12-9-2018

Building solidarity in disease communities’ quest for better care and treatments: a conversation with a young tennis award-winner

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Digital USD Citation

Serbin, Kenneth P., "Building solidarity in disease communities’ quest for better care and treatments: a conversation with a young tennis award-winner" (2018). *At Risk for Huntington's Disease*. 261.
https://digital.sandiego.edu/huntingtons/261

At Risk for Huntington's Disease

HD is a genetically caused brain disorder that causes uncontrollable bodily movements and robs people's ability to walk, talk, eat, and think. The final result is a slow, ugly death. Children of parents with HD have a 50-50 chance of inheriting the disease. There is no cure or treatment.

SUNDAY, DECEMBER 09, 2018

Building solidarity in disease communities' quest for better care and treatments: a conversation with a young tennis award-winner

In disease communities, it's easy for affected individuals and their families to become insular as they struggle with the many challenges posed by their particular illness. To attract the attention and funds needed to combat a disease, sometimes they even portray their condition as more devastating than others.

In the Huntington's disease community, we refer to HD as "the devil of all diseases," like a combination of Alzheimer's, Parkinson's, and psychiatric and behavioral disorders, including a high suicide rate. There is no treatment for stopping disease progression.

However, in the quest to treat difficult chronic illnesses, disease communities need to build solidarity and learn valuable lessons from one another. Also, although the causes and symptoms of diseases vary widely, the different communities share the common cause of overcoming the limits diseases place on people's lives.

I had a reawakening about solidarity a year ago this week. At the University of San Diego (USD), where I'm in my 26th year in the Department of History, a new advisee, 20-year-old sophomore Garrett Kurtz, sat in my office as he began to recount his own battle to live with type 1 diabetes.

Suddenly, Garrett untucked the left side of his shirt to reveal a device about the size of a small smartphone attached to his waist. He explained that it was a pump that gave him injections of insulin, which helps convert sugar in the blood so that it can enter the cells and allow them to use energy. Type 1 diabetics cannot produce this essential hormone.

I felt an immediate bond with Garrett. I shared a bit of my family's fight against HD, including my HD-afflicted mother's death and my condition as a gene carrier.

Remarkably, I learned, despite his potentially limiting condition, Garrett has played competitive tennis since he was seven and a half. By 12, he was ranked in the top 50 male players in the nation, and in the top ten in Southern California. He now plays for USD's men's team, a top 35 National Collegiate Athletic Association (NCAA) Division I team.

As Garrett explained, few prominent athletes have diabetes. Choosing the rare but ingenious combination of a history major and chemistry minor, he aims to work for a biotech or similar firm with the goal of helping physically active people, including athletes, better manage their diabetes.

For his efforts, in July Garrett was named one of two 2018 Novo Nordisk Donnelly Award national winners. The award includes a one-time $7,500

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scholarship towards education, tennis development, and/or medical care. These and smaller awards go to male and female athletes ages 14-21 who are in good academic standing, manage diabetes, and play tennis competitively in tournaments or on their school team.

Garrett received the award from all-time tennis great Billie Jean King, a type 2 diabetic.

Garrett Kurtz and Billie Jean King (photo from @USDmtennis)

The inspiration of Billie Jean King

"To receive an award from someone like her was absolutely incredible, and I'm extremely honored," Garrett said in a November 14 interview with me at USD, recalling King as a "trailblazer" in women's sports, gender equality, and LGBTQ advocacy.

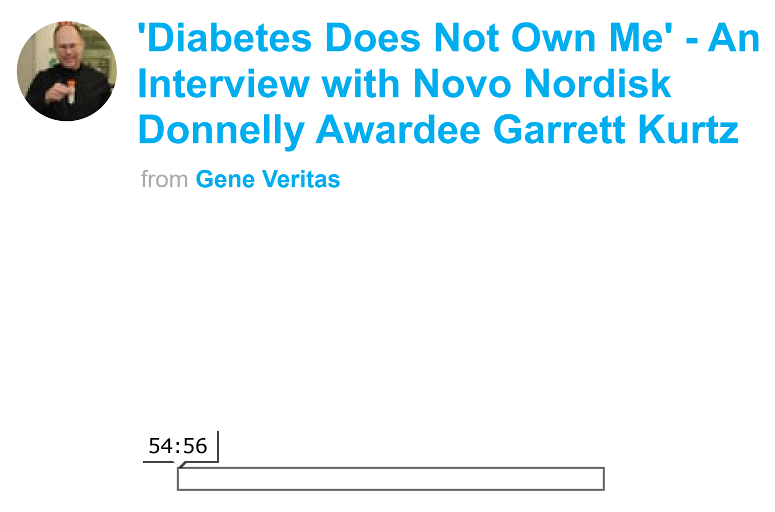
After speaking with King for an hour, Garrett was inspired by her personality and positive attitude.

"She was very direct," he said. "She had an aura of self-confidence. She talked about how having self-confidence and a vision is something so important to people of all ages, but especially young people, wherever they may be in society."

The awards take their name from Diane Donnelly Stone and Tracey Donnelly Maltby, two sisters who became college tennis stars and have lived successfully with type 1 diabetes since childhood. Novo Nordisk, a Denmark-based global healthcare firm with a focus on diabetes, became the award's title sponsor in 2002.

"They want to highlight specifically tennis players who are type 1 diabetics and basically give them a voice or recognition for what they go through every day, the struggles that they have to deal with," Garrett commented.

You can watch my interview with Garrett in the video below.



'Diabetes Does Not Own Me' - An Interview with Novo Nordisk Donnelly Awardee Garrett Kurtz

from Gene Veritas

Diagnosed with type 1 diabetes

Garrett and his parents discovered that he had type 1 diabetes when he was seven, just around the same time he started playing tennis in his hometown of Newport Beach, CA.

"I was extremely thirsty and dehydrated," he recalled. "I also had lost some weight. One of the unrelated members of my family had type 1 diabetes and we had a spare blood sugar test kit in my house. My mom took my blood sugar and I was extremely high and that was a strong indicator of what was happening. I was taken to the hospital and diagnosed pretty soon afterwards."

Other type 1 symptoms include fatigue and weakness, frequent urination, extreme hunger, irritability and other mood changes, and blurred vision.

"I think diabetes is a very unique disease, because you cannot take a medication and just be good for the day," Garrett said. "It's a 24/7/365 type of disease where everything that I do – whether it be studying, exercising, eating, the anticipation of waiting for something, being happy – diabetes affects it."

With vigilant management of the disease, today his symptoms are under control.

Understanding type 1 and type 2

In 2015, more than 30 million Americans had diabetes, 1.25 million with type 1 and the rest with type 2.

Type 1 was previously known as "juvenile diabetes" but actually affects more adults than children. It occurs in all ages and ethnic groups.

Garrett explained the differences between the two types.

"Type 1 is an autoimmune disease, which basically means your immune system attacks part of your body, whereas type 2 comes from your lifestyle, what you eat, and it's not necessarily hereditary," he said. "There's a whole host of autoimmune diseases."

His father has ankylosing spondylitis, believed by some researchers to also be an autoimmune disease. It has the same genetic marker as type 1 diabetes, but the doctors "don't know if there's a link between that and my diabetes," Garrett said.

"Type 1 is something that you cannot control," Garrett continued. "Basically what happens with a type 1 diabetic is that your immune system – and this is the great mystery with type 1 diabetes, whether it's your environment or something you eat or it's just how your body works – attacks all of your beta cells, which are produced by your pancreas."

Beta cells produce insulin, Garrett explained. Insulin breaks food, especially carbohydrates, down into glucose, which is the blood sugar that diabetics measure by pricking their fingers.

"Insulin attaches itself to the sugar and allows it to get transferred to the individual cells and allows them to use the energy, for you to function and exercise," he said.

Type 1 diabetics must "manually administer" their insulin via injection or a pump such as Garrett's.

Type 2 diabetes generally results from an unhealthy lifestyle, including obesity, lack of exercise, and poor diet.

"A type 2 diabetic is different in the sense that they become insulin-resistant," Garrett explained. "You become so used to consuming so much, that your body keeps producing more and more insulin. It becomes a point where it's like taking too much of a drug. It's like becoming addicted. You need more and more and more until the point where the insulin just doesn't become effective."

Unhampered on the court

From 2012 to 2015, another unexpected, painful, episodic condition hit Garrett, this time sidelining him from competitive tennis. After consulting with nearly a dozen sports orthopedic specialists and undergoing many MRI scans, he learned that he had a rare physical abnormality: a blood vessel was sitting on the nerves of his inner right elbow. In late summer 2015, he underwent a successful surgery to relieve the pain, enabling him to return to the court.

In 2016, after another tennis player recommended Garrett, USD head tennis coach Ryan Keckley recruited him for the team.

"With the understanding that he was a top ten player, and understanding his character, his family, and his love for the game, we decided to offer him an opportunity to play for USD," Keckley told me. Since his arrival, Garrett has played in several important matches for USD. Keckley said he expects Garrett to compete in the upcoming spring 2019 season.

Receiving the Novo Nordisk Donnelly Award was "really a testament of his character and his work ethic," added Keckley, a top player while a student at the University of Notre Dame. "There are very few athletes that have been able to manage what he manages, and are successful at it. This gives him an edge in seeking to go into the field of studying diabetes."

Given Garrett's small stature for tennis – 5-7, 150 lbs. – "he needs to be the little engine that could," Keckley observed. "He has learned how to be tougher than his opponents, which is ultimately why he was one of the ten best players in the country in the 14 and unders."

Because of Garrett's careful management of his diabetes, the condition has not hampered his play, Keckley added.

"If you didn't know Garrett, you wouldn't know it was something he dealt with," he said.

Garrett Kurtz at practice (photo courtesy USD Men's Tennis Team)

The hope of managing HD

I told Garrett that we in the HD community hope for the breakthrough that allows patients to manage the disease in a way not unlike how he controls his diabetes with his pump. HD is also a 24/7/365 disease. HD patients, I speculated, might tweak their own administration of drug the way he does.

Still, to affect HD, a drug must cross the highly protective blood-brain barrier, a monumental task for drug researchers.

HD drug developers have discussed the possibility of using pumps to deliver a drug. In 2008, in my first visit to the former Isis Pharmaceuticals, Inc., now Ionis Pharmaceuticals, Inc., the company's senior vice president, Frank Bennett, Ph.D., explained how the company used this approach. (Click here to read my 2008 report.)

Ionis researchers inserted pumps under the skin of mice, then, for each mouse, ran a tube into the brain to deliver an experimental gene-silencing drug. At that time, researchers were considering the use of a hockey puck-sized pump placed in the abdomen of HD patients, which would pump the drug through a tube carefully inserted into the brain.

In our discussion, Dr. Bennett pointed out that people with a number of conditions such as chronic back pain or diabetes already used commercially approved pumps. Doctors could use infrared signals to program the pumps and control the flow of medication and could inject a new supply into the pump through a port just under the skin.

"It's obviously not ideal, but considering the severity of this disease, it's well worth the inconvenience that these pumps produce," Dr. Bennett observed in 2008. "Once patients acclimatize to them, they're really not that bothersome."

A pump instead of spinal taps?

Indeed, Ionis was exploring the possibility of pumping an HD drug into the cerebrospinal fluid (CSF), which bathes the brain, via pump. It had already used one of its drugs to reduce the effects of Lou Gehrig's disease in test rodents using this method.

So far, such pumps aren't being used in HD clinical trial. In its historic, highly successful Phase 1/2a clinical trial, completed in December 2017, Ionis injected the drug via lumbar puncture (spinal tap) four times into the CSF of 46 volunteers, without any serious side effects.

The follow-up Phase 3 trial, to be run by Swiss-based Roche starting in early 2019, will involve 25 monthly lumbar punctures (click here to read more).

Delivering drugs via spinal fluid is a new procedure. There are no studies of the effects of long-term use of spinal taps. I expressed my own concerns about this.

With its current crucial focus on demonstrating efficacy in the Phase 3 trial, Roche is not yet ready to discuss the hypothetical use of a pump or other drug-delivery methods such as its proprietary "brain shuttle" technology (click here to read more).

Medtronic, the medical device and healthcare firm that makes Garrett's pump, has conducted HD research but not initiated any clinical trials. It also makes a pump for delivering drugs into the CSF for treating conditions such as chronic pain.

A revolution in diabetic care

In our November 2018 conversation, Garrett spoke in great detail about his use of the Medtronic MiniMed 670G electronic insulin pump and its companion, linked device, a continuous glucose monitoring sensor.

The Medtronic MiniMed 670G electronic insulin pump (largest device in photo), continuous glucose monitoring sensor (small device on right), and blood sugar test kit (on the left)

"It's like a temporary IV that you have to change every three days," Garrett explained. "You put it on a region of subcutaneous fat [fat under the skin] so that it can absorb and go into your system.

"And the great thing about the insulin pump – and what makes it great for being a tennis player and being active – is you can give yourself insulin at any point in time during the day. I just have to press a few buttons, and I can configure how much insulin I'm giving myself. The great thing about the pump is that it allows you to give insulin in very small samples."

That's important, Garrett said, because the overall volume of insulin needed by a diabetic "is not very much."

The system helps "cover carbs" consumed – plus glucose produced by normal bodily functions – with small, pre-programmed boluses (doses) of insulin.

"In a normal person, their pancreas is doing all this automatically," he continued. "Every few minutes or every few seconds, your pancreas is giving you insulin. It also gives you a shot of adrenalin, which also bumps your blood sugar up."

Garrett used to prick his finger up to a dozen times per day to measure his glucose. Now, with the continuous monitoring glucose sensor, he does it only twice. "My finger pads are in bit better shape now," he observed, laughing.

The monitor is also attached to a small area of subcutaneous fat, generally on the stomach or the back of the arm or hips. It measures blood sugar every five minutes.

"For a diabetic, that's extremely helpful for you to understand where you are and what you need to do," Garrett said, noting that he can thus both anticipate and make adjustments and know whether he needs to consume sugar or insulin.

In this hybrid system, the pump and the sensor "talk to each other," Garrett added. There are still technical difficulties, but "it's revolutionary in terms of diabetic care, because it's that first step in trying to get the artificial pancreas."

He can also download data from the pump and sensor that allows him to analyze his blood glucose trends and insulin consumption for continual adjustments.

Feeling 'on top of your disease'

The devices have not restricted his life in any way, Garrett said. On the contrary, as a tennis player, he can avoid having to take insulin shots during a match.

I asked Garrett what advice he would offer to drug companies working on neurological disease treatments and the potential of long-term drug delivery.

Garrett replied that he has recently been thinking more about the significance of his pump.

The system has allowed him to "fine-tune" his insulin intake, he observed.

"Having a pump kind of makes you feel empowered," he said. "It makes me feel like I control my disease. I own the disease. The disease doesn't own me."

With drugs delivered via pump, people with HD and other neurological disorders could also feel "on top of their disease," he said.

Disease communities learning from one another

Now a junior, Garrett turned 21 in October. As a history major and chemistry minor, he wants to research the history of diabetes and how medical care for the condition has evolved.

After graduation, he would like to work for a company such as Medtronic to focus on diabetic product design and sales. He is especially passionate about mentoring young athletes affected by diabetes. He also envisions starting a division at a healthcare or biotech firm focused on athletes and other physically active people with diabetes.

He's also hoping for progress on the development of the artificial pancreas, the equivalent of a cure for diabetes.

Likewise, the HD community and other neurological disease communities anxiously await the first effective treatments.

"Time is of the essence in many of these diseases," Garrett observed. "The faster you can bring cutting-edge technology to the patient, the better it is. Just 50 years ago for diabetes, you were taking your blood sugar by urinating in a cup. Now I wear a device that literally takes it every five minutes and beams it to a pump."

These communities all can learn from one another, Garrett stressed.

I have already learned much from Garrett and his approach to life.

(This holiday season please donate to the American Diabetes Association and the Huntington's Disease Society of America.)

Posted by Gene Veritas at 5:51 PM

Labels: advocacy , Billie Jean King , chronic illnesses , clinical trials , Garrett Kurtz , Huntington's disease , Ionis , Novo Nordisk Donnelly Award , Roche , symptoms , tennis , type 1 diabetes , University of San Diego

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