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Memories of the DNA car

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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, JANUARY 10, 2011

Memories of the DNA car

We all measure life by milestones: the first steps, graduating from high school, the big raise, sending a child off to college.

For many Americans, cars symbolize important stages in life, from practicing in one for the driver's license test to buying that first shiny new one to driving the family on summer vacations.

We spend so much time in cars that they seem like members of the family.

For me, gene-positive for Huntington's disease, my 1999 Corolla CE took on a very special meaning. Like a quiet but supportive partner, it literally carried me through many crucial moments.

Buying an Altima

With a deep tinge of nostalgia, I parted with my Corolla on January 7. In 2009, thanks to President Barack Obama's efforts to get the economy moving, my wife and I refinanced our mortgage and included in the package a new swimming pool, aka the "[Obama stimulus pool](#)." As 2010 came to a close, my wife urged me to take advantage of the auto companies' big sales, designed to put some pep into that sluggish industry.

I hesitated, but the moment seemed too good to pass up. So, on December 30, the day before my 51st birthday and just four days before the big sales expired, we took the plunge and bought a 2011 Nissan Altima 2.5 S. We got a great deal on the car and the loan.

I felt great driving the car home, especially because the Altima checked in as the top-rated family sedan in the *Consumer Reports* car ratings.

The Corolla, my first new car

After the holidays, I got to work on getting the Corolla ready for sale.



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My 1999 Corolla CE

Important memories flooded into my mind, beginning with the night my wife and I bought the car on a Friday night in fall 1998.

The Corolla was my very first new car, which we financed with an auto loan.

Prior to that, I had a long history with used vehicles.

Used cars, family, and HD

My very first car was a 1970 Volkswagen Beetle that I bought in high school for \$500. In 1982, I received a 1977 Oldsmobile Cutlass S as a gift from my maternal grandparents after graduating from Yale.

My grandfather and I had spent many an hour driving around the Cleveland area in the several Cutlasses that he owned. I couldn't have imagined a better graduation gift.

Eight years after my grandfather died of heart failure at age 79, my mother received her diagnosis of Huntington's disease.

I could only conclude that Gramps had carried the genetic defect at a low level of impact and, in one of the strange twists when the male is the HD carrier, passed it on to my mother in a more pronounced form, dooming her to more than 15 years of symptoms and ultimately death at age 68 in 2006. My grandmother, who died at age 87, also of heart failure, remained sharp until almost the very end. She never displayed any HD symptoms.

In 1991 I bought my next car, a 1987 Dodge Shadow, from my father. Soon thereafter he became the "HD warrior" who cared for my mother until she had to enter a nursing home in mid-2005. The Shadow was the car my wife and I shared at the time of Mom's diagnosis in 1995.

A painful scrape

I'm not at all superstitious, but the Corolla came with an almost prophetic message attached. Its California license plate was "4DNA921." DNA was playing a bigger and bigger role in my life as my mother deteriorated and I worried about my own at-risk status.

Not long after the purchase, in June 1999, I decided to get tested for HD. We needed to know my status to plan for avoiding the disease in the child that we had just conceived.

As I have described in other blog entries ([click here](#) to read more), the news of my positive result left me disoriented.

As I attempted to maneuver the still new-looking Corolla out of the space in the office building's parking garage, I turned the wheel too sharply. The car pulled too far to the right, causing the right front fender to scrape against a column.

I was able to rub out most of the mark. Nobody ever noticed, in fact. But I knew exactly where the scratches were. For many years, just looking at the car brought painful memories of that fateful moment and the feelings of confusion and anger that followed.

License tag 4DNA921

By then, "4DNA921" had taken on an entirely new meaning. The car constantly reminded me that I was HD-positive.

But the tag was also like a badge that I displayed to other members of the HD cause as I became ever more active in the San Diego chapter of the Huntington's Disease Society of America ([HDSA-San Diego](#)). The Corolla was my DNA-powered, anti-HD car.



“Wow, now that’s an interesting license plate,” an HD caregiver remarked to me one time.

Our first pregnancy ended in a miscarriage, but in October 1999 we conceived again. In January 2000, we received the news that our daughter-to-be had tested negative in the womb for HD. That was one of the happiest moments of our lives – to be matched only by the day in June 2000 when we drove our “miracle baby” home from the hospital in the faithful Corolla.

Over the next decade I took the Corolla on countless assignments for HDSA-San Diego. I drove to board meetings at the San Diego Chargers headquarters, where board member Bill Johnston, the team’s PR director, arranged for us to meet. The Corolla seemed puny and insignificant next to the top-of-the-line Mercedes Benzes and other super-luxurious cars in the Chargers’ parking lot. But I didn’t mind. I had the DNA on my side.

I drove the Corolla to Celebration of Hope Galas, HD support group meetings, interviews with members of the HD community, and meetings of the California state stem-cell agency’s oversight committee. The Corolla transported thousands of copies of the HDSA-San Diego newsletter, which I edited and published from 2001 to 2007.

Last February I drove the Corolla to the [Parker Palm Springs](#) hotel for the fifth annual international research conference of the CHDI Foundation, Inc., informally known as the “cure Huntington’s disease initiative.” At such a tony resort the Corolla once again seemed out of place, but it steadfastly carried me to my destination and back.

Balancing frugality and safety

For the longest time, I vowed to myself to keep the Corolla – and the DNA plates that came with it – until researchers found a cure for Huntington’s.

At the time of the sale, it had only 83,000 miles. I wanted to avoid sinking \$25,000 into the new Altima because, like so many HD families, we need to budget conservatively. I will inevitably develop HD symptoms, and that will mean a dramatic loss in income and long-term financial security for my family. I also very much liked the fact that the Corolla got 29 miles per gallon in the city and 40 mpg on extended trips.

But my wife pointed out that the Corolla was starting to have problems. Indeed, although the engine could last much longer – I have a friend who drives a 1978 Corolla! – last year I had to spend several hundred dollars on a new visor and repair work on the starter.

My wife also frequently reminds me of the way [an SUV blind-sided the](#)

Corolla in May 2009, sending me to the hospital and causing more than \$3,000 in damage to the vehicle. Since then, she has become ever more worried that another accident could seriously harm or even kill me or our daughter, whom I drive to school and other activities practically every day. Recently, she started saying she would forbid me to take our daughter in the Corolla!

The 1999 Corolla has just a driver's and passenger air bag, whereas the new Altima has six, along with many other features that make it safer. The Altima is also a much bigger car.

No matter how serious a financial crisis HD might bring for our family, I could not risk our safety on the road.

Opting for some comfort

On the more optimistic side, my wife convinced me that it was time to move up from the Corolla and treat myself with some comfort and enjoyment while driving.

The Corolla is a starter car, she pointed out. At age 51 and with perhaps not much time left before symptoms start, I deserved to drive something better.

At the dealership we could have gotten the base model Altima for \$5,000 less than we spent.

"The \$5,000 we'd save could go into our daughter's education fund," I told my wife.

But, after thinking about how my wife and I would have to manually adjust the driver's seat with a clumsy system, I opted for the more comfortable S model. I also added such conveniences as a power seat and Bluetooth cell phone system.

The S model includes a leather steering wheel with radio controls accessible to the fingertips. This last feature is especially important, because my daughter constantly asks me to switch stations while I'm driving.

Compared to other cars in the market, the Altima is far from luxurious. But it's definitely a big step up from the Corolla.

A new car, a new era in HD research

I'll receive the plates for this car in the next month or two.

I'm wondering: what letters will I get this time?

The Corolla symbolized frugality, worry about HD, and my intense activism for the cause.

What will the Altima symbolize in 2011 and beyond?

In part, I purchased the car because just before Christmas I received a clean bill of health from my doctor at the local HD clinic. Because my mother most likely became symptomatic in her late forties, every moment that I live free of symptoms is a bonus ([click here](#) to read more).

When we bought the Corolla in 1998, only five years had passed since scientists had discovered the HD gene. Relatively little hope existed for my generation of gene-positive individuals.

In contrast, in late 2010 we could feel far more optimistic as scientists sought ways to turn some of the 700-plus potential treatment targets into

actual medicines.

There has never been a more exciting time for HD research. Although there is no guarantee of treatments or a cure, for the first time our community can feel some confidence that help is on the way.

The upcoming drive to Palm Springs

My own confidence has grown in the last few years as I have observed CHDI pursue such revolutionary projects as its collaboration with Isis Pharmaceuticals, Inc., to stop HD at its genetic roots.

As I've written recently, I will deliver the keynote address at the next CHDI conference in Palm Springs on February 7.

With the Altima, I'll drive to Palm Springs much more comfortably and confidently.

Let's all hope that this new confidence will bring a major research breakthrough in 2011.

Posted by [Gene Veritas](#) at 9:22 AM



Labels: [CHDI](#) , [cure](#) , [death](#) , [defect](#) , [diagnosis](#) , [DNA](#) , [gene-positive](#) , [genetic](#) , [HD-positive](#) , [HDSA](#) , [HDSA-San Diego](#) , [Huntington's](#) , [Isis](#) , [mother](#) , [nursing home](#) , [symptoms](#) , [warrior](#) , [Yale](#)

2 comments:

Sean Thompson said...

Gene,

Great post! I totally understand your connection to your Corolla. I felt the same way about my 2004 Honda Civic. The memories tied to my first car (not the actual physical vehicle) were the reason I was sad to see it go after it was totaled in an accident. And especially to have the car tied to such life-altering experiences, I can definitely see why you'd be sentimental about it.

Love the blog!

Sean

2:42 PM, January 10, 2011

Anonymous said...

Fantastic post. Can't wait to learn of your new tags!

4:23 PM, January 31, 2011

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