



Hopes & Dreams

Huntington's Disease Society of America - Illinois Chapter Quarterly Newsletter
 HDSA/Illinois Chapter, P.O. Box 8383, Rolling Meadows, IL 60008 ~ www.hdsa-il.org

Volume 3
 SUMMER 2009

Illinois celebration of hope dinner 2009



Friday, August 28, 2009
Renaissance Chicago Hotel
One West Wacker Drive
Chicago, IL
Grand Ballroom
6:00 p.m.

Cocktail/Business Attire

Special Performance by



Artistic Director, Frank Chaves



- ❖ **Awards of Excellence presented to outstanding leaders in Illinois and the HD community:**
 - Alexi Giannoulis, Illinois State Treasurer
 - Richard L. Rodriguez, President, CTA
 - Mary B. Richardson-Lowry, Partner, Mayer Brown LLP
 - Linda Mastandrea, Attorney; Director, Paralympic Sport & Accessibility at Chicago 2016; Gold Medal winner at Paralympic Games and World Championships
 - Lundbeck, Inc.
 - The Marchetti/Rybarczyk Family
- ❖ **Seated dinner, cocktail reception, and VIP reception with honorees, HDSA Board of Directors, special guests, members of the press**
- ❖ **Silent and live auctions**
- ❖ **Updates on National Huntington's Disease Society and progress being made at the Illinois HDSA Center of Excellence at Rush University Medical Center**
- ❖ **Live music, entertainment and more!**

TICKET ORDER FORM on Page 3

Please contact Blanca McCarthy for more information.

T: 312.265.5840 E: bmccarthy@hdsa.org

Proceeds from this event support the HDSA Center of Excellence at Rush University Medical Center. To make an online donation, visit www.firstgiving.com/cohil.

- Sponsorship packages available
- Program book ads available

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President's Message



Dear Friends,

It is hard to believe that summer is here, although the weather sure has not seemed that way. I hope that everyone is enjoying a good summer and having time to spend with family and friends, making special memories that will last a lifetime.

It has already been a very eventful spring for the Illinois Chapter. We had a great turnout for the **4th Annual Hoop A Thon!** Over \$25,000 was raised this year!!! Kudos to John Cuccinotto and his committee for a job well done. The "KID ZONE" was a terrific idea and it appeared that it was very well received by all that attended. If you were not able to be a part of this year's Hoops, be sure to make plans to join us next year! The **5th Annual Walk For a Cure** saw its biggest turnout ever, over 425 walkers, raising over \$52,000. A very special thank you to HDSA's new CEO, Louise Vetter, for joining us. I hope that many of you were able to meet Louise and speak with her. She is a dynamic young woman and I foresee big things to come for all of us in the HD family under her leadership.

Whew....and that is just for starters folks. We take pride in having a little something for everyone, hoping to meet the needs of all of our families with HD. If "hoops" or "walking" is not your thing...I hope that you get a chance to check out the first **Roller Derby** event for HD in Illinois. The Chicago Outfit Syndicate will take on the Pikes Peak Slamazons on June 27, 2009 at the Windy City Fieldhouse in Chicago. 20% of the gate will be donated to the HDSA Illinois Chapter. Thank you, Blanca McCarthy, for arranging this event. Perhaps none of these events are your "cup of tea"? Then how about a little golf?? The **8th Annual Golf Outing** will be held August 2, 2009 at the Antioch Golf Course. You can contact board members Gus Marchetti or Charlotte Rybarczyk for more information. For those with young people age 10-30, you might want to consider the **Illinois NYA Weekend Retreat** being held August 21-23, 2009. More information on this event can be found elsewhere in this newsletter or call Dave or Susie Hodgson for more information.

Please don't forget to mark your calendars for the **Celebration of Hope Dinner** on August 28, 2009. We need everyone's support for this very special event. Remember that it directly benefits the Center of Excellence at Rush University.

Just a few short weeks ago was the **National HDSA Convention** in Phoenix, Arizona. What a wonderful experience. There were many excellent workshops and great speakers. It was reported that the turnout for this year's convention was the largest in several years. The National Convention next year will be held in Raleigh, North Carolina.

We have talked before about the HDSA **National Youth Alliance (NYA)**. This is a group for young people living with HD. When they started in Orlando, Florida at the 2000 National convention there were 4 young people with a dream, a dream of coming to a National Convention and there actually being sessions and workshops that dealt with their needs as young people growing up in HD families, at risk for or having already tested positive for HD. This year, with money they raised for their scholarship fund, the NYA sent 38 young people to the convention. This year was the second year that there was a complete day built around and geared towards the needs of our young people, the future leaders of our organization. There were over 100 young people who attended the National Convention this year.

HDSA is encouraging all chapters and affiliates to reach out to our young people and create NYA groups within their organizations. We do not want to see anyone left behind! It is the dream and HOPE of the NYA to be "THE LAST GENERATION OF HD". Some of our NYA members have grown up to become Chapter Presidents and some are members of Chapter Boards. We need to have the programs in place to meet the needs of our young people...they are our future. The Illinois Chapter is once again reaching out and attempting to form the Illinois Chapter of the NYA. Susie and Dave Hodgson and Diane Ray will be leading this group. Susie has been an adult advisor to the National NYA since 2001, Dave has been an advisor for the last 5 years and this is Diane's second year. For more information please contact any of them.

As you can see the Illinois Chapter is very active and has events for almost every family member. So as I look ahead I continue to believe that this is the year for great things and I believe that working together we will achieve all that we hope to accomplish. I look forward to seeing many of you at upcoming events. Information about all of our upcoming events can be found in this newsletter or you can go to our Chapter website www.hdsa-il.org. Until next time...

Susie Hodgson

HDSA Illinois Celebration of Hope Ticket Order Form

Contact Information

Name: _____ Phone Number: _____
 Email Address: _____ Organization: _____
 Address: _____ City, State, Zip: _____

Tickets

_____	Individual Dinner Tickets	\$175
_____	VIP Tickets (include VIP Reception)	\$300
_____	Corporate Table for 10 (includes VIP Reception)	\$3,500

Please seat me with: _____

Donation

I cannot attend but would like to make a donation of \$ _____

(You can also make a donation online at www.firstgiving.org/cohil)

TOTAL: _____

_____ Check Enclosed (Make checks payable to HDSA)

_____ Charge to Credit Card (circle): VISA MasterCard AmEx Discover

Card #: _____ Exp. Date: _____

CCV # (3-digit code, back of card) _____

Printed Name of Cardholder: _____

Signature of Cardholder: _____

Please mail this form with payment to the HDSA Illinois office address below.

Event Contact Information

HDSA Illinois Office, 14 N. Peoria Street, Unit 4E, Chicago, IL 60607

Phone: (312) 265-5840 Fax: (312) 733-0056 Email: bmccarthy@hdsa.org www.hdsa-il.org



The Honorable Richard M. Daley, Mayor of Chicago, is Honorary Chairperson of the 2009 Celebration of Hope Dinner. Mayor Daley has earned a national reputation for his innovative, community-based programs to address education, public safety, neighborhood development and other challenges facing American cities.



RHES AND THE HD PROTEIN: ANOTHER PATHOLOGICAL INTERACTION

- Marsha L. Miller, Ph.D., June 12, 2009

Researchers at Johns Hopkins have discovered that a protein called Rhes binds to the HD protein and causes toxicity. Rhes is a protein found mostly in the striatum where brain damage is most extensive in Huntington's disease. It plays an important role in dopamine signaling in the medium spiny neurons; these are the neurons most affected by the disease.

The research team lead by Dr. Solomon Snyder looked at the effect of over and under expressing Rhes in various cell models of the disease. In a mouse striatal cell line, survival time was the same for wild type (normal) or HD (knock in) cells as long as Rhes was absent. When Rhes was over-expressed, survival time decreased by 60% in the HD cell but not the normal one.

The mechanism by which this occurs is sumoylation. SUMO is a Small Ubiquitin-like Modifying protein. The SUMO protein is attached or detached to another protein as part of a post-translational process which modifies the protein's function.

Sumoylation is known to contribute to HD pathology. In 2004, Dr. Joan Steffan and colleagues found that sumoylation decreases aggregation of the HD protein (the soluble HD protein is more toxic than the aggregates), masks a signal for the HD protein to stay in the cytoplasm, and promotes the dysregulation of gene transcription in the nucleus of the cell. Dr. Steffan and her team suggest that disrupting the sumoylation of the HD protein could result in a significant treatment and notes that "The E3 ligase specific for attachment of SUMO-1 to Htt may present a particularly attractive therapeutic target" (p. 103).

"The binding of the Rhes protein to the HD protein and the subsequent induction of sumoylation may explain why the damage is greatest in the striatum in the disease."

The John Hopkins researchers found that Rhes induces sumoylation of the HD protein and that over-expression of Rhes increases sumoylation. Sumoylation occurs at specific lysines on the protein. When those lysines are mutated so that sumoylation can't take place, aggregates continue to be formed and cytotoxicity is reversed. Using RNA interference to reduce the expression of the SUMO1 gene produced the same results while over-expression of the gene increased disaggregation and decreased survival time.

Dr. Snyder and his team plan further research to determine the effect of removing Rhes from the HD mice.

The binding of the Rhes protein to the HD protein and the subsequent induction of sumoylation may explain why the damage is greatest in the striatum in the disease. Significant damage also occurs in the cortex but the authors note that Rhes is also expressed in the cortex although to a lesser degree. Rhes is not the only source of pathology however; there is no area of the brain that is unaffected by Huntington's disease. Still, preventing the sumoylation, the HD protein could be a significant treatment for the disease and blocking the binding of Rhes and the HD protein offers another target to do that.

References:

Francesco Errico, Emanuela Santini, Sara Migliarini, Anders Borgkvist, Diego Centonze, Valentina Nasti, Maolo Carta, Valentina De Chiara, Chiara Prosperetti, Daniela Spanp, Denis Herve, Massimo Pasqualetti, Roberto DiLauro, Gilberto Fisone, and Alessandro Usiello. "The GTP-binding protein Rhes modulates dopamine signaling in striatal medium spiny neurons." *Molecular and Cellular Neurosciences* 2008 Feb;37(2):335-45.

Joan S. Stefan, Namita Agrawal, Judit Pallos, Erica Rockabrand, Lloyd C. Trotman, Natalia Slepko, Katalin Illes, Tamas Lukacsovich, Ya-Zhen Zhu, Elena Cattaneo, Pier Paolo Pandolfi, Leslie Michaels Thompson, and J. Lawrence Marsh. "SUMO modification of huntingtin and Huntington's Disease pathology." *Science* 2004 Apr 2;304(5667):100-4.

Srinivas Subramaniam, Katherine M. Sixt, Roxanne Barrow, and Solomon H. Snyder. "Rhes, a striatal specific protein, mediates mutant-huntingtin cytotoxicity." *Science* 2009 Jun 5;324(5932):1327-30.

MEDIVATION TO BEGIN A PHASE III TRIAL OF DIMEBON

- Marsha L. Miller, Ph.D., June 3, 2009

Medivation, in collaboration with Pfizer, is sponsoring a randomized, double-Blind, placebo-controlled, phase III trial of Dimebon in HD patients with mild to moderate Huntington's Disease. Recruitment will begin this year.

Dimebon was developed and sold as an antihistamine in Russia two decades ago. Newer antihistamines have replaced it but Russian scientists discovered that the drug has neurologic properties and identified it as a potential treatment for Alzheimer's Disease (AD). Medivation licensed the drug and also began researching its potential for Alzheimer's disease; a Phase III trial for AD patients is ongoing.

Medivation also decided to look at its potential for Huntington's Disease since both diseases involve progressive neurodegeneration and have various pathologies in common such as abnormal protein accumulation and abnormal mitochondrial function. The results of a Phase II study in HD patients completed in 2008 encouraged Medivation to conduct the Phase III study. Dimebon was found to be safe and well-tolerated in Huntington's patients and cognition improved in the treatment group compared to the placebo group as measured by the Mini-Mental States Examination (MMSE).

The primary measure of effectiveness in the Phase III trial will be the results of the MMSE. The researchers will

also look at the cognitive subscales of the United Huntington's Rating Scales although they may not change very much since the Scale is more sensitive to decline than improvement. A battery of cognitive tests will be administered at some of the sites to further explore what parts of cognition are improving. Researchers will look at overall functioning as well and of course safety will be monitored.

Approximately 50 research centers across North America, Europe, and Australia, will enroll approximately 350 individuals for a six month trial. The Huntington Study Group will be the repository for all the data and provide the sites in North America. EHDN is going to select the sites in Europe. Dr. Karl Kieburtz is the principal investigator (PI) and Dr. Bernhard Landwehrmeyer is the co-PI. There are also sites in Australia which will work directly with Medivation.

"This trial is exciting because it's an international effort," said Dr. Kieburtz. "This is the first time that we have had global collaboration on a clinical trial for Huntington's Disease."

Prospective participants should keep checking at the [Huntington Study Group website](#) where site locations and contact information will be posted as sites are ready for recruitment.

Full House in Phoenix – National Convention

The 2009 HDSA National Convention drew over 750 family members, researchers, clinicians and other interested parties to Phoenix. The opening ceremonies, Focus on Family Care Forum and the Research Forum drew capacity crowds, as did seven tracks of workshops. Coming soon to the National HDSA website will be presentations from the Convention workshops, visit www.hdsa.org/convworkshops.



Opening Ceremony



Walk-a-Thon Participants



HDSA CEO, Louise Vetter

Registration/Information: www.hdsagolf.org

Antioch Golf Course
Route 59 and
Grass Lake Road
Antioch, Illinois

Date

Sunday, August 2, 2009

Times

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

Fees

\$90 - Golf Only

\$120 - Golf & Dinner

\$150 - Golf for one;
dinner for two
**(fee includes: 18 holes of golf,
golf cart, \$5 certificate toward
lunch, dinner (if chosen),
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
augustinemarchetti@sbcglobal.net



8th Annual HDSA Illinois Golf Outing



All event proceeds will benefit the Huntington's Disease Society of America's Illinois Chapter in its effort to raise funds for research, family services and education to help families in Illinois afflicted with the devastating illness that is 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 and return it with your check made payable to **HDSA, Illinois Chapter**. Mail to: **HDSA, Illinois Chapter - P.O. Box 8383, Rolling Meadows, IL 60008**

GOLFER 1: NAME _____
Golf Only Golf & Dinner Golf for One; Dinner for Two
ADDRESS: _____
PHONE #: _____ (please include number so we can confirm your registration)

GOLFER 2: NAME _____
Golf Only Golf & Dinner Golf for One; Dinner for Two
ADDRESS: _____
PHONE #: _____ (please include number so we can confirm your registration)

GOLFER 3: NAME _____
Golf Only Golf & Dinner Golf for One; Dinner for Two
ADDRESS: _____
PHONE #: _____ (please include number so we can confirm your registration)

GOLFER 4: NAME _____
Golf Only Golf & Dinner Golf for One; Dinner for Two
ADDRESS: _____
PHONE #: _____ (please include number so we can confirm your registration)

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

HELP NEEDED FOR GOLF OUTING... SPONSORSHIP OPPORTUNITIES

The 8th Annual Golf Outing will be held on August 2, 2009 at Antioch Golf Club in Antioch, Illinois. We hope to make this the best golf outing we have ever had. In order to do this we need your help. Perhaps you may own a business or know of a business that would like to help HDSA in some way. Well here's your chance. We are asking for sponsors to help raise funds for making this the last generation of Huntington's disease. You might ask a friend, your employer or a business that you frequent to help by being a sponsor for our outing. We are also hoping to have an Auction at the dinner after the outing so gifts for the auction would also be appreciated.

Below are ways that anyone can help:

SUPER HOLE SPONSOR: \$400.00 Donation - Your business name, address and telephone number will be listed in the golf program, in our Fall newsletter and on a sign on the tee area. This also includes 18 holes of golf for two persons and dinner for two persons.

HOLE SPONSOR: \$250.00 Donation – Your business name, address and telephone number will be listed in the golf program, in our Fall newsletter and on a sign on the tee area.

SPONSOR: \$150.00 Donation - Your business name, address and telephone number will be listed in the golf program and in our Fall newsletter.

Of course, donations of any amount are greatly appreciated and we hope we can attract a lot more golfers this year.

If you know of someone that may help by being a sponsor, please ask. If we don't ask we will not receive. If you have any questions, please email Gus Marchetti at augustinemarchetti@sbcglobal.net.



SUPER HOLE SPONSOR: BUSINESS NAME, ADDRESS & TELEPHONE NUMBER

If you choose the Super Hole Sponsorship, please include the name of your guest.

GUEST _____

HOLE SPONSOR: BUSINESS NAME, ADDRESS & TELEPHONE NUMBER

SPONSOR: BUSINESS NAME, ADDRESS & TELEPHONE NUMBER

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

Please return the completed form and your check to:

HDSA, IL Chapter
P.O. Box 8383, Rolling Meadows, IL 60008

or

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

The Golfer Registration Form can be found in this newsletter. We hope you will join us on August 2nd. Thank you in advance for your participation. For further information or questions, contact Gus Marchetti at 847-838-7027 or 847-356-2880.

IL-NYA WEEKEND RETREAT AUGUST 21 – 23, 2009

"Communing with Nature Living Positively With HD"

LAKE LADONNA CAMPGROUND, 1302 Harmony Road, Oregon, Illinois



The IL-NYA Weekend "Communing with Nature and Living Positively with HD" retreat is for all NYA members, in the Tri-State area of Illinois, Wisconsin and Indiana. If you live outside the Tri-State area and would like to join us we would love to have you! Not an NYA member but would like to know more....come join us and see what

the NYA is all about. This will be a fun filled weekend including camping, swimming, beach volleyball and sharing sessions at our nightly camp fire.

Every weekend at Lake LaDonna has a theme and the theme for the weekend that we will be there is "LUAU BEACH PARTY" On Saturday night there will be a bonfire on the beach, tiki lights lining the shore, appetizers will be served and music will be played by their DJ for dancing under the stars.

The cost for the weekend retreat is \$30.00 per person. This includes the campground fee for 2 nights camping and meals. This cost includes the camping fee for each person for the weekend and entitles each camper to swimming, bathing facilities (bathrooms are handicap equipped), and the weekend activities.

Each camper should bring bedding; if you want an air mattress to sleep on you MUST bring it, and if you have your own tent, please bring it. We do

SAVE THE DATE

**2010 HDSA Illinois State
Conference**

Saturday, March 6, 2010
Hilton Chicago Northbrook

Hopes & Dreams

is the official publication of the Illinois Chapter of Huntington's Disease Society of America, Inc., P.O. Box 8383, Rolling Meadows, IL 60008 (630) 443-9876

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.

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shamrock1959@att.net



JOIN TEAM RUN FOR HDSA ON SEPTEMBER 13, 2009

Join Team Run for HDSA at the 13th Annual Chicago Half Marathon and 5K on **Sunday, September 13, 2009** and change the lives of nearly 10,000 people in Illinois who are either at risk or suffer from Huntington's Disease (HD). Through pledges and donations, Team Run for HDSA will raise funds to support medical, research programs and family services offered by the Huntington's Disease Society of America in Illinois for persons who suffer from HD and their families.

How it works: Sign up to run the Chicago Half Marathon or 5K at www.chicagohalfmarathon.com and enter the HDSA Team Run for HDSA **code: HDSOA09**. Team members will receive a race entry discount. Once you're registered, you will receive an online confirmation from The Chicago Half Marathon. That's it – you're an official member of Team Run for HDSA!

Once you're a member of Team Run for HDSA, please visit the Team Run for HDSA website, at www.teamrunforhdsa.com, where you'll find all the information you need to train for this exciting run, fundraise, and learn about Huntington's disease and why this fundraiser is so important. Team Run for HDSA members will receive a race entry discount, a team t-shirt, online training plans, nutrition guidance, invitation to running groups, fundraising tips, free tickets to our after-party, and more! Please check our website often and pass the link on to family, friends and co-workers. To create your own team member pledge site through FirstGiving, please call our office.

You can make a donation to Team Run for HDSA online or by mail. You can give electronically by visiting www.firstgiving.com/teamrunforhdsa. Make a donation by check or money order by completing the Pledge & Donation Form which can be found on the Illinois Chapter website (www.hdsa-il.org).

You can join our team by volunteering. We're looking for enthusiastic people to help work at the Team Run for HDSA tent, others to help with the after-party, and a few to help distribute water and pass out flyers about HD and HDSA. Please call our office if you'd like to sign up to be a volunteer.

For more information on Team Run for HDSA, please contact the HDSA Illinois office, (312) 265-5840 or by email, bmccarthy@hdsa.org.

HDSA Illinois
14 N. Peoria Street, Suite 4E, Chicago, IL 60607
www.teamrunforhdsa.com
www.firstgiving.com/teamrunforhdsa

The Cure Starts Here. The Caring Never Stops.

IMPROVE BRAIN FUNCTION THROUGH YOUR SENSES

Enhancing awareness of your senses positively impacts the brain – some consider the sense as the “windows to the brain”. Here are some suggestions:

- **TOUCH:** Get a foot rub, use acupressure shoe insoles, rub your hands together, scratch your scalp, or walk barefoot.
- **SMELL:** Try aromatherapy candles, oils or lotions. Try lavender for relaxation and rosemary for memory.
- **TASTE:** Anticipate and savor tastes. Notice smell and color before you take a bite. Compare tastes.
- **SOUND:** Music soothes and stimulates the brain. You respond physically to music. Notice different music, sounds and voices.
- **SIGHT:** Look at details in art, fashion or things at home.

From “A Better Brain at Any Age”

4TH ANNUAL HOOP-A-THON RECAP

by The Cuccinotto Family

On behalf of the entire Cuccinotto family we are so proud to report that we have had our most successful Hoop-a-Thon to date. We raised over \$28,000 with the help of a tremendous committee and all nine (9) Cuccinotto Siblings traveled in from all over the country. The event went on all day and all night! We had two gyms with fun for everyone. Make sure you make this an event you attend next year!



We are so blessed to have so many terrific supporters out there who really gave from the heart!. Ed Harker has reached a complete new level in the art of free throw shooting with 95 baskets made in just five minutes. In addition to his shooting skills he also has now raised \$5,000 for HDSA in the last 4 years. John Cuccinotto reached a new season high in fundraising as he hit the \$7,000 mark in dollars collected this year.



We are so excited to know that we are making a difference with money and bringing friends and families together to provide love and support. We also have really grown the awareness with John Cuccinotto's Facebook page as 200 people have signed on to join the cause in the fight against HD! We also added at least 50 people to this year's event who were there for the first time due to my whole family coming to town.

The total is at \$75,000 in four years. We are going to make the \$100,000 mark in total at next year's event, stay tuned for more info at HDHOOPS.ORG

Thank you to everyone for all your efforts and to all those who are supporting HD!

5th Annual TEAM HOPE Walk for a Cure...HUGE SUCCESS!

by Dave Hodgson

The 5th Annual TEAM HOPE - Walk For A Cure was a huge success! Over 425 walkers turned out on a beautiful Sunday in May, as the Illinois Chapter again set records. Registration began at 9 A.M. and the Walk stepped off promptly at 10 A.M. This year, new HDSA CEO Louise Vetter joined us as we raised over \$53,000 for research, family care and education. We would like to thank all of our sponsors, especially Belgio's Catering, who once again provided lunch for all the walkers. Other sponsors on hand to join us included members of the Wiedemann-Goggin family, Dr. Kathleen Shannon and family, and Rick Law of Law ElderLaw. This year's top fund raisers were Team Stecyk, Kimberly Graff, Jan Skewes, Laura Roberts, and Debbie Sweitzer. Over the past 5 years, the Illinois Chapter of HDSA has raised over \$215,000. **Keep this date open for next year's 6th Annual TEAM HOPE - Walk For A Cure: May 16, 2010!**



COPING WITH THE HOSPITALIZATION OF AN HD FAMILY MEMBER

("Rush Manual for Caregivers")

Sometimes a serious illness requires caregivers to take someone with HD to the hospital or emergency room. This can be an extremely stressful time.

Many hospital employees do not understand HD. When your loved one cannot speak clearly, they may assume he doesn't understand. Your loved one's acute illness may also temporarily increase problems with memory, thinking, judgment, language and behavior. Also, the confusion of a strange place and unfamiliar people may result in agitation, which can interfere with diagnosis and treatment. Medications might be prescribed to control behavior and these can further impair thinking and behavior.

Know to expect and prepare for these difficulties. Realize your family member should return to his previous level of functioning after the illness. Try to take turns with other family members so you can stay with your loved one during his hospitalization. You can be his voice and explain HD to the staff. Your loved one with HD needs you. You are the expert!

FALL PREVENTION: HOW TO STAY ON YOUR FEET

(Info from 2008 HDSA Convention)

What might cause falls?

- Weak hip, knee and ankle muscles because of inactivity
- Poor balance, coordination and speed
- Side effects of medication (such as dizziness and drowsiness)
- Fatigue
- Perceptual impairments (decreased vision and scanning)

How can you prevent falls?

- Exercise
- Monitor medications
- Preserve vision. Wear glasses or increase lighting.
- Rest muscles. Take frequent breaks.

Home safety tips:

- Clean up clutter
- Limit furniture and obstacles
- Don't use throw rugs
- Limit stair climbing
- Turn on enough lights

Bathroom safety tips:

- Use a shower seat
- Use grab bars
- Use a non-slip mat

Other safety tips:

- Rest between activities
- Set priorities
- Break down tasks into steps

FUNDRAISING

IT'S TRUE...FUNDRAISING IS NOT ALWAYS EASY!

We're all busy, time is hard to find, money is tight, you're not very organized, you don't like talking to strangers, your family and friends get tired of you asking for their help. These are all things we think when we hear the word **fundraising**. Dispel those myths! Here are some *easy* ways to help raise the funds that so dearly help HD families, research and education!

- Donate a portion of your profits from your small business
- Donate money from a garage sale, bake sale, etc.
- Have a car wash or a dog wash...just need a hose, some soap and a sign! (and kids can help too!)

Remember, you don't always have to think BIG! Every little bit counts.
Donations can be sent directly to the Chapter P.O. box in Rolling Meadows, Illinois.

Memorial and Tribute Donations

Complete the form below and send along with your contribution to:

HDSA – Illinois Chapter
"Memorial/Tribute"
P.O. Box 8383, Rolling Meadows, IL 60008

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

My Name _____

Address _____

City, State, Zip _____

Amount of Contribution: \$ _____

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I would like to make a special events contribution (birthday, new home, anniversary, graduation, etc.) **in honor of:**

My Name _____

Address _____

City, State, Zip _____

Amount of Contribution: \$ _____

Address Change

Has your address changed? If it has, please notify us. Having current address information on file will ensure that you receive newsletters and other correspondence. Notification of change of address can be mailed to:

HDSA/Illinois Chapter
P.O. Box 8383, Rolling Meadows, IL 60008

Or email: cwwiese@sbcglobal.net

Helpful Information

*Rush University Center of Excellence
Valet Parking*

For people going to the Center (Dr. Shannon's office), valet parking is available in the circle driveway drop-off area for a fee of \$8.00 if you show your handicapped parking placard inside when you pay.

HDSA Center of Excellence at Rush University Medical Center

1653 W. Congress Parkway, Chicago, IL 60612

Director: Kathleen M. Shannon, M.D.

Nurse Contact: Jeana Jaglin, RN, CRC

Tel: 312-942-5003 ~ Fax: 312-563-2684

Email: Jean_A_Jaglin@rush.edu

Social Worker: Marjorie Johnson, MSW, MFT

Tel: 312-563-2698

Email: Marjorie_G_Johnson@rush.edu

MEMORIALS AND TRIBUTES

In Memory of Marylyn Dillion
from Debbie & Michael Howard

In Memory of Doug Flowers
from Mrs. Elizabeth Dietz, Ms. Barbara Morris, East High School

In Memory of Nancy Staray
from Susanne Grady

In Memory of Pauline W. Taylor
from Robert Robinson & Marilyn Meister, Lisa & Les Rich, Lois Wood, June Taylor Beard, Marguerite Roller & Helen Lux

In Memory of Fr. Robert E. Kiefner
from Nancy Howard

In Memory of Jack Bliss
from Louise Brattland

In Memory of Glen A. Guske
from The Carda Family, The De Jesus Family, Mrs. Mabel Richards, Shirley Guske

In Memory of Larry Baskin
from your loving sister Rona, Dawn Smith, Robin & Jeff Wolin, Gwenn & Julian Rosen, Debbie & Gary Collins, Judy & Michael Meyerhoff, Sheri & Collin Alpert, Lynn & Marvin Tenenbaum, Sandi & Les Lasinski, Linda & Joe Szabo, Donna & Chuck Lamensdorf

In Memory of Tom Caldwell
from Wilma Caldwell

In Memory of Mikey Wiese
from Sharon & Clarence, Mike, Diane, & Nanette



SUPPORT GROUP MEETINGS

	Date/Time	Additional Information	Contact Information
Lake Zurich	2 nd Monday of every month TIME: 7:30pm LOCATION: Home of Marilyn and Barry Kahn, 1116 Stratford Lane, Lake Zurich	Call for additional information and directions to their home.	Marilyn and Barry Kahn (847) 438-2403
South Suburban	3 rd Tuesday of every other month TIME: 7:00pm LOCATION: Manor Care Health Service, 940 Maple Road, Homewood, IL.	DIRECTIONS: Take I-294, exit Halsted Street South. Turn right at third stoplight. Manor Care is straight ahead on the right. 2009 meetings: 02/17, 04/21, 06/16, 08/18, 10/20, 12/15	Maryann Moynihan (708) 955-3080 shamrock1959@att.net
Stroger-Cook County	2 nd Thursday of alternate months TIME: 12:00 to 1:20pm LOCATION: Basement of Stroger Hospital in the lower level meeting rooms by the cafeteria - LL661	Group includes Medical Professionals (i.e., Neurologists, Psychologists, Social Workers, Genetic Counselors) as well as members of the Board of the Illinois Chapter. 2009 Meetings: 06/11, 08/13, 10/08, 12/10	Steve Clingerman, Ph.D. (312) 864-6083 Clarence Wiese (630) 443-9579
Central Illinois (formerly Peoria Support Group)	2 nd Sunday of the odd months . Peoria Meetings: St. Francis Hospital 7 th Floor Board Room 530 North East Glen Oak Bloomington Meetings: St. Joseph Medical Center Business Conf. Center – Room 2 2200 E. Washington Street	In order to better serve the HD families of Central Illinois, the bi-monthly support group meetings will be alternated between Bloomington and Peoria. Call for 2009 meeting dates/information.	Jennifer Konczyk (217) 732-4353 Clarence Wiese (630) 443-9579
Geneva	4 th Sunday of alternate months TIME: 2:00 to 3:30pm LOCATION: Delnor-Community Health & Wellness Center, 296 S. Randall Road, South Conference Room	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. 2009 Meetings: 01/25, 03/29, 05/31, 07/26, 09/27, 11/22	Ann Weichbrodt (630) 761-8596
Quincy	2 nd Sunday of the even months TIME: 2:00 to 4:00pm LOCATION: Blessing Hospital, 1400 Broadway, Conference Room G		Barb Hilgenbrink (217) 224-0115
Rockford	2 nd Sunday of every month TIME: 2:00pm LOCATION: OSF St. Anthony Medical Center, 5666 E. State St., St. Anthony Room	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.	Kathie (815) 877-0324 kathie0211@insightbb.com

Let us know if you plan to attend an upcoming meeting. We can keep you up-to-date on any changes.