

# LIVE AGENDA

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ALL TIMES  
IN GMT

## SATURDAY 23RD OCTOBER

TIME	SUBJECT	SUMMARY
14.00 - 14.05	Welcome	
14.05 - 14.15	Meet the team	
14.15 - 14.45	<b>What is Duchenne?</b>	As Duchenne is a very complicated condition, it can be really hard and often overwhelming for parents and families to gather information. This session will give you an easy to understand overview of how Duchenne happens, what it means and an introduction to the science behind the condition. We hope that you will come away feeling empowered by the knowledge you have gained, and more in control of your child or young person's care.
14.45 - 15.15	<b>Adjusting to the diagnosis</b>	When families receive the Duchenne diagnosis, it is normal to feel a range of emotions, from lonely and out of control to angry, devastated and anxious. Seeking information, knowledge, taking control, getting help and keeping positive are all key things you can do right now to reduce those feelings. In this session, you will find out realistic ways to help cope with today, and make plans for tomorrow.
15.15 - 15.30	Break 1	
15.30 - 16.00	<b>Empowering you to make informed decisions</b>	There are many decisions you will be asked to make about your child or young person's care. In this session, we will give you an overview of the topics you are likely to encounter in the first couple of years after diagnosis, including; steroids, genetic testing, diet, behaviour and learning. Once you are equipped with the facts, you will be more informed to make the right choice for your family.
16.00 - 16.30	<b>Building your team</b>	The Standards of Care in Duchenne is a document that sets out the care that people living with the condition should receive. You will find a team of professionals will grow around you and your family over the years, to help your child or young person receive this care. We will help you understand the purpose of each of the professionals, what to expect at appointments and how you can manage the team around you. Once you have a clearer picture of who is who, we hope you will feel confident and empowered to access the right care.

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16.30 - 16.45	Break 2	
16.45 - 17.15	<b>Practical tips</b>	There are many aspects to Duchenne that you learn 'as you go along'. Save your precious time by finding out what you need to know, from fellow Duchenne parents who have trodden the path before you. From getting a Blue Badge to applying for Disability Living Allowance, we will cover practical topics, along with discussing the emotional impact of Duchenne on your family, siblings, partners, friends.
17.15 - 17.45	<b>Duchenne research/ Clinical trials</b>	We know how complicated Duchenne research and clinical trials are for families. Our expert Science Communicator, Neil will give you an easy to understand overview of important techniques, such as gene therapy, stop codon readthrough, exon skipping, stem cell therapy and genome editing/CRISPR. Find out about the existing challenges and opportunities in Duchenne research and what approaches are in development.
17.45 - 17.55	<b>Fundraising and planning for the future</b>	It is important to remember that each Duchenne journey is unique, in the same way that each child, young person and adult living with Duchenne is unique. People reach different milestones at different times and you may feel ready to talk about the future sooner than others around you. When you are ready to, we are here to help you navigate your future. We are here to help you when you are ready to talk about taking action, getting involved in fundraising, volunteering, attending events. We truly are stronger together, and you can help us change the future for everyone living with Duchenne.

 **ACTION DUCHENNE  
NEWLY DIAGNOSED  
CONFERENCE 2021** 