

NEWS & NOTES

A quarterly newsletter from HD Reach

Upcoming Events

**Triangle Support Group
Annual Potluck Dinner**
December 12, 2013 6:00 pm

Bring a dish to share! Doors open at 6:00, we will have a few speakers, and dinner will begin at 6:45. Drinks and paper products will be provided. Questions? Email [Sarah Dawson](mailto:sarah.dawson@hdreach.org).

ITRE Building on NC State Centennial Campus
Research Building IV, Room 2600
909 Capability Drive
Raleigh, NC 27606
Phone: (919) 624-0053
[Campus map](#)



**Charlotte NC HDSA Support Group
Annual Holiday Party**
December 12, 2013 6:30 pm

Meet at City Tavern to celebrate and share a meal with fellow support group members. Individual checks. RSVP to Martha Lentz by [email](mailto:martha.lentz@hdreach.org) or call her at (704) 906-0547.

City Tavern
Stonecrest Shopping Center
7828 Rea Road
Charlotte, NC 28277
Phone: (704) 543-8587

Upcoming Support Group Meetings

Charlotte Area NC HDSA Support Group
January 30, 2014 7:00 pm-9:00 pm
Sharon United Methodist Church, Room A-11, 4411 Sharon Rd., Charlotte, NC 28211
Facilitator: Martha Lentz (704) 906-0547

Did you recently attend the HSG meeting in Charlotte a few weeks ago? Are you feeling overwhelmed, excited, or just feel like you need even more information because of what you learned? Did you miss the HSG meeting and wonder what it was all about? The Charlotte Area NC-HDSA Support Group welcomes HD Reach President, Mary Edmondson, a psychiatrist with over 30 years of experience working with families affected by HD, and Sarah Dawson, HD Reach's clinical social worker, who will be discussing the recent HSG meeting and any questions or concerns that group members present, particularly as related to behavior, coping strategies, long term care ideas, and disability-related issues. They would also like to hear your ideas about what topics would be of interest to the support group in the coming year.

Triangle Area Support Group
TUESDAY, January 21, 2014 6:00 pm-8:45 pm
Seymour Center, 2551 Homestead Road, Chapel Hill 27516
Facilitator: [Sarah Dawson](mailto:sarah.dawson@hdreach.org) (919) 803-8128

The Triangle Area NC-HDSA Support Group is happy to announce that the multi-disciplinary team from Duke Movement Disorders Center will be available to answer your questions in a provider panel format. Available providers will include Duke neurologists Dr. Burton Scott and Dr. Patrick Hickey, psychiatrist Mary Edmondson, Arlene D'Alli (clinical

social worker), Beth Silberman, (physical therapist), and Meghan Ward, a speech language pathologist. Come early to get a good seat, as this meeting is traditionally very popular! Lundbeck will be providing sandwiches starting at 6:00 p.m.; come at 6 to socialize and eat and then the panel discussion will begin promptly at 7 p.m.

HSG WRAP UP

Held on November 7-9, 2013, the Annual International HSG Clinical Research Symposium and Community Workshop drew 425 researchers, healthcare providers, and HD community members from 8 countries and 24 states. The latest research and information was shared, connections and lasting memories were made. Many NC families attended the conference. If you attended and have not yet contacted HD Reach for more information-please email [Sarah Dawson](mailto:Sarah.Dawson@hsg.org) or call us at (919) 803-8128. Like us on [Facebook](https://www.facebook.com/hsg2013) and share your stories and experiences from HSG 2013!



Check out this link to read an [article](#) written by health reporter Taylor Sisk in the NC Health News all about HD and the recent HSG conference.

View Point - a look at living positively with HD

Our guest columnist for the December 2013 newsletter is Sarah Foster. Sarah is from New Bern, NC and is active in the HD community. We thank her for sharing her experience at HSG. Please contact [Krista Keamey](mailto:krista.keamey@hsg.org) if you are interested in writing a guest column for our next newsletter in March 2014.

by Sarah Foster

When I found out I had the HD gene two years ago, I never thought I'd get over the shock of it, much less want to know more about the condition.

But as my acceptance grew, so did my curiosity about the disease, a cure, and about other people with HD.

So when HD-Reach awarded me the scholarship I'd applied for to help me afford to go to the 2013 Huntington Study Group Consortium in Charlotte, NC, I was thrilled to accept it. I am from New Bern, and my best girl friend, Nina, lives in Robbinsville, so we met in the middle, Charlotte, and she served as my "support person" for the weekend.

My expectations were vague, and proved to be largely inaccurate. I knew we were going to be in big rooms all weekend with a lot of people that knew a lot about HD. I expected to feel like an outsider among academics, and for a lot of the material to be over my head.

But as soon as we stepped into the Omni, and we saw the welcoming faces of the HD Reach team, I sensed the weekend would be much more significant than I had expected. This time my instincts were right. We felt embraced by the enormous group of people who all were doing all they could to find a cure or more information about HD. Several of the presenters of academic papers mentioned that their work was driven, ultimately, by the relationships they had formed over the years with HD families.

We met Barb and Fran from Greensboro the first day because we sat at the same table. Fran was probably the first non-family member I had met with HD. The four of us hung out all weekend and exchanged email addresses. I hope I hear from them.

I learned more about HD and research than I could ever write about in this space, but I treasure having that information.

But more than that, I took away the sense that I am part of a community that is vibrant, loving, and growing. I'm grateful for the opportunity to learn these things, and recommend the event to anyone who has an interest in HD.

Clinical Trials News

If you were at the HSG meeting in Charlotte a few weeks ago, you saw clinical trial participants recognized with a blue carnation and applause as they were thanked for being part of the effort to combat HD. At our October Triangle Area support group, you may have heard author Jimmy Pollard say to our local clinical trial participants, "You are not a metaphor!" as he thanked them for helping in the fight to treat and one day cure HD. Want to join the fight? Consider joining a clinical trial at Duke or Wake Forest here in NC; both are currently enrolling patients in CREST and Enroll HD, and Duke has recently added First-HD and ARC-HD. Also, Wake Forest will soon be enrolling patients in a new study called PRIME.

Here are some details on the newly enrolling studies:

The PRIME study is sponsored by Teva Pharmaceuticals. This study focuses on a compound called Pridopidine; the goal is to determine if it reduces chorea and increases functional ability. It is a dose-finding safety and tolerability study; some patients will be given a placebo. The drug has a different mechanism of action than Tetrabenazine (TBZ). It is a six month study. Contact Christine O'Neill at (336)716-8611 for more information about how to enroll and for eligibility requirements.

FIRST-HD is being conducted by the Huntington Study Group (HSG). The investigational drug being studied is called SD-809 ER (extended release). SD-809 ER has the same mechanism of action as tetrabenazine (TBZ). First-HD is designed to determine how effective, safe, and tolerable SD-809 ER is compared to placebo. The study will also determine if SD-809 ER helps to reduce the chorea associated with HD. Participants will be involved for about four months.



The HSG is also conducting another trial of this drug (SD-809 ER) called ARC-HD (Alternatives for Reducing Chorea in Huntington Disease). The ARC-HD trial will determine how safe and tolerable SD-809 ER is in subjects with chorea and HD who "switch" from TBZ to SD-809 ER. ARC-HD is also designed to determine how safe and tolerable SD-809 ER is in subjects who have successfully completed the First-HD trial (go to www.Huntington-Study-Group.org for more info.)

For more information, contact [Peggy Perry-Trice](#), Clinical Trials Coordinator, or [click here](#).

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