Hopes and Dreams
Huntington's Disease Society of America - Illinois Chapter Quarterly Newsletter

Huntington's Disease Society of America
Illinois CHAPTER

Outgoing President's Message

New Roads to Travel in 2016

Thirty years ago, Mary Classen Born was thirty years old and in her prime, working as a family therapist and social worker in New Jersey. We had been married for eight years and life was good. We played in Manhattan on weekends and were about to buy our first condominium on the Jersey side of the Hudson River. I ran a bookstore on Madison Avenue and had just started a PhD program at the City University of New York. Like most trips on nostalgia lane, this one comes complete with its own soundtrack, comprised of cheesy Van Halen and glorious Bruce Springsteen, not to mention excursions down the Jersey Shore for seafood and summer vacations.

Huntington's disease was only a theoretical problem for us then. Mary knew she was at risk; her mother was dying of HD in a nursing home near Bloomington, Illinois, and Mary had witnessed the devastation beginning in childhood, when her mother's behavior became erratic. Still, we were people of faith. Call us innocent, naïve, or both. We had confidence that even if Mary got HD, a cure or at least better pharmaceuticals would smooth the bumpy ride. Mary served on the HDSA New Jersey chapter board with distinguished colleagues including the Governor of New Jersey, Thomas Kean, and Sam Baily, a genial Quaker and professor of Italian studies at Rutgers University who would become HDSA's first national president. The marker for the HD gene had been discovered in 1983. Hope ran very high. Mary was thirty and talented and beautiful, and I suppose that cliché about the young was true for us, too: we believed we were immortal.

A lot can happen in thirty years.

Mary received the diagnosis twenty years ago in Ohio, seven years after our daughter Liz was born. We moved to Chicago in 2001. As a family, we tried with varying degrees of success to live as normally—and intensely—as possible. We took several trips to Europe because we knew time was running out. Mary's neurologist at Rush, Dr. Kathleen Shannon, was a bright light and inspiration during this period. Thankfully, Mary could still understand and celebrate Liz's achievements as a student at Northside College Prep, then at the Art Institute of Chicago, and later as an artist and teacher.

But there is no heroic narrative to the story. Our marriage was ending, and complications from dementia and rapid decline in cognition and motor skills led to Mary's move in 2009 to 24/7 nursing care, when close family members told me it was time. Mary is now in palliative care, the prospect not good for her surviving 2016. When I see her, I often think of Keats's words that he wrote to a friend several months before his death in 1821: "I have a habitual feeling of my real life having past, and that I am leading a posthumous existence."

This disease terrifies me and breaks my heart. But it's important that we—whether as HD sufferers, caregivers, or survivors—not let it break our will. Nor can we allow it to define our lives, of who we are as individuals. That being said, it is sometimes wise to take a break from the action and seek to replenish the spirit. The chapter is in excellent hands, with Susie Hodgson, a longtime veteran of the board, taking the reins as president. Happily, the chapter also enjoys the insight of our social worker, Emily Zivin, who came on board in 2015. She has already provided a needed boost of new ideas and energy to our planning of the 2016 state conference, and I am proud to co-chair that event with her.

I dedicate these thoughts to two women: Dr. Kathleen Shannon, for being the most impressive warrior in the fight against HD that I have met. There are many doctors, but only one Kathleen Shannon. She has my complete admiration, and I wish her well as she travels a new road as chair of the neurology department at the University of Wisconsin.

And I dedicate this to Mary Classen Born, who is beloved, and who travels the final road.

Yours in the fight to cure HD,

Dan

Daniel Born, PhD
(HDSA Illinois Board Member 2005-2015; President in 2015)

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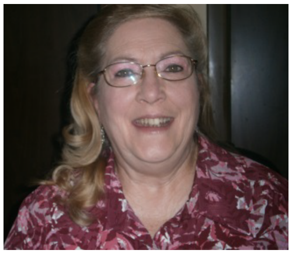
HDSA ILLINOIS CHAPTER

Incoming President's Message



Another year has come and is now almost gone. As we contemplate the New Year and all that it holds for us, it is also a time for reflection. This has been another outstanding year for the Illinois Chapter of HDSA. Without the help and support of all of our families this would not have been possible.

As we look to the New Year our goal is a bigger and better year in 2016. In working towards our goal, we will continue to keep the mission and vision of our organization at the forefront of everything we do.

MISSION: To improve the life of everyone affected by Huntington's disease.
VISION: A world free of Huntington's disease.

For us to succeed it takes ALL of us working together. Many feel that they do not have anything to offer…wrong…we ALL have something to offer. Your gift may be nothing more than offering to stuff envelopes, making a few phone calls, writing letters or it may be volunteering to help with one of our scheduled events. Or possibly, you have an idea that you think might be a good fundraiser…when letting your sense of creativity go wild the possibilities are endless. Do you like to bowl…how about a "Bowling for HD" event, fan of basketball, golf, football, baseball? The possibilities are endless.

Upcoming events that you might think about (the event chairpersons are always looking for volunteers) are our "**Hoe Down for Huntington's**" in February, the "**Team Hope Walk**" and "**Turn Chicago Blue**" in May. We also have the "**Hot Rods for Huntington's**" in the fall.

Not really into working on a fundraiser? How about raising awareness, advocacy is a GREAT way to help the families of Illinois. Again, the possibilities of ways to do this are limited only by your creativity.

On a sad note, we will be saying goodbye to Dr. Kathleen Shannon as she begins a new chapter of her life as the Chair of Neurology at the University of Wisconsin. She will be missed by all of us and in her honor and in recognition of the many families that she has touched through the years, the "Team Hope Walk" committee is dedicating the 2016 TEAM HOPE WALK in her honor. We invite everyone who has been touched by Dr. Shannon to join us at the walk on May 22, 2016 as we thank her for her years of dedication and service to all of the HD families she has touched.

I look forward to working together with all of you in the following year and may this be the year that we FIND A CURE!!!

Susie

Susie Hodgson
HDSA Illinois Chapter President
hdsailchapter@gmail.com

HDSA-IL Chapter 2016 Pledge Drive

Your pledge helps to provide…

- Research
- Chapter Social Worker
- Family Services
- Support Groups
- In-Service Presentations
- Advocacy
- Awareness

Member	$25.00
Benefactor	$50.00
Angel	$75.00
Century Club	$100.00
(Pick Your Own Title)	$500.00

No amount is too large or too small!

Contributions are tax deductible

PLEASE RETURN THIS PORTION WITH YOUR PLEDGE TO:

HDSA Illinois Chapter, P.O. Box 1883, Arlington Heights, IL 60006

Name: ______________________________

E-Mail Address______________________________

THANK YOU FOR YOUR SUPPORT!

JOIN US

HOEDOWN

FOR HUNTINGTON'S

SATURDAY, FEBRUARY 13, 2016

DRINKS ★ DINNER ★ DANCE ★ AUCTION

6:00 PM
COCKTAILS

7:00 PM
DINNER

2 DRINK TICKETS INCLUDED

MEALS UPON REQUEST
GLUTEN FREE
VEGETARIAN

HILTON/CHICAGO
INDIAN LAKES RESORT
250 WEST SCHICK ROAD
BLOOMINGDALE, IL 60108

FOR DIRECTIONS VISIT
ILLINOIS.HDSA.ORG

$109 DISCOUNTED ROOMS SINGLE OR DOUBLE

TICKETS $75
$25 IS TAX DEDUCTIBLE

RSVP
BY FEBRUARY 1

VISIT ILLINOIS.HDSA.ORG FOR:
★ TICKET PURCHASES
★ MONETARY DONATIONS
★ RAFFLE/AUCTION DONATIONS
★ SPONSORSHIP OPPORTUNITIES

Huntington's Disease
Society of America

QUESTIONS:
BARRY KAHN
847.975.2403

Family is everything

Please return this response card by February 1, 2016 with your payment to:

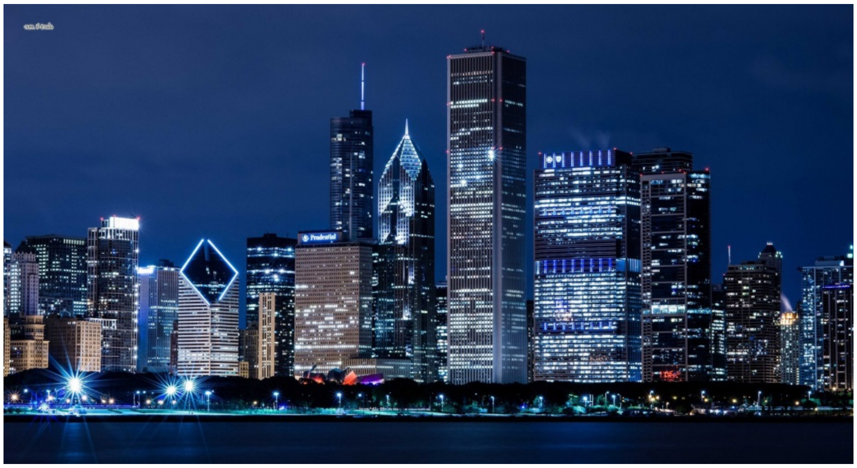
HDSA Illinois Chapter
c/o Marilyn & Barry Kahn
1832 Torrey Parkway
Libertyville, IL 60048
-OR-
Visit our website at Illinois.hdsa.org
& click on Hoedown for
Huntington's Dinner Dance
to register & pay with credit card

Name: ______________________________
Address: ______________________________
E-mail: ______________________________
Phone #: ____________________ # of Guests: __________
Please Seat Me With: ______________________________
Check ☐ Card ☐ AmEx ____ Visa ____ Discover ____ MasterCard ____
Credit Card #: ____________________ Exp: ______ Sec. Code: ______
Signature: ______________________________
I am unable to attend but would like to make a donation: $ __________

All proceeds support HDSA'S fight to improve the lives of people affected by HD and their families

Help Turn Chicago BLUE for Huntington's Disease

By Dave Hodgson



We're at it again, trying to create more awareness for Huntington's Disease. This is the 2nd annual year of **Turning Chicago Blue** during HD Awareness Month, May, 2016. Last year at least 5 Chicago loop buildings turned their spotlights blue for the month of May. This year we'd love to at least double that amount! Won't you help us? Last year your HDSA-Illinois Chapter was presented with the Great Lakes Regional Award for Best Advocacy and Awareness campaign. Please help us help the over 1500 families throughout Illinois who suffer with HD by signing our petition: http://www.ipetitions.com/petition/turn-chicago-blue-for-HD.

Last year over 1200 people from all across Illinois and the nation, as well as several people from Ireland, the United Kingdom, Germany and Australia signed it. Wouldn't you love to say you helped **Turn Chicago Blue**? For more information, contact Danielle at dlk465@gmail.com or Dave Hodgson at spiketdog@softhome.net.

Remember…use the hashtag #Blue4HD to promote this effort via social media.

* * *

Celebration of Hope a Huge Success!

By Deb Boyd

The 2016 Chicago Celebration of Hope surpassed our goal again this year! 150 people enjoyed a lovely auction and Italian dinner. *A Good Time Was Had By All* at Marcello's restaurant in Lincoln Park. That was the consensus of everyone who attended the 11th annual Celebration of Hope fundraiser on Saturday, October 24, 2015.

A successful event only happens because of the generosity, dedication and hard work of many people. We would like to take this opportunity to thank our honorees from Team Run for HD, Rachel Buck and Sara Dean, who were so deserving of the award for HDSA 2015 Volunteers of the Year. Many thanks to the COH Committee: Christina Nealis, Linda Nealis Rachel & Benoit Angulo, Marty & Elaine Jacobson, Teresa & Craig Srajer, and special thanks to our event chairs, Pete Douville & Denice Korcal and to our Master of Ceremonies, Dan Born.

We would also like to take this opportunity to thank our major Sponsors: Teva Pharmaceuticals, Ted & Kathie Ross, The Jacobson Family, Piano Trends, Pete Douville, Denice Korcal, The Jack & Penny Rohrbach Family Foundation, Bob Williams & Films for Good, Lundbeck, and Teresa & Craig Srajer Without their help, we would not have realized the success that we did. The event raised $45,000 for our HD Center of Excellence programs including our prestigious HD Center at Rush Medical Center.

If you are looking for a fun opportunity to get involved, please call Great Lakes Regional Director Deb Boyd at 269-629-5452 and join our 2016 Celebration of Hope Committee!

MEMORIALS AND TRIBUTES

In Memory of Mary Born from Gwendolyn Wiens & Robert Blum, Wally & Millie Kroeker, Kathleen Shannon

In Memory of Nancy Augspurger from M.E. Punke, Charles & Mary Lou Werner, Gary & Barbara Vance, Brian & Julie Stagen, Rodney & Connie Loschen, Laurence & Karla Young, John & Patricia Stevenson, Cheryl Ashby, Barbara Hilligoss, David Ashby, Tim & Bonnie Hoke

In Memory of Ralph Short from Lois Short

In Memory of Fred Purcell from Mary & Gregory Ziegler, Elaine Nelson, Kevin Draftz, Joyce & Donald Franklin, Lucille Carney, Lucia & David Hale, Joann & Bruce Volocyk, Cheryl & Donald Smith, Elizabeth Josephs
In Memory of Marie Pacha from Anita Reher & Friends

In Memory of Raymond, Alice and Karen Carter from Catherine Carter

In Memory of Heidi Hynes from Jean Nielsen, Steven & Linda Neubauer, Kevin & Mary Markwell, Rick Jett & Patricia Cosgrove, Angela DiFranco, James & Michelle Keefe, Larry & Beverly Lotz, Dena Mahon-Bagger & Dave Bagger, Dimitrios & Konstantina Panagiotidis, Eric & Kimberly Vietti, Douglas & Jane Sell, Gary & Christine Stratton, Vernon & Melanie Fischer, Jason & Erin Lockhart, Carolyn Mahon, Gerald & Carolyn Cornell, Todd Martin & Sara Penne-Martin, George & Susan Thies III, Scott & Pamela Witt, Jennifer Leahy, Joanne Rouse, Sara Horkavi, Ken & Karen Nielsen, Gary & Gretchen Brandstetter, Stanford Tack & Paula Hynes-Tack, Thomas DeGeus, Michael & Patricia Kuta, Curtis & Kathryn Witt, Eric Penne, Robert & Jill Powell, Paul & Alice Neidhart, Peter Hynes, Mark & Sherri Hynes

In Loving Memory of Thomas Wickie Ray from Dave & Cheryl Ashby

In Memory of Josephine Kaleta from Terry & Paulette Kaleta

In Memory of Sharon Kay Weaver from Richard S. Weaver

In Memory of Peter Gavras from Mildred Gavras

In Memory of Edward Maly from Integra Graphics and Forms, Inc.

Memorial and Tribute Donations

Complete the form below and send along with your contribution to:
HDSA – Illinois Chapter - "Memorial/Tribute",
P.O. Box 1883, Arlington Heights, IL 60006

I would like to make a contribution **in memory of/in honor of**:
____

My Name_______________________________________
Address____
City, State, Zip__________________________________
Amount of Contribution: $___________________________

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(630) 443-9876 ~ www.hdsa.org/il
This newsletter attempts to report items of interest relating to the individuals with Huntington's Disease, their families, healthcare professionals, and interested friends and supporters. HDSA and the Illinois Chapter do not provide medical advice, nor do they promote, endorse or recommend any product, therapy or institution. Please check all drugs, treatments, therapies and products with your physician. Statements and opinions expressed in articles are not necessarily those of HDSA, Inc. and the Illinois Chapter.

“Heredity and Huntington’s Disease: New Frontiers”

2016 HDSA Illinois State Conference

March 12, 2016

Hilton Chicago Northbrook – Allgauer’s, 2855 N. Milwaukee Ave., Northbrook, IL

Registration is $10.00/person (Continental breakfast, coffee breaks and buffet lunch are provided)
You can register for the state conference online by going to **http://illinois.hdsa.org**
and click on the conference link on the slideshow or the Events or News tabs

Join us for an exciting day with keynote speaker and renowned geneticist Dr. Kimberly Quaid, medical expert Dr. Kathleen Shannon, MD, and other leading professionals who have dedicated their lives to help families in their struggle with Huntington’s disease. *The 2016 conference begins with the insight that we live in a special era: 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.*

Sponsored by the HDSA Illinois Chapter.

AGENDA

8:00am **Registration, Coffee, Networking**
8:45am **Welcome and Introductions** - Daniel Born, PhD and Emily Zivin, LCSW, MPA, conference co-chairs

9:00am **“Heredity and Huntington’s Disease: New Frontiers”** – Kimberly Quaid, PhD, Professor of Medical and Molecular Genetics and Indiana University School of Medicine

10:00am **Break**

10:15am **Morning Breakout Sessions**

- **Family Planning and HD: Current Practices** with Sara Cherney, MS, CGC (Birch Room)
- **Mindfulness** with Angela Waltman (Laurel Room)
- **Making a Long-Term Plan for Care** with Jean Morack, ACSW, MSW and Emily Zivin, LCSW, MPA (Locust Room)
- **Fighting HD on the Nutritional Front** with Susan Hodgson, LPN (Linden 1 Room)

11:00am **Break**

11:10am **Research Update & Report on Clinical Trials** - Dr. Kathleen M. Shannon, Director of the RUMC Huntington’s Disease Society of America Center of Excellence

11:50am **Increase our Participation in Clinical Trials** - Ted Ross

Noon **Lunch - Introducing the HDSA Illinois Chapter Board**

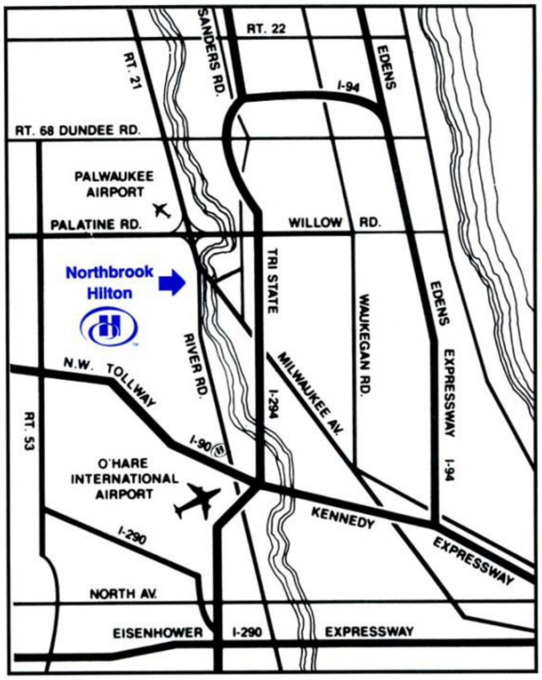
1:00pm **Sharing Our Stories: Evolving Families and Family Plans**
Panel discussion moderated by Emily Zivin, LCSW, MPA, with Liz Born and Alexis Florczak, MSN, MHA

2:00pm **Break**

2:15pm **Afternoon Breakout Sessions**

- **HD 101: Facts and Myths** with Stacey Barton, MSW, LCSW (Laurel Room)
- **Financial Planning for HD Families** with MaryAnne Ehlert, CFP (Linden 1 Room)
- **Five Difficult Scenarios and What You Can Do** with Dr. Kathleen Shannon, MD, and Sara Mitchell, MSW (Birch Room)
- **How to Talk with the Kids About HD** with Stephen Clingerman, PhD, and Liz Born (Locust Room)
- **Advocacy: The Ground Game and Light Show Razzle Dazzle** with Tom Barr and Dave Hodgson (Linden 2 Room)

3:15pm **Adjourn** - Daniel Born and Emily Zivin (Main Hall)



From Downtown Chicago:

90/94 West to O'Hare/Rockford, I-294 North/Milwaukee, WI; Exit at Willow Road. West on Willow Road to Milwaukee, South on Milwaukee 1/2 mile. Hilton Hotel is on left.

From the West:

90 East to I-294 North, exit at Willow Road. West on Willow Road to Milwaukee Avenue, South on Milwaukee, 1/2 mile, Hotel is on left.

From the North:

94 East to I-294 South, exit at Willow Road, West on Willow Road to Milwaukee Avenue, South on Milwaukee, 1/2 mile, Hotel is on left.

From the South:

I-294 North, exit at Willow Road, West on Willow Road to Milwaukee Avenue, South on Milwaukee 1/2 mile. Hotel is on left.

The hotel is located at the intersection of Milwaukee Avenue (Route 21) and Winkelman Road. It is south of Willow Road, north of Lake Avenue, and just west of the Tri-State Tollway. (I-294)

If you have questions, please contact conference co-chair Daniel Born at (773) 896-4327, or email: dankborn@gmail.com

Online Registration: http://illinois.hdsa.org

REGISTRATION FORM

"Heredity and Huntington's Disease: New Frontiers"

2016 HDSA Illinois State Conference

March 12, 2016

Mail this completed form with your check for $10.00 per person
(made payable to HDSA Illinois Chapter) to:

Illinois HDSA Conference Registration, P.O. Box 1883, Arlington Heights, IL 60006

You can also register at the door, but we appreciate early registrations, preferably by March 7, so we can get an accurate headcount.

PRINT NAMES AS YOU WOULD LIKE THEM TO APPEAR ON YOUR NAME TAGS

Participant #1______________________________ **Participant #3** ______________________________

Participant #2______________________________ **Participant #4** ______________________________

Address________________________________ Phone (____)__________________________

City__________________________________ State______________________Zip________

Email _________________________________

HDBuzz

Through the eyes of a friend: changes in mood and behavior in early HD

Companions of HD gene carriers are more likely to notice psychological changes in presymptomatic HD.

By Leora Fox on December 02, 2015Edited by Dr Jeff Carroll

The family and friends of individuals with HD often tell doctors that they began to notice changes in behavior long before a diagnosis was made. To better understand these early signs, researchers analyzed a psychological questionnaire filled out yearly for a decade by thousands of HD mutation carriers and their companions. The companions were more likely to perceive worsening symptoms over time.

Understanding the Early Symptoms of HD

Huntington's Disease is inherited at conception, but for most carriers of the mutation, symptoms don't begin until middle age. Even though the HD mutation is toxic to brain cells called neurons, most mutation carriers spend several decades symptom-free. This means that the brain has a remarkable ability to withstand many years of exposure to the mutation.

The period before major symptoms have developed is known as the *prodromal* phase of HD, when behaviors may begin to change gradually and subtly. Often, the very first symptoms noticed by HD patients or their families involve small alterations in thinking, mood, or disposition. These symptoms are real, but it's not possible for physicians to say that they're definitively due to someone carrying an HD mutation because many people who don't carry the mutation also experience these challenges.

What are these early symptoms like? Maybe a punctual person finds it more difficult to be on time for appointments, or a spouse notes that a good sleeper has become a bit restless. Since these early signs don't usually interfere with daily activities, medical research didn't focus there at first. Now, we are aware that investigating early changes is important, because they can inform when and how to begin treatment, especially when new drugs become available.

Recently, a group of researchers concentrated on understanding the psychiatric and behavioral difficulties that can occur in prodromal HD. The work is just one arm of a huge study that relies on thousands of HD-positive and unaffected volunteers. Over the course of a decade, participants and their companions filled out a questionnaire every year, evaluating the participant's psychological health. The study revealed some of the subtle psychological changes that can occur in pre-symptomatic HD, and showed that close companions were more likely to notice worsening symptoms than the HD mutation carriers themselves.

PREDICT-HD: Studying Prodromal HD

The story behind this research actually began more than ten years ago, when researchers started recruiting for a huge study called PREDICT-HD. The overall goal of the work, which is ongoing, is to identify and understand the earliest signs of HD. HD mutation carriers and their families frequently report early behavioral changes, but diagnosis is usually based on movement symptoms that are more specific to HD.

To create standards for assessing patients and treating them with current and future therapies, clinicians need a clearer picture of what occurs during the years prior to the development of involuntary movements. This way, doctors can make decisions based on documented history from HD carriers around the world, rather than isolated anecdotes from just their own experience with patients.

Volunteers participating in PREDICT-HD came from all over the world, at 33 medical sites in six countries. Each person generously agreed to visit a study site for a whole day or two once a year, for up to 10 years. Participants were examined by clinicians, received brain scans, completed written evaluations, and donated blood samples.

Importantly, participants in the PREDICT-HD study had to have already undergone testing for the HD mutation – a person at risk for HD could only enroll if they knew their gene status. As a comparison, the researchers also included a group of control individuals from HD families who did not inherit the HD mutation. From the test tube to the clinic, the findings from PREDICT-HD are helping us to better understand the earliest changes experienced by HD mutation carriers.

A yearly Psychological Pop-Quiz

In the last decade there have been *hundreds* of publications about early HD based on data from PREDICT-HD volunteers. We'll zoom in on one study, which focused on prodromal psychiatric symptoms. Jane Paulsen, a clinical psychologist at the helm of the PREDICT-HD project, led the research team.

Every year, participants in the study completed a questionnaire about their psychological health. The test is used worldwide for many disorders, and it consists of 90 fill-in-the-bubble questions designed to measure a broad range of psychological problems. For example, a question might ask "In the past week, how much were you bothered by trouble concentrating?"

Often, the very first symptoms noticed by HD patients or their families involve small alterations in thinking, mood, or disposition.

Respondents would rate each question on a scale of 0 (not at all) to 4 (extremely). Questions are designed to ask about feelings related to anxiety, depression, compulsions, interpersonal interactions, and many other categories.

Around 1300 participants took part in the study, both mutation carriers and controls, and most brought along a close companion to help assess their mental health using the same questionnaire. The companion was usually a live-in partner or spouse, but sometimes another family member or friend. The researchers were especially interested to see how mutation carriers' psychological scoring compared to individuals without HD, how their evaluations changed over an entire decade, and whether their companions' ratings matched their own.

Assessing Mental Health in HD: At the Beginning, Over Time, and via a Friend

The authors of the study used different types of mathematical analyses to answer three main questions about prodromal HD:

At the beginning of their participation in the study, were there already psychological differences between HD mutation carriers and unaffected individuals?

Yes. When they enrolled in PREDICT-HD, participants with the HD mutation rated themselves higher than control subjects on almost all aspects of the psychiatric questionnaire, including symptoms like anxiety, obsessive-compulsiveness, hostility, hyperawareness of physical illness or injury, and paranoia. Their companions also noticed these types of mental and mood changes, especially when their participating loved ones were closer to developing movement symptoms (such as those who were older, or had more severe mutations).

Over time, from the beginning to the end of an HD mutation carrier's participation in the study, was there a noticeable change in their psychological health?

Well, their companions noticed a change – but the mutation carriers didn't always agree. The majority of HD mutation carriers did not perceive their mental health to be getting worse over the years they participated in the study. However, their companions reported that certain psychological signs got worse, like anxiety, paranoia, and interpersonal distress.

Was there an overall difference in how participants rated their own symptoms, versus how their companions rated their symptoms?

Yes. The difference between the companions and the participants' ratings was especially striking in those predicted to have a higher likelihood of experiencing motor symptoms within a few years. Companions usually noticed more psychological distress in their loved ones than the HD mutation carriers did in their self-reports.

The Message

What is the meaning of these results? First, analyzing participants at baseline (the very beginning of the study) showed that early on in symptom progression, HD mutation carriers and their companions noticed subtle changes in their behavior and personalities compared to unaffected individuals.

This is important because it confirms on a much larger scale that mood and behavior symptoms are apparent early on to patients and their loved ones. These types of symptoms can increase in severity over time before movement symptoms occur, to an extent that was not previously appreciated. Gaining a better handle on the psychological health of people with presymptomatic HD could help shape how and when people receive a diagnosis, and when might be a good time to begin treating symptoms such as anxiety, depression, compulsions, or difficulty sleeping.

Second, HD mutation carriers and their loved ones may perceive *longitudinal* changes in behavior (those that occur over time) in different ways. While many participants with the HD mutation did not believe that their symptoms were getting worse, their companions definitely noticed increasing psychological problems or mental distress.

One explanation for this finding is that HD affects the complex circuitry of the brain in a way that hinders insight. This could be due to gradual damage in many connected parts of the brain that sync up to control self-awareness. Or it could simply be that when behaviors and habits deteriorate slowly over long periods of time, the change is easier to see from an outside vantage point. A person at risk for HD almost always completes their own health assessments, which may be part of the reason why the psychiatric symptoms have been difficult to link with disease progression.

Considerations and Conclusions

There are a couple of caveats to reflect on when we consider these results. The psychological questionnaire is very general, and it only asks about the previous *week* of the participant's life, so their answers might not always capture their feelings about the whole *year* since they last responded.

Another consideration is that all the participants and their companions were aware of their mutation status from the beginning to the end of the study. Getting tested is an extremely personal choice made by only a small fraction of those at risk for HD, and that knowledge could affect how a person and their friends and family perceive changes in behavior.

Nevertheless, PREDICT-HD is the largest and longest study that has ever been completed about the prodromal phase of HD, and there are many new results emerging from the data. The questionnaire responses show that there are a great variety of psychological and behavioral symptoms experienced by people with prodromal HD.

The results also imply that patients may not always be aware of how their symptoms change, confirming that the input and support of trusted companions can be a great advantage. Importantly, the combined data from thousands of helpful volunteers has turned individual anecdotes into solid data that will inform how we can better evaluate and treat the early symptoms of HD.

12TH ANNIVERSARY

Team Hope – Walk for a Cure - 5K Walk

SUNDAY, MAY 22, 2016

NAPERVILLE RIVERWALK

(RAIN OR SHINE)

REGISTRATION: 9:30AM ~ WALK BEGINS: 10:30AM

The Illinois Chapter invites everyone from the Greater Chicago area and across Illinois to join us for the Illinois Chapter Team Hope Walk in Naperville, IL on Sunday, May 22, 2016. The location is the same as last year: Grand Pavilion at the Naperville River Walk in downtown Naperville. Walk with us as we support the mission of HDSA to improve the lives of everyone with Huntington's disease! For more information and to register for the Walk, please visit our webpage at: **www.hdsa.org/thwnaperville**.

The Riverwalk is very people friendly with park benches, along the way. It is wheelchair, wagon, and stroller friendly! Dogs are welcomed as long as they are on a leash. Please be sure to bring your lawn chairs and plenty of your own non-alcoholic drinks for everyone walking in your group. Don't forget water for your dog too!

Fundraising

Team Hope Walks aim to raise as much money possible in the local community to support the mission and services of the Huntington's Disease Society of America. There are many different fundraising strategies you may use to have a successful fundraising campaign, and HDSA suggests you use all of them! Please go to the walk website and download the Team Hope Walk Participant Packet and check out the Team Hope website's Fundraising Tips & Tools (including some fundraising webinars!) and Participant Resources sections.

Sponsorship

We invite all local companies and small businesses to sponsor this Team Hope Walk. We depend on the generosity of sponsors, and by sponsoring a walk, your company will be supporting a great cause as well as engaging in an exciting marketing opportunity within the local community. If your company or a company you know is interested in sponsoring the walk, please email teamhope@hdsa.org!

Proceeds support HDSA's fight to improve the lives of people affected by HD and their families. As in past Walks, memorial and business signs are available for a $100 donation and will be displayed near the Walk. We hope all of our families affected by HD will join us and make this year's Walk our most successful one!

If you have any questions, please contact Dave Hodgson at 815-498-6092 or email at spiketdog@softhome.net.

This year's challenge: Have 10 FRIENDS sponsor you!

PLEDGE SHEET

Collect pledges from family members, friends, co-workers, neighbors, church members, teachers or anyone who would like to join you in your personal fight against HD. Please place pledge sheet and all collected donations in a sealed envelope with your name and total collected on the outside of the envelope. Please turn in your pledges on Walk Day.

Huntington's Disease Society of America
Illinois CHAPTER
Family is everything

Team Hope – Walk for a Cure - 5K Walk

	NAME	ADDRESS	AMOUNT	
1.				**Good Start**
2.				
3.				
4.				
5.				**Getting Closer**
6.				
7.				
8.				
9.				
10.				**You Did It!**
11.				
12.				
13.				
14.				**Keep Going!**
15.				
16.				

Name: ____
Address: ____
City: ____ St: ________ Zip: ___________

Waiver: I hereby waive all claims against the Huntington's Disease Society of America, sponsors or any personnel for any injury I might suffer from this event. I attest that I am physically fit and prepared for this. I grant full permission for organizers to use photographs of me to promote this event.

Signature: ____

HDSA IL Chapter Hoop A Thon Recap!

The Cuccinotto/ O'Connor Family have once again pulled off another very successful event in support of all those living with HD! We give all the thanks and all the credit to our terrific friends and family who come out and give their time and money to help make this weekend so very special.

The day was filled with love, laughter and a fantastic raffle /auction. We had music from Celebration Authority, Food from Little Villa Pizzeria, and Chicago Hot Dogs from Vienna Beef Co. We also had some terrific basketball shooters and some not so terrific shooters but they all came out in support of HDSA IL.

We were able to raise just over $18,000 this year. FYI, FYI, FYI Keep watching the HDSA IL Website and the Newsletters as we are planning a few different ways to generate Fun, Funds, and Awareness for Huntington's Disease Society of America IL Chapter.

2016 we will have some new ways for you to get involved with the Cuccinotto / O'Connor family to fight HD!

Once again we are so grateful and blessed by so many friends, family and sponsors who helped to make this Hoop A Thon a wonderful success!

John Cuccinotto
HDSA-IL Hoop-A-Thon Committee
630.873.0052

News from Our Illinois Chapter Social Worker Emily Zivin, LCSW

Huntington’s Disease Society of America
Tel: 630-443-9876 or E-mail: ezivin@hdsa.org

The influence of social media is on the rise. More and more people are seeking advice from peers. Individuals are looking for people to share their knowledge, to learn how to make better health choices and for general support. Currently people are looking at Facebook, blogs, health websites and online meeting groups to share their information, gain knowledge and seek support. Our own HD community has many online resources to support and help you and your family. Please contact me if you would like additional resources.

Looking for Participants in HD Research: The Lived Experience of HD

The body of research that currently exists on HD features a distinct lack of scholarly research of the first-person experience of Huntington’s, instead focusing on the symptoms, caretakers, families, genetics, etc. This project aims to capture what it is like to live with Huntington’s disease and to describe any and all concerns and topics that arise therein. It is the hope and desire of this student conducting the research to fill the void of first-person accounts within the academic community and to be able to arm physicians, clinicians, therapists, and psychologists that read this research with the information needed to understand both what is important to those with Huntington’s and how to best help them.

If you choose to participate, the research will involve being interviewed for an hour to an hour-and-a-half. This is an opportunity to tell your story and to, perhaps, be able to help others understand what your journey has been like living with Huntington’s as well as highlight what has been important and unhelpful during this time.

The student conducting the research’s name is Ashton Brunn and is a student at the Chicago School of Professional Psychology. This research is being conducted as a part of his doctoral dissertation project in the field of clinical psychology. He is conducting this research under the supervision of Paul Larson, Ph.D., J.D. If you have any questions, contact HDSA at ezivin@hdsa.org. Thank you for your interest.

Note: This project is still in its development and is still pending IRB approval (the human subjects ethics review committee) and it may be several weeks before you receive confirmation if you choose to participate and/or inquire about more specific information.

Thank you, Good Luck and Best Wishes to you, Ann!

Ann Lizka has moved on to other endeavors after starting and hosting the Geneva support group for the past eleven years. The Huntington’s community offers its sincere gratitude for the time and effort that Ann has contributed. She has been a pillar of support for many HD persons and their families. The group represents the legacy of Ann’s husband Hank, who died with HD.

Support Group Update

The Chicago Support group will resume meeting on October 27th from 7:00 to 8:30pm
Rush University Medical Center
Tower Resource Center, 4th floor, Suite 04527, Chicago, IL

The current schedule is the 4th Tuesday of even months from 7:00-8:30pm

SUPPORT groups

Date/Time	Additional Information	Contact Information
CENTRAL ILLINOIS		
2nd Sunday of **even months** TIME: 2:00 to 4:00pm LOCATION: St. Joseph Medical Center, Bus. Conf. Center – Room 2, 2200 E. Washington Street, **Bloomington, IL**	**2016 Meetings:** 02/14, 04/10, 06/12, 08/14, 10/09	Dave or Susie Hodgson (630) 386-3928 spiketdog@softhome.net
GENEVA		
Specific Sundays of **odd numbered months** (see dates in next column) TIME: 2:00 to 3:30pm LOCATION: Cadence Delnor Hospital, 300 Randall Road, Conference Room #4, Medical Office Building 351, Geneva, IL (park in the southwest lot) * Whether you have HD, are at risk, a caregiver, friend, or just someone who wants to know more about HD, you are welcome.	Immediately after entering the building, turn right down hallway and follow until hallway ends. Conference room #4 is straight ahead on your left. **2016 Meetings:** 01/24, 03/20, 05/15, 07/17, 09/18, 11/20	Joe Wiedemann (847) 505-3933 joseph.wiedemann@gmail.com
LAKE COUNTY		
2nd Monday of **every month** TIME: 7:00pm LOCATION: Advocate Condell Medical Center, 801 Milwaukee Ave., West Tower, Libertyville	Call for additional information and directions.	Marilyn and Barry Kahn (847) 975-2403 marilynkahn1@gmail.com
ROCKFORD		
TIME: 2:00pm LOCATION: OSF St. Anthony Medical Center, 5666 E. State St., St. Anthony Room, Rockford, IL * Use the main entrance - second one back from the parking lot entrance. As you enter the building you'll see a counter staffed by volunteers. Turn right, before you reach the counter. The St. Anthony Room is straight ahead.	Open to people with HD, family members, caregivers, and interested professionals. **2016 Meetings:** TBD (Planned for Quarterly)	Ted Ross (815) 282-0600 tedrosse@comcast.net
SOUTH SUBURBAN		
2nd Tuesday of **odd months** TIME: 7:00pm LOCATION: Thomas Cellini Huntington's Foundation, 3019 East End Avenue, South Chicago Heights	**2016 Meetings:** 01/12, 03/08, 05/10, 07/12, 09/13, 11/08	Maryann Moynihan (708) 955-3080 shamrock1959@att.net TCHF Office (877) 687-8243
CHICAGO – RUSH UNIVERSITY MEDICAL CENTER		
4th Tuesday of **even months** TIME: 7:00 to 8:30pm LOCATION: Rush University Medical Center, 1620 W. Harrison Street, Tower Resource Center, Tower, 4th Floor, Suite 04527, Chicago, IL * Parking is available at the Rush garage on the southeast corner of Paulina and Harrison Streets. From the 4th floor, follow the signs to the Tower.	Valet parking is available in front of 1620 W. Harrison. Parking at both of these venues will be validated in full.	For more information, please call 1-630-443-9876. Open to all: at-risk, gene positive, currently have HD or are a family or friend of someone with HD
MUNSTER, INDIANA		
2nd Tuesday of **even months** TIME: 7:00pm LOCATION: Southside Christian Church, 1000 Broadmoor Ave., Munster, IN	**2016 Meetings:** 02/09, 04/12, 06/14, 08/09, 10/11, 12/13	Cindy Rogers (219) 680-6001 (cellular) (219) 836-2369 (home)

Sadie Foster, M.A., L.C.P.C., has a telephone Information & support call service for HD families. This call is held the fourth Sunday of every month at 7pm. To participate dial 630-300-6276 and when asked, enter code 702087#. You do not need to identify yourself on the call.

For additional support you may call:

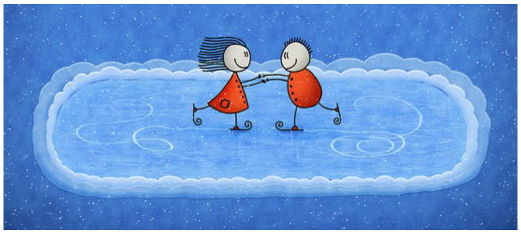
Sadie Foster, MA, LCPC, at the College of Medicine Huntington's Disease
Clinic Tel: 815-271-7101 or E-mail: sadie@sfoster.com

Sarah Mitchell, Rush University Medical Center Social Worker
Tel: 312-942-6445 or E-mail: sarah_mitchell@rush.edu

save
the
date®

February 13, 2016	Hoedown for Huntington’s Dinner/Dance/Auction – Bloomingdale, IL
March 12, 2016	Annual HDSA Illinois State Conference – Northbrook, IL

www.hdsa.org/il



WINTER 2016