



## Annual Alliance Meeting November 25, November 30 - December 2, 2020

*\*all times are shown in Eastern Standard Time (New York)\**

November 25		
6:00 – 7:30 AM	ALS Canada Patient Journey	Lisa Marchitto, Tammy Moore, Ian Chalmers & Iffat Jokhio

November 30		
7:00 - 7:05 AM	Welcome from Alliance Chair	Calaneet Balas
7:05 - 7:10 AM	Welcome from Program Chair	Tammy Moore
7:10 - 7:30 AM	The Australian Summit for MND Research: A collective impact approach to tackling MND	Gethin Thomas
7:30 - 7:50 AM	Zoom Talks with ALS/MND World Experts: A Story of Success during the Pandemic	Pablo Aquino
7:50 - 8:10 AM	Using a Design-Build Approach to Improve International ALS Research News Access in Italy	Silverio Conte
8:10 - 8:20 AM	Small Group Discussion	
8:20 - 8:45 AM	Scientific Advisory Council Q&A	David Taylor (moderator), Gethin Thomas, Nick Cole & Kuldip Dave
8:45 - 8:55 AM	Small Group Discussion	
8:55 - 9:00 AM	Housekeeping + Wrap Up	
9:00 - 9:15 AM	<b>Break</b>	
9:15 - 9:20 AM	Welcome Back from Program Chair	Nick Goldup
9:20 - 9:35 AM	Leveraging Digital Inclusion to Increase Access to Programs and Services	Leslie Ryan
9:35 - 9:50 AM	Supporting the Young Caregiver	Jodi O'Donnell-Ames
9:50 - 10:15 AM	Small Group Discussion	
10:15 - 10:30 AM	The Use of Statistics for Awareness	Lee Millard

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10:30 - 10:45 AM	Quality of care and adherence in ALS in Russia	Gleb Levitsky
10:45 - 11:10 AM	Small Group Discussions	
11:10 - 11:15 AM	Wrap Up	

December 1		
7:00 - 7:05 AM	Welcome Back to Day 2	
7:05 - 7:45 AM	Cystic Fibrosis, A Comparative Case study	Dr. John Wallenburg, Kelly Grover, David Ramsden & Tammy Moore
7:45 - 8:00 AM	How ALS Liga Belgium looks to the future	Evy Reviere
8:00 - 8:15 AM	ALS doesn't stop, neither did we – how COVID-19 helped us challenge the status quo in community engagement	Natalie Russell
8:15 - 8:30 AM	Re-aligning Care during the COVID-19 Crisis and lessons learnt	Nick Goldup
8:30 - 8:45 AM	Meeting the Challenge of ALS During COVID-19	Andrea Pauls Backman
8:45 - 9:00 AM	Home Influenza Immunization during COVID-19	Francisco Rotta
9:00 - 9:15 AM	<b>Break</b>	
9:15 - 11:15 AM	ALS/MND Connect - <i>Facebook Live</i> , Q&A	Nick Cole (Chair), Adam WR, Jinsey Andrews, Chris McDermott, Janice Robertson & Ludo Van Den Bosch

December 2		
7:00 - 7:05 AM	Welcome	
7:05 - 7:20 AM	The Person w ALS & the revocation of Informed Consent pursuant to Law 219/2017	Grazia Micarelli
7:20 - 7:35 AM	ALS Focus: A new survey program informed by people with ALS and caregivers	Sarah Parvanta
7:35 - 7:50 AM	Naiveté is a Superpower	Stuart Moss
7:50 - 8:00 AM	ITAC Update	Nick Goldup
8:00 – 8:15 AM	UCL APP Project	TBD
8:15 – 8:30 AM	Communications Decision Tree	John Costello
8:30 – 9:00 AM	Small Group Discussions	
9:00 - 9:15 AM	<b>Break</b>	

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9:15 - 11:00 AM	Roundtable – The Patient Journey	
11:00 - 11:15 AM	Next year in Basel	
6:00 - 6:05 PM	Welcome to Our Late Session	
6:05 - 6:25 PM	A Review of the Alliance Website by the PCAC and Recommendations Members Can Use on Their Own Websites	Sara Feldman & Phil Green
6:25 - 6:45 PM	Who said it can't be done? When working as one brings great results - AM4MND	Kathy Nightengale
6:45 - 7:00 PM	Multinational Public Policy in ALS/MND	Jerry Kurent
7:00 - 7:20 PM	Podcasting!	
7:20 – 7:35 PM	TBD	
7:35 – 7:55 PM	Reducing ALS Time to Diagnosis	Jill Yersak, Ph.D
7:55 - 8:00 PM	Next Year in Basel	

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