

Muscular Dystrophy & Allied Neuromuscular Conditions

Introduction

Factsheets on a range of neuromuscular conditions, and on some disability issues, are available from the Muscular Dystrophy Campaign. These are constantly reviewed and updated. A full set can be found on and printed off from the organisation's website: www.muscular-dystrophy.org

Alternatively, photocopy the page, indicate the factsheet required and return to:

Information Service
Muscular Dystrophy Campaign
7–11 Prescott Place
London SW4 6BS
tel: 020 7720 8055
fax: 020 7498 0670
e-mail: info@muscular-dystrophy.org

- Alternative Therapies
- Annual Review
- Anaesthetics
- Becker muscular dystrophy
- Booklist on the muscular dystrophies and neuromuscular disorders
- Carrier detection tests and prenatal diagnosis
- Children with muscular dystrophy in mainstream schools

Congenital Myopathies

- Central core myopathy
- Congenital fibre type disproportion myopathy
- Minicore (multicore) myopathy
- Myotubular or centronuclear myopathy
- Nemaline myopathy
- Congenital muscular dystrophy
- Congenital myotonic dystrophy
- Duchenne muscular dystrophy
- Duchenne muscular dystrophy: the older child
- Education
- Emery-Dreifuss muscular dystrophy
- Facioscapulohumeral muscular dystrophy (FSH)
- Facts about muscular dystrophy
- Gastrostomy

- Heart check
- Hereditary Motor and Sensory Neuropathies - HMSN (Charcot-Marie-Tooth disease)
- Holiday factsheet
- Hospital card
- Inclusion Body Myositis
- Inheritance and the muscular dystrophies
- JPT Annual Review
- Joining the Campaign
- Juvenile Dermatomyositis
- Limb-Girdle muscular dystrophy
- Manifesting carriers
- Muscle biopsies
- Making breathing easier
- Metabolic disorders that cause pain and/or weakness on exercise
- Mitochondrial myopathies
- McArdle's disease
- Myasthenia Gravis
- Myositis Ossificans Progressiva
- The Myotonias
- Myotonic dystrophy
- Ocular myopathies
- Periodic paralyses
- Personal relationships and sexuality
- Polymyositis and Dermatomyositis
- Pregnancy and reproduction in muscle disorders
- Student pack
- Surgical correction of spinal deformity
- Target MD
- Transport factsheet
- Weight control in patients with muscular dystrophy
- Would it help to talk? (Emotional needs)

Support Groups

Support Groups are run by and for people with neuromuscular conditions, and their families and friends - and those listed below have very close links with the Muscular Dystrophy Campaign. They offer a variety of services such as a newsletter, providing information and emotional support - and putting individuals and families in touch with each other.

Association for Glycogen Storage Disease

9 Lindop Road
Hale
Altrincham
Cheshire
WA15 9DZ
tel: 0161 980 7303 (after 6pm)
e-mail: info@agsd.org.uk
contact: Mrs Ann Phillips
web: www.agsd.org.uk
*Glycogen Storage diseases including:
Von Gierke's disease, Pompe's disease
Andersen's disease, McArdle's disease*

CLIMB Children Living with Inherited Metabolic Diseases

Climb Building
176 Nantwich Road
Crewe
CW2 6BG
tel: 0800 652 3181
e-mail: info@climb.org.uk
contact: Mrs Lesley Greene
web: www.climb.org.uk
Includes Mitochondrial Myopathy

CMT United Kingdom

PO Box 5089
Christchurch
BH23 2WJ
tel: 0870 7744 314
e-mail: secretary@cmt.org.uk
contact: Karen Butcher
web: www.cmt.org.uk
*Hereditary Motor and Sensory Neuropathy,
also known as Peroneal muscular atrophy and
Charcot-Marie-Tooth disease*

Congenital Muscular Dystrophy Support Group

21 Morrison Drive
Pitcorthie
Dunfermline
Fife
KY11 5DJ
tel: 01383 736 084

Duchenne Family Support Group

37a Highbury New Park
Islington
London
N5 2EN
tel: 0870 241 1857
e-mail: dfsg@duchenne.demon.co.uk
helpline: 0870 606 1604
contact: Rosemary Matthews
web: www.dfsg.org.uk
Duchenne muscular dystrophy

FSH-MD Support Group

8 Caldecote Gardens
Bushey Heath
Herts
WD23 4GP
tel: 020 8950 7500
fax: 020 8950 7300
e-mail: fshgroup@hotmail.com
contact: Mr Norman Jonas
web: www.fsh-group.org
Facioscapulohumeral muscular dystrophy

Guillain-Barre Syndrome Support Group

Lincolnshire County Council
Council Offices
Eastgate
Sleaford
Lincs
NG34 7EB
tel: 01529 304 615
helpline: 0800 374 803
e-mail: admin@gbs.org.uk
contact: Mrs Glensy Sanders
web: www.gbs.org.uk

The Jennifer Trust for Spinal Muscular Atrophy

Elta House
Birmingham Road
Stratford upon Avon
Warwickshire
CV37 0AQ
tel: 0870 774 3651
helpline: 0800 975 3100
(Mon-Fri 9-5)
fax: 0870 774 3652
e-mail: jennifer@jtsma.org.uk
contact: Mrs Anita Macaulay
web: www.jtsma.org.uk
Severe SMA (Werdnig-Hoffman disease)
Intermediate SMA
Mild SMA (Kugelberg-Welander disease)
Adult SMA

Mitochondrial Myopathies

3 Home Farm Cottages
Yearby
Nr Redcar
Cleveland
TS11 8HQ
tel: 01642 480 973
email: mitolinks@aol.com
contact: Vic/June Wood
Mitochondrial myopathies

Myasthenia Gravis Association

Central Office
Keynes House
Chester Park
Alfreton Road
Derby
DE21 4AS
tel: 01332 290 219
helpline: 0800 919 922
e-mail: mg@mgauk.org.uk
web: www.mgauk.org
Myasthenia Gravis, Lambert-Eaton
Myasthenia, syndrome and Congenital
Myasthenia

Myositis Support Group

146 Newtown Road
Woolston
Southampton
SO19 9HR
tel: 02380 449 708
Mon-Fri 9am-3pm
e-mail: enquiries@myositis.org.uk
contact: Mr & Mrs Oakley
web: www.myositis.org.uk
Dermatomyositis and Polymyositis
Juvenile Dermatomyositis
Inclusion Body Myositis

Myotonic Dystrophy Support Group

35a Carlton Hill
Carlton
Nottingham
NG4 1BG
tel: (Answerphone) 0115 987 0080
fax: 0115 987 6462
e-mail: mdsg@tesco.net
contact: Mrs Margaret Bowler
web: www.mdsguk.org
Myotonic dystrophy (also known as
Steinert's disease and Dystrophia Myotonica)
Congenital myotonic dystrophy