



Alliance Meeting Programme December 1 – 2, 2019 Perth, Western Australia

Day 1			
8:30	Welcome and Introduction	Calaneet Balas	
	Annual General Meeting		
10:00	Morning Refreshments		
10:30	PALS & CALS Advisory Council Topic	Sara Feldman	*
10:45	Developing programmes for Children and Young People	Steve Bell	
11:00	Attention to people with ALS through social networks: This is possible! - 6 years of a successful story	Alessandra Dorça	
11:15	Interactive Virtual Forum for PALS	Pablo Aquino	
11:30	Friends4ALS- much more than a Run	Efrat Carmi	
11:45	Innovation of care in the Netherlands	Theo Meister	
12:00	Lunch		
1:00	How to make our life easier	Gudjon Sigurdsson	
1:15	How ARSLA supported caregivers	Christine Tabuenca	
1:30	Landscape Project	Calaneet Balas, Gorrit Jan Blonk, Catherine Cummings,	
2:00	Strategic Workshop on Knowledge Management for Members	Catherine Cummings	*
5:00	Networking - Break		
7:00	Dinner		
Day 2			
8:30	Members Only – Partnering with Industry	Calaneet Balas, Tammy Moore	*
9:00	Scientific Update	Dr. David Taylor, Gethin Thomas, Dave Kuldip, Nick Cole	*
9:30	The Italian ALS Patient-driven registry and The ALS Biobank: two	Christian Lunetta	

	new tools to promote and stimulate the research		
9:45	Medical Assistance in Dying (MAiD) – A Canadian perspective	Tammy Moore	
10:00	Retaining Voice Identity in ALS/MND patients leveraging new generation VOCAs	Rohan Chopra	
10:15	Group Photo		
10:15	Morning Refreshments		
10:45	TMNDA's Efforts in Promoting ALS Research	Lung Kuo	
11:00	Partnerships & Collaborations Les Turner	Andrea Pauls Backman	
11:15	Outreach of Asha Ek Hope Foundation for ALS/MND in India	Dr Hemangi Sane	
11:30	Measuring Outcomes -what evidence do we have that we are making a difference?	Sarah Wiley	
11:45	Only Love to Thaw the Freezing Heart, Promote "4+1" Care Mode	Dr. Zhangyu Zou	
12:00	Invitation to Montreal	Tammy Moore	
12:05	Lunch for Alliance		
12:05	PALS & CALS Lunch		
2:00	ALS Connect	MND Australia	
6:00	Host Dinner		

Alliance Meeting Programme Committee:

Tammy Moore, ALS Canada, Chair
Sara Feldman, The ALS Hope Foundation, USA
Gudjon Sigurdsson, MND Association of Iceland
Kiki Qu, Taiwan Motor Neuron Disease Association
Catherine Cummings, Executive Director