



Christmas Party

for HD families and caregivers

December 15th at 6:30 p.m.
Exchange Tavern
6710 Waters Ave.
Savannah

**Bring the Whole Family for
Good Food & Great Fun with Santa!**

Wheelchair accessible.

For info Call 912-964-0455.



**Lowcountry
Huntington's
Disease Group**
Support/Education

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Autumn Musings

By Cindy Arnsdorff

Do the fall colors seem especially intense this year? I recently had to drive to Statesboro and the vividness and long-shadowed sharpness of the leaf foliage seemed to just reach out and demand attention. Awe inspiring and humbling, it touched me in the same way as many HD families. The beauty of their strength is truly humbling as it instills strength in others, including myself.

Entering the serious season it's time to take stock of the year, and I'm constantly reminded of all our group has to be thankful for and all the work still ahead.

We grieve the loss of our friend, Mary Holt, and bear witness to the enduring nature of the human spirit as told in an article Anne Hart wrote about our board member, Alison, who was recently blessed with a beautiful baby boy.

Though my personal HD story has become more difficult, I am amazed at the kindness of strangers and friends. My husband's church held a Bar-B-Q dinner simply "to honor" my HD husband.

Often I am asked, "What can I do to help?" So I challenge our HD families. What can be done to help? And I challenge others to extend a hand by donating your time or money.

A storm blew through last night and leaves are twirling around like an HD whirlwind. I truly appreciate the brilliant blue sky of today because of the storm. I appreciate life more fully because of HD.

Monthly Support Meetings

The support group meets the last Tuesday of the month except for special programs. For info call Sandra at 912-964-0455.

**Candler Hospital
Heart & Lung Building
2nd floor, room 2
5353 Reynolds St. at DeRenne Ave.
Savannah, GA
6:00 p.m.**

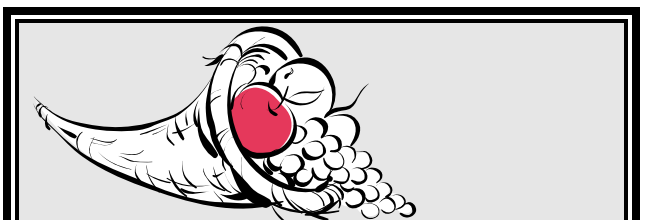
November 17 "Dr. Ruth Abramson"

December 15 "Holiday Dinner"

January 31

February 28

Dr. John Morgan, HD Clinic Director at MCG, is going to be at our January or February meeting.



Thanksgiving Potluck Dinner
Friday, November 17

**Dr. Ruth Abramson, the Director of
the HD Clinic at the University of
South Carolina, will give an update
on her HD research.**
Candler hospital at 6:00 p.m.

FREE

In Loving Memory of Mary Kathleen Holt

By Sandra Freyermuth

The Lowcountry Huntington's Disease Support and Education Group had its organizational meeting in May of 2003. Among those attending were Mary and Bill Holt. Mary had HD and they regularly attended the support group meetings at Emory and were glad to learn of a group forming in our area.

While Mary had gray hair and advanced chorea, it was easy to imagine her once red hair and the personality to go with it. She and Bill did not let her HD keep them from going out and socializing. She had a keen sense of humor and was quick to correct Bill if he made a mistake in one of his stories. Mary was an avid baseball fan. Our meetings were over as far as she was concerned when it was time for a ballgame.

My grandchildren had never been around anyone with advanced HD. Even though they were a little hesitant of her at first, it did not take them long to see the real person behind the HD. She was a role model for all of us, whether we have HD or not. Bill will always be a member of our HD family.

Disaster Preparedness for Disabled Persons

On September 25th Barbara Dunn, owner of Eldercare Management of Coastal Georgia, LLC and chairperson of the multicounty Disaster Services Committee for the local Red Cross, gave a presentation on how to have a safe evacuation. Barbara gave us excellent handouts, checklists to use for preparation, and a detailed CD all of which are available from our library. As she pointed out, the Red Cross and shelters are set up to help with food and a cot, but not the special needs of the disabled. We are doubly thankful to Barbara as she generously offered to make the presentation on "preparedness" after already coming and talking to us about her new business, unique to this area, which offers her services as a personal care planner. Drawing on her extensive nursing and teaching background, she helps arrange optimum care plans for seniors and disabled individuals. The following are just a few of her evacuation suggestions:

✓ Put together an evacuation kit ✓ Keep essentials packed at all times ✓ Study your evacuation route for gas stations, lodging, rest facilities ✓ Get an extra supply of medications ✓ Take change for pay phones as cell phones may not be usable ✓ Plan for your pets ✓ Take valuable documents ✓ Keep gas in your car ✓ Call your local emergency management agency **NOW** and get on their list if you are going to need help!

The New PHDs by Sandra Freyermuth

Have you ever tried to come up with a way to refer to your HD loved one without using the word "patient"? In 2005 at the National Convention in Atlanta I heard a new term. The term was "Phd" and it means "person with Huntington's Disease". Phd puts the focus on the fact our loved one is first of all a "person" who just happens to have HD. Because of the time and energy involved, all too often we focus on the HD first and the person second. Phd helps us get our priorities straight.

HDSA 2007 National Convention σOklahoma City, OKσ June 15th-17th σwww.hdsa.org

Tips & Tidbits

*Have a great idea? Or question?
Let us know and we'll share it in our
newsletter.*

*I'd like to purchase a Broda wheelchair
but I'm worried about how to transport it.
Any suggestions?* Northern Tool &
Equipment catalog has a telescoping 2 pc.
Ramp Set (Item 330316-1701) that can be
used to push a Broda wheelchair into a
smaller SUV, such as a Trailblazer.
Call 1-800-533-5545 for a catalog.

*I often choke on food & drinks. Is there
anything to help?*

Sometimes foods can be too thin or too thick to swallow properly. For drinks, try adding a thickener, which you can purchase at a pharmacy. A new one is "Simplythick" which does not change the taste of the drink or food. Unlike many others, it can be added to water without an aftertaste. Call 1-800-205-7115 or www.simplythick.com. For soups or pureed foods that are too thin, add instant mashed potatoes. For meats or casseroles that are too thick, add milk-or-water-soaked bread before you puree as it adds lightness.

(Side note: You might want to take thickened water for rinsing your mouth to the dentist if you have problems swallowing regular water.)

I keep dropping food on my clothes while eating. What can I do?

Use a disposable apron.
Masure First Aid & Safety at 1-800-831-0894 or www.masure.com carries disposable aprons and many other useful products.

www.LowcountryHD.com/
For the latest news

“Internet Café” Night

We owe a big Thank You to Panera Bread for helping with our “Internet Café” on July 25th. Along with offering free meals for our children and youth, they surprised us with after-dinner brownies and coffee for everyone. Next time you visit be sure to let Andy, the manager, know how much you appreciated their kindness.

Following are just a few of the Huntington’s Disease websites we discussed:

www.hdsa.org

www.hdac.org

www.hdlighthouse.org

www.stanford.edu/group/hopes

www.huntingtondisease.tripod.com

<http://hddrugworks.org/>

<http://huntington-study-group.org/>

www.hdfoundation.org

www.highqfoundation.org/

www.hda.org.uk/

www.hsc-ca.org



Donations

Send to: LHDG
P.O Box 72
Springfield, GA 31329

We appreciate all who have given donations in 2006. In the upcoming year our wish is to obtain and train a social worker to work with Huntington’s Disease families. Often an HD person does not know where to go to find a doctor with HD training in the Lowcountry or how to even file for disability. An educational program is in the works to train healthcare students in local college classrooms about Huntington’s Disease.

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Disclaimer:

In articles the mention of services or products are not an endorsement. Opinions are not necessarily those of the Lowcountry Huntington’s Disease Group. We recommend that any change in services or treatment for HD only be made with the approval of an individual’s physician.