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.