



ALS CONSORTIUM MEETING

New York Genome Center (NYGC)

June 24-26, 2018

Sponsored by The ALS Association Greater New York Chapter

Sunday, June 24, 2018 Keynote Address and Reception

5:00pm-5:30pm	Optional: NYGC Facility Tour (1 st Floor Lobby)
5:30pm - 6:45pm	Welcome, Opening Remarks and Keynote Address (1 st Floor Auditorium) Lucie Bruijn, PhD, MBA, Chief Scientist, ALS Association – Research Tom Maniatis, PhD, Scientific Director & CEO, New York Genome Center Speaker: Cori Bargmann, PhD, Head of Science at the Chan Zuckerberg Initiative, Head of the Lulu and Anthony Wang Laboratory of Neural Circuits and Behavior and the Torsten N. Wiesel Professor at the Rockefeller University
6:45pm-8:00pm	Reception (1 st Floor Cafeteria)

Monday, June 25, 2018

All sessions will be held in the 1st floor Auditorium unless noted otherwise.

8:15am-9:00am	Breakfast
9:00am-9:10am	Welcome and Opening Remarks Hemali Phatnani, PhD, Director, Center for Genomics of Neurodegenerative Disease at NYGC Lucie Bruijn, PhD, MBA, Chief Scientist, ALS Association - Research
9:10am-10:30am	NYGC ALS Consortium Updates Moderator: Samantha Fennessey, MS, Associate Scientific Project Manager at NYGC <ul style="list-style-type: none">• Outline of Agenda and Overview of Progress Speaker: Hemali Phatnani, PhD, Director, Center for Genomics of Neurodegenerative Disease at NYGC• Workflow Updates and Transition to NovaSeq Speakers: Michael Zody, PhD, Senior Director of Computational Biology at NYGC (WGS) Nicolas Robine, PhD, Assistant Director of Computational Biology at NYGC (RNA-seq)

- MetroNome
Speaker: Christian Stolte, Data Visualization Designer at NYGC
 - Discussion
- 10:30am-10:45am Coffee Break
(1st Floor Cafeteria)
- 10:45am-12:15pm NYGC ALS Consortium Updates – continued
Moderator: Michael Zody, PhD, Senior Director of Computational Biology at NYGC
- Genetic Modifiers
Speaker: Terry Heiman-Patterson, MD, Professor of Neurology at Temple University
 - Familial ALS gene discovery
 - **Speaker: John Landers, PhD**, Professor of Neurology at the University of Massachusetts Medical School
 - Repeat expansion and structural variants
Speakers: Robert Sebra, PhD, Associate Professor of Genetics and Genomic Sciences at the Icahn School of Medicine at Mount Sinai
Giuseppe Narzisi, PhD, Lead Bioinformatics Scientist at NYGC
 - Discussion
 - What should we incorporate into our production pipeline?
 - What do we need in order to fill in the gaps?
 - How should we move forward?
- 12:15pm-1:15pm Lunch
(1st Floor Cafeteria)
- 1:15pm-2:15pm Updates from Other Consortia and Partnerships
Moderator: Lucie Bruijn, PhD, MBA, Chief Scientist, ALS Association - Research
- Project MinE updates and repeat expansions
Speaker: Jan Veldink, PhD, Professor of Neurology and Neurosurgery at the University Medical Center Utrecht
 - GTAC
Speaker: Matthew Harms, MD, Associate Professor of Neurology at Columbia University College of Physicians and Surgeons
 - CReATe
Speaker: Gang Wu, PhD, Group Lead of Genomics/Genetics Analysis, Department of Computational Biology at St. Jude Children’s Research Hospital
- 2:15pm-3:30pm Updates from Other Consortia and Partnerships - continued
- Answer ALS
Speakers: Jeffrey Rothstein, MD, PhD, Professor of Neurology and Neurosciences at Johns Hopkins University School of Medicine
Leandro Lima, PhD, Bioinformatics Software Engineer II at Gladstone Institute of Neurological Disease
 - DIALS
Speaker: Katharine Nicholson, MD, Department of Neurology at Harvard Medical School

- Discussion
 - Areas of synergy
 - How can we streamline data flow?

3:30pm-4:15pm

Coffee Break (*1st Floor Cafeteria*)

4:15pm-6:00pm

Facilitating Open and Collaborative Access to Data and Resources

Moderator: Lyle Ostrow, MD, PhD, Assistant Professor of Neurology at Johns Hopkins University School of Medicine

- Presentations from Target ALS Data Users
- Discussion

6:00pm-8:00pm

Dinner

Tuesday, June 26, 2018

All sessions will be held in the 1st floor Auditorium unless noted otherwise.

8:15am-9:00am

Breakfast

9:00am-10:15am

NYGC ALS Consortium Updates

Moderator: Delphine Fagegaltier, PhD, Staff Scientist, Center for Genomics of Neurodegenerative Disease at NYGC

- Analysis of post-mortem samples
 - pH/RIN
Speaker: Lyle Ostrow, MD, PhD, Assistant Professor of Neurology and Pathology at Johns Hopkins University School of Medicine
 - Splicing
Speakers: Delphine Fagegaltier, PhD, Staff Scientist, Center for Genomics of Neurodegenerative Disease at NYGC
Phaedra Agius, PhD, Senior Bioinformatics Scientist at NYGC
 - ALS Biomarkers in cell-free DNA
Speaker: Barbara Celona, PhD, Molecular and Cell Biology Specialist at UCSF

10:15am-10:30am

Coffee Break
(*1st Floor Cafeteria*)

10:30am-12:00pm

NYGC ALS Consortium Updates – continued

- Retroelements
Speakers: Molly Hammell, PhD, Associate Professor of Genomics at Cold Spring Harbor Laboratory
Avindra Nath, MD, Clinical Director of the National Institute of Neurological Disorders and Stroke (NINDS) at the NIH
- Spatial Transcriptomics
Speaker: Silas Maniatis, PhD, Staff Scientist, Center for Genomics of Neurodegenerative Disease at NYGC
- Spatial Transcriptomics in Human Post-Mortem Tissue
Speaker: Jenna Gregory, PhD, ECAT SCREDS Clinical Lecturer and Honorary StR in Histopathology, The University of Edinburgh

12:00pm-1:00pm

Lunch

Last Updated: June 26, 2018

(1st Floor Cafeteria)

- 1:00pm-1:30pm Measuring Progression in ALS
Speaker: Ammar Al-Chalabi, MD, PhD, Professor of Neurology and Complex Disease Genetics, Kings College London; Director, King's MND Care and Research Centre
- 1:30pm-3:00pm Presentations from industry: Analytics
Moderator: Lucie Bruijn, PhD, MBA, Chief Scientist, ALS Association - Research
- GNS Healthcare
Speaker: Diane Wuest, PhD, Director of Precision Medicine Initiatives at GNS Healthcare, Inc.
 - Origent Data Sciences
Speaker: Dave Ennist, PhD, MBA, Chief Science Officer at Origent Data Sciences
 - BenevolentAI
Speaker: Mark Rackham, PhD, Drug Discovery Scientist at BenevolentAI
 - Sage Bionetworks
Speaker: Ben Logsdon, PhD, Director of Neurodegenerative Research at Sage Bionetworks
 - Discussion
- 3:00pm Closing Remarks
Lucie Bruijn, PhD, MBA, Chief Scientist, ALS Association – Research
- 4:00pm-6:00pm Greater New York Area ALSA Clinics Discussion (for ALSA Clinics only)
Moderator: Kristen Cocoman, President & CEO, The ALS Association Greater New York Chapter
- How to encourage participation in the ALS Consortium
 - Multicenter IRB
 - Clinical Research Coordinator/Research Nurse Support

Guest Wireless

Network Name: NYGC-Guest
Username: nycgguest
Password: welcome101