

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

WINTER 2010

HDSA IOWA CHAPTER



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Every winter the HDSA Iowa Chapter gears up for our biggest fundraiser of the year, the Iowa Hoop Tour.

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. There are great prizes for the top fundraiser at each site as well as most baskets made in both adult and youth categories.

Planning for the Hoop Tour starts shortly after last year's

Hoops finish but it is in January that we start to get excited. After all it is the Hoop Tour that gives all of us a chance to not only raise money for HD research but to meet all of you face to face.

Board member and Chapter Treasurer Brian Walker put it this way, "One of the most important aspects of the Hoop Tour is for people dealing with HD to connect, to know they are not alone." Because HD families can feel isolated he also commented that as the board members travel to each Hoop they always meet someone who didn't know that there were others facing the same issues.

*(Continued on page 6)*



**WHAT SHOULD G.I.N.A. MEAN TO YOU?**

The Genetic Information Non-Discrimination Act (GINA) has become law. This new federal law protects Americans against the misuse of their genetic information by health insurance companies and employers. Its passage is significant because it will allow doctors and researchers the power of using genomics and genetic testing for both diagnosis and treatment of chronic diseases.

For group plans and Medicare,

the effective date for GINA is the start date of the plan or policy year beginning after May 21, 2009. This means that if your group plan's start date is before May 21, then GINA will not take effect until the corresponding date in 2010. For health insurance in the individual market, the effective date is May 21, 2009. The effective date of all employment protections of GINA is November 21, 2009.

Medical technology has advanced to allow testing for not only Huntington's Disease but a vast range of diseases. These genetic technologies offer researchers and research participants amazing opportunities. When scientists, policy-makers, and advocates began working on GINA, only about 300 genetic tests were available, mostly for rare diseases. By 2008, nearly 15 years after Congress began examining the

issue, testing was available for more than 1,300 conditions. Although this is good news for the HD community there is a caveat. The late Senator Edward Kennedy observed, "Discrimination in health insurance and the fear of potent discrimination threaten both society's ability to use new genetic technologies to improve human health and ability to conduct the very research we

*(Continued on page 7)*

## ADVOCACY CORNER...HR 678 CONTINUES MOMENTUM

### 78 REPRESENTATIVES HAVE SIGNED ON BUT TOM LATHAM ONLY IOWA SPONSOR

*By Christy Walker, Iowa Chapter Advocacy Chair*

HDSA continues to push for HR 678. This legislation addresses the outdated Social Security Disability guidelines that are responsible for denying coverage for many HD patients. According to HDSA many individuals affected by HD are “under review” for SSA disability and have already lost their employer-provided health insurance benefits for themselves, and often their families. This bill eliminates the 24-month Medicare waiting period in cases of individuals with disabling Huntington’s Disease. This will ensure that individuals will get crucial care in the early stages of the disease. You can find a complete version of the bill, a sample letter and other helpful information at [www.hdsa.org](http://www.hdsa.org).

This important legislation continues to gain momentum with 78 Representative on board and their goal is now 100 co-sponsors by March. **Unfortunately, the only co-sponsor in Iowa is Tom Latham.** If you haven’t contacted your legislator take the time now.

If you have contacted your representative you probably have received a response. Jane Kogan, Manager, Advocacy and Program Services at HDSA, gives the four main responses from legislators and what you can do.

**1. The “Non-Response” Response**—In this response, the

Representative usually thanks you for writing, explains a little bit about HD, and assures you that he will keep your thoughts in mind. The only problem? He didn’t answer your question about co-sponsoring HD 678! Your next step: Please follow-up with a personal letter, call or email to the member of the Representative’s staff responsible for health care. Restate your request and mention that the previous letter did not provide a clear cut answer to your question.

**2. “I’ll Vote for it on the Floor”** - In this response, a representative thanks you for writing and states that he will vote for HR 678 when it comes to the floor of the House for a vote. But that’s not what you asked him to do; You asked him to co-sponsor HR 678! Many members end responses like this because it sounds like they support your cause. However, HR 678 will probably never “come to the floor” for a vote. Instead it will probably be incorporated into a larger health care bill. Your Next Step: Please follow-up with a personal letter, call or email to the member of the Representative’s staff responsible for health care. Thank them for expressing support and restate your request for the Representative to co-sponsor HR 678.

**3. I’m On the Committee/Not on the Committee**—In this response, a Representative will state (or imply) that because he is a member of that committee, he cannot co-sponsor HR 678. Others will state (or imply) that because he is not on the committee, he cannot co-sponsor HR 678. The fact

is any Representative can co-sponsor any bill, regardless of what committee they’re on. Your Next Step: Please follow-up with a personal letter, call or email to the member of the Representative’s staff responsible for health care. Thank them for expressing support and restate your request for the Representative to co-sponsor HR 678.

**4. Look What Else I am Doing!** - In this response, a Representative will not answer if they will co-sponsor HR 678. Instead, he mentions other bills they have supported in the past. This may include funding for medical research at the National Institutes of Health, health care reform or something else. While we appreciate their support of these efforts, what we really want to know is...will he co-sponsor HR 678? Your Next Step: Please follow-up with a personal letter, call or email to the member of the Representative’s staff responsible for health care. Restate your request and mention that the previous letter did not provide a specific answer to your question.

To contact the Representative’s staff responsible for health care go to their website, they are listed on the right. You can usually find a list of staff. If not, call or email them and request the name of who to contact. You can also email Jane Kogan at [jkogan@hdsa.org](mailto:jkogan@hdsa.org) and she will provide you with that name. If you know anyone who is affected by HD you know how important this legislation is. Please consider helping today!

#### 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](http://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](http://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](http://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](http://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](http://www.steveking.house.gov)

**FROM DR. PAULSEN'S LAB...CURRENT STUDIES AT THE CENTER**

These are the current studies available at the University of Iowa HD Center of Excellence

If interested in participating, please contact the coordinator listed for more information.

**Clinical Drug Trials:**

- **HORIZON:** Must be at least 30 years old, have tested positive for HD, have some clinical features of HD and have some difficulty with thinking abilities. **Contact: Elijah Waterman, (319) 353-4131, elijah-waterman@uiowa.edu.**

- **2CARE:** Must be 16 years or older, in the mild to moderate stages of HD, able to independently walk and fully self-sufficient in activities of daily living. **Contact: Nancy Hale,**

**(319) 353-4537, nancy-hale@uiowa.edu.**

- **HART:** Must be at least 30 years old, have tested positive for HD and have some clinical features of HD. **Contact: Nancy Hale (see above).**

- **CIT-HD:** Must be between ages 18-65, have tested gene positive for HD or received a clinical diagnosis and notice a change in level of attention, focus and/or thinking ability. **Contact: William H. Adams, (319) 353-4411, william-h-adams@uiowa.edu.**

**Observational studies**

- **PREDICT-HD:** Must be at least 18 years old, have been tested for the HD gene (positive or negative) and presymptomatic.

**Contact: Anne Leserman, (319) 353-4307, anne-leserman@uiowa.edu.**

- **COHORT:** Must have tested positive for the HD gene; or be

at risk for developing HD due to family history; or a caregiver/family member of a COHORT participant. **Contact: Anne Leserman, (see above)**



We look forward to seeing the group from the Center of Excellence at the University of Iowa at the Iowa Hoop Tour. This is a chance for people across the state to meet the researchers and social workers face to face.

**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 have it postmarked by **February 15, 2010.** Send 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

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# IOWA CHAPTER HDSA CALENDAR

## JANUARY

11th—HD Support Group-Omaha, 6:00 PM  
 17th—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  
 20th—Hoop-A-Thon, Storm Lake, 11:00 AM-2:00 PM, Storm Lake Middle School  
 21st—HD Support Group-Des Moines, 1:30 PM  
 28th—HD Support Group-Iowa City, 1:00-3:00 PM  
 27th—Hoop-A-Thon, Bedford, 12:00-3:00 PM, Bedford High School  
 28th—Hoop-A-Thon, Audubon, 1:00-4:00 PM, Audubon High School

## FEBRUARY

8th—HD Support Group-Omaha, 6:00 PM  
 15th—Deadline for entries for trip to National Convention  
 17th—Iowa Chapter Board Meeting, 1:00 PM, West Des Moines  
 21st—HD Support Group-Des Moines, 1:30 PM  
 28th—HD Support Group-Iowa City, 1:00-3:00 PM

## APRIL

10th—Hoop-A-Thon, Des Moines, 1:00-4:00 PM, AIB College  
 11th—Hoop-A-Thon, Iowa City, 1:00-4:00 PM, Iowa City West High School  
 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

### Join HDSA's

### 2010 Drive Toward a Cure Sweepstakes!

#### Grand Prize:

2010 BMW 328i Sedan  
 Or \$25,000 CASH



Second Prize: \$5,000 CASH  
 Third Prize: \$2,500 CASH  
 Fourth Prize: \$ 750 CASH  
 Fifth Prize: \$ 500 CASH

*Sweepstakes limited to only 2,500 tickets sold! For every two tickets you buy (or sell) at just \$100 each, you receive a third free! Remember that all proceeds will benefit HDSA Research Programs. Winners will be drawn at HDSA's National Convention on June 25-27 In Raleigh, North Carolina.*

For tickets or more information call 1-800-345-HDSA or e-mail [hdsainfo@hdsa.org](mailto:hdsainfo@hdsa.org). You can also log on to [www.hdsa.org](http://www.hdsa.org) to learn more about this year's BMW Sweepstakes.

### In Remembrance...

*We received a tribute in honor of Janet Birkley from Penny and Zane Birkley and Pearl Voss.*

### AREA HDSA SUPPORT GROUP SCHEDULE

- **Omaha Support Group** meets at the \*Perkins Restaurant, 108th and L Street, 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.

## HDSA NATIONAL CONVENTION

June 25-27, 2010

Hilton North Raleigh, Raleigh, North Carolina

Join HDSA in Raleigh for their annual convention. It's an opportunity to make new friends and meet old ones as well as taking part in informative panels and seminars. Lower right: the group from Iowa met to participate in the Walk for Hope in Phoenix in 2009. Early-bird registration through June 1, and special hotel rates through May 30.

[www.hdsa.org](http://www.hdsa.org)





## 2010 HOOP TOUR SPONSORSHIP OPPORTUNITIES

*It's not too late to donate!*

**PRESENTING SPONSOR - \$500 or more ● BASKETBALL HOOP SPONSOR - \$100 or more ● PROMOTIONAL SPONSOR - \$50 or more ● 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 Storm Lake, March 20; Bedford, March 27; Audubon, March 28 Des Moines, April 10 and Iowa City April 11*



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*

### HOOP (CONT.)

*(Continued from page 1)*

Carrie Tibben, former chapter president and the Audubon Hoop Chair, said she will always remember her first hoop in May 2003. It was the first time she met people from the Iowa Chapter and will always remember how caring and welcoming everyone was that day. Those same people are still involved with HDSA today, and I am honored to be working with them now." she commented.



Audubon will be celebrating their seventh Hoop this spring but Carrie's most memorable Hoop

is her first. It was the only Hoop her brother Christopher, who suffered from HD, was able to attend. He passed away two weeks later. "This helped give me the motivation to push forward with future hoops," Carrie said.

For Amanda Damewood, the organizer of the Storm Lake Hoop, it is the great support of her family that makes her Hoop special. "Sometimes when you have HD in your family it brings heartache, but it can also bring gratefulness and that is what this hoop has done for everyone that helps with the Storm Lake Hoop-a-Thon."

The dates for this year's Hoops are:

- Storm Lake**  
**Sat. March 20, 11:00 AM-2:00 PM**  
**Storm Lake Middle School**  
**Bedford**  
**Sat. March 27, 12:00-3:00 PM**  
**Bedford High School**  
**Audubon**  
**Sun. March 28, 1:00-4:00 PM**  
**Audubon High School**  
**Des Moines**  
**Sat. April 10, 1:00-4:00 PM**  
**AIB College Activities Center**  
**Iowa City**  
**Sun. April 11, 1:00-4:00 PM**  
**Iowa City West High School**

If you would like to volunteer you can contact the Hoop Chairman in your area, their contact

numbers are on the back. There is always a need for people to set-up and take-down, rebound and count baskets. This is an opportunity to connect with the HD community. "I have developed some lasting friendships with the people that have went above and beyond the call of duty in volunteering over the years," Carrie Tibben points out.

If you are interested in shooting there is a pledge sheet on page 5. All proceeds support HD's help for today, hope for tomorrow for families affected by HD.

Don't forget we are also still accepting sponsor donations but the time to get your company in the brochure is limited so you need to respond right away.

**G.I.N.A. (CONT.)**

(Continued from page 1)

need to understand, treat, and prevent genetic disease.” GINA helps to address these problems but it is not perfect.

According to the Huntington’s Disease Society of America (HDSA) GINA will:

- Prohibit group and individual health insurers from using a person’s genetic information in determining eligibility or premiums
- Prohibit an insurer from requesting or requiring that a person have a genetic test
- Prohibit employers from using a person’s genetic information in making decisions regarding hiring, firing, job assignments, and the like
- Prohibit employers from requesting, requiring, or purchasing genetic information about persons or their family members

The test for the Huntington’s disease mutation is protected and so are tests for breast cancer, colon cancer and carrier screening for disorders such as cystic fibrosis, sickle cell anemia and spinal muscular atrophy are covered as well. Though the spirit of the law is encouraging, HDSA advises individuals who are considering genetic testing to be cautious. It is still unclear how insurance companies, employers, courts and government agencies interpret

these protections. At the very least HDSA recommends that anyone considering genetic testing speak with a licensed genetic counselor to address concerns, and discuss the various implications of testing and what risks still remain for genetic discrimination.

GINA should still be effective in providing the protections legislators intended it to, said Cheryl Erwin, JD, Ph.D., professor at the John P. McGovern Center for Health, Humanities and the Human Spirit at the University of Texas. Dr. Erwin is the Ethics

**...HDSA recommends that anyone considering genetic testing speak with a licensed genetic counselor to address concerns, and discuss the various implications of testing and what risks still remain for genetic discrimination.**

chair for the PREDICT project.

It is not, however, a comprehensive protection against genetic discrimination, Erwin says. Moreover, people should consider more than just the potential for discrimination when deciding to get genetically tested for Huntington disease.

“Getting tested is not a legal decision,” she said. “It’s a life decision and a medical decision. It’s great that we now have some protection against genetic discrimination, but the decision to get tested needs to be based more on your personal needs and family needs.”

HDSA also points out that there are things that GINA does not do:

- Does not prohibit medical underwriting based on current health status
- Does not cover life, disability, or long-term care insurance
- Does not mandate coverage for any particular test or treatment
- Does not prevent health care providers from recommending genetic test to patients
- Does not apply to members of the military

GINA makes it illegal for health insurance companies to deny coverage or to charge a higher rate or premium to an otherwise healthy individual found to have a genetic predisposition to a disease or disorder. However, once a patient is symptomatic these rules no longer apply. Insurance companies cannot change the terms of the contract but they do have the right to increase contribution amounts or deem the symptomatic individual no longer eligible for coverage. The employment protections covered under GINA Title II also do not extend to individuals once they become symptomatic.

Enrollment in clinical trials has

decreased for several years and researchers partly blame concerns regarding genetic discrimination when research involved genetic testing. This is a big problem for rare diseases such as Huntington’s Disease because the need for clinical trial participants is greater due to a smaller pool of eligible individuals. GINA has been designed to protect trial participants. According to HDSA, “Under GINA, individuals that participate in clinical trials do not have to submit to any genetic test requested by their insurer, and any genetic information discovered is protected.”

Additionally, because of GINA, since July 20, 2009, genetic information is treated as health information under HIPAA (Health Insurance Portability and Accountability Act of 1996) and is subject to HIPAA’s privacy regulations. That limits insurers’ ability to use genetic information to raise rates for an entire group.

Implementing GINA is a big step for people at-risk for chronic conditions such as HD. It gives significant protection from discrimination from insurers as well as employers. The potential for advances in treatment is great but it will take researchers, clinicians, geneticists, ethicists, consumers, patients and caregivers as well as policy-makers and the courts working together to realize the full potential of genomics and genetic testing.

## HDSA IOWA CHAPTER

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



We are on the web!

[www.hdsaiowa.org](http://www.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.**



# IOWA HOOP TOUR 2010

### **Storm Lake—Saturday, March 20**

11:00 AM-2:00 PM, Storm Lake Middle School  
Contact Amanda Damewood 712.200.3076 or  
chacha9800@hotmail.com

### **Bedford—Saturday, March 27**

12:00-2:00 PM, Bedford High School  
Contact Karen Brown, 402.533.4693 or ksbrown@hutel.net

### **Audubon—Sunday, March 28**

1:00-4:00 PM, Audubon High School  
Contact Carrie Tibben, 515.321.8131 or tibbenca@hotmail.com

### **Des Moines—Saturday, April 10**

1:00-4:00 PM, AIB College Activities Center  
Contact Sarah O'Neil, 515.707.4229 or oneil\_timsarah@msn.com

### **Iowa City—Saturday, April 11**

1:00-4:00 PM, Iowa City West High School  
Contact Sean Thompson, 319.384.4094 or sean-thompson@uiowa.edu

All participants get  
a FREE t-shirt and  
the top fund raiser  
at each Hoop gets a  
great prize!



HUNTINGTON'S DISEASE  
SOCIETY OF AMERICA  
IOWA CHAPTER

