HD radio

Biliardi brings HD to the online airwaves with web radio show

By Sean Thompson  
HIND-Sight Editor

Melissa Biliardi has no formal training as a radio show host. She doesn’t have years of experience behind the microphone. She doesn’t even have a big sound mixing board or anything like that.

But she has a passion for advocating for Huntington disease families and a strong love for her son. And for thousands of listeners across the country and around the world, she’s their voice, helping those with HD and JHD every week.

Biliardi is the host of the “HD View,” a weekly online radio show that features conversation about various topics that are important to the HD community. The show’s guest list runs the gamut: Biliardi has had preeminent researchers like the UI HDSA COE’s director, Dr. Jane Paulsen. She’s had prominent leaders in the HD world like HDSA CEO Louise Vetter. And she’s had numerous HD family members who advocate tirelessly for their loved ones and for those with HD.

“The main goal of the show is to get people talking and listening,” Biliardi said from her home in Santa Maria, Calif. “We want to bring the HD community closer to the people trying to help us, and we want to promote an open line of communication for all of the HD community.”

Biliardi’s son, James Birdsall, is the inspiration for the show, she says. Following James’s HD diagnosis in 2008, Biliardi said she didn’t know where to turn for information and support. So she took matters into her own hands, putting together an HD symposium and forming an HD support group in Santa Maria in 2010.

But once she began connecting with other HD families on Facebook, she realized there was an entire community of people who needed support and information about HD. She decided on an online radio show as a new way to connect people in the HD community.

“It’s all about communication; reaching a person where their heart lies,” Biliardi said, explaining why she chose a radio show. “Even chatting on Facebook and in chat rooms, it’s impersonal. But if you hear someone’s voice, you can hear their passion.”

The show has evolved quite a bit since it was called “Help 4 HD” a year ago. Biliardi said going live for her first show was “the scariest thing I’ve ever done,” but at the same time exhilarating. The show has taken on a more conversational tone, with questions submitted from listeners via email and Facebook. James told his mother she needed to address things like pain that weren’t being talked about openly, so she involved more people from the HD community to act as panelists and ask questions of HD researchers and experts. Furthermore, at least one show per month is dedicated to Juvenile HD, a disease Biliardi says is all too often forgotten about.

Biliardi says the show’s episodes have been listened to over 9,000 times either live or via podcast.

“I’m blown away; I’m flabbergasted,” she said. “I had no idea the show would be as popular as it has been.”

Biliardi says she’ll continue “HD View” for as long as she can, so she can continue to provide a much-needed voice in the HD community.

“We all have a voice and we all need to be heard,” she said. “It gives us power over what the devastation of the disease does to people.

“When you hear other people’s stories, you think, we can do this together, we can manage our lives better by knowing people who are going through the same thing.”
From the editor

The weather’s colder, but winter also brings events like the support group holiday party and COH Dinner. Here’s hoping you enjoy your holiday parties this year!

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

COH Dinner returns to IA
Fundraiser featuring dancing, awards in Des Moines on Nov. 19

By Jennifer Rapp
UI HDSA COE Scientific Editor

If you’re looking for a way to jump-start the holiday party season, in addition to supporting a good cause, make sure you attend the 3rd Annual HDSA Iowa Chapter Celebration of Hope Dinner on Nov. 19.

According to Celebration of Hope (COH) Dinner Steering Committee Member Christy Walker, this is the third time there has been a COH dinner in Iowa, but the first time the chapter has been solely in charge of organizing the event. She said it’s been a learning experience for the dinner organizers.

“The Celebration of Hope Committee has been working for months and is very excited to not only honor those who have contributed so much to the HD community, but also have a chance to raise money for the UI HDSA Center of Excellence. The Iowa Chapter recognizes that we have one of the premier facilities in the country for the research and treatment of Huntington’s disease, and we welcome the opportunity to support this program.”

“If the plans we have I feel it will be a very moving night.”

Lori Wesack
HDSA Iowa Chapter President

This fun-filled fundraising event begins at 6 p.m. at the Hotel Fort Des Moines in downtown Des Moines. Whether you’re an HD family or member of the general public, you can choose to attend dressed in business casual or don your tuxes and sparkling evening gowns.

“I think we will have a lot of fun, and it will be great to put more faces to names,” said Lori Wesack, HDSA Iowa Chapter president. “With the plans we have I feel it will be a very moving night.”

The event will kick off with a cocktail hour and live music performed by Kathy and Company, a string trio from the Des Moines area. As the evening progresses, a scrumptious dinner of fine cuisine will be served that includes smoked salmon on rye bread with dill cream garnish, chicken Milano, vegetarian grilled eggplant capri and tiramisu for dessert. Later, attendees can kick up their heels and dance to music provided by Complete Music DJ service and participate in the silent and live auctions. This special event will culminate in an awards ceremony honoring families and individuals affected by HD and recognizing those who make a difference in our local HD communities. Among those being honored is Peg Nopoulos, M.D., a psychiatrist in the UI HDSA COE HD Clinic and an HD researcher at The UI Carver College of Medicine. Nopoulos will be the recipient of the Excellence in Medicine Award.

Tickets are $75 per person and $700 for a table of ten. Attendees can RSVP by Nov. 16 at www.hdsa.org/ia or by calling 1-800-248-4243. Proceeds benefit the HDSA and the UI HDSA COE, the only facility in the state that provides specialized care, treatment and research for HD families and individuals in Iowa and surrounding states.

Never too early for the holidays

(from L to R) Doris Ingram visits with UI HDSA COE Coordinator Anne Leserman and Research Associate Stephen Cross during the 2011 UI HDSA COE Support Group Hodge Podge Holiday Party on Oct. 23. Attendees celebrated a variety of fall/winter holidays with good food and conversation. The past few December holiday parties coincided with treacherous winter weather, and Leserman said moving the date up this year successfully ended that streak of bad weather luck. Happy Holidays to all of our readers!
New online home for PREDICT-HD

The flagship HD study at the UI HDSA COE has a new website that study staff hope will keep participants informed and provide information to those interested in participating.

The ongoing PREDICT-HD study launched the new www.predict-hd.net in August, said Sean Thompson, PREDICT-HD public relations coordinator. Study leaders thought it was important to have a place on the Web where people could come to get basic study information, news articles about the study and more.

“Our goal was to redesign the website to be the online home for PREDICT-HD,” Thompson said. “I’m very pleased with the website our team developed.”

Visitors to the website can fill out an online form indicating they are interested in joining the study or just want more information. Study staff will then follow up with that person within a few days.

The website also features a listing of HD events where study information will be available or study staff will be in attendance; a listing of all published articles in medical journals written by PREDICT-HD researchers and more.

“Not only is there lots of good information for people to browse, but we also tried to make the website easier to navigate to find what you are looking for,” Thompson said.

The website also contains a link to the study’s YouTube Channel.

More than a walk in the park

(from L to R) UI HDSA COE Research Assistant Pat Ryan and Research Associate Michelle Harrel checked out the silent auction items at the 2011 HDSA Iowa Chapter Team Hope Walk in Ankeny on Sept. 17. The fundraiser was held on the campus of Des Moines Area Community College for the second year in a row, a location UI HDSA COE Coordinator Anne Leserman says is a great setting for the walk, featuring a pond and flower gardens. The expanded walk doubled last year’s total by raising over $9,000, which will help to fund patient services at the UI HDSA COE, said HDSA Iowa Chapter President Lori Wesack. Thanks to the HDSA Iowa Chapter and all those who attended for supporting the UI HDSA COE!

I HATE HUNTINGTON’S DISEASE

By Janice Singer

Dedicated to my sister Kathy Peppler

(Editor’s Note: The following poem was submitted by a reader for inclusion in HIND-Sight)

One tiny mutant gene
Creates years upon years
Of lives cut way too short
And way too many fears

Many generations
Have carried this along
With the same old ending
To the same weary song

A 50/50 chance
Hardly seems a fair shake
When the dreaded outcome
Is a family’s heart break

Grandma, two aunts, mother
All lived the wretched pain
And now my sister’s gone
Opens the wound again

Families torn too often
Cutting off life mid stream
It’s not at all discrete
Where it shatters a dream

It spares not the children
From growing up too fast
For they know all too well
Their years here might not last

At-risk are chilling words
That I know all too well
As this heartless disease
Puts a family through hell

No one is free from it
My father was not spared
What would happen to us
This disease never cared

Healthy genes I do have
Knowledge not known for years
Precious time lost indeed
And oh so many tears

HD studies currently enrolling at the UI

• PREDICT-HD: For pre-symptomatic, gene-positive individuals. Contact Sean Thompson, sean-thompson@uiowa.edu, 319-384-4094

• CREST-E: For symptomatic, diagnosed individuals. Contact Jacky Walker, jacky-walker@uiowa.edu, 319-353-4357

• 2CARE: For those with mild-to-moderate HD. Contact Jacky Walker, jacky-walker@uiowa.edu, 319-353-4357
Research study started through social media


After surviving bypass surgery for spontaneous coronary artery dissection, or SCAD, Katherine Leon set out to connect via an online network with other SCAD survivors, one as far away as New Zealand. What distinguishes this group of patients, however, is that they succeeded in persuading researchers at a major medical center to launch a research program to learn more about SCAD.

The results of a pilot study conducted by researchers at the Mayo Clinic were published online in the journal Mayo Clinic Proceedings.

The social network “is a catalyst and it allows us to gather a critical mass of patients,” says Sharonne Hayes, a Mayo cardiologist who is leading the project.

In the past decade, thousands of patients have flocked to Internet chat rooms and message boards for support and advice on managing health problems. The SCAD effort is a rare case of patients using a network as a potent tool to lobby for more research, presenting scientists with a ready-made collection of subjects.

To connect with other SCAD patients, Leon began posting on www.WomenHeart.org, an advocacy group for women with heart disease. She hatched the idea of using the patient group to push for a research project into the disease in the fall of 2009. Around the same time she met online Laura Haywood-Cory, of Durham, N.C., who had suffered her SCAD in March of that year. Together, the two women moved the project forward.

Feeling that SCAD patients were hard to follow on a message board dealing more generally with heart disease, Haywood-Cory started a new thread to link them together. She headlined the post: “All the SCAD Ladies Put Your Hands Up!” – a take-off on the Beyoncé hit “All the Single Ladies.” The thread quickly began filling up with stories.

The next month, Leon and Haywood-Cory attended a workshop on women and heart disease at the Mayo Clinic, where they met Dr. Hayes. Armed with about 80 stories from the SCAD message board, Leon asked Hayes to consider a study, which she tentatively agreed to a couple of weeks later.

The SCAD message board was filled with enthusiasm. “It would be such a relief for all of us to have some real, current, relevant research done on SCAD, and so finally the possibility of some much-needed answers,” wrote Sharon Sutton, 43, of New Zealand.

Within a week of a final agreement to launch the 12-patient pilot study, 18 people had volunteered.