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At Risk for Huntington's Disease

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## Outrage over video of police's rough handling of man with Huntington's disease spurs calls for justice, awareness

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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.*

## Blog Archive

- ▶ 2021 (12)
- ▶ 2020 (16)
- ▶ 2019 (19)
- ▶ 2018 (16)
- ▶ 2017 (14)
- ▶ 2016 (13)
- ▶ 2015 (24)
- ▼ 2014 (24)
  - ▶ December (2)
  - ▶ October (1)
  - ▼ September (2)
    - [Outrage over video of police's rough handling of m...](#)
    - [Moving toward a potential treatment: Isis, CHDI re...](#)
- ▶ August (3)
- ▶ July (1)
- ▶ June (2)
- ▶ May (3)
- ▶ April (3)
- ▶ March (2)
- ▶ February (3)
- ▶ January (2)
- ▶ 2013 (30)
- ▶ 2012 (26)
- ▶ 2011 (33)
- ▶ 2010 (26)
- ▶ 2009 (21)
- ▶ 2008 (7)
- ▶ 2007 (7)
- ▶ 2006 (4)
- ▶ 2005 (17)

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## HD Links

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TUESDAY, SEPTEMBER 16, 2014

## Outrage over video of police's rough handling of man with Huntington's disease spurs calls for justice, awareness

Amateur video has proven crucial to holding police officers accountable around the country.

Now such video of a police encounter with a man suffering from Huntington's disease – held down for nearly ten minutes as he struggled to breathe and pleaded for help – shockingly reveals how rare disease communities must fight against profound ignorance, discrimination, and hostile treatment.

In the small town of Westover, WV, police on September 6 arrested Jeffrey Bane, a 39-year-old father of two from nearby Morgantown, WV, and charged him with disorderly conduct, obstructing an officer, and battery on an officer. At least one officer and a cruiser from the neighboring Granville, WV, police department were also at the scene.

From their actions and attitude, the officers seemed to have no inkling that Bane was ill.

It's a reminder that police should all be exposed to the [Law Enforcement Training Guide](#) produced by the Huntington's Disease Society of America (HDSA), and that those afflicted by the disease would be wise to carry the "[I Have Huntington's Disease](#)" cards recommended by HDSA.

### Behind the incident

Bane has HD, which has left him unemployed. He comes from a family with a long history of Huntington's and has suffered from the disorder for about five years, though he can still accomplish many daily activities. His symptoms include chorea, the involuntary, often jerky movements typical of the disorder.

Bane had been walking down the street with his toddler daughter in a stroller and carrying his infant son when, in response to two 911 calls alleging concern for the children, police accosted him.

According to a [local newspaper](#) that had access to the official police report, the police said that Bane "appeared to be under the influence of narcotics, handled the children roughly and became agitated as officers spoke with him about the children." The police said the children seemed to be "overheated."

[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](#)  
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## HD Blogs and Individuals

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



### *Jeffrey Bane's police mug shot*

When asked what “provisions” he carried for the children, “Bane struck the stroller violently with his hand, pushing it forward abruptly while his infant son was still seated inside,” the official complaint stated. When the officers attempted to restrain Bane, he began to fight. He allegedly kicked one officer and tried to spit on others.

Sara Bostonia, a Grafton, WV, resident and healthcare worker who was driving to her mother’s home in Westover, saw Bane on the ground and started filming the scene with her smartphone. She had not previously known Bane.

“The first thing I saw was blood,” Bostonia said in a phone interview on September 13. “That’s why I stopped. I saw a man with a bunch of other men on top of him. There were no [police] lights on. I just thought there was something wrong about the whole way he was moving.”

Bostonia said that she rolled down her window to get a clearer view.

“I couldn’t believe what I was seeing,” she said. She then started filming.

“I’ve never done that, never,” she continued. “Once he started the gurgling and screaming for help, I could tell he was completely pinned to the ground. I said ‘stop it’ while I was getting out of my car.”

In the video, as the officers hold Bane to the ground, he displays frequent episodes of chorea.

“Stop it!” the officer holding Bane’s head to the ground shouts. Another says: “Stop fighting us.”

“I can’t breathe, goddamit,” Bane says desperately. “Help me. I can’t breathe.... Help me, sir, please help me.”

As Bane appears to choke, one of the officers orders him to “stop spitting.”

"Help me, please," Bane pleads again. "I'm not trying to fight you guys."

The officers misinterpret involuntary movements in Bane's legs as attempts to kick them. They clearly had not been trained to assess the possibility that such actions resulted from HD (or any other condition).

"The scene portrayed on the video is tremendously upsetting and sad to anyone who recognizes the chorea and erratic gait that Huntington's disease causes, that could have been largely or solely responsible for the behavior that led the police to the scene," 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 the *Law Enforcement Training Guide*, wrote in an e-mail. "In the courts, we assume that people are innocent until proven guilty, but on the street, there may be an assumption of the worst until the situation defuses."

During the incident, the children lost contact with their father. They do not appear in the video. Contacted by the police, Bane's girlfriend Delsie Stup, the children's mother, came to the scene to pick them up.

Without knowing Bane nor his HD status, Bostonia put the video on her YouTube channel on September 7. To date it has had nearly 120,000 views.

Bostonia said she posted the video because she wants all the facts "out there. Public scrutiny of the facts is paramount. It is our job. We shouldn't have to police the police, is how I feel about that. As citizens, we do a pretty good job of policing ourselves."

You can watch an enhanced version of the video on another YouTube channel below.

### Westover, WV Police Brutality. Jeffrey Bane Se



After receiving medical treatment and posting bail, Bane was released about 48 hours after his arrest.

"Unfortunately, situations like what happened to Mr. Bane happen far too often in America and around the globe," HDSA CEO Louise Vetter said in a phone interview on September 12. "They are heartbreaking and tragic and they're why we work so hard to educate the community at large about Huntington's disease. That's why it takes all of us sharing our outrage but also committing to educating about Huntington's disease so that circumstances like this aren't repeated."

According to Dr. Nance, no statistics exist on arrests or incidents with the police involving HD-affected individuals. However, difficulties with the police and/or misunderstanding of symptoms – usually mistaken for drunkenness or drug usage – have occurred in many HD families. In 2007 I myself visited a San Diego HD man in jail improperly charged with public drunkenness. HD-affected individuals can appear drunk because of their chorea and also slurred speech.

### **Outrage in the community**

The Bane incident has received newspaper, television, and blog coverage in the U.S. The *London Daily Mail* also ran an article.

The video has also stirred controversy in the greater Morgantown area of West Virginia, home to small towns dependent on the coal-mining and natural gas industries as well as intellectual life at West Virginia University (WVU), with nearly 30,000 students.

“The arrest video on YouTube of Granville man Jeffrey Bane has caused outrage and accusations of police brutality from those who feel Westover and Granville Police were unfair to a man suffering from Huntington's disease,” observed a [report on WDTV](#), a Bridgeport, WV, TV station.

According to that report, the city of Westover views the incident as a “non-issue.”

“The outrage of anything even close to police brutality in the case of Jeff Bane is totally unwarranted,” Westover Mayor Dave Johnson said in a statement released to the station. “If I had any doubt whatsoever I would be the first to bring the officers involved to the carpet, so to speak.... The City of Westover has moved on.”

According to Bostonia, the community was indeed “in an uproar” over the incident. In the wake of intense national discussion following this summer’s police shooting of Michael Brown and riots in Ferguson, MO, “people are trying to get a protest together,” she said. “A couple weeks ago they held a protest for Ferguson with about 20 people down at the courthouse. This one hits closer to home. I wouldn’t be surprised if it happens here, too.”



*Sara Bostonia (personal photo)*

At the same time, people are worried about the community's security, she said.

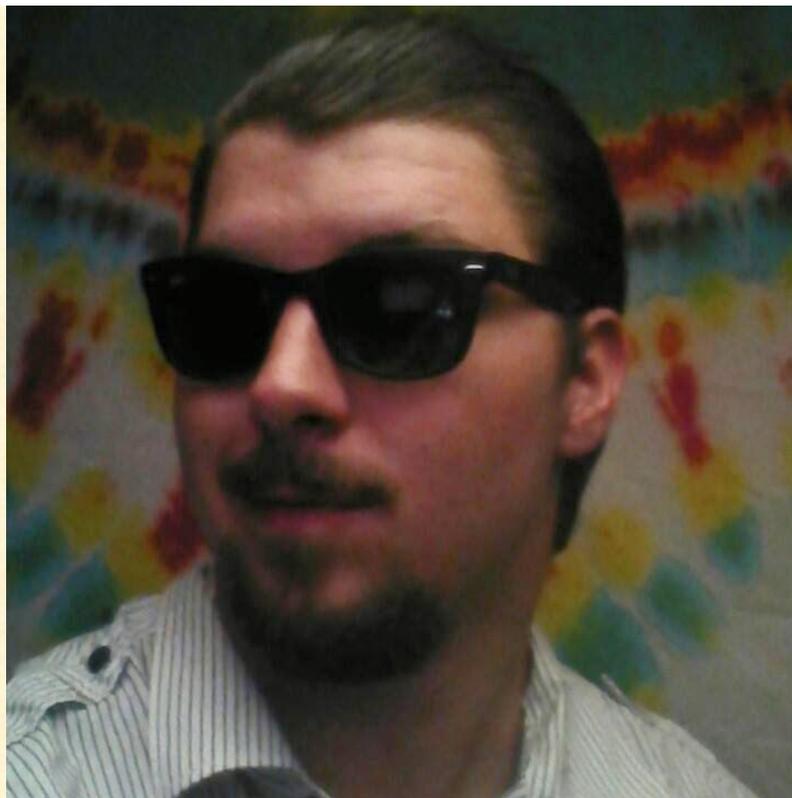
"Everyone in town is invested in this incident in some way," she explained. "Maybe their brother's a cop and they're afraid. Everyone is connected in some way to one another.

"I didn't want to take that video. I wanted them to detain him properly."

#### **'Justice for Jeffrey'**

Bane and Stup have issued no public statements, but Bane's nephew Josh Bane, 22, emerged as the family spokesperson, setting up a public [Justice for Jeffrey Bane](#) page on Facebook.

As the son of a father (Jeffrey's brother) who has already developed HD symptoms, Josh has a 50-50 chance of inheriting HD.



*Josh Bane (personal photo)*

Josh alleges that the police violated his uncle's rights. In the search for truth about the incident, he has sought to obtain and release all related information. The extended Bane family is also considering the possibility of legal action and may seek donations to help cover the cost.

“At the end of the day, someone was detained unlawfully for ten minutes and he was held down and choked on his own blood as he begged for help from anybody,” Josh Bane said in a phone interview on September 13. “It doesn't take that long to detain a 160-pound man with three officers. They mistook his involuntary movements for resisting, when in reality he suffers from Huntington's – all of this in front of his two children, who were unattended.

“They could have easily cuffed him and put him in the car in 30 seconds and continued on as if it were routine. For some reason, they wanted to punish him for ten minutes. It was a brutal timeout, if you want to be sarcastic about it.”

According to Josh, the police sprayed mace on his uncle and punched him in the face. In the video, blood covers Jeffrey's face. The Justice for Jeffrey Bane page includes photographs showing the injuries allegedly suffered by Jeffrey in the incident.



*View of some of Jeffrey Bane's injuries allegedly suffered in police incident (photo from [Justice for Jeffrey Bane](#) Facebook page)*

### **Going to the park**

Josh emphasized that, despite suspicions of child abuse and drug usage, the police did not charge Jeffrey with those crimes. He described as false one [media report](#) asserting that Stup told police Jeffrey had an “opiate dependency” and that the couple had fought and she was planning to leave Jeffrey. He added that when the officers questioned him about drugs, Jeffrey became “agitated,” offering immediately to take a urine test.

“She wasn’t even home when Jeff left with the kids,” he said, adding that the couple has strived to “hold it together and deal with everything they have to go through.”

“Uncle Jeff was just going to the park with his kids,” Josh said, explaining why Jeffrey was walking down the street with his children.

Josh, who lived in the same home with Jeffrey for several years and has watched him decline because of HD, recognized that his uncle’s symptoms have diminished his life.

“He’s not wheelchair-bound by any means, but the jerking is bad,” Josh said. “He’s not to the point where he’s bedridden. He can’t work. He can’t have a normal life by any means.”

However, Josh also asserted that having HD does not prevent Jeffrey from enjoying his family and exercising his rights as a parent.

Josh asserted that the police misunderstood the HD-caused jerky movement of the stroller as lack of concern for the children.

“Who would deny any person the right to their children regardless of how sick they are?” he said. The children represent the one thing that brings Jeffrey and Stup “joy in the world.”

As part of its report, WDTV showed footage of a surveillance video of Jeffrey walking down the street with his children moments before his arrest.

Josh posted the video on the Justice for Jeffrey Bane with a comment: "My uncle walking just prior to his arrest. Does this look like child abuse? He's simply walking to the store with his kids. You tell me if this warranted him being detained in the manner that he was."

You can watch the video below.



### **Seeking to educate the police, society**

Serious questions linger about this incident.

In particular, why did the officers simply not put Bane into a police vehicle immediately after handcuffing him? Why did they not respond to his pleas for help? Did the officers have crisis intervention training?

Westover Police Chief Ken Fike did not respond to my request for an interview to discuss the incident. Nor could I reach the Granville chief. I had hoped to raise awareness about HD. I will send both departments a copy of this article and tell them how to obtain HDSA's above-mentioned *Law Enforcement Training Guide*.

Other HD advocates focused on the incident are also working on awareness efforts.

"We've got to spread awareness," said Josh. "This is a disease that's so unknown. People think it's Parkinson's. This is different. It completely disrupts the mind. If all that comes out of this is awareness for that, I'll be happy."

### **Be brave about your HD**

Josh confirmed that Jeff did not tell the police he had HD. Nor was Jeff carrying the HDSA "I Have Huntington's Disease" card.

"People with HD need to be brave enough to say 'I have Huntington's disease,'" wrote Dr. Nance, who was recently invited to write a book chapter on HD in the criminal justice system. "It is up to the people around them, including law enforcement officers, to understand what that means."

Dr. Nance also pointed out that HD-affected individuals can be extremely “impulsive,” sometimes causing the line between intent and symptom-driven behavior to become blurry.

“And some people with HD do get into drugs and alcohol, so just saying ‘don't hurt me, I've got HD’ may underestimate the danger of HD to self or others,” she observed.

Like Josh and Vetter, Dr. Nance concluded that people should channel their outrage about the Jeffrey Bane incident into proactive, public advocacy.

“Let us all use this opportunity, as citizens, or members of HD chapters, to speak to our local law enforcement – police, fire, emergency – about HD, and to provide them with the *HDSA Law Enforcement Training Guide*.”

Posted by [Gene Veritas](#) at 9:00 PM     

Labels: [advocacy](#) , [awareness](#) , [chorea](#) , [discrimination](#) , [Ferguson](#) , [HDSA](#) , [Huntington's disease](#) , [ignorance](#) , [Jeffrey Bane](#) , [Josh Bane](#) , [justice](#) , [Martha Nance](#) , [police](#) , [Sara Bostonia](#) , [symptoms](#) , [Westover](#)

10 comments:

 **Anonymous said...**

Something like this happened to me a couple of months ago. I'm HD positive too.

[8:25 AM, September 18, 2014](#)

 **Anonymous said...**

I had to tell people that I fell because I was to embarrassed to admit that I was assaulted by several Police Officers. My whole body and face were black and blue for weeks.

[8:29 AM, September 18, 2014](#)



 **Ginny in CO said...**

Personally, the officers' concern for the children is a sham. Apparently they left them unattended for as much as 10 minutes. An infant can die of SIDS in that amount of time. Not to mention the trauma to such young minds. I would add that being attacked, maced and not knowing what was happening to his young children would have flooded Bane's mind with stress hormones at levels that incapacitate frontal cortex (executive function) thinking. He was easily in too much pain and distress to think of telling the officers he has HD. Virginia Cotts RN BSN

[11:04 AM, September 24, 2014](#)

 **Anonymous said...**

There is a need to re-establish professional standards in this department. The public officials who indicated that the standards were not going to be reviewed need to be reviewed by the public. If our designated agents fail at their jobs, our duty as citizens is to terminated their elected or appointed status.

This incident of inhumanity gives those of us in the public service sector a bad reputation.

12:56 PM, September 24, 2014

❁ **Anonymous said...**

I was wondering who was looking after the children while the cops were sitting on this man? And what about the person/s who called 911? I hope they have some guilt associated with this kind of see something say something. Reminds me of stories a friend told me about living in Nazi occupied Europe. Hurrah to brave people who record this kind of brutality. Protect and Serve - what a lot of baloney. Bullies with guns and overstimulated male hormones.

1:47 PM, September 24, 2014

❁ **Anonymous said...**

My husband has H.D. also. He walks alot and when the police see him they seem to think that he's drunk. All police departments need to be educated as to what H.D. is and how it affects people. And they need to see this video!! It not only affects the one that has it but all family members to! Maybe wearing a medical I.d. bracelet or carrying a card might help. That is if the police don't jump to conclusions (as they have many times in my husband's case) and just assume the person is drunk or being combative. This video is not only appalling but completely sad.. I would say to the police that it's called INVOLUNTARY MOVEMENTS!! Get educated about H.D.

3:12 PM, September 29, 2014

❁ **Anonymous said...**

The problem is that HD persons, families, even their organisations are too inclined to remain in the closet. I was a medical social worker who new always extra about various conditions except HD until I did a 9 mth locum for a state HD organisation. Never had before knowingly even come across anyone with HD. I do understand why police with their injury and death rate can be jumpy, kids involved etc., though still a bit too much.

The person I blame is the mother for leaving him with the kids alone once his disease had reached the point where he can have difficulty responding to any unanticipated complexity. By all means keep up his activities and outings with his kids, but don't leave him alone with them. Take them with you or have another adult be with him with the kids. Hope he now wears something that does indicate his cindition, not just for polce, but were an accident that got him to hospital so medically treated more safely. Not all HD persons can be by their reactions be identified as such regardless of learning about the condition.

7:06 PM, October 13, 2014

 **Anonymous said...**

With two brothers now presenting HD symptomatic, I feel they too are at risk of being mistaken for being drunk or intoxicated in some way. Chorea symptoms, and the stumbling and unsteady gait, truly can be misinterpreted as being drunk. Then the other symptoms, anxiety, confusion etc, do not help in situations like we have seen on this video. Due to such sadness, I could not watch it until the end. I praise the lady who videoed this, and the attention it has received. I am in Perth, Australia and have been involved with our HD Assoc. I would like to know if maybe that police dept has in some way assisted in raising awareness or fundraising - this could be such a help in 'healing'. What a terrible, terrible incident for all involved. It really hurts me, and I dread that it may happen to my brothers also. I will be contacting the people involved with this video, thanks. Sandy Hudson

[12:30 AM, January 31, 2015](#)



 **Unknown said...**

My brother in jail was beaten severely. He has HD also.

[1:04 PM, August 17, 2016](#)



 **Lynelle said...**

My brother wrote this song and designed these shirts. My mom enjoyed wearing them, because they are humorous and educational.

<http://www.hdblues.org>

The front says - "NO, SIR, I AM NOT DRUNK"

The back says - "I suffer from a genetic progressive neurodegenerative disease causing gradual deterioration of movement, cognitive function, emotional control, blurring of social boundaries and inherited in an autosomal dominant pattern.... Are we good?"

[11:05 AM, April 22, 2017](#)

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