

LIVE AGENDA

ALL TIMES
IN GMT

SATURDAY 13TH NOVEMBER

TIME	SUBJECT	SUMMARY
10.00 - 12.00	Treating Duchenne and Standards of Care	The Duchenne Standards of Care is a document that sets out the care that people living with the condition should receive. You will hear from leading clinicians from around the world about a range of topics from bone health, heart drugs and use of steroids.
12.00 - 13.00	Break / social time	We know how much you gain from interaction with families, clinicians and researchers, so please head to The Meeting Place during the breaks and social time. There will be lots of opportunities to gain points in our conference game, update your details on the UK DMD registry, meet the speakers, visit the exhibitors, speak with conference partners and share support and knowledge with each other.
13.00 - 15.00	Latest clinical trial news	Professors Francesco Muntoni (UCL) and Volker Straub (Newcastle) have been the lead investigators in many of the Duchenne clinical trials within the United Kingdom and globally. They will host a session exploring the latest advances and results from clinical trials around the world, where you will have the opportunity to pose your questions to the expert panel.
15.00 - 16.00	Break / social time	Remember to head over to The Meeting Place to meet the exhibitors, speak to the experts and chat with Duchenne families.
16.00 - 18.00	Caring for older children and adults living with Duchenne	It is important that adults receive the care and services they need to stay as healthy, independent, and active as they want to be. Hear from leading experts covering topics such as; respiratory management, the benefits and challenges of tracheostomy, gastrointestinal issues and management, nutrition and diet, glucose and exercise, the benefits and challenges of PEG tubes.
19.00 - 21.00	Evening social: Living as an adult with Duchenne	After a quick break, continue the conversations raised earlier in the 'Adults standards of care' session. The evening social is a private session for adults living with Duchenne and their friends/siblings to chat and meet other like minded people. Expect frank and open conversations around topics such as relationships and dating, gaming, finding a job and living independently.
19.30 - 20.30	Music and me	Join the stars of our "Music and Me" podcast for an evening of music and chat.

SUNDAY 14TH NOVEMBER

TIME	SUBJECT	SUMMARY
10.00 - 12.00	The effects of COVID-19 on Duchenne Research and Care	The pandemic has seen huge changes in how medical care is delivered, and how drugs are developed, tested and approved. Our expert panel will be discussing the challenges and successes of the move to hybrid trials with appointments at home, virtual clinic appointments, faster regulation and increased drug manufacturing capabilities.
12.00 - 13.00	Break / social time	Remember to head over to The Meeting Place to meet the exhibitors, speak to the experts and chat with Duchenne families.
13.00 - 15.00	Dystrophin and the brain, learning and behaviour	Starting with the science, you will find out why dystrophin is in the brain, what is its purpose and what happens when it is missing. Explore learning and behavioural issues in Duchenne with our panel which includes a leading SENco and behavioural experts. Find out about how to navigate school and how to manage and support individuals and families living with the condition.
15.00 - 16.00	Break / social time	This is your last chance to clock up points in the conference game! Visit the exhibitors, update your details on the DMD Registry and share your experience with others. Great prizes are up for grabs, so make the most of the final hour's break!
16.00 - 18.00	Living with Duchenne	Hear from young people and adults living with Duchenne as they share their personal experience and knowledge. Gain practical information from our partner organisations on topics to help you navigate your journey such as housing adaptations and benefits. Get inspired and find out what is possible to help you meet your aspirations.

