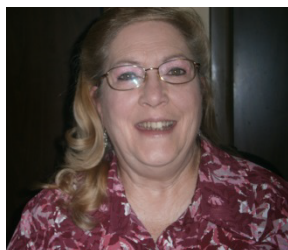


President's Message



Hello Friends,

Fall is upon us again. I think of this time as a time to reflect as we start to settle into routines that will take us through the winter months, until Spring once again bursts upon us and so the hectic days of summer.

I would like for us to take time to look at some of the accomplishments of our chapter as we reflect on the past year. In January we held our winter dinner/dance whose theme was **"Score 4 HD"**. The dinner/dance, co-chaired by Barry and Marilyn Kahn, was once again a huge success. Everyone turned out sporting their favorite team's colors, there was raffles galore, a silent auction, lots of dancing, a great dinner and yes, the famous candy bar raffle to top off the evening.

In February we had our **State Convention Education Day**, held at Northwestern Memorial Hospital. The event was co-chaired by Emily Zivin and Holly Fraleigh who did an awesome job in presenting a day full of programming to meet the needs of our families.

In May we held our 13th annual **Team Hope Walk**, co-chaired by Dave and Susie Hodgson. Once again the walk was the largest in the nation in participants and donations. Our Team Hope Walk is the premiere event for the chapter each year.

In June the Illinois Chapter hosted the **32nd National HDSA Convention** in Schaumburg. This was the first time ever that our Chapter/State has been chosen for this honor and our families did not disappoint! There were so many who gave time to help prepare for and then to volunteer at the convention, we cannot thank you all enough! As a side note...we missed being the LARGEST convention ever by around 17 or 18 people! We are also very proud to have had a 2nd Center of Excellence selected in our state and announced at the convention. Our new Center of Excellence is located at Northwestern Memorial Hospital under the direction of Dr. Danny Bega!

In August we saw two friends come together and "create" a new event, **"The Baggo Tournament"** which was a huge success. The event was the brain child of Board Member Charlotte Rybarczyk and Peggy Monson. Yes, the rumors are true....the brackets were so large they were put up on the side of Steve and Charlotte's house where the event was held. Congratulations to all who helped and participated in this event and I can't wait to see what you do next year!

As in all things, our chapter has been going through changes and with those changes we have lost some events that you may have been looking forward to attending. That being said, there is still time for any of us to put our heads together with a friend and do something fun. That could be "Glow in the dark Bingo", a bowling tourney, a softball game, the possibilities are endless and are only limited by your imagination. Have you attended an event somewhere and you think it would be a good idea to try or was fun and you would like to do it again? It's Fall, how about a chili cook off? Let your mind go wild!

But, we also need YOU! We need board members and volunteers. Have you thought about becoming a board member, but are concerned it would take too much of your time? Being a board member does not take but a few hours of your time for the whole year. There are 6 meetings during the year, 3 of the meetings are held in person (where we all meet together) and the other 3 are phone conferences. We do our best to keep board meetings to an hour and a half. Yes, there are times that it will go a little longer and times that they are a little shorter. Anyone 18 or older can become a board member. We are looking for anyone willing to give a little time and to share their ideas with us. Not sure you would like to join the board but you would like to do something more? Ask how to volunteer to help on one of our events or how to get your own event started! We are here for you, but we need you to help us to continue to grow and do great things. Anyone wanting more information please contact myself or any of the chapter board members. Their names and contact information can be found elsewhere in the newsletter.

My contact: Home phone: 815-498-6092 Cell: 815-508-2370. Email: susan.hodgson53@gmail.com
Wishing each and every one of you a great and happy fall season!

Susie Hodgson
President, HDSA Illinois Chapter
(Illinois@hdsavolunteer.org)



LOL4HDSA



A CELEBRATION OF HOPE

Honoring HDSA Centers of Excellence
at Rush University Medical Center
& Northwestern University

2017 Honoree: Dr. Jennifer Goldman
Rush University Medical Center

11.11.2017

COCKTAILS & APPETIZERS
LIVE & SILENT AUCTIONS
SPECIAL PERFORMANCE BY:
KEVIN BOZEMAN



THE CUBBY BEAR
1059 W ADDISON
CHICAGO, IL.

To purchase tickets, *donate* and
for sponsor information:

HDSA.ORG/COH-CHICAGO

Tickets are \$100 per person (donor benefit of \$62).

HDSA is a 501(c)(3) organization.

EIN #13-3349872

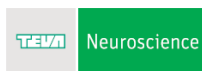
Make checks payable to HDSA | HDSA Great Lakes
Region PO Box 72 Richland, Michigan 49083

HDSA Great Lakes Region
PO Box 72
Richland, Michigan 49083

Join us on Saturday November 11th.
7:00 pm – 10:00 pm
For a Night of Comedy & Celebration!

The Huntington's Disease Society of America is dedicated to improving the lives of everyone affected by Huntington's disease. From community services and education to advocacy and research, HDSA is the world leader in providing Help for today and hope for tomorrow for people with Huntington's disease and their families

Thank you to our Presenting Sponsor



For more information contact Deb Boyd.
dboyd@hdsa.org | 1-269-629-5452

For Ticket Information Contact
Peggy Cribbin (peribbin@hdsa.org) 314-647-4372



"HDSA Quilt for Hope"

Handmade lap quilt, approximately 60 by 70 inches. 100% cotton with cotton batting. Pattern is called Lasting Legacies by Connecting Threads.
Made with love by Denice Korcal



\$10 donation = 1 ticket
\$50 donation (5 tickets + 2 free) = 7 tickets
\$100 donation (10 tickets + 5 free) = 15 tickets

Winner to be announced at the
Chicago Celebration of Hope
Saturday November 11, 2017

Portion of proceeds benefit HDSA's 41 Centers of Excellence
(Need not be present to win- Must be 18)



Research Study at Northwestern University-Chicago

SRX246: Safety, Tolerability, and Activity in Irritable Subjects with Huntington's Disease (STAIR)



Northwestern
University

The study is coordinated by NeuroNext, the Network for Excellence in Neuroscience Clinical Trials, with support and funding from the National Institute of Neurological Disorders and Stroke (NINDS), a division of the National Institutes of Health (NIH) and Azevan Pharmaceuticals.



Purpose of the Study: We are doing this research to find out whether a new investigational drug called SRX246, which might be useful to HD patients who sometimes feel irritable, angry or even aggressive, is well tolerated and safe when it is given two times a day by mouth at doses as high as 160mg. As part of this study, we will ask participants to complete a number of questionnaires related to mood and behavior in HD because we want to learn how to plan future studies of medicines that may help HD patients with these problems.

What is SRX246? It is a new investigational drug which might be useful to HD patients who sometimes feel irritable, angry, or even aggressive. SRX246 is a pill similar in size to other medications you may be taking and is taken by mouth.

What is a placebo-controlled clinical trial? Some people receive active study drug and others receive placebo capsules. This study will compare the study drug, SRX246, to a placebo. The placebo looks like the study drug, but contains no active drug. You will have a 2 out of 3 chance of receiving study drug and a 1 out of 3 chance of receiving placebo. Neither you nor the doctors will know which group you have been randomly selected for.

What will happen if I choose to be in the study? You will first attend a screening visit to determine whether or not you are eligible. If you are eligible, you will have up to six scheduled study visits and two telephone contacts over approximately 12 weeks, or 5 months.

You will come to regular study visits every 2 weeks. At these visits, you will have a HD focused physical examination, complete questionnaires, and have your blood drawn. Your study partner will be asked to attend visits with you and will also complete questionnaires. This study requires both the participant and study partner to make twice daily entries into an electronic diary or eDiary. The eDiary will remind participants when to take their medication and ask questions about their mood.

What are some of the basic things necessary for me to be eligible to be in the study?

- You must be at least 18 years old and have sufficient English skills for the study questionnaires.
- You must have a diagnosis of HD and experience symptoms of irritability and aggression.
- You must have a study partner who is willing to participate in this study.

The study coordinator will provide you with a full list of requirements for participation.

How long will I be in the study? The length of this study is 12 weeks, not including the screening visit. Please ask the study coordinator to explain the details of the visit schedule.

What are the risks of the study? SRX246 may cause the following side effects:

- Mild stomachache, diarrhea, nausea, vomiting, mild headache, sleepiness, mild heart irregularity, cough and throat irritation.
- Since SRX246 has not been given to HD patients before, we will closely monitor your kidney, liver, and heart function to be sure that it is safe.
- Please ask the study coordinator to discuss SRX246 risks in more detail.

What are the benefits of the study? You may or may not benefit from taking part in this research study. Your irritability may decrease while you are taking the medicine; and, if you are sometimes angry or even aggressive, these problems may improve too. Others with HD may benefit in the future from what we learn in this study.

Will I be paid to take part in the research study? We understand that you may have to pay for travel, parking and meals in order to come to your clinic visits and that this can be burdensome. To help solve this problem, we will give you \$50 every time you have a visit. Your study partner or caregiver will get \$30 for every in-person visit.

If you have any more questions, or are interested in being in this research study, please contact Carlos Corado at ccorado@nm.org or 312-503-2778.

Information can also be found on the
NeuroNEXT website:
<http://www.neuronnext.org>

Centers of Excellence Contact Information and Associated Details

By Holly Fraleigh, Barry Kahn, Emily Zivin



The HDSA Illinois Chapter COE Liaison Committee has been working with both Rush and Northwestern to update their contact information and associated details. Both are included below and are available on our website.



Rush HD Clinic

Main Number: 312-563-2030

Fax: 312-563-2024

<https://www.rush.edu/services/conditions/huntingtons-disease>

Jennifer Goldman, MD, MS, Associate Professor Neurology – Director of HD Clinic

Rush University Medical Center

1725 W Harrison St, Suite 755

Chicago, IL 60612

To reach us you may call, email (as listed below) or send us a message via MyChart*.

Response Times: The following contact information is monitored from 8:00am – 4:00pm, Monday –Friday. We will do our best to respond within 24-48 business hours. Please leave specific details as to how to best respond to your message.

Please call 312-563-2030 and follow the prompts to/for:

- Schedule an Appointment
- Medical Records
- Clinic Nurse
- Prescription refills
- Billing Questions
- URGENT and after Hours you will be leaving a message for the on-call team (if emergency please call 911)

General Email: Movement_disorder@rush.edu

Administrative Assistant - Zoe Reagan, BS: 312-563-3796

Genetics Counselor - Alexa Hart, MS, CGC: 312-563-2030

Social Worker - Sarah Mitchell Chen, MSW, LCSW: 312-942-6445; Sarah_M_Chen@rush.edu

Research Coordinator - Alice Negron: 312-563-2030; Alice_Negron@rush.edu

*MyChart

Both outpatients and inpatients can access MyChart by completing an ACCESS REQUEST FORM

<https://www.rush.edu/sites/default/files/Documents/MyChartaccess-request.pdf>

Complete the form and submit via one of these options:

- return it to your doctor's office
- email form to the Rush Health Information Management Office: mychartrequest@rush.edu
- fax to (312) 942-5549
- mail to: Rush Health Information Management Office, MyChart Request, 1611 W. Harrison, St., L1 – Suite 001, Chicago, IL 60612.

Be sure to include your email address at the bottom of the form where indicated and check the box authorizing us to email you an activation code – You CAN NOT get this code over the phone. Once you have this activation code you can go to MyChart and register.

**Northwestern HD Clinic**

Main Number: 312-695-7950

Fax: 312-695-5747

Email: hd@nm.org

<http://huntingtons.nm.org>

Danny Bega MD, MSCI, Assistant Professor – Department of Neurology, Division of Movement Disorders

Galter Pavilion

675 N Saint Clair, # 20-100

Chicago, IL 60611

First time contacting the Northwestern HD Clinic – Call 312-695-7950 or email hd@nm.org

- already have a diagnosis of HD already: you will be scheduled to see Dr. Bega, neurologist, and Dr. Gausche, neuropsychiatrist. You will likely meet our clinical nurse, social worker, and genetic counselor as well.
- do not have an established diagnosis: our genetic counselor, Lisa Kinsley, or clinical nurse, Mickey Domiano, will call you back within 24-48 business hours for a discussion that will cover topics including the following:
 - Testing process
 - Cost of testing
 - Risks involved with testing
 - Concerns about symptoms, if any
 - Discussion about whether or not you wish to obtain life insurance, disability insurance, and/or long term care insurance prior to testing and why this is recommended
 - Your reason for wanting testing
 - Your family history
 - Whether or not you will want a neurological exam

Already a Patient:

Schedule an Appointment: 312-695-7950

Billing Questions: 312-695-9797

Medical Records: 312-926-3376

Clinic Coordinator and Nurse – Mickey Domiano, BSN, RN: 312-695-7950

Social Worker- Pam Palmentera, MSW, LCSW: 312-503-4397

Genetics Counselor – Lisa Kinsley, CGC: 312-503-0154

Research Coordinator – Karen Williams, CCRP: 312-503-5645

Message/Email/Fax Response Times

We make every effort to return your phone call on the day we receive your message. Please understand, however, that our nurses may need to talk with your physician before returning your call. This may slightly delay our callback to you. Also, please leave an alternate phone number where you can be reached.

- Please allow up to 48 hours for phoned medication refills. Keep this in mind if you are running low on your medications.
- Please allow up to 10 business days for prescriptions that must be mailed to you. Test results must be reviewed by your physician. Please allow the nurse sufficient time to contact your physician prior to returning your call regarding test results.
- Please allow up to 10 business days for completion of letters and forms that your insurance company, other physicians, or your employer might request. Note: The Medical Records Department will handle disability applications.

Yes! I would like to support the
Illinois Chapter of HD SA.



Your pledge helps to support research efforts, family services, advocacy, HD awareness, in-service presentations to care facilities, support groups and our chapter social worker.

2017 Pledge Drive

☼ Benefactor	\$500.00 donation	☼ Supporter	\$ 50.00 donation
☼ Patron	\$100.00 donation	☼ Member	\$ 25.00 donation
☼ Angel	\$ 75.00 donation	☼ Friend	\$ _____ donation

Please complete the information below and return with your pledge.

Your Name _____

Email Address _____

Your contribution is tax
deductible to the extent
allowed by law.

Make your check payable to **HDSA Illinois Chapter**
and mail to: P.O. Box 1883, Arlington Heights, IL 60006

Thank You

Spreading the Word

AbbVie, a pharmaceutical company that discovers, develops and markets both bio pharmaceuticals & small molecule drugs, offers their employees an opportunity to donate to their favorite charity by hosting an annual Employee Giving Campaign.

For the third year in a row, the Illinois Chapter has been invited to participate in this Event. Marilyn & Barry Kahn, along with our Chapter social worker, Emily Zivin, and board member, Holly Fraleigh, spent Tuesday and Thursday, September 12th and 14th, sharing the story of HD with hundreds of AbbVie employees! The AbbVie employees visit the various charities onsite and learn about the different causes. The Illinois chapter was present at two different AbbVie locations and talked to many people!



Barry Kahn, Marilyn Kahn, Emily Zivin at
ABV1 in Mettawa, IL

It was a huge success to be able to talk about HD and all the work we do both nationally and in Illinois! There were so many interested people and spreading the word is what it is all about!



Holly Fraleigh, Marilyn Kahn, Michelle
Gallagher (AbbVie employee), Barry Kahn
at AP30 in North Chicago, IL



SAVE THE DATE

HDSA Illinois State Conference - Mind and Body

Saturday, March 17, 2018
8:45 am – 4:00 pm
Harper College, Wojcik Conference Center
1200 W Algonquin Road, Palatine, IL 60067

Join us for the 2018 Illinois State Conference to be held at Harper College in Palatine, Illinois. This year's conference is packed full of information to help improve the mind and body of our HD family members and friends – behavioral management; insights into the benefits of occupational, physical and speech therapies; how to find and manage nursing homes; nutrition in all stages of HD; identifying timing and approaches to dealing with HD and driving; advocacy awareness; at-risk support group; HD 101; and a mock support group for those considering future participation.

Online registration will be \$10/person and will be available online shortly so watch the Illinois Chapter website, hdsa.org/il, for details.



Team Run for HD is excited to once again be an affiliate charity of the Bank of America Chicago Marathon. This year we have 12 amazing runners that will be in Chicago on October 8th representing *Team Run* and taking the fight against Huntington's disease. To our runners...

- Theresa Petrone
- Tiffany Dore
- Elizabeth Stano
- Dave LeVeque
- Ian Kenny
- Betsy Tien
- Rachel Bartunek
- Jennifer Rusniak
- Sara Dean
- Ezekiel Farmer
- Rachel Flowers
- Jeremy Bartunek;

...thank you for your fundraising efforts. We are so thankful to have you running and fighting on behalf of our HD Community! We wish you the best of luck during your marathon training and cannot wait to see you in Chicago!

Save the Date

November 11, 2017

8:30 a.m. – 12:00 p.m.

Feinberg Pavilion, 251 E. Huron, Conf. Room A
Parking provided at NM Parking lot at 222 E. Huron



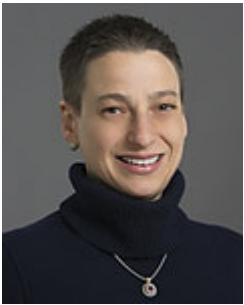
**At risk support group from 12:30pm to 2:00pm*

Sponsored by the Northwestern Medicine Parkinson's Disease and

This symposium is complimentary and open to individuals, their family members and caregivers. Established patients, as well as newly diagnosed and at-risk individuals are encouraged to attend.

To register call 312.926.8400





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)

Tips for Navigating Medicare Open Enrollment

Introduction

Regular appointments with your medical care team (neurologist, primary care physician, etc.) and following your medication regimen are necessary in managing your Huntington's disease care. In order to keep these appointments and obtain your prescriptions, it's important to make sure your health insurance coverage is accurate and up to date. For many, navigating the Medicare system can be tricky so here are some practical pointers for the upcoming open enrollment period for Medicare.

What is Open Enrollment?

Medicare's Open Enrollment is coming soon. This takes place once a year from October 15th – December 7th. During this time people with Medicare have the opportunity to:

- Change from Original Medicare to a Medicare Advantage Plan (also known as Part C)
- Change from a Medicare Advantage Plan to Original Medicare
- Switch from one Medicare Advantage Plan to another Medicare Advantage Plan
- Join a Medicare Prescription Drug Plan (Part D)
- Switch from one Medicare Prescription Drug Plan (Part D) to another

Any changes will be in place as of January 1st of the following year. It is important to look at your plan each year, particularly if you have had changes to your medications. As you look at options, you may find a different plan is more affordable for various reasons and elect to switch plans. If you would like to continue your current coverage it is still very important to look at your plan as premiums and plan coverage, which can change from year to year. So what might have been the best option for you in 2017 may not be the best option in 2018. It is important to understand any changes that may impact your coverage

What do I do next?

If you are already enrolled in a Medicare Prescription Plan (Part D) or a Medicare Advantage Plan (Part C) and you don't want to make changes to your coverage for 2018; you do not need to do anything during open enrollment as long as your current plan will still be available in 2018. If your plan is being discontinued and isn't eligible for renewal, you will receive a non-renewal notice from your carrier prior to open enrollment. If you don't, it means you can keep your plan without doing anything during open enrollment.

In some cases, changes can be made outside of Open Enrollment; everyone's situation is unique. Please call Medicare if you feel this may apply to your situation. For general questions, please call 1-800-MEDICARE or visit www.medicare.gov/find-a-plan. For help in making changes to your current plan, you can contact the State of Illinois Senior Health Insurance Program (SHIP) Counselor at 1-800-252-8966 or a SHIP counselor at Rush by calling 1-800-757-0202.

New this year, Medicare will be issuing new Medicare insurance cards. The new cards will not include social security numbers. It will take a while for the new cards to be sent out to all Medicare recipients. New cards will be issued over the course of the year. Don't be alarmed if your neighbor has gotten a new card and you have not gotten yours yet.

References:

Department of Health & Human Services, USA. (August 2014). *Understanding Medicare Part C & D Enrollment Periods*. Retrieved from <http://www.medicare.gov/Pubs/pdf/11219.pdf>.

Medicare Resources (September, 2017) <https://www.medicareresources.org/faqs/when-is-the-next-medicare-open-enrollment-period/>

This article was written by Sarah Chen, LCSW, MSW at Rush University Medical Center.

Sarah Chen is a Licensed Clinical Social Worker with more than 8 years of experience working with adults with chronic diseases, older adults, and caregivers. Sarah earned a Master of Social Work from The University of Chicago School of Social Service Administration. By integrating social work into the Rush Outpatient Neurology Department, Sarah works to address non-medical barriers to wellness and improve health outcomes for patients and caregivers. She staffs the weekly Integrated Cognitive and Behavioral Movement Disorders clinic.





Welcome to HDSA's on-line support groups! We realize that many do not have access to an in person support group, so join us for an hour-long group to receive support, information, and the necessary resources for those affected by HD. We are pleased to offer the following groups:

Meeting	Date	Time
HDSA Caregiver Support Group	Tuesday, 10/3/17	8:00pm ET
HDSA Caregiver Support Group	Tuesday, 10/10/17	7:00pm ET
HDSA Caregiver Support Group	Tuesday, 10/17/17	7:00pm ET
At Risk / Not Tested Support Group	Tuesday, 10/24/17	6:00pm ET
HDSA Caregiver Support Group	Tuesday, 11/7/17	6:00pm ET
HDSA Caregiver Support Group	Tuesday, 11/14/17	7:00pm ET
At Risk / Not Tested Support Group	Tuesday, 11/28/17	8:00pm ET
HDSA Caregiver Support Group	Tuesday, 12/12/17	8:00pm ET
HDSA Caregiver Support Group	Tuesday, 12/19/17	7:00pm ET

In order to participate you must be pre-registered. To register, please visit www.supportgroupscentral.com/hdsa and select JOIN NOW. Please note that there are a limited number of spots available so we encourage early registration.



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PRESIDENT – Susie Hodgson
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VICE PRESIDENT – Barry Kahn
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Deb Boyd – Regional Director
dboyd@hdsa.org

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



Hopes & Dreams
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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.

NOTES of Hope



Marjorie Guthrie was a global advocacy icon and the wife of folk legend Woody Guthrie. In 1967, Woody died from HD just weeks after Marjorie founded HDSA (formerly known as the Committee to Combat Huntington's Disease).

Marjorie traveled around the world educating families, researchers and doctors about HD. She would write notes along the way encouraging everyone to never give up hope.

Help us pay tribute to the Guthrie Family Legacy by sending a *Note of Hope* on a postcard from your hometown thanking Marjorie Guthrie and discussing the impact that HD has had on your family.

Also, please feel free to send any copies of archival letters, photos or personal stories you may have with Marjorie during her extraordinary crusade against HD. You can also share on social media using #HDSANotesofHope.

We will display all the postcards on social media and at the HDSA Convention in Los Angeles in 2018!

Send your postcards, letters, stories and photos to:
Huntington's Disease Society of America
Attn: Notes of Hope
505 8th Avenue, Suite 902
New York, NY 10018
HDSAINfo@HDSA.org



Huntington's Disease Society of America's 50th Anniversary to Celebrate the Life & Legacy of Its Founder Marjorie Guthrie

New York, NY (September 18, 2017) — Music icon Woody Guthrie died from Huntington's disease (HD) complications when he was only 55 years old, but before he passed his wife Marjorie promised him that she would dedicate her life to fighting this devastating disease that also threatened their children. On September 18, 1967 Marjorie Guthrie founded the Committee to Combat Huntington's Disease, which is now known as the Huntington's Disease Society of America (HDSA).

Fifty years ago, the organization started with just five families. Today, HDSA has grown into the world's largest public nonprofit organization for HD. The mission of HDSA is to improve the lives of people affected by HD and their families. For its 50th Anniversary, HDSA will be celebrating the life and legacy of its founder, Marjorie Guthrie by highlighting her role as a caregiver, global advocate for families affected by HD and other rare diseases, and nonprofit pioneer. For more information, visit <http://hdsa.org/news>.

Memorials and Tributes

In Memory of Carol Kurinsky from Emil Kurinsky

In Memory of Charles Hansel from Richard & Louise Brattland

In Memory of Ralph Short from Lois Short

In Memory of Peter Michael Coorlas from the Iatarola Family, Paul & Adrian Adams, Mr. & Mrs. Michael Nichols, JoAnn, John and James Posch, Peter & Laura Leddy, Milton & Catherine Fasseas

In Memory of Gerald Owens from Annetta Owens

New roles for huntingtin: removing a healthy protein to understand its function

By Leora Fox on September 26, 2017, Edited by Dr. Jeff Carroll - Originally published on September 22, 2017

Some techniques aimed at lowering mutant huntingtin can also affect the normal form of the protein. With clinical trials underway, it's all the more important to understand the role of normal huntingtin in the adult brain. Researchers recently inactivated the huntingtin gene in healthy adult mice of different ages. They found that this could cause neurological and behavioral problems. Mice aren't perfect for modelling human brains, and no huntingtin-lowering drug would remove the protein completely - but this research supports the need for continued caution as we test drugs that lower normal huntingtin.

Understanding huntingtin function

The mutation that causes Huntington's Disease alters instructions for building a protein called huntingtin. In HD, a repeated sequence of letters in this gene leads to an extra-long form of huntingtin protein that can wreak havoc in brain cells over long periods of time. One of the most exciting avenues of HD research is *huntingtin lowering* (also known as *gene silencing*), which aims to reduce levels of the huntingtin protein in cells.

Mice aren't people, but studies in mice can provide important information about the role of huntingtin.



Animal studies have revealed strong benefits of these techniques, showing that reducing mutant huntingtin in the brains of HD mice can improve their brain health and behavior. Rigorous experiments in animals have given way to clinical trials of drugs that target the HD gene in people, and there are more techniques for decreasing or eliminating huntingtin on the horizon. Some of these approaches to attack mutant huntingtin also reduce levels of the normal protein, including the Ionis **huntingtin-lowering drug**.

For this reason, we need to understand more about what happens to the brain when huntingtin is removed. To do this, a group of researchers recently used genetic techniques to remove huntingtin from adult mice of different ages, then studied their brains and behavior until old age.

Huntingtin during development and adulthood

When researchers want to understand the function of a gene, their first move is usually to get rid of it. By studying what goes wrong when a protein is missing, we get clues about its role in cells. If you didn't know the purpose of a belt, and then you removed your belt and found your jeans around your ankles, you'd likely realize what a belt was for.

In mice, when huntingtin is missing from the brain at conception, this causes early and severe neurological problems. When huntingtin is missing from the entire body and brain, the mice will die before birth. This led scientists to deduce that normal huntingtin is very important during development, especially in the brain. "We need to understand more about what happens to the brain when huntingtin is removed".

However, there is far less known about the role of normal huntingtin in adulthood. Mutant huntingtin, although altered, is still present, and most people with HD have normal huntingtin, too. What if huntingtin is around for half a lifetime, and then is suddenly eliminated? That's much more dramatic than what happens in a huntingtin-lowering treatment trial. So far, there are promising reports on the short-term safety of reducing huntingtin levels in adult humans. But continued animal studies can help to inform ongoing trials.

What happens when huntingtin is gone?

To study what happens when huntingtin is removed during adulthood, a team of researchers led by Ioannis Dragatsis at the University of Tennessee used a genetic tool to precisely time the removal of huntingtin in a large proportion of cells all over the body. This is a technique involving specially modified mice that are given a chemical injection to trigger the removal of a chosen gene. It's useful to help researchers understand the function of a gene at a specific time of life, but this particular technique is not being developed as a treatment for any human disease.

It's important to emphasize that this technique completely shuts off production of the huntingtin protein. That's not what we expect when patients are given huntingtin-lowering drugs, which might produce around 50-75% reductions in the mutant and healthy protein. Current huntingtin-lowering drugs, called ASOs, are also given as individual doses separated by several weeks, with normal protein production expected to bounce back somewhat in between.

Nonetheless, the Dragatsis team used this method to try and understand the extreme case of loss of huntingtin during adulthood. They inactivated the huntingtin gene at three different adult ages: 3, 6, and 9 months old. For context in mouse-years, 3 months is sort of like an older teen, and 9 months is about middle-aged. They examined the natural lifespan of these mice and closely studied their brains and behavior over time.

Removing Huntingtin from the brains of mice damaged the thalamus - a key relay station in the brain.



Completely removing normal huntingtin caused the mice to have a shorter lifespan, neurological problems, and trouble with movement tasks. The earlier the gene was inactivated, the more severe the behavioral issues, suggesting that huntingtin is most important in younger adults. Removing huntingtin caused the mice to have slightly smaller brains and overall signs of inflammation. Despite behavioral and neurological concerns, brain areas normally affected by HD, the striatum and cortex, did not contain damaged nerve cells. This is encouraging given that these areas are the main focus for huntingtin lowering drugs in clinical trials.

A new role for huntingtin – and conflicting results

It's difficult to determine the exact cause of the neurological problems that arose when huntingtin was removed in mice, but the researchers uncovered some interesting clues. They found that brain cells in an area called the thalamus had problems processing and using iron, leading to the buildup of iron and calcium inside cells. The thalamus is a main relay station for the brain, often an important middleman in transmitting messages from one area to another. Iron is a mineral that's essential in the brain for generating energy and ensuring the smooth transmission of nerve impulses. It's not clear exactly how huntingtin helps with the efficient use of iron in the thalamus. However, the neurological problems caused by disrupting this pathway have alerted us to a potentially significant role for huntingtin in the aging brain.

Another recent study from Xiao-Jiang Li's laboratory at Emory University used a similar (but not exactly the same) technique to remove huntingtin in mice at 2, 4, and 8 months of age. This was dangerous in the youngest mice, leading to early death due to failure of a digestive organ called the pancreas. However, removing huntingtin in mice older than 4 months appeared to cause no neurological problems, a stark contrast to the Dragatsis lab's work.

One possible explanation is that the mice in the Dragatsis project were unusual to begin with, in that they had only one copy of the huntingtin gene, rather than the usual two. That means they produced less huntingtin throughout development, which might have left the brain more susceptible to the later switching off of the gene. "We will need to continue to use caution when removing or lowering normal huntingtin in human studies".

Such conflicting reports can be confusing, but it's ultimately informative to examine the differences between parallel studies. The slight discrepancies that lead to differing results allow us to gather more information about the underlying biology.

The message

Importantly, both studies suggest that we need to continue our current cautious approach when lowering normal huntingtin in human studies. Another option may be the pursuit of "allele-specific" therapies, those that specifically target mutant huntingtin while leaving the normal form intact. This approach is being used by WAVE Life Sciences, a company working on developing allele-specific huntingtin lowering drugs for HD.

However, it's essential to re-emphasize that the experimental technique used in these mice, permanently removing huntingtin all over the body and brain, is very different from the clinical approach of temporarily lowering huntingtin in selected parts of the brain. In the huntingtin-lowering trial that is currently underway, the treatment is reversible, and participants are being carefully monitored for safety. Irreversible forms of HD **gene editing**, like CRISPR-Cas9, will require meticulous long-term testing before they can be brought to the clinic.

As the short-term administration periods for the huntingtin-lowering drug are extended, clinicians will continue to be watchful and to collect data that is essential to determine whether the treatment is safe and effective. In the meantime, a variety of approaches in animals can deepen our understanding of the biology behind the drugs that are already in the clinic.

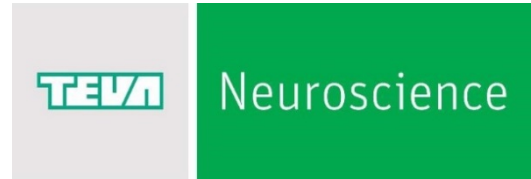
This article was updated on 26th September 2017, in response to reader feedback, to clarify the important differences between total huntingtin removal in mice and partial reduction by huntingtin lowering drugs.

Inaugural **BAGGO** Tournament a Success!!

A HUGE THANK YOU to all of the sponsors, participants, and volunteers who helped to make our first HDSA Illinois Chapter Baggo tournament a success!

On Saturday, August 26th in Rolling Meadows, 23 teams played in a double elimination bracket vying to win \$100 plus their choice of custom Baggo games built by R&R Custom Cabinetmaking. Everyone enjoyed beautiful weather and an Italian Beef and hot dog lunch provided by Vienna Beef. Our winners, Keith and Austin, came back from the losers' bracket to overtake our undefeated winners of the winners' bracket. A very exciting double game final match! And, best of all, over \$5,500 was raised for our HD families in Illinois!

We look forward to next year's event to be held in late August/early September!



FRALEIGH CHARITABLE FUND

DAVE & SUSIE
HODGSON FAMILY



Congratulations to Austin and Keith, winners of the first annual HDSA IL Baggo Tournament!

thank you!



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

Huntington's Disease affects communication in multiple ways. The disease impacts skills that are needed for communication including muscle strength/control, memory, perception, coordination and problem solving.

Some of the common communication issues seen with individuals living with HD include:

- Difficulty holding conversations
- A struggle to articulate thoughts
- A decrease in vocabulary
- Hard time following complex instructions
- Difficulty concentrating
- Decreased ability to make judgements and reason
- Increase in stuttering
- Inability to speak

Speech problems vary in severity and present differently among people living with Huntington's Disease. As the disease progresses, individuals with HD tend to speak more slowly, using fewer and more simplified words. In general, people living with HD can comprehend what is being said to them, but may not be able to respond to conversations. It is important to keep talking and include them in a normal dialogue. It can also be helpful to repeat their own words back to them and let the person living with HD know that you hear and understand what is being said. A person living with HD may ultimately lose the ability to talk. Communication is affected in many different ways for people living with Huntington's Disease.

Speech therapy is an important service for individuals living with Huntington's Disease. A speech therapist can work with an individual to teach him/her exercises that can help with communication and other issues that arise as the disease progresses. A speech therapist can also recommend assistive technology devices that can help with communication. A physician can help provide referrals for speech therapy and many other services that can help individuals living with Huntington's Disease.

The Illinois HDSA chapter is now offering a closed, monitored (by the chapter social worker) google group for individuals who are at-risk/asymptomatic. This is a private online group that allows individuals to ask questions, share ideas and support one another. All members of the group must be 18 years and older. If you are interested in joining, please email ezivin@hdsa.org and ask to join the at-risk/asymptomatic google group.



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	2017 Meetings: 2/12, 4/9, 6/11, 8/13, 10/8 (No meeting in Dec.)	Dave or Susie Hodgson (815) 498-6092 dchodgson1946@gmail.com
GENEVA		
3 rd or 4 th Sunday of odd numbered months (see dates in next column) TIME: 2:00 to 3:30pm LOCATION: Northwestern Medicine - 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. 2017 Meetings: 11/12 2018 Meetings: 1/21, 3/11, 5/6, 7/15, 9/16, 11/11	Joe Wiedemann (847) 505-3933 joseph.wiedemann@gmail.com
LAKE COUNTY		
2 nd Monday of every month TIME: 7:00 – 8:30pm LOCATION: Advocate Condell Medical Center, 801 Milwaukee Ave., West Tower, Libertyville, IL	Call for additional information and directions.	Marilyn and Barry Kahn (847) 975-2403 marilynkahn1@gmail.com
ROCKFORD		
2 nd Sunday of every month TIME: 2:00 – 4:00pm 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.	Cheryl Sutton (815) 262-4889 cjs@hdsupportrockford.org
SOUTH SUBURBAN		
2 nd Tuesday of odd months TIME: 7:00 – 8:30pm LOCATION: Thomas Cellini Huntington's Foundation, 3019 East End Avenue, South Chicago Heights	2017 Meetings: 1/10, 3/14, 5/9, 7/11, 9/12, 11/14 2018 Meetings: 1/9, 3/13, 5/8, 7/10, 9/11, 11/13	Maryann Moynihan (708) 955-3080 shamrock1959@att.net TCHF Office (877) 687-8243
CHICAGO – RUSH UNIVERSITY MEDICAL CENTER		
4 th Tuesday of even months TIME: 7:00 to 8:30pm LOCATION: 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. 2017 Meetings: 7/25, 8/28, 10/24, 12/12	For more info, contact Sarah Mitchell Chen, LSW (312) 942-6445 Open to all: at-risk, gene positive, currently have HD or are a family or friend of someone with HD
CHICAGO – NORTHWESTERN MEMORIAL HOSPITAL		
Meeting Date: 11/11/2017, TIME: 12:30 - 2:00pm Northwestern Memorial Hospital Feinberg Pavilion – Room B (After Northwestern HD Symposium)	For At Risk (non-symptomatic) patients and family members.	Emily Zivin (630) 443-9876 ezivin@hdsa.org
Parking Passes Available		
MUNSTER, INDIANA		
2 nd Tuesday of even months TIME: 7:00 – 8:30pm LOCATION: Southside Christian Church, 1000 Broadmoor Ave., Munster, IN	2017 Meetings: 2/14, 4/11, 6/13, 8/8, 10/10, 12/12 2018 Meetings: 2/13, 4/10, 6/12, 8/14, 10/9, 12/11	Cindy Rogers (219) 836-2369 clrogers111@comcast.net

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



November 11, 2017	A Celebration of Hope Event – Chicago, IL
March 17, 2018	HDSA Illinois State Conference – Palatine, IL
May 20, 2018	HDSA IL Chapter Annual Team Hope Walk – Naperville, IL
June 7 – 9, 2018	HDSA National Convention – Los Angeles, CA

<https://hdsa.org/il>

FALL 2017

