October is Spina Bifida Awareness month, and we are in deep preparation for the many activities still to come this year! Before reporting on the upcoming events, I would like to invite you to join me in celebrating that last month two very deserving students received the 2010 Advanced Education Scholarship granted by the Spina Bifida Association of Alabama. Congratulations to Jenny Oveson and Jeremy Pratt! The SBA of AL is so proud of you and wishes you tremendous success this school year!

After many successful events this year to date, it is hard to believe and very exciting that the calendar of events is still so full! We want to thank all the participating businesses and schools across the state that have agreed to participate in our Adopt-a-ghost program. This endeavor raises tremendous awareness in our communities and allows Alabama to participate in a National Awareness Campaign. If you enter businesses that have our ghosts, please thank them for their participation and honor them with your business! Also, The Children’s Hospital of Alabama and the SBA of AL are co-hosting the 4th Annual Spina Bifida Conference on October 8, 2010. The title of this year’s event is “Spina Bifida~ Staying Healthy and Living Longer”. We are thrilled about the esteemed speakers scheduled to be a part of this year’s conference! As our last fund-raising event of the 2010 year, Gadsden will be having its 4th Annual bowl-a-thon on October 23rd. We are looking forward to another successful event in that very supportive community.

On August 19th the SBA of AL Board of Directors (BOD) had our quarterly board meeting. During this meeting I was truly blessed to see the overwhelming dedication and passion our board feels, for YOU, our members! It was unanimously voted that this year the BOD wants to host a Christmas party for our members and their families. Each child at the party will receive a gift, and we will have many entertaining activities for your family to enjoy. It has been scheduled for Sunday, December 5th, from 2-4:30 pm. at the Vestavia Hills Recreation Lodge, so mark your calendars! Invitations will also be sent and more details can be found on our website soon.

Finally, I would like to sincerely ask that each of you take this opportunity during the month of October to raise Spina Bifida Awareness. A mom recently told me that it is her hope that one day her daughter will not be in the position to have to explain what Spina Bifida is to her peers and to adults. This should really be all of our hope. Let’s use October, Spina Bifida awareness month, to enlighten our communities! If you need brochures on Spina Bifida or the importance of folic acid to use in your awareness efforts feel free to contact Angie Pate.

Thank you so much for allowing us to be a part of your lives,

Betsy Hopson
Bill Whatley was one of 10 people who took out a bank loan to start what is now Phoenix, the organization that's provided jobs, job placement and other services to people with disabilities for the last 37 years. His involvement in Phoenix, which serves about 800 people each year, remains one of his most rewarding efforts.

Whatley - believed to be, at age 80, the oldest active person in the country with Spina Bifida - was recognized with the Huntsville Rotary Club's 2010 Vocational Excellence Award.

"This city has been good to me, but I think I've been good to it," said Whatley.

Dick Reeves, who nominated Whatley for the award, said Whatley's been an "inspiration" to those with disabilities and to many others with no handicaps.

Whatley, a founding member of the Phoenix board of directors, had a hand in hiring Bryan Dodson, the president and CEO of Phoenix, 29 years ago.

Dodson described Whatley as a man of "vision," who was always looking ahead to the next year, the next decade. "He thinks strategically." Whatley set high expectations and standards for himself, Dodson said, and "in a positive way, he expects a lot out of you. He brings out the best in a person."

In the 37 years Phoenix has been in existence, 25,000 people have received employment or other services, and that's a conservative estimate, Dodson said.

"That's a pretty significant legacy," he said.

"Each of us have people in our lives that have been examples, and (Whatley) was one of those for me," Reeves said. "He didn't let (his disability) get in his way," and became a successful businessman.

Whatley moved from Montgomery Aviation to Huntsville in 1965 to start Huntsville Aviation at the old Huntsville airport, then moved the operation near Huntsville International Airport in 1967 and managed it until 1992. He was later appointed to the Huntsville/Madison County Airport Authority's board of directors and served with that group for several years.

The driving force for Whatley: "I love people. I enjoy meeting people smarter than I am and learning from them."

Note from SBA of AL editor: I have had the incredible opportunity to speak with Mr. Whatley several times. Not only has he inspired me, but he is also an incredibly wise man. In speaking with him a few weeks ago, he gave me some of the best advice a parent of a child with Spina Bifida could get. He told me to set goals for my son and keep my expectations high. His exact words were, "Tell your son I said to be glad if you are pushing him to do his best. You need to push him. My parents did, and I am thankful that they did."
Cerebrospinal Fluid (CSF) Shunt Malfunction
By Anthony M. Martino, M.D., F.A.C.S
USA Department of Neurosurgery

Ventriculo-peritoneal (VP) shunts are the primary treatment for hydrocephalus in children with myelomeningocele. They were first developed over 55 years ago with little change during that interval. Shunt malfunction is a very common occurrence with a failure rate as high as 40% during the first year following implantation.

Shunt malfunction can present with a variety of symptoms that are non specific and can be divided by age at presentation.

Infants will have symptoms similar to their presenting signs for hydrocephalus. For example, head circumference may increase across percentiles, the fontanelle (soft spot) may be tense, scalp veins may be prominent, and they may have downward deviation of the eyes. They are often irritable, sleepy, and have associated vomiting (emesis). Seizures may also be a presenting symptom.

Toddlers less frequently develop head enlargement as their fontanelles are more often closed. Headaches, vomiting, irritability, and seizures are prominent symptoms. It is not uncommon to have toddlers lose developmental milestones as a presenting sign.

Children may present with headaches, lethargy, nausea, vomiting, or seizures. Personality changes can be noted by parents. They can complain of double vision which is noted as a lateral gaze palsy on exam.

A CSF shunt malfunction can present with the characteristic symptoms and a CT scan demonstrating enlarged ventricles. However, about 30% of patients present with more subtle signs of malfunction. A CT scan, when compared to a previous study that was performed when the child was without symptoms, can be diagnostic if the ventricles enlarge. In some cases, slit ventricles develop and they do not enlarge with malfunctioning shunts. A shunt tap or nuclear medicine shuntogram may then be performed to diagnose shunt failure.

CSF Shunt Revisions
Shunts are essentially made of three components, a proximal catheter that is placed into the ventricle, a valve and a distal catheter that is tunneled from the valve to the peritoneal cavity in the abdomen. Although any of these components may obstruct, the most common site of obstruction is the proximal catheter. The choroid plexus may scar into the small holes in the catheter tubing. Shunt revisions in these cases may be straight forward with replacement of the proximal catheter.

Valves are less likely to obstruct, but can occur after a shunt revision when blood may enter the shunt system and clog the valve. A valve replacement and careful attention to control of bleeding so as no blood enters the shunt can correct this problem.

Distal shunt obstructions can occur due to intraperitoneal scarring. This can happen after multiple abdominal surgeries causing a diminished absorptive surface within the peritoneum. This will usually require a conversion to a ventriculo-atrial (VA) shunt. Sometimes, there is an abdominal pseudocyst which is often an indication of a low grade shunt infection. This may require treatment with antibiotics and also a conversion to a ventriculo-atrial shunt.

Besides being obstructed, shunts may fracture after being in place for a number of years. Shunt systems, over years, will develop calcifications around them and become adherent to surrounding tissues. This then leads to fractures at these sites. A common location for this is in the neck at the level of the clavicle (collarbone). In infants, they have been noted to migrate along the shunt tract, displacing the ventricular catheter. They can also migrate and erode into abdominal structures.

Although shunts are life saving for children with hydrocephalus they are fraught with complications. We pay close attention to parents' observations as they are very familiar with prior episodes of shunt malfunction. Close follow up and observation for presenting signs and symptoms can lead to prompt diagnosis and treatment for a malfunctioning shunt. This treatment can prevent serious neurological damage.

“This is an informational article. It does not replace medical advice from your physician. If shunt problems are suspected, seek medical attention.”
As parents, of course, we all want the best possible health care for our children, and at times, we are challenged in locating that care. That is especially the case when it goes beyond all local and state health care services and involves care for complex health care needs. One such very unique resource that I am excited to share with you is the Cumberland Hospital for Children and Adolescents.

Cumberland Hospital for Children and Adolescents is an inpatient rehabilitation hospital for children and adolescents from two to twenty-two years of age. The hospital is located in New Kent, Virginia, in a very picturesque, therapeutic location between Williamsburg and Richmond.

Cumberland’s Medical Director and one of its founding physicians, Daniel Davidow, MD, explains, “The vision of the physicians who started Cumberland in 1983 was to create a hospital that could provide integrated care by combining medical, psychotherapeutic, rehabilitative, behavioral and educational services to young people who are challenged by a combination of complex medical and emotional needs.” Dr Davidow proudly says, “We continue to be highly successful in accomplishing this mission.”

Cumberland treats both the mind and the body simultaneously, offering specialized care for young people with disabilities, injuries, lifelong illness, or other medical conditions. By integrating medical rehabilitative and behavioral care, our staff is able to stabilize and treat medical conditions while addressing behavior management problems, helping families cope with their child's illnesses or injuries, and reducing the likelihood of repeated hospitalizations. Dr Davidow puts it this way, “Cumberland may be the breakthrough you’ve been looking for.”

The most commonly treated diagnoses are as follows: Brain Injury, Spinal Cord Injury, Diabetes, Anorexia Nervosa, Bulimia, Clinically Severe Obesity, Autism, Sickle Cell, Cystic Fibrosis, Asthma, Spina Bifida, ADHD, Pervasive Developmental Disorder, Renal Failure, Crohn’s Disease, Encephalitis, Tourette’s Syndrome, Seizure Disorders, Epilepsy, Cerebral Palsy, and other neurological disorders. This is not an all inclusive list. Again, referral and treatment is provided to patients who are dually diagnosed with a complex medical and behavioral/mental health/psychological diagnosis. Cumberland Academy, the on campus school, enables patients to maintain their local school assignments while receiving care at Cumberland. Cumberland’s comprehensive success rate is 70% with a recidivism rate of 6%.

Cumberland accepts virtually all funding sources, including Medicaid, Aetna, TRICARE and many others. The Richmond Airport is about thirty minutes from the campus. During admission, parents may stay up to 3 nights on campus at no charge. They may also stay at either the Holiday Inn Express or the Hampton Inn, two of the Richmond airport hotels. Visitation is very open and strongly encouraged.

Please review our website for additional information at www.cumberlandhospital.com. I am based in Montgomery, Alabama, and cover the states of Alabama, Florida and Georgia. I am available to meet with families, health care providers, educators, agency representatives and others involved with health care services for children and adolescents to review the services of Cumberland and answer any questions. Please feel free to contact me.

John W. Dent, MS
Regional Marketing Liaison, AL, GA, FL
Cumberland Hospital for Children and Adolescents
800-368-3472
866-768-9160 fax
334-462-3426 cell
john.dent@psysolutions.com
www.cumberlandhospital.com

“Good for the body is the work of the body, good for the soul the work of the soul, and good for either the work of the other.”

~Henry David Thoreau
Our organization depends heavily on the incredible dedication and hard work of our volunteers across the state. We can not thank you enough for all your support! We are also so thankful to our Board of Directors and Committee Chairpersons, who volunteer their time to make sure that all of our families are getting the support they need. This January, our Board of Directors will be recruiting even more dedicated and passionate individuals to help chair committees. We want to make 2011 our best year yet, so if you are interested in volunteering your time to help, please contact one of our Board members or Angie Pate at 256-617-1414 (angie.pate@sbaofal.org)!

Check Us Out on Facebook!

We have two pages, the SBA of AL page and our Spina Bifida Connections-Alabama page. You can find out information on SBA of AL and other Spina Bifida related community events, as well as make connections with other families across the state. It is also a great place to share pictures and triumphs! There is no better way to find or give support than by connecting with other families affected by Spina Bifida. Check out what our families are saying!

“Thanks for creating this....I have a 19 yr. old daughter with SB! We have been so blessed to have such a joy in our life! We live in Clanton, Al. and there is only one other person that lives here with SB, so this will be great to talk with others with SB!”
Cynthia Vines

“What a great group! My son is 6 months old and has SB. I am happy to have found this group!”
Mandy Bradford

“This is a great group for us all to connect. Thanks to whoever started it!!!!”
Wendy Bondeson

You can also see lots of adorable photos of individuals and families affected by Spina Bifida, like this one!

SBA of AL Board of Directors

President
Lori Turner
Phone- (205) 370-4548
E-mail- lcturner1978@gmail.com

Vice President
Betsy Hopson
Phone- (205) 939-5281
E-mail- Betsy.Hopson@chsys.org

Ben Chambliss
Bchambliss@allsouthservices.com

Taron Thorpe
taronthorpe@fcb-hsv.com

Cindy Wester
westersbaa@aol.com

Betty Bell
bbell@thebellcenter.org

Martin Nalls
mnalls@homewood.k12.al.us
Even Rainy Days Can’t Take the Joy Away!
By Angie Pate

Our 2010 Horne Family Golf Tournament was a huge reminder to me of the dedication and support of our families and the community! From the very early morning of Saturday, August 14th, it began raining. This wasn’t just a sprinkle with a few clouds! It was a downpour with some pretty scary thunder and lightning. The forecast showed that there wasn’t much hope for a break in the day from the storms, either, so when I left to travel to Eagle Point Golf Club in Birmingham for the event, I expected to show up to an event with no participants. Boy, was I wrong!

When I first arrived, I saw the very dedicated Kohl’s volunteers. I have always been so impressed with Kohl’s dedication to serving their community and their willingness to support ALL of our events, but this went above and beyond! Not only did they get up at around 5 a.m. on a Saturday to be there, but now, here they stood, drenched from head to toe handing out breakfast to golfers! Yes, I said golfers—around 100 of them waiting, some under umbrellas and awnings and some right out in the rain! It was clear to me then that this day was going to be such a blessing, rain or not.

You would have expected that after 2 hours of watching the forecast get worse, the golfers would have begun leaving, but they didn’t. They were determined to wait it out until someone said the event was cancelled. They didn’t sit sulking either. It is actually one of the most fun events I have attended. Instead of complaining about the situation, the golfers all gathered in a room and had a great time talking, hanging out, being entertained by Heath and Seth Horne, and cheering each other on in our raffle and silent auction event. No one seemed to mind the change of plans. When it was finally determined that the storms were not going to stop long enough to golf, the event was cancelled. Even with all of this, the golf tournament still made $5000 to benefit the SBA of AL! What an incredible example of generosity!

One of the reasons that these participants are so dedicated to supporting this golf tournament every year is the hard work and sacrifice of the Horne family. Steven Horne works tirelessly each year to make sure this event is a success. It has grown, year after year, helping to raise more awareness and funding, thanks to his overwhelming commitment. He is also so blessed to have the support of his entire extended family, which helps him raise funding, sign on sponsors, recruit golfers, and even photograph the event each year. The golf tournament could also not happen each year without the continued support of our president, Lori Turner. She has volunteered endless hours over the last four years to ensure the success of the event. On behalf of the SBA of AL, thank you Steven and family, Lori Turner, and to all that faced the weather to come out to support us! We also want to say a very special thanks to our sponsors!

Kohl’s
Southern Company
MC Environmental Services, LLC
Precision Electric Coil
Access Expenditures, Inc.
Jay Electric
Hays Cheatwood Cornelius, Inc.

Heather, Steven, Heath, and Seth Horne

Seth is the only one that got in a quick swing that day!
October is Spina Bifida Awareness Month!

The mission of the SBA of AL is the same as the National Spina Bifida Association’s, to enhance the lives of all affected by Spina Bifida, while also raising awareness of its prevention. This is our mission 365 days per year, but the month of October gives us a very special chance to raise more awareness of Spina Bifida and to educate the community on its prevention through the intake of folic acid.

The CDC now estimates that over 181,000 Americans are affected by Spina Bifida. With this startling number on the rise, it is even more important that we do what we can to raise awareness. Having October as Spina Bifida Awareness Month, gives us a special opportunity to reach more media resources in order to get our message to the public. The SBA of AL also participates in the National Awareness Campaign, Adopt-a-Ghost. During this campaign, which runs throughout the month of October, participating businesses across the state sell ghosts at $1 each to the public. These businesses also help raise awareness during this time by handing out educational pamphlets on Spina Bifida and its prevention.

"National Awareness Month helps us educate the public and further understanding of what it's like to live with Spina Bifida," says Cindy Brownstein, CEO, Spina Bifida Association. "It's essential that people are aware that Spina Bifida affects a startling number of people in the United States. National Awareness Month was created to help us celebrate the lives of those with the birth defect." (excerpt from www.sbaa.org)

Please help us in our mission! Every effort counts! You can help by contacting your local media such as television and radio stations, newspapers, and magazines and asking them to help us raise awareness. If you need assistance in your efforts, please contact Angie Pate at 256-617-1414 (angie.pate@sbaofal.org) or Stacey Courson at 205-417-5330 (staceymoc@comcast.net). You can also be sure to visit our 2010 Adopt-a-Ghost participants during the month of October.

Thank you
Adopt-a-Ghost Participants!

Animal Hospital of North Alabama (Hazel Green)

Black Water Hattie’s Bar and Grill (Huntsville)

Hazel Green Chiropractic (Hazel Green)

Hillcrest Barbers (Mobile)

Mama Goldberg’s (Montgomery)

Mellow Mushroom (two Mobile locations)

Moody Mondays (Huntsville)

Knight Moves (Hazel Green)

Paradise Bowling Lanes (Rainbow City)

Pickens Academy (Carrollton)

Popeye’s (Rainbow City and East Gadsden locations)

Sipsey’s Grocery (Aliceville)

Thorsby High School (Jemison)
All South Services ships catheters and diapers directly to the patient’s home. We will then bill Medicare, Alabama Medicaid, Blue Cross and Blue Shield of Alabama, and other private insurances on the patient’s behalf. Please give us a call at 1-888-303-1164 for free samples or insurance verification.
New SB University on National Spina Bifida Website

The SBA has a new online educational platform. SB University (SBU) is a self-paced educational experience which covers a wide variety of topics of importance to the Spina Bifida community. From seminars featuring leading health care providers from across the country to presentations on educational and vocational opportunities, SBU has something for everyone! SBU is free. All you have to do is go to www.sbaa.org and register to receive a username and password. Here is a schedule of the upcoming sessions.

- **October 4: Education and Employment**
  - Building Independence: How to Develop Better Attention and Initiation
  - College Survival Skills 101
  - STRIVE for Success
  - Nonverbal Learning Disability and Educational Implications
  - Educational and Vocational Guidance for Individuals with Spina Bifida

- **October 11: Urologic and Bowel Function**
  - Management of the Neurogenic Bladder: Late Childhood to Adulthood
  - Evolution and Management of the Neurogenic Bowel in Spina Bifida

- **October 18: Aging with Spina Bifida**
  - Aging and Adulthood
  - Managing Changes in Later Adulthood

- **October 25: General Health and Preventative Medicine**
  - Proper Seating and Wheelchair Fitting for Persons with Spina Bifida
  - Latex Allergy: 2010 Update
  - SOS: Save Our Skin!
  - The Role of Gait Analysis in Persons with Myelomeningocele
New Splash Pad in Hartselle Brings Joy to Special Needs Children and Their Families

This article was published in The Huntsville Times on 8/7/2010 on page A3.

By Yvonne Betowt
Times Staff Writer
yvonne.betowt@htimes.com
Photo courtesy of: Dona Bonnett/A Digital Reflection

After three and half years of fundraising, planning and hard work, Phase 2 of the John Mark Stallings Special Needs Accessible Playground (SNAP) in Hartselle opened last month to the delight of children with disabilities and their families.

For the project director, Bob Francis, it was "an awesome sight" to see all the smiles on the faces of the children, many of whom had never had an opportunity to enjoy a water park.

"It was a joy to see the children and their siblings, parents and grandparents rushing to the Splash Pad to enjoy the water on such a beautiful Saturday with the summer weather approaching 100 degrees," Francis said. "The beauty of this Splash Pad is that any child can play in the water at each play station regardless of his or his ability. This facility is totally special needs accessible and usable."

The playground also includes a special swing area that was built as Phase 1 and dedicated in November of 2008 to the memory of John Mark Stallings. His father, former Alabama football coach Gene Stallings, attended the ceremony.

John Mark, who had Down syndrome, was a familiar face along the sideline when his father coached the Crimson Tide. He died Aug. 2, 2008, at the age of 46. When he was born, doctors had told the family that John Mark would not live past the age of 4.

"His life taught us that every life matters and that anyone, no matter how significant in society's eyes, can make a positive impact on others," Francis said.

Francis is especially grateful to the professional and personal support of state Sen. Arthur Orr, R-Decatur, who he said was instrumental in helping find "significant grants" for SNAP.

Orr "is a man who has dedicated his life to improving the lives of others," Francis said. "He has consistently demonstrated this throughout his life."

Francis, a member of the Hartselle Rotary Club, thanked countless volunteers who "have contributed their time, talent and resources toward completion of this magnificently worthy project."

The SNAP complex is one of, if not the, biggest volunteer efforts ever in Hartselle, said Francis in a June 12, 2007, article in The Times. Four civic groups, as well as many other organizations and businesses, have joined to build a "boundless" playground for the more than 1,700 children with special needs in Morgan County.

The Splash Pad cost $237,000. Phase 3 will be the main playground, which will cost about $365,000. The estimated cost of the completed project is $650,000. Donations are being accepted for the final phase.

The John Mark Stallings Special Needs Accessible Playground (SNAP), 406 Nance Ford Road in Hartselle, is open 8 a.m. to 8 p.m. daily through mid-September. Admission is free. Donations are being accepted to start Phase 3, which will be the main playground area. To donate, mail checks or money orders made payable to JMS SNAP of Morgan County, P.O. Box 512, Hartselle, AL 35640.
SBA of AL Activities

Spina Bifida - Staying Healthy and Living Longer Learning Conference

Friday, October 8th
8:00 a.m.- 4:30 p.m.
The Children’s Hospital Bradley Lecture Center
1600 6th Ave. South
Birmingham, AL 35233

Don’t miss your opportunity to be a part of this very exciting conference hosted by the SBA of AL and The Children’s Hospital of Alabama. Nationally renowned speakers will be discussing topics related to Spina Bifida such as nutrition and exercise, urological and neurological health and maintenance, seating and mobility, overcoming daily challenges, depression and anxiety, and tools for independence training and meeting goals. For more information contact Betsy Hopson at betsy.hopson@chsys.org.

Gadsden’s Fourth Annual Bowl-a-thon

Saturday, October 23rd
1-3 p.m. (12:30 registration)
Paradise Bowling Lanes
729 Sutton Bridge Rd.
Rainbow City, AL 35906

For more information contact Angie Pate at 256-617-1414 or angie.pate@sbaofal.org.

SBA of AL Christmas Party

Sunday, December 5th
2:00-4:30 p.m
Vestavia Hills Recreation Center Lodge
513 Montgomery Highway
Vestavia Hills, AL

SBA of AL families are invited to join us at this Christmas celebration. All children affected by Spina Bifida and their siblings will be given a Christmas gift. We will share some delicious food, time with families, and many other fun activities. Watch for e-mails, newsletter, invitations, and website updates for more details on this celebration!

*SBA of AL Membership Form January 1 – December 31, 2010

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: __________________________State:__ Zip:________
County: ______________State:__ Zip:________
Phone: (Day) __________-_________-(Evening) __________-_________
.Cell) __________-________-

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

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!