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My friend, the fast lane

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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.

TUESDAY, AUGUST 31, 2010

My friend, the fast lane

Living at risk for Huntington's disease often leaves me deeply anguished. My mother was diagnosed with HD in 1995, and I tested positive in 1999. For 15 long years I have worried about whether I will repeat her hellish experience of losing the ability to walk, talk, think, and swallow. Everybody with the HD gene eventually develops the disease, which is fatal. My mother died in 2006 at the age of 68. I'm 50 now, and time is closing in.

I've learned to cope in many ways. I've adapted emotionally – so far – to the idea of getting HD, and I've balanced my fear of HD with the demands, strategies, and joys of life (work, insurance, and family, for instance). A good part of the past year I spent preparing for a month-long cross-country car trip with my wife and daughter – our "miracle child," who tested negative for HD in the womb – in order to enjoy our time together before I develop symptoms. We had a great time (click here to read more).

The importance of exercise

Exercise is another way of coping. Perhaps it even delays the onset of symptoms.

One of my HD heroes is Bryan Medrano, a triathlete and the 2004 "Person of the Year" of the Huntington's Disease Society of America (HDSA). I met Bryan several years ago when he was in San Diego for a kickoff party in honor of him and three other Californians who biked across the country in one just one week in order to raise research funds. I learned that Bryan was gene-positive. I admired the way he trained to stave off symptoms and to raise awareness about HD.

Next to Bryan I've been a couch potato. I get in 30 minutes of focused daily exercise. I usually take a brisk two-mile walk. For a while I took hour-long bike rides up and down the hills of our San Diego neighborhood. For about a year I also worked out once a week on the weight machines at the nearby YMCA. For a few years I also worked out on an elliptical machine in our living room. I also spend 15-30 minutes per day stretching.

I know I need to do more. Dr. LaVonne Goodman, the founder of Huntington's Disease Drug Works, recommended that I put in an hour of aerobic exercise seven days a week. I'll admit, though, that sometimes I'm lazy or too busy, so I rarely get beyond 45 minutes.

The Obama stimulus pool

Over the past year I've rediscovered swimming.

Thanks to my wife's persistence, in 2009 we built a swimming pool in our back yard. I call it "the Obama stimulus pool," because, thanks to President Barack Obama's efforts early on to lower interest rates and get the economy going, we were able to refinance our home with an interest rate of just 4.375 percent and take out $75,000 for the pool and related home

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About Me

GENE VERITAS

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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
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HD Blogs and Individuals

Chris Furbee: Huntingtons Dance
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items such as solar heating and decking.

I like to tell friends that when the history of the recovery from our current recession is someday written, economists will identify our pool project as the turning point.

My wife mainly wanted the pool for get-togethers with friends and our daughter’s play dates. My wife reasoned that it was better to have our daughter within view than off somewhere else as she heads into the challenging teen years. While the kids play, we can read or work on our laptops or join in the fun.

Laps in the back yard

I investigated another very practical benefit: how to set up the pool for the best workout possible.

Our yard was too small for a lap pool. So I started to research alternatives such as a swim tether (holding the swimmer in place with a line) and swim jets (a stream of bubbles). I concluded that neither would give me the kind of challenging, natural workout I wanted.

Years ago I had also heard of a company called Endless Pools. I received some of their promotional DVDs in the mail, but the estimated price of around $20,000 seemed too much for a small pool that could be used only for swimming laps in place.

More recently, however, the company developed a product called Fastlane, a motor that can be installed in a new or existing pool.

A 52-speed motor

From my research I learned that the Fastlane did the best job of recreating the actual conditions of swimming. The Fastlane created a *current* in the pool, not bothersome, dispersing bubbles. The company arranged for me to try out one of its devices at another customer’s home. This gentleman, a Masters swimmer, and his wife graciously allowed my daughter and me to swim in their pool with the Fastlane.

The two horsepower motor operates at 52 speeds (!), allowing for a wide range of swimming abilities.

I was hooked! So the additional $5,000 for the device and installation by our pool contractor has been worth it. (Click on the 'play' button below to watch a video of me with the Fastlane.)

My relationship with water

The physical benefits of swimming are well-known. It’s a great aerobic exercise that involves the whole body and doesn't stress joints as with running or require an uncomfortable position (for me, at least) as with bicycle riding.

Life emerged from water, and to return to water helps me reconnect with nature. The water envelops me as if to protect, and at the same time I must work against it to keep up with the current.

I have an especially complex relationship with swimming pools. When I was about four, my mother took me and my little sister to the pool in our apartment complex. I was floating around in a circular rescue tube. Suddenly I flipped over and was upside down in the water. I didn’t know how to swim, and I started thrashing about in the struggle to right myself.

What’s worse, the lifeguard wasn’t paying attention.

Somehow, I came back up on my own.

I had swallowed some water and was coughing and crying as I came out of the pool. I kneeled down and hid between my mother’s legs and under the towel she had draped over her knees.

I didn’t develop a phobia for water or pools, but I do frequently remember the sensation of helplessness and the subsequent safety I felt under my mom’s towel.

Swimming and HD

Recently I’ve thought even more about this incident because of how helpless my own mother became when struck with Huntington’s disease.

I now return to the water to seek strength against her attacker and mine. Getting in shape, working the heart and muscles, bathing the brain with oxygen and its protective elements – these are my goals when I get into the water.

The Fastlane is my friend.

As its motor hums and relentlessly pushes water at me, I work out my frustrations. Swimming helps me to put the relatively minor but often irksome problems of daily life into perspective.

And rather than fight with people I know who live in denial of HD or fail to understand the need to draw our community closer, I think of accelerating my pace so that my fingertips can reach the edge of the Fastlane. Anger becomes energy, and sadness becomes exhaustion.

When the anguish is worst, swimming makes me feel alive and vital, knowing that for the moment I am still okay and without symptoms.

On those special days the thrill of the swim and the flow of oxygen bring me to a state of exhilaration and optimism about my work as an HDSA activist and the collective search for treatments and a cure.

The Fastlane and I don’t ever talk, but together we’re building hope.

Posted by Gene Veritas at 9:57 PM

Labels: at risk , gene-positive , Huntington's disease

2 comments:

Anonymous said...

Hi Gene,
I got the blog as you said I would.

Hurray! for the fastlane, you look so good and I'm so glad that the exercise is helping. So nice to meet your wife and see you again.
My best to you always,
Love Jeri

9:58 AM, September 08, 2010

Unknown said...

Thanks for sharing your story Gene. Would you like to provide us a quote so we can educate others about HD and the benefits of swimming?

8:55 AM, September 17, 2010

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