After 9 years, Leserman bids farewell

Leserman put HD families first, colleagues and families say

By Sean Thompson  
HIND-Sight Editor

When Anne Leserman came to the UI HDSDA Center of Excellence in 2003 to become the center’s social worker and coordinator, her knowledge of Huntington disease was limited.

“I didn’t really know anything about HD other than Woody Guthrie,” Leserman said, referring to the famous folk singer who died of HD in 1967.

Nine years later, Leserman would not only become a wealth of knowledge of the disease for HD families in the state of Iowa, but she would also be one of the preeminent HD social workers in the country. Her tenure at the UI HDSDA COE comes to an end on April 5 when she will leave for New Jersey, where her husband recently started a new job.

Leserman and the UI HDSDA COE have come a long way together since 2003. The learning curve was steep in those early days, she says, but families helped her by asking questions about HD, and she would learn by finding answers.

“The patients and their families knew a lot more than I did,” Leserman said. “The disease had been in their family, so they had to educate you.”

Colleague and UI HDSDA COE Research Associate Pat Ryan says Leserman has been “the hub of HD in the state of Iowa.” Leserman is often the point of first contact for Iowa families needing clinical care or other assistance.

“Everyone – from families and patients to doctors and long term care managers – goes to her with their questions about HD, HD research, caregiving and to vent their frustrations with HD,” Ryan said.

Leserman’s orbit has often stretched beyond the borders of Iowa, says HDSDA CEO Louise Vetter. Leserman has been involved with many HDSDA national social worker initiatives and other projects.

“Anne has been our ‘go to’ person for the answers to so many questions and collaboration on projects HDSDA has launched in the past few years,” Vetter said. “She has been a partner in the truest sense of the word.”

And because of the prominence of the HD research and outreach programs established by UI HDSDA COE Co-Director Dr. Jane Paulsen, people from around the country often turn to the UI HDSDA COE and Leserman as a catch-all resource. Records indicate Leserman has personally communicated with at least 700 individuals or families with HD-related questions and concerns.

“We know that Anne will always keep HD families in her heart.”

Louise Vetter  
HDSDA CEO

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The combination of deep knowledge about HD and empathy are what have allowed Leserman to connect with families, says UI HDSA COE HD Clinic Psychiatrist Dr. Peg Nopoulos. HD affects every patient and every family differently, but Nopoulos says Leserman’s ability to see the commonality and apply what she’s learned in dealing with families has been invaluable.

“With so many families, because it’s a rare disease, they will frequently have nobody to turn to,” Nopoulos said. “As soon as they talk to Anne, she gets it right away, and that’s comforting to people.”

Leserman has been devoted to making the lives of people in HD families better, says Dr. Pedro Gonzalez, neurologist in the UI HDSA COE HD Clinic. Leserman took steps to improve the clinic experience like arranging for a neurologist and psychiatrist, Gonzalez and Nopoulos, respectively, to be the designated HD Clinic physicians for a consistency of care that has benefited the doctors and patients, Gonzalez says.

“She was the glue who kept clinicians, researchers, patients and their families working as a team to improve the lives of those suffering from HD and their caregivers,” Gonzalez said. “She made their lives better, and helped clinicians to do a better job when caring for her families.”

Leserman says it’s getting to interact with “her families,” as Gonzalez puts it, that she’ll miss the most. Ryan points out those families have always felt at ease with Leserman.

“Anne is so warm and approachable and has been here so long, people who are here with me for a research visit tell her concerns that didn’t come out in the entire rest of the day,” Ryan said. “She doesn’t even have to ask any pointed questions; people just simply open up in her presence.”

As she moves on from the UI HDSA COE, Leserman says she’s not sure what she’ll do next, only that she’s not ready to retire. She’ll no doubt take a lot with her from her time at the UI HDSA COE to wherever that next step leads her.

“This has been a wonderful job” Leserman said. “I’ve learned a lot about both HD and about people’s ability to handle the most difficult situation and still be hopeful about the future. There’s this courage in these families that is commendable and inspiring.”

In my own words...

Thanks for the guidance

As I begin the transition from living and working in Iowa to living on the east coast and central New Jersey, I want to thank the HD families that have educated me in the last nine years. With my understanding of the disease, I have been able to educate and support those that need more information and guidance. Thank you for continuing to keep me on my toes. You have taught me a lot about hope and grace as you deal with this ugly disease. And thank you to Jane Paulsen and my colleagues at the University of Iowa for giving me an exceptional work experience and skills to help me in any new activities.

Anne Leserman
UI HDSA COE Social Worker

Join the 2012 Iowa Hoop Tour

It’s time to dust off your high tops, grab some basketballs and shoot for a cure for Huntington disease during the 2012 HDSA Iowa Chapter Hoop Tour.

The annual round of Hoop-A-Thon fundraisers got underway earlier than usual this year with the inaugural Rock Rapids Hoop-A-Thon in northwest Iowa on Jan. 29. The freshest event on this year’s HDSA Iowa Chapter’s biggest fundraiser.

2012 Iowa Hoop Tour remaining dates

Storm Lake: March 31, 11 a.m. - 2 p.m., Storm Lake Middle School. Contact: Amanda Damewood, (712) 200-3076.

Audubon: April 1, 1-4 p.m., Audubon High School. Contact: Carrie Tibben, (515) 321-8131.

Des Moines: April 14, Noon - 3 p.m., AIB College. Contact: Karen Brown, (402) 533-4693.

Iowa City: April 15, Noon - 3 p.m., Iowa City West High School. Contact: Karen Brown, (402) 533-4693.

Abby Cross of Solon shoots at the 2011 HDSA Iowa City Hoop-A-Thon. Photo by Bill Adams

again, as well as having a presence at each Hoop-A-Thon in the state to help educate the public about HD,” said UI HDSA COE Public Relations Director Sean Thompson.

Organizers say donors and volunteers are welcome at all Iowa Hoop Tour locations. Contact the person listed in the graphic to take part in the HDSA Iowa Chapter’s biggest fundraiser.

Abby Cross of Solon shoots at the 2011 HDSA Iowa City Hoop-A-Thon. Photo by Bill Adams

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Anne Leserman
UI HDSA COE Social Worker

HD Support Groups:

Des Moines
Valley View Village Conference Room
2571 Guthrie Avenue
Third Sunday at 1:30 p.m.
Mark Hillenbrand
(515) 208-3511

Omaha, Nebraska
Perkins Restaurant
108 L. Street
Second Monday at 6 p.m.
Cathy McNeil
(402) 537-0739

Iowa City
University of Iowa Hospitals and Clinics
Della Ruppert Conference Room
Fourth Sunday at 1 p.m.
Anne Leserman
(319) 353-4307
Grants offered for HDSA National Convention

The 2012 HDSA National Convention in Las Vegas June 8-10 is expected to be one of the most fun and informative conventions yet, and the UI HDSA COE wants to help families attend by awarding up to five grants.

The COE would like to help those with a familial connection to HD attend the convention whom otherwise might not be financially able to afford attending. Grants will cover the cost of two convention registrations (up to $125 each) and two nights at the convention hotel ($120 per night plus taxes).

Anyone residing in the United States may apply, though preference will be given to residents of Iowa. Applications must be postmarked or entered online no later than April 7.

On the Web
To apply online or print an application, visit www.uihealthcare.com/depts/huntingtonsisease

Studies on caregiving, testing enrolling young participants

Two studies are offering opportunities for young adults, teens and kids to participate in HD research.

Dr. Kimberly Quaid at the University of Indiana School of Medicine is conducting a study involving interviews with people ages 14-25 years old who are at risk for HD and have been tested for the HD gene mutation, as well as those who are both decided and undecided about whether or not to be tested.

Participants will be interviewed once for up to one-and-a-half hours, and again a year later. Participants will receive a $20 gift card. For more information, contact Quaid at kquaid@iupui.edu or Melissa Wesson at mkwesson@iupui.edu.

In another study that can be conducted in person or by phone, Melinda Kavanaugh, MSW, LCSW, of the University of Wisconsin, is looking for participants ages 10-20 that do things big or small to help care for a parent with HD. The goal of the study is to develop support services for young caregivers.

Participants will receive a $10 gift card for the one-time interview lasting up to 60 minutes. For more information, contact Kavanaugh at mkavanaugh@wisc.edu.

Study focusing on HD weight loss

A University of Iowa researcher is hoping to learn more about weight loss and metabolism in HD.

A pilot study, titled “Body Composition in Prodromal HD,” is being conducted by Nancy Downing, Ph.D, R.N., as an optional add-on study for PREDICT-HD participants at the UI. Downing is taking a closer look at why people with HD experience unwanted weight loss and trying to identify what people might be able to do in order to maintain their body weight and improve overall function.

Previous research has shown that weight loss occurs in the later stages of HD, Downing said, even when the number of calories eaten is increased. This weight loss can be a factor associated with declines in overall functioning and quality of life. Researchers don’t yet know, however, if the weight loss is due to loss of muscle tissue, fat tissue or both.

The pilot study, funded by a grant from the Midwest Nursing Research Society, uses a Dual-energy X-ray absorptiometry (DXA) scanner that can measure a person’s fat grams and lean grams, Downing said, which will indicate which tissue is being lost.

People who are not yet diagnosed with HD are being looked at because if the changes that affect weight loss can be pinpointed at this early stage in the disease process, Downing says there may be interventions that could delay or prevent some of the problems that occur because of weight loss later on.

Some of the interventions or treatments that might be looked at as a result of the conclusions reached in this pilot study could include dietary recommendations, a dietary supplement, an exercise regimen or a combination of treatments. Participants will be asked to complete a diet and activity questionnaire.

“It is not clear whether or not exercise is helpful for delaying symptoms in HD,” Downing said. “We hope our pilot study will provide clues and will lead to larger studies.”

Downing will also be looking at metabolism to see if it is being affected by HD. Additionally, a blood sample will be taken to determine amino acid levels. Research shows people diagnosed with HD have low levels of amino acids that are associated with muscle growth, which could be a weight-loss factor.

Anyone currently enrolled in PREDICT-HD at the UI is eligible and welcome to take part in the study, Downing said. Participants are compensated for their efforts with a $25 Target gift card. Contact Downing at nancy-downing@uiowa to participate.
Study: Parents open about breast cancer test results

Children were not distressed when told parents’ test results, study suggests, except the very youngest

From HealthDay

A new study finds that most parents who have genetic tests for breast cancer risk share the findings with their children.

Researchers interviewed 253 parents who underwent genetic testing for mutations in two common breast cancer-related genes (BRCA1 and BRCA2) that can be inherited. All the participants had children younger than age 25 at the time of the genetic test.

Twenty-nine percent of the parents were found to have a BRCA gene mutation associated with an increased risk of breast cancer, said Dr. Angela Bradbury, of the Fox Chase Cancer Center in Philadelphia, and colleagues.

Most of the parents in the study shared their test results (positive or negative) with at least one of their children. Of the 505 children, 334 (66 percent) were informed about the findings of their parents’ tests.

Parents were more likely to share their test results with older children, but results were shared with about half of children ages 10 to 13, and some children who were even younger.

The researchers also found that parents were more likely to tell their children about negative test results — meaning no breast cancer-related mutation was found — particularly if the child was a girl.

Most children were not distressed when told about their parents’ test results, but they were more likely to be upset when a mutation was detected and when they were younger than age 10, according to the report published online Jan. 9 in the journal Cancer.

“We know that adolescence is a time when children establish many important health behaviors they continue in adulthood. An understanding about children’s reactions to these communications may assist parents in their decisions about whether, or when, to share their genetic test results,” Bradbury said in a journal news release.

“This could help parents begin conversations with their children that can encourage them to adopt healthy behaviors but not cause them distress.”