Welcome to the children’s neuromuscular outpatient clinic

Information for patients, parents and guardians

Our children’s neuromuscular team provides care for children and young people (up to 18 years of age) who have problems with their muscles or nerves. We also support parents, carers and other family members as they look after their child’s health and wellbeing.

Your child has been asked to visit the neuromuscular outpatient clinic so that we can monitor and treat any problems with their muscles or nerves. Your child may not have been diagnosed with a specific neuromuscular condition, but it’s still important that we monitor them regularly.

Visiting the clinic

We will book your child in for an appointment with a neurology consultant or a nurse specialist at one of our regular neuromuscular outpatient clinics. These clinics take place in the children’s outpatients department, usually on Wednesdays.

When you come in for your appointment, please bring:

- any splints that your child uses
- details of any therapy equipment that your child uses
- a list of any medication that your child takes
- any other information that may be useful

Please make sure you arrive in plenty of time for your appointment and check in at reception. Do allow time for car parking as the hospital is very busy. Appointments can sometimes be delayed due to circumstances beyond our control, so we appreciate your patience and apologise for any inconvenience this may cause.

At your appointment the consultant or nurse specialist will carry out a detailed assessment of your child and discuss with you any treatment they may need. We will check your child’s height, weight and blood pressure, and in some cases we may need to take a urine sample.

During your appointment at the clinic, you will have the opportunity to speak to an occupational therapist, and a speech and language therapist if necessary.

Our team look after all aspects of your child’s care. We can give you support and advice about:

- treatment and medications
- general health and wellbeing, including diet, eating, drinking and swallowing
- day-to-day living, such as housing and schooling

If you need a translation of this document, an interpreter or a version in large print, Braille or on audiotape, please telephone 023 8120 4688 for help.

www.uhs.nhs.uk/childrenshospital
**Children’s neuromuscular outpatient clinic**

**Having a blood test**

**Blood tests**

During your visit to the clinic, your child might also need to have a blood test. We know this can be a scary prospect for some children. Our expert team of blood specialists (phlebotomists) will take the test quickly and painlessly in our special butterfly room.

**Visiting other specialist doctors**

We may also refer your child to other specialist teams at the hospital, such as the heart specialist team (cardiology), breathing specialist team (respiratory), foot specialist team (orthotics), spinal team, bone and joint specialist team (orthopaedics) or bone scanning team.

**Physiotherapy**

Children with neuromuscular problems sometimes need physiotherapy to help with stretches, posture and/or joint problems. Our specialist physiotherapists can monitor your child’s progress and offer advice and support for various issues. If we think your child would benefit from physiotherapy, we will give your child an appointment with one of our physiotherapists on the same day as their neuromuscular outpatient clinic appointment.

Please check your letter to see if this applies to you. If it does, you will need to go to the hospital’s therapy department in the West Wing on B level before you go to the outpatient clinic. Don’t worry if you’re delayed in the therapy department, as our team will be aware that your child is receiving treatment and will wait for you to arrive.

**Useful links**

- [www.nhs.uk/conditions/Muscular-dystrophy](http://www.nhs.uk/conditions/Muscular-dystrophy)
- [www.uhs.nhs.uk/childrensbloodtest](http://www.uhs.nhs.uk/childrensbloodtest)

**Muscular Dystrophy UK**

- [www.musculardystrophyuk.org](http://www.musculardystrophyuk.org)

Your nurse or doctor may be able to recommend other websites that provide more specific information about your child’s particular condition.

**Local Offer**

Local Offer is an online directory to help you find what is available in the area for those with special educational needs or disabilities (ages 0-25):
- [sid.southampton.gov.uk](http://sid.southampton.gov.uk)
- [www.portsmouthlocaloffer.org](http://www.portsmouthlocaloffer.org)
- [www.hantslocaloffer.info](http://www.hantslocaloffer.info)

**Fundraising**

- [Southampton Children’s Hospital Charity](http://www.southamptonchildrenscharity.com)

We’re committed to providing the very best service for our patients and we’re always looking for ways to raise funds to support and develop the service. If you’re interested in helping us in our efforts, we would love to hear your ideas and suggestions. The charity registration number for our paediatric neuromuscular service fund is 1051543.

**Your online health record**

We are in the process of setting up optional online health records for our patients. If you would like to track your child’s neuromuscular health care online, please speak to a member of our team.

**Contact us**

Please contact us if you have any questions or concerns before your next clinic appointment.

- **Paediatric neuromuscular team**
  - Mailpoint 44
  - Child health
  - Southampton General Hospital
  - Tremona Road
  - Southampton
  - SO16 6DY

- **Helen Browne, paediatric neurology nurse specialist**
  - Telephone: 07760 176 242 (Monday to Friday, 9am to 5pm)
  - Email: NeuroNurses@uhs.nhs.uk

You can also contact other specialist teams at the hospital.

- **Specialist physiotherapy team**
  - Telephone: 023 8120 4560 (secure answer phone)
  - Email: uhs.nmpaedstherapy@nhs.net

- **Speech and language therapy team**
  - Telephone: 023 8120 6453
  - Email: rebecca.latham@uhs.nhs.uk

- **Occupational therapy team**
  - Telephone: 023 8120 4560
  - Email: uhs.nmpaedstherapy@nhs.net

If you need urgent assistance, please contact your GP or go to the emergency department.

**Dr Neil Thomas, consultant paediatric neurologist**

- Telephone: 023 8120 4457 (secretary)

**Dr Marjorie Illingworth, consultant paediatric neurologist**

- Telephone: 023 8120 5922 (secretary)

**Useful links**

- [www.musculardystrophyuk.org](http://www.musculardystrophyuk.org)
- [www.portsmouthlocaloffer.org](http://www.portsmouthlocaloffer.org)
- [www.hantslocaloffer.info](http://www.hantslocaloffer.info)

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