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S.O.S. for Huntington's disease families, and an important bill in Congress

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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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SATURDAY, MAY 28, 2011

S.O.S. for Huntington's disease families, and an important bill in Congress

Huntington's disease ravages the brains and bodies of its victims, usually leaving them utterly dependent on others. Whereas a child matures, an HD patient regresses.

As a result, HD families face enormous caregiving and financial burdens, ones that neither governmental agencies nor disease organizations yet adequately relieve. (A pending bill in Congress, as described below, could help significantly.)

From the time of my HD-stricken mother's apparent early symptoms in the late 1980s until her death in 2006, I watched her lose the ability to walk, converse, and eat.

Fortunately, my "HD warrior" father could care for her. Ten years her senior, he retired around the time that she began to need full-time care. She mainly sat at home, rode around with him in the car, ate with him at restaurants, and attended Sunday Mass. They did slow walks around the local indoor mall, first with Dad helping support her so that she wouldn't fall, then with her using a walker, and finally with her in a wheelchair.

At home, Mom started to fall more frequently. Once she broke a wrist. Another time she hit her head on a piece of furniture, opening a gash that required five staples. In August 2005, we agreed to put her in a nursing home.

Until that point, my parents had gotten by financially on their modest retirement savings and Social Security.

They had enough money for several years of care at the nursing home, but the monthly nursing home bills of several thousand dollars began to rapidly deplete their savings. They would have to spend virtually every penny before she could qualify for Medicaid.

Her death cut short the need to seek public assistance. My father lived almost four more years, able to survive on his savings and Social Security.

Worries about the future

Now my family also faces potential financial difficulties.

In 1999, I tested positive for HD. Now, at 51, I have reached my mother's age of disease onset. I am doing my best – via exercise, meditation, and supplements – to stave off symptoms. Still, when those symptoms inevitably start, I could lose my job, causing a dramatic drop in family income. Frugality has long been the name of the game in our home.

To prepare for the worst, in recent years we have built a Huntington's disease "war chest" by saving between 15 and 20 percent of our income.

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 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](#)

Our daughter turns eleven next month, so we'll also need to tap those funds for her college education.

Once I become symptomatic, we will have to apply for Social Security disability and Medicare benefits.

Inadequate nursing homes

Often I am painfully reminded of my family's situation and the urgent need for financial and caregiving assistance for our HD families.

Recently, my fellow HD advocate Frances Saldaña of Fountain Valley, CA, unburdened herself to me about her family's struggles.

Frances's first husband died of HD, and her three children developed juvenile Huntington's disease. Her youngest child, Marie, died in late 2009 at the age of 32.

Michael, 38, lives in a care facility in the infamous, crime-plagued Los Angeles neighborhood of Watts, far from Fountain Valley, which is in Orange County.

"It's the only place that would take him," Frances told me over the phone after we discussed advocacy for the Huntington's Disease Parity Act of 2011, a bill in Congress that would make it easier for HD patients to obtain Social Security and Medicare benefits.

In Orange County, all of the care centers she approached refused to take in Michael because of their inability to work with HD patients.

"They require too much work, and we don't have the staff," Frances explained, quoting the comments of care administrators about HD patients.

Frances says these facilities are violating the law by refusing to live up to the contracts they sign with the State of California, which prohibit discrimination against patients in facilities that receive Medi-Cal funds (the name for Medicaid in California).

To my knowledge, nobody in the HD community has had the time or expertise to seek redress from the state.

A family drained by HD

I met Frances's oldest child Margie Hayes when the mother-daughter team advocated for HD stem-cell research at a meeting of the California state stem-cell agency in December 2007. Margie already had noticeable symptoms such as chorea (shaking and trembling), although she could still speak clearly. Everybody in the room was moved by their presentation.



Margie Hayes (right) speaks at California stem-cell meeting in 2007 as mother Frances Saldaña looks on (photo by Gene Veritas).

Now 41, Margie struggles with her worsening symptoms. For more than a year, Frances and other relatives have pooled resources to hire a private caregiver to watch over Margie eight hours per day. Because Margie is not her legal dependent, Frances cannot deduct her contribution on her tax returns.

"Her husband is so drained," Frances said of Craig Hayes' attempt to care for his wife at their home. "He doesn't have the energy to do this anymore. He quit his job in Huntington Beach, which paid a lot more, so he could be close to Margie and the kids."

Craig comes home at midday to give Margie her medications and feed her lunch.

"Not very many men would put up with this," Frances said. "She gets feisty and has behavioral issues when things don't go her way."

Losing control

On one occasion, Craig had to hold Margie to prevent her from running out of the house, Frances told me.

"She's totally disabled," Frances continued. "She can't talk anymore. She's just mumbling. She can't walk without anybody holding on to her. She has grimacing on her face. She refused a wheelchair." The family must chop Margie's food into small pieces so that she can safely swallow it.

In early April, Margie fell in the bathroom, slicing her skin open on a metal rail. She required 30 external and internal stitches. Yet, according to Frances, the emergency room personnel missed another laceration on the crown of Margie's head. Only later, when the home caregiver was brushing Margie's hair, did that cut become apparent. A crust of dried blood had formed, causing it to heal on its own. Luckily, Margie didn't fracture her skull or have internal bleeding, Frances said.

The battle for Social Security

For years, Frances has championed the cause for improved facilities for HD patients in California, but to little avail. The family again faces the extremely difficult challenge of finding a care facility, this time for Margie.

Despite her advanced HD, Margie has not gotten Social Security disability payments. According to Frances, Craig became too overwhelmed to successfully complete the long and bureaucratic application process. Frances, too, feels overwhelmed and wishes she had more time to devote to the matter. Those funds would help defray the cost of Margie's care.

She pointed out the need for the Huntington's Disease Society of America (HDSA) to provide legal services for people in her situation.

After seeing three children devastated by HD, Frances is anxious about her grandchildren, who have not been tested.

"The clock is ticking," she told me. "These kids are getting older. If they have the mutant protein, we still don't have a treatment. The research has to move faster.

"I gave up on the care being there for my children about four or five years ago. My goal now is to make them comfortable. I hope to God that my grandchildren are not carrying it."

Losing a home

James Valvano, a 39-year-old Florida patient with early symptoms, has received a doubly harsh dose of HD reality: he lost his business – and now his home. James has produced an important film on HD titled *The Faceless Faces of Huntington's Disease* ([click here](#) to read more).

“My partner and I lost our home (of 14 years) and have moved in with my parents,” James wrote me a couple weeks ago. “Although something of this magnitude would normally ‘crush’ someone, we have decided to look at this in a positive light.

“Since my diagnosis in 2009, and the fact that I had to let my small business go, financial burdens continued to become overbearing. We will be fine, and I believe there is a reason for everything. I have to apologize for not getting back with you (let alone keeping in touch), however I became overwhelmed by life's curve-balls, and the simple fact that we were struggling to stay afloat.”

James has tried to find the bright side. “The saving grace to all of this is the wonderful people within our ... community, and my Film Team,” he wrote. “I was not willing to let financial hardship destroy what we had worked on for two years ... nor was I going to let the anxiety and depression drown me.”



James Valvano (personal photo)

James receives Social Security disability income and, with the standard two-year waiting period about to expire, will also get Medicare benefits. (The above-mentioned HD Parity Act would eliminate that waiting period.) James's partner was let go from his job at British Petroleum. For a number of months the couple tried to get by on just \$1,000 a month.

“It came down to not having enough money to pay the mortgage, and the mortgage company would not work with us to refinance the house at its current value,” James continued. “We had a lawyer who was keeping them ‘at bay,’ but due to financial (constraints), we were unable to continue to pay him (the lawyer). So, we just decided to pick up and leave.”

Too big a hole to fill

In situations like those faced by Margie and James, HD families often have nowhere to turn.

“Why in this world is there no organization out there to financially set up or give help to HD families?” one woman lamented in an HD discussion group on Facebook.

In an interview on May 19, I put this question to Louise Vetter, the CEO of the Huntington's Disease Society of America, based in New York City.

"The Board (of Trustees) has actually talked quite a bit about it, because it is something that I've heard from the day that I joined," said Louise, now in her third year at the HDSA helm after nine years working for the American Lung Association. "Certainly the financial impact of HD is unique and particularly devastating.

"Unfortunately, it's a hole that we just can't fill, due to our (limited) resources and the overwhelming financial need. How would we choose that somebody's rent is worth paying and somebody else's isn't? It really comes down to that. The board has struggled with this and felt that we cannot be a financial service organization at this time and still meet the other needs of our mission."

HDSA's annual budget is approximately \$8.5 million, with roughly one quarter going for administration and fundraising and the rest for education, research, and the local Centers of Excellence for Family Services and Research.

The organization continues to rely mainly on affected families for its donations.

"There are a lot of smaller foundations that will provide support in specific communities," Louise continued in reference to the dire needs of HD families. However, most national health non-profits do not provide such assistance.

May 31: HDSA's call-in day to Congress

So, for now at least, HD families must depend on public assistance.

Louise pointed out that HDSA staff members can assist family members with questions about government benefits such as Social Security and Medicare. HDSA's number is 800-345-HDSA (4372).

To help get benefits faster into families' hands, HDSA and its many volunteer advocates in the field are making a big push to pass the HD Parity Act.

As of May 27, 2011, 67 members of the House of Representatives and four Senators had co-sponsored the Act.

In mid-May, HDSA announced the key support for the bill from Sen. Charles Schumer (D-NY), who is a member of the powerful Senate Committee on Finance and its Subcommittee on Social Security, Pensions, and Family Policy.

On Tuesday, May 31, HDSA is sponsoring a national call-in day. The organization requests that all HD families, friends, and supporters call uncommitted senators and representatives and urge them to co-sponsor the bill.

To learn more, [click here](#). Also watch the interview on the bill that I conducted on May 19 with HDSA advocacy manager Jane Kogan.



HDSA's Jane Kogan: Time to Contact Congress on Huntington's Disease Parity Act

from [Gene Veritas](#)

09:25 |



[HDSA's Jane Kogan: Time to Contact Congress on Huntington's Disease Parity Act](#) from [Gene Veritas](#) on [Vimeo](#).

S.O.S. HD

The call-in day is the HD community's S.O.S. to Congress and the country. Families like the Valvanos and the Hayeses need our help. Because their burden is so huge, society needs to lend a hand.

Passage of the HD Parity Act of 2011 would provide a tremendous boost to HD families and the cause in general.

Remember: please call your representative and senators on May 31!

Posted by [Gene Veritas](#) at [1:39 PM](#)      

Labels: [brain](#) , [caregiver](#) , [discrimination](#) , [Huntington's](#) , [Medicaid](#) , [Medicare](#) , [nursing home](#) , [Parity Act](#) , [Social Security](#) , [supplements](#) , [symptoms](#) , [tested positive](#)

3 comments:

Anonymous said...

Great work, Gene. Hey, there is a nice shout-out to you in the latest edition of the HD Marker magazine. I'm amazed that you find the energy and the time to be a husband, father, professor, and tireless HD advocate. Thank you!

Beverly

[6:38 PM, June 06, 2011](#)

Anonymous said...

HD has been in our family over 40 years, taking a husband, son and now a daughter in her final stages.

I don't see why funds going to the Huntington's Foundation can't start by opening a facility like the Alzheimer's Units in our little town and just take HD patients...man'd by upcoming nursing students wanting to work with HD patients and Dr.'s of neurology who are specializing in genetics who want to help with medicines, physical therapies and the welfare of our families in caring for our family members who are struggling with this disease.

We need facilities who specialize in the care of our family members, giving them the dignity they deserve and relieving the families to visit and even helping by volunteering some of their time to help more on a giving basis.

Our families need more than just "finding the cure". We need care for our families "NOW".

Thank you...JBG

1:38 PM, June 07, 2011

🌀 **Anonymous said...**

Huntington's has so far claimed the lives of 3 of my family members from the ages of 12-48. I as well have two brothers currently fighting the battle. I just want to say Thank You for all that you do and have done. We all need to keep fighting for a cure!

6:26 PM, August 03, 2011

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