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/381773787359265766

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
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

- Additional postmortem tissue and/or biofluid recovery
- New antemortem tissue and/or biofluid recovery
- 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

- Q&A and General Discussion

1:00 PM  
Lunch Break

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

- Enhanced outreach to national and international ALS laboratories and professional organizations
- 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

- 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