

University of San Diego

Digital USD

At Risk for Huntington's Disease

Department of History

4-16-2019

Comedian Rod Man's heartfelt speech, Ramona Johnston's death remind us of urgent need to cure Huntington's disease

Kenneth P. Serbin
University of San Diego

Follow this and additional works at: <https://digital.sandiego.edu/huntingtons>



Part of the [Nervous System Diseases Commons](#)

Digital USD Citation

Serbin, Kenneth P., "Comedian Rod Man's heartfelt speech, Ramona Johnston's death remind us of urgent need to cure Huntington's disease" (2019). *At Risk for Huntington's Disease*. 270.
<https://digital.sandiego.edu/huntingtons/270>

This Blog Post is brought to you for free and open access by the Department of History at Digital USD. It has been accepted for inclusion in At Risk for Huntington's Disease by an authorized administrator of Digital USD. For more information, please contact digital@sandiego.edu.


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)
 - ▶ November (2)
 - ▶ October (2)
 - ▶ August (2)
 - ▶ July (1)
 - ▶ June (2)
 - ▶ May (2)
 - ▼ April (1)
 - [Comedian Rod Man's heartfelt speech, Ramona Johnst...](#)
 - ▶ March (3)
 - ▶ February (2)
 - ▶ January (2)
- ▶ 2018 (16)
- ▶ 2017 (14)
- ▶ 2016 (13)
- ▶ 2015 (24)
- ▶ 2014 (24)
- ▶ 2013 (30)
- ▶ 2012 (26)
- ▶ 2011 (33)
- ▶ 2010 (26)
- ▶ 2009 (21)
- ▶ 2008 (7)
- ▶ 2007 (7)
- ▶ 2006 (4)
- ▶ 2005 (17)

About Me

 GENE VERITAS

[View my complete profile](#)

HD Links

[Huntington's Disease Society of America](#)
[International Huntington Association](#)
[Huntington's Disease Drug Works](#)

TUESDAY, APRIL 16, 2019

Comedian Rod Man's heartfelt speech, Ramona Johnston's death remind us of urgent need to cure Huntington's disease

In his raw, heartfelt speech in February about the devastation of Huntington's disease in his extended family, comedian Rod "Rod Man" Thompson reminded his audience of the HD community's urgent need for help: "We've got to find a cure. Any disease: you want to kick his ass."

On April 4, the story of yet another fallen "HD warrior" drove home how the condition often strikes in the prime of life and is ultimately fatal. That night, Ramona Johnston, the wife of longtime San Diego Chargers football team public relations director and major HD fundraiser Bill Johnston, succumbed to the disease after more than 20 years of brave struggle. Diagnosed at age 39, Ramona was just 60.

"Ramona passed away last night after fighting unbelievably hard against this horrible disease," Bill [wrote on Facebook](#) on April 5. "As much as I knew this day would come, it hurts so bad that my girl is gone. She's the strongest, toughest, bravest person I know. One of God's angels on earth finally has peace and is with Him in heaven."

Introducing Rod Man

HD affects not just individuals but families. To illustrate that, [as promised earlier](#), I'm now providing a detailed report on Rob's important and moving February 25 keynote address to several hundred scientists, drug hunters, and advocates at the 14th Annual Huntington's Disease Therapeutics Conference. Sponsored by [CHDI Foundation, Inc.](#), the event took place at the Parker Palm Springs hotel in Palm Springs, CA.

A standup comedian, [Rod Man](#) was the winner of season 8 (2014) of NBC's Last Comic Standing reality TV talent competition. He has appeared at Caesar's Palace in Las Vegas, the Apollo Theater in New York City, and the Gibson Amphitheatre in Los Angeles, where he resides. He has also appeared in film and TV roles, and hosts his own [YouTube shows](#).

"That's my passion," said the performer known as Rod Man. "Tonight, we're going to set a different tone. I am Rod Thompson tonight."

A native of the small Georgia town of Villa Rica, Rod was the first African-American CHDI keynoter. His family's story underscored the fact that HD affects people of all ethnicities, as well as both sexes.

"As an African-American, I know that sometimes we don't get the information," Rob commented. "I'm here as a black man."

[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](#)

However, he said, he recognized that HD affects his family just as it does others. He said that he aimed to “promote conversation” and awareness about HD, no matter what a person’s personal or educational background.



Rod "Rod Man" Thompson (right) exchanges laughs with leading HD researcher Steven Hersch, M.D., Ph.D., of Voyager Therapeutics, after Rod's keynote speech (photo by Gene Veritas).

The challenges families face

Rod titled his presentation “The Cycle: My Mother’s Story.” Interlacing humor with wrenching stories of HD’s debilitating physical and mental impact on his 66-year-old mother Shirley, Rod captured the many aspects of HD that families struggle with and doctors and scientists seek to alleviate.

His speech reflected once again how, as an inheritable disease, HD affects the extended family. His elder daughter prepared the slides for his talk. It included photos of Shirley and three aunts – all now in nursing homes – and a cousin also stricken with the disease.

Rob recalled how his maternal grandmother was initially misdiagnosed with cerebral palsy. Growing up, he was unaware of HD. “I just knew my grandmama was mean,” he said, referring to HD’s psychiatric and behavioral symptoms.

Before arriving in Palm Springs, Rod interviewed his sister, the primary caregiver for his mother in Villa Rica. She described details of Shirley’s daily struggles with HD, as well as the constraints it imposes on her own life.

“I understand how it affects her life,” Rod said. “She said, ‘Yes, it’s a lot to deal with.’”

Because of her “sacrifice” to care for Shirley, Rob’s sister has for now given up her own career dreams in fashion design, Rob added. “I could see the anger build in her, because she feels like, ‘If I don’t, who else is going to?’”

Rod recognized that other HD families face a similar battle. “It’s like having a child sometimes,” he said of the inability of HD people to care for themselves and the challenges faced by caregivers.

Shirley’s decline

Shirley showed symptoms before her official diagnosis in 2016, Rob explained.

“Once they told her, she broke down and cried, because she knows from her sisters and her mama what it does,” he said.

Rod described the terrible physical, cognitive, and psychiatric decline that HD has wrought in his mother.

"I see depression and sadness about stuff that can be a misunderstanding to most people, and they'll let it go, but she still holds on to it and harbors it," Rod said.

Because of Shirley's involuntary movements, the family also keeps kitchen utensils away from her to prevent her from injuring herself or others. She can no longer walk normally.

"Now it's better for her to eat with her hands, because she's a little shaky," Rod explained. "Her body's not the same."

Inspiring the scientists

Untested, Rod and his two daughters – a college graduate and a high school student – are also at risk.

Rod and members of his extended have candid conversations about testing. However, he added, "Most people in my family are scared to get tested." That reflects the majority attitude in the HD community.

However, Rob hopes for a cure, hence his motivation to keynote the conference. "I appreciate what you guys do in your work day to day," he said. "You all do admirable work. Hopefully, by telling my story, and others like me, you'll get inspired."

Rod received a standing ovation.

You can watch Rod's address in the video below.



Comedian Rod "Rod Man" Thompson keynotes Huntington's disease research conference

from **Gene Veritas**

54:45 |



Celebrating Ramona's life

Ramona died at Edgemoor Hospital in Santee, CA. The highly regarded public long-term care facility has cared for dozens of HD patients over the last few decades.

In early 2017, when the Chargers announced their move to Los Angeles, Bill made a gutsy, loving decision: after 38 years with the team, he quit so that

Ramona could stay at Edgemoor. He visited her there each morning before heading to work.

"Everybody would make the same decision I am making if they were in my shoes," Bill said at the time. "It's just the situation I find myself in." ([Click here](#) to read more.)


Bill now works for the San Diego Padres baseball team, which has supported his advocacy.

Ramona's son Jared tested negative for HD. Untested, daughter Hayley is the vice president of the [San Diego Chapter](#) of the Huntington's Disease Society of America (HDSA). She and Bill continue as leading advocates in Southern California. Their efforts have raised almost \$3 million for HDSA.

A Celebration of Life will take place at 1 p.m., April 17 at Skyline Church, 11330 Campo Road, La Mesa, CA. In lieu of flowers, memorial contributions may be made to [HDSA](#) or www.HelpCureHD.org.



The Johnston team at the 2014 Rock-n-Roll Marathon raising funds and awareness for HDSA. Bill has his arm around Ramona, in wheelchair. Daughter Hayley stands directly behind Bill (photo by Andrew McClanahan/PhotoRun.net).

Posted by [Gene Veritas](#) at 4:37 PM 

Labels: [Bill Johnston](#) , [caregiver](#) , [CHDI Foundation](#) , [genetic testing](#) , [Hayley Johnston](#) , [HD Therapeutics Conference](#) , [HD warrior](#) , [Huntington's disease](#) , [Ramona Johnston](#) , [Rod "Rod Man" Thompson](#) , [standup comedy](#) , [symptoms](#)

No comments:

[Post a Comment](#)

[Newer Post](#)

[Home](#)

[Older Post](#)

Subscribe to: [Post Comments \(Atom\)](#)