

**Federal Interagency TBI Research Informatics System**  
**2<sup>nd</sup> Stakeholders Meeting**  
**NIH Porter Neuroscience Research Center**  
**April 21, 2015**

The Federal Interagency Traumatic Brain Injury Research (FITBIR) Informatics System aims to accelerate progress on how to prevent, diagnose and treat traumatic brain injury (TBI) by providing controlled access to high quality research data. The purpose of this 2<sup>nd</sup> Stakeholders Meeting is to provide an update on the status and capabilities of FITBIR, and to gather input on how to enhance it to meet the needs and expectations of the TBI research community.

8:00 am        **Registration**

8:30            **Welcome**

Walter Koroshetz, MD, NIH, NINDS and COL Dallas Hack, MD, DOD

**Session I: Accomplishments of the 1<sup>st</sup> Four Years**

8:45            **Overview of the FITBIR Informatics System & Data Sharing Policy**  
Patrick Bellgowan, PhD, NIH, NINDS (10 min + 5 min Q&A)

9:00            **FITBIR Process & Terminology** (from GUID to Form Structure)  
Alison Garcia, BSE, NIH, CIT (10 min + 5 min Q&A)

9:15            **FITBIR Demonstration**  
Matthew McAuliffe, PhD, NIH, CIT (30 min + 15 min Q&A)

10:00          **Break**

10:15          **FITBIR Holdings** (12 min + 3 min Q&A)  
TRACK-TBI Pilot  
Pediatric TBI Data  
COBRIT Data  
MRI TBI Data  
PROTECT Data  
DOD Projects

11:45          **Lunch Break**

**Session II: Tools and Data Resources for the “Collaboratory”\***

12:45pm       **Tools and Data Resources**  
Geoffrey Manley, MD, PhD, UCSF (30 min)

### Session III: Stakeholders Breakout Groups

1:30 The goal is to gather input on the following topics (30 min/topic)  
(Moderators will rotate so each group addresses all issues)

#### **FITBIR's Evolution**

Moderators: Matthew McAuliffe & Margaret Sutherland, PhD, NIH, NINDS

- What do you view as the strengths and weaknesses of FITBIR?
- How might we enhance FITBIR to meet your needs and expectations (e.g., data federation)?
- What resources or tools might be leveraged to enhance FITBIR?

#### **Assessing FITBIR's Strategic Plan**

Moderators: COL Dallas Hack & Ramona Hicks, PhD, One Mind

- Recommendations for 3 top scientific goals or deliverables for FITBIR
- Prioritization of research questions supported by FITBIR
- How should FITBIR measure success

#### **Best Practices for FITBIR Community Use**

Moderators: Crystal Hill-Pryor, PhD, DOD & Patrick Bellgowan

- How might we enhance or establish collaborations and reduce concurrent and competitive hypothesis testing using FITBIR?
- Can the Data Sharing Agreement be enhanced to support FITBIR's goals?
- How can FITBIR be best used to maximize available research funds?
- How can we promote the use of common data elements and case report forms?

3:00 **Break**

### Session IV: Breakout Group Recommendations

3:30 **Moderated Panel Discussion of Breakout Group Leaders**

Patrick Bellgowan & B. Christie Vu, PhD, DOD (30 min)

4:00 **Adjourn**

COL Dallas Hack

4:15 **Summary and Action Plan**

Moderator: Vinay Pai, PhD, NIH, NIBIB

Strategic Vision Committee: Patrick Bellgowan; Ramon Diaz-Arrastia, MD, PhD, USUHS; Thomas DeGraba, MD, DOD; Gregory Farber, PhD, NIH, NIMH; Robert Harbaugh, MD, Penn State; Frank Lebeda, PhD, DOD; Geoffrey Manley; Matthew McAuliffe; Vinay Pai; Rema Raman, PhD, UCSD; Michael Schoenbaum, PhD, NIH, NIMH

### **\*Tools for the “Collaboratory”**

Over the past several years it has become clear that a better understanding of the human pathophysiology and recovery processes associated with traumatic brain injury (TBI) is essential for developing effective treatments and diagnostic tools. Several major TBI clinical studies are in progress or will begin soon that aim to compare the effectiveness of current treatments, validate biomarkers and assessment tools, and create a more precise classification scheme. In addition to these large multicenter observational studies, there are smaller clinical studies that are more focused on a particular research question. Collectively, the studies investigate TBI across the spectrum of age, time, and severity. Many of these studies are required to load their data into the Federal Interagency TBI Research (FITBIR) Informatics System or other searchable databases, such as the OBI-BrainCODE or INCF/CENTER-TBI databases. These research studies and databases provide an unprecedented opportunity for collaboration and advancements in TBI health care.

The benefits of collaboration are many, but so are the challenges. To address the challenges, the concept of the “*collaboratory*” has emerged. The goal is to go beyond data sharing and develop strategies, incentives and tools to make it possible for scientists to work together to find answers to difficult problems. Similarly, the scientists who are building the informatics platform for TBI research also need to collaborate. The purpose of this presentation is to provide an overview of some of the tools that are currently available to the TBI research community and how they are integrated to optimize collaborative data sharing and analysis.