



Alliance Meeting Agenda
November 28, 29 & 30, 2022

November 28		
CEO Welcome Reception (Invitation only)		
Welcome & Looking to the Future		
1:00 – 2:30 PM	Welcome From Alliance Chair	Calaneet Balas
	March of Faces	
	Welcome from the Program Chair	Gudjon Sigurdsson
	Using technology to plan for the future	Lori Banker-Horner & Maureen Clark
	Access, collaboration, and innovation	Daniel Vance
	Global Clinic Locator	Maureen Clark, Amanda Stanko & Pat Dolan
2:30 – 3:00 PM	Coffee Break	
Research & Science		
3:00 – 4:00 PM	Developing young carer education and support programs in South Africa	Dr. Melinda Kavanaugh, Dr. Andre Mochan, Sheila Slabber & Prof. Thobeka Nkomo
	The ALS Association strategy to increase the number of clinical trials in the ALS ecosystem	Kuldip Dave
	The registry matters: Strategies for successful engagement	Patricia Stanco
4:00 – 4:30 PM	Virtual Networking	
ALS Association Host Dinner		

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November 29		
8:00 – 9:00 AM	Annual General Meeting	
Advocacy		
9:00 – 10:30 AM	Welcome back	
	UK government investment in MND research - one year on	Sally Light
	Laying the groundwork for regulatory approval	Tammy Moore & Lauren Poplak
	Securing funding from government entities for ALS Research	Kathleen Sheehan
	ALS/MND fundamental rights survey 2021 Report from Turkey	Alper Kaya
10:30 – 10:50 AM	Coffee Break	
Organizational Development		
10:50 AM – 12:15 PM	Rebranding a much loved organisation to better deliver your message	Rachel Maitland
	New offices of ALS Liga Belgium: finally home after a long odyssey	Evy Reviere
	The public value contribution of the ALS Organisation Switzerland	Walter Brunner
	Integrating the perspective of people affected by MND/ALS in our organisation	Rachel Maitland
12:15 – 2:00 PM	Group Photo & Lunch	
Alliance Advisory Councils		
2:00 – 3:15 PM	Welcome back	
	Q & A with the Alliance’s Scientific Advisory Council (SAC)	Dr. David Taylor, Dr. Gethin Thomas, Dr. Kuldip Dave & Dr. Adriano Chio
	ITAC update	Phil Green & Blair Casey
3:15 – 3:35 pm	Coffee Break	
Programming for PALS/CALS		
3:35 – 5:20 PM	PALS & CALS Advisory Council Update	Sara Feldman, Gudjon Sigurdsson, Angelique van de Lit, Phil Green, Bruce Virgo & Felipe Ocampo

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	ALS community support assessment to improve online access to information and resources in Italy	Daisy Sproviero
	My ALS Decision Tool™ and information guides	Lauren Webb
	Beyond ALS - Scenery of a family living with public nursing services	Hitomi Hasebe & Katsushi Tamaki
Dinner		

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November 30		
7:30 – 8:00 AM	Virtual Networking	
Programming for PALS/CALS & Multi-Disciplinary Care		
8:00 – 10:00 AM	Welcome back	
	Empowering ALS community ambassadors	David Taylor & Lauren Poplak
	The Hope Bridges program	Mary Holt-Paolone
	Multi-disciplinary care – An organizational perspective	Sally Hughes, Dean Feener & Tammy Moore
	Looking forward to 2023	ALS Schweiz
ALS/MND Connect		
10:00 AM – 12:00 PM	ALS/MND Connect	Phil Green, Eugene Brandon, Dr. Caroline Ingre, Dr. Angela Genge & Dr. Colleen O’Connell
12:30 -2:00 PM	Luncheon & Keynote: The Right to a Quality of Life, Dr. Colleen O’Connell Honoring 30 Years and Celebrating PALS & CALS	
5:30 PM	ALS/MND Walk	
6:00 PM	Cytokinetics Reception	

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