Doubling impact for HD families

Angel Dominguez, the new UI HDSA COE social worker, wants to end each day at work knowing that she made an impact, no matter how big or small.

**Dominguez provides help and hope in social work and research role**

**By Sean Thompson**

**HIND-Sight Editor**

On its face, the job title that Angel Dominguez holds, “social worker,” is not all that descriptive. In fact, it can be downright confusing.

Instead of trying to define social work, let’s instead ask Dominguez, the UI HDSA Center of Excellence’s new social worker, why she wanted to be one in the first place.

After personal experiences as a patient at a young age, Dominguez knew she wanted to work in the health care field where she could help people in some way. In college, she found that becoming a social worker was the perfect way to fulfill those goals.

“I was really into working with people and I was especially interested in medical social work,” Dominguez said, “being there for families who were going through medical hardships. I’ve always had a passion for being around others and working with people and being that advocate or a resource for those in need.”

A 2014 graduate of the UI with a bachelor’s degree in social work, Dominguez also earned a master of social work degree from University of Southern California. The Davenport native came to the UI HDSA COE in February after providing social work services for dialysis patients in end-stage renal disease in Orange, Calif. She says that experience left her well-prepared to establish tight-knit relationships with HD families.

“I want to be someone patients and families can lean on and turn to for whatever they need,” Dominguez said.

The ability to double her impact by adding direct involvement in research to social work role was one of the highlights of Dominguez’s new gig.

**SSA to update disability benefits criteria**

Thanks to the efforts of many in the HD community over several years, the Social Security Administration (SSA) will soon be considering the full picture when it comes to HD symptoms, a big step toward equitable decisions regarding benefit eligibility.

Previously, with regards to the eligibility criteria for Social Security Disability Insurance (SSDI) benefits, the SSA considered HD strictly a movement disorder, which ignores the cognitive and behavioral aspects of the disease. The addition of these previously overlooked symptoms to the SSA’s medical criteria describing HD could lead to many more people with HD receiving much-needed disability benefits.

“For individuals who have HD but are experiencing more of the cognitive and behavioral symptoms, this will provide them the opportunity to apply for benefits,” said UI HDSA Center of Excellence Social Worker Angel Dominguez. “That’s why it’s exciting because as we know, HD can manifest and affect people differently.”

The new guidelines go into effect on Sept. 29, 2016. At that point, both applicants and social workers will begin to understand the full impact of the updates.

All involved in this effort to have the SSA criteria updated credit the HD community for speaking up and remaining steadfast and optimistic. While this ruling accomplishes part of what the HD community hoped to see addressed with the federal HD Parity Act legislation, there is still a need to pass the second part of the act’s two-fold aim, which is to remove the two-year waiting period to receive Medicare benefits.
A month of HD awareness

**DOMINGUEZ continued from P. 1**

her social work duties drew Dominguez to the UI HDSA COE. She relishes the chance to not only help those in the HD community with what they need right now, but also give them hope through involvement in research.

“I think it’s a pretty unique opportunity,” Dominguez said. “You get to see the impact on multiple levels.”

Dominguez said her patients and research participants have also been her best educators when it comes to HD.

“When I first started, I would say that I was new and I want to know what HD means for you and your family,” Dominguez said. “I’ve found a lot of people really wanted to share their story.”

For Dominguez, in the end, social work does come down to being “social.” She says the best part of her job is interacting with HD family members in her dual research-and-helping role. And she is grateful for the social reciprocation that HD family members have given her.

“Thank you for being so open and honest about your experiences, both good and bad,” Dominguez says to those she’s interacted with so far. “That provides me with a better understanding of how I can be a better researcher and social worker for the HD community.”

**Miller departing as COE social worker**

When Amanda Miller closes her eyes to reflect on her time at the UI HDSA COE, she sees the faces of patients, research participants, and colleagues that have meant so much to her.

“Many of those faces remind me of fun, laughter and friendship,” Miller said. “Many remind me of the pain that this disease inflicts on the lives of those it touches. Many give me hope. Their faces are resilient, hopeful and determined.”

On June 1, Miller began a new position as program director for a forthcoming UI mood disorders center.

Amanda Miller has always been able to process whatever problem an HD family member came to her with and work to find a way forward, says HDSA Iowa Chapter President Tammy Miller, often relying on resourcefulness to do so. “She genuinely cares about the people she is helping,” Tammy Miller said. “She doesn’t just give up if the easy answers don’t work. She does all this with a genuine and caring heart.”

HD families have shown Miller that even though HD is very hard to deal with, HD families are doing great. There are going to be impossibly challenging days, and Miller has been happy to be there during those challenging times.

“Thank you for helping us fight this disease,” Miller said. “Thank you for your volunteerism in research, for your patience with us as we try to find the right medication dosages to help with your symptoms. Thank you for not giving up and for giving us hope.”

Several upcoming HD events in Iowa

There’s no shortage of educational, social and fun HD events in the coming months in Iowa.

HDSA’s 2016 Person of the Year Krissi Putansu will give a presentation Oct. 14 at 2 p.m. in the Damasio Conference Room (Elevator C, 7th Floor) in the UI Hospitals and Clinics in Iowa City. Putansu will discuss her experiences with HD as a caregiver and at-risk individual. Contact Angel Dominguez at 319-353-4162 or angel-dominguez@uiowa.edu for more information.

Iowa features two Team Hope Walks this season, one in Ankeny on Sept. 24 at 4 p.m. at Des Moines Area Community College; and one in Coralville on Nov. 12 at 9 a.m. inside Coral Ridge Mall. Contact the chapter at hdsaiowachapter@gmail.com for more information.

Finally, the annual HDSA Iowa Chapter Celebration of Hope Dinner takes place on Nov. 5 in Des Moines at the Holiday Inn & Suites in West Des Moines. The event features live music, live/silent auctions and awards. Contact hdsaiowachapter@gmail.com for tickets, auction donation and sponsorship information.

In our most active HD Awareness Month yet, UI HDSA COE staff organized (from top clockwise) a “Lindy Bomb” swing dance event, an Iowa Memorial Union (IMU) info table, and a blue flags-and-pinwheel display on the Pentacrest. Other activities included lighting the IMU blue.

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**HD Support Groups**

**Des Moines**

Valley View Village Conference Room
2571 Guthrie Avenue
Third Sunday at 1:30 p.m.
Mark Hillenbrand
(515) 277-0814

**Omaha, Nebraska**

Valentino’s Italian Buffet
5022 S. 108th Street
Second Thursday at 6 p.m.
Tiffany Smith
(402) 880-7694

**North Liberty (Iowa City)**

North Liberty Recreation Center
520 W. Cherry Street
Fourth Sunday at 1 p.m.
Angel Dominguez
(319) 335-6640
Weekly HD Clinic to serve more patients

To meet the growing needs of the HD community in Iowa and beyond, the UI HDSA COE’s HD Clinic is expanding to take place each week. This expansion means more patients will have quicker access to specialized care from the clinic’s team of multidisciplinary care providers.

“Providing excellent patient care is our number one priority,” said Shawna Feely, coordinator of the HD Clinic and a UI HDSA COE genetic counselor. “Expanding the clinic to weekly allows us to meet all of our patients’ clinical needs in as timely a manner as possible.”

In order to expand, the team will soon include three new staff members: Psychiatrist Dr. Kathryn Kenney, Neurologist Dr. Annie Killoran and Genetic Counselor Kaylee Faulkner. Existing patients will continue to see their current doctors, Feely says, in order to maintain continuity of care that is a priority for HD patients.

The expansion of the clinic adds to the highly-specialized care and research offered by clinicians and researchers who know HD very well and work well together, Feely says. In addition to seeing a neurologist and psychiatrist, patients are provided the care that they specifically need. Participation in research studies like Enroll-HD is also available as part of a comprehensive clinic visit.

“I have worked in different HD clinics during my career, and I can definitely say at this point that if I had a loved one with HD, I would bring them to this clinic,” Feely said. “Every single team member really cares about the patients and families we serve. That is their number one priority.”

To make an appointment with the HD Clinic, please contact the UI HDSA Center of Excellence at 319-353-4307 or hdcenter@uiowa.edu.

Training helps law enforcement understand HD

training helps law enforcement understand HD

Amanda Miller. “Sometimes these are easily resolved, although sometimes they end in a court case. But for the most part, this training is meant to be a preventative measure.”

Sharing clinical facts and personal experiences to build understanding

The 90-minute training sessions offered to Iowa police departments and other first responders are a joint effort from the UI HDSA COE and the HDSA Iowa Chapter. UI HDSA COE staff provide general information about HD and descriptions of different psychological and physical symptoms and HDSA Iowa Chapter President Tammy Miller and Vice President Jamie Parish discuss their own family experiences with HD and law enforcement.

Parish’s personal connection to HD allows her to give police officers a real-life, first-hand account of the different stages of HD. “At the beginning I tell a short version of my story and let the officers know I’m gene positive for the disease, so I may look normal now but when I do get sick I will slowly develop symptoms that aren’t visible. This also shows how the disease has very different stages and looks different in everyone.”

Leading the way in HD trainings

Having a personal connection to HD, Altoona Chief of Police Jody Matherly was the first in Iowa to seek the training for his officers to ensure safe interactions between law enforcement and persons with HD and other mental illnesses.

“Up to 60 percent of individuals in prison are affected by mental illness,” said Matherly. “The first step in any resolution is keeping out those in prison who don’t need to be there. It is very important for us to be keenly aware that these illnesses do exist and we need to recognize them when we see symptoms and we need to know what to do.”

The training focuses on crisis intervention, de-escalating a situation, and then identifying the mental illness.

Trainings met with success

Approximately 200 officers from four departments have already been through these sessions with great success, and the trainers are hoping to reach a few more departments by the end of the year.

Matherly has noticed the benefit of these sessions in his precinct. “The officers left with a better understanding of HD—they know what it is and how it directly relates to law enforcement concerns, and this was key.”

HD studies currently enrolling at the UI

- Enroll-HD: An observational study for anyone in the HD community. Contact Angel Dominguez, angel-dominguez@uiowa.edu, 319-353-4212.
- Exercise-HD: An observational study for gene-positive PREDICT-HD participants who do not engage in vigorous exercise. Contact Emily Shaw, emily-m-shaw@uiowa.edu, 319-353-3861.
- HD Mobile App: An observational study for gene positive, gene negative and diagnosed individuals. Contact Owen Wade, owen-wade@uiowa.edu, 319-353-5336.
Scientists have discovered a bacterium living inside the human nose that produces an antibiotic capable of killing one of the most hard-to-treat pathogens — a pathogen that causes serious, even deadly skin and wound infections, bloodstream infections and pneumonia.

German researchers found that this antibacterial substance was effective in treating skin infections in mice caused by Staphylococcus aureus bacteria, according to a study published in *Nature*. The scientists said the substance, which they named lugdunin, has potent antimicrobial effects against a wide range of bacteria, including antibiotic-resistant strains such as methicillin-resistant S. aureus (MRSA).

The scientists said their find represents the first known example of a new class of antibiotics. That’s particularly welcome news given the urgent global problem of antibiotic-resistant superbugs and the dwindling arsenal of drugs to replace ones that no longer work.

Until now, conventional antibiotic discovery has focused on looking for compounds from bacteria living in dirt. The new research, from Andreas Peschel and colleagues at the University of Tübingen, suggests that the immense variety of microorganisms living in the human body, particularly in the nose, may be a potential source of new antibiotics.

The German researchers said lugdunin also is not prone to causing *S. aureus* to develop resistance. They are not exactly sure how it works, and clinical development is many years away and will require partners from the pharmaceutical industry, they said.

Bacteria that live in the human body number more than a thousand species. Many compete for space and nutrients. Perhaps the pathogen residing in the nose developed the mechanism to produce an antibiotic that knocks out other bacterial species, allowing it to survive in a “nutrient-poor” environment filled with “soggy fluids,” Peschel said.

In testing the lugdunin on mice that had skin infections caused by *S. aureus*, the researchers said some of the infections were completely cleared and others dramatically reduced. In two mice, the infection was not cured.

“Some mice just licked off the antibiotic,” Peschel said.