



Agenda

Thursday, March 14, 2019

7:00 a.m. Registration

INTRODUCTION

8:00 a.m. Welcoming Remarks and Introduction
Walter Koroshetz, MD, Director, National Institute of Neurological Disorders and Stroke

8:10 a.m. Perspective
Laura Gitlin, MD, PhD, Chair, Advisory Council on Alzheimer's Research, Care, and Services

8:20 a.m. Progress and Updating Research Recommendations for the Alzheimer's Disease-Related Dementias
Julie Schneider, MD, MS, Scientific Chair, and Roderick Corriveau, PhD, NIH Lead, ADRD Summit 2019, National Institute of Neurological Disorders and Stroke

SESSION 1: Multiple Etiology Dementias – Diagnosing Dementia in the 21st Century

Chairs: David Knopman, MD, and Kate Possin, PhD

8:40 a.m. Session Introduction – Revised Recommendations: Reconciling the Gap between Aspirational and Operational Goals
David Knopman, MD

8:47 a.m. Recommendation 3: Advance Basic and Clinical Research in MED
David Knopman, MD

8:59 a.m. Recommendations 1 and 2: Progress and Next Steps in Detection and Diagnosis of Cognitive Impairment and Dementia
Kate Possin, PhD and Alireza Atri, MD, PhD

9:15 a.m. Recommendation 6: Implementing Effective Dementia Care
Kate Possin, PhD

9:27 a.m. Recommendation 4: Progress and Work Needed to Increase the Dementia Capable Workforce

Heather Snyder, PhD

- 9:39 a.m. Recommendation 5: Conduct Intervention Studies to Mitigate Reversible Causes of Cognitive Dysfunction**
Sharon Inoue, MD, MPH and David Knopman, MD
- 9:55 a.m. Open Microphone Discussion and Panel – Multiple Etiology Dementias**
Alireza Atri, MD, PhD; Patricia Boyle, PhD; Cynthia Carlsson, MD, MS; Sharon Inouye, MD, MPH; David Knopman, MD; Kate Possin, PhD, Heather Snyder, PhD
- 10:20-10:40 a.m. BREAK**

SESSION 2: Health Disparities in AD/ADRD

Chairs: Lisa Barnes, PhD and Hector Gonzalez, PhD

- 10:40 a.m. Introduction**
Lisa Barnes, PhD and Hector Gonzalez, PhD
- 10:50 a.m. Recommendations 1 and 2: Assessment**
Jennifer Manley, PhD
- 11:06 a.m. Recommendations 3 and 4: Epidemiology and Pathway Analyses Toward Culturally Appropriate Interventions**
Rebecca Gottesman, MD, PhD
- 11:22 a.m. Recommendations 5 and 6: Monitoring Trends**
Elizabeth Rose Mayeda, PhD, MPH
- 11:38 a.m. Recommendation 7: Workforce Development**
Luis Medina, PhD
- 11:54 a.m. Open Microphone Discussion and Panel – Health Disparities in AD/ADRD**
Lisa Barnes, PhD; Myriam Fornage, PhD; Hector Gonzalez, PhD; Rebecca Gottesman, MD, PhD; J. Taylor Harden, PhD, RN; Jennifer Manly, PhD; Elizabeth Rose Mayeda, PhD, MPH; Luis Medina, PhD
- 12:20-1:20 p.m. LUNCH ON YOUR OWN**

SESSION 3: Lewy Body Dementias

Chair: Bradley Boeve, MD and Carol Lippa, MD

- 1:20 p.m. Introduction**

Bradley Boeve, MD and Carol Lippa, MD

- 1:30 p.m. Clinical Science – Progress and Changes to Recommendations 1-4**
Jennifer Goldman, MD, MS; Kirk Frey, MD; Dennis Dickson, MD
- 2:05 p.m. Basic Science – Progress and Changes to Recommendations 5-8**
Douglas Galasko, MD, Sonja Scholz, MD, PhD; Mark Cookson, PhD
- 2:40 p.m. Open Microphone Discussion and Panel – Lewy Body Dementias**
Bradley Boeve, MD; Mark Cookson, PhD; Dennis Dickson, MD; Kirk Frey, MD; Douglas Galasko, MD; Jennifer Goldman, MD, MS; Peter Lansbury Jr, PhD; Carol Lippa, MD; Sonja Scholz, MD, PhD; Angela Taylor, BMus; Daniel Weintraub, MD

3:00-3:20 p.m. BREAK

SESSION 4: Dementia Nomenclature

Chairs: Ronald Petersen, MD, PhD and Angela Taylor, BMus

- 3:20 p.m. A Rising National Priority: Recommendations to Form Integrated Workgroups on Nomenclature in Research, Clinical Practice, and Society**
Angela Taylor, BMus
- 3:25 p.m. Stakeholder Engagement Strategy: The Needs of the Research Community**
Ronald Petersen, MD, PhD
- 3:40 p.m. Translating the Science into Clinical Practice**
Jim Leverenz, MD
- 3:48 p.m. Living with a Dementia Diagnosis: The First-Person Experience**
Cynthia Huling Hummel, BS, MDiv, DMin
- 3:53 p.m. Insights from a Caregiver**
Mark Herthel, BS
- 3:58 p.m. Cultural Considerations: Giving Meaning to and Responding to Dementia**
Peggye Dilworth-Anderson, PhD
- 4:06 p.m. Stigma: Considerations of Ethics and History**
Jason Karlawish, MD
- 4:14 p.m. Categories and Controversies: Insights from DSM-5**
Dominic Sisti, PhD

4:22 p.m. Integration of Stakeholder Input and Next Steps

Sandy Weintraub, PhD, ABCN/ABPP

4:30 p.m. Open Microphone Discussion and Panel – Dementia Nomenclature

Peggye Dilworth-Anderson, PhD; Mark Herthel, BS; Cynthia Huling Hummel, BS, MDiv, DMin; Jason Karlawish, MD; Jim Leverenz, MD; Ron Petersen, MD, PhD; Dominic Sisti, PhD; Angela Taylor; Sandy Weintraub, PhD, ABCN/ABPP

5:00 p.m. Adjourn Day 1

Friday, March 15, 2019

7:30 a.m. Registration

SESSION 5: Vascular Contributions to Cognitive Impairment and Dementia

Chairs: Donna Wilcock, PhD and Jeff Williamson, MD, MHS

8:00 a.m. Introduction and Overview of Recommendations

Donna Wilcock, PhD

8:10 a.m. Basic Science and Mechanisms Recommendations

Andy Shih, PhD and Roxanna Carare, MD, PhD

8:30 a.m. Clinical Science Recommendations

Kristine Yaffe, MD and Eric Smith MD, MPH

8:50 a.m. Translational Science Recommendations

Jeff Williamson, MD, MHS

9:10 a.m. Open Microphone Discussion and Panel – VCID

Roxanna Carare, MD, PhD; Susan Catalano, PhD; Rebecca Gottesman, MD, PhD; Douglas Gould, PhD; Anne Leonard, MPH, RN; Henrieta Scholtzova, MD, PhD; Andy Shih, PhD; Eric Smith, MD, MPH; Heather Snyder, PhD

9:40-10:00 a.m. BREAK

SESSION 6: Frontotemporal Lobar Degeneration

Chairs: Leonard Petrucelli, PhD and Adam Boxer, MD, PhD

10:00 a.m. Introduction and Changes to Basic Science Recommendations 1-4

Leonard Petrucelli, PhD

- 10:05 a.m.** **Basic Science: Advances in tau Biology**
Anthony Fitzpatrick, PhD
- 10:15 a.m.** **Basic Science: Advances in FTL D C9ORF72, and GRN Biology**
Jeff Rothstein, MD, PhD and Michael Ward, MD, PhD
- 10:25 a.m.** **Basic Science: Single Cell ‘Omic Analysis for FTL D**
Manolis Kellis, PhD
- 10:35 a.m.** **Open Microphone Discussion and Panel – Basic Science of FTL D**
Patrick Brannelly, MBA; Anthony Fitzpatrick, PhD; Manolis Kellis, PhD; Rodney Pearlman, PhD; Leonard Petrucelli, PhD; Jeff Rothstein, MD, PhD; Nadine Tatton, PhD; Michael Ward, MD, PhD
- 10:50 a.m.** **Changes Made to Clinical Science Recommendations 5-8**
Adam Boxer, MD, PhD
- 10:55 a.m.** **Clinical Science: Biomarkers**
Henrik Zetterberg, MD, PhD and Jon Rohrer, MD, PhD
- 11:05 a.m.** **Clinical Science: Genetics and Natural History Studies**
Bradley Boeve, MD
- 11:15 a.m.** **Clinical Science: Clinical Trials**
Adam Boxer, MD, PhD
- 11:25 a.m.** **Open Microphone Discussion and Panel – Clinical Science FTL D**
Adam Boxer, MD, PhD; Patrick Brannelly, MBA; Nick Fox, MD; Rodney Pearlman, PhD; Jon Rohrer, MD, PhD; Holly Soares, PhD; Nadine Tatton, PhD; Henrik Zetterberg, MD
- 11:40-12:40 p.m.** **LUNCH ON YOUR OWN**

SESSION 7: Emerging Scientific Topics

Chairs: Kristen Dams-O’Connor, PhD and Julie Schneider, MD, MS

- 12:40 p.m.** **Introduction to TDP-43 in Common Dementias & Recommendations 1-4**
Julie Schneider, MD, MS
- 12:45 p.m.** **TDP-43 in Common Dementias: Rationale for Clinical Recognition and Biomarkers Studies**
Julie Schneider, MD, MS
- 12:50 p.m.** **Rationale for Studying Risk Factors, Genetic Drivers and Pathologic Phenotypes of TDP-43 in Common Dementias**

Pete Nelson, MD, PhD

- 1:00 p.m.** **Rationale for Basic Science and Animal Model Studies Specifically Targeted Toward TDP-43 in Common Dementias**
Aaron Gitler, PhD
- 1:10 p.m.** **Open Microphone Discussion & Panel – TDP-43 in Common Dementias**
Aaron Gitler, PhD; Pete Nelson, MD, PhD; Julie Schneider, MD, MS
- 1:30 p.m.** **Introduction to TBI and AD/ADRD Risk**
Kristen Dams-O'Connor, PhD
- 1:40 p.m.** **Summary of NIH/VA-ORD Workshop: TBI as a Risk Factor for AD/ADRD among Veterans**
Kristen Dams-O'Connor, PhD
- 1:45 p.m.** **Recommendations 5-8 for the Study of TBI and AD/ADRD Risk**
Kristen Dams-O'Connor, PhD
- 1:50 p.m.** **Open Microphone Discussion and Panel – TBI and AD/ADRD Risk**
Kristen Dams-O'Connor, PhD; Mary Jo Pugh, PhD, RN; Douglas H. Smith, MD; Henrik Zetterberg, MD, PhD
- 2:20-2:30 p.m.** **BREAK**
- WRAP-UP**
- 2:30 p.m.** **Scientific Chair's Highlights and Cross-Cutting Themes**
Julie Schneider, MD, MS, Scientific Chair
- 2:55 p.m.** **Further Public Input and Open Microphone Discussion**
Lisa Barnes, PhD; Bradley Boeve, MD; Adam Boxer, MD, PhD; Kristen Dams-O'Connor, PhD; Hector Gonzalez, PhD; David Knopman, MD; Carol Lippa, MD; Ronald Petersen, MD, PhD; Leonard Petrucelli, PhD; Kate Possin, PhD; Julie Schneider, MD, MS; Angela Taylor, BMus; Donna Wilcock, PhD; Jeff Williamson, MD, MHS
- 3:20 p.m.** **Conclusion of ADRD Summit 2019**