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V Illinois Chapter

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

President's Message



Fall is upon us and, to me, it seems that I find myself drifting more and more into times of reflection. There are times that I question myself...what am I doing, what if I should be doing this another way, am I doing enough, what more could I do, what could I do differently? I glance out the window and see two squirrels playing chase or is it a game of peek-a-boo, I see you? As I continue to watch, it soon appears that it is a game of catch me if you can as they scamper up and down, around and around the tree trunk. As I watch, several brightly colored leaves begin their magical dance as they drift closer and closer to the ground. As I continue to observe the happenings outside; the squirrels and their cute antics, the falling leaves doing a colorful magical dance on their way to the end of their life's journey, I allow my mind to drift, question and wonder...to ask what if...what if...

I look back to that naive 18 year old, eagerly looking forward to her wedding, believing in happily ever after. She looks into the future and sees herself sitting on a porch swing beside her husband, both watching as the children arrive with their families and soon they are both swarmed with hugs and kisses from adoring grandchildren...there is a loud yell, "I need help" and I am suddenly snapped back to reality. I jump up and run to my son to see what he needs, to assure myself he is not hurt and that all is right with my world.

As we travel through the seasons of our life, our dreams of what our life will be like "when we grow up" are often changed by reality. This is not a bad thing. As reality and circumstances change the course of our lives, and yes, sometimes turns our world upside down, it is what we do with these changes that are important. We can sit around moaning and groaning about how unfair life is, or we can take control of the situation and do everything we can to turn those sour lemons into lemonade.

At 18, my idea of my role as a caregiver was light years from my reality. At age 24, I first heard the words, Huntington's Disease and I became the primary caregiver for my mother-in-law. A role that was incredibly different than anything I had ever experienced before. I felt as though I had been set adrift in an ocean with no land in sight. At age 30, my husband told me he thought he had early signs of HD. At age 37 my husband was finally diagnosed with HD. Who would have thought that providing care for your husband with HD could be so different from providing care to your mother-in-law with HD. After all, it was the SAME disease, but, nothing was the same. At age 46 I was a widow.

At age 48, I found love again and was blessed with an extended family. At age 49 my oldest son was diagnosed with HD, and again, the role of caregiver was completely different than either role of caregiver I had done before.

My story is no different than that of so many of our HD families. Dreams shattered, trying to pick up the pieces, not knowing where to turn. Questioning ourselves; doubting ourselves; beating ourselves up. What I have come to know is that all of this is normal, we are only human. It is what we do with these thoughts and emotions that are important. The most important thing you can do as a caregiver...take care of yourself, give yourself permission to make mistakes and remind yourself that you are not perfect and that is okay.

Things you can do to take care of you, get involved in a support group, have someone stay with your loved one for at least an hour a week, so that you have the opportunity to do something for you. (No! Running errands is NOT doing something for you.) I found the following paragraph which sums up what caregivers do.

"You may be wondering what the seasonal metaphor has to do with our experience of caregiving. Well, consider the following questions. What seasons do you associate with caregiving? The fall and winter of life? Seems logical. Aging naturally results in physical and cognitive demise. As we age, we are more vulnerable to illness. Hence, in the later seasons of life, caregiving becomes a significant issue for most of us. But isn't caregiving a concern in the spring of life as well? As infants, we are totally dependent on others for our care – not unlike the experience at the end of life. Interesting, isn't it? We begin and end the journey of life as care receivers, dependent on personal and professional caregivers. During the intervening years, we will likely serve as caregivers periodically and/or require additional care. Thus, caregiving is a concern for ALL seasons."

Remember you are not alone, WE ARE FAMILY! Wishing you all a happy fall and holiday season.

Most sincerely,

Susie Hodgson, HDSA Illinois Chapter President (hdsailchapter@gmail.com)



We are pleased to announce a new section in our quarterly newsletter hosted by Dr. Jennifer Goldman, movement disorder neurologist at Rush University Medical Center and the new Director of the HDSA Center of Excellence at Rush. Dr. Goldman and her team will be answering questions and providing updates and news to the HD community.



Jennifer G. Goldman, M.D., M.S., is an Associate Professor in the Department of Neurological Sciences, Section of Parkinson's Disease and Movement Disorders at Rush University Medical Center in Chicago, IL, USA. Dr. Goldman is a movement disorder neurologist with specialty training in Behavioral Neurology and Neuropsychiatry. She graduated from Princeton University and received her MD from Northwestern University Medical School. She completed her neurology residency at Washington University in St. Louis, followed by a movement disorder fellowship and a Master of Science degree in clinical research at Rush University in Chicago. She is board certified by the American Board of Neurology and Psychiatry as well as its subspecialty, Behavioral Neurology and in Neuropsychiatry.

As a movement disorder specialist, Dr. Goldman sees and treats patients with Parkinson's disease, dystonia, Huntington's disease, and other movement-related conditions at the Rush University Movement Disorder clinic. Dr. Goldman is also recognized as a researcher in movement disorders, and her research focuses on understanding the cognitive and behavioral issues that frequently accompany movement disorders and on developing improved treatments for them. In this research, she uses brain imaging techniques (MRI scans) and other biomarkers to examine cognitive and behavioral features of Parkinson's disease, parkinsonian syndromes, and Huntington's disease. In addition, she has over 10 years of experience with clinical trials at Rush University and has authored numerous articles and publications on movement disorders. Her research has been supported by the National Institutes of Health, The Michael J. Fox Foundation, Parkinson's Disease Foundation, pharmaceutical companies and private

foundations. She recently has mentored a Rush medical student who received the Donald A. King HDSA summer research fellowship in 2015 to study brain imaging and psychiatric symptoms in people with pre-manifest HD. Dr. Goldman also is actively involved in education for healthcare providers and patient/caregiver communities. She was the 2013 recipient of the



Rush University Faculty Award for Excellence in Education, has lectured nationally and internationally on movement disorders, and mentors trainees at all levels. Dr. Goldman serves as the Chair of the International Parkinson and Movement Disorder Society Pan-American Region Education Committee and is a member of the Movement Disorder Society Study Group on Parkinson's disease-Mild Cognitive Impairment (PD-MCI), the Lewy Body Disease Scientific Advisory Committee, Parkinson Study Group and Huntington Study Group.

Jennifer G. Goldman, M.D., M.S. Associate Professor, Section of Parkinson Disease and Movement Disorders Department of Neurological Sciences Rush University Medical Center 1725 W. Harrison St., Suite 755 Chicago, IL 60612 312-563-2900 (office) 312-563-2024 (fax) 312-942-8007 (voice mail)

At the **<u>GENEVA SUPPORT GROUP MEETING</u>** on November 20, 2016, we will have speaker Jimmy Pollard presenting to the group about "Thinking About Thinking with HD", as related to communicating with a family member or other person with HD.

The meeting is from 2:00 to 3:30pm **at** 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.

If you have any questions, contact Joe Wiedemann at 847-505-3933.



Score for HD!

(Winter Dinner/Dance)

Saturday, January 28, 2017

Eaglewood Resort & Spa 1401 Nordic Road, Itasca, IL 60143

Get out your favorite sports jersey and join us for a fun evening of fundraising and fellowship. Additional information will be provided on the Illinois Chapter website http://illinois.hdsa.org.

COPING

HDSA Illinois State Conference

Caring: Empowerment for Managing HD

Saturday, February 25, 2017

9:00 am – 3:30 pm Northwestern Memorial Hospital Feinberg Pavilion 251 E. Huron Street, 3rd Floor, Chicago, IL 60611

Join us for the 2017 Illinois State Conference to be held downtown Chicago. This year's conference is packed full of empowering information to assist in the management of our everyday lives with HD – technology, financial positioning, physical therapy, reproductive options, and more. Online registration will be \$10/person and will be available online shortly so watch the Illinois Chapter website http://illinois.hdsa.org for details and, as always, you will also be able to register by USPS mail.

Subjects Needed for Research Study

We are researching cognition, balance, and walking patterns in people with Huntington's Disease (HD)

We are looking for persons with gene confirmed HD.

You may be able to participate in this study if:

- ✓ You are able to walk for at least 2 minutes
- ✓ You are able to stand unassisted for at least 30 seconds

You will be asked to:

- Have your balance and walking tested while wearing sensors around your wrists, ankles, chest, and waist; these are worn outside of your regular clothing. Your balance will be tested while standing on and off a foam pad with eyes open and closed and your walking will be tested by having you walk up and down the hallway at different speeds. These will be done with and without a simultaneous thinking task.
- 2. Perform a short series of thinking tasks and a functional balance test.
- Answer questionnaires about your balance confidence, quality of life, and any symptoms of anxiety and depression.
- 4. Have a short neurological examination to rate your symptom severity.
- ✓ The testing will be performed in Dr. O'Keefe's office in the Rush University Armour Academic Center at 600 South Paulina and the Movement Disorders Clinic in the Rush Professional Building at 1725 West Harrison.
- ✓ The time it takes to complete the above tests is ~ 90 minutes.

Participants will NOT be monetarily compensated for participation in this study but may be reimbursed for transportation costs.

For more information, contact:

Joan Ann O'Keefe, PT, PhD at 312-563-3940 or joan_a_okeefe@rush.edu Rush Co-Investigators: Jennifer G. Goldman, MD, MS and Nicollette L. Purcell,

BS



HDBuzz

Ultra-rare mutations highlight the importance of the HD gene in brain development

New technology enables researchers to find ultra-rare mutations in the HD gene, distinct from the one causing HD By Megan Krench on August 29, 2016Edited by Dr Jeff Carroll

A relatively new technology called exome sequencing has identified a few families with novel mutations in their HD genes. These are different than the mutation that causes HD, but allow researchers to better understand the normal role of the HD gene.

Normal HD gene function

The mutation that causes HD instructs brain cells to make an abnormal, mutant protein scientists call huntingtin. We've long known about the many ways mutant huntingtin protein can interfere with cells' normal processes. For example, mutant huntingtin can interfere with brain cells' ability to move cargo from one end of the cell to the other and impair cells' abilities to produce energy.

With whole exome sequencing, scientists can reduce how far they have to search for rare mutations - from the whole field to focusing



only on the bales Image credit: By foxypar4 - originally posted to Flickr as Harvest Time, Alness (Ross-Shire), CC BY 2.0

What we're less sure about is: what exactly is *healthy* huntingtin supposed to be doing in the cell in the first place, and what happens when it's not around to do its job? (You can read more about the "Hunt for the Function of Huntingtin" here: http://en.hdbuzz.net/221.) Two recent discoveries highlight how healthy huntingtin may play critical roles in the development of our brains and

nervous systems, giving us new information to keep in mind as we develop treatments for HD.

Before we go into the findings, here's a quick crash course on the technique that made it all possible: whole exome sequencing. Our DNA is comprised of over 3 billion letters. But surprisingly, the cell only reads about 1.5% of that genetic blueprint to make proteins. The 1.5% of our DNA that codes for proteins are called **exons**.

Sequencing technologies, which allow scientists to read the information coded in DNA, have advanced very rapidly over the past decade or so. It's now possible for researchers to read all 3 billion letters to get a person's complete genetic code. Researchers call this whole genome sequencing. But, sequencing all 3-billion letters to look for a tiny mutation is like looking for a needle in a haystack. To make the haystack smaller, researchers instead can sequence only a subset of the genome - often just the subset of a person's DNA that codes for proteins, the exons.

This process of sequencing only the protein-coding regions is called whole exome sequencing, and results in a haystack about 1.5% as big as a whole genome. Two different research groups using whole exome sequencing incidentally made important new insights about the normal function of the HD gene.

Rare HD gene mutations discovered

"We aren't certain what impact the new, non-HD genetic mutations are having on the huntingtin protein. But, based on the genetic region where the mutations occur and what we know about the protein's structure, it is likely that the mutations are dramatically reducing the amount of huntingtin protein in the cell".

The first group of researchers was searching for genetic mutations in a group of nineteen people with severe developmental disorders. Their symptoms, including intellectual disability, limited speech and motor abilities, and repetitive motions such as hand wringing, were characteristic of a disease called Rett syndrome. But, like HD, Rett syndrome is caused by a mutation in a specific gene-and these people did not have the mutation known to cause Rett syndrome.

To try and solve this mystery, researchers used whole exome sequencing to search for the mutations in every gene that might explain these symptoms. They identified several new mutations in these individuals, but one person in particular is relevant to our story here at HDBuzz: a woman with mutations in both copies of her HD genes. The woman didn't have HD because her HD gene mutations were different than the type that causes HD. And, while most carriers of HD only have the mutation in one huntingtin gene, both copies of this woman's huntingtin genes carried these novel mutations.

At the same time this study was happening, another group of researchers were searching for the cause of a developmental disorder in an Ecuadorian family. The family was comprised of two healthy parents, one healthy child, and three children with severe developmental delays. The affected children's symptoms included little or no language skills, dramatically impaired motor abilities, and repetitive motions like hand wringing. None had a mutation in the gene that causes Rett syndrome.

- 5 -

To try to discover the underlying mutation, these researchers performed whole exome sequencing on the Ecuadorian family. They discovered that the developmentally delayed children had mutations in both copies of their HD genes. Again, they were new mutations—not the specific mutation that causes HD.

In both of these studies, researchers also performed whole exome sequencing on the healthy parents of the people with developmental disorders. In both sets of parents the mother and father each carried one mutated HD gene. However, their other copy of huntingtin was healthy. In the Ecuadorian family, the sibling that didn't have developmental delays also carried one copy of mutated HD gene and one healthy copy. The only people that experienced developmental disorders were those that inherited two mutated HD genes.

Researchers finally identified previously unknown mutations causing severe developmental delays in the HD gene Image credit: Pixabay

We aren't certain what impact the new, non-HD genetic mutations are having on the huntingtin protein. But, based on the genetic region where the mutations occur and what we know about the protein's structure, it is likely that the mutations are dramatically reducing the amount of huntingtin protein in the cell. This type of mutation (called loss of function) is different than the type of mutation that causes HD. In HD, the mutation leads to production of a toxic, abnormal huntingtin protein—but it does not affect the amount of huntingtin protein that's being made.

So - just to be clear - these mutations are **not** the same as the mutations which case HD. But by random chance they happened to occur in the HD gene, and so help us better understand what the HD gene does, beyond being mutated in people who develop Huntington's Disease.

What do we learn?

These studies have taught us several important things about huntingtin. First, they show that just a single copy of "healthy" huntingtin is sufficient for the brain to develop and function normally. We know this because parents and siblings that had one "healthy" huntingtin gene were fine, even though their other copy was mutated.

This finding also supports what we've observed in two other people with rare huntingtin mutations that caused one copy of the gene to be inactivated, or turned off. People with one inactivating mutation were healthy as long as their other copy of huntingtin was ok. We have also seen the same type of outcomes when we study huntingtin in mice. Mice missing one copy of the huntingtin gene are healthy, as long as their other copy of huntingtin is still intact. Together, these findings suggest just one copy of functional huntingtin is enough to carry out most of its essential functions.

"These discoveries have taught us that there is a critical role for huntingtin in brain development. Each of the people with loss-offunction mutations in both copies of their huntingtin genes were diagnosed with severe developmental disorders."

Next, these discoveries have taught us that there is a critical role for huntingtin in brain development. Each of the people with loss-offunction mutations in both copies of their huntingtin genes were diagnosed with severe developmental disorders. Whole exome sequencing did not reveal any other mutations that were likely to be the culprit. Hence, these rare, unfortunate cases have given us a glimpse into the normal function of huntingtin and what happens to the brain when there's insufficient huntingtin to support normal brain development.

Gene silencing for HD - still OK?

Understanding the normal functions of huntingtin has long been a focus of the HD research community. Knowing what huntingtin is doing in the cell may lead to new insights about HD or spark ideas to develop treatments. Importantly, the normal function of huntingtin is relevant to an investigational HD treatment called gene silencing. (You can read more about gene silencing in this post: http://en.hdbuzz.net/204.)

Gene silencing turns down the levels of the HD gene to prevent the production of mutant, toxic huntingtin protein. Given what now know about the critical role of huntingtin in brain development, it will be important to carefully monitor HD patients receiving gene-silencing treatment. It also means we will have to strategically evaluate the age of HD carriers undergoing huntingtin gene silencing - attempting to silence the HD gene in the brains of very young people would raise serious safety concerns.

But, since the vast majority of HD patients are adults whose brains are already fully developed, it's unlikely that gene silencing will lead to the problems seen in these patients who had low huntingtin levels throughout development. Researchers and physicians will be sure to keep all of this in mind during clinical trials with gene silencing drugs.

And of course, none of these insights would have been possible if it wasn't for whole exome sequencing. This powerful technique allowed researchers to identify for ultra-rare mutations that advance our understanding of many diseases—including HD. This new research shines a light onto huntingtin's critical role in brain development, adds to our knowledge about HD, and helps us plan gene silencing studies which are safer for participants.



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

There are many different kind of benefits available within the United States. It is important to understand our government benefits and which ones you might be eligible for. Below is a description of health care and disability benefits offered by the government.

Medicare: Medicare is a federal program that provides health care coverage for individuals and their spouses who are 65 and older. Medicare is less comprehensive than many of the private health insurance plans, but it is an important part of health care planning. Individuals enrolled must pay co-

payments and deductibles. A large part of your medical costs will be covered by Medicare. There are multiple aspects of Medicare including Part A which covers hospital bills, Part B covers outpatient bills, Part C provides a managed care option and Part D offers prescription drug coverage.

Huntington's Disease patients who are younger than 65, must first apply for SSD (see below). Once approved for disability benefits, HD patients become eligible for Medicare after a two year waiting period. HDSA is currently lobbying Congress to approve The Huntington's Disease Parity Act, which will waive the 2 year waiting period for Medicare. For more information: https://www.medicare.gov or The Department on Aging (800) 548-9034.

Medicaid: Medicaid is a health insurance program for families and individuals with limited resources. It is a meanstested program that is jointly funded by both state and federal governments and managed by the states. This allows each state to determine who is eligible for Medicaid and how the program will be implemented. Not all states are required to participate, although every state has participated since 1982. For more information: **https://www.medicaid.gov** or 312 353-1133.

Supplemental Security Income (SSI): SSI is a federal program that provides stipends to low income people who are either aged 65 or older, blind, or disabled. Social Security Income provides cash to meet the basic needs for food, clothing and shelter. Individuals and their children might be eligible for SSI regardless of their work history and status for SSDI. For more information: https://www.ssa.gov or 1-800-772-1213.

Social Security Disability Insurance (SSDI): SSDI is a payroll tax-funded federal insurance program. This non-medical insurance is designed to supplement income to people who are physically restricted in their ability to work/be employed because of his/her disability. Unlike SSI, SSDI is not dependent on the income of the recipient. Spouses and children of SSDI recipients may also be able to receive cash benefits. The qualifications for this benefit include:

- 1) Having a physical or mental condition that prevents him/her from being employed.
- 2) The condition is expected to last at least 12 months.
- 3) The recipient must be under the age of 65.
- 4) Accumulated 20 social security credits in the last 10 years prior to the onset of the disability. In general terms, have worked at least 5 out of the last 10 years.

For more information: https://www.ssa.gov or 1-800-772-1213.



October 9, 2016 - We are currently out of guaranteed spots for the <u>Chicago Marathon</u>, but runners are encouraged to sign up with the general public via the registration lottery, and fundraise with us if accepted. We have a donor drive page set up at the following link: http://hdsa.donordrive.com/index.cfm?fuseaction=donorDrive.event&eventID=912

Anyone with questions can reach out to Sara & Rachel at TeamRunforHD@gmail.com for more information!

TUNE IN!

Joe 'JT" Makoviecki performs at the Guthrie Sessions at HDSA.

The Guthrie Sessions at HDSA

The Huntington's Disease Society of America was founded by Marjorie Guthrie, the wife of music icon Woody Guthrie. Woody died from Huntington's disease in1967 when he was only 55 years old. In honor of Woody, and to raise awareness of Huntington's disease, HDSA has organized the 'Guthrie Sessions at HDSA' that feature various artists performing many original songs.

You Tube URL:

https://www.youtube.com/playlist?list=PLLQmMRDsNEY1hldbiAv5HuFRjGOzqX3Z

#HDSAGuthrieSessions

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Save the Date!

Join us for the 32ND Annual HDSA Convention right outside of Chicago at the elegant Renaissance Schaumburg Hotel & Convention Center.

June 22-24, 2017 / Schaumburg, IL

Stay tuned for more details at HDSA.org





Society of America



Hot Rods for



For more photos, check out our Facebook page at HDSA Illinois Chapter

Huntington's

By Danielle Karlson

What a day we had and we couldn't be happier with the results. Beautiful cars and people yet again joined us for our fourth annual Hot Rod's for Huntington's car show on Saturday, September 17th at the world famous Volo Auto Museum. It was filled with great music by Cadillac Casanova's who did an amazing show for us all to watch and listen to. Each guest had their chance to view the Volo Auto Museum and bid on many of the great items in our silent auction. A big thank you to Pete's Rodschicago for yet again designing and welding together this year's car trophies; and for the Perrott's families efforts in painting each one HD Blue to stand out and make their mark.



For the past four years, the Perrott family and friends have joined forces and put together an amazing show for all and a touch of flare to a fundraiser and awareness event for the Illinois Chapter. This though, will be the last year that the family

will host the show. Where I, Danielle Perrott, had an emotional and heartfelt good bye at the end of the event, I am truly blessed to have been a part of it and watching all the wonderful smiling faces each and every year. I want to send a huge thank you to all of the volunteer's for many years of hard work and support for a cause that personally affects our family. Thank you to our sponsors, Volo Auto Museum, Teva CNS, Petes Rodschicago, Eyeless Photography, Pawsitive Ideas and of course the support of all the wonderful IL Chapter Board members.



It is because of all of your support and donations to this event that we have been able to donate over \$27,000 to the cause over the past four years. Being that this is the last year the Perrott's will host this event, it does not

mean the event will end. We were approached by a wonderful lady and leader of the Hardcore Hearse Club and they will continue on the show in honor of HD. The Perrott's will still be a big part of the event and will be honored to volunteer at all future shows. Thank you everyone for being so wonderful to us all, and keep hope in your heart for a cure for Huntington's Disease will come.

Memory of Mary Classen Born from Randall & Marta Isaac, Norma & Luis Librodo, Rolland K. Wiens, Larry Gruber & Elise Teichert, Brad & Diane Born, Vanessa Rago, Gwendolyn Wiens, R. & B. Koontz, Mary Cohen In Memory of Sheron Kay Weaver from Richard S. Weaver In Memory of Sheron Kay Weaver from Richard S. Weaver In Memory of Ralph Short from Lois Short In Memory of Eric Porter and Family from Akron Services, Inc In Memory of Carol L. Kurinsky from Emil Kurinsky In Memory of Margaret M. McCarthy from William & Kathleen Schnoebelen In Memory of K. Michaela Nibbs from Leecia Hillebrenner

The Huntington's Disease Society of America Board of Trustees and the Great Lakes Region invite you to the

12th Annual

Honoring The Jim & Jan Skewes Family

Saturday, October 8, 2016

Marcello's Restaurant | 645 W. North Avenue Chicago, Illinois 60610

Program of Events

6:30 pm - Cocktails & Silent Auction 7:30 pm - Dinner is served 8:00 pm - Honoree presentation 8:30 pm - Live Auction

Buy Tickets Online at www.hdsa.org/coh-chicago

All contributions are tax deductible to the extent provided by law. HDSA operates under section SO1(c)(3) of the IRS code. We estimate the fair market value of one ticket to be \$44. The charitable contribution per ticket is \$66, HDSA EIN#: 13-3349872





CHAPTER OFFICERS

PRESIDENT – Susie Hodgson 815-498-6092 ~ sue_angels@softhome.net

VICE PRESIDENT – Barry Kahn 847-975-2403 ~ barrykahn1@comcast.net

TREASURER – Charlotte Rybarczyk 847-259-3593 ~ charlotte82963@gmail.com

SECRETARY – Joe Wiedemann 847- 505-3933 ~ joseph.wiedemann@gmail.com

BOARD MEMBERS

Thomas Barr - thomasabarr@aol.com 708-447-2597

Erin Bentz – erin.m.bentz@gmail.com 630-201-7396

Mary Bos – mary_bos@att.net 630-830-5329

- John Cuccinotto johnnycooch@gmail.com 630-873-0052
- Holly Fraleigh holly.fraleigh@gmail.com 708-790-9618
- Danielle Karlson-Perrott hotrods4hd@gmail.com 847-529-3374
- Jennifer Placek jenniferplacek09@gmail.com 630-995-6440

George Stecyk – g.stecyk@att.net 630-961-9080

OTHER CHAPTER MEMBERS

Deborah Boyd – Regional Director dboyd@hdsa.org

Maryann Moynihan – Newsletter Editor 708-955-3080 shamrock1959@att.net



Hopes & Dreams is the official publication of the Illinois Chapter of Huntington's Disease Society of America,

Inc., P.O. Box 1883, Arlington Heights, IL 60006-1883 (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.

SUPPORT groups



Date/Time	Additional Information	Contact Information
CEN	TRAL ILLINOIS	
2nd Sunday of even months TIME: 2:00 to 4:00pm <u>LOCATION:</u> St. Joseph Medical Center, Bus. Conf. Center – Room 2, 2200 E. Washington Street, Bloomington, IL	Remaining 2016 Meetings: 10/09 2017 Meetings: 2/12, 4/9, 6/11, 8/13, 10/8 (No meeting in Dec.)	Dave or Susie Hodgson (815) 498-6092 spiketdog@softhome.net
Specific Sundays of odd numbered months (see dates in next column) <u>TIME:</u> 2:00 to 3:30pm <u>LOCATION:</u> 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. Remaining 2016 Meetings: 11/20 2017 Meetings: 1/29, 3/26, 5/28, 7/23, 9/17, 11/12	Joe Wiedemann (847) 505-3933 joseph.wiedemann@gmail.com
2 nd Monday of every month <u>TIME:</u> 7:00pm <u>LOCATION:</u> 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		
2 nd Sunday of every month <u>TIME:</u> 2:00pm <u>LOCATION:</u> OSF St. Anthony Medical Center, 5666 E. State St., St. Anthony Room, Rockford, IL	Open to people with HD, family members, caregivers, and interested professionals.	Cheryl Sutton (815) 262-4889
* 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.	Remaining 2016 Meetings: 10/9, 11/13, 12/11	
SOUTH SUBURBAN		
2 nd Tuesday of odd months <u>TIME:</u> 7:00pm <u>LOCATION:</u> Thomas Cellini Huntington's Foundation, 3019 East End Avenue, South Chicago Heights	Remaining 2016 Meetings: 11/08 2017 Meetings: 1/10, 3/14, 5/9, 7/11, 9/12, 11/14	Maryann Moynihan (708) 955-3080 shamrock1959@att.net TCHF Office (877) 687-8243
CHICAGO – RUSH U	INIVERSITY MEDICAL CENTER	
4 th Tuesday of even months <u>TIME:</u> 7:00 to 8:30pm <u>LOCATION:</u> Rush University Medical Center, 1620 W. Harrison Street, Tower Resource Center, Tower, 4 th Floor, Suite 04527, Chicago, IL * Parking is available at the Rush garage on the southeast corner of Paulina and Harrison Streets. From the 4 th 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
CHICAGO – NORTHWESTERN MEMORIAL HOSPITAL		
11/7/2016, 7:00 to 8:30pm <u>LOCATION:</u> Prentice Women's Hospital, 250 East Superior St., Conference Room N	For At Risk (non-symptomatic) patients and family members. 2017 Meeting dates will be	Emily Zivin (630) 443-9876 ezivin@hdsa.org
	available on our Illinois Chapter website in January.	Parking Passes Available
MUN	STIER, INDIANA Bomaining 2016 Mostinger, 10/11	Cindy Pogers
<u>LOCATION</u> : Southside Christian Church, 1000 Broadmoor Ave., Munster, IN	12/13 2017 Meetings: 2/14, 4/11, 6/13, 8/8, 10/10, 12/12	(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



https://illinois.hdsa.org		
June 22-24, 2017	HDSA 32 nd Annual Convention – Schaumburg, IL	
February 25, 2017	HDSA IL Chapter State Conference - Northwestern Memorial Hsp Chicago	
January 28, 2017	HDSA IL Chapter Score for HD Dinner/Dance – Itasca, IL	
October 8, 2016	12th Annual Celebration of Hope – Marcello's Restaurant – Chicago, IL	

