Pa. girl helps others like her

She inspires researchers, others and raises funds for a cure for JHD

By Sean Thompson
HIND-Sight Editor

Nine-year-old Virginia Buck does not ask for much for herself. In fact, the only thing she really asks is that you try and understand what she and other kids like her are going through. Virginia is living with Juvenile Huntington disease, a fatal neurodegenerative genetic disorder that causes problems with walking, talking, thinking and behavior.

She might also ask you to donate a few pennies for her water-cooler jug, which she uses to collect donations to send to the UI HDSA COE to support Juvenile Huntington disease (JHD) research. The Tyrone, Pa., girl says she does this to help other kids living with JHD. The loose change will add up, she says; it will mean something. It means something for the kids who need research to find a cure for a disease that makes their bodies behave differently than other kids, makes them take longer to say what they are trying to say and makes them feel misunderstood.

Virginia's simple wish to fill her water jug with pennies led to a day-long event that raised a wealth of awareness and nearly $2,400 for JHD research that is urgently needed but underfunded, according to Prof. Jane Paulsen, Ph.D., co-director of the UI HDSC COE.

Virginia's father Michael is in the late stages of HD. Virginia was diagnosed in 2008 with JHD, a rare, more rapidly-progressive form of HD that is often fatal within 10 years of onset. An article in PLOS Currents Huntington Disease says only about five percent of all HD cases are JHD.

Shortly after her diagnosis, Virginia told her mother she wanted to make a difference and help find a cure for JHD. She decided to start collecting the pennies that many people don't even think about or would rather leave behind. “People don't look at [pennies] as valuable, but to her, they mean something,” her mother, Lisa Buck said. “And in a lot of ways, she feels like those pennies that people don't want or understand. She wants to make people know that pennies do mean something.”

Virginia met Ryan Myers, 18, when she was an honorary cheerleader for a local high school team that Myers helps coach. The two decided to hold a fundraising event, and Virginia suggested they hand out coffee. Myers, who said in an article in the Centre County Gazette he was inspired by Virginia's positivity and desire to help others, got the word out about the “Coffee for a Cure” event and recruited volunteers. Virginia told everyone she encountered about the event, Lisa Buck said.

On a chilly Nov. 13, Virginia, her family, Myers and a team of volunteers stood in front of The State Theater in State College, Pa. for 10 hours, handing out coffee and collecting donations. Katie Moser, a former president of the HDSA's National Youth Alliance and a well-known HD advocate who herself tested positive for HD, heard about the event on Facebook and decided it was well worth the two-hour drive to meet Virginia and show her support.

“Coffee for a Cure” was a hub of endless activity, Moser said, as an estimated 1,500 people stopped by. Several local newspapers and TV stations covered the event. Some local families affected by
Measuring quality of life in HD

Study develops measure to be used in clinical trials to improve health

A new measure being tested through a study at the UI HDSA COE and elsewhere aims to combine new and existing tests in order to measure quality of life in HD.

The study, Validation of the Huntington disease Quality of Life Measure (HDQLIFE), attempts to develop a new tool to evaluate quality of life (QOL), specifically for people affected by HD, said Principal Investigator Noelle E. Carlozzi, assistant professor at the University of Michigan.

In this context, quality of life refers to how one’s health affects the different areas of their life, Carlozzi said. That’s why she’s collecting data relating to HDQLIFE participants’ social, mental, physical and cognitive health. Some existing ways to measure QOL are part of this study, but other HD-specific measures of things like chorea and speech/swallowing difficulties are also being implemented in order to make this new QOL measure more meaningful for people with HD.

“We want something that addresses the special needs of the HD population,” Carlozzi said. “A lot of times we use general measures that don’t address HD-specific issues.”

Once the HDQLIFE measure has been refined and validated through this study, researchers could use the measure in future clinical trials, to see if quality of life improves as a result of a treatment.

“Ultimately as we find treatments for people, we don’t only want to prolong life or minimize symptoms,” she said. “We want to make sure that people are also feeling better.”

HDQLIFE researchers will also be working to develop a computer adaptive testing (CATS) format. Courtney Shadrick, a research associate at the UI HDSA COE who will be coordinating the study here, says CATS will be able to eliminate parts of a given questionnaire that aren’t applicable based on previous answers given by the participant. Shortening an otherwise lengthy questionnaire is important, as they can be burdensome for people with HD.

“CATS give you all the information of a longer test but in a shorter amount of time,” Shadrick said.

Anyone who has tested positive for the HD gene expansion as a part of PREDICT-HD study are already being collected as a part of PREDICT-HD.

Shadrick says she’s looking forward to working with participants and meeting lots of new people, as this is the first study she’ll be coordinating since joining the UI HDSA COE in August.

“Hopefully this measure will become the gold standard for measuring quality of life in HD patients,” Shadrick said. “And hopefully it’ll be used to improve the lives of people with HD.”

If you are interested in participating in this study, please contact Shadrick at courtney-shadrick@uiowa.edu or 319-353-5443.

Closing the year with hope

(L to R) UI HDSA COE staff Stephen Cross, Pat Ryan, Michelle Harreld and Joy Goins at the tropical dinner.
Support group holiday party gets crafty

UI HDSA COE HD Support Group Facilitator Shawna Feely decided to add a new element to the group’s annual holiday party on Dec. 9. In addition to delicious holiday treats and good conversation, the group worked on an art project consisting of a colorful array of the attendees’ handprints surrounding a traditional HDSA-blue ribbon with the words “Cure Huntington’s.” Above, (L to R), UI HDSA COE Co-director Jane Paulsen, Carolyn Speth, Terry Speth and Jane Knudson leave their handprints on the canvass.

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HD and JHD stopped by to connect with the Buck family. And throughout, Virginia was there, with a smile on her face, telling people about JHD and that even if they just donate a penny, it will help.

“I don’t know many kids her age who could have been there all day, especially in the cold,” Moser said. “She’s a wonderful and caring young lady; very inspiring. I enjoyed getting to know her and hang out with her.”

Weeks after “Coffee for a Cure,” Virginia still speaks of it with much enthusiasm.

“It was awesome,” Virginia said. “We raised a lot of money, and I met more people with JHD.”

The amazing effort put forth by Virginia has inspired researchers at the UI HDSA Center of Excellence, Paulsen said.

“We are so very proud of Virginia’s efforts,” Paulsen said. “To know she’s out there raising money and telling people about JHD motivates us to do more.”

The funds raised support research like Paulsen’s JHD Natural History Study, which attempts to learn more about the disease and improve tools to follow the course of the JHD.

Virginia knows the impact HD has had on her dad and on her friend in Michigan who has JHD. She has had friends on Facebook that have lost their lives to JHD. Lisa Buck says her daughter understands that as it stands, there is no cure for her, either. But Virginia’s goal is to help someone else if she cannot be helped in time.

It’s difficult to find the words to describe that level of selflessness from a nine-year-old, but her mom does.

“It makes me one proud mother, very proud, but in the same sense, it hurts,” Lisa Buck said, pausing for several seconds at the thought of her daughter’s cruel prognosis. She continues.

“She has said to me that whenever she passes, she wants me to please continue the fight for funds for research,” Buck said, “and I have given her my word that I will do whatever I can for that.” She pauses again.

“To me, Virginia is my hero. She has taught me more than I could ever teach her.”
In the aftermath of Christmas, a parent could be forgiven for thinking that materialism has trumped human kindness.

Take heart. Children can easily become kinder and more helpful. And that behavior makes them more positive, more accepting and more popular.

At least that’s how it worked for fourth and fifth graders in Vancouver, Canada. Researchers there have been studying empathy and altruism in schoolchildren for decades.

“How do we decrease bullying, increase empathy and caring for others?” says Kimberly Schonert-Reichl, an applied developmental psychologist at the University of British Columbia who helped lead the experiment.

They wanted to see how performing random acts of kindness would influence that. But one measurement thrown into the mix almost as an afterthought — being liked by peers — was the quality most improved by helpful acts.

The researchers asked 9-to-11 year-olds in 19 classrooms to either perform three acts of kindness or visit three places each week (the tourists were the control group).

After four weeks, the researchers tested the kids and compared the results with tests they’d taken before. All the children had more positive emotions, and were slightly happier.

But the children who performed acts of kindness were much more likely to be accepting of their peers, naming more classmates as children they’d like to spend time with.

“I do think we’re on to something,” said Schonert-Reichl. The children were at an age when bullying can be more extreme, she says, and children become more self-conscious. So an increase in peer acceptance could benefit in the classroom and in social life. The study was published online in the journal PLOS One.

Parents don’t have to have a Ph.D. to encourage these sorts of simple acts of kindness in children — or in themselves.

“I think of ways to start the New Year, and people making resolutions,” says Schonert-Reichl, a former middle school teacher and mother of two boys. “Can I do an act of kindness for someone every day?”

Acts of kindness could lead to more accepting and positivity, researchers say.