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An expedition to the brain

Kenneth P. Serbin

University of San Diego

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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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THURSDAY, OCTOBER 21, 2010

An expedition to the brain

Could the cure of Huntington's, Alzheimer's, Parkinson's, and other devastating neurological diseases finally become the national priority that the millions of us affected by these diseases have yearned for?

We may be one step closer to such a campaign, thanks to the drive and imagination of Maria Shriver, one of our country's most articulate and outspoken leaders.

Speaking about Alzheimer's on ABC-TV's "This Week" news program this past Sunday, October 17, Shriver coined a phrase – "an expedition to the brain" – that could help spark a national campaign against neurological diseases.

"This president (Obama) could say, I want to launch, just like Kennedy launched an expedition to the moon, he could launch an expedition to the brain," said Shriver. "There are so many secrets in the brain that can uncover the cures for Alzheimer's, Huntington's, Parkinson's, intellectual disabilities, how we learn, how we love, how we remember. All of this is in the brain. Why not have something like that in this country to galvanize people around?"

As someone who is gene-positive for Huntington's disease, I was overjoyed to hear Shriver bring attention to the disease that took my mother's life in 2006 and could destroy my own brain, leaving me unable to walk, talk, think, and swallow.

[\(Click here to watch a video of the program and read related articles.\)](#)

An Alzheimer's "tsunami"

Shriver, the First Lady of California and the niece of President John F. Kennedy, became an Alzheimer's disease activist after watching the condition afflict her father [Sargent Shriver](#), the founder of the Peace Corps during the Kennedy administration.

Mr. Shriver was diagnosed in 2003. He can still pray the rosary, Maria recalled in another recent interview, but he no longer remembers who she is.

The program included an interview with former First Lady Laura Bush recalling how her own Alzheimer's-stricken father had forgotten the identity of her husband, George W. Bush, when Bush was governor of Texas. Her father ultimately succumbed to the disease.

Shriver's appearance followed the release of *The Shriver Report: A Woman's Nation Takes on Alzheimer's*, which describes the enormous financial and personal burden the disease has created for millions of families and for the country as a whole.

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

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Families hit by the disease spend an average of \$56,000 on care. An Alzheimer's "tsunami" is about to hit America, with a projected cost of \$20 trillion over the next 40 years as tens of millions of Baby Boomers move into old age.

HD also exacts a huge social and financial cost. An estimated 30,000 Americans have HD, and some 150,000-250,000 are at risk.

Time to stand up

"I think this president and this Congress can stand up and say, 'This is a national epidemic,'" Shriver said in a separate ABC interview. "We can get a national strategy. If we launch a national endeavor to underscore and find out what's going on in the brain, I think we can get the money."

Shriver added that both the media and businesses need to pay more attention to the Alzheimer's epidemic. She proposes changes in national family leave legislation so that more people can take off time for elder care.

Shriver's prominence and passion for eliminating brain diseases – together with the growing awareness about these conditions and their enormous negative impact – might finally bring them onto the national political radar screen.

The "cure industry" and the brain

I share Shriver's passion and determination that our country embark on an expedition to the brain.

Early last year, as our country was plunging into its worst economic crisis since the Great Depression, I wrote a blog entry titled "[Our economic comeback and the cure industry.](#)"

"America's call to action today should focus on the elimination of disease," I wrote. "America proclaimed a war on poverty and another one against drugs. What we need now is a mission to find treatments and cures for all diseases."

Instead of borrowing our way out of economic crisis, I proposed that we "create our way out" by stimulating the growth of the cure industry. America can and should lead the world in producing cures, and our biotech industry can reap profits and create the kind of high-paying jobs necessary for maintaining our standard of living and economic leadership.

The expedition to the brain and the new cure industry would go hand in hand.

Purpose and urgency

Clearly our country has already begun to move in this direction. In recent months TV journalist Charlie Rose has broadcast *The Brain Series*, which explains the huge strides being made in brain research.

But we need a greater sense of purpose and urgency to meet the challenges of HD, Alzheimer's, and other neurological disorders.

Lamentably, I noted in last year's posting, none of our national leaders has spoken out about this great potential.

"Great commentary!" wrote one of my blog commentators. "How do 'we' get our ideas to the legislators for consideration? It HAS to be done."

Leadership required!

We need *leadership*. Once again the current electoral campaign is

illustrating a dearth of this capacity.

A case in point is the race to succeed Shriver's husband Arnold Schwarzenegger as the governor of California.

Once again, the candidates are employing attack ads – not new ideas. Jerry Brown appears to be on an end-of-career adventure, and, spending \$140 million of her own cash on her campaign, Meg Whitman seems to be thinking more about a future run at the presidency than about solving California's current problems.

None of the candidates has put forth a convincing proposal for solving California's debt and jobs crises.

In this climate of uncertainty and indecision, it's no wonder that an independent movement like the Tea Party is gaining steam.

Shriver as candidate?

Maybe it's time for Maria Shriver to run for office. Because of her intelligence, passion, and vision, she would make a strong and provocative candidate.

At Yale I studied in a seminar with her brother Tim. He projected an air of both confidence and concern – both still very much evident in his leadership of the Special Olympics, where he became CEO in 1996.

"I've tried to shift the conversation here from what Special Olympics does to what it means," Tim wrote last year. "It's often seen as a service organization, but I believe that it's a civil rights movement. Volunteers might think that they're only coaching or serving water at a track and field event, for example, but they are doing far more. My mission has been to remind them that they are serving the search for human dignity and acceptance." ([Click here](#) for the full article.)

We need more leaders with the Shriver's' common sense and compassion.

A call to action







The care for people debilitated by disease and the search for cures should also be a civil rights movement that awakens Americans to our biotechnological and moral potential.

The expedition to the brain is one that we should all embark upon. These issues affect Republicans, Democrats, and independents alike. And the cure industry can and should involve all sectors of society: government, business, labor, and academia.

Like the expedition to the moon, the exploration of the brain could produce numerous spinoffs that would benefit people in as yet unimaginable ways. When future generations look back, they will admire the foresight and courage of those like Maria Shriver who inspired us to take the journey.

Let's everybody in the HD, Alzheimer's, Parkinson's, and other neurological disease communities rally around Shriver's call to action.

It's time to launch the expedition to the brain!

Posted by [Gene Veritas](#) at [10:34 PM](#)      

Labels: [Alzheimer's](#) , [biotech](#) , [brain](#) , [Bush](#) , [civil rights](#) , [cure](#) , [cure industry](#) , [gene-positive](#) , [Huntington's](#) , [leadership](#) , [mother](#) , [Obama](#) , [Shriver](#)

1 comment:

🌀 **Anonymous said...**

Hi Gene. My name is Vance. I am hospice chaplain and was diagnosed with HD several years. Love your blog. I have one dealing with the spiritual, emotional and physical aspects of my journey ever since I was diagnosed. Feel free to read it and be blessed.

<http://vtchaplain.wordpress.com/>

[6:08 AM, October 29, 2010](#)

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