

09

Chapter 09 - Contacts

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In a nutshell - Your contacts

Your child and family can get the help you need from healthcare professionals, education professionals, the local authority and the Duchenne community.

But keeping track of all these people can take a bit of effort.

So, we've put together these pages with our suggestions for the people who can help you most.

We hope you'll find them useful.



The Duchenne Community	
Duchenne UK	<p>www.duchenneuk.org</p> <p>We are a charity focused on funding and accelerating treatments and a cure for DMD. We also support families with DMD.</p>
Duchenne UK's Parent Network	<p>Please contact support@duchenneuk.org. We can put you in touch with other local families.</p>
DMD Hub website	<p>www.dmdhub.org</p> <p>The DMD Hub website has a clinical trial finder for every existing and pending clinical trial for DMD in the UK. It's run by Duchenne UK.</p> <p>The website has information about clinical trials – including the different types of trials and the things you should think about if you are considering taking part in a clinical trial.</p>
Decipha	<p>www.decipha.org</p> <p>A not-for-profit organisation set up by DMD parents who are experts in special education needs.</p> <p>They provide educational advice. They can help you with assessments and Education Health and Care Plans (EHCPs). They also provide reading, maths and social skills programmes for children with special needs. And they provide family coaching sessions.</p>

Organisations which can help	
Charities which support children with disabilities and their families	<ul style="list-style-type: none"> Contact a Family - www.contact.org.uk Rainbow Trust - www.rainbowtrust.org.uk Together for Short Lives - www.togetherforshortlives.org.uk Sebastian's Action Trust - www.sebastiansactiontrust.org Caudwell Children - www.caudwellchildren.com SEN!SOS (educational advice) – www.sossen.org.uk
Organisations which provide help in your local area	<ul style="list-style-type: none"> Citizens' Advice Bureau – www.citizensadvice.org.uk Carers' alliance – google the name of your local authority + carers' alliance Disabled Children's Register – google the name of your local authority + disabled children's register Home improvements agencies (can help with adaptations) – google the name of your local authority + home improvement agency

Your personal network	
Your local authority	<ul style="list-style-type: none"> Social worker Children with disabilities team Occupational therapist – social care Occupational therapist – healthcare
Healthcare professionals	<ul style="list-style-type: none"> GP Neuromuscular clinic Consultant neurologist Physiotherapist Occupational therapist Orthotist Hydrotherapist Dietician Counsellor
Education Professionals	<ul style="list-style-type: none"> School Teacher Special education needs co-ordinator (SENCO) Speech therapist
Research and clinical trials	<ul style="list-style-type: none"> Clinic/hospital Lead researcher

Personal notes and contacts

Your name: _____

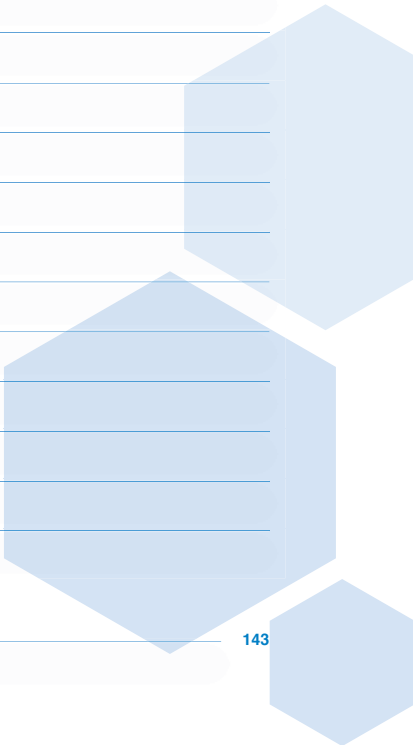
Your child's name: _____

Your address: _____

Your consultant/s: _____

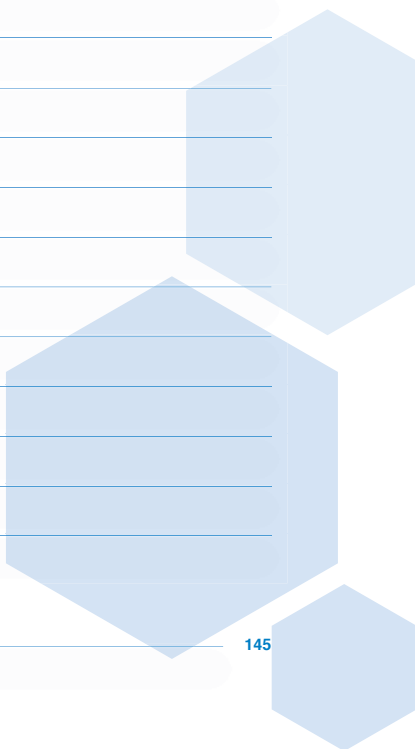
Other useful information: _____

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