



## Great Ormond Street Hospital for Children NHS Foundation Trust

### Neuromuscular outpatient clinics at GOSH: information for families

#### What happens in specific clinics?

Clinics specialising in different Neuromuscular conditions are held on specific days. For all appointments, you should bring:

- All the medicines (including inhalers) that your child takes regularly, as the clinic doctor may want to see them.
- A pair of shorts for your child to change into if the doctors want to see your child's legs during physical examination.
- A list of any questions you want to ask the doctors, nurses or therapists at the appointment.
- Something to eat and drink, as your child's appointments may last several hours
- Things to do, such as a toy, game, book or magazine, as there may be some waiting time between appointments
- Wheelchair, if required, as you may be required to travel between different areas of the hospital

If you are unable to keep this appointment, please telephone the Neuromuscular team on 020 7405 9200 extension 1132 between 9am and 5pm Monday to Friday.

#### What does the clinic code mean?

Each clinic is given a code to identify it on the hospital computer system. You will find your child's clinic code on their appointment letter. Further information on each clinic follows below.

**Due to high patient volume you may receive an appointment in an alternative Neuromuscular clinic. Please be reassured that all clinics are run by the Neuromuscular team and have the same level of expertise to manage your child's condition.**

#### ***New Patient Clinic (NMDUF2 or NMMOPM)***

Note: These appointments last all day.

- Your child is coming to this clinic because they have been referred to the service for the first time or has not had an appointment for two years or more.
- Your child's appointment may include some or all of the following:
  - A detailed history taken by one of the junior Neuromuscular doctors
  - A physiotherapy assessment
  - Clinical photography
  - Electrocardiogram (ECG)
  - Lung function testing
  - Muscle ultrasound
  - Blood tests
- All tests will be discussed and agreed with you before they are done. Some of the tests take place in other department of the hospital.
- Your child will be reviewed by one of the Neuromuscular Consultants. They will discuss any further tests needed for your child's diagnosis as well as plan a schedule for these tests with you.



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### **Results Clinic (NMDUF3)**

- Your child is coming to this clinic because we would like to discuss their test results with you.
- If you would prefer to see the doctor without your child present, please speak to the Neuromuscular Clinical Nurse Specialist(s) who will arrange this.

### **Neuromuscular Follow Up Clinic (NMDUFR)**

Note: This appointment may last between three and five hours.

- Your child is coming to this clinic for a routine review
- Your child may have a physiotherapy review which could last up to 1½ hours.
- They may also see other members of the Neuromuscular team,
- Your child may also have an x-ray or ECG booked
- Your child will be reviewed by a specialist Neuromuscular doctor
- The Social Worker/Care Advisor and Clinical Nurse Specialist(s) will also be available in this clinic

### **Charcot Marie Tooth Clinic (NMCMT)**

- Most children and young people attending this clinic have a type of Charcot Marie Tooth disease
- Your child may have a physiotherapy review which could last up to 1½ hours
- Your child will be reviewed by a specialist Neuromuscular doctor
- The Social Worker/Care Advisor will also be available in this clinic

### **Congenital Myopathy Clinic (NMCMYO)**

Note: This appointment may last between three and five hours.

- Most children and young people attending this clinic have a type of Congenital Myopathy
- Your child is coming to this clinic for a routine review
- Your child may have a physiotherapy review which could last up to 1½ hours.
- Your child may also have an x-ray or ECG booked
- Your child will be reviewed by a specialist Neuromuscular doctor
- The Social Worker/Care Advisor and Clinical Nurse Specialist(s) will also be available in this clinic

### **Scoliosis Clinic (NMSCL)**

Note: Your child will need an x-ray before seeing the doctors. Please arrive 1½ hours before your child's appointment time to collect an x-ray request form from the Outpatients Department before going to the X-ray Department.

- Children attending this clinic have scoliosis – curvature of the spine
- Monitoring of the degree of curvature is carried out in this clinic
- Decisions about the need for spinal surgery are made at this clinic
- Your child may be given an appointment to see our Orthotist if they require a spinal jacket to be made or altered
- Your child will be reviewed by members of the Spinal Surgeons as well as members of the Neuromuscular team



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### ***Duchenne Muscular Dystrophy Clinics (NMPDDC/NMPODC/NMFMDM)***

Note: These appointments last all day.

- These clinics are for boys aged eight years or older who have Duchenne Muscular Dystrophy
- Your child may have a physiotherapy review which could last up to 1½ hours
- Your child will be reviewed by a specialist Neuromuscular doctor
- Your child may also have an echocardiogram
- They may also need an x-ray – please allow an extra hour for this
- If required, they may also see a Dietitian
- A Family Therapist will also be available in this clinic
- The Social Worker/Care Advisor and Clinical Nurse Specialist(s) will also be available in this clinic
- Older boys attending the NMPODC clinic may also see our Orthotist

### ***Congenital Myasthenia Clinic (NMSRCM)***

- Most children and young people attending this clinic have an acquired or congenital myasthenia
- Every other month, the Neuromuscular team are joined by colleagues from the Specialist Myasthenia Service in Oxford
- Your child may have a physiotherapy review which could last up to an hour
- Your child will be reviewed by a specialist myasthenia doctor
- The Clinical Nurse Specialist(s) will also be available in this clinic

### ***Becker Muscular Dystrophy Clinic (NMBMD)***

- This clinic is for children who have Becker Muscular Dystrophy
- Your child may have a physiotherapy review which could last up to 1½ hour.
- Your child will be reviewed by a specialist Neuromuscular doctor
- Your child may have an ECG/echocardiogram booked
- A Family Therapist will also be available in this clinic
- The Social Worker/Care Advisor and Clinical Nurse Specialist(s) will also be available in this clinic

### ***Spinal Muscular Atrophy Clinic (NMSMAC)***

- Your child's appointment may include some of all of the following:
  - A detailed history taken by one of the junior Neuromuscular doctors
  - A physiotherapy assessment
  - An orthotic assessment
  - ECG
  - Lung function
- They may also need an x-ray – please allow an extra hour for this
- Any additional tests will be arranged for the same day where possible
- A Family Therapist will also be available in this clinic
- The Social Worker/Care Advisor and Clinical Nurse Specialist(s) will also be available in this clinic



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### **Joint Neuromuscular and Orthopaedic Clinic (NMORTH)**

- Your child is coming to this clinic for a joint review with the Neuromuscular team and Orthopaedic surgeon to discuss the possibility of tendon or joint surgery

### **Neuromuscular Review Clinic (NMAMRE)**

- Your child is coming to this clinic for a Neuromuscular assessment and/or to discuss results
- This clinic may be scheduled at short notice

### **General Neuromuscular clinic (NMFMG)**

- Your child is coming to this clinic for a Neuromuscular/Neurology appointment

### **Shoulder Clinic (NMMULA)**

- Your child is coming to this clinic because they have a shoulder problem
- Your child will be reviewed by Mr Simon Lambert, a shoulder surgeon from the Royal National Orthopaedic Hospital at Stanmore

### **Neuromuscular Clinic for Joint Laxity (NMPORC)**

- Your child is coming to this clinic because they have problems with their skin or joint laxity
- Your child will be reviewed by Professor Michael Pope or a member of his team who is a specialist in collagen disorders

### **Specialist Neuropathy Clinic (NMFMRI)**

- Your child is coming to this clinic because they have nerve problems that are difficult to diagnose

### **Neuromuscular Echo Clinic (NMECHO)**

- Your child is coming to this clinic because they require an echocardiogram. This is a regular monitoring of your child's heart in some Neuromuscular conditions
- Please ensure that your child has their height and weight recorded on the ECHO request form before arriving at the ECHO department.

### **Orthotics Clinic (WEDNEU)**

- Your child may be given an appointment to see our Orthotist if they require an orthosis – such as callipers, leg or ankle splints or a spinal jacket – to be made or altered.

### **Transition Clinic (NMDAMC)**

Transition is when your teenager moves from paediatric into adult care. Ideally, there is no fixed age for transfer as this will depend on several factors including: age, maturity and medical status. It is best to transfer a young person with a Neuromuscular condition when they are in a more stable phase of their condition.

- This clinic is held with the adult Neuromuscular service from the National Hospital for Neurology in Queen Square
- We will introduce you and your teenager to the adult team
- This will be your last appointment at GOSH