Chapter 17
Resources list and glossary

Muscular Dystrophy UK publications


A guide for parents: Duchenne muscular dystrophy

A guide for parents: children recently diagnosed with a muscle-wasting condition


Relevant charities and organisations

Muscular Dystrophy UK
61A Great Suffolk Street
London SE1 0BU
020 7803 4800
0800 652 6352
www.musculardystrophyuk.org

ACE Education Advice & Training
72 Durnsford Road
London N11 2EJ
020 8888 3377
www.ace-ed.org.uk

Carers UK
20 Great Dover Street
London SE1 4LX
020 7378 4999
080 8808 7777
www.carersuk.org

Centre for Studies on Inclusive Education (CSIE)
The Park Centre
Daventry Road
Knowle, Bristol BS4 1DQ
011 7353 3150
www.csie.org.uk

Children 1st
83 Whitehouse Loan
Edinburgh EH9 1AT
0131 446 2300
www.children1st.org.uk

Children in Scotland
Level 1 Rosebery House
9 Haymarket Terrace
Edinburgh EH12 5EZ
0131 313 2322
www.childreninscotland.org.uk

Contact a Family
209-211 City Road
London EC1V 1JN
020 7608 8700
www.cafamily.org.uk

Trailblazers, Muscular Dystrophy UK
61A Great Suffolk Street
London SE1 0BU
020 7803 4846
www.musculardystrophyuk.org/trailblazers
<table>
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<tr>
<th>Organization</th>
<th>Contact Information</th>
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<tr>
<td>Council for Disabled Children</td>
<td>8 Wakley Street, London EC1V 7QE</td>
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<td></td>
<td>0207 843 1900</td>
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<td></td>
<td><a href="http://www.councilfordisabledchildren.org.uk">www.councilfordisabledchildren.org.uk</a></td>
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<tr>
<td>Disability Rights Commission</td>
<td>0845 7622633</td>
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<td></td>
<td><a href="http://www.drc.org.uk">www.drc.org.uk</a></td>
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<tr>
<td>Independent Panel for Specialist Educational</td>
<td>0800 018 4016</td>
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<tr>
<td>Advice (IPSEA)</td>
<td><a href="http://www.ipsea.org.uk">www.ipsea.org.uk</a></td>
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<tr>
<td>Disability Rights UK</td>
<td>Ground Floor CAN Mezzanine 49-51 East</td>
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<tr>
<td></td>
<td>Road, London N1 6AH</td>
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<td></td>
<td>020 7250 8181</td>
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<td></td>
<td><a href="http://www.disabilityrightsuk.org">www.disabilityrightsuk.org</a></td>
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<tr>
<td>ROSPA (Royal Society for the Prevention of</td>
<td>RoSPA House, 28 Calthorpe Road Edgbaston</td>
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<td>Accidents)</td>
<td>Birmingham B15 1RP</td>
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<td></td>
<td>012 1248 2000</td>
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<td></td>
<td><a href="http://www.rospa.com">www.rospa.com</a></td>
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**Glossary**

- CSP   Co-ordinated Support Plan
- EHCP  Education health care plan
- EPIOC Electrically powered indoor or outdoor wheelchairs
- EP    Educational psychologist
- EPS   Educational psychology services
- ESA   Educational support assistant
- IASS  Information, advice support service
- ICT   Information and communication technology
- IEP   Individual education plan
- IHCP  Individual health care plan
- INSET In-service training
- IPSEA Independent parental special education advice
- LA    Local authority
- NC    Neurology consultant
- NCA   Neuromuscular care advisor
- OT    Occupational therapist
- PT    Physiotherapist
- SEN   Special educational needs
- SEND  Special educational needs and disability
- SENCO Special educational needs co-ordinator
About Muscular Dystrophy UK

Muscular Dystrophy UK is the charity bringing individuals, families and professionals together to beat muscle-wasting conditions.

► We support high-quality research to find effective treatments and cures, and lead the drive for faster access to emerging treatments for UK families.
► We ensure everyone has the specialist NHS care and support they need, with the right help at the right time, wherever they live.
► We provide a range of services and opportunities to help individuals and their families live as independently as possible.

Find out more here:
www.musculardystrophyuk.org
info@musculardystrophyuk.org
@MDUK_News

Trailblazers

Trailblazers is a UK-wide network of over 700 young disabled people, aged between 16 and 35. We fight social injustices that affect all young disabled people.

Trailblazers hold regional group meetings, where members get to share ideas and experiences, and build friendships. You may also want to consider volunteering or getting involved in our work experience programme.

We’ve also developed some resources and top tips with the help of our members, to help you live as independently as possible.

We are part of Muscular Dystrophy UK.

Find out more here:
www.musculardystrophyuk.org/trailblazers
trailblazers@musculardystrophyuk.org
@MD_Trailblazers

Get involved

There are lots of ways to support Muscular Dystrophy UK’s work to beat muscle-wasting conditions. If you’d like to fundraise to accelerate the pace of research, or to support our care and information services, please get in touch with us.

You may wish to fundraise for us. You may also have contacts that could support our work by, for example, putting Muscular Dystrophy UK forward for a charity of the year partnership.

Muscular Dystrophy UK
61A Great Suffolk Street
London SE1
Tel: 020 7803 4800
Email: info@musculardystrophyuk.org
Web: www.musculardystrophyuk.org

Registered Charity No 205395 and Scottish Registered Charity No SC039445

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