

THE IOWA CONNECTION

SPRING 2008



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THE 2008 HOOP TOUR IS UNDERWAY

A year after joining the Iowa Chapter as a volunteer and then as the Chair of the Bedford Hoop-A-Thon, Karen Brown decided that there was a need to expand and reach out statewide. "It's not all about the dollars we raise, but just as important are the people we have been able to meet, and hopefully help along the way," and so the Iowa Hoop Tour was born. Our first Hoops are becoming established and just keep getting better every year.

Karen encourages anyone interested in helping or starting a Hoop in their town to let us know. "We would be glad to get it going, you won't be sorry for doing it!" she remarked.

Amanda Damewood, who chairs the Hoop in Storm Lake, wants people to know if they are considering a Hoop to just jump in. "If your Hoop brings in \$100 or \$10,000 the money is very effective but the interaction of HD families is priceless!"

It was a cool spring day this year when the 2008 Hoop Tour rolled into Des Moines, our first stop on this year's tour. The people of Des Moines, however, were anything but cold as they kicked off our statewide event with over \$6,000 raised. The attendance was up and so were the donations. "We organized a fun event where people could come and participate,



Cedar Rapids/Marion has been rescheduled!
Saturday, May 3
11:00 -2:00
Vernon Middle School

volunteer and socialize all while raising funds for HDSA. Everyone who attended made a difference in some way," commented Sarah O'Neil, Des Moines Hoop Chair.

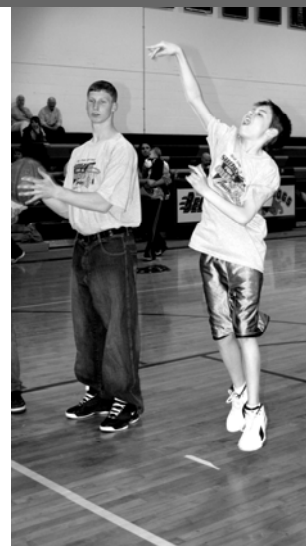
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The Audubon Hoop featured entertainment by Nicole Bruch and Myles Nielsen



Above—Ben Easter, one of our favorite volunteers originally from Des Moines, paints faces in Audubon. On the right—A shooter from Bedford is helped by a rebounder from the Clarinda Academy.



The Hoops are great for all ages. Above—a young shooter from Des Moines gets a little help.

PRESIDENT'S CORNER...THANKS TO OUR IOWA HD FAMILY



Our Hoop Tour is well on it's way! By the time you receive this newsletter, we will have one more hoop left in Marion. This hoop has had a change in time to Saturday, May 3rd, from 11:00 A.M. to 2:00 P.M. at Vernon Middle School. We hope this change in time will help more people in the Cedar Rapids/Marion area be able to participate.

Of the hoops that are done, I feel like we have continued to have good community support. Now that we have our Celebration of Hope Dinner in the fall, we have more of a variety of fundraising going on across the state. It is a good feeling knowing that when we add new fundraisers, we can continue to have just as much success at the events that have been in place for several

years.

May brings about Huntington's Disease Awareness Month. In the past we have had good support at the Capitol for promoting this awareness. We hope all our HD community will make an extra effort to raise HD awareness in your communities. As an educator, I will take time to give presentations to our Biology classes when they are studying genetic diseases. It helps give them more of a personal connection to HD rather than just the basic textbook explanation given.

June is just around the corner, which means National Convention. This year's convention will be in Pittsburg. I have attended three conventions, and I have walked away from each feeling a new energy for our efforts at the state level. I feel I am constantly learning more about HD and the resources available for individuals and families dealing

with HD. Most of this knowledge comes from the sessions I attend at Nationals. If you have not attended a convention, I strongly encourage you to attend this year. More information can be found at www.hdsa.org.

Finally, I would like to take time to thank everyone that is helping with the Iowa Chapter efforts across the state. We are thankful for those that have been involved for a number of years and continue to help our chapter grow, and we welcome the new help that has come our way. We look forward to building new relationships with our new volunteers. If your or anyone you know would like to participate in any way, please contact us. Working together is how we will truly make this the last generation of HD!

Best wishes to a happy spring!

Carrie Tibben



Iowa Chapter President Carrie Tibben, right, illustrates how much we all love the HD Center of Excellence at the University of Iowa and Anne Leserman, LISW, who steers the support group in Iowa City.

HDSA NATIONAL CONVENTION TO BE IN PITTSBURGH

The 23rd Annual Convention will be held this year June 6th-8th in Pittsburgh, PA. This year's event will be at the Omni William Penn Hotel, 530 William Penn Place, Pittsburgh, PA 15219.

The workshop topics being featured cover a wide variety of issues and are divided by subject. If you are new to HD or at-risk there is *Understanding How the HD Gene Works*

or perhaps *Social Aspects of Living at Risk*.

There are workshops devoted to living with HD. You might be interested in *Medications for Psychiatric Issues, Balance, Falls and Safety in the Home, or Managing Cognitive and Behavioral Symptoms*.

Many attendees are caregivers and support people so *Working with Non Family Caregivers or Communications Strategies*

may be of interest.

We are excited to note that our own Jane Paulsen, PhD., from the Center of Excellence at the University of Iowa will be giving a *Predict Update* in a convention workshop. Other topics for general attendance are *Getting Involved in Clinical Trials, Advocacy 101* and *Medications for Movement* among others.

There are special needs and treatments for Juvenile Onset

HD. One of the best things about the convention is the ability to meet and talk with others who are going through the same things. *Getting to Know You—Parents of Children with JHD* is a workshop specifically geared for networking and sharing. You may also be interested by *Diagnosing Juvenile HD* and *Special Needs Planning*.

(Continued on page 3)

FROM DR. PAULSEN'S LAB... EYE TRACKING: ESTABLISHING A BIOMARKER FOR HD

The Center of Excellence at the University of Iowa has many ongoing studies and research for Huntington's Disease patients, their families and individuals at-risk. Some of the studies they are working on at this time are eye tracking, fMRI, Juvenile HD and an at-risk support group. These programs are outlined below.

Eye Tracking

Eye Tracking is a study designed to utilize advanced eye-tracking methods to establish a biomarker for HD by investigating subtle motor and cognitive eye tracking problems in individuals tested for HD. Participants 18 years of age or older who have completed an HD gene test are invited to participate in this 60 minute eye tracking session. Participants will include people who have tested both positive and negative for the HD gene. Compensation

is available to study participants. For more information call Jana Hanson at (319) 353-4537 or email jana-hanson@uiowa.edu.

fMRI

In this study, functional Magnetic Resonance Imaging (fMRI) scanning will be used to examine brain changes in HD during cognitive tasks. **Participants currently enrolled in the PREDICT-HD study are being invited to participate in an fMRI study at either the University of Iowa or the Cleveland Clinic in Cleveland, Ohio.** Participants will undergo fMRI scanning for three visits with 12 months between each visit. This 5-6 hour study takes place over the course of two days. Compensation is available. Questions? Please contact Andrew Juhl by email at andrew-juhl@uiowa.edu or (319) 353-5451.

Juvenile HD

In partnership with the European Huntington's Disease Network (EHDN), the University of Iowa is recruiting individuals who are affected by JHD. One study is recruiting the parents/guardians of children with JHD. An informal interview will be conducted to examine the views and opinions of families affected by JHD regarding their healthcare needs and their experiences with JHD. This study also hopes to understand the various coping mechanisms families affected by JHD may use, in addition to other support systems through family, friends, professionals, etc. The second JHD study is recruiting both parents and individuals affected by JHD to research the effectiveness of clinical measurements. This study will compare the current adult version of the Unified Huntington's Disease Rating Scale (UHDRS

'99) with a new modified version specifically developed for the JHD population. The purpose of this research study is to better understand JHD and to improve the currently available tools that evaluate the course of the disease. For more information about these studies, contact Stacie Vik at Stacie-vik@uiowa.edu or 319-353-3716.

At Risk Group?

Are you 18 or older and at risk for HD? Would you be interested in a support group to talk about your experience?

Are you willing to come to Iowa City? Would a Saturday, Sunday or evening time work?

This could be a one time group or possibly meet every few months.

Please email me if you are interested.

anne-leserman@uiowa.edu

NATIONAL CONVENTION (CONT.)

(Continued from page 2)

The National Youth Alliance will host workshops as well as a convention reception and Talent Show on Friday, June 6.

Saturday features an HDSA Research Forum with James Gusella, Ph.D. and Robert Pacifici, Ph.D., as well as the popular 40th Anniversary Gala and Awards Dinner in the evening. The winner of the BMW

Sweepstakes will also be announced.

The complete convention agenda and workshop topics are now available on-line at HDSA's website www.hdsa.org. You can also register on-line too. Early-bird registration available until May 16 as well as on-site registration until the convention. There are also links to the Omni William Penn Hotel for booking your room, note

that a special rate is available until May 14, as well as discount rates with Continental Airlines.

Karen Brown, past Iowa Chapter President said that going to the convention makes you realize that everything you do is needed, appreciated and worthwhile. "It's an experience I will never forget, and definitely one everyone should have."

Jane Paulsen from the HD Center of Excellence in Iowa City will present an update on the Predict HD study being conducted around the country.

IOWA CHAPTER HDSA CALENDAR

MAY

MAY IS HD AWARENESS MONTH!

11th—HD Support Group-Omaha, 6:00 PM

18th—HD Support Group-Des Moines, 1:30 PM—HD Support Group-Fonda, 1:30 PM

25th—HD Support Group-Iowa City, 1:00-3:00 PM

JULY

14th—HD Support Group-Omaha, 6:00 PM

20th—HD Support Group-Des Moines, 1:30 PM—HD Support Group-Fonda, 1:30 PM

27th—HD Support Group-Iowa City, 1:00-3:00 PM

JUNE

6th-8th—HDSA 23rd Annual Convention, Pittsburgh, PA

9th—HD Support Group-Omaha, 6:00 PM

15th—HD Support Group-Des Moines, 1:30 PM—HD Support Group-Fonda, 1:30 PM

22nd—HD Support Group-Iowa City, 1:00-3:00 PM

AUGUST

11th—HD Support Group-Omaha, 6:00 PM

17th—HD Support Group-Des Moines, 1:30 PM—HD Support Group-Fonda, 1:30 PM

24th—HD Support Group-Iowa City, 1:00-3:00 PM

May is HD Awareness Month!

We have a short video available that can be used for meetings or promotion.

We also have Hearts for Huntington's, paper hearts that can be sold to raise money for HD. Hearts for Huntington's is a program started by a young girl, Katie Long, as a school project to increase awareness of the effects of HD.



Contact us toll free at 1.866.248.IAHD (4243) if you are interested.

2008 Drive Toward a Cure BMW Sweepstakes



Grand Prize: Model Year 2008 BMW 328i Coupe 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! Winners will be drawn at HDSA's National Convention on June 7th, 2008 in Pittsburgh, PA (You do not need to be present to win). Go to www.hdsa.org to order on-line or contact us toll free at 866.248.IAHD(4243)

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.
- **NEW SUPPORT GROUP!** The **Northwest Iowa Support Group** meets at the Fonda Nursing and Rehab Center in Fonda, IA, the third Sunday of the month beginning at 1:30 PM. Call Wilma Frey at 712-288-4441 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.

Save the Date

HDSA's 23rd Annual Convention

June 6th-8th, 2008

Omni-William Penn Hotel, Pittsburgh, PA

SPOTLIGHT ON SUPPORT GROUPS—FONDA

By Wilma Frey

I am a native Iowan, but have the opportunity to live many places and do many things while my husband was in the service. In my prior lives (among other things), I worked as an administrative assistant for US Space Command; a military hospital managing their clinics, and as an administrative assistant for a congressional appointed task force. When we returned to Iowa, I worked 10 years for The Good Samaritan Society in resource development, as an Eden Associate and as business office manager. In 2002 I graduated from Bellevue University with a Bachelor of Science in Healthcare. Fonda Nursing and Rehab is my second facility as an Administrator.

My connection with HD began when we had our first admis-

sion of a HD patient. He stole my heart and each HD admission we receive gets a little firmer grip on it. As I began to learn more about the disease I found it very interesting. I also found that caregivers found it a very difficult disease to deal with. With regulations of having to keep people from falling, keeping them safe and meeting their psychosocial needs at this younger age, nursing homes are very cautious of admitting a person with HD.

I am very fortunate to have a wonderful staff that is up to meeting all challenges, and there were challenges. First was helping staff to understand that not all residents have the same life styles or schedules for eating, sleeping, and bathing. Sleeping all day and being up all night was a first for my staff. Night shift having to fix a nutritional meal was an easy concept to get across.

When a resident is admitted to Fonda we like to approach care from what the resident can do. Safety is a major concern, but we also understand that it has to balance with feelings of dignity and self worth. When we have to use a safety device we try to make it as



Wilma Frey leads the Northwest Iowa Support Group. Here she is pictured (center) with residents from Fonda at the recent Storm Lake Hoop.

acceptable as possible. Pillows or cushions may be covered with material of a favorite football team or a field of butterflies, trying to take the focus from the disability and make it something fun and interesting to look at. Communication can be augmented with special communication boards made specifically for that person and may even include phrases, jokes, or swear words that that person wants to use. As we know Huntington's can also interrupt a person's brain pathways and thinking processes. At Fonda that does not excuse a person from taking part in decision on how they will be cared for. Instead we work very hard at helping them to make wise choices and then supporting and reinforcing those decisions.

An HD support group is important to patients and families so that they can understand the disease process rather than to fear it. By understanding the disease process we can face

the challenge of dealing/living with it. Finding the cure is important but in the meantime we have to continue living life to the fullest and making every day count. HD victims and their families have to learn to deal with abilities and disabilities, how to handle relationships when things are going well, and when they aren't, how to bring joy and happiness in their lives according to their own milestones, and to know they can succeed at having a life worth living.

Support groups also have to be willing to take up the hard issues and work them through. It is OK and necessary to be angry, depressed, feel fear and jealousy and every other emotion you can name. It is only after recognizing them that we can deal with them and keep them from taking over our lives. We all have to be there for one another during the hard times and know we will all have them but the sun will shine tomorrow if you just let it.



Wilma received a recliner from all the grateful people at the Storm Lake Hoop.

HOOP TIME (CONT.)

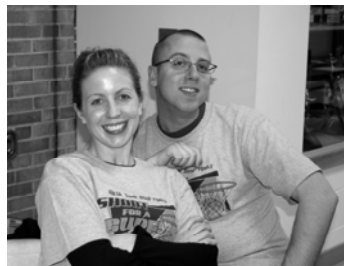
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Sarah also wants to thank all of the businesses who donated funds or items for the Hoop and of course all the volunteers who took the time either before or during the event to lend a hand.

The next week found the Tour in Bedford, the home of the Iowa Hoop Tour, and Audubon, home to the Iowa Chapter. Both events were a success and the totals are still being counted.

In Bedford, although the attendance was down the money raised was not. Karen Brown, chapter past-president and the Bedford and CR/Marion Chair remarked "It's always rewarding to see some of the same people come out year after year. It means we have made an impact on the community and people do want to come out and help our cause."

Karen says that there are so many people to thank in the Bedford and Clarinda area, especially the businesses who are so great donating year after year. She doesn't leave out thanks for the many volunteers who she says make the Bedford Hoop "run like clockwork".



The HD Center of Excellence is represented at every Hoop and helps to raise awareness for HD as well as the Center

Audubon has become one of the favorite stops on the Hoop Tour. Carrie Tibben, chapter president and Audubon Chair, teaches in the Audubon School District so the Hoop has loads of youthful energy and this year was no exception. Participants were treated to the singing duo of Senior Myles Nielsen and Junior Nicole Bruch. They wowed the crowd and received a standing ovation.

Although happy with the Audubon event Carrie has set higher goals for the future. She would like to get the shooters to raise more dollars and she always wants to see more people involved.

Carrie gives a big thank you to Audubon Real Estate-Stone Creek Homes, Bauer's Floral Design and Miss Davis' junior high social studies classes and of course her family and friends. She commented that her wonderful help was the reason that this year's event went extremely well.

Storm Lake is our big money maker. This year they have raised over \$17,000. Each year the people in northwest Iowa open their hearts and billfolds in support of HD patients and their families.



The members of Jun Tae Kwon Do raise money the hard way at the Storm Lake Hoop

The crowd was entertained this year by Jung's Tae Kwon from Alta, under the instruction of Jennifer Brechwald. They not only put on a great show they raised money during the Hoop with an impressive board breaking demonstration.

The children went wild over the screamer slide which was provided by Sky High Bounce and sponsored by Security Bank, Storm Lake Honda and Larson Oil.

However, it's not all about the money for Amanda Damewood, the driving force in the Storm Lake Hoop. "I hope people take away a sense of unity. HD affects the entire family and if we can come together not only to raise money but to blend together and understand there are other families out there that are in the same situation."

One of the high points of this year's Hoop was a recliner that was donated to Wilma Frey, the Northwest Iowa Support Group leader and advocate for HD patient care.

Amanda wants to thank her family for their amazing turn-

out and help, especially her parents and her right hand ladies, Colleen and Trish. She also commented that they had a lot of businesses donate from Storm Lake and Cherokee.

Although fundraising is an important aspect of the Hoop-A-Thons it isn't the only benefit. We are thrilled to have the presence of the HD Center of Excellence at the University of Iowa at each of our Hoops. This offers an opportunity not only for people affected by HD but people at-risk to be introduced to the programs and research being done at the Center. Everyone involved in the Hoop-A-Thon program thinks that awareness is one of the major components of the

"The most important thing I hope people take away from the hoop is hope."

*Sarah O'Neil,
Des Moines Hoop Chair*

events. "I believe we have raised awareness about HD, however I believe we can reach out to so many more families," said Amanda Damewood.

As Sarah O'Neil from Des Moines puts it, "The most important thing I hope people take away from the hoop is hope. We come together as a family who wants to make a difference in the lives of those who face HD each day in some way."

HDSA IOWA CHAPTER

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We are on the web!

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.



HDSA's SHOOT FOR A CURE 2008

CEDAR RAPIDS/MARION HAS BEEN RESCHEDULED!

It will be Saturday, May 3

11:00 AM-2:00 PM, Vernon Middle School

Contact Karen Brown, 402.533.4693 or ksbrown@huntel.net

Thanks to everyone who has participated in this year's Hoop Tour! We appreciate every business and volunteer who helped but we especially thank the hundreds of people who participated by getting pledges and raising money for HD Research!

Let's make this "The Last Generation with HD"!

All participants get a FREE t-shirt and the top fund raiser wins an iPod!

HDSA Iowa Chapter

