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At risk, but not alone

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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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HD Links

[Huntington's Disease Society of America](#)
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SATURDAY, FEBRUARY 12, 2005

At risk, but not alone

It's hard to be optimistic when writing about Huntington's disease. The immense suffering and stress caused by this malady weigh heavily in the lives of at-risk individuals and their families. But sometimes a ray of hope brightens my day.

The other night I left a meeting of HD activists touched and energized by the commitment of the numerous people who attended.

When I arrived, a group was wrapping up a discussion about a local fundraiser. I could feel the excitement as these people put the final touches on an event months in the making and already guaranteed to bring in thousands of dollars for HD research.

I took part in a second session about other fund-raisers and other HD-related issues. Although everybody around the table had put in a long day at their regular jobs, we worked late into the evening with the liveliness of the morning hours.

This group puts on a half dozen events every year. Each requires attention to hundreds of details, networking throughout the community, and finding fresh ideas for attracting the public and donors. The smooth and timely execution of these events and the teamwork involved rival much of what I have witnessed in both the non-profit and business worlds.

All of this comes on top of the group's array of other activities such as sponsoring a HD support group and educating the public about the disease.

The most impressive fact is that everybody is a volunteer.

But my admiration doesn't end there. Some of the volunteers have family members affected by HD. They live the triple burden of breadwinner, householder, and caregiver. I am relatively lucky: I still have my health and can work and help my wife with managing the home.

Many members of the group have no connection to Huntington's disease. Some of these not only work full-time but also have families and significant commitments to church and other activities. These individuals truly sympathize with the plight of families affected by HD and are drawn to the challenge of conquering a seemingly insurmountable disease.

As one activist put it, there is something special about being part of a grass-roots effort to stop a devastatingly cruel disease that doesn't get the same amount of dollars and publicity that so many other diseases receive.

Many nights I lay down distraught about HD. I would prefer another life. But facing HD has also revealed a world of caring and dedicated people. I am at risk, but I am not alone.

[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](#)

Posted by [Gene Veritas](#) at [9:58 AM](#)



2 comments:



Unknown said...

Sounds like a great group. I plan to help out with MN HDSA's martini bash next Friday. MN HDSA rocks the fundraisers!

[10:36 AM, February 12, 2005](#)

Anonymous said...

Hello, I found out 2 years ago that I have a 50/50 chance of having HD (blindsided by it). Do you regret getting tested to find out that you are HD gene positive? I'm having that internal battle at the moment.

[12:27 PM, August 18, 2011](#)

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