7-7-2009

A life-or-death walk into the future

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Digital USD Citation

Serbin, Kenneth P., "A life-or-death walk into the future" (2009). *At Risk for Huntington's Disease*. 43.
https://digital.sandiego.edu/huntingtons/43

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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, JULY 07, 2009

A life-or-death walk into the future

On June 15, 2009, I walked again into the epicenter of what could be the first treatment for Huntington's disease: the Isis Pharmaceuticals, Inc. research facility in Carlsbad, California.

It was like a walk into the future. I am gene-positive for Huntington's, and Isis is seeking to make a drug that could save me from one of humanity's cruelest diseases. My mother, who passed on the defective gene to me, died of the disease in February 2006 at 68, after struggling with the disease for about twenty years. (Click here to read about how I said good-bye to her.) This year I turn 50, the age at which she was already showing symptoms.

Will I someday take the Isis drug for HD? Or will I be doomed to end up unable to speak and in a wheelchair?

Those were some of my thoughts as I followed up my April 2008 visit, when I learned how Isis was aiming to create a "laser-guided missile" to attack Huntington's. (Please click here to read my entry on that visit.)

Cautious optimism

I heard great news: the project is on schedule, and both Isis and the sponsor of the research, the CHDI Foundation, Inc., are optimistic that they will find a drug molecule by the end of this year. Human testing would begin in 2011.

Last year I brimmed with enthusiasm about Isis, but the project was only in its early stages. My optimism was justified: this year I sensed great confidence at Isis. (Please click here to see my detailed update on the project.)

However, I am also tempering my optimism with the knowledge that pharmaceutical research – even in the case of a brilliant, cutting-edge company such as Isis – is always a long-shot. Only one in ten drugs that enter human trials will ever make it to market.

Effective research requires time – a commodity in short supply for those of us racing against the clock. As Dr. Frank Bennett, the Isis senior vice president for research, pointed out, even if everything goes perfectly, it would still take at least ten years for the drug to be fine-tuned for use as a preventive measure in asymptomatic, gene-positive individuals like me.

Fighting for the cause

But I am not disheartened. On the contrary, I feel the same confidence as Dr. Bennett and the other people I spoke with at Isis such as Dr. Alejandro Lloret, who is fighting passionately to find the treatment. (Please click here to read my article about Dr. Lloret.)

I know that I too must fight – to raise awareness about Huntington's

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GENE VERITAS

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disease and to help bring more support for our cause. Isis is deepening its commitment to research on other neurological diseases. With its unique technology it could start a revolution in the pharmaceutical industry. We HD activists need to educate the public about the potential benefits of Huntington's research for all of humanity.

Above all, I've got to stay healthy until the possible Isis treatment for at-risk people comes online. No gene-positive person can know the exact moment symptoms will start. All we can do is take care of ourselves and keep hoping.

Part of good health is staying informed and remaining optimistic. It was a tremendous boost to shake the hands of the people working to stop HD, to hear their own optimism, and to see them at work in the lab. They care about people like me, and that gives me the energy I need to keep up the fight.

Posted by Gene Veritas at 11:49 PM

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