



NEWS & NOTES

A quarterly newsletter from [HD Reach](#)



Upcoming Events

Join us for a screening of *Twitch*, a film by Kristen Powers

[Twitch](#) is the first documentary to follow the life of an individual going through genetic testing for Huntington's Disease.

Wednesday, March 26, 7 PM

[Varsity Theater, Chapel Hill](#) - \$5 donation suggested



Official Twitch Trailer



Upcoming Support Group Meetings

Charlotte Education Series tailors meetings to member's specific needs

The Charlotte Support Group has invited Dr. Mary Edmondson to meetings each month to discuss topics of interest to the group. The general format is a short talk about a symptom, and then an opportunity for the group to discuss their experience with that symptom. Then there is another short talk about coping strategies, followed by sharing of skills that have been effective for group members. Following the meetings, Dr. Edmondson and Martha Lentz write questions for the group to see how well the material was taught and presented. The handouts, questions and answers will be on our [blog](#) each month, so check them out!

Charlotte Support Group

Thursday, March 27, 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

The Charlotte Area Support Group welcomes HD Reach President, Dr. Mary Edmondson, a psychiatrist with over 30 years of experience working with families affected by HD to the next meeting to continue her educational series of talks on Huntington's disease. This month's topics will include unawareness, secrets and decision making. Please plan to attend and bring any questions you may have. Please RSVP by emailing or calling Martha. If you are not sure you can come until the last minute and have not sent an RSVP, please attend anyway! Looking forward to seeing you on Thursday night!

Triangle Support Group

Thursday, April 10, 2014 at 7:00 pm-8:45 pm

Duke Raleigh Hospital, 3400 Wake Forest Rd, Raleigh, Cancer Center classroom
Facilitator: [Sarah Dawson](#) (919) 803-8128

We are happy to have registered dietitian Sue Steves as our featured speaker as we draw attention to the nutritional challenges faced by people with HD. Sue has worked as a Registered Dietitian for 26 years, and has worked at Duke for 14 years in Neurosciences. She has served the Duke ALS clinic for 10 years. She is originally from Western NY and graduated from Buffalo State College with a BS in Dietetics. Before her Dietetics career, she was a chef for 10 years and graduated from a culinary arts program. We will discuss nutritional information as well as local and national nutrition resources. Please also check [our website](#) for upcoming blog posts about nutrition, including recipes! Also, in the spirit of helping needy families with HD, please consider bringing a six-pack of Ensure or financial donation for nutrition support!

HD Reach News

HD Reach creates Family Advisory Committee

The Family Advisory Committee strives to provide a voice on behalf of the HD community and improve communications between families affected by HD and the medical community that supports them. It's the first of its kind in NC and the surrounding region.



FAC Leader
Cassandra Allison

HD Reach welcomes Cassandra Allison as the leader of our newly formed Family Advisory Committee. Ms. Allison joins the group from Washington, DC and also currently serves as the Vice-President of the DC Metro Chapter of HDSA. Seated on the committee are a diverse group of people from the North Carolina Huntington's disease community.

Do you have input or comments on your family's needs to submit to the FAC? Please email Cassandra Allison, FAC leader at FAC@hdreach.org. The Committee welcomes your input and ideas.

Duke Provider Panel at Triangle Support Group meeting

On February 18, 2014, the Triangle HD support group met with the Duke HD Clinic Team led by Dr. Burton Scott and Dr. Mary Edmondson and UNC-Chapel Hill genetic counselor Debbie Keelean-Fuller to answer questions from quite a large audience of families, some of whom had traveled from as far away as South Carolina and Wilmington, NC. Many in the audience asked about genetic testing, clinical trials, nutritional supplements, and issues faced by people with HD who are in the military. The Duke team discussed services that were available at the HD clinic at Duke Movement Disorders Center, including neurological evaluations, psychiatry services, physical therapy, speech therapy, and clinical social work services.



The Enroll HD trial, its goals and opportunities, issues of confidentiality, and reasons people participate in clinical trials in general were topics discussed. Clinical trial subjects present at the meeting described how they felt about participation and knowing that they are contributing rich information to the world-wide effort to better understand and treat HD.

Interested parties can call Peggy Perry- Trice at Duke at (919)684-0865 or Christine O'Neill at Wake Forest Baptist Medical Center at (336)716-8611. Questions about genetic testing? Call Debbie Keelean-Fuller at UNC at (919)966-4380. Need psychiatric care? Call the Duke Psychiatry program to make an appointment with Dr. Edmondson at (919) 684-0105. Want to be seen by the Duke multi-disciplinary team? Call 919-668-7600.

Clinical Trials News

FIRST-HD trial at Duke needs participants; travel compensation

First-HD and ARC-HD are clinical trials investigating a new drug, SD-809 ER (Extended Release), in people who have chorea associated Huntington disease (HD).

The two trials are currently being studied at Duke University in Durham, NC. The study has been amended to include participants who have previously used Tetrabenazine, so you may now be eligible to participate.



The search for new treatments will require the participation of 50% of the HD community. Your participation not only helps people with HD and their families everywhere now, it will have a critical impact on future generations of people affected by HD! It is a very

exciting time in history as new drug candidates are being developed for the treatment for HD, more than at any time in history. We will keep you informed as these possibilities come available.

The study will help with travel costs! If you need assistance getting to and from Duke for participation, let the study coordinator know

Why would a person consider this trial?

-New treatments for HD must be tested in human beings. There will be no other way that new treatment will become available.

-Drugs usually need to be "tweaked" for tolerability. SD-809 provides the same actions as TBZ but the hope is that the benefits will come with fewer side effects and fewer doses of medication per day.

-People who participate in clinical trials generally do better because of increased contact with HD experts.



The ARC-HD trial will determine how safe and tolerable SD-809 ER is in subjects who are currently taking tetrabenazine to treat chorea and "switch" to SD-809 ER. ARC-HD will enroll subjects who are currently taking tetrabenazine and "roll-over" subjects from First-HD.

Subjects who qualify for the study will be switched from tetrabenazine to a dose of SD-809 ER that is approximately comparable to their tetrabenazine dose. The dose of SD-809 ER can then be adjusted over 4 weeks, if necessary. Remember that all participation in research is voluntary and you may reconsider participating at any time in order to change back to tetrabenazine.

If you are interested in participating in the ARC-HD study and have successfully completed the First-HD trial, you will be started on therapy with SD-809 ER. Subjects will be involved in this trial for up to 14 months and will remain on study drug for a total of 54 weeks.

We hope you will consider participating. You can learn more about the trial here. Peggy Perry-Trice is the study coordinator at Duke and can determine if you meet study criteria. You can contact her at peggy.perrytrice@duke.edu.



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