this year's tournament.

Every court was filled during the tournament and 3 of our members were able to be on hand to talk with players about our chapter and the important role folic acid plays in preventing birth defects.

Following the tournament, Emily Berg presented us with a check for $2,000! The amount they were able to generate is incredible, considering the entry fees were only $20 and it was limited to 70 players!

Our Association is grateful to have had the opportunity to increase spina bifida and folic acid awareness to a wonderful group of women.

This donation will make a tremendous difference! With the proceeds of the Tournament, our chapter will be offering to purchase Medic-Alert bracelets for all people in Mississippi with spina bifida. Call (601) 957-2410 for info.

Hope Ratcliff, Emily Berg, Event Chair & Amy Wilkinson

Tournament winners with Emily Berg