Presidential Commission

for the Study of Bioethical Issues

Private Sector Partners in the BRAIN Initiative - Ethical Issues in Neuroscience

December 18, 2013

Miyoung Chun, Executive VP of Science Programs
The Kavli Foundation: Science Programs

Goal: Advancing Science

- Kavli Institutes
- Research Programs
- Meetings Program

Kavli Frontiers of Science

U.S. Symposium
Indo-American Symposium
Israeli-American Symposium
Korean-American Symposium
Chinese-American Symposium
German-American Symposium
Indonesian-American Symposium
Japanese-American Symposium

- Academy Collaborations
- Scientific Society Collaborations
- Kavli Futures Symposia
- Kavli Royal Society Centre
<table>
<thead>
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Scientific Workshops

- 9/11: Allen/Gatsby/Kavli Workshop
- 12/11: OSTP NIH DARPA visit
- 1/12: 6th Kavli Futures
- 3/12: OSTP NIH NSF visit
- 5/12: OSTP-hosted discussions for the BAM
- 8/12: 8th Kavli Futures
- 10/12: 9th 10th Kavli Futures Futures
- 12/12: OSTP
- 1/13: NIH DARPA visit
- 2/13: State of the Union Address (BRAIN Initiative Announced)
- 4/13: BRAIN Initiative Announced

- 3/12: OSTP NIH NSF visit
- 6/12: 8th Kavli Futures
- 12/12: OSTP

- Birth of BAM*: White paper to OSTP
  - Neuron publishes NeuroView article
  - Science Perspective article: BAM Definition
  - ACS Nano article: BAM Tool dev. road map

*BAM: Brain Activity Map
# Inter-agency Brainstorming Meetings

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*Image: A group of people standing in front of a building.*
“The next great American project, the BRAIN Initiative”

(Brain Research through Advancing Innovative Neurotechnologies)

“….we’re still unable to cure diseases like Alzheimer’s or autism, or fully reverse the effects of a stroke. The BRAIN Initiative will change that by giving scientists the tools they need to get a dynamic picture of the brain in action and better understand how we think and how we learn and how we remember. And that knowledge could be -- will be -- transformative.”
Question from Tom Insel, Director of National Institute for Mental Health:

“Thanks to better early detection, there are 63% fewer deaths from heart disease than there were just a few decades ago. Could we do the same for [brain disorders]?”
BRAIN Initiative & Alzheimer’s Disease

- 20 years of intense research and more than $1 billion worth of clinical trials: No effective drug treatment for Alzheimer’s disease
- Current thinking: early intervention
- Major stumbling block: absence of tools to reveal the first expression of the disease. All the current approaches that are used to diagnose Alzheimer's are crude and unreliable.

Macroscopic changes
Molecular changes

Imaging

Mesoscopic brain circuitry change

(Study neuron networks to tackle Alzheimer’s, Kosik, Nature 2013)
Alzheimer’s Disease with Genetic Cause: Clear Diagnosis

Mrs. Cuartas (82) takes care of her son Dario (55) and daughter Maria (61)
The Case of Colombian Family

- World’s largest family to experience early-onset Alzheimer’s: extended clan of 5,000 people who live in Medellin, Colombia
- Specific genetic mutation begin showing cognitive impairment around age 45, and full dementia around age 51, debilitated in their prime working years as their memory fades and the disease quickly assaults their ability to move, eat, speak, and communicate
- No treatment today

- Ethical Issue: To diagnose or Not to diagnose
Alzheimer’s Disease: Preventive Treatment

<table>
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<tr>
<th>Trial name</th>
<th>Aim</th>
<th>Length</th>
<th>Size</th>
<th>Cost</th>
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<td>Alzheimer’s Prevention Initiative</td>
<td>To test crenezumab in people who have mutations in the presenilin 1 gene and other genes that cause Alzheimer’s in middle age.</td>
<td>5 years</td>
<td>~ 300 people</td>
<td>$100 million</td>
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<td>Dominantly Inherited Alzheimer Network</td>
<td>To test three drugs on asymptomatic people with Alzheimer's-linked mutations in genes for presenilins 1 and 2, and amyloid precursor protein.</td>
<td>5 years</td>
<td>160 people</td>
<td>$60 million for 2 years</td>
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<td>Anti-amyloid treatment in asymptomatic Alzheimer’s disease</td>
<td>To test a drug in asymptomatic people who have high levels of amyloid-β, and some who have a gene variant that increases their risk of Alzheimer’s.</td>
<td>3 years</td>
<td>1,000 people</td>
<td>$110 million</td>
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- Ethical Issue – To treat or Not to treat
BRAIN Initiative & Deep Brain Stimulation

Courtesy of John Donoghue and Arto Nurmikko
Neurotechnology Development
Ethical Issues

http://www.youtube.com/watch?v=FqrTEQ_1h68