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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.

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SATURDAY, JULY 07, 2018

In Harriet's tragic death, the vulnerability caused by Huntington's disease – but also the story of a beautiful soul

On the morning of April 8, while out for her cherished daily walk, 71-year-old Huntington's disease patient Harriet Hartl died tragically after being struck by an Amtrak train at a pedestrian crossing near her apartment in Del Mar, CA, in San Diego County.

The story of Harriet's death encapsulates the fear of all Huntington's families – indeed, the family of *any* individual suffering from diseases that hamper perceptions and mobility. HD, Alzheimer's, Parkinson's, and other such disorders make people extremely vulnerable to the world.

Harriet's passing further highlights the need to find effective treatments for these conditions, which scientists have found especially difficult to fathom.

However, the shock of Harriet's death should not overshadow the beautiful, beloved soul she represented for her family, friends, and fellow members of the San Diego-area HD community, including the monthly support group she loved to attend.

That's where I met her: she always had a smile and kind words for others. She participated in the breakout group for the affected, separate from the untested at-risk and presymptomatic gene carriers like me.

We got to know each other better through this blog, which Harriet read regularly. She sometimes responded with encouraging e-mails regarding my family's struggles with HD. She also shared some of her journey with the disease.

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Brett Hartl holding photo of mother Harriet (photo by Gene Veritas, aka Kenneth P. Serbin) (To enlarge a photo, just click on the image.)

'Bad things can happen' to HD people

On May 17, I spoke with Harriet's only child and caregiver Brett Hartl at their Del Mar residence, just a few yards from the train track and the Pacific Ocean.

"It was a tough blow when she died, because it was sudden, and sort of an accident, in the sense that it wasn't the down-the-road thing that would have come eventually," said Brett, 39, an attorney for the [Center for Biological Diversity](#). "It's been relatively easy for me to wrap my head around it and process it, because frankly I know enough about HD to understand that bad things can happen. It's difficult for people with HD to deal with complex tasks that we take for granted.

"At her age, when she would take her walk, that would take all of her focus. I can just totally envision her focusing on walking and tuning out the rest of the world."

The morning of April 8, a Sunday, Brett went out for a run. Noting that Harriet had been out longer than usual, he checked her GPS location on his smartphone and saw that she was nearby. He expected to meet up with her as she returned home.

However, as Brett neared the railroad pedestrian crossing, he noticed a train stopped on the tracks and many police cars.

"I started to get a little bit of that feeling," Brett recalled sadly.

He returned to the apartment, hoping to find his mother. Instead, checking her GPS location again, he saw that she was located right on the track.

Fearing the worst, Brett drove to the scene. He saw her body, which the police had covered. Because the officers had Harriet's smartphone, driver's license, and Huntington's disease identification card, they quickly confirmed her identification with Brett.



Brett observes the scene of the accident. The official pedestrian crossing is located at the sidewalk on the far side side of the street (photo by Gene Veritas).

Crossing the tracks

How, some wondered, could a person not notice an oncoming train?

“People don’t realize all the little things that just don’t quite work right in someone’s mind with Huntington’s,” he explained. “When she was focusing on exercise and walking, that was it. That was probably all she could comprehend at one time.”

Brett, who is still awaiting an official accident report from Amtrak, said the train was traveling at about 50 miles per hour, a standard speed for that stretch. He believes she was killed instantly.

“It was not a glancing blow,” he observed. “I doubt she even noticed.”

To complicate matters, the crossing is located just around a bend in the track, at a busy traffic intersection, and just a few yards from the ocean. The surf, vehicle traffic, and other noise probably obscured the train’s advance, Brett said. In that area the train rarely uses its klaxon (horn), he added.

“Here in Southern California, everybody crosses the railroad tracks illegally,” Brett continued, recalling that another individual was killed on the tracks recently. In other words, they *don’t* use the legal pedestrian crossings.

As we observed the crossing, we noted the posted suicide prevention sign. We saw a number of people go through the crossing without looking down the tracks.

“She had a route,” Brett remembered. “Sometimes she would say, ‘I took the shortcut. I crossed the tracks.’ I said, ‘Don’t do that. Only cross at the crossing station [the legal pedestrian crossing] down there. It’s too dangerous. What if you fall and can’t get up?’”

‘A terrible confluence of events’

The weakened sense of one’s surroundings caused by HD surely exacerbated the situation, he said.

“You’d have to almost turn around over your shoulder to look – which, again, normal people can do,” Brett said. “She was walking in the same

direction as the train, so it came up behind her, and the train was in reverse. So the engine was in the back, so it's extra quiet until it's actually passed. It was just a terrible confluence of events.”

Brett is not angry at Amtrak. He asked administrators there to tell the employees on the train that they were not responsible for Harriet's death.

“HD is in my mind was responsible for her death, because she couldn't handle the normal things that we take for granted,” he said. “In this case, it was crossing the train tracks.”

A passion for travel

Harriet Potash was born in New York City in 1947 and grew up in the area. She studied sociology at Monmouth University in New Jersey. Around that time, she met future husband, Larry Hartl.

Harriet worked as a travel agent, in advertising, and as a teacher. Larry became a producer for the ABC-TV newsmagazine *20/20*. He also worked at NBC-TV.

His job took him and Harriet to dozens of countries, including the former Soviet Union, a closed Communist regime.

“Travel was one of her big passions,” Brett remembered. “She'd been to over 50 countries. Even after her diagnosis, in 2011 [at age 64], she didn't let that stop her from traveling. We did a trip together to Japan in 2013. Then we did the trip to see the polar bears just this last November up in Canada, which was hard for someone for HD.”

Before HD struck, Harriet and Brett also did challenging hikes such as a 15-mile trek in Montana's Glacier Park.

Brett reflected: “I think people sometimes forget that people with HD used to be completely capable and healthy and active.”



Above, Harriet in Moscow, 1973. Below, in Ecuador in the mid-2000s (family photos).



Confronting HD

Not long after Larry died, Harriet in 2003 moved to the San Diego area to escape the harsh East Coast winters.

In 2010, she started falling a lot. Brett recommended that she see a neurologist. That led to testing for HD, a disease unknown to the family.

Now, however, it became clear that Harriet's father had also had HD and passed it down to her: he had emotional outbursts and chorea (involuntary movements), two typical symptoms of HD. His apparent onset – without testing – came very late. He died at 90.

Both Harriet and Brett took a proactive approach to HD.

"I got tested also, in 2011," Brett said, disclosing that the result was negative. "Most of the immediate family did. My approach, just being who I am, was that I wanted to learn everything I could about it and understand it, the consequences."

Most people in Brett's situation postpone or avoid testing.

"For me it was: 'Well, better to learn now than finding out 30 years from now,'" he said. "It's not fun. But in the long run it was a good choice."

So far, none of Harriet's father's siblings or her cousins have tested positive, Brett said. He knows of only one other relative with HD.

Harriet's approach

Harriet regularly attended the [San Diego support group](#) of the Huntington's Disease Society of America (HDSA).

"Having a strong community of other folks going through that was very helpful to her," Brett said. "She really enjoyed those other people a lot."

Harriet also participated in research studies and clinical trials aimed at understanding HD and finding treatments.

She also hoped to participate in the Phase 3 trial of IONIS-HTT_{Rx}, developed by [Ionis Pharmaceuticals, Inc.](#), in nearby Carlsbad, CA. The drug lowered the amount of the disease-causing mutant huntingtin protein in patients' cerebral spinal fluid in [Ionis's historic Phase 1/2a trial](#).

Swiss pharmaceutical giant Roche, which now holds the license to the drug, renamed RG6042, has not yet announced the Phase 3 timeline but has confirmed that trial sites in the U.S. will be included. (The Phase 1/2a trial was not open to U.S. residents.)

“She had something to look forward to,” Brett said. “She was very excited about the Phase 3 for that next drug. She wanted to make sure that she got in the study.”

Harriet had also just started taking Austedo, another drug developed in San Diego that controls chorea more effectively and with fewer side effects than a similar but older drug, Xenazine (click here and here to read more). Xenazine and Austedo are the only drugs approved for HD in the U.S.

“I think it made a difference,” Brett said of Austedo. “It calmed down some of the movements. She liked it. It helped her sleep better at night. She wasn’t as restless.”

In addition to daily walks, Harriet also worked with a physical therapist and practiced yoga, Brett noted.

“She really got a lot out of daily exercise,” he said. “That was one of her greatest joys and things to plan her day around.”

Just weeks before Harriet’s death, she had decided to donate her brain for HD research. Sadly, the damage from the accident made that impossible, Brett said.

‘A very friendly lady’

Although HD impedes speech, Harriet could still communicate. She kept mentally active and reached out to the community. After her diagnosis, she continued to teach herself Spanish, a skill that allowed her to do volunteer tutoring at a school for underprivileged children. She also volunteered at the San Diego Botanic Garden.

Family, friends, and acquaintances remembered Harriet as outgoing and kind. During a trip to Costa Rica, she started talking with children on a beach. “She just struck up a conversation in Spanish with them,” Brett recalled.

“She was very, very outgoing and open with people,” Brett commented. “She cared a lot about their own personal issues. Even just the other day, at the pizza place down the street, I told some of the folks what happened. They always recognized her as ‘the very friendly lady.’ It didn’t really matter if she knew you for a minute, or a year.”

Remembering Harriet’s whole life

There was no religious service for Harriet. According to her wishes, her body was cremated.

However, three weeks after her death, Brett and Harriet’s San Diego-area friends held a small remembrance of her at the beach.

Later this summer, Brett and friends and family will scatter her ashes in the Atlantic Ocean near Jones Beach, Long Island, where husband Larry’s ashes were spread.

“She loved both oceans,” Brett said.

He also encourages people to view the online memorial photo album he posted: <https://photos.app.goo.gl/2sjV7LltaohhVq1>.

“It’s a better story than I could actually tell,” he said of the album. “She sure did a lot. She shouldn’t be remembered just in her HD state.”

Brett also set up a [donation page](#) in Harriet's honor to support HDSA-San Diego.

Posted by [Gene Veritas](#) at 1:07 PM      

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