



Newborn Screening & Sequencing for Myotonic Dystrophy Mini-Symposium 2025

The RNA Institute, University at Albany, LSRB, 1400 Washington Ave, Albany NY 12222

Day 1 Thursday February 13th, 2025

Check in after 3PM at the Hilton Garden Inn, 1389 Washington Ave, Albany NY 12206

7:15 – 9:15 PM Welcome dinner- Athos Restaurant, 1814 Western Ave, Albany, NY 12203

Day 2 Friday February 14th, 2025

See attached map for the RNA Institute in the Life Sciences Building on the UAlbany campus. Talks will be in the D'Ambra Auditorium, closed session in the RNA Conference Room.

- 8:00 8:30 AM Coffee, yogurt, fruit & pastries D'Ambra Auditorium
- 8:30 9:00 AM Welcome, Introduction to Myotonic Dystrophy and Therapeutic Landscape Andy Berglund, PhD Professor, Director of the RNA Institute Co-Director, Center of Excellence in RNA Research and Therapeutics University at Albany, Albany NY Andy Rohrwasser, PhD, MBA Chief Scientific Officer, Myotonic Dystrophy Foundation Oakland, CA
- 9:00 9:30 AM Introduction to Newborn Screening: How and Why Now? *Andy Rohrwasser, PhD, MBA* Chief Scientific Officer, Myotonic Dystrophy Foundation Oakland, CA
- 9:30 10:00 AM Introduction to Congenital Myotonic Dystrophy Nicholas Johnson, MD, MSc, FAAN Professor, Director of the Center for Inherited Muscle Research Virginia Commonwealth University, Richmond, VA
- 10:00 10:15 AM Coffee break
- 10:15 10:45 AMNICU Sequencing: Ultrafast Solution: Scientific Evidence, Economic Sense
Stephen Kingsmore, MD, DSc
President/CEO of Rady Children's Institute for Genomic Medicine
San Diego, CA







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Day 2 Friday February 14th, 2025 continued

| 10:45 – 11:15 AM | Pilot Study: Towards Population Wide Sequencing Wendy Chung, MD, PhD |
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| | Chief of Pediatrics, Boston Children's Hospital |
| | Professor, Harvard Medical School, Boston MA |
| 11:15 – 11:45 AM | Newborn Sequencing in Public Health: How would it work in NY? |
| | Michele Caggana, ScD, FACMG |
| | Deputy Director, Division of Genetics |
| | Director, Newborn Screening Program |
| | Department of Health, Wadsworth Center, Albany NY |
| 11:45 – 12:30 PM | Lunch & Discussion |
| | LSRB 1143 |
| 12:30 – 1:00 PM | Rapid Advance in Analysis and Interpretation; Opportunities in EHR mining - |
| | before population wide screening? |
| | Mark Yandell, PhD |
| | Professor, Director Eccles Institute Bioinformatics Program |
| | Technical Director, Utah Genome Project |
| | The University of Utah, Salt Lake City, UT |
| 1:00 – 1:30 PM | Potential Positive Outcomes for Newborn Screening for Myotonic Dystrophy |
| | John W. Day, MD, PhD |
| | Professor, Neurology, Pediatrics and Pathology |
| | Director, Neuromuscular Division and Clinics |
| | Stanford Medicine, Palo Alto, CA |
| 1:30 – 3:00 PM | Coffee and Next Steps – Closed session |
| | Summary and Implementation Opportunities for Myotonic Dystrophy |
| | By invitation only. RNA Conference Room LSRB2033C. |
| | Depart for airport/train station |

