

Public Announcement

Investigator-initiated and ALS Community-supported International ALS Conference: To Promote Clinical Research to Find the Pathogenesis and Cause of ALS

Eleanor and Lou Gehrig MDA/ALS Research Center, Columbia University
September 7, 8, and 9, 2011 at Tarrytown House, New York

The Organizing Committee

Hiroshi Mitsumoto (chair), Richard Bedlack (vice chair), Richard Barohn, Merit Cudkowicz, Chris Henderson, Catherine Lomen-Hoerth, Robert Miller, Ericka Simpson, Eric Sorenson, Valerie Cwik (ex officio), Lucie Bruijn (ex officio), and Denise Figlewicz (ex officio)

Funding

NIH (NINDS and ORDR), MDA Wings Over Wall Street, ALS Association, The Judith & Jean Pape Adams Charitable Foundation, Sanofi-Aventis, ALS Society of Canada, Ride for Life, Knopp Neurosciences, Biogen Idec, Avanir, ALS Outreach Foundation of Westchester, Bill Spina, British MND Association, and Les Turner Foundation

Tentative Program

(This conference is not the type of conference that is based on didactic or research presentations. Rather, it will be discussion-based, initiated by brief topic presentations to find ways to promote clinical research aimed at identifying the pathogeneses and cause of ALS in the future)

Tuesday, September 6, 2011: Check-in

A satellite meeting: NINDS Common Database Element (CDE) (everyone welcome): 7:45 pm – 9:15 pm

FIRST DAY (Wednesday, September 7, 2011)

Phenotype variation and disease target to study the pathogenesis/cause (8:30 am - 12:00 pm) Moderator: Dr. Steven Ringel

UMN vs. LMN (ALS, primary lateral sclerosis, progressive muscular atrophy)

Clinical and Basic

Specific LMN Involvement (bulbar, respiratory, regional spinal MN): Clinical and Basic

Motor cortex vs. other brain regions (or ALS vs. FTD): Clinical and Basic

Neuron (proximal vs. distal)

Astrocytes:

Microglial cells:

ALS as a systemic disease

Potential ALS Biomarkers leading to the pathogenesis/cause (1:30 pm – 5:00 pm)

Moderator: Dr. Kenneth Fischbeck

Oxidative Stress

Inflammatory cells

Excitotoxic biomarkers

Mitochondrial dysfunction

Muscle biomarkers

Skin biomarkers

ipS cells
Lipid markers
Cerebrospinal fluid markers
Neurophysiological markers
Neuroimaging markers

SECOND DAY (Thursday, September 8, 2011)

Epidemiological studies leading to the pathogenesis/cause (8:00 am – 11:30 am)

Moderator: Dr. Andrew Eisen

Population-based studies: Ireland, Finland, Italy, England, Japan
VA-based studies
Kaiser Permanente Study
Cancer Prevention Study
Guam ALS
Cyanobacteria and ALS Globally
ALS Center-based Studies
Chronic traumatic encephalopathy and motor neuron disease

Potential genetic and epigenetic studies leading to the pathogenesis/cause (1:00 pm – 3:30 pm) Moderator: Dr. P Nigel Leigh

fALS vs. sALS
GWAS
Deep sequencing of exome for ALS
Other genes for fALS
Modifier genes
RNA and epigenetic mechanisms

Breakout Sessions

How do we make the process move forward? (4:00 pm – 5:30 pm)

Post-Dinner Breakout Sessions Continued (8:30 pm – 9:30 pm)

THIRD DAY (Friday, September 9, 2011)

Infrastructure and Methodological issues (8:00 am – 10:00 am) Moderator (to be announced):

Database
Center-based or national patient registry
How national study groups (NEALS, WALS, ALSRG) can incorporate patient-oriented research into finding the disease mechanism and cause
Tissue banking
DNA and Biobank

Wrap-up: Summary and Recommendations (10:30 am – 12:30 pm)

Moderator: Dr. David Chad

Reports from Breakout Sessions 1, 2, 3, 4, 5, and 6
Funding agencies' recommendations (NINDS, ORDR, MDA, ALSA, ASC, Adams Foundation, BMNDA)
Patient Advocacy recommendations (Monti)
Final Sum-Up and Thank you

Adjourn (12:30 pm) and Optional lunch

Please e-mail Allison DiRienzo (Conference Manager) with any questions. She can be reached at amd2194@columbia.edu or via phone at 212-305-4746.