Action Duchenne
2026 Community Summit Agenda

DAY 1

Friday, 13th Nov	11:00-12:00	12:00-13:00	13:00-13:30	13:30-14:30	14:30-15:30	15:30-15:45	15:45-16:45	16:45-17:45	19:30-22:00
KNOWLEDGE (Room 17)	**Registration and meet the team and other families** (The Street)	**Lunch and Networking** (Fifty The Street, Business Lounge 1 & 2 and Carney & Scott's)	**Welcome** (Rooms 14 &16)	Duchenne, Clearly Explained: What It Is and What It Means ***Michela Guglieri*** ***Anna Sarkozy***	Duchenne Carriers: Understanding the Genetics and Supporting Mental Wellbeing ***Anna Sarkozy*** ***Uruj Anjum***	**Break**	Understanding the Duchenne Standards of Care: What Matters When ***Michela Guglieri***	Coordinating Care in Adulthood: Making the Multidisciplinary Model Work ***Lisa Cutsey*** ***Pippa Page*** ***Andrew Curtis***	**Dinner** (Rooms 1-4)
COMMUNITY (Rooms 14 &16)				Moving Forward: Living with Duchenne and Finding Your Way ***David Schonfeld***	Neurodiversity: Understanding cognitive and behavioural changes in Duchenne ***James Poysky***		More than Movement: How Sport supports Mental Health ***Rachel Morris MBE***	Your Home, Made Simpler: Adaptations and Accessibility ***Rachel Russell***	
CARE (Room 19)				Navigating Healthy Relationships for parents and carers: Tools and takeaways to build on going forward ***Mark Ashton*** ***Kelly Molkenthin*** ***Alex Berbank***	Making Everyday Life Easier: Getting the Most from Occupational Therapy ***Denise Wooding*** ***Holly Wright***		Adapting with Confidence: Supporting Comfort, Movement & Positioning (Non-Ambulant) ***Nicola Burnett*** ***José Longatto***	Navigating Education system without the stress ***Emma Simmonds*** ***Maria Sherwood***	
1:1 Information and Support sessions (Rooms 6,9,10,12)				**Rachel Morris MBE** (Accessible sport and inclusion) **Marion Main and José Longatto** (Physiotherapy support, ambulant) **Nicola Burnett** (Physiotherapy support, non-ambulant)			**David Schonfeld** (Support through life's challenges) **Emma Simmonds and Maria Sherwood** (Education, transition and future planning)		
Hangout Zone (Rooms 1-4)			**Mighty Minds (4-11 years)**	Young Engineers, Inclusive Sports, Karaoke, Gaming and Digital, Bop Don't Drop, Arts and Crafts					
			Trail Blazers (11-15 years)	Inclusive Sports, Karaoke, Gaming and Digital Technology, Interactive Physics, Billy and Andy's Music, Guest sessions					
			Yes I Can (16+ years)	Karaoke Sessions, Gaming & Digital Activities, Technology & Online Safety, Peer Conversations					
Créche (Room 18)			Créche provided by Scalliwags for under 5 years						
Wellbeing Zone/Pitstop (Room 8)			Counselling Support, Hand Massage, Mindfulness, Quiet Space, Bitesize Cognitive Behavioural Therapy, Beauty therapies, Sensory sandtray, Headsets						
Wellbeing Zone-Peer Support Groups (The Common Room)					**Dads group**		**Mums Group**	**Newly Diagnosed Family Group**	
Exhibitor Expo (Business Lounge 1 & 2)			Centrobed, Resources Table, Duchenne Family Support Group, Foundations, Karen Jessop, Muscular Dystrophy UK, Neuromuscular Centre Design & Print, Pathfinders Neuromuscular Alliance, HealthSpectrum – Rachel Morris MBE, Treloar College						

DAY 2

Saturday, 14th Nov	10:30-11:00	11:00-11:30	11:30-12:30	12:30-13:30	13:30-13:45	13:45-14:30	14:30-15:30	15:30-16:30	16:30-17:00
KNOWLEDGE (Room 17)	**Registration**	**Welcome** (Rooms 14 &16)	Duchenne Treatments Explained: Unpack the Science behind Current and Emerging Therapies ***Marianela Schiava***	Clinical Trial Updates 2026: Ongoing and Upcoming trials ***Sithara Ramdas*** ***Mariacristina Scoto***	**25 Years Alongside the Duchenne Community** (Rooms 14 &16)	**Lunch** (Fifty The Street, Business Lounge 1 and Carney & Scott's)	Navigating Steroid Therapy: A Joint Approach to Steroid Management ***Rebecca Moore*** ***Sithara Ramdas***	Beyond Childhood: Transition, Independence and Quality of Life ***Sanjeev Mann*** ***Rhys Bowler*** ***Lisa Cutsey***	**Closing Remarks** (Rooms 14 &16)
COMMUNITY (Rooms 14 &16)			Work, Purpose & Possibility: Employment for People Living with Duchenne ***Jake Hudson*** ***Sarah Lalieu*** ***Jessica Glendennan***	Driving Forward: Exploring Learning to Drive with Duchenne and accessible mobility cars ***Linda Ball***			Duchenne and Finances ***Holly Sibley*** ***Mandy Rollins*** ***Dave James***	More Than a Chair: How the Right Chair Supports Independence and Health ***Rachel Morris MBE***	
CARE (Room 19)			Supporting Movement Early: Making Physiotherapy Part of Everyday Life (Ambulant) ***Marion Main*** ***Jose Longatto***	Navigating Healthy Relationships While Living With Duchenne *(LWD Adults only! 16+ years)* ***Sanjeev Mann*** ***Jennie Williams*** ***Zoe Lloyd*** ***Jay O'Reilly***			Supporting Young People to Navigate Healthy Relationships While Living With Duchenne *(For parents)* ***Sanjeev Mann*** ***Jennie Williams*** ***Zoe Lloyd*** ***Jay O'Reilly***	Beyond Physical Health in Duchenne: Mental Health, Education and Quality of Life ***Janet Hoskin***	
1:1 Information and Support sessions (Rooms 6,9,10,12)			**David Schonfeld** (Support through life's challenges) **Rachel Morris MBE** (Accessible sport and inclusion) **Nicola Burnett** (Physiotherapy support, non-ambulant) **Emma Simmonds & Maria Sherwood** (Education, transition and future planning)				**Marion Main and José Longatto** (Physiotherapy support,ambulant)		
Hangout Zone (Rooms 1-4)		**Mighty Minds (4-11 years)**	Young Engineers, Inclusive Sports, Karaoke, Gaming and Digital, Bop Don't Drop, Arts and Crafts				DNA Kids Science Party		
		Trail Blazers (11-15 years)	Inclusive Sports, Karaoke, Gaming and Digital Technology, Interactive Physics, Rokzkool Academy, Special Guest sessions				Special Guest session with a Dinosaur enthusiast		
		Yes I Can (16+ years)	Karaoke Sessions, Gaming & Digital Activities, Technology & Online Safety, Peer Conversations				Karaoke Sessions, Gaming & Digital Activities, Technology & Online Safety, Peer Conversations		
Créche (Room 18)		Créche provided by Scalliwags for under 5 years					Créche provided by Scalliwags for under 5 years		
Wellbeing Zone/Pitstop (Room 8)		Counselling Support, Hand Massage, Mindfulness, Quiet Space, Bitesize Cognitive Behavioural Therapy, Beauty therapies, Sensory sandtray, Headsets					Counselling Support, Hand Massage, Mindfulness, Quiet Space, Bitesize Cognitive Behavioural Therapy, Beauty therapies, Sensory sandtray, Headsets		
Wellbeing Zone-Peer Support Groups (The Common Room)			**Grandparents Group**	**Non-verbal support group**				**Newly Diagnosed Family Group**	
Exhibitor Expo (Business Lounge 1 & 2)		Centrobed, Resources Table, Duchenne Family Support Group, Foundations, Karen Jessop, Muscular Dystrophy UK, Neuromuscular Centre Design & Print, Pathfinders Neuromuscular Alliance, HealthSpectrum – Rachel Morris MBE, Treloar College							