



## Building Knowledge Networks for Neuroscience Magali Haas

### Executive Summary

#### Background:

Research into brain disease and mental illness is currently fragmented by disease and limited by traditional approaches to research. Little “big science” has been undertaken until now. Datasets, if available to the research community, are often limited in size and incompatible with other datasets with the result that “big data” advances in data analysis and new methods of disease modeling are not currently being used to their full advantage.

#### Case Study:

Since October 2001, approximately 1.64 million U.S. troops have been deployed for Operations Enduring Freedom and Iraqi Freedom (OEF/OIF) in Afghanistan and Iraq. It is an undeniable fact that the psychological toll of these deployments—many involving prolonged exposure to combat-related stress over multiple rotations—is disproportionately high compared with the physical injuries of combat. Post-traumatic Stress (PTS), Depression, and Traumatic Brain Injury (TBI) have been identified as the signature 'wounds' of these conflicts. Moreover, as large as the number affected in the military, these numbers are a small fraction of the impact of TBI and PTS on the civilian population. TBI affects an estimated 10 million people worldwide and more than 1.7 million in the U.S. every year. TBI is a silent epidemic--its symptoms are frequently invisible, thus difficult to diagnose and treat. TBI can lead to motor, cognitive, and social impairments that interfere with an individual's ability to be productive.

PTS is a severe anxiety disorder that follows an experience causing psychological trauma. Early evidence suggests that as many as 20% of the approximately 1.64 million U.S. troops returning from deployments to Afghanistan and Iraq show symptoms of PTS or major depression, making PTS the most common serious injury of these wars. It is also estimated that 8 percent of Americans will, in their lifetime, experience PTS from a traumatic event (e.g., sexual assault, severe storms, first responders to violent crime).

#### Proposed Solution:

The “GEMINI PROGRAM” is a Public-Private Partnership combining best-in-class science, technology, and expertise. One Mind is catalyzing collaboration between international research centers of excellence, industry, and government to accelerate the translation of basic science into breakthrough diagnostics and improved treatments for TBI & PTS.

Gemini will accelerate advancements in diagnosis and treatment for veterans and civilians alike.

In 2013, One Mind will launch this multi-country, multi-site initiative to create a large-scale

## Project J)



database of individuals with acute head trauma and/or psychological trauma with rigorous biomarker (e.g., genetics, imaging) and clinical measures to:

- Identify biological indicators of the causes and effects of diseases, or pathology.
- Investigate disease progression for earlier, more accurate diagnosis and treatment.
- Create new ways to share data between academia, industry, non-profits and government.
- Empower patients to take a more active role in their own care, thereby contributing to the acceleration of research.

Gemini will enroll and follow 3000-5000 patients with head trauma for a minimum of three years. A study of this scale will yield results that can be very rapidly translated into improved patient outcomes.

Through the “APOLLO PROGRAM,” the One Mind Brain Data Exchange Portal, we aspire to create the largest “open source” repository for brain disease and injury in the world: designed to be the gateway through which research and data mining by thousands of scientists and clinical researchers in industry, academia and industry, using open and proprietary tools, with the goal of accelerating advances in diagnosis, treatment and, ultimately, cure of brain diseases and mental illness, can be conducted.

One Mind, in partnership with the International Neuroinformatics Coordinating Facility (INCF), Sage Bionetworks, the TranSmart Foundation and others, is building this digital environment for multiple-source data sharing, with open analysis tools and provenance tracking systems for working with complex data. This system could foster an unprecedented open science approach among academia, industry, advocacy groups, and governments that will remove the barriers to effective scientific and clinical research and speed improvements to diagnosis and treatment.

### **The Challenges**

Achieving these goals will involve overcoming technological and scientific challenges while ensuring that patients’ rights and needs are addressed in an ethical manner. These challenges include:

#### **Technology**

- How can we balance the need for data scientists to have freedom in what tools they use against the need to have standardization in order to harmonize research efforts across disciplines?
- How can we accelerate the flow of information between patients, clinicians, researchers, patient advocates and technology providers, who are all fighting disease, when those individuals have not met each other personally or are aware that they can help each other?
- How can standardization in data collection emerge when the standards are complex and time consuming to agree on, and are constantly evolving as we learn more?
- How can we use technology to improve the reproducibility of results in complex biological and medical experiments?

#### **Policy**

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- How can we address incentives for data sharing at both the researcher and patient level?
- At the researcher level, how can researchers (and more importantly the institutions for which they work) be incented to share data “early and often” in light of technology transfer policies, and proprietary data and peer reviewed publications being the currency of academic advancement and research funding?
- At the patient level, how can patients be educated, informed consent procedures developed and necessary safeguards developed so that patients will be willing to allow use of their data on a broad basis in such a portal, especially given the recently publicized advances in analysis that allow a patients identity to uncovered and the issues of stigma associated with mental illness and brain injury?
- How may unique issues with informed consent (e.g. TBI) and other conditions as mental capacity be overcome?

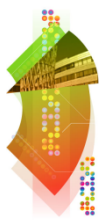
### **Knowledge**

- What scale and types of data do we really need to build predictive models and how do we acquire them?
- How do we grow the computational community and share disease models?

## Over to You

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<b>G</b>	<b>Organization</b>	<b>Last name</b>	<b>First</b>
J-Anchor	Sage Bionetworks	Chaibub Neto	Elias
J	Seattle Children's Research Institute	Cunningham	Michael
J	UCSD	Dutkowski	Janusz
J	Multisensor Science	Earp	Sam
J	Journalist	Ewing-Duncan	David
J-Anchor	Sage Bionetworks	Guinney	Justin
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J	Pull 4 Parkinson's Foundation, Inc.	Joos	Sarah
J	Ashoka/Transverse Myelitis Association	Krishnan	Chitra
J	Takeda	Lai	Eric
J	Stem CentRx	Loving	Kathryn
J	MGH	MacDonald	Marcy
J	GE healthcare	Modrek	Barmak
J	Lilly	O'Neill	Michael
J	Johnson and Johnson	Rajagopal	Gunaretnam
J	Mt. Sinai School of Medicine	Sklar	Pamela
J	UCSC	Sokolov	Artem
J	Prize4Life	Zach	Neta



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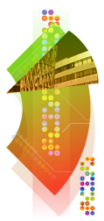
## Magali Haas, One Mind For Research

- One Mind is catalyzing collaboration between international research centers of excellence, industry, and government to accelerate the translation of basic science into breakthrough diagnostics and improved treatments for TBI & PTS.
  - Identify biological indicators of the causes and effects of diseases, or pathology.
  - Investigate disease progression for earlier, more accurate diagnosis and treatment.
  - Create new ways to share data between academia, industry, non-profits and government.
  - Empower patients to take a more active role in their own care, thereby contributing to the acceleration of research.



# Potential alignment with existing Commons' approaches

- Patient Engagement
- Using bioinformatics approaches to drive a new scientific model
  - Build guidelines
  - Build decision support tools
- Incentives for Participation
- Metrics for Recognition



# Unmet needs and issues

- Veterans concerns about “being labeled” and lack of awareness of the consequences of TBI/PTS leads to fear in engaging the medical community
- Current diagnostics are poor and often delayed (troops)
- Lack of guidelines and decision support tools
- Lack of mechanistic understanding of disease course – prognosis
- Lack of Patient Advocacy voice for TBI/PTS
- Need for caregiver and family engagement
- Need for data repositories accessible to teams of scientists
- Care Delivery: Lack of long-term follow-up



# 1-year vision for the future of this project

## **Online patient & caregiver community:**

- [anonymous] for sharing experience with disease/symptoms and care delivery experience
- Provide feedback to patients on how they compare to “peers”
- Recruitment to registries and/or clinical studies for rapid data collection

## **Guidelines Now:**

Use current experience and practice to establish a baseline for Clinical Practice Guidelines  
Revise as evidence is generated

## **National Intrepid COE Pilot:**

Accelerate data analysis of deep phenotyped database  
Build a soldier-to-soldier community around those engaged in this program  
Build enhanced understanding of the condition and consequences & a Trust Forum

## **Other:**

Metrics for recognition  
Incentives for participation in study  
Analyze EHRs to generate hypotheses to validate in prospective study  
Build clinical decision support tools & outcomes

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