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At Risk for Huntington's Disease

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## Are pre-existing conditions returning, and Obamacare ending?

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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](#)

FRIDAY, JUNE 14, 2019

## Are pre-existing conditions returning, and Obamacare ending?

Nine years ago, with passage of the Patient Protection and Affordable Care Act (ACA) under Democratic President Barack Obama, I [celebrated with an article](#) titled “Good-bye, pre-existing conditions!”

Widely known as Obamacare, the ACA prohibited insurance companies from denying coverage to people with pre-existing conditions, a widespread practice that severely endangered the genetically unlucky. It also made health insurance available to millions of people previously unable to obtain it, and it extended family coverage for children up to age 26.

In 2012, the U.S. Supreme Court [upheld Obamacare](#) by a 5-4 decision, with conservative Chief Justice John G. Roberts Jr. joining the court’s four more liberal judges. However, with the long political fight over the ACA heating up again, and a more conservative Supreme Court, Obamacare could be abolished if the court agrees with right-wing challenges to it.

Along with many other disease groups, the Huntington’s disease community could face declining quality of care, increased costs, and renewed discrimination and stigma.

### Hiding the central fact of my health

I am an HD gene carrier.

In my 2010 article on the ACA, I wrote that, because of the insurance restrictions for pre-existing conditions, I had “never used my health coverage to help me deal with the central fact of my health: my gene-positive test for this horrible brain disease.” I described the complicated and expensive lengths I went to in securing alternative assistance with HD.

Concealing my HD status from my health plan had produced “an absolutely absurd situation,” I observed in a 2019 HD Awareness Month [podcast](#). People like me used to hide our conditions because we feared losing our coverage.

“Thank goodness for the Affordable Care Act,” I commented. The ACA “got rid of this nonsense about pre-existing conditions.”

Indeed, the enactment of the ACA had helped convince me to go fully public about my HD status in 2012 and inform my health plan of my HD status ([click here](#) to read more).

In all, this has made me a more effective HD advocate – and more organized and confident regarding my daily fight to stave off symptoms.

[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](#)

### New attacks on the ACA

The Republican Party has officially opposed Obamacare, but – because of its popularity – failed to repeal it even when the party controlled both houses of Congress under President Donald Trump in 2017 and 2018. (The 2017 major tax bill signed by Trump did eliminate, starting this year, the ACA penalty for not having insurance.)

However, the Trump administration has carried out a multi-front [attack on the ACA](#). Among other things, it has promoted insurance plans that do not comply with the protection for pre-existing conditions, and it has allowed states to impose work requirements for Medicaid recipients. America's number of uninsured had fallen to record lows by the end of the Obama administration in early 2017, but the number has started to rise again.

Then, on March 25, Trump's Department of Justice filed a brief supporting a Texas federal judge's December 2018 ruling that the entire ACA was unconstitutional.

On May 22, California Attorney General Xavier Becerra, a Democrat and one of the lead defenders of the ACA, joined 20 other attorneys general in filing a brief in defense of the ACA in the U.S. Court of Appeals for the Fifth Circuit in New Orleans.

"The Trump Administration has made clear that it will not defend Americans' healthcare and the law that tens of millions of Americans across the country depend on – so our fight continues," Becerra stated in a [press release](#).

The appeal will be heard on July 9. Depending on the ruling, the case could go to the Supreme Court. With two Trump appointees, the Supreme Court has become potentially more [hostile to the ACA](#).

### HDSA's support

The [Huntington's Disease Society of America](#) (HDSA) supports the ACA.

"HDSA believes that any attempts to repeal or dismantle the ACA without providing a replacement plan that maintains [the] protections and benefits for Americans impacted by complex and chronic diseases like HD is unacceptable," the HDSA national office wrote me in a June 10 e-mail. "HDSA is committed to protecting access to healthcare for individuals impacted by HD."

According to HDSA, the ACA "has created safeguards for vulnerable Americans who are impacted by chronic, complex diseases like HD from being denied healthcare coverage or being purposefully priced out of the healthcare market." The ACA has "provided important avenues to access care for families with HD and we believe that they need to be protected."

Thus, without the ACA or a robust equivalent, HD families could face greater difficulties in finding quality, affordable care.

### We must not return to the 'HD closet'

In addition to supporting HDSA and other advocacy organizations, HD family members can contact their state attorney general to support or join the appeal of the anti-ACA Texas ruling.

In California, where I reside, Becerra has sent several recent e-mails to political supporters asking them to sign a petition in support of the ACA. The e-mails have also asked for donations to help support the defense of the ACA.

According to Becerra, 133 million Americans have pre-existing conditions. He calls the ACA a "life-saving law."

(The debate over the ACA has also helped stimulate calls by many of the 20-plus 2020 Democratic presidential contenders for a "Medicare for All" program. The debate is also related to the anti-science agenda of the Trump administration. I hope to address these issues in future articles.)

As I wrote in 2010, the passage of the ACA "brought a new beginning for the Huntington's disease community – and for everybody in America."

We must not regress to a system that forces people to hide in the "terrible and lonely HD closet," as so many of us did in the past.

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Posted by [Gene Veritas](#) at 3:57 PM     

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