



Alliance Meeting Agenda

November 22 & 23, 2021

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

November 22		
7:00 – 10:25 AM		
Kick-off		
7:00 – 8:20 AM	Welcome from Alliance Chair	Calaneet Balas
	March of Faces	
	Welcome from Program Chair	Gudjon Sigurdsson
	Cytokinetics' Virtual Tribute Video	
	Fundamental Rights of People Living with ALS/MND	Angelique van der Litt, Jessica Mabe & Cathy Cummings
	The IMPACT ALS survey: comparison of EU and US data	Evy Reviere & Mark Heverin
8:20 – 8:35 AM	Break	
8:35 – 10:25 AM	Spinal Muscular Atrophy (SMA) Experience	
	The Experience of Persons with Locked-in Syndrome: insights from an ongoing study	Yukiko Himeno, Fernando Vidal, Tatsuya Mima & Yumiko Kawaguchi
	Networking	
7:00 – 10:55 PM		
Thought Provoking		
7:00 – 8:50 PM	Welcome Back	
	Online Interactive Decision Support Resources: My ALS Decision Tool™	Lauren Webb
	thinkALS – A user-friendly and comprehensive ALS diagnosis and referral tool for general neurologists	Jill Yersak
	Say Through Eyes	Hitomi Hasebe & Katsushi Tamaki
	Diversity in ALS/MND "I Heard It's Not Common in Black People": Identifying and Understanding Lived Experiences of Black people with ALS	Chelsey Carter
	Genetic diversity in ALS: an African perspective	Jeanine Heckmann
8:50 – 9:05 PM	Break	



Supporting PALS & CALS		
9:05 – 10:55PM	Improving Online Caregiver Training for ALS and Complex Fragile Patients Using Design-Build in Italy	Silverio Conte
	What do the numbers tell us? Caregiver Rights	Jessica Mabe & Cathy Cummings
	ALS Caregiver Needs: Results from an ALS Focus Survey of Current and Past Caregivers	Sarah Parvanta
	A Life Purpose in ALS/MND Caregivers	Jessica Mabe, Marcela Santos & Lucy Barrera
	Networking	

November 23		
7:00 – 11:40 AM		
Research & Science		
7:00 – 9:10 AM	Welcome Back	
	Q & A with the Alliance’s Scientific Advisory Council (SAC)	SAC Representatives
	Improving Regulatory Pathways	Wendy Selig & Tammy Moore
	Advocating for research funding from government – a partnership approach	Sally Light
	Making ALS a Livable Disease by 2030	Lance Slaughter & Neil Thakur
	The ALS Association Research Strategy to make ALS a Livable Disease	Kuldip Dave & Neil Thakur
9:10 – 9:25 AM	Break	
9:25 – 11:40 AM	Workshop: Open Science	
	Looking forward to 2022	