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At Risk for Huntington's Disease

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## How to make law enforcement a friend – not a foe – of people with Huntington's disease (and other disabilities)

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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)
  - ▼ December (3)
    - ▶ [‘Concussion’: advocating for the truth about brain...](#)
    - ▶ [‘Twas the morning after Christmas – and Huntington...](#)
    - ▶ [How to make law enforcement a friend – not a foe –...](#)
  - ▶ November (2)
  - ▶ October (2)
  - ▶ September (3)
  - ▶ August (1)
  - ▶ July (1)
  - ▶ June (1)
  - ▶ May (3)
  - ▶ April (2)
  - ▶ March (1)
  - ▶ February (3)
  - ▶ January (2)
- ▶ 2014 (24)
- ▶ 2013 (30)
- ▶ 2012 (26)
- ▶ 2011 (33)
- ▶ 2010 (26)
- ▶ 2009 (21)
- ▶ 2008 (7)
- ▶ 2007 (7)
- ▶ 2006 (4)
- ▶ 2005 (17)

## About Me

 GENE VERITAS

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WEDNESDAY, DECEMBER 09, 2015

## How to make law enforcement a friend – not a foe – of people with Huntington’s disease (and other disabilities)

Encounters with misinformed, sometimes insensitive police are one of the most vexing and tragic problems faced by people disabled by Huntington’s disease. So HD advocates and organizations are proactively trying to help law enforcement officers understand symptoms of the disorder and properly handle individuals in distress.

“We want them to be a friend, not a foe,” Doug Schulte, a long-time caregiver to his HD-afflicted wife Dorlue, said of the relationship between HD-affected people and police officers.

Doug, a retired fire captain with the San Diego Fire-Rescue Department, has joined HD advocates in the area and around the country in raising awareness about the disease. Its many behavioral disorders have often been misinterpreted as drunkenness, drug usage, or intentional hostility. People with HD often have an unsteady gait, involuntary movements, slurred speech, aggressiveness, and other difficulties that hamper social interaction. But those are warning signs for police untrained for such interactions.

An informal survey, which I conducted among HD families on Facebook recently, revealed that police misunderstanding and harsh treatment of affected individuals continue, but also that some officers respond with respect. (Click [here](#) and [here](#) to read about two previous controversial cases, in West Virginia and Pennsylvania.)

The survey also showed that some HD families are taking the initiative to contact the local police to educate them about the disease and their loved ones.

At the same time, thanks to both disease advocates and changing perceptions of police officers’ responsibilities, some law enforcement agencies have established programs to increase officers’ sensitivity when encountering or responding to calls involving the cognitively disabled and the mentally ill.

On October 3, California Governor Jerry Brown signed into law a bill mandating that police officers receive more [in-depth training for helping citizens](#) with mental illness or developmental disabilities, or who are under the influence of certain substances.

### ‘Take Me Home’

Doug recently registered Dorlue in the [“Take Me Home” Program](#) of the San Diego County Sheriff’s Department. Under the program, people with Huntington’s, Alzheimer’s disease, autism, and other cognitive disabilities or their loved ones can register their information online. Registrants can

## HD Links

[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](#)  
[HD Free with PGD!](#)  
[Stanford HOPES](#)  
[Earth Source CoQ10, Inc.](#)

## HD Blogs and Individuals

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

upload a photo of the disabled individual and provide a description of the person and symptoms that officers should know about.



*Dorlue Schulte (family photo)*

Lt. Mike Knobbe, a 24-year veteran of the sheriff's department and the coordinator of Take Me Home, said that the program aims for good relations between the police and the disabled.

“The whole goal of this program is to build that partnership and to build that understanding, to allow you to tell us what you want us to know about your individual with special needs,” said Lt. Knobbe in a December 2 interview at sheriff's headquarters.

Lt. Knobbe runs Take Me Home as part of his work as head of the department's search and rescue unit. He also represents the department at the ambitious [Alzheimer's Project](#) established by the San Diego County Board of Supervisors to seek treatments and improved care for that disease. The region has some 60,000 people affected by Alzheimer's, some of whom dangerously wander from home and need a program like Take Me Home, Lt. Knobbe said.

Advocates for the disabled and affected families might not trust the police, he said, if officers don't understand the dynamics of a disorder and the difficult situations that can result.



*A display table with items from and about the "Take Me Home" Program (photo by Gene Veritas)*

“So this is our opportunity to say, ‘Hey, we want to understand,’” he said. “What do you want to tell us, so when we get a call referencing your loved one, or to your residence, it will automatically come to our deputy, and we can have that knowledge ahead of time.”

With more than 500 individuals registered in the sheriff’s department’s countywide database, Take Me Home allows the department and other local police agencies to send to patrolling officers’ computers a photo of the disabled individual, medical information, and an explanation of unusual symptoms or behaviors. So far, the department has not tracked results, but may do so in the future. It is actively promoting the program to other law enforcement agencies in San Diego County and with disability organizations.

As Lt. Knobbe explained, typically misunderstood HD symptoms such as aggressiveness can “absolutely” go into the database.

“That’s something we want to know,” he said. “We still have a duty and a responsibility as a law enforcement officer to respond, yet it gives us a chance to have some information as to why might this be occurring.”

To register, go to [www.sdsheiff.net/tmh/](http://www.sdsheiff.net/tmh/). You can listen to Lt. Knobbe introduce the program to the HD community in the video below.



## 'Take Me Home': A Police Aid for Assisting the Disabled

from [Gene Veritas](#)

05:02

['Take Me Home': A Police Aid for Assisting the Disabled](#) from [Gene Veritas](#) on [Vimeo](#).

### **An online database**

The San Diego Sheriff's Department adopted Take Me Home in 2010 at the initiative of [Brian Herritt](#), a former Palomar College officer with an autistic son who once wandered from the family car and encountered a policeman. The boy was unhurt, but the incident prompted Herritt to think about why officers should understand the behaviors resulting from autism, Lt. Knobbe said.

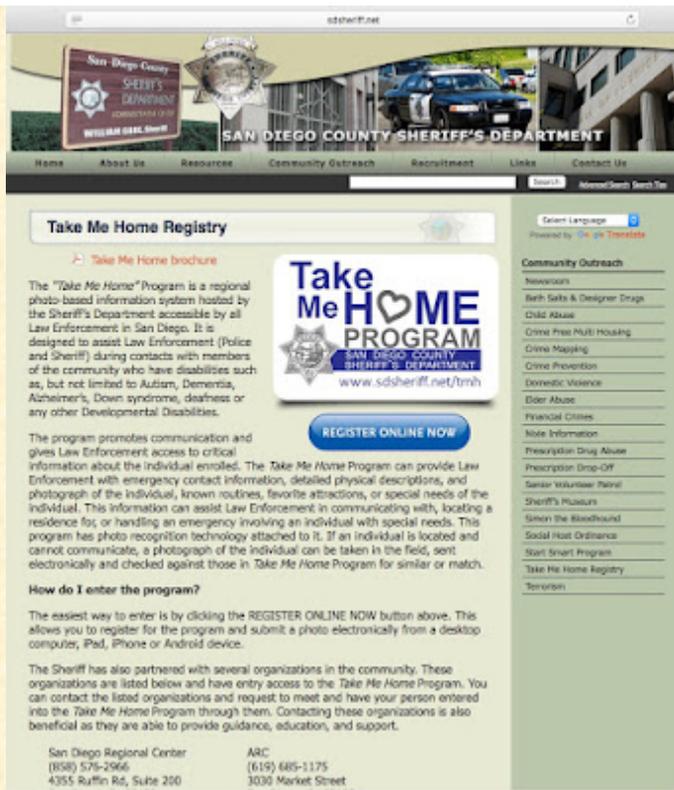
In advocating for the program in San Diego, Herritt studied the Take Me Home program of the Pensacola (Florida) Police Department. Other departments around the country have similar programs.

In San Diego, Take Me Home first relied on patient advocacy groups such as the local Alzheimer's association to provide a list of individuals for the database.

This process proved cumbersome, lengthy, and inconvenient, and the program was falling into disuse, Lt. Knobbe said. In early 2014, Sheriff Bill Gore tasked him with revamping the program.

"You can now register online on your own," Lt. Knobbe said of the most important change in the program. "If you're a caregiver, and you want to register your loved one, you can access our website and the Take Me Home registry and you can actually do your own online registration via your Android device, your iPhone, your iPad, your home computer, attach your own photograph, give us the information you want us to know, and do it from the comfort of your home."

People register voluntarily, but the information remains confidential, he explained.



*A screenshot of the Take Me Home webpage, December 9, 2015*

### Encouraging participation

Lt. Knobbe credited Doug Schulte with introducing him to HD and getting the disorder listed in the registry.

Before the introduction of the online option, Take Me Home “wasn’t utilized,” said Jamie Jirik, the board secretary for the San Diego Chapter of the Huntington’s Disease Society of America (HDSA). “The information wasn’t being updated effectively.”

“We want this to stay around,” Doug said, adding that he and Jamie are encouraging all San Diego County HD families to participate. “We want this to be something that law enforcement is used to using for people not only with Huntington’s, but Alzheimer’s, autism, and other mental illnesses. People who are deaf, too. It’s equipped with photo recognition software.”

Take Me Home gives law enforcement a good option: contacting a family member instead of arresting an HD person, Doug continued. “It’s what law enforcement wants to do,” Doug said. “They don’t want to take someone down and detain them. It’s a big waste of time for them.”

“If we have a lot of individuals in the database, we’ll have more resources available to us from law enforcement and other first responders,” Jamie added.

“There’s no risk to it,” said Doug. “It’s all reward. There’s no way that putting the information in there is going to be a detriment.”



*Jamie Jirik and Doug Schulte (photo by Gene Veritas)*

### **A problem 'easy to fix'**

Using HDSA's Law Enforcement Toolkit, Jamie and Doug have teamed up to raise awareness about HD among police agencies, paramedics, and other first responders in the San Diego region. They have made presentations at training sessions and other departmental-sponsored events.

Doug calls on his personal experiences as a caregiver to get across the message about HD.

"When you explain how it unfolds in a person's life, it brings a new dimension of understanding," he said.

Dorlue has not experienced difficulties with the police, but Doug recognizes that the potential exists, as it does for many HD-afflicted people. He's also listened to the sufferings of other families.

"The problem of police detention of HD-affected individuals is an awareness issue that is easy to fix," he said. "We want the resources that society puts in place to protect the HD community to work with us, not against us. My background in fire was to help solve people's emergencies. Police want to be there helping us, not detaining us if it isn't warranted. I understand, because I have worked beside law enforcement. They have an extremely difficult job – they just are not aware of HD."

### **Teaching response teams about HD**

Jamie, 28, watched the disease kill her father in her home state of Illinois when she was 12. "He suffered from a lot of the behavioral aspects of HD," recalled Jamie, who has tested negative for HD. "We saw his personality change greatly as the disease progressed."

Jamie's father was "confrontational at times" with the police and arrested several times, but her mother "actually had a great relationship with law enforcement," Jamie said. "They did a really good job because they didn't beat him up and respected him as much as possible."

In addition to promoting Take Me Home to the local HD community, Jamie and Doug have explained the disease to local police agencies'

Psychiatric Emergency Response Teams (PERT). Such teams act as a liaison between law enforcement and health resources.

“They have the training and experience to interact with individuals with psychological difficulties,” she said. Departments activate PERT when people become a threat to themselves or to others, cannot communicate, or cannot clothe or bathe themselves, Jamie explained. PERT gets a trained clinician inserted into a police situation.



*Raising awareness about HD: Jamie Jirik (left), Dr. Mark Marvin, director of the San Diego County PERT, Lt. Debra Farrar of the San Diego Police Department, and Doug Schulte (personal photo)*

### **Feeling safer**

Jamie and Doug are promoting other ways of insuring the proper treatment of HD people, including the newly standardized Huntington's Disease ID Bracelet sold by HDSA.

“It's a tool for law enforcement,” Doug explained. “They can pop this open and get the specific information about the person's medical situation. When a paramedic has an interaction, they need to see the medical history and medications. There's a piece of paper in here where you can write all that.”

Other resources can be viewed at HDSA's [Law Enforcement Education webpage](#).

The HD advocacy organizations HDCare.org and WeHaveAFace.org have announced a cooperative effort to provide a new medical ID alert bracelet for HD people. (Click [here](#) to read more.)

“There's not one way that's going to work for everyone, but having all these [resources] available for HD families to utilize will allow people to feel safer and just communicate with first responders,” Jamie observed.



*Jamie Jirik displays the Huntington's Disease ID Bracelet (photo by Gene Veritas).*

Posted by [Gene Veritas](#) at 9:14 PM      

Labels: [cognitively disabled](#) , [Doug Schulte](#) , [drunkenness](#) , [Huntington's disease](#) , [involuntary movements](#) , [Jamie Jirik](#) , [Mike Knobbe](#) , [police](#) , [San Diego County Sheriff's Department](#) , [symptoms](#) , [Take Me Home Program](#)

1 comment:



**WonkaVater said...**

Gene, I swear, your blog entries and articles of interest read like a combination of NY Times and Charles Osgood's CBS Sunday Morning TV show. Your blog never misses the mark, and if you are not a journalist commanding top dollar in New York City, then you have missed your calling! Excellent, as always.

*7:53 AM, December 13, 2015*

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