



# SPINA BIFIDA ASSOCIATION OF ALABAMA

## April-June 2011

P.O. Box 13254, Birmingham, AL 35202

[info@sbaofal.org](mailto:info@sbaofal.org)

[www.sbaofal.org](http://www.sbaofal.org)

*Our mission is to promote the prevention of Spina Bifida and to enhance the lives of all affected*

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## *Walk N Roll for Spina Bifida in Alabama*

We are so excited to announce that the SBA of AL will host our first Walk N Roll this year on September 24th at the Montgomery Zoo. Registration will begin at 9 a.m., and the one mile walk and roll around the beautiful Montgomery Zoo and other festivities, such as face painting and a live band will kick off at 10 a.m.

The Walk N Roll is a National Spina Bifida Association campaign. Each year they ask that their chapters host this campaign locally in order to raise statewide awareness and funding. Being a statewide event, our association is thrilled at the boundless opportunities to raise awareness of Spina Bifida and its prevention.

We have been blessed with an incredible group of women from Montgomery who have agreed to serve on the 2011 Walk N

Roll committee: Dr. Lamenda Blakeney, Missy Stewart, Candi Bowdoin, Teresa Treloar, Laura Killough, Kelci Bixenman, and Ruth Brewbaker. These women have already been hard at work to ensure the success of the event. Each of these committee members are also moms of children with Spina Bifida, so they are extremely passionate about raising awareness and bettering the lives of families affected by this birth defect.

To be a participant or to find out more information is easy. Just visit our new Walk N Roll website at [www.walknroll4SBAofAL.kintera.org](http://www.walknroll4SBAofAL.kintera.org), visit our website at [www.sbaofal.org](http://www.sbaofal.org) and click the Walk N Roll logo, or call one of our staff members. We hope to see you there!



# Implication for Driving

by Dr. Charles Law



**L**ike most able bodied teenagers it is often the dream of a young person with Spina Bifida to one day be able to drive an automobile. It is a great step towards ultimate independence. Fortunately, many are able to do so. Unfortunately, there are

multiple considerations to be addressed prior to attempting to get a license. Some of these factors are medical but others are social, cognitive, behavioral, and financial. As we know, the deficits associated with Spina Bifida are broad so not all of these issues will apply to all persons with Spina Bifida.

The motor deficit can be very mild in a person with a sacral lesion but in a person with a thoracic or cervical lesion it can be severe. Depending on the motor deficit, the automobile will need to be modified to the ability of the person. Some will need no modifications while others will need extensive modification. Although it seems that this would be the most important factor, it is actually one of the least because modifications can be made to compensate for almost any physical deficit. Specific automobile modifications are beyond the scope of this article.

One of the more important factors to consider is visual deficits. Many children with Spina Bifida have visual deficits. Some are obvious such as esotropia or exotropia (eye deviation). Others are more subtle such as visual field cuts where there are "holes" in one or more fields of vision. A person can have a large visual field cut and still have good visual acuity. As you can imagine a visual field cut could have devastating consequences behind the wheel of an automobile if not recognized. These deficits are difficult to detect by anyone other than an ophthalmologist with sophisticated equipment.

Another important topic to consider is executive function deficits. Executive functions include a person's capacity for judgment, planning, sequencing, self assessment, and ability to self correct. Deficits in this area would affect a person's ability to anticipate problems, predict consequences, and plan ahead to avoid danger. Other cognitive/behavioral considerations include attention and memory. Unfortunately, attention and memory are often affected in persons with Spina Bifida. A neuropsychologist can assess a person for these deficits.

Most persons with Spina Bifida will need to have a formal driver's evaluation performed by a CDRS (certified driver rehabilitation specialist). Please go to the ADED website for a listing of CDRS evaluators in any state. The CDRS used most frequently in Alabama for this population is Craig Rogers (205-870-5999). He will be able to perform most of the assessments for the above mentioned problems and some will be able to provide training as well. They will also make specific recommendations for adaptations to your automobile.

As you can imagine, modifications to an automobile can be expensive. More than one hundred thousand dollars was recently spent on one young man's vehicle that required a joystick to operate his car. Fortunately, Vocational Rehabilitation can help offset the cost of adaptations.

Driving is often considered a rite of passage for many teenagers. With proper assessments and training many persons with Spina Bifida can also achieve this milestone. Driving can open a whole new world of opportunities for socialization, education, and eventual vocation.

## Family Connections

We are happy to announce that Stephanie Brazier has agreed to be the new Family Connections Committee Chairperson. Stephanie, who has been a volunteer for our organization for more than two years now is also the very proud mother of Brodie. As a mom of a child with Spina Bifida, she is dedicated to helping families across our state make connections with one another.

Stephanie plans to help coordinate statewide picnics for our families this summer. These picnics will be the perfect opportunity for families to meet and will be filled with lots of great food and other fun activities. If you are interested in helping host of one these picnics in your area, please contact her.

**Stephanie Brazier**  
**256-655-7496**  
**Sbrazier71@bellsouth.net**

# Urinary Tract Infections~ When to Treat?

by Dr. David Joseph

A urinary tract infection is identified when bacterial colonies are grown from a urine specimen. The method used to obtain the urine determines the significance of the number of colonies identified. A voided specimen can be difficult to obtain and often contains urinary contaminants. A sterile catheterized specimen is the most accurate way to identify the presence of bacteria within the urine. But, the presence of bacteria in the urine is not always a cause for alarm or an indication for treatment.

Everyone will intermittently have bacteria in their urine, but if your urinary system is normal and you have normal voiding function you will effectively clear the bladder of bacteria when you completely empty. Children and adults with Spina Bifida (SB) have more complicating factors such as abnormal urinary systems, ineffective emptying, a strong likelihood of intermittent catheterization, and a possibility of previous urinary reconstruction. All of these factors make individuals with SB more susceptible to having bacteria in the urine.

There are several different pathogens (types of bacteria) that can live within the urinary system. The most common bacteria, E Coli, is often encountered because of its predominance within stool. An E Coli urinary infection often raises concerns because of its similarity in name to other E Coli intestinal and blood infections but it rarely results in the same serious problems. Other bacteria found in the urine, however, do have a tendency to cause generalized illness and in some cases formation of urinary stones.

It must be appreciated that individuals with SB are unique and each individual will be treated in a different fashion. Comparing what has happened with yourself or your child to that of a friend or another child is not beneficial.

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## Saying Goodbye to a Hero

Our state and the Spina Bifida community said goodbye to a true hero on February 2nd of this year. Mr. Bill Whatley, who was known for many years as the oldest, active living person with Spina Bifida, was not only an inspiration to those with disabilities but to everyone who knew him. Even at the age of 81, there was nothing that could hinder the incredibly infectious spirit of this awe-inspiring man.

Mr. Whatley spent his life helping others with disabilities reach their dreams. Thirty-seven years ago, he helped to start Phoenix, a nonprofit organization in Huntsville that provides jobs, job placement, and other services to people with disabilities. This organization, that began as just a dream of his, has now grown to \$30 million in annual revenue, 450 employees, and serves thousands of individuals with disabilities.

His strong work ethic was undeniable, and even though his work kept him busy, he always took every opportunity to speak to others about overcoming challenges in order to reach their dreams.



Our organization had the privilege of having Mr. Whatley speak at our 2009 annual learning conference. During his talk, he told the audience that he owed his success to parents who “never treated him like he was any different”. He said that his parents had made every effort to treat him exactly like other children without disabilities and always encouraged him to reach his goals. Mr. Whatley said it was very important to his parents that he grew up independent, and that even though he had to learn to do some things differently, that it was important that he learned to do them himself. He was sure to encourage the parents of children with Spina Bifida who attended the conference to do the same.

These were such wise words from a tremendously wise and successful man. Mr. Whatley will be greatly missed by our organization and by everyone who knew him.

*Note: Some information provided by Keith Clines, staff writer, The Huntsville Times. Photo provided by The Huntsville Times.*





## Turning Disabilities Into Possibilities



### Orthotics

- Foot, Ankle, Leg, Hip, & Spinal Bracing
- Trauma Bracing
- Wrist, Arm Bracing
- Cervical Collars
- Foot Orthotics
- Diabetic Shoes and Custom-Molded Diabetic Inlays
- Compression Hose and Garments
- Orthopedic & Custom Molded Shoes
- On-Site Fabrication

### Prosthetics

- Upper and Lower Extremity Prostheses
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## **2011 National Conference and Kids!Camp Scholarships**



The 38<sup>th</sup> National SBA Conference will be held June 26 - 29<sup>th</sup> at the Disneyland Hotel in Anaheim, California. The conference, *Today's Magic, Tomorrow's Vision*, will offer a wide variety of accredited speakers focusing on medical, educational, social, and vocational issues relevant to Spina Bifida. The conference is also an opportunity for your child to attend Kids!Camp, a specially designed camp experience for children with Spina Bifida and their siblings. For additional conference/registration information go to [www.sbaa.org](http://www.sbaa.org) or call (518) 399-7181.

The Alabama Council for Developmental Disabilities (ACDD) is a great resource for assisting families of children with special needs attend both state and national conferences. The ACDD can reimburse up to 75% of your conference expenses (\$1,000 maximum per person) through their Consumer Involvement Fund if you are selected. You can download an application at [www.acdd.org](http://www.acdd.org) or call the Council Office at (800) 232-2158. The ACDD has been extremely generous to our families in the past and we encourage you to apply as soon as possible if you are interested in their assistance.

For the sixth straight year our Association is offering Conference and Kids!Camp scholarships for our Alabama families. Please email Cindy Wester at [westersbaa@aol.com](mailto:westersbaa@aol.com) or call (205) 706-7187 to apply. Recipients will be selected by our grant committee based on availability of funds with priority given to families who are first time applicants. Our scholarships are paid directly to the SBAA toward conference registrations, so please, do not prepay your registration if you apply. All applicants will be contacted during the first week in May with our committee decisions. Completed scholarship applications for the National Conference and Kids!Camp must be postmarked or emailed by April 30<sup>th</sup> to be considered.



## **New Mylar Balloon Program**

We have a brand new program in place that we hope will be a wonderful blessing to our families! At the February Board of Directors meeting, it was voted that our organization would begin the Mylar Balloon Program. This program is simple. If someone you know with Spina Bifida is in the hospital due to issues related to this birth defect, go online to our website at [www.sbaofal.org](http://www.sbaofal.org), and fill out an application to have a mylar balloon delivered from our organization directly to the hospital room. This program is statewide, so if your friend or family member is in a hospital within the state of Alabama, don't hesitate to fill out the form! You can also contact our staff with any questions about this program.

## **Coming Soon...**

**The SBA of AL website will soon have a brand new look! Don't miss out on all the new updates and information that will be included! Visit [www.sbaofal.org](http://www.sbaofal.org) after May 1st to see the changes!**

### **Don't Forget!**

**The SBA of AL Advanced Education Scholarship Deadline is April 30, 2010**

Applications can be found on our website at [www.sbaofal.org](http://www.sbaofal.org) under Programs, or you can contact Angie Pate for more information.

## **SBA of AL Calendar of Events**

### **Huntsville Bowl-a-thon**

Madison Bowling Center

Madison, AL

**April 30th, 2-4 p.m. (1:30 registration)**

Contact Stacey Courson for more information at [staceymoc@comcast.net](mailto:staceymoc@comcast.net) or 256-682-0394.

### **Birmingham Bowl-a-thon**

Lightning Strikes

Trussville, AL

**June 4th, 11a.m.-1p.m. (10:30 registration)**

For more information, contact Betsy Hopson at [betsy.hopson@chsys.org](mailto:betsy.hopson@chsys.org) or 205-939-5281.

### **Horne Family Annual Golf Tournament**

Information TBA

Contact Steven Horne at [shorne9603@yahoo.com](mailto:shorne9603@yahoo.com).

### **Family Connections Statewide Summer Picnics** Information TBA

Contact Stephanie Brazier at [sbrazier71@bellsouth.net](mailto:sbrazier71@bellsouth.net) or 256-655-7496

### **Walk N Roll For Spina Bifida**

Montgomery Zoo

Montgomery, AL

**September 24th, 10 a.m. (registration at 9 a.m.)**

Contact SBA of AL staff, or Laura Killough at [lkillootr@aim.com](mailto:lkillootr@aim.com).

### **Gadsden Bowl-a-thon**

Paradise Lanes

Rainbow City, AL

**October 15th, 1-3 p.m. (12:30 registration)**

Contact Angie Pate at 256-617-1414 or [angie.pate@sbaofal.org](mailto:angie.pate@sbaofal.org).

### **SBA of AL and The Children's Hospital**

**Annual Learning Conference,**

**"Spina Bifida~Back to the Basics"**

The Children's Hospital in Birmingham

**October 28th, 8 a.m.-4 p.m.**

Contact Betsy Hopson, [betsy.hopson@chsys.org](mailto:betsy.hopson@chsys.org), 205-939-5281 or Angie Pate, [angie.pate@sbaofal.org](mailto:angie.pate@sbaofal.org), 256-617-1414.

### **Annual Christmas Party**

Vestavia Hills Recreational Center Lodge

**December 4th**

Time and more details to be announced at a later date



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**1-888-844-0528**

**[www.nationalrehab.com](http://www.nationalrehab.com)**



## Other Events

### **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](mailto:BAtkins@CASTforKidsAlabama.org).

### **National Spina Bifida Association 38<sup>th</sup> Annual Conference Anaheim, California June 26-29**

To find out more information, you can visit [www.sbaa.org](http://www.sbaa.org). If you are planning to attend the National Conference, please be sure to contact Cindy Wester at for more information on the **SBA of AL National Conference grant**. The application deadline for this grant is April 30<sup>th</sup>.

### **Lakeshore Foundation in Birmingham**

Lakeshore has many programs going on this spring and summer to benefit people of all ages with disabilities. For more information on all their events, visit [www.lakeshore.org](http://www.lakeshore.org).

### **June 24-26, 2011 - Camp Strive Overnight Family Camp at Children's Harbor, Age: 4-17, plus family**

For more information contact  
[loriw@lakeshore.org](mailto:loriw@lakeshore.org)

### **SB University**

New sessions have been added to SB University, SBA's new online education platform. The new sessions cover some important health topics, Medical Management of the Neurogenic Bladder (Birth to Age 10), Sexual Function in Men with Spina Bifida, and the importance of Folic Acid intake (in Spanish). A total of sixteen educational sessions are now available to view free of charge 24/7. Sessions cover a number of Spina Bifida related issues including aging, bowel and bladder management, general health and preventive medicine, and education and employment.

**For more information, go to [www.sbaofal.org](http://www.sbaofal.org)**

*Please help us update our membership database. If it has been longer than one year since you last filled out a membership form, please do so and send it to our P.O. Box. We want to make sure that we have the most updated information on our families, so you don't miss anything! If you have filled out a membership form in the last year but are still not receiving e-mails about upcoming events, please e-mail Angie Pate at [angie.pate@sbaofal.org](mailto:angie.pate@sbaofal.org) with your new e-mail address. Thank you so much for allowing us to serve you!*

## **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) \_\_\_\_\_ - \_\_\_\_\_ - \_\_\_\_\_

(Cell) \_\_\_\_\_ - \_\_\_\_\_ - \_\_\_\_\_

E-mail: \_\_\_\_\_

Name of person with Spina Bifida and date of birth:

\_\_\_\_\_/\_\_\_\_/\_\_\_\_

Person with SB is (circle) Male / Female

**Please check all items that best describe you.**

☐ Parent of a child w/SB

☐ Adult with SB

☐ Family member with SB (not parent)

☐ Friend/Supporter

☐ Medical Professional

☐ Other

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

**Send a copy of this to:**

SBA of AL  
P.O. Box 13254  
Birmingham, AL 35202

☐ I/We am/are willing to be included in the directory

☐ I/We am/are willing to be contacted as a source of support to individuals/families affected by Spina Bifida.

**Signature** \_\_\_\_\_

**Date** \_\_\_\_\_

**Donations are welcomed!**



**P.O. Box 13254  
Birmingham, AL 35202**

**Phone: 256-617-1414**

**E-mail: [support@sbaofal.org](mailto:support@sbaofal.org)**

**Website: [www.sbaofal.org](http://www.sbaofal.org)**

**RETURN SERVICE REQUESTED**

**SBA of AL's next events are right around the corner!**



**Huntsville Bowl-a-thon  
April 30th  
2-4 p.m.**

**Madison Bowling Center  
Madison, AL**

**Birmingham Bowl-a-thon  
June 4th  
Lightning Strikes  
Trussville, AL  
11a.m.-1p.m.**