



# SPINA BIFIDA ASSOCIATION OF HOUSTON GULF COAST

## THE WAVE

April 2010

### Volume 2, Issue 2

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Spring has finally arrived and with the new year we are very excited about all the programs and services we are planning for 2010. We are growing and reaching more families than ever before. Behind the scenes we are continuing to update our website. We want this site to be a place to educate, inspire, and to keep you updated on what is going on with your association.

SBAHGC is the resource center for the Houston Gulf Coast area for our SB families, our SB friends and the community at large. Let us know if there is something you would like to see or if there is something you feel would benefit others on the website. SB families are our guides to where the association goes, our doors are always open, we would love to hear from you.

The 'CAMP THAT LOVE BUILT' committee is busy putting the finishing touches on camp. Everyone should have received their application by now, if you have not please contact Darlene Collier at XXXXXXXX. Remember we have a limited number of spaces so get your application sent in, you don't want to miss camp.

The "SUMMER IS ALMOST OVER BOWL-A-THON" will be held Saturday, August 14th so mark your calendars now. There will be more information to come as we get the planning underway.

Respectfully,

Yvonne Horner, Chair

### March/April/May Birthdays

Megan Schneider, Scott Husband, Sue Anne David, Carlos Robles, Shanna Host, Graciela Caballero, Kevin Patterson, Phillip Wolfe, Amanda Mendoza, Toni Chimento, Callie Saunders, Jason Delaney, Kelsey Ray, Kadi Conner, Heather Meyer, LaTrisia Gardner, Heaven Holt, Matthew Micetich, Pedro Macias, Haley Abernathy, Chris Young, Steven Edwards, Lesly Herrera, Lizet Herrera, Ryan Bell, SaDaerrick Josey, Sydney Smith, Anastasia Radcliff, Clifford Sloan, Kyla Glover, Emili Ingram, Lorena Nino, Natalia Cris, Anette Ramirez, Roy Sanchez, Brennan Emeka, kristyn Harvey, Katherine Armenta, Faith Olson, Alejandro Juarez



- 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.

### BOARD OF DIRECTORS

#### Board of Directors:

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

## SBAHGC CAMP THAT LOVE BUILT

by Darlene Collier

The camp dates this year are from Sunday, July 4<sup>th</sup> through Friday, July 9<sup>th</sup>. The activities have not all been ironed out yet but, of course we have the yearly swimming, horseback riding, cooking, arts & crafts, ropes course, canoeing, target shooting, petting zoo , etc.

We are hopeful that the HOGS will again come to provide motorcycle rides for everyone, and of course we are working on getting the hand cycle bikes again. As usual Thursday night will be the ever favorite "DANCE". This year our camp theme is "Disney"

Camp Applications must be postmarked no later than May 1<sup>st</sup>. Physicians forms need to be completed for all campers and volunteers in time for orientation at Shriner's Hospital on Saturday, June 12th at 9:00 am unless, pre- approved by the Camp Nurse Dorothea (Dory) Parker. It may be filled out by a physician, physician's assistant or nurse practitioner and must have been filled out within the last 6 months from camp (no earlier than January).

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## SINCEREST SYMPATHY

To the SBAHGC Camp That Love Built family: it is with a heavy heart that I inform you all of the passing of our beloved camp charge nurse, Pat Reid, R.N. of 22 years, on March 12, 2010.

Her love for all of our children and adults will be greatly missed. We wish to express our love to her family and Kevin Reid for giving her to us for all those years. God Bless each one of you.

Any donations, in lieu of flowers, that want to be made, can be made via the following memorial website: [www.memorialsolutions.com/sitemaker/sites/sites/emken10/obit.cgi?user=180242Reid](http://www.memorialsolutions.com/sitemaker/sites/sites/emken10/obit.cgi?user=180242Reid)

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## Online Research Study on Self-Care

Do you have a child (ages 10 - 29) with Spina Bifida? If so, researchers from Kennedy Krieger Institute invite you to participate in an online research study! We are interested in learning more about how and when children with Spina Bifida learn to manage their medical self-care and home responsibilities. The study does not require a clinic visit and can be completed using a computer in your home or elsewhere. The online survey usually takes about 15-20 minutes to complete and is anonymous, so no personal information such as names, social security numbers, or IP (computer) addresses will be collected. Please be aware that if your child is over the age of 18, we will ask you to obtain your child's consent. If you have questions about this study, Dr. Zabel can be reached at [zabela@kennedykrieger.org](mailto:zabela@kennedykrieger.org).

If you are interested in participating in this study, we invite you to go to [www.psychdata.com](http://www.psychdata.com) and enter survey # 128186. We thank you very much for being willing to help us and other individuals with

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## Astros vs Rockies

The Houston Astros has again donated tickets to our association. The date is Thursday, May 20th at 7:00 pm at Minute Maid Park where the Astros will play the Rockies. If you are interested in attending please contact Joan Peck at 281-320-8008 or email her at [joanpeck48@comcast.net](mailto:joanpeck48@comcast.net) . So that Joan can ensure you get the tickets you request the response deadline is May 10th.

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## **SBAHGC SUMMER IS ALMOST OVER BOWL-A-THON**

Planning is underway for the "SUMMER IS ALMOST OVER BOWL-A-THON. This event proved to be very successful last year and we hope to make it bigger and even more successful this year. Funds raised will pay for a variety of programs and services that we offer including a summer camp for children and young adults with spina bifida, new parent contact services, educational scholarships, health & education conferences, and many others.

The bowl-a-thon is scheduled for Saturday, August 4th. More information will be coming soon on how to register online for the bowl-a-thon and where it is going to be held.

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## **WE WANT TO HEAR FROM YOU**

If you would like more information on a resource, health procedure, or if there is a program you would like to see us offer please let us know. We want to offer information and programs that meet the needs of all affected by Spina Bifida.

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## **SBAHGC CONFERENCE**

Our one day conference was held Saturday, March 27th at the Marriott Hotel in Greenspoint. The Board of Directors would like to thank each of you that were able to take time out of your busy schedules to attend, we hope that the information you received will be helpful to you and your families. We would like to thank our speakers Dr. Jack, Fletcher, Dr, Catherine Ostermeyer, Dr. Robert Dauser, Dr. Mark Sutton, Dr, David Antekeier, Lisa Osten, Raceilli Dalida, Paula Mrowczynski-Hernandez, Adam Blumberg, and Andrew Harpold for taking time out of their busy schedules to present relevant and informative information for all of you. In addition we would like to thank our vendors Advocate Medical, Wheelchair Shop, Medical Technologies of Georgia, AMS Vans, Spina Bifida Research Resource, In Home Products, Turning Point, Accessible Housing, Verne Cox Recreational Facility, J & R Medical, and Calmoseptine for their insight into their products and services. The teachers Jennifer Davis, Sandra Gibson, Katrina Lyons, Cherie LaBlanche, Belinda Jones, Gina Batie, Versie Turner, and the nurses, Judy Locke, Jane Head, and Dory Parker, made the kids activities a resounding success and allowed parents to enjoy the conference knowing their children were well taken care of. Thanks also to Toni Maheshwari who assisted our Spanish speaking families and to Jennifer Franklin who manned the SBAHGC table in the vendor room.

I would like to take this opportunity to thank the Conference Committee Joan Peck, Helen Jones, Cathy Delaney, and Delores Houston for all their time and effort, without which this Conference would not have been successful. Also a very special thanks to Dr. Fletcher for providing the bound and printed copies of the speakers presentations and In Home Products our GOLD SPONSOR.

Pictures from this event will be posted on our website soon and will be in the next newsletter.

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## **SBAHGC 2010 INFORMATION UPDATE**

If you have moved, changed your email address, or phone number please take a moment to email us at sbahgc77@att.net and let us know. We have found many contact numbers and addresses that are incorrect due to moving, changing emails addresses, and phone numbers/cell numbers. This information is used only by SBAHGC to update you on upcoming events, medical updates that we receive, and to ensure that you all get the newsletters. We will not sell or give out this information to anyone else and will be kept in the strictest of confidence.

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## **PARENTS SUPPORT GROUP**

We have some excellent speakers for Spring. April 22nd. Dr. Kathryn Ostermaier will provide an overview of the Spina Bifida Clinic; May 27th. Dr. Sherry Vinson Sellers will provide an Overview of Development in Children with SB; and June 24th. Dr. William Whitehead will discuss Hydrocephalus

We invite all of you to attend these meetings and hope that the information provided will be beneficial to all.

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# SPINA BIFIDA ASSOCIATION OF HOUSTON GULF COAST

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**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

**Dates to Remember:**

April 22nd—Parent Support Group  
June 24th—Parents Support Group

May 20th—Astros vs Rockies  
July 4th—Camp That Love Built

May 27th—Parents Support Group  
August 14th—Bowl-a-Thon

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