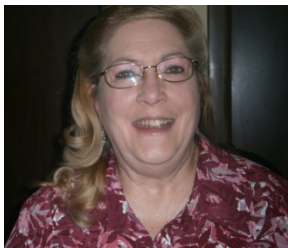


President's Message



Hello Friends,

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 2018. 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. This year more than ever, we need YOU! We need someone just like you who would be willing to give a few hours of their time to help us make our chapter grow and remain one of the top chapters in the country. We are seeking new board members and volunteers. If you would be interested in learning more please contact Susie Hodgson or any of our board members. You can find all contact information for board members elsewhere in the newsletter.

By choosing to give a few hours of your time as either a board member or volunteer, you can help us grow by bringing new ideas and insights. Being a board member requires only a few hours a year. We have 6 meetings, three are by phone and 3 are in person. We try to keep meetings to 1 ½ hours or less. Being a volunteer is simple, just let us know where you would like to help, and then the amount of time you volunteer is up to you.

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 fund raiser...when letting your sense of creativity go wild the possibilities are endless.

As many of you are aware we will not be having our annual "Dinner Dance" in February this year. This has always been a great event, lots of fun and a time to get together and celebrate. Maybe, you are that person that likes to plan parties and events, why not consider chairing this event and help to bring it back?

The Team Hope Walk in May is always a fun event and can always use volunteers. If you would like to be a part of this fun and exciting event contact Dave or Susie Hodgson.

This year we saw creativity come alive with the new BAGGO TOURNAMENT. Thank you Charlotte and Peggy for this fun day and I look forward to next year's tournament.

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.

This year more than ever we have HOPE! Our researchers and scientists are working very hard to bring us new treatments or a cure and they are getting very close. 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 Hodgson
President, HDSA Illinois Chapter
(Illinois@hdsavolunteer.org)

The Illinois Chapter now has its own unique email address for contacting the chapter for problems, questions, and comments.

illinois@hdsavolunteer.org

While hdsailchapter@gmail.com is still active, it's no longer on our state webpage.



HDSA Illinois State Conference **Mind & Body**



Saturday, March 17, 2018

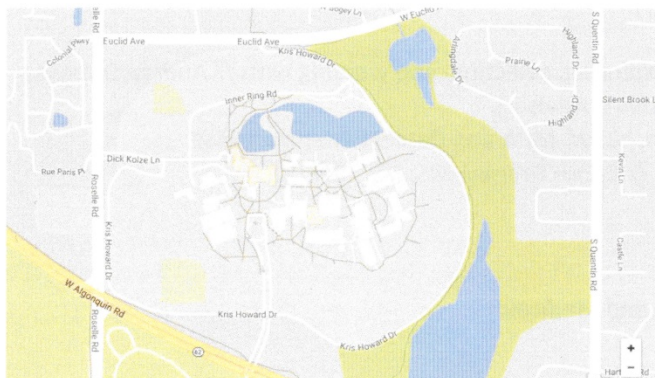
@ Harper College, Wojcik Conference Center
1200 W. Algonquin Road
Palatine, IL 60067

3 ways to register

In an effort to continue to keep the costs down and ensure that we are not incurring excessive food and beverage costs we request that you register for the conference online @ hdsa.org/il

If you are unable to do so, please contact us at holly.fraleigh@gmail.com or 708.790.9618 and a mail-in registration form will be sent to you.

Register in-person the day of the event (please only use this as a last resort) at the front door.



Enter Harper College at the Roselle Road entrance.

Take a left at the second 4-way stop and park in the lot.

The Wojcik Conference Center is Building - W, immediately adjacent to the parking lot.

This event is funded by the Huntington's Disease Society of America through an unrestricted educational grant from Teva.



HDSA Illinois State Conference – 2018

Mind and Body

- 8:15 **Registration Opens**
- 8:45 - 9:45 **Welcome**
Introduction of Illinois Board
Behavioral Challenges with HD
Dr. Eric Gausche, MD, Northwestern Medical Group
- 9:45 - 10:45 **Physical Rehabilitation Sciences: Speech, Occupational and Physical Therapy**
Dr. Santiago Toledo, MD, Shirley Ryan Abilities Lab Medical Director of Orthopedic Rehabilitation Program; Amy Watt, PT; Joelle Johnson, OT; and Danielle Williams, SLP
- 10:45 - 11:00 **Break**
- 11:00 - 12:00 **Morning Break-out Sessions**
- Advocacy // Jennifer Simpson, HDSA Manager of Advocacy
 - Driving and HD // Anne Hegberg, OTR, CDRS
 - HD 101 // Dr. Jennifer Goldman, MD, MS, Rush University Center of Excellence Director
 - Mock Support Group // Facilitated by Emily Zivin, LCSW, MPA; Barry and Marilyn Kahn
- 12:00 - 12:45 **Lunch**
- 12:45 - 1:45 **Clinical Research Update**
Dr. Jennifer Goldman, MD, MS, Rush University Center of Excellence Director and Dr. Danny Bega, MD, MSCI, Northwestern Memorial Hospital Feinberg School of Medicine Center of Excellence Director
- 1:45 - 2:00 **Break**
- 2:00 - 3:00 **Afternoon Break-out Sessions**
- Nursing Homes - How to navigate exploring, selecting, and working with // Andrea Donovan, President, Andrea Donovan Senior Living Advisers
 - At-Risk Support Group // Emily Zivin, LCSW, MPA and Danielle Marino, LCSW
 - Nutrition and Weight Management // Carrie Draney, MS, RD, LDN
- 3:00 - 3:15 **Break**
- 3:13 - 4:00 **Current HealthCare Climate - Medicare and Medicaid**
Mary Anne Ehlert, CFP
- 4:00 **Raffle Winner Selected and Adjourn**



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)

Season's greetings and happy holidays to the entire Illinois HD community!

This month's column is a reflection on the 2017 Celebration of Hope Gala held November 11, 2017 at the historic Cubby Bear in Chicago honoring the Rush University Medical Center HDSA Center of Excellence. I want to thank the Great Lakes Region HDSA and the Illinois HDSA chapter for this terrific event. The following includes excerpts from remarks made at the event.

For our Celebration of HOPE, let us look at several ways to convey HOPE and really spell it out (both literally and figuratively!).

H – H can easily stand for **Huntington's disease** which what brings us together and the reason we are all here tonight for the 2017 Celebration of Hope event.

But H stands for so much more...It is for **HOPE**. Hope that we can beat this illness, slow it down, and cure it. Hope that we will have new treatments now and more on the Horizon. It stands for health and happiness and humor, particularly when times get rough. For example, keeping with the Cubby Bear baseball theme, the American baseball catcher Yogi Berra once said - "Think! How the heck are you gonna think and hit at the same time?"

O stands for **Opportunities**. There are a growing number scientific research studies that provide Opportunities for people to play a role in reshaping the disease and developing new treatments, new tools, and new opportunities. O also stands for **Options**. Our options for new treatments, advances in family planning, and ways to live better with HD are increasing. In 2008, we had the first medication approved in the United States for chorea and in the past year, we had a second one approved. Just recently, an incredible scientific discovery in HD was announced.

On December 11, 2017, Ionis and Roche pharmaceuticals released a statement about the first human trial of a huntingtin-lowering drug, IONIS-HTTRx, an antisense oligonucleotide or 'gene silencing' drug studied in HD patients. In this 3-month long study trial, the drug was found to be safe and well-tolerated and also to reduce the disease-causing protein huntingtin in the nervous system. These findings are slated to be some of the most significant breakthroughs in HD research since the discovery of the HD gene in 1993. This news and other ongoing scientific studies bring an expanded definition of hope to our HD patients and their families.

P stands for **Progress**. This is an exciting time in neuroscience as we start to see gene editing and silencing studies in action and others being developed. While there is much more to learn and we still hope for a cure, we have made a lot of Progress in understanding HD and its symptoms. We recognize that there may even be genetic and environmental modifiers that may explain why HD can be different in different people, even in the same family. P is for **Prevention** - and also **Positivity** - in the field and for the future.

Lastly, **E** is for **Education**. Efforts by the HDSA, all of you, and around the world like the address made by the Pope this past spring (May 2017) all serve to increase awareness of HD and educate others about it. **E** is also for **Empowerment**, which is important as a way to help people live better with HD - to help them be stronger, more confident and empowered. **E** is also for **EVERYONE**. It really does take a village – from people with HD, their families, health care professionals and allied therapists, researchers, scientists, pharmaceutical companies, and many more.

It would only be fitting to end with a baseball quote, even if isn't from a local Cubs player. Bob Feller, a pitcher from the Cleveland Indians, once said "Every day is a new opportunity. You can build on yesterday's success or put its failures behind and start over again. That's the way life is, with a new game every day, and that's the way baseball is."

From all of us at the Rush University Medical Center HDSA Center of Excellence, I wish you and yours a happy and hopeful 2018!

Understanding Irrational Behavior in Huntington's Disease

by Debra E. Andrew

It happens out of the blue. There you are, going along with what appears to be a somewhat normal moment in time, when suddenly the irrational behavior rears its ugly head! It isn't that you have never seen this before. It's that even though you *have* seen it, you are still caught off guard. One second, your loved one who has Huntington's disease seems rational, and then suddenly, he or she is anything but. How does one cope with irrational behavior?

First, let's talk about the why. Knowing the why won't change the behaviors you see, but it may help you to wrap your head around what is going on. The brain of the person with HD is being attacked. We could go into all kinds of medical and scientific descriptions about that, but rather than do that, let's understand it in simple terms. The brain is being attacked, injured, damaged, and brain cells are being murdered. When that happens in the frontal lobe of the brain, it impacts behaviors. Some factors that trigger irrational behaviors are:

Impulse control

Frontal lobe damage erodes impulse control. At times, we may all have some irrational thoughts, but our impulse control allows us to get rational again and to get control of any irrational thoughts. That is an impossibility for people with Huntington's disease who are experiencing irrational thoughts or irrational understanding. The brain has taken off on its own direction of thought, and what the brain believes to be true is true to that person. To someone with HD, every one of those thoughts is real and true. And they behave accordingly.



Anxiety

People with Huntington's disease can feel very anxious when their brains aren't working for them like they realize they should be. Their ability to cope is undermined, they feel a loss of control, and their anxiety begins to rise. This isn't the basic anxiety that a person without Huntington's disease faces. This is an intense, all-consuming anxiety that begins to overwhelm them completely.

Being overwhelmed

With so many emotions swirling around all at once, it is confusing and extremely overwhelming. There is no way for people with Huntington's disease to sort through all of those extreme emotions. It becomes so overpowering that it removes rational thought from them. Just coping with those emotions is more than they can do; forget adding rational thought to that. Even if the processing of the brain allowed rational thought at that point, this extreme mixture of emotions would hijack it.



Confusion of thoughts and emotions

There's a part of the person with HD that will fight to find what is true, what is going on, and even what is rational. Much like being in a room full of mirrors with hundreds of reflections, people with HD are seeing all of these thoughts and emotions, and they're trying to figure out which is real. They may doubt if any of them are real, yet then believe *all* of them are real. Imagine how overwhelming that would be. The only survival available is to choose, to decide what is real and hang on to it. Unfortunately, that often can be the irrational thoughts that take over.

Frustration

Things just aren't adding up. Things aren't working like they should work. And there is no way to understand why, or to sift through things and get them

lined up again like they should be. That is where the frustration begins. A loss of control. A loss of understanding that is frightening and overwhelming. It often comes out as frustration because acknowledging the fear that they truly are "losing their mind" is too much to process or accept.

Unmet Needs

Being hungry, thirsty, or having pain or other unmet needs isn't something that people with HD can always express or process. Their bodies may hurt, but their minds may not tell them what they are feeling is pain. They may be hungry but can't express their hunger. Gnawing at them is some feeling they can't communicate, process, or meet for themselves. And yet, the feeling is relentless. They are at a loss of what to do. Remember, HD erodes the ability to know how to choose or how to do an act. The desire to act is there, yet all that comes out is to be frozen, unable to act on what they want to act on or unable to choose how to do it.

Perception, Unawareness, Lack of Emotional Recognition



Adding to this terrifying scenario is the inability to perceive exactly the responses around them. People with HD may be unaware of others' responses, emotions, and much more. Although the facial cues that we normally would see and understand are there, they can't pick up on those cues. They are left without understanding of any response, or they become extremely confused at the responses being received. When responses are negative or unexpected (and they are all unexpected), it's like being hit in the head with a two by four. They are caught off guard, and now, added to all the above extreme confusion they are going through, they are baffled and often irrational. Reality is fractured.

Conclusion

Although it is natural to attempt to rationalize with a person who is behaving irrationally, all these factors make a rational discussion or reasoning with an irrational person with HD futile. This may sound hopeless, but it isn't. Thankfully, there are ways to manage and to cope with irrational behaviors. Those will be discussed in a follow-up article.

About the Author

Debra E. Andrew lives in Utah, is happily married, has seven children, 23 grandchildren, and one soon-to-be great grandchild. Her love of health and wellness has led her to empower others in all eight areas of health and wellness in her daily life and businesses.

Debra is the creator of Business Hands, a non-profit serving those who are disabled and their caregivers; the founder of Power HC, PWR HC – Preventative Wellness Resource Health Community; a Huntington's Disease Regional Advocate; and she has established several Facebook groups supporting those with Huntington's disease, their caregivers, and families. She also has a blog, <http://hdinsider.weebly.com>, where you can find more of her articles.

Debra's educational background includes Business Management, Marketing, and e-Commerce, and she holds a B.S. in Community Health and a minor in Community Health Education. She is also a Certified Brain Health Coach.

Debra's husband, Allen, has Huntington's disease, and Debra is his full-time caregiver. The Huntington's disease incidence rate in Allen's family is 80 percent.

The Huntington's Post is made possible by grants from Teva Pharmaceutical and The Griffin Foundation.

**14th
Annual
Team
Hope
Walk**

**Sunday,
May 20,
2018**

Mark Your Calendar NOW!

The Illinois Chapter of HDSA's 14th Annual Team Hope Walk will be held on Sunday, May 20, 2018, at the beautiful Grand Pavilion on the Naperville Riverwalk. Our award winning, nationally recognized, Team Hope Walk is one of the biggest fundraisers for HDSA in the nation! Over the past 13 years, the HD families and friends have raised approximately \$800,000.00! The two mile walk along the DuPage River begins and ends at the Grand Pavilion.

This is a family friendly walk for everyone. Dogs on a leash are more than welcome to attend. Lunch is included in your registration fee (\$20.00 per person if you pre-register, \$25.00 if you pay the day of the walk). The **first 400 walkers who pre-register are guaranteed a correctly sized T-shirt**. The Dunk Tank will be back!

Fee:
Pre-register is
\$20/person

Day of the Walk
is \$25/person

T-shirts for
first 400
walkers who
pre-register!

For Pre-registration: <http://www.hdsa.org/thwnaperville>

For any questions, please contact Dave Hodgson at dchodgson1946@gmail.com or 815-498-6092. Feel free to start collecting pledges now using the pledge sheet in this issue of Hopes & Dreams. Stay tuned to our Illinois Chapter Facebook page and well as our Chapter webpage for more information!

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.



Family is everything



13th ANNUAL TEAM HOPE WALK

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



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 ZsaZsa Brown at zsazsa.brown@northwestern.edu or 312-503-4121.

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

Stunning gene therapy breakthroughs are a riposte to our truth-tarnished times

<https://www.theguardian.com/science/2017/dec/17/stunning-gene-therapy-breakthrough-riposte-to-truth-tarnished-times>

Robin McKie Sat 16 Dec '17 19.05 EST

There has been a surprising outbreak of the use of the c-word among medical researchers over the past few days. Normally cautious in their language, they have nevertheless been wielding the term “cure” when discussing the long-term potential of two separate treatments for inherited ailments that were announced last week. Such enthusiasm is striking.

In one case, scientists based at St Bartholomew's, London – who have been working on the inherited bleeding disorder haemophilia A – outlined how they had used a virus to carry the gene for the blood-clotting chemical, factor VIII (which patients lack) to their livers. Production of the missing chemical was restored and their bleeding halted. The development, according to the World Federation of Hemophilia, now points “the way to a cure” for the condition, which affects around 400,000 people worldwide.

In the other case, scientists led by **Professor Sarah Tabrizi**, of University College London, revealed they had found a way to suppress the build-up of harmful proteins in patients suffering from the incurable degenerative condition, Huntington's disease. Injections of the drug Ionis-HTTRx destroyed genetic messengers that directed the manufacture of these proteins. Dementia experts hailed the news as a “tremendous step forward” because it could be used not only to target proteins involved in Huntington's but in other neural conditions, such as Alzheimer's disease.

Please note: neither the work on haemophilia or the work on Huntington's can yet be termed as cures, but they point to the prospect of effective treatments being developed in future. Hence the outbreak of the use of the c-word last week. It is also worth noting that both techniques are forms of gene therapy, in which a mutated gene is either replaced with a healthy copy (as with the haemophilia trials) or is inactivated or “silenced” (as with the Huntington's work). And that development is also worthy of note.

Twenty-five years ago, as molecular biologists first honed the tools that now allow them to manipulate DNA at will, it was claimed that gene therapy could soon free humanity from the misery of countless conditions including haemophilia, Alzheimer's and some cancers – simply by altering a person's genetic make-up. It proved to be an overly ambitious goal, as gene therapy pioneer **Professor Eric Alton**, of Imperial College London, acknowledged. “Over the past couple of decades, the reputation of gene therapy has gone from being a cure for all known diseases to something that you wouldn't give your dog.”

Part of the problem lay with the deaths of some patients during trials of different gene therapies. However, the main reason for gene therapy's fall from grace was its simple failure to produce the goods as quickly as predicted. Fiddling with our genes proved to be a lot trickier than anticipated by some scientists.

This point is acknowledged by Professor **James Gusella**, the Harvard University geneticist who first pinpointed the gene that causes Huntington's and who was always cautious about the likely rate of developing gene therapy. “You have to appreciate that the symptoms of the disease, like any other illness, are the end result of a long series of processes that take place inside the body,” he said.

And it takes time to understand that pathway. It begins with the cause of a particular disease – an infection or the inheritance of a gene – and then leads through a series of knock-on effects that eventually produce symptoms. Researchers then have to pinpoint which stage is the one most susceptible to intervention. It has taken 25 years to get to this position with Huntington's disease.

Alton agreed progress has been slow. For decades, his team has been developing gene therapy treatments for cystic fibrosis – an inherited lung and digestion disorder that affects 10,000 people in Britain – and only now is it emerging as a potential treatment. “However, the crucial point is that we getting there.”

And that point needs stressing. Others may have dismissed the prospects of gene therapy, after its initial hyping, but its advocates still ploughed on, bouncing back after each setback, until success was eventually achieved. Apart from last week's developments, gene therapy has also helped treat immune conditions and some forms of blindness. In each case, it has taken a great deal of hard graft to reach these goals.

This is the way that science progresses, of course – not along an unswerving trajectory towards the truth but by staggering through disappointments, reversals and reappraisals. “Progress is usually a very slow, drawn-out business that features many setbacks and occasional small advances,” says **Professor Robert Lechler**, of King's College London. Eureka moments of triumphant discovery are certainly the exception.

The fact that science is rarely presented this way has much to do with the natural enthusiasm of scientists for their particular projects and with the tendency of journalists like myself to push them into guessing when their work might be ready for clinical use. Five years is the usual answer I get, no matter what the trials involve.

In the case of gene therapy, the answer should have been about 25 years – though I would have had difficulty selling such a remote prospect as a story to my news desk, while the poor scientists would have found it hard to acknowledge how long they still had to toil to achieve their goal. Hence those over-optimistic claims.

That last issue should be kept in mind when considering other medical developments that are being worked on, added Lechler. “Both stem cell science and gene editing have been highlighted as having enormous potential to treat illnesses – and of course they do. However, it may take longer than we expect – certainly if the example of gene therapy tells us anything. We shouldn’t disparage these technologies if they don’t reach fruition straightaway, however.”

Scientists are human and are sometimes prone to exaggeration and a bit of self-deception for good measure. But they do seek the truth. Even in relatively sane periods, that urge should be cherished. In today’s truth-tarnished times – assailed as we are by the egregious advocates of unreason who promote climate change denial, vaccine repudiation and other deceptions – we have never needed an example of dedicated, effective science so desperately. Researchers – working in the face of setbacks for decades – have now come close to finding treatments for some truly terrible conditions and have rightly been hailed for their work.

Their achievements should also be borne in mind the next time someone challenges a scientific truth just because it is inconvenient. That truth, no doubt gained at some personal cost, is something to be treasured, not denied.

Robin McKie is science and technology editor for the Observer

Yes! Count me in!!

2018 Pledge Drive



Your pledge helps to support the HD SA mission to improve the lives of everyone affected by Huntington's disease and our vision of a world free of Huntington's disease.

- Research efforts
- Family services
- Advocacy
- Support groups
- HD awareness
- Our chapter social worker
- In-Service Presentations to Care Facilities

Please complete the information below and return with your pledge:

Your Name _____

Email Address _____

- | | | | |
|----------------------------------|-------------------|---------------------------------|-------------------|
| <input type="radio"/> Benefactor | \$500.00 donation | <input type="radio"/> Supporter | \$ 50.00 donation |
| <input type="radio"/> Patron | \$100.00 donation | <input type="radio"/> Member | \$ 25.00 donation |
| <input type="radio"/> Angel | \$ 75.00 donation | <input type="radio"/> Friend | \$ _____ donation |

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



Make your check payable to
HD SA Illinois Chapter and mail to:
P.O. Box 1883, Arlington Heights, IL 60006
To make your pledge online go to HDSA.org/il – click
DONATE and choose **pledge drive** on the drop down
menu for the solicit code

**HD Living Positive
Support Group for At-
Risk and Asymptomatic
Individuals and Family
Members**

CHANGE OF LOCATION:
Logan Square Library Meeting Room
3030 W. Fullerton Avenue, Chicago, IL 60647

**M Northwestern
Medicine®**

- Bi-Monthly meetings (dates to be determined)
- Time: 10:00am – 11:30am
- Parking Passes Available
- Contact Person: Emily Zivin, ezivin@hdsa.org or (630) 443-9876

STATEMENT BY LOUISE VETTER, PRESIDENT & CEO OF THE HUNTINGTON'S DISEASE SOCIETY OF AMERICA REGARDING IONIS-HTTRX ANNOUNCEMENT

New York, NY, December 11, 2017 – Today, the Huntington's disease community achieved a goal that would not have been possible without the support and dedication of the families, physicians and researchers who passionately pursue a treatment for Huntington's disease (HD). Ionis' announcement of the completion of the Phase 1/2a study of IONIS-HTTRx is a historic moment in the fight against HD as it represents the successful completion of the first trial to treat the underlying cause of Huntington's disease, the genetic mutation itself. The fact that levels of mutant huntingtin were reduced in correlation to the dose of IONIS-HTTRx that was given is significant, and the fact that participants in this first Phase 1/2a study are able to continue on the drug through open label extension gives us optimism regarding its safety. As the next phase of clinical study of IONIS-HTTRx gets underway, we look forward to continuing to partner with Roche and the many dedicated clinicians and scientists who work tirelessly to bring greater help and hope to Huntington's families everywhere. We know families will have many questions about what happens next. We always recommend you speak with your doctor about any medical questions you may have. HDTrialFinder.org and HDSA.org will continue to provide the timeliest information regarding development of meaningful treatments for HD.

More information on the latest news about IONIS-HTTRx can be found at <https://en.hdbuzz.net/250>. For those of you who aren't familiar with this research you can learn more from this presentation by Dr. Wild at the 2017 HDSA National Convention in June, "Dr. Ed Wild delivers an update on Ionis Pharmaceuticals 443139-CS1 trial, testing HTTRx, a huntingtin-lowering antisense oligonucleotide or 'gene silencing' drug in Huntington's disease patients." by watching/listening to this 18 minute video on YouTube here: <https://www.youtube.com/watch?v=UKEGaJMZOcQ>

While the news this past week is exciting, we've still got a lot of work ahead. If you haven't registered with HDTrialFinder.org, what's holding you back? <http://www.hdttrialfinder.org/>. Also you can find out about other drug trials by registering here: <https://www.enroll-hd.org/>

Memorials and Tributes

In Memory of Peter M Coorlas from Milton & Catherine Fasseas

In Memory of Ralph Short from Lois Short

In Memory of Peter Stecyk from William & Donna Cuny, Dennis & Phyllis O'Connell, Gus & Mary Marchetti, William & Sara Michelini, Bob & Donna Maloney, Teresa Wisniewski, Vole & Anna Skibicky, Uliona Skibicky, Taras Skibicky, Keny & Vera Page

In Memory of Paul David Willis from Daniel & Jeri Barr

In Memory of Josephine Kaleta from The Kaleta Family, The Finco Family, The Jasinowski Family, The Barthel Family, The Skwerski Family

In Memory of Lorene Lindsay from James & Diana Brown, James & Barbara Ely, Tom & Shirley Boward, Maurice Sprout, Carlton & Sandra Jenkins, James & Margo Shawgo, Gary & Edwina Christianson, David & Lenora Guth, Vonnie Troyer, Bill & Rosa Dawson, David & Suetta Overholt, Richard & Carolyn Smith

In Memory of Nancy Howard from Dennis & Darlene Kress, Robert & Karen Kilpo, George & Delores Zdralevich, C. Dennis Erickson, Denis & Mary Lou O'Brien, Robert & Kathleen Beaudry, Ruth Ann Ungeran, James & Janette Fleming, Jay & Lori Wait, Beverly Nolan, Bruce & June Shipp, V.R. & K.A. Kitchen, Norbert & Ruth Seiler, Deborah Howard, David & Jane Foskett, Susan Zuck, Carole Coleman, Barbara & K.A. Kiegerich, Richard & Virginia McLellan, Mr & Mrs Ruffner, Childerguild- Silver Cross Hospital, Baron & Barbara Westphal, Mr & Mrs Paul Hopkins

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



Our local Illinois chapter has social work services available to individuals and families within the Huntington's Disease community. Whether you have HD, have a family member or know someone with Huntington's Disease, free social work services are available to anyone who needs help. Some examples of services you can inquire about include:

- Long term care referrals
- Support groups
- Information about government benefits
- Assistance identifying local services
- Supportive counseling
- HD specific resources
- Community education
- Advocacy
- Nursing home education

Wherever you live in Illinois, It is important to remember that you are not alone. Please reach out if you need any help. For more information contact Emily Zivin at ezivin@hdsa.org or 630-443-9876.

ON-LINE SUPPORT for Those At-Risk and Asymptomatic

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.

Emily Zivin, LCSW
Illinois Chapter Social Worker
Huntington's Disease Society of America
(630-443-9876)

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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.



HDSA
33RD ANNUAL
CONVENTION
LOS ANGELES, CA
JUNE 7-9, 2018

Please visit
www.hdsa.org/convention
for details on registration
and scholarship
applications for the HDSA
Annual Convention to be
held in Los Angeles, CA
June 7-9, 2018!!



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	2018 Meetings: 2/11, 4/8, 8/12, 10/14 (No meeting in June because of Natl Convention)	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. 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	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. 2018 Meetings: Please call for specific dates	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 MEDICINE		
LOCATION: Logan Square Library, 3030 W. Fullerton Ave., Chicago, IL – Room: Meeting Room TIME: 10:00am – 11:30am ***Please note, the March 17th support group will run as a break out session at the HDSA Illinois State Conference at Harper College, Wojcik Conference Center, 1200 W. Algonquin Road, Palatine, IL 60067. 2-3PM	For Asymptomatic/at-risk patients and family members. 2018 Meetings: 1/20, 3/17*, 5/5, 7/7, 9/22, 11/3	Emily Zivin (630) 443-9876 ezivin@hdsa.org
MUNSTER, INDIANA		
2 nd Tuesday of even months TIME: 7:00 – 8:30pm LOCATION: Southside Christian Church, 1000 Broadmoor Ave., Munster, IN	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



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>



WINTER 2018