

Utilization of the VA National ALS Biorepository Brain Bank for Multi-omic Molecular Studies and Biomarker Discovery

June 15-16, 2020

VIRTUAL Meeting (both days): 11:00 a.m. to 5:00 p.m. EDT

Meeting Goals

The goals of this meeting are to share the “state of the science” for 1) current state of knowledge and gaps in knowledge regarding ALS pathogenesis and biomarkers, 2) mechanisms of ALS pathogenesis, and 3) challenges for molecular pathogenesis and biomarker discovery, to increase the current and future utilization of the VA Biorepository Brain Bank (VABBB) ALS biorepository.

MEETING WEBSITE

https://www.research.va.gov/programs/tissue_banking/als/default.cfm#natl-meeting

Registration Link: Registration is required to receive the online meeting link

Monday’s registration link: <https://attendee.gotowebinar.com/register/1363774155443114498>

Tuesday’s registration link: <https://attendee.gotowebinar.com/register/3817737873592657666>

AGENDA

Monday, June 15, 2020 – Meeting Host, VA Boston Healthcare System

11:00 AM **Welcome and Introductions**

Dr. Carolyn M. Clancy, Deputy Undersecretary for Health, Discovery, Education and Affiliate Networks (DEAN), Veterans Health Administration, US Department of Veterans Affairs, Washington, DC

Dr. Christopher Bever, Director of Biomedical and Laboratory Research and Development, Office of Research and Development, Veterans Health Administration, US Department of Veterans Affairs, Washington, DC

Dr. Terry Keane, Associate Chief of Staff for Research, VA Boston Healthcare System, Professor of Psychiatry and Assistant Dean for Research, Boston University School of Medicine, Boston, MA

11:45 AM **Overview of the meeting objectives and deliverables**

Dr. Neil Kowall, Principal Investigator, VABBB, Chief of Neurology, VA Boston Healthcare System; Professor of Neurology & Pathology, Boston University School of Medicine

Dr. Eric Huang, Professor & Vice Chair for Research, Department of Pathology, University of California San Francisco

12:00 PM **VABBB presentation – ALS brain bank status/discussion**

Dr. Christopher Brady, Co-Principal Investigator/Director of Scientific Operations, VABBB, VA Boston Healthcare System; Assistant Professor of Neurology and Behavioral Neuroscience Ph.D. Program, Boston University School of Medicine

Dr. Thor Stein, Staff Neuropathologist, VABBB and VA Boston Healthcare System; Assistant Professor in Pathology, Boston University School of Medicine

Dr. Ian Robey, Director of Technical Operations, VABBB, Southern Arizona VA Healthcare System; Research Assistant Professor, Department of Medicine, University of Arizona

1:00 PM **Lunch Break**

1:30 PM

Presentations - New or understudied research topics in ALS that could be addressed through the use of postmortem CNS tissue and associated phenotype data

- **ALS Neuropathology and Spread: Synchronization, Desynchronization, and Saturation**
John Ravits, M.D.
Professor of Clinical Neurosciences
University of California, San Diego

- **Could a Fungal Infection Cause Some Cases of ALS?**
Richard Bedlack M.D., Ph.D.
Professor of Neurology
Duke University
Durham VAMC

- **The Power of Biospecimens in Understanding Disease Progression in ALS**
Peter H. King, M.D.
Chief of Neurology, Birmingham VA Medical Center
Professor and Vice Chair of Neurology
University of Alabama at Birmingham

- **Future Directions in the Genomics of ALS: Importance of Biobanking**
Bryan J. Traynor, M.D., Ph.D.
Senior Investigator, NIA

- Q&A and General Discussion

3:30 PM

Break

3:45 PM

General discussion and development of action items

5:00 PM

Adjourn

Tuesday, June 16, 2020– Meeting Host, VA Boston Healthcare System

11:00 AM **Previous day review**

11:30 AM **Panel Discussion - The future roles of the VA Biorepository Brain Bank (VABBB) to support research on new/understudied topics, and Multi-omic Molecular studies and Biomarker discovery**

- o Additional postmortem tissue and/or biofluid recovery
- o New antemortem tissue and/or biofluid recovery
- o Additional phenotype data collection

Panel

Lyle Ostrow, M.D., Ph.D.
Assistant Professor of Neurology
Johns Hopkins University
Human Postmortem Tissue Core Director, Target ALS

Bryan J. Traynor, M.D., Ph.D.
Senior Investigator, NIA

Neil Kowall, M.D., Chief of Neurology, VA Boston Healthcare System; Professor of Neurology & Pathology, Boston University School of Medicine

Eric Huang, M.D., Ph.D.
Professor & Vice Chair for Research, Department of Pathology, University of California San Francisco

Christopher Brady, Ph.D., Health Science Specialist/Neuropsychologist, VA Boston Healthcare System; Assistant Professor of Neurology and Behavioral Neuroscience Ph.D. Program, Boston University School of Medicine

Thor Stein, M.D., Ph.D., Staff Neuropathologist, VA Boston Healthcare System; Assistant Professor in Pathology, Boston University School of Medicine

Ian Robey, Ph.D., Supervisory Research Health Specialist, Southern Arizona VA Healthcare System; Research Assistant Professor, Department of Medicine, University of Arizona

- o Q&A and General Discussion

1:00 PM **Lunch Break**

1:30 PM **Discussion - Increased utilization of VABBB tissue and data**

- o Enhanced outreach to national and international ALS laboratories and professional organizations
- o Participation in national/international biorepository consortia

The CSPEC-Durham Data and Specimen Repository and the ALS Registry

Dawn Provenzale, M.D., M.S.
Director, VA Cooperative Studies Program Epidemiology Center-Durham
Professor of Medicine
Director, GI Outcomes Research
Duke University School of Medicine

Kellie J. Sims, Ph.D.
Statistician & Data Steward
Cooperative Studies Program Epidemiology Center – Durham VA Medical Center

Target ALS Postmortem Tissue Core

Lyle Ostrow, M.D., Ph.D.
Assistant Professor of Neurology
Johns Hopkins University
Human Postmortem Tissue Core Director, Target ALS

VA Biorepository Brain Bank: The Importance of Collaboration in ALS Research

Neil Kowall, M.D., Christopher Brady, Ph.D., Thor Stein, M.D., Ph.D., Ian Robey, Ph.D.
Co-Principal/Co Investigators, VABBB
VA Boston Healthcare System/BU School of Medicine, Southern Arizona VA Healthcare System/University of Arizona

- o Q&A and General Discussion

3:00 PM **Break**

3:15 PM **General discussion and development of action items**

5:00 PM **Adjourn**

Meeting Deliverables

Following discussion with content experts and representatives of funding agencies, meeting organizer and Chairs will turn discussion notes into a final report, which will include, but is not limited to:

1. Identification of gaps or under-studied areas that are highly prevalent in or unique to the Veteran population, described in a format actionable by VA ORD.
2. Specific research roadmaps in the areas identified by the content experts. Roadmaps will describe in specific detail the types of near-term research needed to advance basic understanding of injuries and potential diagnostic and treatment options.
3. Summary of any additional discussion points and actionable recommendations for use in the development of new funding opportunities from various agencies, including VA, NIH, CDMRP, DoD, ALS foundations