

ALS/MND NHC ANNUAL MEETING AGENDA

DAY 1

Monday, February 24, 2025

9:00 – 12:00	REGISTRATION
9:00 – 10:00	BREAKFAST
10:00 – 10:05	WELCOME <i>Alex Sherman</i>
10:05 – 11:00	NHC: A YEAR IN REVIEW AND UPDATES Introduction of New Sites <i>Terry Heiman-Patterson + Investigators</i>
11:00 – 12:15	KEYNOTE LECTURE Causal AI-led Precision Medicine, Repurposing and Rapid Validation Strategies for ALS <i>Dr. Steve Gardner, CEO, PrecisionLife, Oxford UK</i>
12:15 – 12:30	BREAK
12:30 – 1:30	REGULATORY LANDSCAPE FOR REAL-WORLD DATA, NATURAL HISTORY STUDIES, AND DATA SHARING <i>Alex Sherman, Natalia Tarasenko</i> Review of NHC Practices, GDPR, Data Requests and Sharing. Conference Group Discussion: Conference Participants
1:30 – 2:30	LUNCH
2:30 – 4:00	INDUSTRY ADVISORY PANEL How My Company Plans to Benefit from RWD/RWE <i>Industry Supporters and Advisors</i> <i>Moderators: Terry Heiman-Patterson, Alex Sherman</i>
4:00 – 4:15	BREAK
4:15 – 5:30	BLITZ-REVIEW: ALS NATURAL HISTORY RESEARCH PRESENTATIONS/PROPOSED PROJECTS/PUBLICATION IDEAS <i>Site Investigators, Industry Partners</i>
5:30 – 6:00	AWARDS
7:00	DINNER

DAY 2

Tuesday, February 25, 2025

9:00 – 12:00	REGISTRATION
9:00 – 10:00	BREAKFAST
10:00 – 11:15	PATIENT AND CAREGIVER PERSPECTIVE ON THE NHC EFFORTS Patient Advisory Panel <i>Moderators: Allison Bulat, David Walk</i>
11:15 – 11:30	BREAK
11:30 – 1:00	SCIENTIFIC PANEL ML/AI in Drug Discovery and Clinical Research <i>Industry Supporters and Advisors</i> <i>Moderators: Alex Sherman, Thomas Meyer</i>
1:00 – 2:00	LUNCH
2:00 – 3:30	BLITZ-REVIEW PART 2: ALS NATURAL HISTORY RESEARCH PRESENTATIONS/PROPOSED PROJECTS/PUBLICATION IDEAS <i>Site Investigators, Industry Partners</i>
3:30 – 4:00	CONSORTIUM FUTURE DIRECTION, WRAP UP/NEXT STEPS
4:00	ADJOURNED