

 ACTION DUCHENNE
INTERNATIONAL
CONFERENCE 2022
11-12 NOVEMBER 



WELCOME

Florence Boulton, National Director

#ADCONF22 – Educating, Enabling & Including

Equipping you With knowledge and Support.

Helping Young people and adults develop confidence.

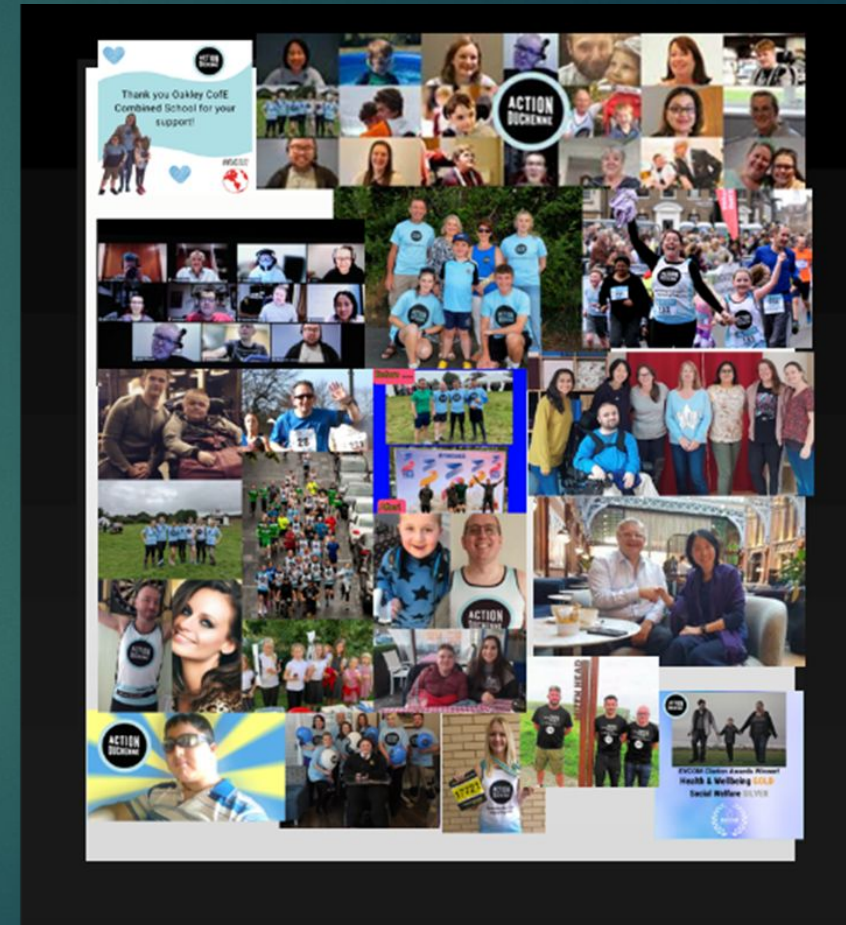
35 sessions: 4 streams Cover every aspect of life with Duchenne.

Creche + Hangout

Exhibitor Stalls

Dinner + Raffle + Band!

My team and I are here for you!



Educating, enabling and including

FRIDAY 11
NOVEMBER

CONFERENCE AGENDA

	08.30 - 09.00	09.00-09.30	09.30 - 10.30	10.30 - 10.45	10.45 - 11.45	11.45 - 12.00	12.00 - 13.00	13.00 - 14.30	14.30 - 15.45	15.45 - 16.00	16.00 - 17.00	19.00 - 23:00						
WHAT IS NEW IN RESEARCH PARIS SUITE	REGISTRATION	WELCOME REMARKS	Corticosteroids in young boys with DMD: the results of the FOR DMD study Michela Guglieri	SHORT BREAK	Update to the standards of care Michela Guglieri John Bourke Cathy Turner	SHORT BREAK	Future strategies to combat Duchenne (Pre-clinical) Dariusz C. Gorecki Dr Yung Yao Lin	LUNCH	What's in the pipeline? (beyond gene therapy) Tom Roberts Linda Popplewell	SHORT BREAK	Latest Clinical trial updates (outside of gene therapy) Volker Straub Mariacristina Scoto	DINNER						
THE DUCHENNE JOURNEY PICCADILLY SUITE			Talking to your Child about Duchenne David Schonfeld		Parent led discussion - "What I wish I had known when my child was diagnosed" Victoria Young, Gary Fegan, Linda Hawthorn		Coping with Grief and Loss David Schonfeld		Building resilience - finding ways for your family to thrive with Duchenne David Schonfeld and Panel Discussion		Exhibitor Demo Access & Mobility Late Ambulant Felix Ledger-Beadell & Product Specialists							
GROWING UP WITH DUCHENNE WESTMINSTER SUITE			Transitioning into adulthood from paediatric services Mahalekshmi Desikan		Exhibitor Demo Sleeping & Rest James Leinhardt		Storoids - the pros; cons and how to make difficult decisions Michela Guglieri Jarod Wong		Physiotherapy - Part 1, revised standards of care Part 2, fingertips to shoulder blades Marion Main Nicola Burnett Jose Longatto		Parent lead on sharing practical advice and tips - housing, adaptations, fundraising and grants Panel Discussion							
ADULTS WITH DUCHENNE MAYFAIR SUITE					Peer lead - experiences of adult care (11.00-11.45) Ravi Mehta Luke Millington Angela Stringer		Nutrition, swallowing and feeding tubes Jodi Allen Angela Reddy		Respiratory care inc tracheostomy (14-18 years) Niamh Galway		Peer lead - sex, relationships and making the most out of life with Duchenne Ravi Mehta Kelly Gordon Luis Canto E Castro							
HANGOUT ACTIVITIES 11-17 yrs TRIUMPH BAR			HANGOUT ACTIVITIES															
CRÈCHE x 2 (0 - 10yrs) MEETING ROOMS II & 12			CRÈCHE															
EXHIBITOR AREA ROTUNDA			EXHIBITOR AREA															

THANK YOU TO OUR SPONSORS:



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Educating, enabling and including

SATURDAY 12 NOVEMBER

CONFERENCE AGENDA

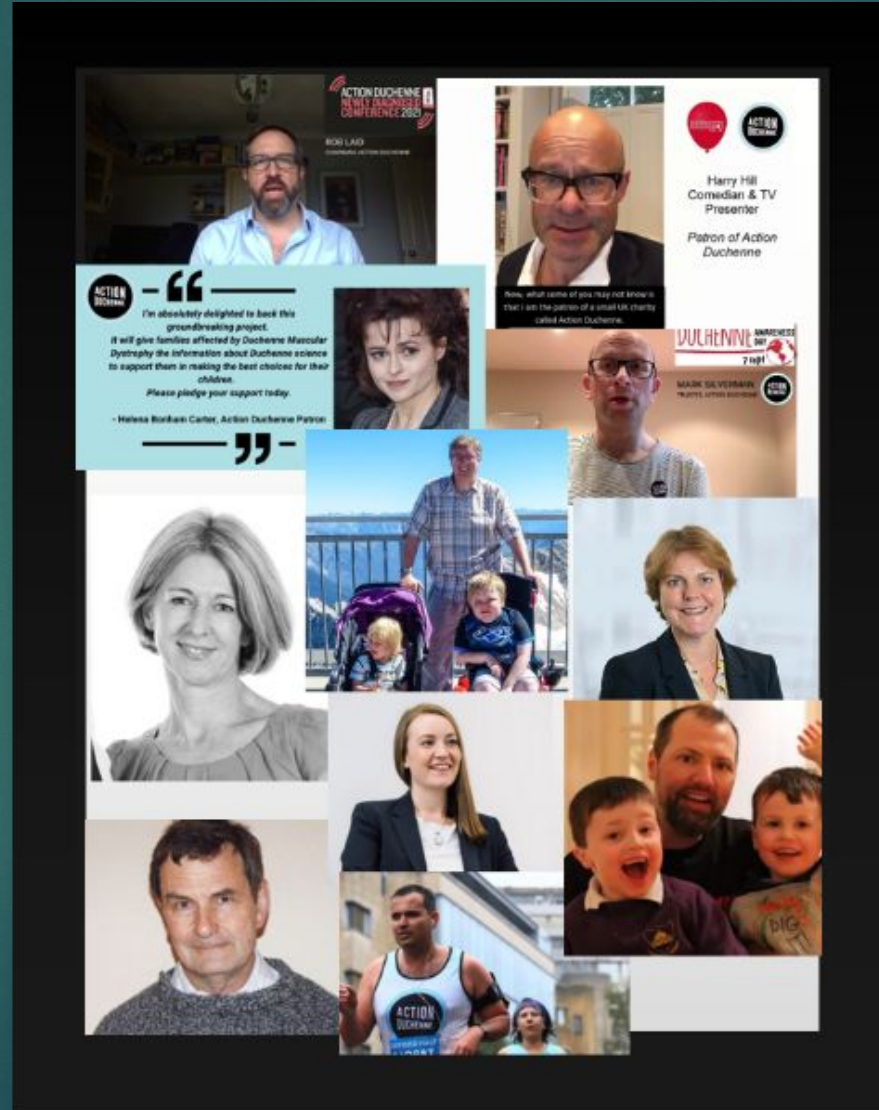
	08.30 - 09.00	09.00-09.10	09.10 - 10.30	10.30 - 10.45	10.45 - 12.00	12:00 - 12.15	12.15 - 13.00	13.00- 14.30	14.30 - 15:30	15.45 - 16.00	16.00 - 17.00	19.00 - 23:00					
WHAT IS NEW IN RESEARCH PARIS SUITE	REGISTRATION	WELCOME TO SATURDAY	Gene Therapy IOI Anemielke Rus Linda Poplewell	SHORT BREAK	What's in the pipeline? (Gene Therapy) Volker Straub Francesco Muntoni	SHORT BREAK	Latest Clinical trial updates (Gene therapy) Volker Straub Francesco Muntoni Emma Heslop	LUNCH	Gene Therapy Panel Q&A Volker Straub Francesco Muntoni Emma Heslop Anemielke Rus Linda Poplewell	SHORT BREAK	Q&A with Pharmaceutical companies Volker Straub and Francesco Muntoni (Moderators)	CONFERENCE ENDS					
THE DUCHENNE JOURNEY PICCADILLY SUITE			Learning and Behaviour in Duchenne - coping with Autism, ADHD and other comorbidities James Peysky		Parent and expert lead - sharing experiences and advice with learning and behaviour James Peysky and Panel Discussion		School -EHCP's and inclusion Clair Warner		Exhibitor Demo Staying Active Felix Ledger-Beadell & Product Specialists		Parent lead - experiences of being a carrier, physical and emotional implications Panel Discussion						
GROWING UP WITH DUCHENNE WESTMINSTER SUITE			Bone, puberty, adrenal insufficiency: Current standards of care (09.30-10.30) Jarod Wong		Exhibitor Demo Access & Mobility Late Ambulant Felix Ledger-Beadell & Product Specialists		SHORT BREAK		Exhibitor Demo Access & Mobility Early Ambulant Felix Ledger-Beadell & Product Specialists		Siblings - lived experiences from siblings of those living with Duchenne Hazel Weaver, Duchenne Sibling Support Network		Parent led - what has worked for us Mark Silverman Simon Dadd Alex Borbank Andrew Maurice				
ADULTS WITH DUCHENNE MAYFAIR SUITE			Wellbeing, anxiety and depression in Duchenne. Accessing treatment and support Jatin Pattni Linda Bouquillon		Building peer to peer support and mentoring (11.00-12.00) Panel Discussion		SHORT BREAK		Living independently and building a care team Panel Discussion		Accessible travel Panel Discussion		Accessible Gaming Rob Sleight Sanjeev Mann				
HANGOUT ACTIVITIES 11-17 years TRIUMPH BAR			HANGOUT ACTIVITIES														
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EXHIBITOR AREA ROTUNDA			EXHIBITOR AREA														

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Rebuild, Refocus and Reinvent



Bringing support, care and education to life...

ACTION DUCHENNE **NEWLY DIAGNOSED FAMILY ONLINE EVENT**

INFORMATION
Build a strong foundation of knowledge about Duchenne. Ideal for recently diagnosed families, and their team of professionals

SUPPORT
Meet the Action Duchenne team and other Duchenne families.

UNDERSTANDING
Get up to speed with 'the basics' before the main Action Duchenne International Conference 11 & 12 November in Leicestershire, UK

14:00 - 17:00 GMT SATURDAY 22 OCTOBER 2022 | ONLINE VIA ZOOM
ALL WELCOME | REGISTRATION IS FREE



<p>Support for parents through diagnosis</p> 	<p>Help to make more informed decisions</p> 	<p>Peer-to-peer support groups; helping people to help others</p> 	<p>Support for young people transitioning to adulthood</p> 
<p>Bereavement support for families at end of life</p> 	<p>Funding our research strategy</p> 	<p>Maintaining the UK DMD Registry</p> 	<p>Campaigning for access to and improvements in standards of care</p> 

SUPPORT FOR DUCHENNE PARENTS & CARERS

FRIDAYS 10AM ONLINE




SEIZING CONTROL: EMPOWERING ADULTS BY TRANSFORMING TRANSITION

YES I CAN

TRAVELLING

12TH OCTOBER 7PM ONLINE

[HTTPS://BIT.LY/YESICANONLINE](https://bit.ly/yesicanonline)



Duchenne Research Fund

JoiningJack

Duchenne Now

DUCHENNE UK

Alex's Wish His wish our mission

ACTION DUCHENNE

harrisons fund

Muscular Dystrophy UK

NICE National Institute for Health and Care Excellence

ACTION DUCHENNE

Muscular Dystrophy UK
Fighting muscle-wasting conditions

abilities in me

Genima Keir

Out Now!



Sporting Bears Motor Club
Driving for Charity



ACTION DUCHENNE

Demelza
Hospice Care for Children



All-through Support in Numbers

Supporting families by building online peer-to-peer support groups:

- 1180 support calls made/meetings held
- 337 video support calls made
- 598 individuals supported
- 21 group support meetings held
- 17 peer to peer support groups established



Supporting parents through diagnosis & helping families make informed decisions:

- 21 newly diagnosed families offered support
- 20 Science on Tour events successfully delivered across the UK and Ireland
- 5 hospital contacts made to develop vital support for families
- 68 new contacts made
- 391 people registered for a SOT workshop



Supporting young people transitioning to adulthood:

- 45 young people living with Duchenne have signed up to a 'Yes I Can' event
- 10 young people on average attending each online session
- 12 online sessions have been successfully delivered
- 12 young people and their parents/carers have attended a 'Yes I Can' residential weekend at the Calvert Trust in Exmoor
- 100% of young people said that meeting others living with Duchenne was the highlight of their residential weekend



THANK YOU

Our vision A world where lives are no longer limited by Duchenne muscular dystrophy.

Your support With you we can help even more families in the UK and across the world.

Together We can change and improve the lives of thousands of young people and adults living with Duchenne.

Thank you Thanks to all of our generous supporters. You made the conference happen.



Bringing our whole community together



Sporting Bears Motor Club
Classic and Sports Cars Driving for Charity

Lottery backs 'All-through Support' for Duchenne

Action Duchenne receives peer-to-peer support grant



Supporting parents through diagnosis and impossible decisions

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Action Duchenne receives funding for transition project,

