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A Huntington's Thanksgiving message: gratitude for health and the ability to work

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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

TUESDAY, NOVEMBER 26, 2013

A Huntington's Thanksgiving message: gratitude for health and the ability to work

Thanksgiving, my favorite holiday, leads me to take stock of the many good things in my life.

First, I am thankful that I have not yet experienced the classic symptoms of Huntington's disease. At year's end, I will turn 54 – at least several years beyond the age of onset for my HD-afflicted mother. At my annual HD checkup last month, my neurologist said I was symptom-free.

After testing positive for HD at the age of 39 in 1999, I had expected to be incapacitated by now. Doctors and scientists still don't know enough about HD to explain why someone like me has remained asymptomatic beyond the parent's age of onset. As I have written in the past, I keep striving toward a well-informed strategy for avoiding onset.

I am thankful for many of the other reasons people celebrate Thanksgiving, especially family. My HD-free daughter is a thriving eighth grader, and next month my wife and I will commemorate 21 years of marriage.

This year, I am particularly thankful that, without the symptoms that typically disable HD people, I can still perform my job as a university professor.

The financial burdens of HD

This past Monday night, attending our local HD support group's annual holiday potluck, I saw once again how Huntington's causes the involuntary movements known as chorea and inexorably robs people of their cognitive abilities, severely hampering their capacity for work.

As a result, HD devastates families financially. When an HD-affected breadwinner loses his or her job, family income falls dramatically.

Other family members often must reduce their own work hours to help care for the sick individual. In some instances, they change occupations to adjust to care needs. They might even quit salaried work altogether.

As the story of caregivers Mike and Raima Fernald illustrates, local and state government assistance in such situations is solely lacking. The HD community also has fought to improve access to Social Security benefits, denied to many because outdated government guidelines don't account for HD's cognitive and behavioral symptoms.

In the case of my parents, HD wiped out their "golden years." Instead of enjoying retirement, my "HD warrior" dad became my mother's full-time caregiver from the mid- 1990s until her death in 2006 at the age of 68.

[View my complete profile](#)

HD Links

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

[International Huntington Association](#)

[Huntington's Disease Drug Works](#)

[Huntington's Disease Lighthouse](#)

[Hereditary Disease](#)

[Foundation](#)

[Huntington's Disease](#)

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HD Blogs and Individuals

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Instead of trips and time with their grandchildren and friends, they struggled together to address my mom's decreasing ability to walk, talk, and eat. In the last six months of her life, they spent several thousand dollars per month on nursing home care.

"HD is more than a disease," I wrote as my heartbroken father precipitously lost his own cognitive abilities in the wake of my mother's death. "It is a [destroyer of families](#)."

One thing I fear most about the inevitable onset of my own HD is that it could put my family into a similar financial bind. Both my wife and I work full-time, and my salary currently accounts for more than half of our income.

"What if I become disabled before my daughter finishes college?" I frequently ask myself. "What if my wife must work many extra years to compensate for my lost income? What if I become a burden to my family?"

Happy to be busy

News reports about the needy at Thanksgiving remind me of the troubling backdrop to the holiday: the anemic state of our economy.

As a [local radio report](#) noted yesterday, "food stamp cuts that took effect this month will make Thanksgiving even harder for low-income San Diegans. A typical Thanksgiving meal will cost the average family nearly \$50 this year, which is far beyond reach for the nearly half-million people in San Diego County who struggle every day to put food on the table — especially the 270,000 people who depend on food stamps for meals."

So this Thanksgiving I am grateful that I can work, help support the household (including our daughter's private school tuition), and save for the future. I've also enjoyed the present with family vacations and home improvements such as my just remodeled home office, which replaced a rickety and ugly setup persisting from my days as a frugal graduate student and starting assistant professor.

This year, I'm thankful for the health that has allowed me to have a highly productive year at the [University of San Diego](#), where I am wrapping up my fifth calendar year as department chair. It's been especially busy as my colleagues and I search to fill an exciting new position in the history of science, technology, and medicine.

With the [gift of being asymptomatic](#), I've also maintained the pace of my HD advocacy, with major trips to [Iowa](#) in August and to the [World Congress on Huntington's Disease](#) in Rio de Janeiro in September. Until today I've written 26 blog articles this year, my second-highest annual output since starting *At Risk for Huntington's Disease* in 2005.

This is article No. 27, written with a deep sense of gratitude for the gift of life, family, and health — and the hope of effective treatments and a better future for the entire Huntington's community.

Posted by [Gene Veritas](#) at 9:03 PM



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