



Allied Professionals Forum Agenda

December 1 & 2, 2021

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

December 1		
7:00 – 11:20 AM		
Technology		
7:00 – 9:00 AM	Welcome & About the Alliance	Calaneet Balas
	Welcome from the Program Chairs	Sara Feldman & Rachael Marsden
	March of Faces	
	Person Centered Approach to Communication and Assistive Technology in ALS/MND: A Clinical Guide for Patients and Clinicians	John Costello
	Project Activate: an Android app for activating preset actions (phrases, text messages, and more) using only face gestures. Try the app at g.co/ProjectActivate	Lisie Lillianfeld
	How we built an online platform enabling PALS to find out about voice banking and submit reviews about their experience....and what happened next	Richard Cave
	Maintaining Social Connection through Augmentative Alternative Communication (AAC) Systems	Gabrielle Nicolais & Candice Lane
	UCL Projects	University College London
9:00 – 9:15 AM	Break	
Genetics		
9:15 – 10:50 AM	Allied Professional Award	
	A PALS' View on Genetics	Paula Webb
	Genetics Roundtable Outcomes	Kristiana Salmon
	Ethical Considerations for Genetics	Nita Farahany & Kristiana Salmon
	Perspectives on Clinical Trials: A View from the Clinic	Sara Feldman
10:50 – 11:20 AM	Networking & Poster Presentations	



7:00 – 11:10 PM		
Multi-Discipline		
7:00 – 9:05 PM	Welcome Back	
	Developing information about end-of-life care and motor neurone disease: lessons learned from the United Kingdom and Australia	Ben O'Mara & Kaye Stevens
	Voice Banking – Team Gleason	Phil Green & Blair Casey
	Voice Banking - Google	Bob McDonald & Julie Cattiau
	Voice Banking - Microsoft	Bernice You & Edward Un
	Neck Weakness in MND: An Investigation of Prevalence and Physiotherapy Management - A Retrospective Descriptive Study	Timothy Sheehy
	Exploring Action Plans to optimise Community Respiratory Care	Vivienne Travlos & Leah Epton
9:05 – 9:20 PM	Break	
Resources		
9:20 – 10:40 PM	Luka and the Lights	Melinda Kavanaugh & Sasha Groen
	thinkALS – A user-friendly and comprehensive ALS diagnosis and referral tool	Jill Yersak
	Online Interactive Decision Support Resources: My ALS Decision Tool TM	Lauren Webb
	Genetic counselling and diagnostic genetic testing for ALS/MND and FTD: outcomes of a modified Delphi Consensus Survey	Ashley Crook
10:40 – 11:10 PM	Networking & Poster Presentations	



December 2		
7:00 – 11:20 AM		
Quality of Life		
7:00 – 8:50 AM	Welcome back	
	Doing Research? Tools to do research for Allied Professionals	Helen Walthall
	Interpreting end-of-life experiences of the person with motor neurone disease	Denise Andrea Harris
	Can the use of virtual reality technology support wellbeing and quality of life in patients with Motor Neurone Disease	Malaika Ghosh
	I would rather die from sex than ALS/MND	Gudjon Sigurdsson
	Exploring the acceptability of an online, self-help psychological intervention for MND	Cathryn Pinto
	PALS view on Multi-Disciplinary Care	Jessica Mabe & Cathy Cummings
8:50 – 9:05 AM	Break	
Support		
9:05 -10:50 AM	Towards family-centered ALS care: Development of a guide for ALS care professionals on how to support parents and children in families living with ALS	Marion Sommers-Spijkerman
	The experience of having a spouse with MND – from diagnose until death: A qualitative study	Solveig Haraldsdóttir Helga Jónsdóttir Marianne Elisabeth Klinke
	Panel: Caregiving	Melinda Kavanaugh, Jessica Mabe & Bugyeong Son
	Looking forward to 2022	
10:50 – 11:20 AM	Networking & Poster Presentations	