Volunteer rewards HD families with $5,000 grant

By Kristine Bjork
UI Editorial Associate

For almost 40 years, Mary Winnie has been a dedicated volunteer with The University of Iowa Hospitals and Clinics. She recently accumulated 5,000 hours of volunteer work. When a volunteer at UIHC accumulates this many hours, they are allotted $5,000 to donate to the UI clinic or center of his or her choice. Last December, Mary chose to give this gift to The University of Iowa Huntington Disease Center of Excellence (UI HDSA COE) to support Huntington disease patient care.

This devastating disease hits home with Mary because her son-in-law suffered from HD and was a patient at UIHC. He passed away from the disease last year.

For the sake of her grandchildren and others who are at risk for HD, Winnie wants to support Huntington disease care however she can.

“It has affected my entire family, so I wanted any money that I could donate to go toward Huntington disease,” she said.

The COE has chosen to use her money in two ways. Part of her donation will go toward developing a Huntington disease resources library, which will contain booklets that families can keep. The library’s literature will cover topics such as care giving, understanding behavior, juvenile HD and more.

The rest of her donation will pay for five grants for participants to attend the 2011 HDSA National Convention in Minneapolis in June (see the article on page 2 for more information regarding these grants).

“I want to applaud Mary for her many hours of volunteer service to the hospital and thank her for her donation to our center,” said Anne Leserman, UI HDSA COE coordinator. “I know there are many worthwhile clinics and services in the hospital that could benefit from this donation, but I deeply appreciate that she has chosen our HD Center for this gift.”

Winnie says her favorite part about volunteering is meeting people and visiting with other volunteers.

“It has affected my entire family, so I wanted any money that I could donate to go toward HD.”

Mary Winnie
UIHC Volunteer

Winnie has lived in Iowa City since the 1950s. Her volunteer efforts have included buying baby clothes to sell at the hospital gift shop, where she was one of the original volunteers, according to Volunteer Services Associate Director Amy Rood.

Winnie’s other volunteer activities have included: pricing gifts in the store room; working at the Art Cart; assisting nurses in the Otolaryngology Clinic; and working in the patients’ library. She currently knits baby items.

“It was assigned to gift services as a buyer and coordinator of the gift cart (hospitality). In early years, this service was a welcome diversion to patients who were hospitalized for long periods of time. I no longer have contact with patients, but do cherish those contacts, and the friendships with volunteers and staff,” Winnie said.

Winnie’s love of her customers and love of serving hospital patients and their families as well as other visitors was evident in all that she did, Rood said.

“It exemplifies the caring spirit of those whose goal was, and still is, to improve the patient and family experience through voluntary contribution,” Rood said.

The UI HDSA COE would like to extend a sincere thank you for Winnie’s generous donation. Her gift will improve patient care by providing resources for patients and their families, as well as enabling five individuals to connect with the HD community at the 2011 HDSA National Conference.
Coming together for the holidays

Lisa Freeney (left) and UI HDSA COE Coordinator Anne Leserman (right) chat at the UI HDSA COE HD Support Group holiday party on Dec. 12. Attendance at the party was affected by a snow storm, but those who made it enjoyed delicious food and friendly conversation.

HDSA Iowa seeks board members

The HDSA Iowa Chapter is looking for folks willing to give their time to help HD families in the state by serving on the chapter board.

HDSA Director of Development for the Upper Midwest Region Michele Asmussen said the board would like to have as many as five new members join the 11 current members. New Board President Lori Wesack of Ankeny said the board is looking for people who are ready to jump right in and join an experienced team.

“We will train them on what they need to know,” Wesack said, “we just need willing people who want to help with a great cause.”

Board members will attend meetings in person every other month. Wesack said other activities carried out by board members include helping with fundraisers, spreading awareness of HD and monitoring a help line.

Asmussen says they’re looking for members who don’t have HD in their families as well as those that do.

“We want people that are dedicated, passionate about the cause and people that have time to give,” Asmussen said.

Being on the board is very rewarding, Wesack said, providing the opportunity to make friends with people from across the country who share the same goals.

“It will be something you will not regret doing,” she said. “We have a great group of people to work with and are anxious to have even more people become involved in helping to make this the last generation with HD.”

To apply to join the board, contact Wesack at loriwesack@gmail.com or (515) 314-7262.

National Convention grants to be offered

Thanks to a generous donation from University of Iowa Hospitals and Clinics volunteer Mary Winnie (see page 1), the UI HDSA COE is awarding five grants to help Iowa families attend the 2011 HDSA National Convention in Minneapolis.

Grants will cover the cost of up to two registration fees ($120 per person) for the June 24-26 convention. The grant will also pay for two nights at the convention hotel, the Sheraton Bloomington Hotel in southern Minneapolis.

To qualify, you must be a resident of Iowa and a member of an HD family. Applications must be completed online or postmarked no later than May 1, 2011. Winners will be notified no later than May 10.

With the convention being in the Twin Cities this year, UI HDSA COE Coordinator Anne Leserman said the center saw an opportunity to help Iowa families make the short trip.

The convention is a great opportunity to see presentations from HD experts from around the country, Leserman said, covering topics such as new treatments, research and advocacy. Most importantly, the convention is a terrific chance to meet others in the HD community.

To enter, please fill out the application online on our website, www.uihealthcare.com/depts/huntingtonsisease. We have an online form and a form you can print and fill out and return by mail. You may also send a request to the address on the back of this newsletter or call (319) 384-4094 for a paper copy.

From the editor

It’s February, and that means I can see the light at the end of the tunnel: the end of another brutal Iowa winter. That also means the 2011 Iowa Hoop Tour begins soon (see page 3). I can’t wait to travel the state again, shoot some free throws and eat some delicious food! I hope to see you at one of the five locations.

As is always the case, feel free to contact me with feedback at sean-thompson@uiowa.edu or (319) 384-4094. Also, if you want to write something for HIND-Sight, please contact me with your ideas!

Sean Thompson, HIND-Sight editor
2011 Hoop-A-Thon right around the corner

By Kaitlin Basic
UI HDSA COE Intern

When describing the upcoming 2011 HDSA Iowa City Hoop-A-Thon, event co-chair Kelly Herwig says two words sum up the expectations for this year’s event: bigger and better.

“Last year was a success, and we hope to build on that,” Herwig said. “We’re hoping for an even bigger turnout this year. This event really is for the entire community, from elementary school students to college students to adults.”

The Hoop-A-Thon, taking place on March 27 from 1 to 4 p.m. at Iowa City West High School, is a fundraiser for the HDSA Iowa Chapter during which participants shoot for a cure for Huntington disease. Each participant is asked to raise a minimum of $10 or collect pledges per shot made from friends and family. Shooters will have five minutes to make as many baskets as they can from the free-throw line (or closer for younger shooters). Prizes are awarded for top shooters by age as well as for the top fundraiser, and this year, participants can also enter as teams of three or five.

If free throws aren’t your thing, you can win big with the silent auction and raffle. Items available for bid from last year’s event included Chicago Cubs baseball tickets, Iowa football tickets, a Riverside Casino package, Running Wild gift cards, a 90-minute massage from Kratz Massage and various gift cards. The cake walk, Nintendo Wii contest and the concession stand will all be back this year as well.

The event is a great opportunity to learn more about HD and to contribute to finding a cure. Herwig says the event is fun for all ages, and she encourages everyone to join in on the fun (and bring along a friend or two).

As the Hoop-A-Thon makes its second appearance in Iowa City, aspirations are high to increase last year’s success of $5,500 raised for HD research and care. To help further the cause, the coordinators are asking for donations for the silent auction, corporate sponsors and volunteers for the event.

For more information on the 2011 HDSA Iowa City Hoop-A-Thon go to www.ichoopathon.com or search “Iowa Huntington disease” on Facebook. Any inquiries regarding donations or volunteer opportunities contact event co-chair Sean Thompson at sean-thompson@uiowa.edu or (319) 384-4094.

Interns helping plan Hoop-A-Thon

With the success of last year’s first annual HDSA Iowa City Hoop-A-Thon, expectations are high to expand and produce a greater showing this year.

To reach those goals, the HDSA Iowa City Hoop-A-Thon planning committee has hired two public relations/event planning interns who are eager to contribute their thoughts and ideas. Kaitlin Basic and Chelsea Harrison are undergraduate students at The University of Iowa, with career interests in public relations.

Basic is a junior from Lemont, Ill., and is majoring in business and marketing with a minor in Spanish. Upon graduation, she would like to obtain a career in public relations, with the dream of being an event coordinator for a nonprofit organization or medical center.

Harrison is a senior from Urbandale and is majoring in international studies and communications with a minor in Spanish. Upon graduation, she would like to assist with preparations for the second-annual Hoop-A-Thon and are committed to making this year’s event an even greater success.
Protection from HIV leads Top 10 medical breakthroughs of 2010

Excerpts adapted from Time Magazine online at www.time.com.

1. AIDS drugs lower the risk of HIV infection: New research suggests that antiretroviral drugs that have thwarted the virus in HIV-positive patients may have another benefit — as a weapon against HIV infection in healthy individuals.

2. Synthetic cell: The entire genome of a bacterium has been synthesized. The results are already generating organisms that may serve as new types of biofuel, or may even speed up flu vaccine production.

3. Blood test for Alzheimer’s: A new blood test may help confirm a diagnosis of Alzheimer’s disease early in the disease’s progression, which opens the possibility for prevention of dementia and mental decline even before the earliest onset of symptoms. Early results suggest that the test may be 80 percent accurate in identifying patients with the disease.

4. FDA approves Botox for migraines: Allergan, the manufacturer of Botox, successfully convinced the FDA that patients receiving Botox in the facial area experienced fewer days of migraine pain each month than those who did not get the muscle paralyzing injections.

5. Taking the resuscitation out of CPR: New data has shown that chest compressions alone, without mouth-to-mouth, is just as effective as traditional CPR. New rules for CPR put more emphasis on the chest compressions, and in some cases do away with resuscitating breaths altogether.

6. The FDA restricts Avandia: Avandia (rosiglitazone), the medication that helps control blood sugar in patients with Type II diabetes, is under more stringent restrictions and can be prescribed only by physicians who are part of a registry certifying that they are aware of the increased risk of heart attack associated with the drug.

7. Blood test for heart attack: Researchers have identified a panel of 23 genes that code for blood proteins, which is 83 percent accurate in detecting blood-vessel obstructions typical of heart disease. When added to existing measures, it improved by 16 percent the ability to classify patients as being at high or low risk for heart attack.

8. Predicting IVF Success: Researchers have reported a new method for selecting the strongest embryos for in vitro fertilization (IVF), which would drastically increase its success rate.

9. Artificial Ovary: Scientists reported success in creating an artificial ovary that could one day nurture immature human eggs outside the body. In the lab, the cell types functioned for all intents and purposes like a real ovary. The structure could help IVF technicians improve success rates.

10. Creating iPS Cells Safer and Faster: A groundbreaking type of stem cell known as induced pluripotent stem (iPS) cells can be generated from a skin cell, bypassing the need for embryos. The process for generating these cells has just become much safer for patients, plus the technique is about 100 times more efficient.