



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 – 11:15 AM EST		
7:00 – 9:00 AM	Welcome from Alliance Chair	Calaneet Balas
	Welcome from Program Chair	Tammy Moore
	The Australian Summit for MND Research: A collective impact approach to tackling MND	Gethin Thomas & Bec Sheean
	Zoom Talks with ALS/MND World Experts: A Story of Success during the Pandemic	Pablo Aquino
	Using a Design-Build Approach to Improve International ALS Research News Access in Italy	Silverio Conte
	Scientific Advisory Council Q&A	David Taylor (moderator), Gethin Thomas, Caroline Ingre, Nick Cole & Kuldip Dave
9:00 - 9:15 AM	Break	
9:15 – 11:15 AM	Leveraging Digital Inclusion to Increase Access to Programs and Services	Leslie Ryan
	Supporting the Young Caregiver	Jodi O'Donnell-Ames
	The Use of Statistics for Awareness	Lee Millard
	Quality of care and adherence in ALS in Russia	Gleb Levitsky

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

December 2 7:00 – 11:15 AM EST		
7:00 - 9:00 AM	Welcome	
	The Person w ALS & the revocation of Informed Consent pursuant to Law 219/2017	Stefania Bastianello
	ALS Focus: A new survey program informed by people with ALS and caregivers	Sarah Parvanta
	Naiveté is a Superpower	Stuart Moss
	ITAC Update	Nick Goldup
	UCL APP Project	Jessica Hong and Richard Cave
	Communications Decision Tree	John Costello
9:00 - 9:15 AM	Break	
9:15 - 11:15 AM	Design Workshop: The Patient Journey Applied	
	Next year in Basel	

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**December 2 Continued
6:00 – 8:00 PM EST**

6:00 – 8:00 PM	Welcome	
	A Review of the Alliance Website by the PCAC and Recommendations Members Can Use on Their Own Websites	Sara Feldman & Phil Green
	Who said it can't be done? When working as one brings great results - AM4MND	Kathy Nightengale
	Multinational Public Policy in ALS/MND	Jerry Kurent
	Connecting ALS: Reaching New Audiences Through an Emerging Media Platform	Mike Stephenson, Jeremy Holden
	Reducing ALS Time to Diagnosis	Jill Yersak, Ph.D
	Next Year in Basel	

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