

Who we are

The Duchenne Family Support Group (DFSG) is a national charity run by families for families affected by Duchenne muscular dystrophy. Our small group of trustees all have direct experience of raising a young person with Duchenne. Our aim is to help support other families and ensure a good quality of life.

What we do

The DFSG helps families to come together and provide a positive, mutual support network for one another. We do this by:

- Organising days out for families
- Running holidays at accessible centres
- Putting families in touch with one another

We run a helpline, for people who need support or advice relating to any aspect of Duchenne and our members receive a newsletter four times a year.



Living and coping with Duchenne is not easy – but our members find that they can help, support and inspire one another. The boys (and few girls) really appreciate getting together and strike up supportive friendships. We celebrate their achievements in our newsletter, including sporting or academic successes, creative activities or just finding ways of having fun!



Fundraisers always needed

The work of DFSG depends upon donations and fundraising activities. We have wonderful fundraisers who support us in different ways including sponsored events, raffles, using our collecting boxes and taking part in runs such as the London Marathon. If you would like to help in any way, large or small, please contact us.

The DFSG is free to join – please send this form to DFSG, 78, York Street, London, W1H 1DP or go to www.dfsg.org.uk

Name

Address

Phone

Email

Name of person with Duchenne

Date of birth

Relationship

I am interested in:

- Joining the DFSG
- Fundraising for the DSFG
- Helping to organise events
- Joining the Committee

I would like to donate £

tick box for Gift Aid, which increases the value of your donation at no extra cost. Please make cheques payable to DFSG.

The Duchenne Family Support Group

Duchenne muscular dystrophy (DMD) is a severe and progressive muscle wasting disease. It is a genetic disorder that almost entirely affects boys, who appear normal at birth but fail to meet developmental milestones and are usually diagnosed at around the age of 3. The boys become progressively weaker and most are wheelchair users by the age of 11.



With appropriate treatment and support, many young men with DMD can live into their twenties – but there is no cure. There are about 1,500 boys and young men, and a few girls and young women, living with DMD in the UK.

“Please pass on our thanks to all those who arranged the day out. Mark is really looking forward to the next event!”



There are other charities that help families with Duchenne, for example by funding research and awarding grants for equipment. These include the Muscular Dystrophy Campaign, Action Duchenne and the Muscle Help Foundation. The DFSG is in touch with these charities and we complement their work by providing support and activities for families.

The DFSG also has input into consultations by policy makers, and professional or scientific bodies, that affect people with Duchenne and their families. For example, we respond to consultations on good practice for conducting clinical trials of potential drugs to help treat Duchenne, helping to ensure that families know what to expect and can give their informed consent.

“Thanks for pointing us in the right direction, your help has been invaluable”

Online: www.dfsg.org.uk
Twitter: @DuchenneFSG
Facebook: /TheDFSG
Email: info@dfsg.org.uk
Helpline: 0800 121 4518 – we cannot run this full time, but please leave a message if you get the answerphone and we will call you back.
78 York Street, London, W1H 1DP



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