

University of San Diego

Digital USD

At Risk for Huntington's Disease

Department of History

2-28-2017

Staying when the Chargers leave: a leading Huntington's disease advocate sets a gutsy, loving example

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., "Staying when the Chargers leave: a leading Huntington's disease advocate sets a gutsy, loving example" (2017). *At Risk for Huntington's Disease*. 235.
<https://digital.sandiego.edu/huntingtons/235>

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.

More

[Create Blog](#) [Sign In](#)


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)
 - ▶ December (2)
 - ▶ November (1)
 - ▶ October (1)
 - ▶ June (1)
 - ▶ May (4)
 - ▶ April (1)
 - ▶ March (1)
 - ▼ February (2)
 - [Staying when the Chargers leave: a leading Hunting...](#)
 - [Banning college football: an urgent objective for ...](#)
- ▶ January (1)
- ▶ 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](#)

TUESDAY, FEBRUARY 28, 2017

Staying when the Chargers leave: a leading Huntington's disease advocate sets a gutsy, loving example

After the San Diego Chargers' recently announced [move to Los Angeles](#), team public relations director and Huntington's disease advocate Bill Johnston made a gutsy, loving decision: after 38 years with the Chargers, he will quit so that his HD-afflicted wife Ramona can stay at the highly-regarded San Diego nursing home where's she spent the last decade.

Bill made his decision after thoroughly researching nursing homes in Orange County, which is much closer to the Chargers' new Los Angeles headquarters than San Diego County. He visited seven facilities, paying special attention to their ability to conscientiously care for someone with HD. As the HD community is all too painfully aware, such facilities [often provide poor care](#).

Bill did not find what he wanted. He opted for Ramona to remain at [Edgemoor Hospital](#) in Santee, located next to San Diego. A public nursing home, Edgemoor has cared for dozens of Huntington's patients over the past several decades.

"Everybody would make the same decision I am making if they were in my shoes," Bill told the [San Diego Union-Tribune](#). "It's just the situation I find myself in."

Bill awakes at 4:55 a.m. daily and visits Ramona at Edgemoor before heading to work. She was diagnosed with HD in 1999 but had showed symptoms earlier. She is now in the late stages of the disease, confined to a wheelchair and unable to care for herself. The native San Diego couple met in high school and married in 1983.

"She can't talk anymore, but she'll make some sounds," Bill told the [Union-Tribune](#). "Sometimes, I think she's trying to say my name. Maybe it's just wishful thinking."

[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](#)

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

'I'll always do what I can'

By interrupting his career and staying in San Diego, Bill is rolling with one of the many punches thrown by HD. His son Jared, 31, tested negative for HD. Daughter Hayley, 28, remains untested; she has a 50-50 chance of having inherited the HD genetic defect from Ramona.

Other HD families have adapted their lives dramatically to meet similar challenges. In my family, my mother died of HD, and I carry the gene. Since my mother's diagnosis in 1995, HD has frequently dominated my family's life. Fortunately, our daughter tested negative and is today a healthy teenager.

Bill's situation reminded me of my own. In 2007, in a wrenching, [career-changing decision](#), I turned down a major job offer in Miami to remain in California, a biotech state with crucial public support for stem cell research. California also has HD-involved companies such as Ionis Pharmaceuticals, Inc., which is currently running a historic Phase I [clinical trial of a gene-silencing drug](#). Most important, remaining in California allowed my wife to keep her relatively well-paying teaching job and pension, our financial lifeline if I become disabled.

I had also bonded with Bill and many other members of the San Diego Chapter of the Huntington's Disease Society of America ([HDSA-San Diego](#)). Through chapter events, Bill and his family have raised nearly \$3 million for HDSA. Their leadership and fortitude have inspired people in the local HD community and beyond.

In response to my e-mail query about his plans for future advocacy, Bill wrote: "I'll always do what I can."

"Bill has been a 'tour de force' in advocating for the HD community in San Diego and nationally," HDSA-San Diego president Beth Hoffman, Ph.D., wrote in an e-mail. "Bill has tremendous energy and passion, and brings wonderful and new ideas to our fundraising efforts. He's always been there to drive the chapter's success. We are thrilled that Bill will remain in San Diego and look forward to expanding our efforts towards the HDSA mission with him."

"I am not surprised by Bill's decision to stay," long-time HDSA-San Diego board member Misty Daniel wrote. "His dedication to Ramona and our HD community has never faltered over the years. Bill's decision to stay reaffirms what most HD families know: that family truly is everything."



Ramona with Chargers star and HDSA supporter Antonio Gates at the 2007 Celebration of Hope Gala (photo by Gene Veritas)

Change means new opportunities

After 56 seasons in San Diego, the Chargers' departure angered local football fans and civic leaders. "The Los Angeles Judases have betrayed us for 30 pieces of silver," wrote *Union-Tribune* sports columnist Nick Canepa, who is also a member of HDSA-San Diego's advisory board, in reference to the move

The team's exit has also posed a huge challenge for HDSA. Bill's involvement since 1999 added the team's high-profile pro-football brand to most major fundraising events, including the chapter's annual gala. For years, HDSA-San Diego board meetings took place at Chargers' headquarters, and team owner Dean Spanos allowed use of that facility for fundraisers. In 2003, Spanos and his wife Susie received HDSA's Harold Leventhal Community Service Award at a dinner in New York City.

However, Bill's decision to remain has helped offset the feelings of desertion resulting from the Chargers' move. His connections, creativity, and dedication will help the chapter strike out in new directions. As Bill has always made clear, he's also in this fight for Hayley – and for all families affected by HD.



Bill and Hayley Johnston exchange ideas at an HDSA-San Diego event in May 2016 (photo by Gene Veritas).

Over the years, other chapter members and even Bill himself recognized the danger of relying too heavily on the Chargers. As a result, the chapter has strived to diversify its sponsor and donor base.

The Chargers' exodus might also provide unforeseen benefits such as distancing HDSA-San Diego from the uncomfortable connection to a sport now [linked to brain diseases similar to HD](#).

“The Chargers organization has been stellar in its support,” Dr. Hoffman wrote, noting the chapter's gratitude for the players' “enthusiastic participation” at fundraisers. “We will miss our Chargers.

“That said, the HDSA-San Diego board and all of our wonderful volunteers are hard at work attracting sponsors and making our events even more exciting. Whenever there are changes, there are

new opportunities. Our job is to find and leverage these opportunities to their maximum potential.”

Posted by [Gene Veritas](#) at [3:27 PM](#)



Labels: [Bill Johnston](#) , [career](#) , [clinical trials](#) , [Edgemoor Hospital](#) , [fundraising](#) , [gene carrier](#) , [Hayley Johnston](#) , [HDSA-San Diego](#) , [Huntington's disease](#) , [love](#) , [nursing home](#) , [Ramona Johnston](#) , [San Diego Chargers](#) , [wheelchair](#)

No comments:

[Post a Comment](#)

[Newer Post](#)

[Home](#)

[Older Post](#)

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