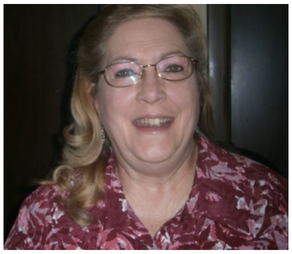
Hopes and Dreams

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

Huntington's Disease Society of America
Illinois CHAPTER

President's Message



FAMILY IS EVERYTHING…what does that mean to you? Does the phrase take on a different connotation when you think of it as related to Huntington's disease and how it affects your loved ones as you fight daily to ensure the best quality of life possible for your loved one(s)?

Family to you may be your immediate family; it may also include your extended family. Family may include the area you live in, your church family, your city. Your idea of family may include all those you know who are affected by HD.

To me, ***FAMILY IS EVERYTHING***, means all of the above. My immediate family always has and always will be my first priority. With that being said, without the support of my extended family, my church family, my community and my HD family I cannot ensure the best quality of life for my immediate family who are struggling with HD.

Within every family there are differences of opinions, goals, and the best way to achieve things. Our HD family is no different. We all have differing views, ideas of what should be done and how it should be done. There is nothing wrong with that. It is how and what we do with these differing ideas that are important. We can work together to achieve the common goal or we can sit back and snipe at each other when we have a difference of opinion. I feel that unless I am willing to do whatever I can to help achieve the goals of the FAMILY I have no right to sit back and complain about the decisions and choices made to help the family.

Just as our world is constantly changing, so is our HD family. There are many ways to take an active part and make a difference in the direction OUR family takes. In the battle against Huntington's disease no one fights alone. At the Illinois Chapter of HDSA, ***FAMILY IS EVERYTHING.***

As a Chapter Board, we are the "head" of the family. It is our duty to reach out, to listen and to hear what the members of our family need as they traverse this battlefield we know as Huntington's disease. Can we as the leaders of our Illinois family solve and find answers for every problem or concern? Certainly not, just as in your immediate families you cannot always find the one right answer. If we have the "family" working together to find the answer or solution we will only be stronger and then more able to find the solutions or answers.

To achieve this it takes ALL of the family working together towards the common goal, DEFEATING HUNTINGTON'S DISEASE! What can you as a family member do to help find the answers?

- You can volunteer; there are many opportunities to do this and it does not take a lot of your time. Have you thought about volunteering for one of the committees on the Chapter Board, or perhaps becoming a Chapter Board Member?
- You can educate; have you thought about sharing your personal story with a local organization?
- You can advocate by writing your state and federal representatives and senators about the HD Parity Act. You could help TURN CHICAGO BLUE.
- You can donate; think about donating your time or talent.

If you would like to become an active part of our FAMILY as we search for answers and solutions please feel free to contact me. Remember…there is no idea or talent that cannot be used successfully to make our FAMILY stronger.
WE ARE FAMILY…FAMILY IS EVERYTHING

Most sincerely,

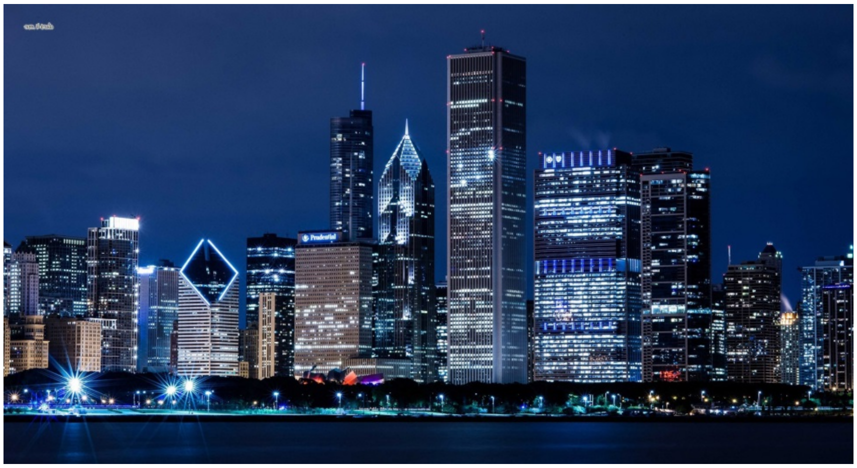
Family is everything

Susie

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

Help Turn Chicago BLUE for Huntington's Disease

By Dave Hodgson



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

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

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

Register for the 31st Annual HDSA Convention in Baltimore

The 31st Annual HDSA Convention will be held on June 2-4 in Baltimore, Maryland.

This year's Convention will be bigger and better than ever before, with a new schedule of educational tracks, workshops, interactive sessions and new presenters.

Please visit **www.hdsa.org/convention** to learn more, to register online or download registration forms to attend this year's event.

Please note that if you register by April 30, 2016, you will be rewarded by being charged the Early Bird Rate. Also, don't forget to take advantage of the many scholarships available to attend.

HD Trial Finder identifies trials nationwide looking for participants that share the same diagnosis, stage and treatment history.

First Ever Hoedown for Huntington's

By Marilyn & Barry Kahn

"Hoedown for Huntington's' was this year's theme for our annual fundraiser! And a great Hoedown it was!!! That was the consensus of everyone who attended our 9th annual event held on Saturday, February 13, 2016 at Indian Lakes Resort in Bloomingdale, IL. It was attended by nearly 150 people and was enjoyed by all!

We would like to take this opportunity to thank the following sponsors who helped make this event a success! A successful event only happens because of the generosity, dedication and hard work of many people!

"Platinum Sponsor"	**"Gold Sponsors"**	**"Silver Sponsors"**
Team McCallum	MCJ Jewelers & Goldbuyers	Arlington Construction Services
	Teva Pharmaceuticals	Lundbeck, Inc.
	Vienna Beef	

Hoedown for Huntington's Committee and Helpers

Marilyn Kahn – Co-Chairman
Barry Kahn – Co-Chairman
Peggy Monson (Chair, Raffle & Auction)
Eileen Barker (Registration)
Tom Barr (Photos)
Mary Bos (Registration)
Nancy Corbige (Line Dancing)
Rachael Fraleigh (Invitations & Graphics)
Holly Fraleigh (All around helper!)
Lisa Froman
Conny Heggen
Dave and Susie Hodgson (Candy Bar Raffle Sales)
Candy Matheson
Jim Meredith
Sheri Mueller
Danielle Karlson-Perrott (Program)
Charlotte Rybarczyk
Illinois Chapter Board Members

We would also like to take this opportunity to thank and name all of the businesses and individuals who helped make this a success with their generous donations. Without their help, we would not have realized the success that we did. Please make an effort to frequent these businesses and mention that you appreciate their support of Huntington's disease!

ABT Electronics
Ace Hardware – Libertyville
Jan & Tom Barr
Annette & Brian Bernard
Sheree Block
Liz Born
Eleanor Botker
Tracey & Joshua Buchman
Buffalo Wild Wings – Vernon Hills
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Dover Straits Restaurant & Lounge, Mundelein
Eric & Molly Droze
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Eddie Merlot's – Lincolnshire
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Lori Friend Hair Studio – Libertyville
Kim Lyle & Dan Soicolowski
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Marlene Manso
Massage Envy Spa – Hoffman Estates
Candy & John Matheson
Me & My Crafty Mom
Joan Meredith
Metropolis Performing Arts Centre
Angie Miller
Lynn & Steve Miller
John & Peggy Monson
Lisa Mooney
Dr. Richard Morimoto – Northwestern University
Art & Sheri Mueller
Mike & JoanAn Murawski
Steve & Tracy Norman
Helen O'Connor
Origami Owl – Kristin Rybarczyk
Joy & Gerry Orlowsky
Philly G's – Vernon Hills
Sandy Plesha
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The Theatre School at DePaul University
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The Twisted Cow – Michelle & Pat Gallagher
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Patty & Steve Vos
Westwood Tavern – Schaumburg
Sallie & Joe Wiedemann
Emily & Steve Zivin

For those who donated after this went to print, we thank you for your continued support!

A special thank you goes to Marty Jacobson, Martin Jacobson Jewelers, who donated the beautiful diamond pendant won by Margaret Osimani! Congratulations, Maggie!

It was once again a very special evening of music by our DJ, Scott Socha, of Absolutely Entertainment, Inc. A special highlight of the evening was our line dance professional, Nancy Corbige, who had everyone on the dance floor for most of the evening. Thank you, Nancy, for your expertise and your time!! It was so nice to socialize with 'old' and 'new' acquaintances during our cocktail social hour. Barry Kahn welcomed everyone and then introduced the Illinois Chapter Board, as well as the sponsors and others who contributed to the evening's success. This was followed by Dr. Kathleen Shannon, Director of the Center of Excellence at Rush University Medical Center, who gave a brief update on the Center and current exciting research!

Charlotte Rybarczyk reminded everyone of the importance of raising funds to keep the positive momentum of finding a Cure for HD. This was realized by so many donating to the Cure for HD initiative. Thanks to all who did!!

The evening was a huge success. Everyone in attendance had a wonderful, fun-filled time and left with the knowledge that the net proceeds would support HDSA's fight to improve the lives of people affected by HD and their families.

Thank you to all who supported this event. Please plan to attend next year and bring your family and friends!! And if you want to get involved and help on next year's event, please reach out to us!!

Hoe Down for HD 2016

MEMORIALS AND TRIBUTES

In Memory of Glen A. Guske from Irene Guske

In Memory of Fred Purcell from Harold & Sylvia Elden

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

In Memory of William A. Howe DDS from R. C. Howe

In Memory of Ralph Short from Lois P. Short

In Honor of Alvin Eckhoff from Mildred McKinley

In Memory of Steven Jacobson from Barry & Marilyn Kahn

In Memory of Heidi Knauer Hynes from Carolyn Mahon, Tom & Carol Mahon, Connie Damery & Rhonda Trimble, David & Dawna Hackman, Dave & Dena Bagger, Mike & Pat Kuta, Dan & Jennifer Leahy

In Memory of Terry Bruno from Craig & Teresa Srajer

In Memory of Tonya Stewart from Bruce Bauer, Howard & Shirley Boward, Carlton & Sandra Jenkins, Charles Stewart, Richard & Carolyn Smith, Lawrence & Arlene Pennie, Laura Smith

In Memory of Cindy Fullenkamp from Wayne & Rita Eichelberger, Richard & Susan Pickett, Betty Lawler, John & Patricia Graham, Joseph & Lori Burnett, Stan & Patricia Early, William & Joan Sheridan, William & Jo Ann Lucera, William & Jane Oldham, Dennis & Anne Long, Robert & Rebecca Read, Roger & Susan Quinlan, Charles & Karen Baglama, Darrell & Katherine Lee, Kim Lawler, Mark Fullenkamp, Tom & Stephanie Franey

In Memory of Erwin Plavec from George & Susan Zahrobsky

In Memory of Patricia Ross from Steve & Cindy Button, Curt & Kathleen Winhold, Gary & Vallie Gould, RJ, Kathy & Sara Shaffer, Mark Bortmess

In Memory of Mary Williams from David Coe & Donna Gannon, Judith Conway

In Honor of Joe Etchingham from John M. Russo

Memorial and Tribute Donations

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

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

My Name______________________________________
Address_______________________________________
City, State, Zip_________________________________
Amount of Contribution: $____________________________

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Hopes & Dreams
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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.

4 PAWS 4 4 4 A CAUSE

Norwood Park Fest and Parade

in support of Huntington's disease

Huntington's Disease Society of America
Great Lakes REGION

Saturday, September 10, 2016

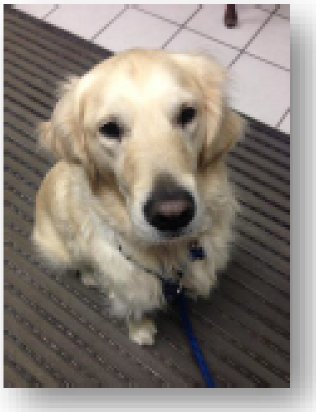
10 am - Noon

Norwood Park ~ 5899 N. Avondale, Chicago

4 Paws 4 a Cause, in support of Huntington's Disease, is an event dedicated to our four-legged friends and their pet loving humans.

Participants will enjoy loads of pup centered activities and entertainment including:

- **Contests**
- **Training Tips**
- **Games**
- **Parade**
- **Raffles**
- **Treats for the whole family to enjoy**



Meet Marley ~
Last year, Marley was our star pup, this sweet boy was HDSA's biggest fundraiser! Come out and meet 2015's "Most Helpful Hound." That's right, our Hounds were instrumental in raising money for HDSA! Your pup can be the star of 2016!

For more information and to register for this event, please visit us at www.shorturlcoming.com

Thank you to our generous partner,

Dilly Dally Dog Club

DILLY DALLY
DOG CLUB
3151 N. Elston
Chicago, Il 60618 773.865.7025

Dog Walking And Day Care Services

2016 HDSA Illinois State Conference Explores "New Frontiers"

by Daniel Born

Nearly 150 people gathered at the Chicago Hilton Northbrook hotel on March 12th for the annual HDSA Illinois state conference, in a day that focused on how the predictive test has transformed the HD community.

Keynote speaker, Kimberly Quaid, PhD, Professor of Medical and Molecular Genetics at Indiana University, set the tone for the day's discussions when she observed that "for at least two decades, individuals choosing to get the predictive test tended to be in their mid-to-late-thirties. For them, the introduction of the test came after they had already made major life decisions about education, careers, marriage, and reproduction."

But Quaid observed that this is beginning to change. Lately she has seen a significant shift in the at-risk population choosing to be tested. "I have noticed the population choosing to be tested is trending younger, with many more at-risk individuals eighteen to twenty-one years of age as well as those in their mid-twenties. This is the first generation," she went on to say, "to grow up knowing their entire lifetime that a test for HD is available, and that they can be tested when they reach the age of eighteen."

Quaid spoke about the medical technologies now available to women who want to ensure their offspring do not carry the mutant gene for HD. These procedures include IVF (in vitro fertilization, which can use donor eggs or sperm) as well as PGD (preimplantation genetic diagnosis). The latter is especially relevant for parents who are either gene positive or don't know whether they carry the HD gene. These parents now have the choice to test the zygote before implantation in the uterus, to ensure that the offspring is not gene positive for HD. It is also possible with this technique to guarantee the implanted zygote is free of HD, without telling the parent whether he or she is HD-positive.

Quaid's talk stimulated more than half an hour of intense dialogue. A panel in the afternoon continued this conversation: "Sharing Our Stories: Evolving Families and Family Plans." The panel was moderated by chapter social worker Emily Zivin, LCSW, MPA, and featured a young woman in her mid-twenties who does not plan to have children, is at risk but has not been tested; a woman in her thirties who is gene-positive and has had two children free of HD by way of PGD; and a woman in her mid-thirties with four children, who is at-risk but has not taken the predictive test.

Other highlights of the day's events included Dr. Kathleen Shannon, MD, on the current state of international research on HD, which has begun to move beyond studies with mice to drug trials for humans. This certainly marks a new frontier in the battle to end HD. Shannon's afternoon breakout session on "Five Difficult Scenarios" was packed with more than sixty people; other breakout topics of the day included "Mindfulness," "Making a Long-Term Plan for Care," financial planning, nutrition, and advocacy. This year's conference was co-chaired by Emily Zivin and Daniel Born; the 2017 state conference will be chaired by Emily Zivin.

TEAM RUN FOR
HD
THE CURE STARTS HERE.

April 28-30, 2016 - We have a team affiliated with the **Illinois Marathon in Urbana-Champaign**. There is a coupon code available for runners of any distance, and donor drive page set up. Please see info at link below.
http://hdsa.donordrive.com/index.cfm?fuseaction=donorDrive.event&eventID=972

July 23, 2016 - We are the charity partner for the **Amita Fitness for America Sunset half marathon, 10k & 5k** (and night time glo run!) in Hoffman Estates, IL. We have a coupon code available for runners of any distance, and a donor drive page set up at the link below. We are also looking for 40 volunteers for this event (i.e., handing out water and finishers medals, etc.)
http://hdsa.donordrive.com/index.cfm?fuseaction=donorDrive.event&eventID=971

October 9, 2016 - We are currently out of guaranteed spots for the **Chicago Marathon**, 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!

HDBuzz

Harnessing the power of viruses to treat Huntington's disease

By Leora Fox on February 03, 2016; Edited by Dr. Ed Wild

New therapies for disorders like Huntington's disease are on the way, but getting the drugs to enter brain cells can be a major challenge. A group of scientists has redesigned and tested a harmless virus that can efficiently deliver a 'gene silencing' message throughout the brain in mice, much further than naturally occurring viruses can reach. What's more, it can be given with a simple injection into the blood, offering great potential for research in gene silencing research and beyond.

The surface of a virus is coated in molecules that act like keys to trick a cell into unlocking its doors and letting the virus in.

Delivering advanced therapies to brain cells

Huntington's disease is caused by an error in the genetic code – a DNA misprint that leads to the construction of a toxic protein, mutant huntingtin. Over time, this bad building block is destructive to brain cells.

One basic strategy in the pursuit of treatments for HD is to send a message to brain cells, telling them to halt production of the harmful huntingtin protein. This is the basis for HD **gene silencing**. There are several different approaches to this type of therapy, including an ongoing clinical trial that was the subject of recent Buzz news.

Since every cell contains the HD error in its genetic blueprint, a major challenge in gene silencing research is how to get the drugs to as many brain areas as possible, ideally without needing invasive treatments like brain surgery. Since HD is increasingly thought of as a whole-brain disorder, the most effective therapy would have widespread reach, eliminating mutant huntingtin in a large percentage of nerve cells.

We're excited about a recent technological advancement in this realm, a modified virus that has the potential to deliver an HD-fighting therapy more effectively than was previously possible. It's in an early stage of research and is not ready to test in humans, but ultimately it could allow gene silencing drugs to be given non-surgically while traveling farther and more efficiently through the brain.

Harnessing the power of viruses

Researchers have long used viruses to study the delivery of genetic material throughout the brain. We're not talking about illness-causing agents like the flu – these are naturally-occurring but harmless viruses that scientists have modified for research purposes. The goal in the Huntington's disease field is to harness the viruses' natural ability to enter cells, and then fill them with genetic messages that will stop the brain from producing mutant huntingtin.

Importantly, one special feature of 'gene silencing' drugs is that they are made from chemicals similar to DNA. That's how they can interact with the machinery in cells that turns a genetic recipe into a protein.

Viruses are essentially little packages of genetic material – DNA or a related substance called RNA – surrounded by an outer shell. The surface of a virus is coated in molecules that act like keys to trick a cell into unlocking its doors and letting the virus in. Once inside, the virus bursts open and releases its genetic material. This is sneaky, because the cell handles the new genetic blueprint as though it was meant to be there all along, churning out virus parts alongside its own business.

In the case of most viruses, like the common cold, this new genetic information hijacks the cell's machinery, causing it to generate millions of new viruses until the immune system notices the invader and kicks them out. But for the purpose of brain research, scientists can redesign both the virus packaging and its contents. They can equip the capsid with a new set of molecular keys, then fill it with genetic material to perform a therapeutic function – such as blocking the HD gene.

"One virus, AAV-AS, happened to be very good at entering neurons. The protein keys they had attached were highly effective at opening molecular doors on the surface of neurons. ”

To experiment with delivering gene silencing drugs in the lab, researchers have historically used a type of harmless virus called an **adeno-associated virus** or **AAV**. While many AAVs can travel from the bloodstream into the brain, they don't usually excel at entering neurons, the cells that are essential for brain function. Instead, they are more likely to get into the brain's 'support' cells. To treat neurodegenerative disorders like HD, it's important to deliver the cargo directly to neurons – and as many as possible.

Designing a virus to get into neurons

Recently, a team of collaborators from Massachusetts and Alabama modified AAVs and tested them to see if they could enter neurons more easily and travel widely throughout the brain. Miguel Sena-Esteves, a scientist working at the Gene Therapy Center at UMass Medical School, headed the study. The scientists genetically modified the AAV's outer surface, adding extra strings of proteins and testing whether these new 'keys' would better allow the virus to enter different types of cells in the brain.

They tested their newly minted molecular keys by injecting the viruses into mice through a vein. This is an important point – the AAV can travel through the bloodstream and enter the brain without the need for invasive surgery.

Breaking and entering – and blocking huntingtin

One virus, called **AAV-AS**, happened to be very good at entering neurons, more so than any of the others. The protein keys they had attached were highly effective at opening molecular doors on the surface of neurons. By filling the AAV capsids with genetic code to make a glowing green protein, they could easily show that the virus had reached many, many parts of the mouse brain and spinal cord.

The new virus is highly effective at breaking into neurons to deliver gene silencing material.

A more effective and far-reaching delivery system like this has huge potential, not only for developing new drugs, but also for basic research about how the brain functions.

The next step was to fill the neuron-friendly virus capsid with gene-silencing material and see whether it was effective in mice. In this case, they used a gene-silencing molecule called microRNA. They chose a microRNA that would block the manufacture of mouse huntingtin, packaged it up in the AAV-AS virus, and tested it in a normal mouse.

A single treatment with the virus into the vein in the mouse's tail reduced the level of mouse huntingtin in many areas of the brain – including up to a 40-50% decrease in the striatum – a very deep brain region affected early in Huntington's disease. This is impressive, even compared with studies where surgery was used to get gene-silencing treatments into the brain.

The next steps for AAV technology

This is undoubtedly exciting stuff, and in time it could be really important for future gene silencing drugs to treat Huntington's disease. As always, there are a few important points to note.

Importantly, the researchers did not use a mouse model of HD to test their virus – they silenced **normal huntingtin** in healthy mice, to prove the point that their virus could enter neurons and complete a gene silencing job. This, of course, is not the ultimate goal – HD gene silencing treatments aim to silence **mutant** huntingtin, the real culprit. But now that the technology exists, these scientists have the ability to fill the new AAV-AS capsid with an HD gene silencing drug against mutant huntingtin and see whether this could have a beneficial effect on symptoms in mice. That's one likely next step.

The virus travels fairly well through the brain, but it's not perfect, and further studies will continue to address the challenge of delivering drugs to neurons. Like many scientific breakthroughs, part of this discovery was accidental – no one's sure exactly why this molecular key on the AAV-AS surface was so effective for getting the virus into neurons. That will be another subject for future research.

In the meantime, here are the main things that are cool about the newly developed virus:

1. It can be injected into the bloodstream and reach the brain
2. It can get into neurons more efficiently than previously tested viruses
3. It can spread all over the brain
4. It can carry effective gene silencing material

This technology is far from ready to try in people – it will first require careful testing in multiple species to see if it would be safe and effective. Nevertheless, this work will be important for developing gene silencing therapies for Huntington's disease and other disorders. More effective viral delivery systems also open up many new avenues of research into brain function.

12TH ANNIVERSARY

Team Hope – Walk for a Cure - 5K Walk

SUNDAY, MAY 22, 2016

NAPERVILLE RIVERWALK *(RAIN OR SHINE)*
REGISTRATION: 9:30AM ~ WALK BEGINS: 10:30AM

ONLINE REGISTRATION: $20.00
WALK-IN REGISTRATION: $25.00

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

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

Fundraising

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

Sponsorship

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

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

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

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

PLEDGE SHEET

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

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

Team Hope – Walk for a Cure - 5K Walk

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

Name: ____
Address: ____
City: ______________________________ St: __________ Zip: ____________

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

Signature: ______________________________________

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

According to estimates from The National Alliance for Caregiving, 44 million Americans served as family caregivers for a disabled or ill relative over the past year. Caregiving for a family member or friend can be rewarding, but also involves additional stress which includes financial pressure, changes in the family dynamic, distribution of duties in the household and additional work at home.

Caregiver stress and burnout is a common concern. Without adequate support and help, the caregiver is vulnerable to both physical and emotional problems. Managing the caregiver's stress level is very important and we must remind the caregiver to take time, rest, relax and recharge.

Respite care is planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to families who are caring for a loved one. Respite often provides a positive experience for the person receiving the care and provides the caregiver a "short break" to take some time for him/herself.

Some examples of respite care include:

Home based services: Respite services that may be offered through a public health nursing agency, volunteer association, social service department, private nonprofit and a homemaker/home health service.

Consumer-directed respite: This is when the person providing the care is identified, selected and trained by the families. Providers might be paid or unpaid.

Out of Home Models: Residential respite facilities and/or adult day care.

The Illinois Department of Human Services offers a home service program, which provides services to individuals with severe disabilities so they can remain independent in their homes (it takes about 8 months for the state to process the application and begin services).

Services offered under the program include: Personal assistant, homemaker services, maintenance home health, Electronic Home Response, home delivered meals, adult day care, assistive equipment, environmental modification and respite services.

More detailed information is available at: **http://www.dhs.state.il.us/page.aspx?item=29738**

A recent survey was sent out to support group leaders to forward to members for completion. Over 300 responses were received. The feedback was very upbeat with most members feeling very positive about their group experience. Over 50 support group leaders also completed a survey. HDSA is still looking at the data but wanted to share a few things with you. Lots to think about as we try to provide the best opportunities for our families.

Member comments

- Some wanted groups closer to them or at different times or locations.
- Caregivers often wished that there were separate caregiver and HD person groups as they sometimes found it difficult to share their true feelings with their loved one present.
- Young people at risk or pre-symptomatic want to have groups specific to their age and disease status.

Leader comments

- Some wanted to know more about what's happening in research and wanting to improve their HD knowledge. Here are some options that can help **everyone** improve their HD knowledge:

Research updates: are you signed up on the hdsa.org website for updates on research, advocacy?
Look at www.hdsa.org and newsletter signup.

Have you considered creating a google alert? You can enter *Huntington's disease* and get daily or weekly hits on HD news around the world? https://support.google.com/alerts/answer/4815696?hl=en

Have you considered getting an HDBuzz alert? This is a great site to get research updates in layman's language. http://en.hdbuzz.net/follow/email

SUPPORT groups

Date/Time	Additional Information	Contact Information
CENTRAL ILLINOIS		
2nd Sunday of **even months** TIME: 2:00 to 4:00pm LOCATION: St. Joseph Medical Center, Bus. Conf. Center – Room 2, 2200 E. Washington Street, **Bloomington, IL**	**2016 Meetings:** 02/14, 04/10, 06/12, 08/14, 10/09	Dave or Susie Hodgson (630) 386-3928 spiketdog@softhome.net
GENEVA		
Specific Sundays of **odd numbered months** (see dates in next column) TIME: 2:00 to 3:30pm LOCATION: Cadence Delnor Hospital, 300 Randall Road, Conference Room #4, Medical Office Building 351, Geneva, IL (park in the southwest lot) * Whether you have HD, are at risk, a caregiver, friend, or just someone who wants to know more about HD, you are welcome.	Immediately after entering the building, turn right down hallway and follow until hallway ends. Conference room #4 is straight ahead on your left. **2016 Meetings:** 01/24, 03/20, 05/15, 07/17, 09/18, 11/20	Joe Wiedemann (847) 505-3933 joseph.wiedemann@gmail.com
LAKE COUNTY		
2nd Monday of **every month** TIME: 7:00pm LOCATION: Advocate Condell Medical Center, 801 Milwaukee Ave., West Tower, Libertyville	Call for additional information and directions.	Marilyn and Barry Kahn (847) 975-2403 marilynkahn1@gmail.com
ROCKFORD		
TIME: 2:00pm LOCATION: OSF St. Anthony Medical Center, 5666 E. State St., St. Anthony Room, Rockford, IL * Use the main entrance - second one back from the parking lot entrance. As you enter the building you'll see a counter staffed by volunteers. Turn right, before you reach the counter. The St. Anthony Room is straight ahead.	Open to people with HD, family members, caregivers, and interested professionals. **2016 Meetings:** TBD (Planned for Quarterly)	Cheryl Sutton (815) 262-4889
SOUTH SUBURBAN		
2nd Tuesday of **odd months** TIME: 7:00pm LOCATION: Thomas Cellini Huntington's Foundation, 3019 East End Avenue, South Chicago Heights	**2016 Meetings:** 01/12, 03/08, 05/10, 07/12, 09/13, 11/08	Maryann Moynihan (708) 955-3080 shamrock1959@att.net TCHF Office (877) 687-8243
CHICAGO – RUSH UNIVERSITY MEDICAL CENTER		
4th Tuesday of **even months** TIME: 7:00 to 8:30pm LOCATION: Rush University Medical Center, 1620 W. Harrison Street, Tower Resource Center, Tower, 4th Floor, Suite 04527, Chicago, IL * Parking is available at the Rush garage on the southeast corner of Paulina and Harrison Streets. From the 4th floor, follow the signs to the Tower.	Valet parking is available in front of 1620 W. Harrison. Parking at both of these venues will be validated in full.	For more information, please call 1-630-443-9876. Open to all: at-risk, gene positive, currently have HD or are a family or friend of someone with HD
MUNSTER, INDIANA		
2nd Tuesday of **even months** TIME: 7:00pm LOCATION: Southside Christian Church, 1000 Broadmoor Ave., Munster, IN	**2016 Meetings:** 02/09, 04/12, 06/14, 08/09, 10/11, 12/13	Cindy Rogers (219) 680-6001 (cellular) (219) 836-2369 (home)

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

For additional support you may call:

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

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

☑ SAVE THIS DATE!

April 28 – 30, 2016	Team Run for HD: Illinois Marathon Race Weekend in Urbana-Champaign
May 2016	**HD Awareness Month!**
May 22, 2016	Team Hope Walk for a Cure – Naperville, IL
June 2- 4, 2016	31st Annual HDSA Convention in Baltimore, MD
July 23, 2016	Team Run for HD: Amita Fitness for America Sunset Half Marathon
September 10, 2016	4 Paws 4 a Cause – Norwood Dog Park, Chicago
October 8, 2016	Celebration of Hope – Lincoln Park, IL

https://illinois.hdsa.org

SPRING 2016