



President's Message

On March 9 we held our annual State Convention, *How Do We Tell the HD Story?* More than 170 people comprised of families, friends, and caregivers attended this year's event. I want to share some excerpts from my lunchtime speech which shares the HDSA-IL Chapter story. Thanks to Dave Hodgson, Clarence Wiese, Joyce Burns, and Mollie Simon for providing the history.

In 1967, after famed American folk singer Woody Guthrie's death from Huntington's disease, his wife, Marjorie, decided to form a group dedicated to finding the cure that took her late husband's life. Her group, *The Committee to Combat Huntington's Disease*, came to life.

In 1969, while in Chicago, she met with Mollie Simon and formed the Midwest Chapter of CCHD. Mollie had a profound interest in HD as it ran in her family also. Calling upon a few friends of hers, including Jay and Beverly Peddy, Mollie began what has become the Illinois Chapter of the Huntington's Disease Society of America. Initially the Chapter covered Illinois, Indiana, and Wisconsin. In time, the Chapter gave birth to chapters in Indiana and Wisconsin, and its territory shrank to Illinois. In view of this fact, in 1985 the Chapter changed its name to the **Illinois Chapter**.

The original board of three slowly grew to five to eight to our current board of 14 members. It is easy to be President when you are surrounded by a great team! If you have an interest in serving on the Board please let me know. We do most of our board meetings via conference call to make it easier for members from various locations to participate.

Over the years, the Chapter has tried to meet in different parts of the state to give everyone a chance to attend our State Convention. The past several years we have chosen to meet at a central location that we hope accommodates everyone. I would like to thank Dan Born, our Convention chairman, for all the work he has done to make this a successful event for 2 years in a row!

Our chapter sponsors support groups from Rockford to Peoria and Bloomington to Quincy. In the past year we have hired a chapter social worker to help with family services, in-services to nursing homes, and support group training. Cori Robin can be reached using the chapter phone at 630-443-9876 or via e-mail at crobin@hdsa.org.

Our chapter holds various fundraisers throughout the year in order to support the stated mission of the national organization as well as our Center of Excellence at Rush University Medical Center. In February we held our annual *Hearts for Huntington's Dinner Dance*. Many thanks to Barry and Marilyn Kahn for a job well done. Look for their write up in this newsletter. On May 19 we will hold the *Walk for a Cure* event, this year on the Riverwalk in Naperville. On June 22 we will hold a new event, *Hot Rods for Huntington's*, at the Volo Auto Museum which will include a car show and Baggo tournament. Then, on August 4, we will have our annual *Golf Outing*. In the Fall watch for our annual *Hoop-A-Thon* event. We hope that many of you will join us at one or more of these events throughout the year. We are also looking for volunteers to serve on committees to help run these events.

The Illinois Chapter takes an active role locally as well as nationally. We have won two awards for "*Best Fundraiser*" for our Walk for a Cure event. In addition, our newsletter has won an award for "*Best Newsletter*". We are also proud to say that our chapter had a member selected as "*HD Person of the Year*", Bob Leck. In 2007, the Illinois Chapter was named, "*Chapter of the Year*" by HDSA.

Our story, however, does not end here. The chapter will continue to provide support groups, a social worker, in-services, educational materials and fundraising to support HDSA and its mission to improve the lives of people with Huntington's Disease and their families. We will support research, assist families and educate the public. This is a great time for you to become a part of our HD story. Make a donation, write to your congressman, join a committee, or create your own mini fundraiser! Contact any Board Member to find out what part you can play in our ongoing effort to treat and eradicate this disease. We will continue until we get our happy ending, a world free of Huntington's disease.

Yours in the fight to cure HD,

Charlotte

Charlotte Rybarczyk
President, HDSA Illinois Chapter



Like us on
Facebook

HDSA Illinois Chapter

Huntington's Disease Parity Act of 2013

The *Huntington's Disease Parity Act of 2013* was introduced in the House of Representatives, by Congressman Bill Pascrell of New Jersey, and Congressman Adam Kinzinger of Illinois. Our new bill number in the House is H.R. 1015.

Take Action

Go to www.hdsa.org/takeaction to personalize a letter to Congress! Your Rep. needs to hear from YOU to cosponsor H.R. 1015!

Thank Congressman Kinzinger

Thank Congressman Kinzinger for being a champion for HD by sending an email to his staff person, Michael Essington, at michael.essington@mail.house.gov.

Get Involved

Go to www.hdsa.org/join to become an E-Advocate, and receive updates when YOUR voice can make a critical difference.

If passed, *The Huntington's Disease Parity Act* would improve access to Social Security Disability and Medicare benefits for individuals disabled by HD by updating the outdated medical criteria that SSA uses to evaluate individuals with HD, and by waiving the two year waiting period to receive Medicare once an individual is granted Disability. For more information, you can contact Jane Kogan at jkogan@hdsa.org.

SSA Compassionate Allowance

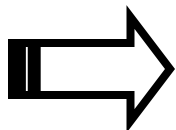
- The Social Security Administration's Compassionate Allowances (CAL) program fast-tracks disability decisions for the most serious conditions. Juvenile Huntington's disease (JHD) became one of the CAL conditions in August 2012. Adult Onset HD became a CAL condition in December 2012.
- Although the Compassionate Allowance designations for HD and JHD will make the disability review process easier, **it does nothing about the 24-month waiting period for Medicare. Nor does it fix SSA's outdated guidelines for Huntington's disease.**
- This is why we still need to advocate for the *Huntington's Disease Parity Act*. The legislation has been reintroduced in the House as H.R.1015. HDSA is working on reintroducing the legislation in the Senate.
- Keep up with HDSA updates by becoming an E-Advocate! Sign up at www.hdsa.org/join

Get Advocacy & Education Updates! Follow Jane Kogan, HDSA Education & Advocacy Manager, on Twitter [@JaneHDSA](https://twitter.com/JaneHDSA)!

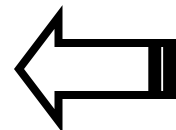
Jane Kogan, LMSW (JKogan@hdsa.org), Manager, Advocacy & Education
Huntington's Disease Society of America, 505 8th Ave, Suite 902, New York, NY 10018
p: (212) 242-1968 extension 226, f: (212) 239-3430

UPCOMING MEETING LOCATION CHANGE FOR STROGER-COOK COUNTY SUPPORT GROUP

Please note: the Chicago HD Support Group that currently takes place at Stroger Hospital will be looking to transfer to Rush Hospital. The group, which will be co-facilitated by Cori Robin and Steve Clingerman, will most likely begin at Rush in June and will be held on one Tuesday evening per month from 7-8:30p. Please stay tuned and we will email more solidified specifics on dates, time and location in the coming weeks. Please call or email Cori Robin, LCSW with any questions.



The Governor of the State of Illinois has declared the
week of May 19-26, 2013 as Huntington's Disease Awareness Week!



Author and Historian Alice Wexler Keynotes HDSA Illinois 2013 Conference

By Daniel Born

More than 170 people gathered at the Northbrook Hilton Hotel on February 9th for the 2013 Huntington's Disease Society of America (HDSA) Illinois state conference. They spent the day participating in breakout sessions and listening to plenary talks on the conference theme of *How Do We Tell the HD Story?* and they shared their stories with one another—over lunch, between sessions, and in the breakout sessions themselves.

Major underwriting for the conference was provided by the Huntington's Disease Society of America through an unrestricted educational grant from Lundbeck. As in the previous two years, individuals who preregistered were able to attend the conference for free.

Author and historian Alice Wexler, a research scholar from UCLA, gave the keynote address. She told the audience, "We have to write the story down to know what the story is." She went on to say, "You might be thinking, don't we have too many stories already? Perhaps—but the main thing is what we do with our stories. They can shape how research will be done." Her talk chronicled the way the Huntington's disease narrative has been changed by those who have experienced it. "Before the 1960s, all the HD stories were told by doctors or researchers." That has changed profoundly in the years since, to the point that HD is now not only the subject of many memoirs, but also material in popular culture including TV programs and contemporary memoir and fiction.

Wexler also pointed out that many HD storytellers since the 1960s have "rebelled against the tragic narrative they've been presented with." That is partly a result of better treatment of the disease, breakthroughs in medical research including discovery of the gene marker and the gene itself, and the hope that further medical interventions will go far toward alleviating the suffering if not addressing the root cause of HD.

Wexler comes from a family of gifted storytellers, researchers, and advocates in the fight against Huntington's. Her father Milton Wexler, a psychoanalyst and Hollywood screenwriter, co-founded the Committee to Combat Huntington's Disease with Marjorie Guthrie in 1967, then founded the Hereditary Disease Foundation a year later. Alice's sister, Nancy Wexler, a professor of neuropsychology at Columbia University, did groundbreaking research in Venezuela that led to the discovery of the HD gene marker in 1983. Alice's books stand out as some of the most important to date that have been written about HD. *Mapping Fate* (1995) reveals the

Wexler family's response to the disease, and *The Woman Who Walked Into the Sea*, which won a 2009 American Medical Association Book Award, is the definitive history of HD in North America.

Attendees lined up to buy signed copies of Wexler's books, and later in the morning listened to Dr. Kathleen Shannon, Director of the HDSA Center of Excellence at Rush University Medical Center, give her annual talk on the state of HD research. Maybe most alarming of all Shannon's remarks was her observation that "86 percent of U.S. trials [for HD treatments] fail to recruit on schedule." Shannon observed that this lack of willing research subjects adds to the cost of drug development, and she encouraged the audience to become more involved in ongoing research.

The panel after lunch, *How Do We Live With HD? Stories from the Front Lines*, drew some of the most enthusiastic comments from the audience. Moderated by chapter social worker and family therapist Cori Robin, the panel included Liz Born, Ann Terry, and Laurie Jacobson Ulrich. All three shared their direct experience with the disease as it has affected their immediate families. One of the crucial points of conversation revolved around the question of how—and when—do families talk with their children about HD.



Author and keynote speaker, Alice Wexler, signs books at the 2013 HDSA Illinois State conference. With her is Laurie Jacobson Ulrich, one of the day's presenters.

Breakout sessions during the day addressed this and other questions. Chapter board members Susie Hodgson

and Tom Barr led sessions on nutrition and advocacy. Janna Dutton, a Chicago attorney, spoke to "Financial and Legal Planning." A panel on the predictive test, "Positive, Negative, and No Testing at All," featured speakers Emily Hodgson, Amy Merkel, and Angie Vestal, moderated by Jean Morack. About fifty people listened to their stories. Stacey Barton led a session on "HD 101: Getting Your Facts Straight"; and Sadie Foster spotlighted the question, "Who Cares for the Caregiver?" During the afternoon, Amy Merkel led a group of 25 people in "Yoga and Balance." Andria Besser spoke to the topic "Family Planning and HD." Cori Robin's breakout session, "How To Tell Your Kids About HD," and Daniel Born's "Keeping a Journal: Writing About HD," rounded out the day's program. As in 2012, activities including an art workshop were available for children ages 6 and up.

Plans for the 2014 HDSA Illinois state convention are already underway. Comments on the 2013 conference and suggestions for next year should be directed to Illinois chapter board member Daniel Born, who chaired this year's event. Contact: dankborn@gmail.com, or (773) 896-4327.

Prana Biotechnology publishes positive results for PBT2 in animal models of HD

By: George Yohrling, PhD, Director of Scientific and Medical Affairs at HDSA
Reprinted with permission from Ohio Valley HDSA Newsletter Winter 2013

Researchers from Prana Biotechnology and UCSF have recently published data on the small molecule, PBT2, in two different animal models of Huntington's disease (Cherny et al). PBT2 is a novel compound that is known to cross the blood-brain barrier, appears safe to humans and has demonstrated neuroprotective effects in various brain disease models. The purported mechanism of action of PBT2 is to act as a chaperone of metals such as iron and zinc. Both iron and zinc are thought to play an important role in the aggregation of proteins, such as huntingtin. PBT2 is thought to sequester these metals away from the mutant huntingtin protein and prevent the formation of toxic, oligomeric (multi-subunit) forms of huntingtin.

In the newly published paper, Cherny et al tested PBT2 in both a worm and mouse model of HD. While PBT2 delayed the paralysis commonly observed in the HD worm, it is interesting to note that PBT2 had no apparent effect on the aggregation of the short polyglutamine-containing protein that is expressed in their worm. This suggests that the worm model used here is not ideal for understanding the impact PBT2 has on the different forms of huntingtin.

More striking results were seen when the researchers administered PBT2 to a commonly used mouse model of HD (R6/2 mouse). The R6/2 mice express just a short fragment (3%) of the total human huntingtin protein. When dosed beginning at just three weeks of age, PBT2 had a significant impact on motor behavior, body weight, brain weight and survival of the HD mouse. They reported that HD mice treated with PBT2 lived 26% longer than the same HD mice treated with a vehicle control.

While these results are certainly encouraging they are not entirely unexpected. Previous work from Nguyen et al in 2005 showed that clioquinol, a compound very similar to PBT2 in terms of chemical structure and mechanism of action, improved survival in the R6/2 mouse by 20% and had a significant effect on huntingtin aggregation.

Based on these results, as well as previous data suggesting PBT2 may positively impact cognition (thinking) in Alzheimer's disease, Prana set out to discover if PBT2 will have similar effects in HD patients. PBT2 is currently being tested in a Phase II clinical study called Reach2HD for patients with early to mid-stage HD in Australia and the United States. The Reach2HD trial is now fully recruited. The HD research community will be anxiously awaiting the results from this pivotal study.

References:

Nguyen T, Hamby A, Massa SM. [Clioquinol down-regulates mutant huntingtin expression in vitro and mitigates pathology in a Huntington's disease mouse model.](#) Proc Natl Acad Sci U S A. 2005 Aug 16; 102(33):11840-5.

Cherny RA, Ayton S, Finkelstein DI, Bush AI, McColl G, Massa SM. PBT2 reduces toxicity in a C. elegans model of polyQ aggregation and extends lifespan, reduces striatal atrophy and improves motor performance in the R6/2 mouse model of Huntington's disease. J Huntington's Disease 2012, 211-219.

REMINDER: We are going Green!

As previously mentioned, we are going GREEN! We will continue to provide a quarterly newsletter, however, we will no longer be printing and mailing that newsletter unless you inform us that you need a printed copy. We estimate that the chapter will save \$6,000 to \$8,000 annually by making this change. These are funds that could be better spent on Family Services, Education and Research.

There are several ways you may continue to view the newsletter. You can receive it by e-mail, view it through a link on our website, or let us know that you require a paper copy which we will mail to you. If you wish to get your e-mail added to our list or continue to receive a paper copy, please email Dave Hodgson at [**spiketdog@softhome.net**](mailto:spiketdog@softhome.net) with 'HD Newsletter' in the subject line. To view it on our website, go to [**HDSA.ORG/IL**](http://HDSA.ORG/IL) and **click on the link**. To continue to receive the newsletter by mail, fill out the form below and mail it to the chapter P.O. Box. Make your decision...it's up to you!



9TH ANNUAL TEAM HOPE - WALK FOR A CURE 5K WALK

SUNDAY, MAY 19, 2013

NEW LOCATION: NAPERVILLE RIVERWALK

(RAIN OR SHINE)

REGISTRATION: 9:00AM ~ WALK BEGINS: 10:00AM

The young person pictured above is balanced on a fence, much like a person at risk for HD balances life on a tightrope. A person at risk for HD has a 50-50 chance of inheriting the defective HD gene and losing his/ her footing on the genetic tightrope of HD.

The Illinois Chapter of HDSA will be hosting its 9th Annual Team Hope Walk on Sunday, May 19, 2013 in a **NEW location!** The Walk will be held along the beautiful Naperville Riverwalk in downtown Naperville, Illinois. Registration is available online at www.hdsa.org/thwil. This year's registration fee will again be \$20 per participant and will include a Walk T-shirt as well as a picnic hotdog lunch. Pre-registered participants will be guaranteed a Walk T-shirt.

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!

This year our goal is to raise \$75,000 to support the mission of HDSA. All 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!

Watch your mail for the Walk brochure as well as www.hdsa.org/il for more information. If unable to register online, the registration form below may be mailed to: **HD Walk, PO Box 6624, Aurora, Illinois 60598** along with the registration fee(s) for each walker. Please use a separate sheet of paper if registering more than one walker. If you have ANY questions, contact Dave Hodgson at 1-815-498-6092.

REGISTRATION FORM

I would like to register _____ walker(s) at \$20.00 each.
TOTAL ENCLOSED: \$ _____

Walker's Name _____
Address _____
City _____ St _____ Zip _____
Phone (home) _____ (work) _____
E-mail _____

If registering more than one walker, please include name(s) and T-shirt size(s) on a separate piece of paper.

T-Shirt Size: S _____ M _____ L _____ XL _____ XXL _____
Each registered walker will receive one T-shirt

I can't walk but would like to donate \$ _____

Please make all checks payable to:
HDSA-Illinois Chapter
Please note in the memo line that it is for **Team Hope-Walk For A Cure**.

Mail registration form to:

HD Walk For A Cure

P.O. Box 6624
Aurora, IL 60598

Dave Hodgson : Phone: 815-498-6092
Website: www.hdsa.org/il



Hot Rods for Huntington's Disease

June 22, 2013 10am to 4pm (gates open at 9:30am for car show)

Volo Auto Museum, 27582 Volo Village Road, Volo, Illinois



Huntington's Disease Society of America
Illinois CHAPTER

HOT RODS FOR Huntington's Disease

ALL-AMERICAN CAR SHOW

June 22, 2013
10am - 4pm
Gate opens for car show registrants @ 9:30am
\$15 pre-register by 5/22
\$20 at the gate

Volo Auto Museum
27582 Volo Village Road
Volo, IL 60073

Prizes & Awards Ceremony

BAGGO TOURNAMENT LIVE MUSIC
SILENT AUCTION 50/50 RAFFLE

Baggo Tournament: \$30 per team pre-registration by 6/1 \$40 per team day of event
Museum Admission fee: \$ adult \$ per child ages entrance into the museum
Admission fee waived for a car show and baggo participants

The Illinois Chapter of the Huntington's Disease Society of America presents a premier event being run by one of our newest board members!! *Hot Rods for Huntington's* consists of a souped-up car show, a tournament featuring the ever increasingly popular sport of Baggo, a silent auction including many valuable items, live music from hot local bands, a very special guest, and much more! While there, be sure to take a tour through the Volo Auto Museum to see some of the most spectacular vintage cars of our time!

You may register online through our website for the Car Show or Baggo Tournament (www.hdsa.org/il), and click on CHAPTER EVENTS and scroll down to HOT RODS FOR HUNTINGTON'S).

To register for the Hot Rods contest, once online click on this link: <https://www.firstgiving.com/hdsa-il/hotrods-for-huntingtons-disease-hot-rod-reg>

To register for the Baggo Tournament, once online click on this link: <https://www.firstgiving.com/hdsa-il/hotrods-for-huntingtons-disease-baggo-registration>

There is a general admission cost of \$13.95 for adults, \$11.95 for seniors and \$8.95 for kids (general admission is waived for car show and Baggo registrants). With this admission you not only take part in our event but will also get to take a tour of the Volo Auto Museum which is rated #2 in the world!

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



Sponsored by
Snap-on
Pre-Register online @ www.hdsa.org/il
for discounted Car Show/Baggo Entry
Questions call Danielle 847-329-3374
Danielle.KarlsonPerrott@gmail.com



Come join us for some family time and fun in the sun. More information available at www.hdsa.org/il. Sponsorship opportunities also available. Contact Danielle Karlson-Perrott for questions: Daniellekarlsonperrott@gmail.com.



JAX 2013

Huntington's Disease Society of America
28TH ANNUAL CONVENTION
Jacksonville, FL June 21-23, 2013



Like us on
Facebook

Visit us on Facebook at:
HDSA ILLINOIS CHAPTER

Up to the minute posts!!!

News from Our Social Worker

CORI ROBIN, LCSW

HDSA Center of Excellence at Rush University Medical Center
Tel: 630-443-9876 or E-mail: crobin@hdsa.org



Illinois Health Matters: Your Source for Healthcare Reform in Illinois

The new health care laws will bring much change both nationally and on a local level. As these changes may be overwhelming or confusing, it is important to obtain up-to-date and correct information for you and your family.

Health and Disability Advocates, in partnership with a collaborative of Illinois health policy and community based organizations, created Illinois Health Matters, which is a “one stop shop” for all things healthcare reform in Illinois.

Illinois Health Matters is the statewide digital hub to raise awareness and provide clear, non-partisan information about how the new health care laws will affect Illinois residents, communities, and small businesses.

Illinois Health Matters can assist families affected by HD as it features informative fact sheets and infographics, expert Questions & Answers, events, social-media outreach, stories of how health care reform impacts vulnerable populations and linkages to local and national preventative health initiatives.

You can even ask the experts your own questions regarding the effect of healthcare reform on people with disabilities or pre-existing conditions.

To access the website, please visit: www.illinoishealthmatters.org

New Medicaid Changes

There are currently 2.7 million adults and children enrolled in Illinois Medicaid and All Kids. Medicaid has and will be going through changes due to it being a fragmented healthcare delivery system, with few linkages among providers. Currently, it can be quite difficult for people with disabilities or those with complex conditions to try to navigate this complicated healthcare system. The current Medicaid program has also been shown to have outdated long-term care services and protocols.

Due to budget issues and the impending Affordable Care Act, Medicaid is undergoing a redesign to its healthcare delivery system. The main goal for this redesign project is to create an integrated delivery system that provides quality care and results in better health outcomes for clients. At the centerpiece of this redesign is care coordination, especially for those with health, behavioral health and social needs. Changes will be implemented gradually by geographic location. Clients will have to choose a managed care entity. A care coordinator from these managed care entities will help the client and family navigate the fragmented system and will work with a multidisciplinary team focused on the client’s holistic needs: health, behavioral health and social needs. It is hoped that this holistic implementation will prevent provider networks from remaining in silos and will instead provide integrated, collaborative and comprehensive care.

For more information and to obtain up to date information on the roll-out of this program in your specific local area, please visit: <http://www2.illinois.gov/hfs/ManagedCare/Pages/IntegratedCareProgramInformation.aspx>

Medicaid Redetermination Project

The Medicaid Redetermination Project is an annual project in which the state determines whether those receiving Medicaid are still eligible for this program. To obtain information about this redetermination project, as well as those documents that may be needed to prove continued eligibility, please visit the Q&A page here: <http://www2.illinois.gov/hfs/SiteCollectionDocuments/EEVClientFAQ.pdf>

As there will be many new changes to our healthcare system in the coming years, please continue to check the above sites as well as the HDSA IL chapter site. Please also feel free to contact Cori Robin, LCSW with questions at 630-443-9876 or CRobin@hdsa.org.

NEW LOCATION!!!

Fox Lake Country Club
7220 State Park Rd.
Fox Lake, Illinois

Date

Sunday, August 4, 2013

Times

Registration: 10:00 a.m.
Tee Times: 11:00 a.m.

Fees

\$100 - Golf Only

\$140 - Golf & Dinner

\$175 - Golf for one;
dinner for two

\$40 - Dinner Only

(Fee includes: 18 holes of golf, golf cart, \$5 certificate toward lunch, dinner (if chosen), and extra dinner for significant other (if chosen).

PRIZES PRESENTED AT DINNER

Shower facilities will be available for our use.

Event Contact

Gus Marchetti
Tel: (847) 356-2880
ajmar45@gmail.com

Visit our Chapter website at
www.hdsa.org/il



 Huntington's Disease
Society of America

Illinois CHAPTER

12th Annual Golf Outing Sunday, August 4, 2013

All proceeds support Huntington's Disease Society of America's efforts to provide help for today, hope for tomorrow for families affected by Huntington's Disease. We hope you will join us this year in making our event a success. Your support will allow us to continue helping HD patients and their families throughout the state. We're counting on you for a record turn-out! Invite your family and friends – sign up now!

COURSE RULES...THERE'S GOTTA BE RULES!!

1. EACH PLAYER IS REQUIRED TO HAVE HIS/HER OWN CLUBS
2. NO SPECTATORS ON COURSE. PAYING CUSTOMERS ONLY
3. PROPER ATTIRE REQUIRED: NO TANK TOPS OR BATHING SUITS
4. FOOTWEAR: SOFT SPIKES OR ATHLETIC SHOES (NO METAL)

Please complete the registration form by July 15th and return it with your check made payable to **HDSA, Illinois Chapter**.

Mail to: **HDSA, Illinois Chapter** - c/o Gus Marchetti,
2021 Woodlane Drive, Lindenhurst, IL 60046

GOLFER 1: NAME _____

Golf Only Golf & Dinner Golf for One; Dinner for Two

ADDRESS: _____

PHONE #: _____ (please include number so we can confirm your registration)

E-MAIL ADDRESS _____

GOLFER 2: NAME _____

Golf Only Golf & Dinner Golf for One; Dinner for Two

ADDRESS: _____

PHONE #: _____ (please include number so we can confirm your registration)

E-MAIL ADDRESS _____

GOLFER 3: NAME _____

Golf Only Golf & Dinner Golf for One; Dinner for Two

ADDRESS: _____

PHONE #: _____ (please include number so we can confirm your registration)

E-MAIL ADDRESS _____

GOLFER 4: NAME _____

Golf Only Golf & Dinner Golf for One; Dinner for Two

ADDRESS: _____

PHONE #: _____ (please include number so we can confirm your registration)

E-MAIL ADDRESS _____

DINNER ONLY: NAME(S) _____

ADDRESS: _____

PHONE #: _____ (please include number so we can confirm your registration)

E-MAIL ADDRESS _____

HOLE-IN-ONE WINS A NEW AUTOMOBILE!!!

Photos taken at these events may be displayed on the HDSA website and/or in HDSA printed material. Individuals may opt out of having their photos taken by contacting an HDSA volunteer at the event.

Dear Business Partner,

We hope you will take a few minutes to read this letter regarding our golf outing to be held in August 2013. We realize that August is a long way off but we are hoping you might put us in your 2013 budget for this event. If you would like to reserve a sponsorship at this time it would be greatly appreciated. If you would like to donate at a future date we will send out a sponsorship form again in June 2013.

We cordially invite you to become a part of HDSA Illinois Chapter's 12th Annual Golf Outing to be held on August 4, 2013 at Fox Lake Country Club in Fox Lake, Illinois. To make this the best golf outing ever we need your help. Perhaps you may own a business or know of a business that would like to help HDSA in some way. We are asking for sponsors to help raise funds for making this the last generation of Huntington's Disease; a fatal neurological disease for which there is no cure. Money raised will be used for research, family services and education vital to HD families. You might ask a friend, your employer or a business that you frequent to help by being a sponsor for our outing. There are many ways to get involved in sponsoring this event:

All course sponsors will receive mention in the event program, on corresponding signage, in our newsletter and on our HDSA Illinois Chapter Website. Please forward your logo in jpg format to: ajmar45@gmail.com

Please indicate which SPONSORSHIP you would like and fill out the business information below:

ACE SPONSOR - \$2,000.00

Includes one hole sponsorship, 8 golfers with dinner, and your company name on the event banner.

EAGLE SPONSOR - \$1,500.00

Includes one hole sponsorship, 6 golfers with dinner, and your company name on the event banner.

BIRDIE SPONSOR - \$1,000.00

Includes one hole sponsorship plus 4 golfers with dinner.

PAR SPONSOR - \$500.00

Includes one hole sponsorship plus 2 golfers with dinner.

HOLE SPONSOR - \$250.00

Your business name, address and telephone number listed in the golf program, our Fall/Winter newsletter and on a sign on the tee area.

Hole Sponsorships are limited; they will be filled on a first-come, first-served basis.

Other Sponsorship Opportunities include donating prize package items and goodie bags, donating event needs such as gift certificates, raffle items, water bottles etc., or donating items for our Sand Trap Auction. Gift contributors will be listed in the program and on the HDSA website.

Yes, I would like to donate a gift for the outing, description _____

Business Name:	
Contact Name & E-Mail address:	
Address:	
City/State/Zip:	
Phone:	
Golfer 1:	Golfer 2:
Golfer 3:	Golfer 4:

Attach a listing for additional golfers.

Please return the completed form and your check to:

HDSA, IL Chapter, c/o Gus Marchetti
2021 Woodlane Drive, Lindenhurst, IL 60046

We hope you will join us on August 4th. Thank you in advance for your participation.

For further information or questions, contact Gus Marchetti at 847-356-2880 or e-mail at ajmar45@gmail.com

Photos taken at these events may be displayed on the HDSA website and/or in HDSA printed material.
Individuals may opt out of having their photos taken by contacting an HDSA volunteer at the event.

The Sweetness Continues

By Marilyn & Barry Kahn, Illinois Chapter Board Members

On Saturday, February 9, 2013, the Huntington's Disease Society of America's Illinois Chapter, held its 6th annual 'Hearts for Huntington's Valentine Dinner Dance' fundraiser at The Legendary Bristol Court, 828 E. Rand Rd., Mt. Prospect, IL.

A successful event only happens because of the generosity, dedication and hard work of many people. We would like to take this opportunity to thank the following:

"LOVE SPONSOR"

Lundbeck, Inc.



"SWEETHEART SPONSORS"

Kathie Ayers & Ted Ross

Liberty Auto Plaza – John Massarelli

Martin Jacobson Jewelers – Marty & Elaine Jacobson

William E. Spencer

HEARTS FOR HUNTINGTON'S COMMITTEE

Jim Carli

Dave Hodgson

Susie Hodgson

Peggy Monson

HEARTS FOR HUNTINGTON'S HELPERS

Eileen Barker

Mary Bos

Joyce Clark

John Cuccinotto

Conny Heggen

Julie Kirkorsky

Maryann Moynihan

Charlotte Mueller

Riley Mueller

Sheri Mueller

Kimberly Peterik

Charlotte Rybarczyk

The 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 once again by donating items to our raffles. Without their help, we would not have realized the success that we did. Please make an effort to frequent these businesses and maybe mention that you appreciate their support of Huntington's Disease!

Ace Hardware – Libertyville

Agio Italian Bistro – Palatine

American Flyers

Arlington Park Race Track

Auction Merchandise Services

Art Berns

Blue Planet Aquarium Services –

Norm Osimani & Jon Wolf

Liz Born

Buffalo Wild Wings – Vernon Hills

Chicago Bears

Chicago Cubs

Chicago White Sox

Cooper's Hawk Restaurant

Costco Wholesale – Mettawa

Cubby Bear North

John Cuccinotto

Donkey Inn Restaurant

Elgin Public House

Hilton Northbrook Chicago

Susie & Dave Hodgson

Jerry's Hockey Warehouse

Images Plus – Sheri Mueller

Corinne Kukulski

Rita & Don Larson



Legendary Bristol Court

Lynfred Winery – Wheeling

Main Street Smokehouse

Marianos – Vernon Hills

Jeff Markarian

Metropolis Performing Arts Centre

Peggy Monson

Dr. Richard Morimoto

Partylite – Charlotte Rybarczyk

Second Nature Salon – Lake Zurich

Colleen Shannon – www.pickypickyme.com

Dr. Kathleen Shannon

Slice of Chicago – Palatine

Stella & Dot – Toni Guziec

Sunset Foods – Libertyville

Sunset Foods – Long Grove

Superdawg Drive-In

Target – Vernon Hills

Tasting DeVine Cellars – Naperville

The Theatre of Western Springs

The Theatre School & DePaul's Merle Reskin Theatre – Chicago

The Twisted Cow – Michelle & Pat Gallagher

Viccinos Pizza – Libertyville

A special thank you goes to Marty Jacobson, Martin Jacobson Jewelers, who donated the beautiful diamond pendant won by Alecia Bernau!

It was once again a very special evening of music by Kenny Gutstadt (Kenny G), terrific food, and socializing with 'old' and 'new' acquaintances during the social hour. After dinner there was a program emceed by Barry Kahn, with a welcome from our Love Sponsor, Wali Bandawal, representing Lundbeck, Inc. Dr. Kathleen Shannon, Director of the Center of Excellence at Rush University Medical Center, gave a brief update on the Center. The Program continued with Dave Hodgson & Dan Born, both members of our Board, giving personal views of their lives with Huntington's disease in their families. Everyone got a picture of why we are working so hard to raise funds for this horrific disease!

The evening turned to fun and we managed to get in dancing and continued to bid on our favorite auction & raffle items. New this year were the Money Tree won by Lisa Froman & a Wishing Well won by Judy DeAngelo! Thank you to all who participated!

We turned up the volume on our Candy Bar Raffle and gave everyone more chances to win prizes. It was so successful that we sold all of the 150 candy bars so next year, be ready for more candy bars and more prizes!!

The evening was a huge success. Everyone in attendance had a wonderful fun-filled evening 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.

Please plan to attend next year and bring your family and friends with you!!

Memorials and Tributes

In Memory of Dina Kotrolos from Bertha Phillipps
In Memory of Josephine Kaleta from Terry & Paulette Kaleta
In Memory of Sharon Lee Spaid from Jeannette Spaid, Family and Friends
In Memory of Harry Rueckel from Wilma Caldwell & Bill Braucher
In Memory of Nina Modean Taylor from Richard S. Weaver
In Memory of James Contis from Gus Phillips
In Memory of Terry Bruno from Craig & Teresa Srajer
In Honor of Craig Srajer on his Birthday from Catherine Bruno Evers

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: \$ _____

CHAPTER OFFICERS

PRESIDENT – Charlotte Rybarczyk
 847-259-3593 ~ flameboyant1@comcast.net

VICE PRESIDENT – John Cuccinotto
 630-873-0052 ~ hdhoops@yahoo.com

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

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

ASST. TREASURER – Peggy Monson
 847-392-3450 ~ pabmonson@sbcglobal.net

BOARD MEMBERS

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

Daniel Born, Ph.D. - dankborn@gmail.com
 773-896-4327

Dave Hodgson - spiketdog@softhome.net
 815-498-6092

Susan Hodgson - sue_angels@softhome.net
 815-498-6092

Barry Kahn – barrykahn1@comcast.net
 224-433-6319

Marilyn Kahn – marilynkahn@comcast.net
 224-433-6319

Danielle Karlson-Perrott – dlk465@gmail.com
 847-529-3374

Augustine "Gus" Marchetti – ajmar45@gmail.com
 847-356-2880

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

COMMITTEE MEMBER

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

Hopes & Dreams
 is the official publication of the
 Illinois Chapter of Huntington's Disease Society of America, Inc.,
 P.O. Box 1883, Arlington Heights, IL 60006-1883
 (630) 443-9876 ~ www.hdsa.org/il

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



SUPPORT GROUP MEETINGS

Date/Time	Additional Information	Contact Information
CENTRAL ILLINOIS		
2 nd Sunday of even months <u>TIME:</u> 2:00 to 4:00pm <u>LOCATION:</u> St. Joseph Medical Center, Bus. Conf. Center – Room 2, 2200 E. Washington Street, Bloomington, IL	2013 Meetings: 02/10, 04/14, 06/09, 08/11, 10/13, 12/08	Dave or Susie Hodgson (630) 386-3928 spiketdog@softhome.net
GENEVA		
Specific Sundays of odd numbered months (see dates in next column) <u>TIME:</u> 2:00 to 3:30pm <u>LOCATION:</u> Delnor-Community Hospital, Main Entrance, 300 S. Randall Road, Conference Room #4 in the 351 Medical Office Bldg., Geneva, IL Whether you have HD, are at risk, are a caregiver or a friend, or just someone who wants to know more about HD, you are welcome.	Conference room #4 is in the 351 Medical Office Bldg. which can be reached by entering through the main entrance to the hospital. Please ask reception for directions. 2013 Meetings: 01/27, 03/24, 05/05, 07/28, 09/22, 11/10	Ann Liszka (630) 761-8596 Weichann56@hotmail.com Joe Wiedemann (847) 505-3933 joseph.wiedemann@gmail.com
LAKE COUNTY		
2 nd Monday of every month <u>TIME:</u> 7:00pm <u>LOCATION:</u> Advocate Condell Medical Center, 801 Milwaukee Ave., West Tower, Libertyville	Call for additional information and directions.	Marilyn and Barry Kahn (847) 975-2403
LAKE COUNTY 'YOUTH'		
2 nd Monday of every month <u>TIME:</u> 7:00pm <u>LOCATION:</u> Advocate Condell Medical Center, 801 Milwaukee Ave., West Tower, Libertyville	Call for additional information and directions.	Marilyn and Barry Kahn (847) 975-2403 Charlotte Rybarczyk (847) 259-3593
QUINCY		
2 nd Sunday of even months <u>TIME:</u> 2:00 to 4:00pm <u>LOCATION:</u> Blessing Hospital, 1400 Broadway, Conference Room G	LOOKING FOR INTERESTED GROUP MEMBERS!	Call Cori Robin at (312-942-6087) so we can assess whether we have enough people to form mtg.
ROCKFORD		
2 nd Sunday of every month <u>TIME:</u> 2:00pm <u>LOCATION:</u> OSF St. Anthony Medical Center, 5666 E. State St., St. Anthony Room, Rockford, IL 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. 2013 Meetings: 01/13, 02/10, 03/10, 04/14, 05/12, 06/09, 07/14, 08/11, 09/08, 10/13, 11/10, 12/08	Ted Ross (815) 282-0600 tedrosse@comcast.net
SOUTH SUBURBAN		
2 nd Tuesday of odd months <u>TIME:</u> 7:00pm <u>LOCATION:</u> Thomas Cellini Huntington's Foundation, 3019 East End Avenue, South Chicago Heights	2013 Meetings: 01/08, 03/12, 05/14, 07/09, 09/10, 11/12	Maryann Moynihan (708) 955-3080 shamrock1959@att.net TCHF Office (877) 687-8243
STROGER-COOK COUNTY		
2 nd Thursday of every month <u>TIME:</u> 12:00 to 1:20pm <u>LOCATION:</u> Stroger Hospital - Basement by cafeteria - LL661 1835 W. Harrison St., Chicago, IL	Group includes Medical Professionals (i.e., Neurologists, Psychologists, Social Workers, Genetic Counselors) as well as members of the Board of the Illinois Chapter.	Stephen R. Clingerman, Ph.D. (312) 864-6083 Call for 2012 meeting dates/information.
MUNSTER, INDIANA		
2 nd Tuesday of even months <u>TIME:</u> 7:00pm <u>LOCATION:</u> Southside Christian Church, 1000 Broadmoor Ave., Munster, IN	2013 Meetings: 02/12, 04/09, 06/11, 08/13, 10/08, 12/10	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:

Cori Robin, LCSW, at the HDSA Center of Excellence at Rush University Medical Center
Tel: 312-942-6087 or E-mail: cori_b_robin@rush.edu (Office hours are Fridays from 9:00am – 3:00pm)

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

Mark Your Calendar

May 19, 2013	HDSA Illinois Chapter TEAM HOPE Walk
June 22, 2013	HDSA Illinois Chapter Hot Rods for Huntington's
August 4, 2013	HDSA Illinois Chapter Annual Golf Outing
Fall 2013	HDSA Illinois Chapter Hoop-a-Thon

www.hdsa.org/il



P.O. BOX 1883, Arlington Heights, IL 60006-1883
(630) 443-9876



SPRING 2013