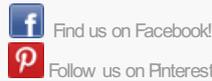


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July 2014

NEWS & NOTES

A quarterly newsletter from [HD Reach](#)

HD Reach News

Greetings HD Reach Friends and Families!



In just the few weeks I've been on staff here at HD Reach, I've shaken hands and gotten hugs. The sense of welcoming and belonging you all have extended to the "new guy" has been overwhelming. You all have been nothing short of kind and courteous.

A lot of folks have asked me about why I wanted to work with families with Huntington's. A lot of folks have also asked if I had personally dealt with Huntington's or if I was a person at risk. The answer is a little complicated. While I am not at risk for Huntington's, I have had many family members who have had

Parkinson's and Alzheimer's. Too many to count, really, and too many whose lives were taken away by these diseases.

My social work experience has focused on working with populations affected by diseases like Huntington's, Parkinson's, Alzheimer's, and ALS. My clinical experience has focused on working with individuals with progressive motor and cognitive impairments, as well as their families and caregivers.

For me, the treatment of a disease is not just about the diagnosed individual; it's about the people who love and care for that same individual. For me, it's always been about the families - and this is why I am drawn to the Huntington's community. HD is a genetic disease that affects the entire family, whether its through the passing of genetic material or for the people that come together to support a mother, a father, a brother, a sister, etc. I look back at my own family and think how much strength and support they've provided me. It doesn't really matter if you are a family facing the usual developmental stuff of life or challenges like HD, your family provides the tools and beliefs that help us rise to the occasion.

Henry Ford said, "Coming together is a beginning; keeping together is progress; working together is success." Some of you may know that I spent seven years in the private sector before coming to work with social service nonprofits, so I thought you might appreciate the reference from an industrialist. In all honesty though, it is that coming together that makes me want to work with families with Huntington's. It is in working together that we find ways to treat and cope with the disease.

I look forward to coming together and working together with each of you. Feel free to email me at jhusketh@hdreach.org.

~Jared



Upcoming Events

Support HD Reach with a great night out at The Comedy Zone of Lake Norman!

HD Reach Fundraiser, featuring: Julie Scoggins, "Red haired, white knuckled, blue collar comedy" (LKN Women's Social Meetup Night). Proceeds will benefit the programs and services of HD Reach, a non-profit dedicated to assisting NC families affected by Huntington's disease.

Tuesday, July 22, 2014 8:00 pm
[The Comedy Zone at Lake Norman](#) - \$15 tickets (in advance)
www.juliescoggins.com



Upcoming Support Group Meetings

Triangle Support Group

Thursday, July 17, 2014 7:00 pm-9:00 pm

Duke Raleigh Hospital, 3400 Wake Forest Rd, Raleigh, Cardinal/Dogwood Rooms
Facilitator: Jared Husketh & Dr. Mary Edmondson (919) 803-8128

We invite all Triangle Support Group members, both past and present, to attend this meeting, where you will be able to meet our new Director of Clinical Services, Jared Husketh. Dr. Mary Edmondson, Board President and co-founder of HD Reach, will also be on hand to answer questions. Light refreshments provided. Please note this meeting will be in a different room than our usual meeting space. The Cardinal/Dogwood Rooms are located in the main hospital building, near the gift shop in the main lobby.

Charlotte Support Group

Thursday, July 31, 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.

Triad/Winston-Salem Support Group

Tuesday, August 5, 2014 3:00 pm-5:00 pm

Williams Senior Services Center, 231 Melrose Street, Winston-Salem, NC
Facilitator: [Steve Schlecta](#), (919) 803-8128 for more info

Meet HD Reach Director of Clinical Services, Jared Husketh, as he speaks to the group about HD Reach's programs and services.

Help HD Reach Build our Network of Care Providers

Attention Charlotte area families!

Who are your healthcare providers? We need your help in building a network of care providers in the Charlotte area. Who helps you or your family members manage Huntington's disease?

Click [Here](#) to provide your responses. This information is confidential, and no personal data will be collected. Help us help others in your area to connect with great providers!



Viewpoints: Life with HD

Lauren Holder, friend of HD Reach and former president of HDSA NC Chapter, on winning award at annual convention



"I had the honor of being awarded HDSA Person of the Year this year at the HDSA Convention in Louisville, KY. It was a huge surprise to me, and I can't adequately put into words how much it meant to me. The HD community is not just a community to me, it is my extended family. Everything I do, I do for this HD family, so that we may have a better quality of life now and one

day a cure. I'm so grateful to not only the HDSA, but also the National Youth Alliance for their support. I will continue to live by the motto, "Help For Today. Hope For Tomorrow". – Lauren Holder, HD positive and LIVING."

Clinical Trials News

Two well known observational studies of Huntington's disease conducted in North American and Europe, Cohort and Registry, started the search for a broad understanding of HD across the lifecycle. CHDI Foundation has collaborated with Cohort and Registry research sites to continue the work through ENROLL-HD, **now the world's largest Huntington's study**. Enroll-HD will result in an immense database of information for researchers to study. According to HD Buzz, "Studying many patients repeatedly over several years can give us powerful insights that can't be gained through other research techniques". Enroll-HD will allow scientists to do just that.

Thanks to the generosity of CHDI investors, the money needed to pay for research is available now, but it won't last forever. As Mary Edmondson, a psychiatrist and HD specialist at Duke University, puts it, "this is our window of opportunity." HD researchers



are currently on the cusp of several breakthroughs involving unconventional approaches to treatment, and the best part is, those who enlist in Enroll-HD studies are very likely the individuals who will be chosen to take part in clinical trials when new ****treatment targets**** debut. In fact, ENROLL-HD serves as a platform for launching research of all kinds, from translational science, bringing the best of basic science to modify or reverse disease course, to health care delivery research, assessing currently available symptomatic care for HD with an eye toward improving quality of life... NOW.

High participation rates in studies like Enroll- HD will indicate to the sponsors of HD research that the Huntington's community is excited and ready to take part in research. Low participation rates in Enroll-HD could give investors the impression that we have little interest in helping finding a cure.

Any member of a family affected by HD can take part. This includes:

- * Individuals who know they carry the expanded gene, whether or not they show signs and symptoms of the disease
- * Individuals who are at risk of developing the disease (but have not undergone genetic testing)
- * Individuals who have a family history of HD but know they do not carry the expanded gene
- * Spouses/partners (not blood-related) of family members with HD

Children under the age of 18 with clinically diagnosed juvenile HD may be included in this study with the consent of a parent or legal guardian.

Enroll-HD is an open-ended study, which means it has no defined end time, but you can leave at any time you choose. You will attend one study visit each year.

During each study visit, you will undergo a series of movement and behavioral tests. Functional tests will be given to determine how well you perform tasks on your own. You will also answer questions to help the study team evaluate your emotional state and quality of life. Additionally, if you wish, you can choose to donate a small volume of blood at each visit to help the study team:

- * Understand why and when certain symptoms appear
- * Identify possible ways to develop new, effective drugs

PLEASE ENROLL TODAY, BEFORE OUR WINDOW OF OPPORTUNITY CLOSSES.

To enroll, visit www.enroll-hd.org or contact:
Christine O'Neill, BS, CCRC
Wake Forest School of Medicine
Winston-Salem, NC
Phone: 336-716-8611
conell@wakehealth.edu

Peggy Perry-Trice, SC
Duke University Movement Disorders Clinic
Durham, NC
Phone: 919-684-0865
peggy.perrytrice@duke.edu



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