

The Conference will take place over two days on Friday November 12th and Saturday November 13th at the Hilton Hotel Canary Wharf in London from 9.00am until 6.00pm.

There will be key note speakers, major presentations, breakout sessions and workshops. The final agenda will be published on our website.

Come to the Gala Dinner on the Friday evening at 7.30 pm with presentations to our Genius Duchenne volunteers, comedians, auctions and more. There is a Conference creche for younger children organised by expert professionals at Jack in the Box.

For a special rate deal for accommodation and details of transport to the Hilton go to: www.londoncanarywharf.hilton.com/actionduchenne



Dr John Bourke



Dr Mike Gait



Professor Kate Bushby



Professor Steve Wilton



Professor Dame Kay Davies



Professor Veronica Hinton



Dr Steve Shrewsbury



Professor Mehul Dattani



Supported by Genzyme and Care Management Services



CONTACT US:

Action Duchenne
Epicentre
41 West Street
London
E11 4LJ
Tel: 0208 556 9955
Email: kelly@actionduchenne.org
Web: www.actionduchenne.org

Registered Charity No: 1101971



IT'S TIME TO STOP WASTING! 8th International Annual Duchenne Conference

Friday 12th November 9am – 6pm Gala Dinner at 7.30pm
Saturday 13th November 9am – 6pm

Register online at
www.actionduchenne.org/conference2010



**Hilton Hotel
Canary Wharf London**

FRIDAY 12 NOVEMBER

Time	8.00 - 8.50	9.00 - 9.30	9.30 - 10.00	10.00 - 10.30	10.30 - 11.00	11.00 - 11.30	11.30 - 12.00	12.00 - 12.30	12.30 - 1.00	1.00 - 1.45	1.45 - 2.00	2.00 - 2.30	2.30 - 3.00	3.00 - 3.30	3.30 - 4.00	4.00 - 4.30	4.30 - 5.00	5.00 - 5.30	5.30 - 6.00	6.00 - 6.30
Main Hall Presentations - Quayside Suite	Registration Tea & Coffee	Discussion - Will the Government's Health Reforms improve Standards of Care for young people living with Duchenne? Views from the Government and examples of best practice care for Duchenne Chair - Nick Catlin CEO Action Duchenne - Panel: Professor Kate Bushby (Newcastle), Dr Jes Rahbek (Denmark), Dr Adnan Manzur (GOSH), Stuart Wickison, Invited DH speaker				Coffee	Caring for the Heart Dr John Bourke Newcastle	New methods for detailed genetic analysis Dr Steve Abbs Guys Hospital London	Autonomy - the Transition to Adulthood 14 - 19 years Emily Ballard Guys and St Thomas' London, Gordon McClurg Care Management Services and Dr Jes Rahbek (Denmark)	Lunch	Research Updates Nick Catlin AD CEO	Physiotherapy - Exercise and Fitness Marian Main Great Ormond Street Hospital London	Respiratory Care for Duchenne Dr Nick Hart Lane Fox Unit London	Bone protection for children with DMD treated with corticosteroids Dr Ros Quinliven Oswestry	Duchenne, ADHD, Dyslexia and Autism Professor Veronica Hinton Columbia University USA, Dr James Poysky USA	Coffee	Pilot Trials Now Dr George Vella Charley's Fund	Melatonin as a treatment for Duchenne Dr Dario Acuña-Castroviejo University of Granada Spain	Laminin 111 Dr Brad Hodges and Richard Cloud Prothelia USA	ACE - 031 Dr Ken Attie Shire and Acceleron
Meeting Room 7 (40)	Registration Tea & Coffee	Genius Project Film Master Classes - Young people 16 - 25 - Final pro Cut editing skills, creative interest, Team Building, Camera and Sound Recording, Evaluation of a campaign, budgeting and how to storyboard Industry Professionals who have worked with the Barbican, Edinburgh Festival, Talawa Theatre Productions and the Massive Attack Meltdown Festival (Southbank Centre) to name a few																		
Meeting Room 2 (25)	Registration Tea & Coffee	Understanding Duchenne Research - the basic facts for beginners Dr Karl Bettelheim Action Duchenne Scientific Advisor					Care NMD Sunil Rodger Newcastle University	Caring for the Heart Dr John Bourke Newcastle			Autonomy - the transition to Adulthood 14 - 19 years Emily Ballard, Gordon McClurg and Dr Jes Rahbek	Respiratory Care for Duchenne Emily Ballard Lane Fox Unit London	Steroids and bone protection Ros Quinliven							
Meeting Room 3 (40)	Registration Tea & Coffee	Speaking to your Children and the Community about Duchenne Dr David Schonfeld Cincinnati Children's Hospital USA					Building Action Duchenne's Campaigns to improve Standards of Care Chair Nick Catlin, National Advocacy Council members	DMD Registry Steering Committee Meeting Chair Dr Steve Abbs			Join the DMD Registry - UK patient registry for clinical trials Angela Stringer	Physiotherapy - Exercise and Fitness Marian Main Great Ormond Street Hospital London			Problems at School? Veronica Hinton, James Poysky and Janet Hoskin					
Meeting Rooms 4&5		Creche (under 12 yrs)																		

SATURDAY 13 NOVEMBER

Time	8.00 - 8.50	9.00 - 9.30	9.30 - 10.00	10.00 - 10.30	10.30 - 11.00	11.00 - 11.30	11.30 - 12.00	12.00 - 12.30	12.30 - 1.00	1.00 - 1.45	1.45 - 2.00	2.00 - 2.30	2.30 - 3.00	3.00 - 3.30	3.30 - 4.00	4.00 - 4.30	4.30 - 5.00	5.00 - 5.30	5.30 - 6.00	
Main Hall Presentations - Quayside Suite	Registration Tea & Coffee	Human genome at 10: Patient trials for Duchenne Professor Dame Kay Davies University of Oxford	Exon skipping - improving delivery and efficiency Professor Steve Wilton Western Australia, Dr Mike Gait MRC lab of molecular biology Cambridge and Dr Aurelie Goyenville University of Oxford		Coffee	How will the regulatory framework help to support the development of new gene therapies for Duchenne? Dr Pavel Balabanov European Medicines Agency	Improving clinical trial design and outcomes Professor Kate Bushby Newcastle and Treat NMD	Duchenne Research in China Professor Haifang Yin Tianjin Research Centre of Basic Medical Science Tianjin Medical University	Endocrine issues and long term steroid use Professor Mehul Dattani Great Ormond Street London	Lunch	Research Updates Nick Catlin AD CEO	Rare Diseases and personalised medicines Pdraig Wright Vice President Clinical Neurosciences at GlaxoSmithKline	AVI 4658 Clinical Trials Dr Steve Shrewsbury AVI Biopharma USA	The development of Idebenone (Catena) for the treatment of DMD Dr Raffaele Robino Santhera	Coffee	PRO044 - extending the family Dr Giles Campion Prosensa Netherlands	Micro-dystrophin gene therapy: the next generation Professor George Dickson Royal Holloway College London	Ataluren - progress of clinical trials Dr Stuart Peltz CEO PTC	BMN 195 Clinical trial progress Dr Jackie Walling Biomarin	
Meeting Room 7 (40)	Registration Tea & Coffee	Genius Project Film Master Classes - Young people 16 - 25 - Final pro Cut editing skills, creative interest, Team Building, Camera and Sound Recording, Evaluation of a campaign, budgeting and storyboard Industry Professionals who have worked with the Barbican, Edinburgh Festival, Talawa Theatre Productions and the Massive Attack Meltdown Festival (Southbank Centre) to name a few																		
Meeting Room 2 (25)	Registration Tea & Coffee	Development of personalised medicines for Duchenne Chair - Dr Karl Bettelheim, Panel - Professor Steve Wilton, Dr Mike Gait and Dr Aurelie Goyenville					Working with regulatory agencies to develop new gene therapies for Duchenne Professor Kate Bushby and Dr Pavel Balabanov													
Meeting Room 3 (40)	Registration Tea & Coffee	How is Duchenne research progressing? Dr Karl Bettelheim					Talking to your Children about Duchenne for Dads Dr David Schonfeld Cincinnati Children's Hospital USA	An introduction to procedural Learning Difficulties in Children with Duchenne Professor Angela Fawcett University of Swansea and Janet Hoskin												
Meeting Rooms 4&5		Creche (under 12 yrs)																		

Information correct at time of going to press.