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Police killing of man with Huntington's disease spotlights need for affected families to emphasize proactive, dignified approach

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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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TUESDAY, JANUARY 06, 2015

Police killing of man with Huntington's disease spotlights need for affected families to emphasize proactive, dignified approach

The shooting death of a Philadelphia-area man apparently suffering from Huntington's disease, which perhaps led him to try to run over police officers with his car, has once again raised the perilously common issue of how police misunderstand HD.

Beyond prompting anger and the need for better police preparation, the death of [Joseph A. Pacini](#) can also stir the HD community to combat the stigma of the disease, redouble efforts towards treatments, and emphasize the dignity of affected individuals.

According to reports in the *Philadelphia Inquirer* ([click here](#) and [here](#)), Pacini, 52, died Dec. 30, 2014, in a town near Philadelphia after officers from three departments fired at least 22 shots, wounding him in the head, neck, shoulders, and chest.

Pacini's one-time girlfriend and a close friend told reporters that he suffered from HD. Family members said that Pacini's father, who had HD, committed suicide when Pacini was 21.

For the second time in less than four months, the incident raised the issue of police response to HD-afflicted individuals. In September, police in the small town of Westover, WV, held down Jeffrey Bane for nearly ten minutes after he clashed with officers; he struggled to breathe and pleaded for help. A bystander captured the scene on video ([click here](#) to read more).

Investigators in the Pacini case are conducting tests to confirm his HD status and whether he was using drugs and/or alcohol. The local district attorney is also investigating the justifiability of the shooting.

(Sadly, most media reports missed the HD angle. One, in the *New York Daily News*, reinforced the ignorance and stigma surrounding neurologically and mentally impaired individuals by poking fun at Pacini and referring to him in tabloid parlance as a "sicko.")

[Huntington's Disease Society of America](#)
[International Huntington Association](#)
[Huntington's Disease Drug Works](#)
[Huntington's Disease Lighthouse](#)
[Hereditary Disease Foundation](#)
[Huntington's Disease Advocacy Center](#)
[Thomas Cellini Huntington's Foundation](#)
[HDSA Orange County \(CA\) Affiliate](#)
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Joseph A. Pacini (from his Facebook page)

HD Blogs and Individuals

[Chris Furbie: Huntingtons Dance](#)
[Angela F.: Surviving Huntington's?](#)
[Heather's Huntington's Disease Page](#)

A volatile situation

According to the *Inquirer*, Pacini led a troubled life, failing to finish his college studies, posting conspiratorial and threatening YouTube videos, and fighting with his mother, the police, and others.

"[HD] is very often confused with schizophrenia, especially with those who do have the mental disorder predominant in the beginning," Louise Vetter, CEO of the [Huntington's Disease Society of America](#) (HDSA), told the *Inquirer*. She said that HD can involve "paranoia, anxiety, really, really strong fixation on things."

"HD does not fit well into the norms of society," advocate [Jonathan Monkmeier](#), a Philadelphia-area resident whose wife Sheryl died of HD in 2009 at 46, said in a Facebook conversation with me. Jonathan did not know Pacini, but as Sheryl's full-time caregiver for many years he understood the awkward and difficult social situations HD people face.

"This describes another tragic end to a difficult life for a person thought to have HD," Martha Nance, M.D., the director of the HDSA Center of Excellence at Hennepin County Medical Center in Minneapolis, MN, and the author of the preface to HDSA's *Law Enforcement Training Guide*, wrote in an e-mail after reading press coverage of the incident.

"It is easy to focus on the police departments' actions that directly led to Mr. Pacini's death, and shout for a different approach, criticize the police for 'not knowing he had HD,'" she added. "But I'm not sure that the presence or absence of HD would necessitate a difference in the officers' approach to a volatile situation."

In the Pacini case, mental illness independent of HD seemed to play a role, Dr. Nance observed. She pointed to the "general issue of access to mental health care" as a key factor in such situations.

"In medicine, we believe that the police need to be involved if there are homicidal threats, and we, too, call the police if we feel that we are unsafe or in danger as we see a patient in the clinic or the hospital," Dr. Nance emphasized.

'Be more public about HD'

“The other issue, and more relevant to the HD community, is WHAT CAN WE DO to keep our Joseph Pacinis from getting to these kinds of crisis points,” Dr. Nance continued. “And I think the first thing is to be more public about our disease. HD families, more than anyone else, treat their disease as a terrible secret, a stigma, something to hide and be ashamed of. This creates a mindset that passes through the generations, that HD is like being in a terrible underground tunnel filled only with darkness, and the only way out is suicide, or to emerge with explosiveness and anger.”

By avoiding genetic testing and contact with doctors, HD people “delude themselves into thinking that they are not entering the dark tunnel,” she wrote.

The community needs to stop viewing HD “with hopelessness and despair,” she added.

“What makes a difference is what you do BEFORE you die,” she wrote. “I can tell any number of amazing stories of amazing people with HD and their families who have done amazing things for themselves, each other, the HD community, and the world at large. There IS life after a diagnosis of HD, but it can’t emerge if you are stuck in the dark tunnel.”

Everybody in HD families can and should to get involved, Dr. Nance observed.

“If you are scared, find a support group, or talk to your parent, sister, cousin, friend, pastor, teacher, or perhaps even your doctor,” she wrote. “If you have a family member who is unconnected, floating out there, undiagnosed, struggling, reach out to them. Bring them to an HD meeting, or have them come with you to YOUR appointment.”

Enroll-HD: proactive participation

I was numbed by the news of Joseph Pacini’s death.

After I had explored the Jeffrey Bane incident and then noted in [my most recent](#) article that HD activists had skillfully reacted by building HD awareness at an international police officers’ conference just weeks later, the Pacini incident seemed surreal.

Emotionally, I cast about for a way to react. I concluded that I could do nothing in the case of someone who had already died.

Then, reflecting on Dr. Nance’s encouraging words, I focused on how I could best contribute to the cause: I went for my January 5 appointment to register in [Enroll-HD](#), a worldwide registry and observational study of HD patients, HD gene carriers like me, untested at-risk individuals, family members, and volunteers.

Enroll-HD aims to facilitate scientific understanding of HD, identify potential participants in all-crucial clinical trials, and therefore speed the process of finding treatments. Enroll-HD is sponsored by the [CHDI Foundation, Inc.](#), the non-profit virtual biotech focused solely on developing HD therapies.

I recalled what Joe Giuliano, CHDI’s director of clinical operations and the chief Enroll-HD administrator, told me last year: the larger the pool of potential clinical trial participants, the faster trials can take place.

At the HDSA Center of Excellence for Family Services and Research at the University of California, San Diego, I provided a research assistant with information on my health and HD status, answered several health- and HD-related questionnaires, performed a battery of cognitive tests, underwent a neurological exam, and gave three vials of blood, which will

be used to confirm my gene-positive status and provide evidence in the search for HD biomarkers (signs of the disease that can be used to test the efficacy of potential drugs).

I also participated in several HD research studies sponsored by the Center of Excellence.



A nurse (above) prepares to draw blood from Gene Veritas for the Enroll-HD study (photo by Ajay Nathan, HDSA Center of Excellence research assistant). Below, Gene Veritas and Ajay Nathan discuss Gene's participation in Enroll-HD (photo by Andrew Herndon, HDSA Center of Excellence).



Striving for a life lived well

During the four hours of testing, I worried that I might someday lose control as Joseph Pacini did.

My thoughts were troubled: what if I act aggressively towards my wife and daughter?

I found strength in Dr. Nance's concluding observation about the HD-affected and gene carriers:

"A life lived WELL with HD can resonate into future generations just as easily as a difficult life or a terrible death."

As long as I can, I will strive to defeat HD by assisting in the search for treatments and by spreading awareness and understanding.

Posted by [Gene Veritas](#) at 7:29 AM



Labels: [advocate](#) , [aggressiveness](#) , [CHDI](#) , [diagnosis](#) , [Enroll-HD](#) , [HD gene carrier](#) , [Huntington's disease](#) , [Jeffrey Bane](#) , [Joseph Pacini](#) , [Martha Nance](#) , [police shooting](#) , [schizophrenia](#) , [stigma](#) , [suicide](#) , [support group](#) , [symptoms](#)

7 comments:

 **Jimmy Pollard said...**

Wonderful piece, Ken!!!! Thanks for this! The sTruggle continues...

[8:28 AM, January 06, 2015](#)



 **Unknown said...**


Thank you for your positive response to this tragic situation.

[8:35 AM, January 06, 2015](#)

 **Dave Hodgson said...**

Ken, as usual, you caught the crux of the matter: more public awareness of HD and its many different symptoms. Thanks for all you do for the HD Community!

[9:26 AM, January 06, 2015](#)

 **Judy Roberson said...**

Your article is a must read for everyone in our community. Dr. Nance's thoughts on stigma are true but I never thought of it this way: "HD families, more than anyone else, treat their disease as a terrible secret, a stigma, something to hide and be ashamed of." We can each make a difference by join studies and trials! I'm going to look into Enroll-HD.


[2:19 PM, January 06, 2015](#)

 **Anonymous said...**

My friend from Waverly my got beat twice from Sayre police and she has HD

[6:21 PM, January 06, 2015](#)




 **Unknown said...**

Thank you for your post. Joe was my brother. I can tell you that for years we have been trying, to no avail, to get him to see a doctor. He refused to even acknowledge the problem.

Eventually he became convinced that we were just trying to control him and that we were somehow evil. This disease has ravaged my family. My father had it and my sister is currently in a nursing home with it. There was no stigma. We pleaded with Joe to get help. Whether it was HD or something else we just wanted him to get help. You are right. The police need to do what they can to protect themselves and the public. We do not in any way blame them for what Joe forced them to do. We believe he wanted to end his pain.

[6:43 PM, January 06, 2015](#)

 **Unknown said...**

This could have been my Andrew..... he was diagnosed with HD in 2005 and tried hard to be independent and refused to take medicines for his psychosis because he believed he was ok. He started with the emotional/behaviorial aspect of the disease. He, too, suffered paranoia, delusions, especially about the FBI. He threatened his former girlfriend on FB and his mom took action. She called authorities and explained HD to them. She explained he was harmless even though he made a threat. But he needed to be taken to the ER and then to the psych ward. In 2 months, Andrew was given medicine and B12 injections which stabilized his psychosis and brought him back to his calm, sweet, witty, intelligent self. He has not had any yelling outbursts and his delusions have stopped. He is the guy pictured in my profile picture. This situation saddens me on both sides of the issue. 1. This man was not diagnosed.... but he clearly had mental health issues regardless of HD. The police did not know if he was a murderer like the man who killed a state trooper in the autumn and fled into he woods. He was finally found. As a law enforcement officer, who is trying to protect the community and themselves, can't always second guess the individual. They have to take the threats seriously. 2. On the other hand, the police went way over board: shot 22 times?? Why didn't they shoot the tires? Stop the vehicle? There were better ways the officers should have handled the situation. Calling the car a weapon is outrageous. Police need better training in all mental health issues. 3. If he was arrested before and let go, they had a file on him. Perhaps they should have done some background research on this individual and then, they could have handled it differently knowing this man needed HELP..... He was not a murderer..... 4. This poor soul should have been on medicine. Or taken to the ER and a psych ward to get him on meds. HD takes away the rational part of the brain. My Andrew was diagnosed and it is very common to refuse meds. It is a standard part of HD to be in denial. It isn't from secrecy, but that area of the brain that doesn't work properly. Many friends on the HD support sites share how their loved one refuses meds. 5. So, not only do we all need to share HD and make law enforcement aware of HD, we need to figure out a way to HELP our HD friends take the proper meds to help with the psychosis. Even on meds, HD friends can be violent. But if the police are aware of all that, know who these people are, then violent deaths like this one can be avoided. Police need to know the community and who they are dealing with. That goes for any mental health issues. 6. I am proud of Andrew's mom for stepping in and having her loving son taken into custody. She has her son back to himself, on proper meds, and living with HD as best he can. In the face of this disease, MY Soulmate is fighting to LIVE each day as best he can. He's cheerful, witty, and very loving. I came back into his life after

the crisis was over, but our love for each other has healed him in so many ways. Let's all continue to educate the community.

6:23 AM, January 07, 2015

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