

## Gift Aid Declaration

I wish the charity Myotonic Dystrophy Support Group to treat the enclosed amount of £ ..... as a gift aided donation. I declare that I am a UK taxpayer and wish the Myotonic Dystrophy Support Group to reclaim tax under Gift Aid on this and all future donations, understanding that I must have paid Income Tax or Capital Gains Tax equivalent to or greater than the amount claimed in the appropriate tax year.

Signed:..... Date:.....

Please return this form along with your subscription to Myotonic Dystrophy Support Group, 19/21 Main Road, Gedling, Nottingham. NG4 3HQ

### Thank you for your support.

#### Other publications available from the Myotonic Dystrophy Support Group:

- Anaesthesia and Sedation for patients with Myotonic Dystrophy
- Basic Information for Midwives
- Bowel Problems in Myotonic Dystrophy
- Congenital Myotonic Dystrophy
- Excessive Daytime Sleepiness and Myotonic Dystrophy
- Facts for patients, family members and professionals
- Myotonic Dystrophy and the Eye
- Relatives Information
- The Heart and Myotonic Dystrophy
- Why do we get new families with Myotonic Dystrophy?

Myotonic Dystrophy Support Group Helpline 0115 987 0080

**Advisors** both research and clinical enable the Support Group to offer the latest information and advise us on all aspects of understanding and clinical management of Myotonic Dystrophy.

**The Annual Conference** and AGM is held in spring/early summer.

**A newsletter** is produced for and by the Support Group. Copies are sent to subscribing members.

**Funding** As a charity we depend upon donations and the support of members, their families and friends for fundraising activities. All our administration costs and expenses are kept to a minimum.

#### Membership of the Myotonic Dystrophy Support Group

There is an annual subscription fee, currently £15 per family. Please make cheques or postal orders payable to 'Myotonic Dystrophy Support Group'.



SUPPORT GROUP

#### National Co-ordinator

Mrs M A Bowler SRN, SCM  
19/21 Main Road, Gedling, Nottingham. NG4 3HQ

Telephone Helpline: 0115 987 0080

Office Telephone/Fax Number: 0115 987 5869  
Open Tues/Wed/Thurs 9am to 1pm

Email: [contact@mdsguk.org](mailto:contact@mdsguk.org)

Website: [www.myotonicdystrophysupportgroup.org](http://www.myotonicdystrophysupportgroup.org)

**Patron:** Professor J. David Brook  
Professor of Human Molecular Genetics, University of Nottingham.

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Charity No. 1134499.

National Helpline  
0115 987 0080

Contact Families

Regional Meetings

Information Leaflets

Website

Alert Cards

Care Cards

# Myotonic Dystrophy

Myotonic Dystrophy can affect either sex and the affected parent has a 50% risk of passing the condition on with each pregnancy.

Myotonic Dystrophy is the most common muscular dystrophy of adult life. Age of onset can be from birth (Congenital Myotonic Dystrophy) to late adult onset. This genetically inherited neuromuscular condition affects one person in 8,000, and is the most variable, often involving other body systems in addition to muscle weakness and wasting. Myotonia (muscle stiffness) especially in the hands is characteristic.

This complex condition can sometimes result in a correct diagnosis being delayed or even missed.

**The Myotonic Dystrophy Support Group** offers the hand of friendship, endeavouring to reduce the sense of isolation often experienced both before and after diagnosis. We are here when you want to share concerns or need to talk with someone who understands.

**We are a self-help group** of volunteers working nationally and internationally to promote awareness of Myotonic Dystrophy and to provide information and support to individuals, families and health care professionals.

**Contact families** know much of what you may be experiencing through their own personal experiences of day to day living with this neuromuscular disorder.

**The Myotonic Dystrophy  
Support Group  
National Helpline  
0115 987 0080**

can be used for enquiries, guidance and support. We aim to respond quickly to all calls, but ask callers to remember that the trained volunteers taking the calls on the Helpline each have family members who have the condition. Delays are occasionally unavoidable.

**Regional meetings** enable members to meet together informally, with contact families.

**Information leaflets** and booklets dealing specifically with Myotonic Dystrophy and related issues are produced by the Support Group, details available on request.

**The website** provides information about the condition, research and forthcoming events. - [www.myotonicdystrophysupportgroup.org](http://www.myotonicdystrophysupportgroup.org)

**Alert cards** give immediate vital information in an emergency. These are available from the Support Group. The pocket/purse size plastic cards have space for contact details and highlight that the card holder may have difficulties associated with:

- Anaesthetics and sedation: the condition may cause an adverse reaction to commonly used anaesthetic agents.
- Extreme tiredness.
- Muscle stiffness and wasting.
- Indistinct speech.
- Abnormal heart rhythm.
- Learning difficulties.

**Care cards** are patient-held record sheets. When completed and regularly updated the care cards are a useful 'at a glance' record of clinics attended and the details of health care professionals involved in the ongoing management of the patients condition.

Please consider being a member, we value your support. Thank you.

## Myotonic Dystrophy Support Group Membership Subscription Form

**Subscription Fee is £15**

*(this covers a whole family living at the same address)*

Title:..... First Name:.....

Surname:.....

Address: .....

.....

Postcode:.....

Tel No (incl. area code):.....

Email:.....

### Payment can be made by the following methods:

**Cheque/Postal Order** made out to 'Myotonic Dystrophy Support Group' £ .....

**Standing Order/Direct Debit**, please return details so that we can acknowledge your membership.

Bank details are: NatWest, Nottingham City Branch.  
Account number 61408948 Sort Code 60-80-09

Amount £ .....

Donation in addition to subscription: £ .....

**Total sent: £ .....**

continued overleaf.....

