

THE IOWA CONNECTION

NEWSLETTER OF THE IOWA CHAPTER OF THE HUNTINGTON'S DISEASE SOCIETY OF AMERICA

FALL 2009



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DES MOINES WALK DOUBLES LAST YEAR'S DONATIONS!

Team Hope Walk for HD took place across the country this fall in a united effort to raise money for Huntington's Disease research. In Iowa our walk was held in Des Moines on September 12, at scenic Gray's Lake.

The weatherman was wrong as usual and the cold rainy day that was expected didn't materialize. Participants were treated to a beautiful Iowa fall day and it was perfect for a walk around the lake. The best part was the over \$7,000 raised for HD research. This amount is more than double last year's event.

A huge thank you goes to event chairmen Jenna Carnahan and Lori Wesack. They worked hard

to make sure this event was bigger and better than last year.

The Team Hope Walk for HD would not have happened without the generous support of our sponsors. Please support them with your business.

Lundbeck Pharmaceuticals

**Medivation and Pfizer
Pharmaceuticals**

Cargill Inc.

Modern Woodmen of America

Casey's General Stores

Treasurer House, Ankeny

**Dollar General Stores
of Des Moines**

We also would like to thank the
(Continued on page 5)



Participants enjoyed the beautiful trails around Gray's Lake in Des Moines.

RESEARCH OPPORTUNITIES...WHY YOU SHOULD TAKE PART

If you have been tested for Huntington's Disease one of the most important things to consider is participation in research. At the HDSA national convention in Phoenix last June, Charles Sabine, a NBC news correspondent told attendees, "No one should be tested to help clinical trials. You should be tested for your own personal reasons. However, if you have been tested of course

you should consider research." Sabine speaks from experience, his father died from HD, his brother is symptomatic and he is gene positive.

And why is research so important? As Sabine says, "A cure is not the only goal. Potential treatment gives hope. A cure is the holy grail but anything less is not failure." Joseph Giuliano of the CHDI Foundation stated "Time is **not** on our side." One

source reported that so far in the study of Huntington's it has taken longer to find patients for a clinical trial than to complete it. Giuliano says that 50% of all trial delays are due to poor recruitment and 86% of all clinical trials in the United States fail to recruit on time. In rare diseases such as Huntington's it is even more difficult to find enough participants to

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"Time is *not* on our side."

Joseph Giuliano, CHDI Foundation

ADVOCACY CORNER

BECOME AN HD ADVOCATE

By Christy Walker, Iowa Chapter Advocacy Chair

There are many opportunities to advocate as a member of the HD community. There is such a lack of information about the disease that we can all help by simply talking about Huntington's Disease and its effects on not only people diagnosed with HD but their families as well. One very important aspect of advocacy is keeping in touch with the media and our politicians to make them aware of HD and keep them apprised of research and ways they can support the HD community.

Right now the Iowa Chapter is advocating for HR 678. Although information about this bill was in the last newsletter is important that we continue to fight for this important legislation for HD patients and families. Although they recently reached their goal of 50 co-sponsors the more they can get the bigger impact we have when the time comes for a vote. Time is running out for this year so it is important to get your representative on board. We are very excited to announce that Iowa Representative Tom Latham has agreed to be a co-sponsor! Thanks to everyone who has contacted

his office. We are committed to getting all five of Iowa's representatives on board. Every contact helps. Please become an HD advocate to help advance this important legislation.

Additionally, your contact with your representative raises awareness of HD to the general public. This is an important opportunity to advocate for HD on a national level.

House Resolution 678, introduced by Bob Filner, D-CA, will update the definition of onset for Huntington's

Thanks to the honorable Tom Latham who has become a co-sponsor of HR 678!

Disease in the Social Security handbook. It is difficult for many HD patients to get Social Security Disability (SSDI) until they exhibit the physical symptoms of the disease. The name of Huntington's Disease has been changed from Huntington's Chorea because it is important for people to realize part of the disease is the cognitive decline as well as the physical symptoms. Often it is these "softer" symptoms that make it difficult for people to hold a job. Because the Social Security

Administration currently does not take into account this cognitive decline many HD patients who are unable to work cannot quality for SSDI because they do not yet exhibit the physical symptoms associated with HD.

The second part of this bill would allow Medicare benefits to begin immediately after being accepted for disability benefits. Currently a person must wait two years until the Medicare benefits kick in. The only other disease that currently has that exemption is Arterial Lateral Sclerosis or ALS.

We are asking everyone to contact their representative. The Iowa representatives are listed on the left. You can contact them through the mail, email or a phone call. You can also go to our website www.hdsaiowa.org and click the link on your representative or go to www.hdsa.org and click on their advocacy link. The national website also provides sample letters to send and a complete version of the bill.

Advocacy is an important aspect for families affected by Huntington's Disease. Teaching others about the disease, whether it is politicians, health care professionals or the people you come in contact with every day can be a small thing that can make a big difference.

The Representatives for Iowa are:**Rep. Bruce Braley**

District 1, (D)—Waterloo
1019 Longworth HOB
Washington, DC 20515-1501
202.225.2911
www.braley.house.gov

Rep. David Loebsack

District 2, (D)—Mt. Vernon
1221 Longworth HOB
Washington, DC 20515-1502
202.225.6576
www.loebsack.house.gov

Rep. Leonard Boswell

District 3, (D)—Des Moines
1427 Longworth HOB
Washington, DC 20515-1503
202.225.3806
www.boswell.house.gov

Rep. Tom Latham

District 4, (R)—Ames
2217 Rayburn HOB
Washington, DC 20515-1504
202.225.5476
www.tomlatham.house.gov

Rep. Steve King

District 5, (R)—Kiron
1131 Longworth HOB
Washington, DC 10515-1505
202.225.4426
www.steveking.house.gov

IN MEMORIAM

The Iowa Chapter gratefully acknowledges Laura and Jeffrey Hakes, Kelly and Carmen Taylor, Lois Brass and everyone who contributed to the golf tournament held in honor of Judith Hakes. We also appreciate the donation of Shirley and Donald Twarog in memory of Donald Eden and Roger and Harriett Waugh's donation in memory of Lillian George.

FROM DR. PAULSEN'S LAB...HORIZON STUDY TO BEGIN

The exponential growth of clinical drug trials targeting thinking in HD is continuing with the new HORIZON trial.

HORIZON will examine the effectiveness of Dimebon, an experimental drug, on cognitive abilities and overall functioning in people with HD. The trial will also evaluate behavior and motor symptoms.

The UI is a pending HORIZON site. There are currently 17 sites confirmed to enroll participants in this international trial.

"This trial is exciting because

it's an international effort," said Dr. Karl Kieburtz, professor of neurology at the University of Rochester and HORIZON principal investigator. "This is the first time that we have had global collaboration on a clinical trial for Huntington's Disease."

Trial participants should be at least 30 years old, have tested positive for the HD gene, have clinical features of HD and have some difficulty with thinking abilities.

Participants will either receive daily oral doses of Dimebon or

a placebo for 26 weeks. Eight visits and one phone interview will evaluate general health, thinking abilities, memory, mood, and overall functioning and movement.

The goal of this trial is to confirm positive results of an earlier study that suggested Dimebon may improve thinking abilities in persons with HD.

The trial is sponsored by Medivation, Inc. in collaboration with Pfizer, Inc., and is an official Huntington Study Group trial.

"This is the first time that we have had global collaboration on a clinical trial for Huntington's Disease."

Dr. Karl Kieburtz

SASSER FOUNDATION TO PARTNER WITH UI RESEARCHER

A University of Iowa researcher is making strides in HD genetic therapy thanks to the Lori C. Sasser Foundation.

Ryan Boudreau, Ph.D., is a post-doctoral fellow in the research lab of Beverly Davidson, Ph.D., at the University. He is also the recipient of the Lori Sasser Fellowship, a \$60,000 grant awarded in 2008. Boudreau spoke in September at the UI HD Support Group about the research he is conducting with RNA interference (RNAi).

According to an article on the Lori C. Sasser Foundation Web site, a major breakthrough was published in 2005, when Boudreau and others found that HD was a viable candidate for RNAi-based therapeutics.

The general idea behind such therapy is to silence or "turn off" the disease-causing gene.

In Boudreau's research, RNAi was used to silence the expression of the mutant huntingtin protein in an HD mouse model. The treated HD mice showed improved behavior and motor skills, and prolonged survival as compared to untreated mice.

In an article published earlier this year in *Molecular Therapy*, Boudreau and others discovered that turning off both the normal and mutant huntingtin proteins simultaneously was beneficial to HD mice. It had been previously unknown whether silencing the normal huntingtin protein would be tolerated in the brain.

Such a strategy may be necessary for RNAi therapy since targeting the mutant huntingtin protein alone could be difficult.

"These are exciting and surprising advances which support further investigation of RNAi as a therapeutic strategy for HD," Boudreau said.

Going forward, Boudreau hopes his HD RNAi research will include pre-clinical testing of HD RNAi therapies in non-human primates.

According to its Web site, the Lori C. Sasser Foundation partners with top researchers in the fight to end HD. The foundation honors the memory of Lori Sasser, who lost her seven-year battle with Huntington's disease in 2007.

IOWA CHAPTER HDSA CALENDAR

NOVEMBER

9th—HD Support Group-Omaha, 6:00 PM
15th—HD Support Group-Des Moines, 1:30 PM, Nancy Hale, BS,RN
18th—Board of Directors Conference Call 7:00 PM
22nd—HD Support Group-Iowa City, 1:00-3:00 PM

JANUARY

11th—HD Support Group-Omaha, 6:00 PM
20th—HD Support Group-Des Moines, 1:30 PM
24th—HD Support Group-Iowa City, 1:00-3:00 PM

MARCH

8th—HD Support Group-Omaha, 6:00 PM
14th—HD Support Group-Des Moines, 1:30 PM
21st—HD Support Group-Iowa City, 1:00-3:00 PM
27th—Hoop-A-Thon, Bedford High School, 12:00-3:00 PM
28th—Hoop-A-Thon, Audubon High School, 1:00-4:00 PM

DECEMBER

14th—HD Support Group-Omaha, 6:00 PM
20th—HD Support Group-Des Moines, 1:30 PM
27th—HD Support Group-Iowa City, 1:00-3:00 PM

FEBRUARY

8th—HD Support Group-Omaha, 6:00 PM
14th—HD Support Group-Des Moines, 1:30 PM
21st—HD Support Group-Iowa City, 1:00-3:00 PM
27th—Board of Directors meet in Des Moines, 1:00 PM

APRIL

12th—HD Support Group-Omaha, 6:00 PM
18th—HD Support Group-Des Moines, 1:30 PM
25th—HD Support Group-Iowa City, 1:00-3:00 PM

2008

Winter Ca\$h Spectacular

Grand Prize: \$7,500 Cash

Second Prize: \$5,000 Cash

Third Prize \$2,500 Cash

Tickets \$20 each...

3 for \$50 or a book of 10 for \$100

Drawing will be held Monday, January 5, 2009

Remember all proceeds will benefit HDSA Research

You can get tickets by contacting us at

mail@hdsaiowa.org

Or go to www.hdsa.org

AREA HDSA SUPPORT GROUP SCHEDULE

- **Omaha Support Group** meets at the Village Inn Restaurant, 78th and Dodge Streets, the second Monday of the month beginning at 6:00 PM. Call Cathy McNeil at 402-537-0739 for more information.
- **Central Iowa Support Group** meets at the Valley View Village Conference Room, 2571 Guthrie Ave., Des Moines, the third Sunday of the month beginning at 1:30 PM. Call Mark Hillenbrand at 515-208-3511.
- **Iowa City Support Group** meets at the University of Iowa Hospitals and Clinics, Della Ruppert Conference Room-6612 JCP, 6th floor Colloton Pavilion (elevator H), the fourth Sunday of the month from 1:00-3:00 PM. Snacks are provided. Call Anne Leserman at 319-353-4307 for more information.

TEAM HOPE (CONT.)

(Continued from page 1)

following people for their sponsorship as well:

Brian and Christy Walker

Kevin and Lori Wesack

**Valley Junction Lodge #604
I.O.O.F., Des Moines**

HDSA Iowa Chapter would like to encourage people to hold a

walk in their community. The start-up cost is covered by the Chapter and support is also provided. Please contact us if you are interested in beginning a Team Hope Walk for HD in your town. Call toll free at 866.248 IAHD(4243) or mail@hdsaiowa.org.

Iowa Chapter Family Picnic

Following the walk the Iowa

Chapter held it's first Family Picnic. It was a time for families and friends to come together for fun and fellowship. Attendees enjoyed a delicious meal provided by Lundbeck Pharmaceuticals. A weekend in Des Moines was given away to a lucky winner and there was a silent auction as well.

The HD Center of Excellence at the University of Iowa at Iowa City was there to provide information on current research opportunities. We thank both the Center of Excellence and Lundbeck for taking the time to visit with the people of the HD community in Iowa.

We invite everyone to join us next year for this great event.



Co-chairman Jenna Carnahan thanks participants

IOWA CHAPTER TO SPONSOR TRIP TO HDSA NATIONAL CONVENTION

TRIP FOR TWO TO RALEIGH, NORTH CAROLINA TO BE AWARDED

Through a generous bequeath from the Carol Sorenson estate the Iowa Chapter will be able to sponsor a trip for two to the 2010 HDSA National Convention in Raleigh, NC on June 25-27. This trip will include round-trip airfare, registration to the convention and your hotel room. Personal expenses and meals not provided by the convention will not be covered.

The HDSA National Convention is full of information and events geared specifically for HD patients, caregivers and profes-

sionals. Topics can range from research opportunities and breakthroughs, patient care, fundraising and even a meditation room.

The award committee will be choosing one or two people to attend. If you are interested we want to know your story and why you would like to go to Raleigh. Fill out the form at the right and send it to:

**HDSA Iowa Chapter
1824 G Ave.
Essex, IA 51638**

Or email us at
mail@hdsaiowa.org

Name_____

Address_____

Phone_____

Email_____

Please share your story...Additional pages may be attached

2010 HOOP TOUR
SPONSORSHIP OPPORTUNITIES

PRESENTING SPONSOR - \$500 or more

- Listed as Presenting Sponsor on ALL Hoop brochures distributed.
 - Logo printed prominently on the back of ALL Hoop t-shirts.
 - Listed as Presenting Sponsor on ALL Hoop related materials.
 - May display corporate banner at location of Hoops.
 - May distribute promotional materials at the Hoops.
 - Company name printed in event brochure at Hoops.
- Acknowledgement as Presenting Sponsor on chapter newsletter.



BASKETBALL HOOP SPONSOR - \$100 or more

- Sponsor logo displayed beside one basketball hoop.
 - Company name printed on the back of Hoop t-shirts.
 - May distribute promotional materials at the Hoops.
- Company name printed in event brochure at Hoops.

PROMOTIONAL SPONSOR - \$50 or more

- May distribute promotional materials at the Hoops.
- Company name printed in event brochure at Hoops.

SILENT AUCTION – Donated items used at Hoops for Silent Auction

DONATIONS – Donated items will be used as prizes for shooters and Raffle items.

Your sponsorship will be included throughout the Hoop Tour unless designated to a specific hoop. This year's Hoops are being held in Bedford, March 27; Audubon, March 28; and Des Moines: Storm Lake; and Cedar Rapids/Marion, TBA

Company Name _____

Address _____

City _____ State _____ Zip _____

Phone# _____ Fax# _____ Email _____

Contact Name _____ Specific Hoop (opt.) _____

My Company Has a Matching Gift Program

We are interested in becoming a HDSA "Shoot For The Cure" Sponsor!

Presenting \$ _____ Basketball Hoop \$ _____ Promotional \$ _____

We would like to give a Donation \$ _____ Item Donation _____ Value _____

Please return the form to HDSA Iowa Chapter, 1824 G Avenue, Essex, IA 51638

JOIN THE 2010 IOWA HOOP TOUR, PLANS ARE UNDERWAY

The biggest fundraising event for the HDSA's Iowa Chapter is our annual Iowa Hoop Tour. With stops in Audubon, Bedford, Cedar Rapids/Marion, Des Moines and Storm Lake we cross the state raising money for research and raise awareness about Huntington's Disease. Our goal this year is to exceed the over \$40,000 raised last year but each year we need the help of countless volunteers.

We encourage anyone who is considering starting a Hoop in their hometown to make this the year you jump in. Fundraising Chairman and Bedford Hoop Coordinator Karen Brown said, "We would really like to help you start one in your community. Hoop-A-Thon's are fun

for everyone and are rewarding too! You can enjoy a fun filled day and help raise awareness and funds for Huntington's Disease. If you would like help starting a Hoop a Thon in your area, contact the Iowa Chapter for help. There is no expense involved, just your time and much needed help! Please help us "Make This The Last Generation to Suffer with HD".

In addition to fundraising an important aspect of the Iowa Hoop Tour is raising awareness. Advocacy Chairman Christy Walker commented that every year at every Hoop we touch the lives of someone who didn't know there were others out there in the same situation. Part of what makes Huntington's Disease so difficult for

families is the feeling they are alone in their battle. There is an alarming amount of misinformation about HD and the Iowa Chapter uses the media coverage we get during the Hoops to help inform the general public about HD.

We are also looking for sponsors for the 2010 Hoop Tour. If you or your business is interested a sponsor form is included. Why not consider a sponsorship in honor of a loved one?

If you are not interested in starting a Hoop or your town already has a Hoop volunteers are always needed. You can contact us toll-free at 1-866-248-IAHD(4243) or email us at mail@hdsaiowa.org and we can put you in touch with the chair-



These dedicated volunteers from Storm Lake took time for a picture at last year's Hoop

What is a Hoop-A-Thon?
 It's a Free Throw shooting event for all ages and abilities to benefit medical research for Huntington's Disease. "Shooters" get pledges and stand at the foul line and shoot free throws for five minutes, trying to sink as many baskets as they can.

AMARYLLIS SALES JUST GOT EASIER

GROWING A BRIGHTER FUTURE...HDSA'S ANNUAL AMARYLLIS CAMPAIGN

Every year the Iowa Chapter participates in the HDSA's Amaryllis Campaign. This year we are again offering five beautiful colors each with their own unique qualities for only \$10.00. This is the same price as last year and you get the same quality bulb that you find in garden centers.

Choose from the following beautiful varieties:

- ❁ Ferrari—Deep Red
- ❁ Apple Blossom—Pink and White
- ❁ Clown—Red and White Striped
- ❁ Mont Blanc—Pure White
- ❁ Pink Diamond—Blushing Pink

This year it is even easier to order. You can call us toll-free at 1.866.248.IAHD(4243) or email us at mail@hdsaiowa.org. Now can also place your credit card order on-line at www.hdsa.org/amaryllis. When you place your order you will have a chance to select from a

drop down menu and designate the Iowa Chapter to benefit from your purchase.

100% of the profits from this annual event will benefit the Huntington's Disease Society of America's Research, Care and Educational Programs

Your kit comes with everything you need for spectacular winter color; bulb, potting mix, pot and complete instructions. These make perfect gifts for friends and family. Keep one on hand for those last minute gifts or keep one for yourself to perk up that tired houseplant.



RESEARCH (CONT.)

(Continued from page 1)

make a trial statistically significant. In the pamphlet, *A Brief Guide to Clinical Trials* published by the Huntington's Disease Society of America, there are nine studies listed. It will take approximately 2,100 people to populate these studies. According to Giuliano they will probably have to look at 6,000 people because not everyone will meet the criteria for the study.

Delays in recruitment add millions of dollars of cost to drug companies. The competition for the research dollar is great. Jane Paulsen, PhD, from the HD Center of Excellence in Iowa City told the convention in Phoenix that the two main obstacles to bring a new treatment to market are time and money. It costs upwards of \$200 million for a drug company to get through trials and approved for use.

There are many ways a person can participate. Research begins with the idea to observe or document different symptoms. In observational or cross-sectional studies there is no treatment for participants but the study is designed to better understand the nature of the disease. These studies give researchers a chance to understand how the disease progresses over time. The PRE-DICT-HD study coordinated at the University of Iowa is an example of an observational

study. Results from these studies are critical for designing effective clinical trials. Paulsen noted that it is observational research that helps enable rapid startup of treatment studies.

Clinical trials provide another opportunity for participation. A researcher gets an idea for treatment from other studies or perhaps a close association with another treatment. For example, a drug used to treat dementia in Alzheimer's Disease may potentially be effective for dementia in Huntington's Disease. Clinical trials and studies commonly involve an intervention with a potential medication or other form of treatment such as surgery. Clinical research is divided into three phases.

Phase I trials normally focus on side effects and possibly provide early evidence of effectiveness. This phase generally uses a small number of participants.

Phase II trials continue to monitor safety, dosage and side effects. Participants are typically divided into two groups, those receiving treatment and a control group.

Research only moves to Phase III after Phase I and II studies have shown some evidence of effectiveness. At the end of Phase III a decision will be made on the overall potential of the new drug or treatment. Phase III needs the largest number of participants.

Please consider participation in a clinical trial because you might receive some benefit from having access to potential treatments or therapies that are not readily available. Consider that you may be helping other family members with HD or helping the next generation with improved therapies. There is generally no cost to participation and sometimes you may be reimbursed for travel expenses.

It is important that you know and evaluate both the rewards and risks of participation. You will be asked to sign an informed consent form before you can begin a study or trial. Carefully review this and take everything into consideration. The HDSA guide to clinical trials pamphlet mentioned earlier has an excellent list of questions you should ask before you take part in any research.

There are several ways to become involved. Of course you can always contact the HD Center of Excellence in Iowa City at 800.777.8442 or visit their website, www.uihealthcare.com/depts/huntingtondisease/ to find out what is going on in Iowa in terms of opportunities for participation. You can also email Anne Leserman, the Center's Social Worker, at anne-leserman@uiowa.edu. We are fortunate in Iowa to have one of the premier HD research facilities in the United States.

There are also several excellent

websites that detail HD studies:

A private and federally funded site, www.ClinicalTrials.gov, has broad information about studies and trails across the country. This site is not specific to HD but does have excellent resources.

The Huntington Study Group, www.Huntington-Study-Group.org, has information about current research across the country. This is a good site to find out which trials are currently going on and which ones are actively recruiting. The type of study, duration, inclusion criteria and contact numbers are included as well as the funding source.

A new site, www.HDTrials.org, provides information to registered users. Information is collected by zip code only to protect anonymity. This site promises to deliver information more quickly to people who might qualify for current and upcoming research but still ensures the privacy of its users.

Playing an active role in medical research can have big payoffs because research benefits the entire population of people affected by a disease. Patient involvement is first in overcoming the obstacles associated with research development says Jane Paulsen. You can make a difference, in your life and in the lives of others. "Get well soon?" Paulsen asked the crowd in Phoenix, "I prefer stay healthier longer."

ATOMOXETINE PROVES UNSUCCESSFUL IN TREATING HD

A new study from UI researchers suggests a common attention-deficit/hyperactivity disorder drug is not effective at improving attention or psychiatric and motor symptoms in people with early HD.

The study by Leigh Beglinger, Ph.D., and others published in the October issue of the *Journal of Clinical Psychopharmacology*, shows no significant improvements in cognition for those who took atomoxetine versus those who took a placebo. The hope was that a

medication approved for ADHD, a condition which produces similar cognitive impairments in attention and executive functions, would be effective in patients with early HD.

Taking atomoxetine did improve self-reported attention, Beglinger said, but the placebo group also reported the same improvement.

“Although this drug was not effective at improving cognition in patients with Huntington disease, there are more clinical

trials targeting symptoms that people with HD experience now than there have ever been in the past,” Beglinger said. “So it’s an exciting and hopeful time in that we are exploring a number of treatments.”

A study examining the effect on cognition of citalopram (CIT-HD) is enrolling at the UI, the University of Rochester, Rochester, N.Y., and the Mayo Clinic Arizona in Scottsdale, Ariz. Also, the HORIZON study, detailed further on page 3 in this newsletter, will begin enrolling soon.

IOWA CHAPTER BEGINS MEMBERSHIP DRIVE

The Huntington’s Disease Society of America Iowa Chapter works hard to raise money and awareness of Huntington’s Disease.

Our biggest fund raiser is the 2010 Iowa Hoop Tour which raised over \$40,000 last year. We have also added the Walk For A Cure in Des Moines in September. Our newest fund raiser, a Pickle Ball Tournament, was held in Blair, NE last spring and won the Best New Fundraiser at the HDSA National Convention in Phoenix last June.

We take part in the National Programs such as the Growing a Brighter Future Amaryllis Sale, the BMW Sweepstakes and the Summer and Winter Cash Giveaways.

Education is a big part of the Iowa Chapter as well. We hold State Educational Conferences and are planning on offering a free educational

conference for the first time. It will be held in Des Moines next year.

Every other year we sponsor the Celebration of Hope Gala to honor those who have contributed to the success of the Chapter and support of our HD families as well as raise money for research at the HD Center of Excellence in Iowa City.

The Iowa Chapter has a newsletter that is published quarterly and a web page, www.hdsaiowa.org. We use these tools to reach not only HD patients and families but medical professionals and caregivers as well.

Members of the Iowa Chapter strive to be advocates for Huntington’s Disease patients and families. In the spring we have been to the Iowa state legislature as well as the governor’s office to have May declared Huntington’s Disease Awareness Month. The Advo-

cacy Committee is also actively working to get HR 678, the Huntington’s Disease Parity Act of 2009, passed and effectively rewrite the Social Security Disability regulations to include the cognitive symptoms of HD.

The Iowa Chapter Board sends a representative to the National Convention each year and recently voted to sponsor a couple to attend the convention as well.

We have two Support Groups, Des Moines, moderated by Mark Hillenbrand, MSW,LISW, and Iowa City, moderated by Anne Leserman, MSW,LISW.

We are asking you to become a part of the Iowa Chapter through your membership donation. For only \$15.00 per person or \$25.00 per family you can help us to continue the important work of our Chapter. Please fill out the form on the back and help us continue our service to the HD Community.



Dr. Peg Nopoulos presented at our state conference



Board members Brian and Christy Walker and emcee Billy Aaron Brown with the chapter's fundraising award at national convention in June

HDSA IOWA CHAPTER

1824 G Avenue
Essex, IA 51638
Phone: 866-248-IAHD(4243)
Fax: 712-379-3317
E-mail: mail@hdsaiowa.org



OUR MISSION: WE ARE COMMITTED TO PROMOTING AND SUPPORTING RESEARCH TO FIND A CURE, HELPING FAMILIES AND COMMUNITIES AFFECTED BY THIS DISEASE AND EDUCATING THE PUBLIC AND HEALTHCARE PROFESSIONALS ABOUT HD.

HDSA Iowa Chapter Annual Membership Drive

Each year the Iowa Chapter offers the opportunity to support the programs that we offer for the HD Community in Iowa. We have three support groups, Des Moines, Fonda and Iowa City and will be sponsoring an educational conference in 2010. We have a quarterly newsletter and webpage to keep people informed about fundraising, services, support and education. All of these services are offered free of charge. Please consider helping out by sending your donation today.

Please accept my donation of *\$15.00 Individual* *\$25.00 Family* *Other* _____

Name _____

Address _____

Town _____ *State* _____ *Zip* _____

