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At Risk for Huntington's Disease

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## My Huntington's disease sister – and a hero who strives for the unthinkable

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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)
  - ▶ November (2)
  - ▶ October (2)
  - ▶ August (2)
  - ▶ July (1)
  - ▶ June (2)
  - ▼ May (2)

[My Huntington's disease sister – and a hero who st...](#)

[Let's Talk About Huntington's Disease': 2019 HD A...](#)

- ▶ April (1)
- ▶ 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

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## HD Links

[Huntington's Disease Society of America](#)

FRIDAY, MAY 24, 2019

## My Huntington's disease sister – and a hero who strives for the unthinkable

Sharon Shaffer is my Huntington's disease sister – and my hero.

Afflicted with progressively worse HD symptoms the past 15 years, San Diego area resident Sharon decided to once again attempt the unthinkable for someone heading into the final years of the fatal, incurable disorder: she rowed the equivalent of an aquatic marathon (26.2 miles) on a gym machine in six and a half hours.

The May 10 event, with loved ones and supporters cheering her on, was called "Sharon's Marathon Row for Huntington's Disease Awareness Month."

Sharon's feat was captured in a five-minute video titled *Magic on Marathon Row*, produced by filmmaker [Nathan Apffel](#), who also directed the feature-length documentary *The Longest Journey*, about the Shaffer nuclear family's epic battle against Huntington's.



*A scene from Magic on Marathon Row*

"When disease takes your health and mobility and will take your life, you have a choice," the video's overlying text says. "Meet Sharon, a real-life super woman. As Sharon's body gives out, her determination grows. As her world contracts, her commitment to raising awareness intensifies. As her body breaks down, one thing remains consistent: her determination to fight."

Sharon's husband Renato told me in an e-mail that, despite her advanced HD symptoms, she did the "marathon" through "sheer perseverance."

[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

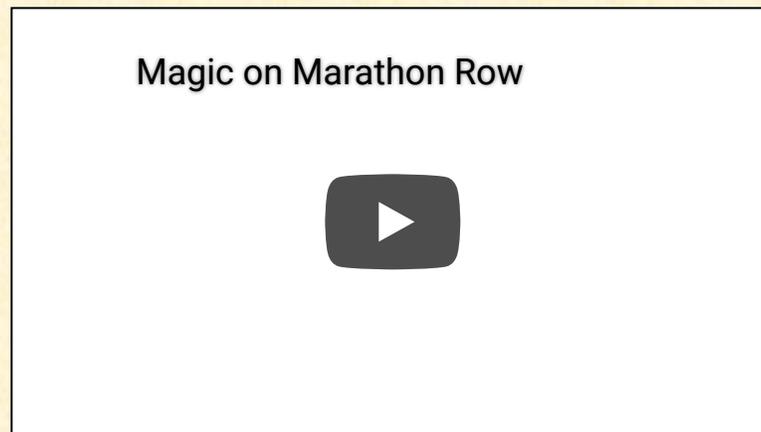
[Chris Furbee: Huntingtons Dance](#)  
[Angela F.: Surviving Huntington's?](#)  
[Heather's Huntington's Disease Page](#)

“It is the only exercise she is able to do without assistance,” he added.

“Sharon, you truly are an inspiration to so many,” wrote E.J. Garner, the [chair of the board](#) of the Huntington’s Disease Society of America, in response to my Facebook posting of the video. “Thank you for being such a beautiful example of persistence to fight and bringing awareness to Huntington's disease.”

“She completed a feat only few in the entire world, even healthy and athletic, would not dare approach, let alone finish,” observed LeeJ Razalan, a friend and the owner of [Stay Classy CrossFit](#), the San Diego gym where the event took place. “Sharon's statement in life and in disease will forever ring: we shall overcome and we will finish this together.”

Watch Sharon in the video below.



### Advancing symptoms

The “marathon” exhausted Sharon. “She could barely move when we got home and took a good three days for full recovery,” Renato explained.

With her family’s help, Sharon has remained one of the most physically active HD-afflicted individuals I have encountered. The highly demanding [CrossFit workouts](#) have been one of her favorite activities.

Renato believes that CrossFit delayed Sharon’s need for a wheelchair.

“I also believe the people she worked out with gave her motivation,” he added. “She always looked forward to working out.”

However, Renato also described CrossFit as a “barometer” of HD progression.

In recent years she has become physically weaker, and the involuntary movements caused by HD have increased.

“We have witnessed a rapid decline in the past twelve months,” Renato wrote. “She is no longer able to walk unassisted, and her speech is becoming more labored every day. We have full-time in-home care and are so fortunate they are doing a really great job taking care of her.”

Sharon still exercises, but “it gets more difficult every week,” Renato added.

Renato allowed Sharon to row in the “marathon,” he wrote, because as symptoms worsen, exercise will become impossible. That moment will be "heartbreaking."

### An upbeat family

I met Sharon about two decades ago at the HDSA-San Diego support group. With others in the breakout group for presymptomatic gene carriers like us and also the untested at-risk, we shared our fears about the disease and its consequences for our children and extended families.

The Shaffers became one of the most active supporters of the cause. Between 2005 and 2015, with Sharon, family members, and others following in support vehicles, Renato and three other riders competed *four times* in the [Race Across America](#), a non-stop coast-to-coast bicycle race. They always completed the race in fewer than the required eight days.

*The Longest Journey* documentary chronicles the 2015 race. “In contrast with most presentations of HD I’ve witnessed in the two decades since my mother’s diagnosis for the disorder, this often emotionally wrenching film left me, an HD gene carrier, feeling upbeat,” I wrote in a review of a private screening of the film in 2016 ([click here](#) to read more).

The closing words of Sharon’s rowing video ask viewers to learn more about Sharon’s story by watching *The Longest Journey*. (It’s on Amazon and free to Prime members.)

According to Renato, Amazon statistics reveal that the film has been viewed 200,000 times.

### **The essential goal: treatments**

Sadly, I’ve witnessed how HD has overcome Sharon, transforming her from a healthy and vibrant woman into someone now dependent on a wheelchair and the assistance of others.

However, Sharon has demonstrated that, despite the ravages of the "devil of all diseases," the core of her personality has survived.

As we enter the final week of HD Awareness Month, Sharon’s gutsy fight reminds us all that we must not give up in the face of Huntington’s difficult challenges.

For me, Sharon’s devotion to exercise is a cue to spend more time swimming.

At the same time, exercise, although certainly important, has not stopped Sharon’s HD from progressing.

We need effective treatments – urgently.

In the HD movement, advocates create moments that capture the essence of the cause.

In defying seemingly insurmountable obstacles, the Shaffers remind us of the immense scientific, financial, political, and social challenges that the HD community faces in seeking to find the first effective treatment – and perhaps even a cure – for a neurological disorder.

Posted by [Gene Veritas](#) at 3:34 PM      

Labels: [advocacy](#) , [care](#) , [CrossFit](#) , [exercise](#) , [HD Awareness Month](#) , [HD gene carrier](#) , [HDSA](#) , [Huntington's disease](#) , [involuntary movements](#) , [Renato Shaffer](#) , [rowing](#) , [Sharon Shaffer](#) , [symptoms](#) , [The Longest Journey](#) , [wheelchair](#)

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