



2019 North Carolina Huntington's Disease Education Day

April 6, 2019



**LOOKING BACK &
REACHING FORWARD**

Celebrating 10 Years of Serving HD Families

Presented by



AGENDA

Time	Room	Session Name	Audience
8:30 - 9:00	1A	Registration and Breakfast	All
9:00 - 9:20	1D	Welcome and Introductions	All
9:20 - 10:00	1D	Looking Back Over the Last 10 Years - With a Special Message from Charles Sabine	All
10:00- 10:15	1A	QUICK BREAK	All
10:15- 11:15	1D	A Hope Filled Future - Latest and Greatest in Clinical Research	All
11:15 - 12:00	1D	The Future - A Young Adult's Perspective	All
12:00 - 1:00	2C	LUNCH	All
Breakouts Sessions (A)			
1:00 - 1:50	7B	How to Navigate Your HD Journey	Youth
	1D	Providing Care of Every Stage of HD	Caregivers
	2C	Drumming and Wellness	Persons with HD
	8A	Talking to Your Children About HD	Families
1:50 - 2:10	1A	BREAK & SNACKS	All
Breakout Sessions (B)			
2:10 - 3:00	8A	Specialty Care for At-Risk Individuals	At Risk
	1D	Partnering With Your Therapists - OT, PT, & Speech	Caregivers
	8B	Mindful Moments	Persons with HD
	7B	Detangling the Disability Application	Families
3:00 - 3:15	1A	QUICK BREAK	All
3:15 - 4:00	1D	Closing Session - Ask the Experts	All

Meet HD Reach's New Executive Director, Debbi Fox-Davis!

Meet the New ED! Take this opportunity to meet HD Reach's new Executive Director, Debbi Fox-Davis. Debbi's compassion and concern make her an excellent choice to lead HD Reach into the next chapter for North Carolina families affected by Huntington's disease. She brings to HD Reach a strong history of caring for those who struggle with apparently insurmountable challenges such as children in need of loving, stable homes; unemployed and under employed women; and those affected by homelessness. Debbi's care, compassion, and skills will build expand HD Reach's programs and services to best achieve our mission of providing access to care, education, and support to those affected by Huntington's disease.



MORNING SESSIONS AT A GLANCE

Looking Back Over the Last 10 Years (All)

9:20 - 10:00: Room 1D

Presenters: Dr. Mary Edmondson and Dr. Don Lo

Join HD Reach's founder, Dr. Mary Edmondson and founding board member, Dr. Don Lo, as they provide their view of the progress HD Reach and the scientific community has made since HD Reach's inception over the past 10 years. There will be a special video message from Charles Sabine you won't want to miss!

A Hope Filled Future—Latest and Greatest in Clinical Research (All)

10:15 - 11:15: Room 1D

Presenters: Dr. Miroslav Cuturic and Dr. Francis Walker

During this informative session you'll learn from Dr. Miroslav Cuturic from the University of South Carolina and Dr. Walker from Wake Forest University about the advances being made in HD clinical research. The doctors will also discuss which clinical trials are currently enrolling. There will be an opportunity for questions and answers.

The Future—A Young Adult's Perspective (All)

11:15 - 12:00: Room 1D

Presenters: Darcy Hawkins and Casey Herrington

With the advent of promising new therapies for Huntington's disease, the future looks very different than it did 10 years ago. The way our parents approached living with HD is vastly different than how today's young adults view their future. Join Darcy Hawkins and Casey Herrington, young adults affected by Huntington's disease, as they share how they view their future—one of promise and hope.

LUNCH (All)

12:00 - 1:00: Room 2C

Want to get to know other people living with HD in your community? The lunch tables are color coded to match your name tag and if you want to connect with them, sit at the table color that corresponds to your name tag. Watch a slideshow of 10 years of HD Reach, created by HD Reach's videographer volunteer, Taylor Lang. Finally, enjoy a 10 Year Anniversary celebratory piece of cake to top off your lunch!

AFTERNOON SESSIONS AT A GLANCE

How to Navigate Your HD Journey (Youth)

1:00 - 1:50: 7B

Presenter: Chandler Swope, LICSW

HD is unique in the journey it takes its patients, caregivers and families on. It is often hard to discuss the impacts, how to stay positive and how to make decisions when HD is in the picture. This session will be an open dialogue about HD, its impact and how to navigate your own HD Journey.

Proving Care at Every Stage of HD (Caregivers)

1:00 - 1:50: 1D

Presenters: Erin Blaha, Jamaal Brodie, Barb Egloff, and Ann Lassiter

Would you like to learn from caregivers who have provided care to people with HD? Caregivers come from many backgrounds and settings. Learn from these experienced caregivers: Erin Blaha, who provides care in a small group home; Jamaal Brodie, whose mother lived in a long-term care facility; Barb Egloff, who cares for her husband at home, and Ann Lassiter, HD Reach's Executive Director and family caregiver. Be ready with your questions!

AFTERNOON SESSIONS AT A GLANCE (cont.)

Talking to Your Children About HD (Families)

1:00 - 1:50: 8A

Presenter: Dr. Bonnie Hennig-Trestman

Coping with a diagnosis of HD is not easy for anyone. When children are involved families can have an even more difficult time. Families may feel the best way to protect children from HD is to avoid talking about it. Dr. Hennig-Trestman presents the who, when, how and what of talking to kids about HD to make families more comfortable having this discussion. She offers information on how to talk to children at different ages, and how to learn approaches of sharing information. Her goal is to provide you with the tools needed to feel more comfortable having the discussion about HD with children.

Specialty Care for At-Risk Individuals (At Risk)

2:10 - 3:00: 8A

Presenter: Dr. Mary Edmondson

When you are at risk for HD, deciding to test is one of the most important decisions you'll ever make. People at risk have special considerations. Dr. Edmondson will review some critical aspects of testing including understanding your goals, obtaining accurate information, decision-making, and coping skills, in addition to the testing process itself. Learn more about how to better prepare for this very important decision.

Detangling the Disability Application (Families)

2:10 - 3:00: 7B

Presenter: Allison Bartlett, Esq.

Those with chronic illnesses such as HD often have to make the difficult decision to stop working before reaching full retirement age. Social Security disability benefits can provide continued income and health insurance options. Like many government benefits programs, however, the pathway to receiving disability benefits can be confusing and time consuming. Join Allison to gain a better understanding of what benefit type you're eligible for, how the Social Security Administration (SSA) will analyze your claim, what evidence to compile, how to prepare the strongest argument for your case and where you can turn to for help.

Drumming and Wellness (Persons with HD)

1:00 - 1:50: 2C

Presenter: Ronnie Pulley

This energetic experience offers participants a safe and non-judgmental space in which they can escape the fast paced world, learn together, laugh together, make mistakes together, support each other, and thus grow together in wellness. Through this wonderful journey, participants experience a heightened sense of joy that accesses the 'feel-good' endorphins thus reducing stress and anxiety at a level that is long lasting.

Partnering With Your Therapists—OT, PT, & Speech (Caregivers)

2:10 - 3:00: 1D

Presenters: Katie Broadwell, Melissa Werz, and Robyn Wilson

Your multidisciplinary team can really make a difference in the quality of care you provide to those with HD. Join your Duke HD Multidisciplinary Team of Robyn Wilson (Physical Therapist), Melissa Werz (Occupational Therapist), and Katie Broadwell (Speech Therapist) to learn how their specialty care can help the person you care for live well with HD.

Mindful Moments (Persons with HD)

2:10 - 3:00: 8B

Presenter: Holly Edmondson

Mindfulness can empower us to live peacefully and revel in the good things. During this session, Holly will be presenting some of the tools from mindfulness and meditation practices that can help you to heal, manage life and reconnect. Holly will also lead a guided relaxation exercise culminating in a mindful connection to our senses through chocolate!

Ask the Experts (All)

3:15 - 4:00: Room 1D

Panel of Experts

We will wrap up the day with an opportunity for you to ask the experts in the room those questions you have on your mind. With so many experts in one room, you won't want to miss this opportunity! Be sure to stay for this last, but highly enlightening session!

Our Presenters

Allison Bartlett, Esq. is a Disability Attorney who specializes in the representation of clients with rare, chronic conditions like HD to navigate them through the complex disability system. She is a passionate advocate for HD families throughout the disability process and in the community, attending HD advocacy days on Capitol Hill and giving disability trainings at multiple HD Education days. Allison holds a J.D. from the University of Cincinnati College of Law and a BA in international affairs from James Madison University. She is admitted to the Virginia Bar.

Dr. Miroslav Cuturic joined the University of South Carolina School of Medicine in 2003. He has been medical director of the Huntington's disease clinic in Columbia, SC, since 2003. He is the author of several published articles relating to his studies and trials in HD. His training and years of practice in psychiatry make him uniquely qualified to address the complex neuropsychiatric aspects of HD. He is an HSG investigator and the primary investigator for Enroll HD at the USC School of Medicine.

Dr. Mary Edmondson is a psychiatrist, internist, and the founder of HD Reach. Having watched her father succumb to HD, she is committed to ensuring HD patients receive the care they need. Dr. Edmondson's expertise in the psychiatric care of HD patients is well known locally and throughout the world. She currently serves as HD Reach's Medical Director.

Holly Edmondson is a Registered Yoga Teacher with training in yoga and meditation practices developed for chronic stress, pain and promoting mental wellness. Holly developed a mindfulness project geared toward enhancing participants' mindfulness practice. She is also HD Reach's Social Work intern and has a passion for providing these resources to people affected by HD.

Darcy Hawkins is an HD warrior who serves many roles in the HD community such as a volunteer for HDSA's Minnesota Chapter, Regional Lead for the Upper Midwest Region for HDSA's NYA, Marketing Coordinator for HD GEM. Darcy has also been featured on the Because I Can website and is known for sharing her story openly around the world. She won HDSA's Top Fundraiser Award, Giving A Voice to HD Award, and Leadership and Alumni Award.

Dr. Bonnie Hennig-Trestman has a private teletherapy practice and serves on the HDYO Board of Directors. Dr. Hennig-Trestman has over 30 years of experience providing clinical service and supervision with patients and family members suffering from neurodegenerative, physical, and psychiatric illnesses. Her book, "Talking to Kids About HD" has been translated into five languages. She is a member of the HSG, the EHDN, and HDYO.

Casey Herrington is the founder and project director of the Huntington's Disease Global Ecosystem Map which aims to lower the barriers for people looking to discover Huntington's disease related resources. His involvement in the HD community was sadly inspired by personal loss; his mother passed away from Huntington's disease in 2013 when she was just 46 years old. He and his three sisters remain at risk of developing the disease. With an entrepreneurial passion, Casey is striving to aid in the fight of creating a world without Huntington's disease.

Ann Lassiter is the soon to be retired Executive Director of HD Reach and a former member of the HD Reach board of directors. She has been involved in HD since 1980 when her father was diagnosed with the disease. Ann has led many training sessions on leadership, behavior change, and managing change. Her experience as a special education teacher, corporate learning leader, and HD family member brings a practical approach to living with HD.

Dr. Don Lo has been engaged in basic science and drug discovery research for neurological diseases for over 25 years at Duke and is currently Director of the Therapeutic Development Branch with the National Institute of Health. Dr. Lo is a founding Board Member of HD Reach and will discuss Looking Back & Reaching Forward in celebration of HD Reach's 10th Anniversary.

Ronnie Pulley is the Founder of Triangle Drumming and Wellness and Dayo Rhythms. He is a graduate from the TTM Djembe Academy, the world's leading entity for teaching Djembe and Dunun rhythms, certified with Health Rhythms, and a member of the Drum Circle Facilitator's Guild. With the use of drumming, small percussion, and music Ronnie engages participants in a rich and robust experience of organic music making through inclusion, diversity, and creative self-expression.

Chandler Swope, LICSW is the director of Youth Services for HDYO. In 2014, she launched the first HD-focused youth service program in the US. Focused solely on HD youth, HDYO provides support, education, advocacy, and advice. HDYO hosts events where young people can connect with each other and build a network of peer support through recreation and education.

Dr. Francis Walker has worked with HD patients and families for 35 years at Wake Forest University. He conducts HD clinical research and helped to author over 50 HD research papers. As a passionate advocate for HD treatments, he serves on the steering committee for the Enroll-HD study. Dr. Walker serves on HD Reach's Medical Advisory Committee.

Current HD Clinical Trials

Enroll-HD

Study Sponsor: HSG, CHDI

Phase: Observational

Clinical Sites in NC: Duke, Wake Forest University, USC **Website:** <http://enroll-hd.org/>

Description: Enroll-HD is a worldwide observational study for Huntington's disease families. It collects information about how disease symptoms first appear and change over time. It is open to people who have the HD gene, at-risk individuals, and spouses or caregivers. Enroll-HD is a prospective observational study, meaning it tracks people over time, rather than asking them to recall how their symptoms have changed. Enroll-HD is also an important platform for helping to launch important clinical trials. The goal of this study is that it will make other HD research easier to conduct, thereby speeding up the process of developing new drugs and other treatments that really work.

Wave - PRECISION HD - No Longer Enrolling

Study Sponsor: Wave Life Sciences

Phase: Phase Ib/2a, Safety and Tolerability

Clinical Sites in NC: Wake Forest University **Website:** <http://www.wavelifesciences.com/>

Description: The purpose of the study is to find out if the investigational drug WVE-120101 is safe and if it will reduce the production of the mutant huntingtin protein (mHTT). The intent is that if in reducing or removing the mutant protein (mHTT), there will be an improvement in the symptoms of HD. The study will measure the safety and tolerability of the new drug and assess the effect of the drug on signs and symptoms of HD.

SIGNAL - No Longer Enrolling

Study Sponsor: Vaccinex Pharmaceuticals

Phase: Phase II, Safety and Efficacy

Clinical Sites in NC: Duke, Wake Forest University **Website:** <http://huntingtonstudygroup.org/current-clinical-trials/signal-trial/>

Description: The SIGNAL trial is designed to assess the safety, tolerability, and effectiveness of VX15, a novel monoclonal antibody, in people with late prodromal or early manifest Huntington's disease (HD). VX15 is a different class of drug than any other drug used in previous HD clinical trials. Monoclonal antibodies are more specific than most other drugs because they only bind to and neutralize their desired target.

LEGATO-HD

Study Sponsor: Teva Pharmaceuticals, HSG, EHDN

Phase: Phase II, Safety

Clinical Sites in NC: None **Website:** <http://huntingtonstudygroup.org/current-clinical-trials/legato-hd-trial/>

Description: The purpose of the LEGATO-HD trial is to see what effect different doses of an investigational drug called laquinimod may have on people with Huntington's disease (HD) after 12 months of administration. You may be eligible to participate in the study if you are between the ages of 18 and 55 and have HD.

Research Coordinator Contact Information

Christine O'Neill: coneill@wfubmc.edu 336-716-8611

Wake Forest Baptist Medical Center, Winston Salem, NC



McKenzie Luxmore: mckenzie.luxmore@duke.edu 919-684-0865

Duke Movement Disorder Center, Durham, NC



Alyson Grant: alyson.grant@uscmcd.sc.edu 803-545-6104

University of South Carolina School of Medicine, Columbia, SC



2019 North Carolina Huntington's Disease Education Day

Welcome to HD Reach's 2019 HD Education Day! 2019 marks a special year for us—10 years of service to the HD community. Today, we will take a look back at how far we've come as a community, but most importantly, we will look to a new view of the future—one of hope and promise! You'll learn from the best around North Carolina and our neighboring states—professionals and families alike.

A special shout out goes to the HD Reach Education Day committee without whom this day would not have been possible: Dr. Don Lo, Tony Morris, Kelly Yaworski, Katherine Sherry, Carol Ragan, and Mauri Douglas. They worked tirelessly to make sure your day is worthwhile, informative, and fun. Our sponsors make it possible to bring this day to you at no cost. Be sure to stop by their tables in the exhibit room and say thank you! Our volunteers are the best, doing the work to make sure it all runs smoothly.

As I head into retirement, I look back and I'm so honored to have served you. I marvel at your hope, your resilience, and your steadfast fight against HD. Thank you for allowing me to be a part of your lives.

With warm regards,

Ana Lassiter

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Champion



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Jerry Jones Insurance

Earth N Wear Whisper

1004 Dresser Court, Suite 107
Raleigh, NC 27609
Office: 919.803.8128



www.hdreach.org
