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Striving for brave new brains

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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.

MONDAY, JANUARY 02, 2012

Striving for brave new brains

As I turned 52 on December 31 and a new year dawned on the world, I came ever closer to onset of Huntington's disease, the cruel killer that took my mother's life in 2006 at the age of just 68.

However, in 2012 I also will live with the hope that, as science and medicine progress with time, researchers will control and perhaps even eradicate HD.

Indeed, we stand on the verge of a new age. Neuroscience, brain scans, our understanding of genetics, and brain-machine interfaces will vastly improve the health and capabilities of the brain and perhaps enable the cure of HD, Alzheimer's, Parkinson's, Lou Gehrig's, stroke, and numerous other maladies of the central nervous system.

On Christmas and my birthday I was able to celebrate the results of my annual check-up at the local HD clinic on December 20: the doctor marveled at how, despite carrying the same genetic defect as my mother, I have yet to show any apparent external symptoms of the disease (click here and here to read about my HD-avoidance strategies).

With the predicted biotechnological advances, those of us who are gene-positive may someday put bionic brains on our birthday wish lists – brains without risk of HD and that enhance mental capabilities far beyond anything we can currently imagine. Even sooner, advances in medicine may deliver drugs and techniques that counteract the cruel changes wrought in HD brains.

Breathtaking predictions

I contemplated these possibilities during my holiday reading, which included Judith Horstman's *The Scientific American Brave New Brain: How Neuroscience, Brain-Machine Interfaces, Psychopharmacology, Epigenetics, the Internet, and Our Own Minds Are Stimulating and Enhancing the Future of Mental Power*, an exciting, easy-to-read synopsis of recent advances in brain science.

Horstman outlines how brain scientists predict breathtaking breakthroughs by mid-century – most with a firm foot in current reality.

According to scientific forecasters, "computer chips or mini-processors in the brain will expand memory; control symptoms of brain disease, from Parkinson's disease to depression and anxiety; and wirelessly receive and transmit information so that you won't need a cell phone or a computer to stay in touch."

"Brain surgery will be a thing of the past except in the most severe cases," Horstman continues. "Advanced neuroimaging will identify mental illness and brain disease before symptoms show and in general be used to 'read' minds and predict and control behavior. Microscopic robots – nanobots –

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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
HD Free with PGD!
Stanford HOPES
Earth Source CoQ10, Inc.

HD Blogs and Individuals

Chris Furbee: Huntingtons Dance
Angela F.: Surviving Huntington's?
Heather's Huntington's Disease Page

will enter your bloodstream to diagnose and repair brain damage. Protein molecules will travel your brain in a similar way to turn on or off brain cells or genes responsible for brain diseases."

Brave New Brain explores numerous other current and potential facets of brain health and related technologies, including:

● neurogenesis (the growth of new brain cells);

● deep brain stimulation and "brain pacemakers" (using electricity to stimulate brain health and performance);

● brain-nurturing mental and physical practices such as meditation, breathing, and yoga;

● the impact of digital technology on the brain and its integration into the brain;

● artificial intelligence;

● miniature cameras for broadcasting images of the inner workings of the brain;

● thought-activated neural implants (for example, for working mechanical limbs);

● prostheses of portions of the brain (people are already living with artificial retinas and cochleas, the auditory portion of the inner ear);

● and, in one forecaster's view, the downloading of our brains onto chips "so our consciousness can live on forever, perhaps even downloaded into robots – or into an avatar, an ageless biological clone," perhaps making us an endangered species increasingly replaced by cyborgs.

"Neuroethicists" and others worry that "humans will become machines," Horstman observes. These individuals also point out new issues involving privacy in genetic testing; ownership of body parts, tissues, and genes; insurance discrimination; potential abuse of new technologies by employers and others; and the impact of all of these changes on social equality and our way of controlling criminals. Neuroethicists are grappling with these many issues.

Curing dementia

According to Horstman, Alzheimer's, other dementias, and perhaps even mental retardation will be "preventable, curable, and even reversible in many people."

The demand for cures is immense: some two billion people worldwide suffer from a brain-related illness, with an annual economic cost of more than $2 trillion, Horstman writes. Almost half of all people over age 85 develop dementia, and by 2050 an estimated 100 million individuals will experience this condition.

Offering a glimpse of how these cures could take place, Horstman writes of "brain boggling" nanotechnologies such as "preparing specialized protein molecules that swim to a predetermined site and are activated externally by probes or lasers that turn off or on specific genes."

This kind of "nanomedicine" would allow medical treatments to leap across the formidable blood-brain barrier, which separates the bloodstream from the fluid that bathes and cushions our brains, Horstman explains.

Alnylam's HD gene-silencing trial

The trends in neuroscience and related fields mean that scientists someday will likely control HD and perhaps, as Horstman describes, completely turn off the gene that causes it.

Key research in "gene silencing" already holds great promise.

In partnership with Medtronic, in 2012 Alnylam Pharmaceuticals plans to apply to the federal Food and Drug Administration (FDA) to conduct a Phase I clinical trial of a drug containing ALN-HTT, a small interfering RNA molecule (siRNA) that doctors will inject into the brains of trial participants.

Conducting a brain operation, doctors will run thin tubing under the skin from a Medtronic-designed pump to a nodule at the top of the patients' heads, and from that point a very fine needle will deliver the drug into the putamen, one of the regions of the brain most devastated by HD (click here to read more).

If the Phase I trial demonstrates the safety of ALN-HTT, Alynlam will proceed to Phase II to measure the efficacy of the drug.

Alnylam intends to use ALN-HTT to silence the huntingtin gene so that less huntingtin protein is produced to harm brain cells. If successful, the treatment would save brain cells from dying and slow down and possibly even reverse the course of HD.

A decade ago, this approach seemed like science fiction. Today, it provides immense hope that HD will be controlled in our lifetimes.

On December 28, 2011, Alnylam presented a highly positive report: testing of ALN-HTT in non-human primates demonstrated "widespread distribution of the siRNA and significant silencing of the huntingtin mRNA." The drug was well tolerated.

Conducted in collaboration with Medtronic and a research team at the University of Kentucky, the study will greatly facilitate the FDA application for a human trial.

Isis Pharmaceuticals, Inc. is developing a similar approach for treating HD and hopes to apply for its own Phase I clinical trial, perhaps within the next year or two (click here to read more).

The pioneering HD community

As Horstman describes, such gene silencing techniques only scratch the surface of the great potential in brain-disease treatments. Indeed, we may someday look back on these initial attempts as primitive.

But they *are* revolutionary. We in the HD community are helping to pioneer this revolution in brain science by participating in research studies and clinical trials, fighting the terrible stigma associated with the disease, and, as I did last February, exiting the terrible "HD closet" to tell the world about the need to defeat HD and other neurological disorders.

HD families no longer stand alone. Our movement has gone global – with international conferences run by research organizations, numerous HD-related websites, and the establishment of Enroll-HD, a multi-country database of HD-affected, gene-positive, and untested at-risk individuals. Just last month a new HD group formed in China, the world's most populous country.

We stand on the frontier of science, and for this reason in 2012 and beyond we can forge ahead proudly and bravely.

It's up to *us* to lead the way. If we all unite and participate in this great movement, we can help build toward the bionic brains of the future.

Posted by Gene Veritas at 3:24 PM

Labels: ALN-HTT , Alnylam , anxiety , dementia , depression , discrimination , drug , gene , gene silencing , gene-positive , HD closet , Huntington's , meditation , memory , neurogenesis , siRNA , stigma

1 comment:

Anonymous said...

Nothing you did contributed to your good fortune on remaining negligable in symptoms. I came across a number of elderly persons who were gene positive and had relatives with latish earlier onsets of HD. It was viewed that they would die of other causes well before HD made any significant mark on their lives . Well aside from some of the worries that exist around the disease.Essentially it's a form of unusual individual luck.

7:31 AM, December 13, 2013

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