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Just living life: a focus on what matters most in coping with the risk of 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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HD Links

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

MONDAY, APRIL 04, 2016

Just living life: a focus on what matters most in coping with the risk of Huntington's disease

As a carrier of the Huntington's disease gene who's reached the age of 56 without apparent HD symptoms, I believe that the emotional release associated with this blog – sharing my fears, hopes, and advocacy – has helped me stave off the inevitable onset of the disorder.

Ideally, I'd like to write in this blog weekly.

However, I don't always have time, as evidenced by my taking nearly a month to post an update.

I regret the delay, because I have a growing list of critical developments in advocacy and research to report on, for example, the results of the [11th Annual HD Therapeutics Conference](#), held in February.

However, like so many people in this harried world, I juggle multiple demands involving family, career, and community.

Beyond that, those of us in the HD movement (and in other disease communities) have the added responsibility of caregiving, multiple forms of advocacy, and/or living with the disease or its threat.

Ever more conscious of life's brevity and my good fortune in remaining asymptomatic, I've been focusing on what matters most.

Being there for the family

One of my deepest fears about HD concerns losing the ability to support my family. Having seen my mother decline terribly because of HD, I long worried that I would become a financial and medical burden for my wife Regina and daughter Bianca, or, worse, that I might not see Bianca graduate from high school.

In my current stable health, I devote time and energy to helping Bianca transition from teenager to young adult.

A few weeks ago, I acquired a third family car so Bianca can drive my "old" Nissan Altima when she gets her license. While we're fortunate to afford an extra car, it's no luxury; it will allow her to drive to school, freeing Regina and me each from several hours of driving weekly. We also recognize that having a car is a rite of passage in America, especially in the auto-oriented culture of Southern California.

Once again, HD factored into our family decision-making: seeking to economize and plan prudently, we bought a used 2013 Honda Accord in good enough condition that, as Regina put it, could last me until retirement.

[Huntington's Disease Drug Works](#)
[Huntington's Disease Lighthouse](#)
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HD Blogs and Individuals

[Chris Furbee: Huntingtons Dance](#)
[Angela F.: Surviving Huntington's?](#)
[Heather's Huntington's Disease Page](#)

As my trusted mechanic put it, the four-cylinder Accord's engine is "God's gift to humanity" because of its reliability. As a teenager, I had always admired the Accord and daydreamed about owning one. Lately, I've come to detest driving because of the crazy Southern California traffic – I long for a mass-transit system like those in European cities – but the Accord has brought back some of the enjoyment.

Priority over the blog

I had planned on buying a car only when Bianca received her license later in the year, but a major connection in my HD journey saved me the headache of shopping for one by alerting me to the availability of the low-mileage Accord.

Rob Millum, a friend whom I met while serving on the board of the San Diego Chapter of the [Huntington's Disease Society of America \(HDSA\)](#) and also a former member of the HDSA national board, works as a consultant for [Affinity Development Group](#) and administers the [Costco Auto Program](#).

Rob's a natural leader who cares about serving humanity. With his auto dealer's license he helps people save money on nearly new cars and recreational vehicles. He doesn't need to work full-time but does so to help support the HD community and other causes.

Rob and I have had deep conversations about HD, this blog, and life in general. When I couldn't attend the 2011 HDSA convention to receive the [HDSA Person of the Year Award](#), Rob accepted the honor in my name.

And Rob's a darn good car guy, too!



At 2011 HDSA national convention, HDSA Chairman of the Board Don Barr (left), Rob Millum, and HDSA CEO Louise Vetter as Rob accepts HDSA Person of the Year Award for Kenneth P. Serbin (aka Gene Veritas) (photo by Ashley Miller).

In 2010, Rob helped me purchase my 2011 Altima through Costco's no-hassle program; his nephew was the salesman. I then parted with my 1999 Corolla, my so-called "DNA car," which had those highly symbolic letters on the license plate and which had carried me through many miles of HD advocacy ([click here](#) to read more).

We had upgraded to the bigger, sturdier Altima for safety reasons. Now it will become Bianca's car.

Dealing with my credit union's loan department, figuring out the high-tech gadgetry of the Accord (the owner's manual is 595 pages long!), and other

details of the purchase took priority over this blog.

Other aspects of my HD advocacy have also reduced the time for the blog, for example, raising funds for the 2016 HDSA-San Diego Hope Walk, set for April 10 ([click here](#) to donate to our team). Support for HDSA is essential in the quest for treatments.

Just living life

Despite the new financial load of car payments along with our mortgage and other payments, I felt grateful about handling the details of the Accord purchase for my family.

It's reminded me how quickly our "miracle baby" – who tested negative for HD in the womb in 2000 – is growing up. The toddler I used to push in a stroller at the zoo now practices driving the Altima on the freeway. We're starting the search for colleges.

I also remind myself to focus on the basics to help avoid HD onset: a healthy diet, good sleep habits, and regular, vigorous exercise. I can get lackadaisical about all three!

Spending more time on the essentials, as well as enjoying life more fully, takes time away from HD advocacy and blogging.

I feel that I need a break from the din of the Internet, the 2016 presidential campaign, the TV commercials, the political crisis in Brazil (the country I research), the e-mails and Facebook postings concerning HD, and all the other things that diminish my peace of mind.

The Easter Vigil Mass I attended on March 26 provided a respite, with two hours of chanting and scriptural readings, a stark contrast with our daily lives outside the sanctuary.

Knowing how many of my symptomatic "HD brothers and sisters" valiantly cope with the disease, I'm thankful for the chance to just live life.

Posted by [Gene Veritas](#) at [12:53 PM](#)      

Labels: [advocacy](#) , [asymptomatic](#) , [cars](#) , [diet](#) , [exercise](#) , [family](#) , [financial burden](#) , [HDSA](#) , [Hope Walk](#) , [Huntington's disease](#) , [Huntington's disease gene carrier](#) , [medical burden](#) , [miracle baby](#) , [Rob Millum](#) , [sleep](#) , [symptoms](#)

2 comments:



Julie W said...

Thanks for your post. I am also in my 50s LIVING at risk. Julie W

[12:05 PM, April 09, 2016](#)

Anonymous said...

Thank you so much for your blog and contributions. I am gene positive (recently discovered) and learning how to live every day with this new reality. Your blog has served as an inspiration for how you can continue to live life, contribute to HD advocacy, and retain hope.

I'm working on reminding myself that sure it's a death sentence, but we all have a death sentence. And the magic lies in how we live our lives before that.

It was particularly powerful to read about how you are managing the balance between advocacy and self-care and living life to its fullest. I'm managing that balance right now, and it helps to read your story.

9:29 AM, May 12, 2016

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