News, literature, and events in the ethical, social, and legal implications of psychiatric, neurologic, and behavioral genetics.

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Braingenethics Update

Vol. 2, No. 3 April 2015

braingenethics.cumc.columbia.edu/

In the Literature

Ethics of Genetic and Biomarker Test Disclosures in Neurodegenerative Disease Prevention Trials

By Scott Y.H. Kim, Jason Karlawish & Benjamin E. Berkman

The authors applied four key ethical criteria—favorable risk-benefit ratio, informed consent, fair subject selection, and scientific validity—to blinded vs transparent enrollment in prevention trials for neurodegenerative diseases. They concluded that considerations of risks and benefits, informed consent, and fair subject selection do not require

In the News

New Brain Science Shows Poor Kids Have Smaller Brains than Affluent Kids

By Lyndsey Layton

New research showing poor children have smaller brains than affluent children has deepened the national debate about ways to narrow the achievement gap. Neuroscientists who studied the brain scans of nearly 1,100 children and young adults nationwide from ages 3 to 20 found that the surface area of the

the use of blinded enrollment for Alzheimer disease (AD) prevention trials. Blinded enrollment in AD prevention trials may sometimes be necessary because of the need for scientific validity, not because it prevents coercion or undue influence.

Unwarranted Optimism in Media Portrayals of Genetic Research on Addiction Overshadows Critical Ethical and Social Concerns
By Jenny E. Ostergren, Molly J. Dingel, Jennifer B. McCormick & Barbara A. Koenig

The authors conducted a textual analysis of 145 news articles reporting on genetic research on addiction from popular print media in the United States and from popular news and medical internet sites. In articles that report on prevention, the media emphasize vaccine development and identifying individuals at genetic risk through population screening. Articles that emphasize treatment often promote current pharmaceutical solutions and highlight the possibility of tailoring treatments to specific genetic variants. The authors raise concerns about the tendency of this coverage to focus on the benefits of pharmaceutical treatments and gene-based approaches to prevention while neglecting or downplaying potential risks and ethical issues.

Overcoming Challenges to Meaningful Informed Consent for Whole Genome Sequencing in Pediatric Cancer Research
By Jennifer A. Oberg et al.

cerebral cortex was linked to family income.

Autism and Prodigy Share a Common Genetic Link
By Jeff Grabmeier

A new study found that child prodigies share some of the same genetic variations with people who have autism. These shared genetic markers occur on chromosome 1, according to the researchers from The Ohio State University and Nationwide Children's Hospital in Columbus.

Thought-Controlled Genes Could Someday Help Us Heal
By Simon Makin

Scientists combined a brain–computer interface with an optogenetic switch to create the first-ever brain–gene interface.

Unregulated Web Marketing of Genetic Tests for Personalized Cancer Care Raises Concerns in New Study
By Dana-Farber Cancer Institute

Websites that market personalized cancer care services often overemphasize their purported benefits and downplay their limitations, and many sites offer genetic tests whose value for guiding cancer treatment has not been shown to be clinically useful, according to a new study from Dana-Farber Cancer Institute.

Introducing whole genome sequencing (WGS) into pediatric cancer research at diagnosis poses unique challenges related to informed consent. A qualitative study was conducted to investigate parental knowledge about genetic concepts and WGS, thoughts about the informed consent process, and preferences for secondary findings. Focus groups were conducted with parents/guardians of children with cancer and semi-structured interviews were conducted in a control group without cancer. Parents/guardians of children with cancer have limited knowledge about WGS. A two-step consent process may improve their ability to provide meaningful informed consent.

Media Debates and 'Ethical Publicity' on Social Sex Selection Through Preimplantation Genetic Diagnosis (PGD) Technology in Australia
By Andrea Whittaker

This paper offers a critical discourse analysis of media debate over social sex selection through pre-implantation diagnosis (PGD) in the Australian media from 2008 to 2014. It concludes that within Australia, the issue of PGD sex selection is framed in terms of questions of individual freedom against the principle of sex discrimination – a principle enshrined in legislation – and a commitment to publically-funded medical care.

Sexual Offending Runs in Families: A 37-Year Nationwide Study
By Niklas Långström, Kelly M Babchishin, Seena Fazel, Paul

Commentaries

Study Reveals How Genetic Changes Lead to Familial Alzheimer's Disease
By National Institutes of Health

Mutations in the presenilin-1 gene are the most common cause of inherited, early-onset forms of Alzheimer's disease. In a new study, published in Neuron, scientists replaced the normal mouse presenilin-1 gene with Alzheimer's-causing forms of the human gene to discover how these genetic changes may lead to the disorder. Their surprising results may transform the way scientists design drugs that target these mutations to treat inherited or familial Alzheimer's, a rare form of the disease that affects approximately 1 percent of people with the disorder.

The Tide Has Come in and the Line in the Sand Is Gone: Decision Time on Human Germline Engineering
By Laura Hercher

In response to recent debates on

Lichtenstein & Thomas Frisell

The authors examined familial aggregation and the contribution of genetic and environmental factors to sexual crime by linking longitudinal, nationwide Swedish crime and multigenerational family registers. Included were all men convicted of any sexual offense (N = 21,566), specifically rape of an adult (N = 6,131) and child molestation (N = 4,465), from 1973 to 2009. They report strong evidence of familial clustering of sexual offending, primarily accounted for by genes rather than shared environmental influences.

Presenilin-1 Knockin Mice Reveal Loss-of-Function Mechanism for Familial Alzheimer's Disease
By Dan Xia et al.

Presenilin genes play essential roles in memory formation, synaptic function, and neuronal survival. Mutations in the Presenilin-1 (PSEN1) gene are the major cause of familial Alzheimer's disease (FAD). The authors generated Psen1 knockin (KI) mice carrying the FAD mutation L435F or C410Y. Remarkably, KI mice homozygous for either mutation recapitulate the phenotypes of PSEN1 mice. Their findings reveal that FAD mutations can cause complete loss of Presenilin-1 function in vivo, suggesting that clinical PSEN mutations produce FAD through a loss-of-function mechanism.

The Hidden Efficacy of Interventions: Gene×Environment Experiments from a Differential Susceptibility Perspective

CRISPR/Cas9 use, Hercher raises four points for public consideration related to the emergence of new technologies in human germline research. Technological innovation comes with positive and negative consequences, and Hercher argues that risk is not adequate evidence in and of itself that something is bad and should be avoided.

To contribute a news item, an academic article, or an event on the ethical, legal, and social implications of psychiatric, neurological, and behavioral genetics research please email us.

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By Marian J. Bakermans-Kranenburg & Marinus H. van IJzendoorn

This review moves beyond the problems thwarting correlational gene-environment (GxE) research to propose genetic differential susceptibility experiments. G×E experiments can test the bright side as well as the dark side of the moderating role of genotypes traditionally considered to represent vulnerability to negative conditions. The differential susceptibility model predicts that carriers of these risk genotypes profit most from interventions changing the environment for the better. The authors suggest possibilities to broaden the G component in the G×E equation by including genetic pathways, and to broaden the E component by including methylation level and gene expression as promising ways to probe the concept of the environment more deeply.

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