



Duchenne Family Support Group

A support group for families affected by Duchenne Muscular Dystrophy



National Conference to be held at

The Park Inn Hotel, North Street, York YO1 6JF

on Saturday and Sunday, 6 and 7 June 2009

**to include our Annual General Meeting at
10.30am on Saturday, 6 June 2009**



Supported by
The National Lottery[®]
through the Big Lottery Fund



Saturday, 6 June 2009

10.00 – 10.25	Registration and Coffee	
10.25 – 10.30	Welcome and Introductions	Sherri Jay, Chair
10.30 – 11.00	ANNUAL GENERAL MEETING	
11.05 – 11.15	The work of the DFSG, our current activities and plans for the future	Phillippa Farrant, Vice Chair
11.15 – 12.15	<p>WORKSHOPS</p> <p>A. Benefits</p> <p>B. Post 16 Education</p> <p>C. Respite Care</p> <p>D. Physiotherapy and Respiratory Care</p>	<p>Sarah Rush, Head of Advice Contact a Family</p> <p>Angus Collins and Simon Brown Victoria Education Centre, Poole, Dorset</p> <p>Members of the Care Team, Demelza House Children's Hospice</p> <p>Lindsey Pallant Senior Physiotherapist on the Paediatric Neuromuscular team at Leeds General Infirmary</p>
12.15 – 12.45	The work of the Neuromuscular Centre in Winsford, Cheshire and their new project in Newcastle, including a Question & Answer session at the end.	Matthew Lanham, Executive Director, and Sally Lawson, Newcastle Project Manager
12.45 – 13.30	LUNCH	
13.30 – 14.15	Non-invasive imaging in mouse and man for the development of novel approaches to therapy for Duchenne muscular dystrophy – a project supported by the Muscular Dystrophy Campaign and funded by the Big Lottery Fund. A presentation on the findings of this research project and an update on current research and clinical trials, including a Question & Answer session at the end.	<p>Professor Dominic Wells Imperial College London</p> <p>and</p> <p>Dr Penny Garrood University of Newcastle</p>
14.15 – 14.45	A presentation on the research being undertaken at Bristol University into the experiences and needs of young men with Duchenne muscular dystrophy on transition from children's to adult services, including a Question & Answer session	Prof John Carpenter, University of Bristol
14.45 – 15.15	An update from the Muscular Dystrophy Campaign	Lyn Inman Director of Care and Support Services, MDC
15.15 – 15.30	TEA and COFFEE	
15.30 – 16.30	<p>WORKSHOPS</p> <p>E. Benefits</p> <p>F. Post 16 Education</p> <p>G. Respite Care</p> <p>H. Physiotherapy and Respiratory Care</p>	<p>Sarah Rush, Head of Advice Contact a Family</p> <p>Angus Collins and Simon Brown Victoria Education Centre</p> <p>Members of the Care Team, Demelza House Children's Hospice</p> <p>Lindsey Pallant Senior Physiotherapist on the Leeds Paediatric Neuromuscular team at Leeds General Infirmary</p>
16.30 – 16.45	Review of the day and close	Sherri Jay, Chair
19.00	DINNER	

Sunday, 7 June 2009

10.00 – 10.15	TEA and COFFEE	
10.15 – 10.30	Staff from Demelza House hospice will introduce themselves and invite those who wish to speak to them on an individual basis to book a time slot. Staff will then be available throughout the morning to see people.	OR Informal visits to York Minster and the National Railway Museum
10.30 – 11.00	Neater Eater. John Foster of Neater Eater will explain how the Neater Eater works and will give a demonstration.	
11.00 – 11.30	A presentation by Chris Gilding on the work of Remap, a charity that designs custom made equipment for disabled people	
11.30 – 12.15	Dogs for the Disabled A talk by Louise Hart, Instructor – North Region, on the work of the charity, including how to apply for a dog, and a demonstration of how a dog can help	
12.15 – 12.30	Closing Remarks	Sherri Jay, Chair
12.30	LUNCH and depart	

COSTS

We are able to offer the following subsidised rates for family members of the DFSG. **The costs are per person, including children aged 15 years and over, and are applicable to immediate family members only.** Children under 15 years not sharing a family room will be charged half the subsidised rates stated below.

To attend the whole conference (including overnight accommodation)	£65 (Child rate £32.50)
(A child under the age of 15 sharing a room with parents will incur a single nominal charge of £10)	
To attend Saturday only, including dinner	£35 (Child rate £17.50)
To attend Saturday only, excluding dinner	£22 (Child rate £11)
To attend Sunday only, including lunch	£15 (Child rate £7.50)

Child Care for under 13s will be available on Saturday, but not Sunday, at a nominal charge of £5 per child

Professionals and others who are not members of the DFSG will be charged as follows:

To attend the whole conference	£120
To attend Saturday only, including dinner	£65
To attend Saturday only, excluding dinner	£45
To attend Sunday only, including lunch	£30

If you also wish to stay on the Friday night, each individual will be responsible for paying for their room. We have negotiated a price of £99 per room bed and breakfast (double occupancy) or £89 bed and breakfast (single occupancy).

BOOKING AND PAYMENT INFORMATION

Please complete the attached booking form and return it by no later than **Tuesday, 5 May 2009** to:

Ann Patterson
DFSG Secretary
6 Laburnum Road
Sandy
Bedfordshire
SG19 1HQ

Please remember to enclose your payment. Cheques should be made payable to **DFSG**. We prefer payment to be made in full at the time of booking, but we can offer the option of payment in two instalments. In this case, please enclose two cheques – one for 50% of the cost payable on receipt of the booking form, and one for 50% of the cost post dated to 29 May 2009. Unfortunately, we are unable to accept payment by credit or debit card.

Refunds in the event of cancellation of your booking can only be considered in exceptional circumstances and will be at the discretion of the Management Committee.

If you have any queries please contact Ann on 01767 680644 or e-mail ann.patterson@dfsg.org.uk

ACCOMMODATION AND TRAVEL INFORMATION

The Park Inn Hotel in North Street, York is in the centre of the city and has its own car park, which can accommodate vehicles up to medium size (there is a maximum headroom of 6' 6"). For larger vehicles, there are three disabled parking spaces at the front of the hotel. If you are travelling by rail or bus, the railway station and the bus station are both only 5 minutes walk away.

The DFSG has reserved a number of rooms for those attending the conference. Please telephone 01904 459988 to make a reservation and state clearly that you are attending the DFSG conference. The hotel has a limited number of disabled accessible rooms, but the ordinary double rooms have a reasonable circulation area for wheelchairs, and the beds have space for a portable hoist to fit underneath when transferring.

For those attending the whole conference, overnight accommodation on the Saturday night is included in your delegate fee. One child under the age of 15 can share a room with 2 adults for a single additional charge of £10 (see Costs above). Some of the rooms are interconnecting, should you require two rooms for your family. As stated in Costs above, we would reiterate that, if you also wish to stay on the Friday night, each individual will be responsible for paying for their room at a price of £99 per room bed and breakfast (double occupancy) or £89 bed and breakfast (single occupancy).

Alternative hotels nearby with disabled accessible rooms are:

Ibis Hotel	Ramada Encore Hotel
77 The Mount	Micklegate
York	York
YO24 1BN	YO1 6JG
01904 658301	01904 697600

