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The Team Hope Walk: reinforcing the first line of defense 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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MONDAY, APRIL 02, 2012

The Team Hope Walk: reinforcing the first line of defense against Huntington's disease

In the fight against Huntington's disease, hope begins at home.

That's the message I took away from yesterday's inaugural Team Hope Walk of the San Diego Chapter of the Huntington's Disease Society of America ([HDSA-San Diego](#)) after my family's team traversed the 3.1 mile route. It was the first time my wife, my eleven-year-old daughter, and I participated together in an HDSA event.

We walked to honor the memory of my mother, who succumbed to HD in 2006 at the age of 68, and my father, her "HD warrior" caregiver, who died with a broken heart in 2009.

Civic leaders Allan and Jane Rappoport, long-time supporters of HDSA-San Diego, joined our team. They are close friends and our daughter's surrogate grandparents – an especially important relationship because her lone surviving grandparent lives in Brazil.

Below I've posted our team picture, another family milestone: it's the first time I'm presenting a photo of my wife and daughter to the readers of this blog. I'm taking one more big step out of the "HD closet," a long and emotionally trying process that began almost two years ago with my first [public speeches](#) about my family's struggle with HD.



The Serbin Family "Beat HD" Team: Kenneth Serbin (left), Regina Serbin, Bianca Serbin, and Allan and Jane Rappoport (photo by E. J. Garner)

So often eroded by the fear, stigma, and denial that accompany HD, such togetherness at the starting line provides the love and strength that sustain families in the long, arduous journey with this fatal disorder.

[International Huntington Association](#)
[Huntington's Disease Drug Works](#)
[Huntington's Disease Lighthouse](#)
[Hereditary Disease Foundation](#)
[Huntington's Disease Advocacy Center](#)
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HD Blogs and Individuals

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[Heather's Huntington's Disease Page](#)

The Team Hope Walk held special significance for me because I am gene-positive for Huntington's. At 52, I have reached the age of my mother's onset. Each moment without symptoms is a precious gift – and a beautiful reminder of how our daughter tested negative and can thrive as she approaches adolescence.

As I walked alongside my family and friends, I felt protected by my family and the Rappaports. All of us renewed our hopes that researchers would soon find effective therapies for HD.

Striking a balance between elite and grassroots events

In all, 34 teams and more than 200 walkers took part in the event.

In the 1990s and early 2000s HDSA focused on simple, family- and community-based events such as hoop-a-thons and walks. However, as the organization grew along with the demand for research dollars in the quest for therapies, its emphasis shifted towards elite fundraisers such as galas with expensive tickets and pricey auction items. In this respect, HDSA-San Diego excelled, bringing in several hundred thousand dollars some years with signature events such as the [Celebration of Hope Gala](#) and the Shoot to Cure HD.

For financial or health reasons, HD people and their families often couldn't participate in the signature events.

Responding to grassroots accusations of aloofness and recognizing the need to draw families into the organization, HDSA now seeks to strike a better balance between big fundraisers and community-oriented events. (For background on HDSA issues, please [click here](#). You can also learn more by listening to Melissa Biliardi's March 27, 2012, interview with HDSA CEO Louise Vetter by [clicking here](#).)

Since the inception of Team Hope in 2007, the walks have spread to 80 cities across the country. HDSA reports that these events have [raised more than \\$3 million](#).

Bringing families under the umbrella

Yesterday's San Diego walk raised nearly \$30,000, well above the goal of \$25,000. Presenting sponsor [Vertex Pharmaceuticals](#) donated \$2,500, recruited a team of nearly 50 walkers, and staged a pre-event fundraiser at its San Diego facility. [Elmcroft Senior Living](#) also donated \$2,500 and set up a large team. [Elite Security](#) contributed with an additional 48 walkers. A number of local businesses supported the event with gifts of raffle items, food, and supplies, and the [Lawrence Family Jewish Community Center \(JCC\)](#) provided tables, equipment, and other items.

[Lundbeck](#), the title sponsor of the Team Hope Walks program, has provided a substantial educational assistance grant to HDSA at the national level.

Nan Pace, a JCC manager, served as event co-coordinator along with health researcher Misty Oto. Both women serve on the HDSA-San Diego board.



Above, San Diego Team Hope Walkers, and, below, walk co-coordinator Nan Pace (second from left) with friends (photos by Gene Veritas)



“The importance of this walk was to give Huntington’s disease families in San Diego an opportunity to express themselves not only visually but through their families, by contacting them and letting them know that there will be fundraising and also bringing awareness to a very important cause,” said Oto. “It was so surprising to see new families that we haven’t been in touch with create [First Giving pages](#), fundraise, and participate. Now we have new families that are under the umbrella of HDSA because of this event.”

The dream of participation

“This is the very first time that San Diego has offered an event that all people of all abilities could participate in,” Oto added. “All of our events have been centered on marathons, bike rides, and races that were a little bit longer, and where someone with Huntington’s could not participate or someone who had a family member with Huntington’s felt that the fundraising goals were a little bit out of reach.”

Registrants paid just \$25 to participate.

For HD-affected individuals who could not walk the course, HD activist [Silvia Gonzalez](#) provided a ride on her three-wheeled motorcycle.



Silvia Gonzalez gives HD patient Hank Hahnke a ride at Team Hope Walk (photo by Gene Veritas).

“That was such a huge thing, because not only did they get to participate in the event, but they got to live out the dream of riding on a motorcycle,” Oto pointed out.

Local HD families “know that they have a voice, that we are paying attention,” continued Oto, whose mother died of HD several years ago. Oto tested negative for HD but has a number of affected relatives.

HDSA has “struggled” with the need to strike a balance between research and families, Oto suggested. The Team Hope Walk “unified in one cause” three key aspects of its mission: research, fundraising, and awareness.



Team Hope Walk co-coordinator Misty Oto running the charity raffle (photo by Gene Veritas)

Preparing for the challenges ahead

The San Diego Team Hope Walk brought out the very large extended Huntington's disease family of this metropolitan area: HD people, asymptomatic gene-positive individuals like me, gene-negative HD family members, other family members, friends, corporate and local business sponsors, and key players in the search for therapies such as Vertex and Lundbeck.

I believe that, with the proper planning and exposure, the Team Hope Walks can help inform and galvanize the HD community for a major challenge as researchers ramp up to clinical trials for potential therapies: [recruitment of individuals for research studies and clinical trials](#).

Without such participation, scientists cannot test potential remedies for safety and efficacy, thus delaying or even preventing the arrival of treatments.

Ultimately, Team Hope involves families in the fight against HD. Families are the first line of defense – and the seed of hope.

Posted by [Gene Veritas](#) at [12:14 PM](#)      

Labels: [asymptomatic](#) , [awareness](#) , [caregiver](#) , [clinical trial](#) , [denial](#) , [fear](#) , [gene-negative](#) , [gene-positive](#) , [HD closet](#) , [hope](#) , [Louise Vetter](#) , [Lundbeck](#) , [research](#) , [stigma](#) , [tested negative](#) , [therapies](#) , [treatment](#) , [Vertex](#)

1 comment:

 **Beverly said...**

What a beautiful family you have, Gene! Your daughter is lovely. Thank you for sharing such a joyful picture.

[7:08 AM, April 07, 2012](#)

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