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At Risk for Huntington's Disease

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## Getting the COVID-19 vaccine and a new exercise bike to keep stable in the fight against Huntington's disease

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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.*

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## About Me

 [GENE VERITAS](#)

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## HD Links

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

THURSDAY, FEBRUARY 25, 2021

## Getting the COVID-19 vaccine and a new exercise bike to keep stable in the fight against Huntington's disease

In my fight against Huntington's disease, I have strived to delay the inevitable onset by working hard to [keep my overall health stable](#). This strategy has included avoiding potential shocks to my system.

Now the [leading cause of death](#) in the United States, COVID-19 poses a threat to all of us. As a 61-year-old HD asymptomatic gene carrier, I have religiously followed recommendations on social distancing, mask use, and handwashing.

As a university professor, I have taught online since March 2020. The pandemic has [rocked universities' finances](#) and employees' benefits. Despite serious precautions by the schools, the coronavirus has surged among some students, [including at my campus](#), the University of San Diego.

On February 6, I got a last-minute opportunity to get vaccinated with the [Moderna COVID-19 vaccine](#). A San Diego nonprofit clinic that was following guidelines to first vaccinate individuals 65 and over announced around midday that not enough people from that group had responded, thus making available extra doses that needed to be injected that day. Educators and healthcare workers were invited to get that first of two doses.

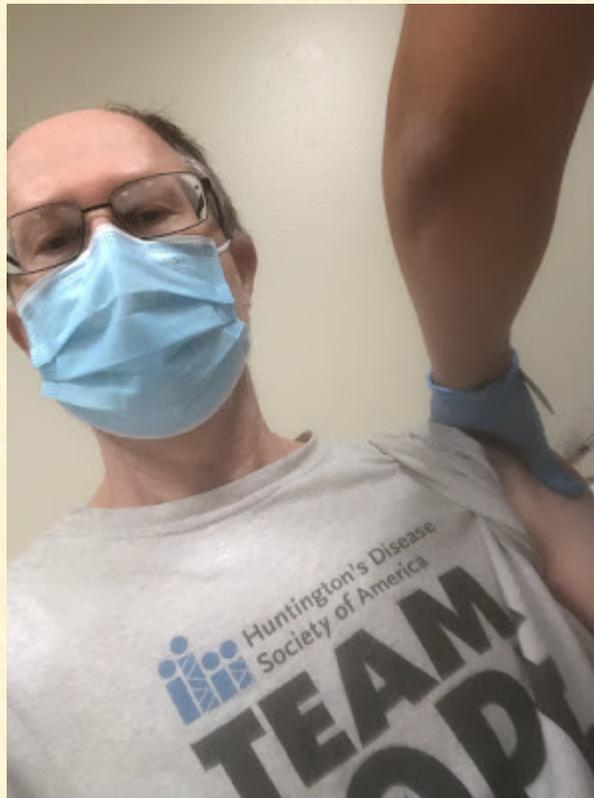
My wife Regina, an instructional coordinator for the [San Diego Unified School District](#), and I jumped at the chance. After a two-hour wait, including filling out forms and questionnaires, we

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[Huntington's Disease Advocacy Center](#)  
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## HD Blogs and Individuals

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

received our shots! We were jubilant. Getting vaccinated also felt like an extra gift for Regina: February 6 was her birthday.



*Gene Veritas, aka Kenneth P. Serbin, receiving an injection of the Moderna COVID-19 vaccine (selfie by Gene Veritas)*

As one of the tens of millions of Americans now at least partially vaccinated, I am protecting not only my health, but also limiting the spread of the pandemic. (For an expert discussion of the ethics of COVID-19 vaccination, including the phenomenon of “vaccine guilt,” [click here.](#))

I was also proud to get the Moderna vaccine because its RNA-based approach resembles some of the treatment strategies being tried in HD clinical trial programs. Furthermore, the scientist-written HDBuzz website has [urged HD-affected individuals](#) to get vaccinated for COVID-19.

Though I had a sore arm and felt a queasy for a couple of days, I have felt normal since. We are scheduled to get the required second shot on March 6. I also have participated voluntarily in the federal government’s [V-safe After Vaccination Health Checker](#), a

mobile phone app including questions about pain and other potential side effects.

### **An innovative, ‘neurobic’ spin bike**

Four days after our COVID shots, technicians delivered and set up our long-awaited new exercise machine, the [Peloton Bike+](#), which has a screen for watching online classes.

Regina and I have always prioritized exercise. This has become ever more important as we have aged. When we had a backyard pool built in 2009, I insisted on installing a [Fastlane](#) swim device so that I could exercise vigorously.

I have varied my exercise – swimming, walking, riding a stationary bike – to focus on different parts of the body.

In general, avoiding physical and mental routine can reinforce brain and overall health. This has led me to practice “neurobics,” a word that combines words “neurons” and “aerobics.” Such brain workouts can include something as simple as engaging with interesting people or taking a different route every time I walk. Neurobics can increase levels of the critical brain nutrient BDNF, brain derived neurotrophic factor. ([Click here](#) to read more.)

After the start of the pandemic, we noted the extensive TV advertising for Peloton (which even became the subject of a recent *Saturday Night Live* [skit poking fun](#) at the motivational online workouts).

The Peloton bike and other online exercise apps that feature live and recorded exercise classes are an innovative, neurobic way of connecting with coaches and others. Users can expand their physical and mental horizons with the [wide variety](#) of online cycling classes, strength exercises, stretch classes, yoga, and other activities.



*Gene Veritas riding the Peloton Bike+ (photo by Regina Serbin)*

We have found the Peloton Bike+ and the app to be far superior to our previous exercise bike, which had begun to deteriorate. A spin bike, the Peloton allows for a more versatile workout.

In the psychologically devastating social isolation of the pandemic, the Peloton is also allowing us to thrive indoors. Despite a significant sticker price, the bike makes sense budget-wise, since the money from Regina's cancelled gym membership goes to a monthly payment plan.

### **Subtle impairments predate onset**

On February 16, I received a stark reminder of how Huntington's disease can impair gene carriers, however slightly, in the years leading up to an actual clinical diagnosis.

I attended an online presentation by [Paul Gilbert, Ph.D.](#), a professor and the chair in the Department of Psychology at San Diego State University, to the University of San Diego Neuro and Psych Research Club. Titled "Neuropsychological Changes in the Premanifest and Manifest Stages of Huntington's Disease," Dr.

Gilbert's talk highlighted some of the key findings in his ongoing research on this topic, including data from a 2020 [article](#) by his team in the journal *Cognitive and Behavioral Neurology*.

Premanifest HD involves the period before a neurologist can actually observe a gene carrier as having experienced the onset of the disorder's typical motor, cognitive, and/or behavioral symptoms, stated Dr. Gilbert. In the past, physicians only saw the motor symptoms – involuntary movements and unstable gait, for example – as signs of the malady

Using verbal learning and memory tests, the research has demonstrated that these individuals can develop subtle cognitive symptoms – in particular, memory loss – ten to fifteen years before the formal diagnosis, Dr. Gilbert explained. The memory deficits increase dramatically after HD onset, he added.

“It really argues that we as clinicians need to be looking at not just the motor symptoms to make a diagnosis of Huntington's disease, but really starting to look at cognitive symptoms,” Dr. Gilbert asserted.

That position echoes the general trend towards a view of Huntington's as a multi-symptom disease over the past several decades.

### **Statistical versus clinical signs**

As a regular participant in research studies, I have performed a number of the tests that Dr. Gilbert described.

During the Q&A, noting that gene carriers like me worry about where we stand on the road to onset, I asked Dr. Gilbert whether the premanifest impairments hamper “actual functioning,” for example, daily activities such as driving, balancing a checkbook, and communicating with others.

“They're statistically impaired, but they're not clinically impaired,” Dr. Gilbert observed about the gene carriers in the

research studies. The deficits are “very subtle” and can only be picked up on testing, he added.

Nevertheless, he added that his research has also determined that subtle memory impairment does have a “measurable but quite mild” impact on activities like handling finances or taking medications, but that only after onset does the disease seriously interfere with daily living.

(Dr. Gilbert’s work also echoes the recent landmark study of [young HD gene carriers](#), ranging in age from 18-40 and illustrating no significant cognitive or psychiatric decline. [Click here](#) to watch Dr. Gilbert’s 2018 presentation on HD to University of San Diego students.)

### **Anticipating a brighter future**

With the pandemic and the worst economic crisis since the Great Depression, I am very fortunate to have a job and work remotely.

Because an estimated 20 percent of HD onset results from [non-genetic factors](#), my imminent protection from COVID-19 and anticipation of new neurobic adventures with the Peloton can help me maintain stable health.

They certainly have helped me to feel optimistic about the future – for the first time in a year. I am also looking forward to news on the key HD clinical trials in progress.

Although we recognize the long-term social impact of the pandemic, Regina and I are especially looking forward to a healthier and happier 2022 for all, and the chance to travel: we hope to attend my 40th college reunion, celebrate our 30th wedding anniversary, and watch our HD-free daughter Bianca graduate from college.

We are thankful for every moment of life.

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Posted by [Gene Veritas](#) at 11:36 PM      

Labels: [asymptomatic](#) , [BDNF](#) , [cognitive impairment](#) , [COVID-19](#) , [exercise](#) , [HD gene carrier](#) , [Huntington's disease](#) , [memory loss](#) , [neurobics](#) , [onset](#) , [Paul Gilbert](#) , [Peloton](#) , [premanifest](#) , [research](#) , [spin bike](#) , [symptoms](#) , [vaccine](#)

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