

# 2022 National ALS Registry Annual Research Symposium and Meeting August 29-30<sup>th</sup>, 2022

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## AGENDA

### Day 1: Monday, August 29<sup>th</sup>, 2022

(Please note that all times are in Eastern Standard Time [EST])

<b>Zoom sign-in</b>	<b>8:00 am</b>
<b>Welcome</b> Danielle Boyce, DPA, MPH Moderator Johns Hopkins School of Medicine	<b>8:15 am</b>
<b>Opening Remarks</b> Patrick Breyse, PhD Director National Center for Environmental Health/Agency for Toxic Substances and Disease Registry	<b>8:20 am</b>
<b>National ALS Registry Update</b> Paul Mehta, MD National ALS Registry, Principal Investigator Registries and Surveillance Section, OIA Agency for Toxic Substances and Disease Registry	<b>8:25 am</b>
<b>Questions and Discussion</b>	<b>9:00 am</b>
<b>Harvard University</b> Pre-disease Biomarkers of Persistent Organic Pollutants, Immune System, and Amyotrophic Lateral Sclerosis Marc Weisskopf, PhD, ScD Professor of Epidemiology	<b>9:30 am</b>
<b>Questions and Discussion</b>	<b>9:50 am</b>
<b>BREAK (10 Minutes)</b>	<b>10:00 am</b>
<b>National ALS Biorepository Update</b> Laurie Wagner, MPH Coordinator, National ALS Biorepository McKing Consulting Corporation	<b>10:10 am</b>
<b>Update on Collaboration with John's Hopkins Tissue Core</b> Lyle Ostrow, MD, PhD Director Johns Hopkins University Tissue Repository	<b>10:30 am</b>
<b>Questions and Discussion</b>	<b>11:00 am</b>
<b>Open Ended Question Analysis</b> Danielle Boyce, DPA, MPH Executive Director Robert Packard Center for ALS Research	<b>11:10 am</b>
<b>Questions and Discussion</b>	<b>11:30 am</b>

<b>State – Based ALS Registries</b>	<b>11:40 am</b>
Elijah Stommel, MD, PhD Professor of Neurology Geisel School of Medicine at Dartmouth	
<b>Questions and Discussion</b>	<b>12:00 pm</b>
<b>Break &amp; Lunch</b>	<b>12:10 pm</b>
<b>National ALS Registry Funded Research Presentations</b>	
<b>Harvard University</b>	<b>1:30 pm</b>
Serological Profiling of the Human Virome and ALS Risk in a Military Population Alberto Ascherio, MD, DrPH Professor of Epidemiology	
<b>Questions and Discussion</b>	<b>1:50 pm</b>
<b>Columbia University</b>	<b>2:00 pm</b>
Novel Extracellular Vesicle and Molecular Biomarkers of Environmental Exposure and Disease Progression in ALS Diane B. Re, Ph.D. Assistant Professor	
<b>Questions and Discussion</b>	<b>2:20 pm</b>
<b>University of Michigan</b>	<b>2:30 pm</b>
Targeting the ALS Exposome for Disease Prevention: Air Pollution Update Eva Feldman, MD Professor of Neurology	
Stephen Goutman, MD Assistant Professor of Neurology	
<b>Questions and Discussion</b>	<b>2:50 pm</b>
<b>University of Pittsburgh</b>	<b>3:00 pm</b>
Identification and Characterization of Potential Environmental Risk Factors for ALS Using the ALS Registry Cases and a Control Population Evelyn O. Talbott, DrPH Professor of Epidemiology	
William Tennant PhD Candidate	
<b>Questions and Discussion</b>	<b>3:20 pm</b>
<b>BREAK (10 Minutes)</b>	<b>3:30 pm</b>
<b>The Dartmouth Institute</b>	<b>3:40 pm</b>
Environmental Risk Factors for ALS: Critical Time Periods and Genetic Interactions Jiang Gui, PhD Associate Professor	
<b>Questions and Discussion</b>	<b>4:00 pm</b>
<b>End of Day Discussion</b>	<b>4:10 pm</b>
<b>Adjourn</b>	<b>4:55 pm</b>

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**AGENDA**

**Day 2: Tuesday, August 30th, 2022**

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<b>Zoom sign-in</b>	<b>8:00 am</b>
<b>Welcome to Day 2</b>	<b>8:15 am</b>
<b>National ALS Registry Funded Research Presentations - Continued</b>	
<b>Trinity College (Dublin)</b>	<b>8:30 am</b>
ALS Risk in Latin Americans- A Population Based Case Control Comparative Study with Three European Population Based Cohorts Orla Hardiman, MD, PhD Professor of Neurology	
<b>Questions and Discussion</b>	<b>8:50 am</b>
<b>Karolinska Institute (Sweden)</b>	<b>9:00 am</b>
Identify and Evaluate Potential Risk Factors for Amyotrophic Lateral Sclerosis – Sweden Fang Fang, PhD Professor of Epidemiology	
<b>Questions and Discussion</b>	<b>9:20 am</b>
<b>Northwestern University</b>	<b>9:30 am</b>
A novel innate immunity risk factor for amyotrophic lateral sclerosis Teepu Siddique, MD, PhD Professor of Neurology	
<b>Questions and Discussion</b>	<b>9:50 am</b>
<b>BREAK (15 Minutes)</b>	<b>10:00 am</b>
<b>Results from the Registry Engagement Session &amp; Future Priorities</b>	<b>10:15 am</b>
Danielle Boyce, DPA, MPH Session Participant(s)	
<b>Questions and Discussion</b>	<b>11:30 am</b>
<b>Break &amp; Lunch</b>	<b>12:00 pm</b>
<b>ALS Patients Perspectives – In Your Own Words</b>	<b>1:00 pm</b>
Diane Mummaw Joel Shamaskin Brad Dusek	

**End of the Day Wrap-up/Questions/Open Discussion**

**2:30 pm**

Danielle Boyce, DPA, MPH  
Moderator  
Johns Hopkins School of Medicine

**Closing Remarks**

**3:00 pm**

Paul Mehta, MD  
National ALS Registry, Principal Investigator

**Adjourn**

**3:30 pm**