### **About the Neuroscience Forum**

The Institute of Medicine (IOM) in 2006 established the Forum on Neuroscience and Nervous System Disorders. The Forum is designed to provide its members with a venue for exchanging information, presenting individual views, and allowing a structured opportunity for dialogue and discussion while scrutinizing critical and possibly contentious scientific and policy issues. Representatives from government, industry, academia, patient advocacy organizations, and other interested parties serve on the Forum. It convenes three times a year to confer on subject areas of mutual interest and concern. At its meetings, the Forum discusses emerging scientific and policy issues related to basic neuroscience and nervous system disorders, as well as effective clinical interventions and policy options. The Forum sponsors workshops (symposia) as an additional mechanism for informing the membership of the Forum, other relevant stakeholders, and the public. Information about past or upcoming meetings is available at the Forum's website, www.iom.edu/neuroforum.

#### **About the Institute of Medicine**

The Institute of Medicine serves as adviser to the nation to improve health. Established in 1970 under the charter of the National Academy of Sciences, the Institute of Medicine provides independent, objective, evidence-based advice to policy makers, health professionals, the private sector, and the public. The mission of the IOM embraces the health of people everywhere.

# **Forum Staff**

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Project Director

**Sarah Hanson** 

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**Lora Taylor** 

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**Board on Health Sciences Policy** 

Andrew Pope, Ph.D.

Director

# THE NATIONAL ACADEMIES

Advisers to the Nation on Science, Engineering, and Medicine

For additional information on the Forum on Neuroscience and Nervous System
Disorders visit the Forum's website at www.iom.edu/neuroforum,
or call Bruce Altevogt at (202) 334-3984.

# FORUM MEMBERS

(December 2008)

#### Alan Leshner (Chair)

American Association for the Advancement of Science

#### Huda Akil

University of Michigan, Ann Arbor

#### **Marc Barlow**

GE Healthcare, Inc.

#### **David Bredt**

Lilly Research Laboratories

#### **Daniel Burch**

CeNeRx Biopharma

#### **Dennis Choi**

**Emory University** 

#### **Timothy Coetzee**

FastForward of the National Multiple Sclerosis Society

## **David Cohen**

Columbia University, Society for Neuroscience representative

#### Richard Frank

GE Healthcare, Inc.

#### **Richard Hodes**

National Institute on Aging

#### **Katie Hood**

The Michael J. Fox Foundation for Parkinson's Research

#### **Steven Hyman**

Harvard University

#### **Judy Illes**

University of British Columbia

#### **Thomas Insel**

National Institute of Mental Health

#### **Story Landis**

National Institute of Neurological Disorders and Stroke

#### Husseini Manji

Johnson & Johnson Pharmaceuticals

#### Michael Oberdorfer

National Eye Institute, NIH Neuroscience Blueprint representative

#### **Kathie Olsen**

National Science Foundation

#### Atul Pande

GlaxoSmithKline

### **Menelas Pangalos**

Wyeth Research

#### Steven Paul

Eli Lilly and Company

#### **William Potter**

Merck Research Laboratories

## **Paul Sieving**

National Eye Institute

#### Rae Silver

Columbia University

#### William Thies

Alzheimer's Association

#### Nora Volkow

National Institute on Drug Abuse

#### Kenneth Warren

National Institute on Alcohol Abuse and Alcoholism

#### Frank Yocca

AstraZeneca Pharmaceuticals

#### **Christian Zimmerman**

Neuroscience Associates



Forum member Timothy Coetzee and Venture Philanthropy Workshop October 2008 speakers Peter Heinecke and Kenneth Schaner.

# **SPONSORS**

Sponsoring members include federal agencies, patient advocacy organizations, industry, and a non-profit membership society.

Alzheimer's Association

AstraZeneca Pharmaceuticals

CeNeRx Biopharma

Eli Lilly and Company

GE Healthcare

GlaxoSmithKline

Johnson & Johnson Pharmaceuticals

Merck Research Laboratories
The Michael J. Fox Foundation for

Parkinson's Research

National Eye Institute

National Institute of Mental Health

National Institute of Neurological Disorders and Stroke

National Institute on Aging

National Institute on Alcohol Abuse and Alcoholism

National Institute on Drug Abuse

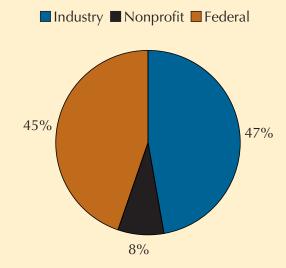
National Institutes of Health Neuroscience
Blueprint

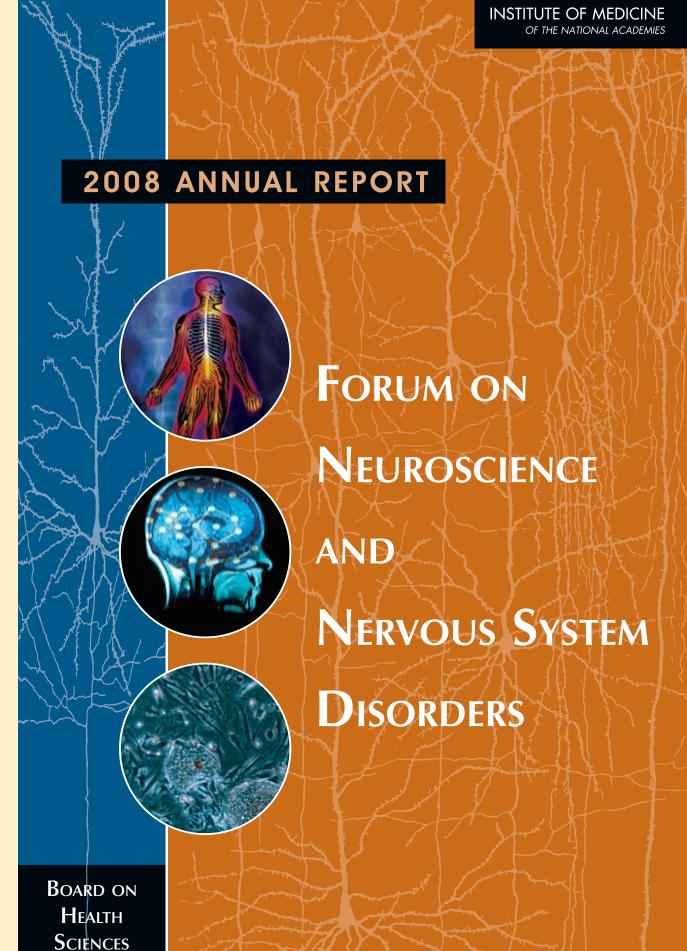
National Multiple Sclerosis Society

National Science Foundation Society for Neuroscience

Wyeth Research

# **Neuroscience Forum Funding: 2008**





POLICY

# MESSAGE FROM THE CHAIR

ecognizing the need to bring together the diverse set of stakeholders involved in the neurosciences, the National Academies established the Forum on Neuroscience and Nervous System Disorders to engage leaders from private-sector sponsors of biomedical and clinical research, federal agencies sponsoring and regulating basic biomedical and clinical research, private foundations, the academic community, and other consumers.



Through its quarterly meetings and public workshops, the Forum has provided a venue where its members, other leaders from the neurosciences, and members of the public can have candid discussions about issues of mutual interest. We believe these discussions enhance understanding of research and clinical issues associated with the nervous system among the scientific community and the general public, and provide a mechanism to foster partnerships among stakeholders. Two particular examples include a Forum workshop and report on autism and the environment that brought together advocates, scientists and funders, and a series of meetings on venture philanthropy, a relatively new phenomenon where advocates and patient groups become both funders and partners in research programs.

Forum members Rae Silver and Richard Nakamura, Venture Philanthropy Workshop October 2008



# **FORUM ACTIVITIES IN 2008**

# **Grand Challenges in Neuroscience**

The concept of outlining grand challenges for a given field is not new. Their purpose usually is either to highlight major opportunities or to help mobilize and unify the field to address particularly complex but timely questions that require the coordinated work of scientists in many subdisciplines. However, major grand challenges have not been articulated for the neurosciences in many years. In response, the Forum held a public workshop that featured presentations and discussion on a set of guiding principles, fundamental scientific questions, resource requirements, and long- and short-term goals for a grand challenge in neuroscience. The unifying theme for this workshop was the need to expand understanding of how perception, cognition, and action emerge in the human brain from interactions among molecules, chemicals, neurons, and circuits; the brain's fundamental building blocks. Top experts from a diverse range of fields came together at this workshop to discuss these issues. The summary of the workshop was released in October 2008 and can be found at www.iom.edu/neurograndchallenges.

# Patient Advocacy Organizations and Venture Philanthropy

Voluntary health organizations—that is, nonprofit charitable organizations, patient advocacy groups, and foundations—have increasingly begun to shift from providing care, educational resources, and funding research grants to supporting the earliest stages of drug development and engaging in translational research. These organizations have utilized principles from venture philanthropy, which stems

from venture capitalism, but is unique in that its mission is aligned with philanthropic goals and outcomes, as a critical way to advance their mission of helping patients and working to cure disease. Individuals from several voluntary health organizations, academia, government, and industry attended a Forum-sponsored public workshop to discuss and share their experiences and lessons learned as their organization moved into a translational research program supported through venture philanthropy strategies. The summary of the Workshop participant Judy Woodcock



workshop was released in February 2009 and can be found on the Forum's website

# Mental Health and Neurological Disorders in sub-Saharan Africa

The Forum, in collaboration with the Uganda National Academy of Sciences, is striving to enhance understanding of research and clinical issues associated with the nervous system among the scientific community and the general public, and to provide a mechanism to foster partnerships among stakeholders. The Forum and Uganda National Academy of Sciences held two stakeholders meetings—in Kampala, Uganda, and in Washington, DC, in 2008—in order to receive input to help inform the agenda for a workshop in Kampala, Uganda, in August 2009.

# FORUM ACTIVITIES FOR 2009

# Mental Health and Neurological Disorders in sub-Saharan Africa: A Workshop

Described in the activities for 2008, the Forum, in collaboration with the Uganda National Academy of Sciences, will host a workshop "Quality of Care Issues for Mental Health and Neurological Disorders in sub-Saharan Africa" in Kampala, Uganda, in August 2009. The purpose of this workshop is primarily to engage policy makers, international stakeholders, local parishioners, and rising leaders in the area of brain disorder research, to examine issues related to the burden of brain disease in the region, cost-effectiveness and quality of care in resource poor settings, best practices and care strategies, and identification of challenges and opportunities in sub-Saharan Africa.

# Neuroscience and Society Initiative at Society for Neuroscience Meeting 2009

The Forum will be responsible for organizing the Social Issues Roundtable at the 2009 meeting of the Society for Neuroscience. The purpose of this session, and initiative, will be to start engaging in a dialogue about the critical time neuroscience is entering with regard to ethical and social issues that arise as we begin to further understand what makes us human. Topics will include:

- An overview of the current and predicted conflict between research findings and an individual's understanding of their humanity;
- The implications of the potential conflicts between improved scientific understanding of the brain and society's views and values; and
- The need to acknowledge potential conflicts and develop a strategy for engaging with the public in such a way as to minimize conflict and ensure that society can and will in fact reap the benefits of neuroscience research.



Forum members Story Landis and Richard Hodes

# Suicidality in CNS Clinical Trials

A public workshop will be held in June 2009 and will involve individuals from the FDA, pharmaceutical industry, academia, and the NIH to make presentations and stimulate discussions focused on how best to integrate the current tools for data collection with current methods of data analysis. In addition, the workshop participants will discuss opportunities for potential partnerships with various stakeholders. Specifically, participants will be invited to present and discuss information that will:

- Identify areas of opportunity to improve or optimize the current methods of data collection specifically related to C-CASA categories of ideation, preparatory behavior, or aborted attempt, and examine if they constitute risk factors for suicide incidence in the short term.
- Discuss potential analyses of the data that would better delineate the extent to which C-CASA categories of ideation, preparatory behavior, or aborted attempt constitute risk factors for suicide incidence in the short term.
- Examine potential partnerships between the FDA, pharmaceutical industry, academia, and the NIH that could be used to generate the necessary data and analyses.



Panel discussion, Venture Philanthropy Workshop October 2008

# **WORKING GROUPS**

Working groups are established and maintained by interested members and are open to all membership. The Forum's working groups engage in regular discussions, usually via teleconferences, on topics of interest to that group. Workshop topics often originate from working groups and are organized by an independently appointed workshop planning committee.

# **Grand Challenges in Neuroscience**

This working group is following up on the efforts set out by the workshop on grand challenges in neuroscience. The group is also discussing strategies to help guide the initiative, including establishing common messaging on the grand challenges that could be utilized by stakeholders.

# **Public-Private Partnerships**

A working group has been established to identify areas of synergy where public- and private-sector stakeholders can partner to improve the efficiency and effectiveness of drug discovery and development for neurological and mental disorders.

# Suicidality in CNS Clinical Trials

This multi-sector working group has been established to further explore the technical implications of a recent announcement from the FDA requiring assessments of suicidality in all CNS clinical trials. The working group consists of stakeholders from various areas of industry, academia, and government.

