



# SPINA BIFIDA ASSOCIATION OF HOUSTON GULF COAST

## THE WAVE

**JANUARY 2009**

**Volume 1, Issue 1**

### Letter From the President

I hope you all had a wonderful Christmas and a great New Year. It was a great year for our association, we have accomplished a great deal this past year. "The Camp That Love Built" was a resounding success with everyone I talked to reporting that they had a great time and are looking forward to next year. The Christmas Party this year was held at the Verne Cox Recreational Center in Pasadena and allowed plenty of room for all of us. We hope that next year more of you will be able to attend. Those that attended were really pleased with the new facility. The new Chairperson for the Young Adult Group is busy getting input from the Young Adults to better serve their needs for educational and social activities. She is planning a Valentine's Party for February as a kickoff event. Please contact Erica Jones at EricaJ1073@aol.com for more information. 2009 is going to be even busier as we continue to strive to meet the requirements for our affiliation with National. I hope that we all have a great new year and always remember that yesterday is over, tomorrow is yet to come, all we have is today. Spend it wisely.

Respectfully, Yvonne Horner

January Birthdays:

- Marcos Callas
- Megan Davis
- Jennifer Hernandez

February Birthdays:

- Lucas Loizos
- Jason Starbuck
- Deisy Torres
- Javier Garcia
- Stephanie Cemino



### SBAHGC REMOVES MEMBERSHIP

In our efforts to serve all individuals and families living with Spina Bifida and women of childbearing age, the SBAHGC has decided to follow the lead of the national SBA and eliminate membership in the association. The SBAHGC newsletter will continue to be subscription based to help cover the cost of preparation and distribution. The national SBA "INSIGHTS" magazine will continue to be subscription based as well. The 2009 Information/Subscription form has been mailed to everyone that we have addresses for, please complete the form and return to SBAHGC along with your subscription fee as soon as possible to the office. The information forms are necessary so that we may notify everyone of upcoming educational and/or social events.

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- Here is an easy way to help SBAHGC earn money.
- Every time you search for something on the internet use GoodSearch instead of



your usual search engine. For every search you perform GoodSearch donates a penny. Give it a try. It is so easy.

- Another way to help SBAHGC raise money is to enroll in Kroger's share program. Go to [www.krogerneighborhood.com](http://www.krogerneighborhood.com) and enter Spina Bifida Association of the Greater Houston Gulf Coast.

## MEDICARE/MEDICAID REIMBURSEMENT CHANGES

On April 1, 2008, the Centers for Medicare and Medicaid Services (CMS) changed its reimbursement policy on intermittent catheterization. The previous policy allowed reimbursement for only one intermittent catheter per week unless an individual user could prove the existence of at least 2 urinary tract infections in the course of one calendar year. The revised policy now allows reimbursement for up to 200 catheters per month per individual which means no reuse.

This change was advocated for by medical equipment companies, health organizations, and universities which saw the manufacturer's term "single-use" to mean that the sterile catheter should only be used one time and then discarded.

This new policy better supports an individual's desire to void their bladder with a new catheter on a more consistent basis than once a week. For more information of the reimbursement policy change log on to [www.medicarehic.com](http://www.medicarehic.com).

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## Housing and Employment Resource Expo for People with Disabilities

The Housing and Employment Resources Expo (H.E.R.E.) is now in its second year. It is the product of a coalition of community partners who recognize that our disability community faces a unique set of challenges when it comes to obtaining employment and affordable, accessible housing. Today, Houstonians with disabilities will have the opportunity to meet with prospective employers, as well as representatives from various housing related entities and other resource agencies. Last year's event attracted over 1,000 participants and over 100 employers and nonprofit organizations.

Wednesday, February 11, 2009 at the George R. Brown Convention Center

This free event promises to be mutually beneficial for all participants. For more information call 713-837-9097 or email [houstonhere@cityofhouston.net](mailto:houstonhere@cityofhouston.net). If you are interested in volunteering at the SBAHGC booth please email [sbahgc77@att.net](mailto:sbahgc77@att.net) or call the office at 281-447-2707.

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## Custom Clothing for the Physically Challenged

I received a small brochure in the mail for a company called SPECIALLY FOR YOU, INC. They design, sew and sell adaptive clothing for the special needs of the physically challenged person. If you are interested in getting a brochure their email address is [www.speciallyforyou.net](http://www.speciallyforyou.net) or you may call them at 1-605-765-9396. If anyone knows of any other organizations that specialize in clothing of this type please let us know so that we may share that information with everyone else.

## SBAHGC ANNUAL CHRISTMAS PARTY

By Yvonne Horner and Helen Jones

The annual SBAHGC Christmas Party was held Saturday, December 13th at the Verne Cox Recreational Center in Pasadena. All of our children, young adults, and parents had a great time. The choir from the High School for the Visual and Performing Arts came and sang a number of carols for us. After the choir, lunch was served and no one went home hungry. Dessert was provided by Walmart, there were no leftovers.

Just as lunch and cake were finished we received a surprise visit from a right jolly old elf, Santa Claus. He seemed to have something for all the children and young adults. After Santa left there was a drawing held for door prizes. A good time was had by all.

We would like to thank Mr. Castille Hibbert of Compass Bank, Mr. Francis Miro of Majors Medical, and Jim Higgins and Haley Abernathy of Nearterm, for their generous support of the Christmas Party and our Association.



## YOUNG ADULT VALENTINES PARTY

by Erica Jones

WHERE: VERNE COX RECREATIONAL CENTER  
5200 Burke Road  
Pasadena, Texas

WHEN: February 14, 2009

TIME: 7 PM TO 10 PM

We will need volunteers to help with setup, cleanup, and to bring snacks. If you can help or bring something please contact Erica Jones at EricaJ1073@aol.com.



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## TURNING POINT ACTIVITIES

- Turning Point Gulf Coast is not sure if they will be able to have activities in 2009 due to Hurricane Ike.
- Turning Point North Texas has a number of activities scheduled for 2009. For information on their activities go to [www.turningpoint.org](http://www.turningpoint.org).



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## FUNDRAISING SUCCESSES

by Joan Peck

Two fall campaigns raised more than \$10,000 for our Association. These funds will help support our 2009 programs and activities.

During the month of October, 40 Cici's Pizza Restaurants sponsored our Adopt-a-Ghost campaign where Cici's customers donated one dollar for each ghost. This was the third year for Cici's sponsorship and the most successful. Cici's collected a total of \$5,469 in donations from its customers. We extend a hardy thanks to Ken English and the participating restaurants for their hard work and continued support of our organization.

During October and November, we raised \$4,961 from the distribution of Renaissance Festival tickets to the public in exchange for a reasonable donation. The Texas Renaissance Festival provided these tickets on a complimentary basis and also donated 25 tickets for our young adult community.

### CHRISTMAS PRESENT

The true spirit of Christmas is giving. As has been their tradition, the employees of American Alloy Steel donated \$3,000 to SBAHGC as a Christmas present in honor of their owner, Mr. Art Moore, whose daughter has Spina Bifida. We are truly humbled by the generosity and Christmas spirit of the American Alloy Steel employees.

## PUBLIC AWARENESS

The following article, written by Lucretia Cardenas appeared in the Conroe Courier during October,

Seven months into her pregnancy, Yvonne Horner’s daughter was told her new baby girl would have a challenging life. It was at that time doctors learned that Taylor Hardin has spina bifida, a developmental birth defect. Twenty-one years later, Taylor has undergone 21 surgeries. Paralyzed from the waist down, she lives a life of pain. However, she still lives a fulfilling life, said Horner, who is president of the Spina Bifida Association of Houston Gulf Coast. “Spina bifida happens before you even know you are pregnant”, Horner said. “The most important message we can send out is prevention”. “They don’t really know what causes it but 400 micrograms of folic acid decreases the chance by 70 percent. But this doesn’t mean a child won’t be diagnosed with spina bifida.” Since spina bifida sets in before women experience signs of pregnancy, Horner recommends all women of childbearing age take a multivitamin daily that includes the 400 mcg of folic acid, a B-vitamin that helps build healthy cells. This is especially important for Hispanic women, as statistics show Hispanic babies are up to two times more likely to be born with spina bifida, Horner said.

October is National Spina Bifida Month, and the SBA is working to encourage prevention and raise awareness that an estimated 70,000 to 130,000 people in the United States are living with this condition. As part of the efforts, SBA encourages physicians to educate women about the benefit of folic acid. According to SBA, approximately 66 percent of professionals surveys are sharing the message with patients.

If a family has a child with spina bifida, Horner wants them to know resources and support exist. The Local SBA chapter has regular meetings and events, including a summer camp. For more information about spina bifida or the local association call (281) 447-2707 or email sbahgc77@att.net. Information is available online at [www.spinabifidaassociation.org](http://www.spinabifidaassociation.org).

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## PUBLIC AWARENESS

The following article, written by Marquita Griffin appeared in the /Fort Bend Herald during October.

A week after her second child was born, doctors told Helen Jones her daughter Erica had spina bifida– a serious and permanent birth defect. The bones of Erica’s spine didn’t form properly during the first month of development, leaving her with an incomplete and exposed spinal cord, Jones was told, and it’s irreversible. Sitting in the living room strapped into her wheelchair, Erica, now 30, reflects on how devastating that news must have been for her parents. Before she was born, when all the doctors knew about Erica was determined through ultrasound, the consensus was Jones was going to have a boy. What the doctors mistook for male anatomy however, turned out to be a disfigured spine. What heavy news to lay on someone, Erica said. Especially a mother. Unfortunately, a lot of mothers hear such news about their newborn because spina bifida is the No. 1 birth defect, Erica said. But no one seems to know enough about it. A neural tube defect, spina bifida occurs when the spinal cord, brain and their protective coverings aren’t completely developed during the mother’s first month of pregnancy and, in severe cases, the spinal cord will protrude through the infant’s back. Even if surgery is performed within 24 hours, significant nerve and spinal damage will result, leading to bladder difficulties, degrees of paralysis and learning disabilities later on in life. Erica, who went through her local public school system from elementary through high school, said she made it through school like her peers, but she’s aware of her learning disabilities. “I have a tough time with math” she said lightheartedly. And I go to the doctor as much as I need to. And that is often, because almost every problem associated with the defect, Erica’s been to the doctor for it - bladder infections, scoliosis, and even skin surgery.

Although October is the official spina bifida awareness month, Erica said promoting awareness about the birth defect should be a year-round effort. “One out of every eight newborns has spina bifida” said Erica who was born and have lived her entire life in Missouri City. She straightens slightly in her wheelchair and stares piercingly. “Did you know spina bifida can be prevented just by taking folic acid supplements” she said. Pausing to let the information sink in, Erica adds, “a lot of mothers don’t know that.” Folic acid is a B vitamin that builds healthy cells and a daily dose of it can prevent not only spina bifida but other birth defects as well. This is the information women who are planning on having children need to know, Erica said. It’s a subject that needs to be studied. But spina bifida awareness isn’t limited to studying its preventions, she added. It’s also about helping those with spina bifida find the courage to enjoy their lives. Since she was 7, Erica has been a member of the Spina Bifida Association (SBA) of Houston Gulf coast and it is here, she discovered, where there is courage, there is a life. Participating in the organization’s annual camp for children with spina bifida is where Erica, and her mother, discovered the courage to both accept their hardships and living their lives to the fullest anyway. Erica said she knows she will forever face difficulties and frustrations, but she also knows that’s no excuse to stop living. When asked what she likes to do, Erica smiled, slightly amused by the question. The same thing other people do, she said. Swimming, working out, listening to music, traveling, going to sporting events, a lot of things, she said. There will be rough days Erica admitted. “But you have to stay positive, stay active.” You also have to be willing to put your fears on the line and get out there, she said. Staying on the go is what Erica and her mother do best. “Having a disability does not disable you from living” Jones said. “I tell Erica all the time that those wheels are her legs. She doesn’t have to stay put.”

**Our Mission is to promote the prevention of Spina Bifida and enhance the live of all affected.**

**We are on the Web  
sbahgc.org**

Help us to cut costs and "GO GREEN" by receiving "THE WAVE" by email in pdf. Format.

Send your request to:

sbahgc77@att.net

## About Spina Bifida

Spina Bifida is a neural tube defect and is one of the most devastating of all birth defects. The National Institutes of Health state that Spina Bifida will occur in 1 of every 1000 births in the U.S. It occurs more frequently than Muscular Dystrophy and Multiple Sclerosis combined and cripples more children than Polio at its peak. It results from the failure of the spine to close properly during the first month of pregnancy. In severe cases, the spinal cord protrudes through the back and may be covered by skin or a thin membrane. Surgery to close a newborn's back is generally performed within 24 hours after birth to minimize the risk of infection and to preserve existing function in the spinal cord.

### Dates to Remember:

- January 31, 2009—Mail in Your Information/Subscription Form
- February 12, 2009—Valentines Party
- March TBD—Little Rustlers and Rodeo Performance

and then some



- Wheelchair Accessible Vans
- Adaptive Equipment
- Lowered Floor Mini Vans
- Orthopedic Lift Chairs
- Rental Equipment
- Stair Lifts and Scooters

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1789 Upland Drive, Houston, Texas 77043