HD: Thinking About the NEXT GENERATION

In 1983, HUNTINGTON’S DISEASE became the first disease to be mapped to a previously unknown genetic location on chromosome 4. Predictive testing for HD became available soon after. When the actual genetic mutation that causes HD was found in 1993, direct testing for HD became possible.

For at least two decades, individuals choosing to get the predictive test tended to be in their mid-to-late thirties. For them, the introduction of the test came after they had already made major life decisions about education, careers, marriage, and reproduction. Lately, however, the population choosing to be tested is trending younger, with many more at-risk individuals eighteen to twenty-one years of age as well as those in their mid-twenties.

One reason for this may be the fact that this is the first generation to grow up knowing their entire lifetime that a test for HD is available, and that they can be tested when they reach the age of eighteen. For this cohort, a major reason behind the decision to test is the desire to avoid passing on the HD mutation to their offspring. Those who test negative can proceed to have children free from the worry that they or their children will be affected with HD in the future.

For those who test positive, the choices are less clear. Both donor egg and donor sperm are possible, depending on the gender of the person at risk. Preimplantation genetic diagnosis is an option for some couples, but the process is very expensive, may be beyond the budget of many young couples, and does not guarantee a viable pregnancy. Perhaps it is time to think creatively about how best to provide assistance to couples who wish to avoid the possibility of HD in their children.

Saturday, March 12, 2016
8 a.m. to 3:15 p.m.
Hilton Chicago Northbrook – Allgauer’s
2855 N. Milwaukee Ave., Northbrook, IL 60062
Registration: $10 per person.
We encourage preregistration so that we can have an accurate meal count.
### TOPICS AND SCHEDULE

- **8:00 AM** Registration, Coffee, Networking
- **8:45 AM** Welcome and Introductions
  - Daniel Born, PhD, and Emily Zivin, LCSW, MPA
- **9:00 AM** Heredity and Huntington's Disease: New Frontiers
  - Kimberly Quaid, PhD, Professor of Medical and Molecular Genetics, Indiana University School of Medicine
- **10:00 AM** Break
- **10:15 AM** Morning Breakout Sessions
  - Sara Cherny, MS, CGC, “Family Planning and HD: Current Practices” (BIRCH)
  - Jean Morack, ACSW, MSW, and Emily Zivin, LCSW, MPA, “Making a Long-Term Plan for Care” (LOCUST)
  - Susan Hodgson, LPN, “Fighting HD on the Nutritional Front” (LINDEN 1)
  - Mary Anne Ehler, CFP, “Financial Planning for HD Families” (LAUREL)
- **11:00 AM** Break
- **11:10 AM** Research Update and Report on Clinical Trials
  - Dr. Kathleen M. Shannon, MD, Director of the RUMC HDSA Center of Excellence
- **11:50 AM** Increasing our Participation in the Clinical Trials
  - Ted Ross, Enroll-HD Advocate
- **NOON** Lunch: Introducing the HDSA Illinois Chapter Board
- **1:00 PM** “Sharing Our Stories: Evolving Families and Family Plans”
  - Panel discussion moderated by Emily Zivin, LCSW, MPA, with Liz Born and Alexis Floczak, MSN, MHA
- **2:00 PM** Break
- **2:15 PM** Afternoon Breakout Sessions
  - Stacey Barton, MSW, LCSW, “HD 101: Facts and Myths” (LAUREL)
  - Angela Waltman, “Mindfulness” (LINDEN 1)
  - Dr. Kathleen Shannon, MD, and Sarah Mitchell, MSW, “Five Difficult Scenarios and What You Can Do” (BIRCH)
  - Stephen Clingerman, PhD, and Liz Born, “How to Talk With Children About HD” (LOCUST)
  - Tom Barr and Dave Hodgson, “Advocacy: The Ground Game and Light Show Razzle Dazzle” (LINDEN 2)
- **3:15 PM** Adjourn
  - Daniel Born and Emily Zivin, LCSW, MPA (MAIN HALL)

### FEATURED SPEAKERS

**KIMBERLY QUAID, PhD,** is Professor of Medical and Molecular Genetics at Indiana University School of Medicine in Indianapolis. In 1990 she was named Director of the Predictive Testing Program at Indiana University School of Medicine, and since 2005 she has served as Director of the HDSA Center of Excellence. She joined the HDSA Indiana Chapter board in 2011.

Quaid received her doctorate in medical and molecular genetics at the Johns Hopkins University in 1985. She has earned numerous awards including the Indiana University Trustees Teaching Award in 2015, Outstanding Female Faculty (2002), and the Indiana Chapter AFL-CIO Award for Outstanding Contributions to Women and Work (2001). She was appointed by Governor Mitch Daniels to the Board of Directors of the Indiana Cord Blood Bank for the 2012-14 term.

She is a co-author of *Early Warning: Cases and Ethical Guidance for Presymptomatic Testing in Genetic Diseases* (Indiana UP, 1998), and has published chapters in books including *Essentials of Molecular Genetic Pathology, Pediatric Bioethics, and Genetic Testing for Alzheimer’s Disease: Ethical and Clinical Issues.* Her articles have appeared in numerous journals such as the *Journal of Genetic Counseling, Journal of Molecular Neuroscience*, and the *American Journal of Medical Genetics.*

**DR. KATHLEEN SHANNON, MD,** is Professor of Neurological Sciences at Rush University Medical Center in Chicago. On July 1, 2016, she became the chairmanship of the department of neurology at the University of Wisconsin School of Medicine and Public Health in Madison.

Following her internal medicine internship, neurology residency, and movement disorders fellowship at Rush, she taught at Vanderbilt University. Returning to Chicago, she joined the faculty at Rush's department of neurology, and also became Director of the HDSA Center of Excellence. During more than two decades of her work in Chicago, she has become familiar with hundreds of HD patients and their stories. Her clinical interests include clinical trials in movement disorders and Huntington's disease, and intestinal biomarkers of Parkinson's. Besides maintaining her medical practice, Shannon is an accomplished artist, metalworker, and jewelry designer.