

# Your child's two day case assessment at the Dubowitz Neuromuscular Centre: information for families

This information sheet from Great Ormond Street Hospital (GOSH) tells you about your child's two day case assessment at the Dubowitz Neuromuscular Centre at GOSH. For more information about the Centre, please visit our website at <a href="https://www.gosh.nhs.uk/medical-information/clinical-specialties/dubowitz-neuromuscular-centre-dnc-information-parents-and-visitors">www.gosh.nhs.uk/medical-information/clinical-specialties/dubowitz-neuromuscular-centre-dnc-information-parents-and-visitors</a>. If you have any questions, please call the Neuromuscular Clinical Nurse Specialists on 020 7405 9200 ext 1195. You can also send an email to neuromuscular.cns@gosh.nhs.uk.

# About the Dubowitz Neuromuscular Centre

The Dubowitz Neuromuscular Centre (DNC) is a leading clinical and research centre specialising in neuromuscular disorders affecting children. The DNC provides clinical assessment, diagnostic services and advice on treatment and rehabilitation.

# What should we bring?

You should allow the whole morning for your child's appointment. You will need to bring a packed lunch and drinks for yourself and anyone else accompanying your child. Alternatively, you might want to buy refreshments on the day from the Lagoon at GOSH or a café in the local area.

Please also bring the following:

- Your child's favourite toy or comforter
- Their bottle or feeding cup plus some food and drink
- Spare nappies or pads and a change of clothes
- Any medicines that your child uses regularly (including inhalers)

 A pair of shorts for the physiotherapy and physical examinations

## What will happen?

The order that the following assessments happen may vary from child to child – we will tell you at the start on Day 1 what is planned for each day.

#### Day 1

Your child will be seen by one of the neuromuscular doctors, who will review your child's current condition.

Your child may also have some of the following:

- Physiotherapy assessment
- Speech and language therapy assessment
- Dietetic assessment
- X-ray
- Echocardiogram (ECHO)
- Electrocardiogram (ECG)
- Blood tests
- Lung function tests
- Nerve function test (EMG)
- Clinical photography

Information about these tests is available on our website at www.gosh.nhs.uk.

We try to keep delays to a minimum and appreciate your patience. However, some children we see have very complex medical conditions and it can take a long time for the neuromuscular team to assess them. If there are any delays, we will always do our best to keep you informed.

Once these tests have been done, you and your child will be able to leave the hospital, ready to return the following day. We will tell you when to come back before you leave.

#### Day 2

In most cases, you will need to go to the 1st Floor of the Royal London Hospital for Integrated Medicine (RLHIM). If the doctor has not seen your child on Day 1, they will be seen today by one of our neuromuscular doctors. You and your child will also see a senior member of the neuromuscular team (consultant).

During this consultation, you can expect the following:

- Repeat of some of the key elements of your child's examination
- Discussion about the findings from this examination
- Making a plan with you and your child for further tests that might be required to find

- out your child's condition, possibly to be carried out on the same day
- Agreeing when your child needs to have another appointment

#### Questions

Please ask any questions at any point of the day. Detailed medical queries are probably best saved until your see the senior neuromuscular doctor (consultant). We realise that it can be difficult to remember everything during the busy day so it may help to write down a list of questions before the appointment. If there is anything you wish to discuss without your child being present, please let us know so we can try to arrange it.

## After the appointment

We will give you a summary of what we discussed during the assessment. If you have any questions about it, please call the Neuromuscular Clinical Nurse Specialists.

Tell us about your visit — you can give us feedback using Friends and Family Test cards or using our online feedback form at <a href="https://www.gosh.nhs.uk/your-opinion-matters">www.gosh.nhs.uk/your-opinion-matters</a>. This helps us improve what we do.

You can also visit our Patient Advice and Liaison Service (Pals) office in the main reception area of the hospital. They are open from Monday to Friday from 10am to 5pm or you can call 020 7829 7862 or email <a href="mailto:pals@gosh.nhs.uk">pals@gosh.nhs.uk</a>