



Great Ormond Street Hospital for Children NHS Foundation Trust: Information for Families

# Needle muscle biopsy for children with neuromuscular disorders

**This information sheet is one of a series produced for children attending the Children's Neuromuscular Centre at Great Ormond Street Hospital (GOSH). It has been provided to help answer some of the questions you may have about your child's needle muscle biopsy.**

## What is a muscle biopsy?

A needle muscle biopsy is a short procedure to remove a small piece of muscle tissue from your child's thigh using a hollow needle. Once in the laboratory, the muscle cells are checked for various proteins, which may be responsible for neuromuscular disorders.

The benefit of muscle biopsy is that allows us to reach a diagnosis in most children with muscle disorders.

## What are the risks and benefits of muscle biopsy?

The amount of muscle biopsy needed for the investigations is small and therefore will not raise any problems using that muscle after surgery. There is a small risk (1 in 3500) of bleeding at the biopsy site. If this were to happen, it would happen immediately after the biopsy while your child is still in hospital and will stop when pressure is applied to the site. There is a certain risk for an infection around the surgical site. This risk is minimal, as the procedure takes place in theatre. Your child might complain about some pain afterwards. Paracetamol or other pain medication appropriate for your child can be offered.

## Are there any alternatives?

A needle muscle biopsy is usually suggested when a child has a muscle abnormality of some kind, which might show up as unusually tense or floppy muscles and/or there is suspicion that important energy producing structures called mitochondria are not working properly. The doctors can tell a certain amount by examining your child's blood but there are some diseases that can only be diagnosed by looking at a sample of muscle. The reason for your child's biopsy will be discussed with you fully by your child's doctors.





## What should I bring?

You should expect to be at GOSH for most of the day. Snacks and drinks will be given to your child after the biopsy. 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 one of the eating facilities at GOSH or in the local area.

Please also bring the following:

- Your child's favourite toy or comforter
- His or her bottle or feeding cup if used
- Spare nappies (if used) and a change of clothes
- Any medicines that your child uses regularly (including inhalers)

## What happens before the biopsy?

As your child will be having a general anaesthetic for the needle muscle biopsy, it is very important that his or her stomach is as empty as possible on the day of the procedure, as this reduces the risk of vomiting during and after the anaesthetic. If someone vomits during an anaesthetic, there is a chance that the stomach contents could get into the lungs, damaging them. Your child's nurse will explain exactly what time your child can last eat or drink before the procedure, but as a general rule, the following applies.

- Your child can have his or her last solid food, cow's milk or formula milk six hours before the appointment time.
- Your child can have his or her last breastfeed four hours before the appointment time
- Your child can have his or her last drink of clear fluids two hours before the appointment time.

**Please follow these instructions carefully, otherwise your child's procedure may be delayed or even cancelled.**

The doctors will explain the procedure you in detail and they will ask you to give permission for the biopsy by signing a consent form. This will either already have been discussed before your child is admitted, or when your child's doctors see you when you arrive on the ward. If your child has any medical problems, including allergies, please tell the doctors. We will also ask if your child or anyone else in the family has problems with blood clotting. If this is the case, we will check your child's blood for abnormalities before we do the biopsy. An anaesthetist will also see you to discuss your child's anaesthetic.



## What does the biopsy involve?

We will use a special needle to remove one or two pieces of muscle about the size of an orange pip from your child's thigh. The muscle pieces will be taken to the laboratory in the hospital to be examined closely. This will help us make progress towards finding or confirming your child's diagnosis.

## Will the biopsy hurt?

No. It will be carried out while your child is under a general anaesthetic so he or she will not feel any pain during the procedure. The site of the biopsy will have some local pain relief injected during the procedure, which lasts for one to two hours afterwards. Your child can be given some paracetamol if needed.

## What happens afterwards?

Your child will be able to recover from the biopsy on the ward and may be sleepy for a few hours as the anaesthetic wears off. Your child's blood pressure, pulse and breathing rate will be monitored frequently as your child recovers. The anaesthetic may make your child sleepy and fairly floppy too, which may make breathing quite noisy while he or she is recovering. Your child's head will need to be in a comfortable position that does not cause any problems breathing. Chewing and swallowing are also affected by the anaesthetic, so your child should not have anything to eat or drink until fully awake.

As soon as your child has woken up fully, he or she will be able to have a small drink. If this is tolerated, you will be able to give something to eat. Once we are happy that your child is recovering well, you will be able to go home.

## When your child goes home

- Your child will probably be quite sleepy for the rest of the day. This is due to the anaesthetic and is quite normal.
- Most children do not need pain relief when they get home after a muscle biopsy, but you can give your child a dose of paracetamol if necessary.
- The area where the needle was inserted will not need any stitches but it will leave a circular scar about 4mm across. The area will be covered with a small plaster, which should be left on for five days. Your child can have a bath or shower but try to keep the area clean and dry.
- Your child should be able to return to normal everyday activities within 24 hours of the biopsy. However, we advise against swimming for the first five days as the biopsy site needs to be kept clean and dry.
- We will send you the date and time of the follow up appointment. We will also write to your family doctor (GP) to inform him that your child has had a muscle biopsy. Please make sure that we have correct details for you and your family doctor (GP) before you leave GOSH.



## How do I make a comment about my child's treatment?

The Pals Office is in the main reception area. Pals are available Monday to Friday from 9am to 5pm and on Saturdays from 10am to 12.30pm. The Pals staff are able to help you with any concerns that you might have about your child's care or other difficulties you have while staying at the hospital. Pals can also help you with benefit and financial issues and other problems not immediately related to your child's health care. Pals are also happy to sit and listen if you feel the need to talk to someone in more general terms about what you and your child are currently going through. Pals operate an 'open door' policy so feel free to drop in. Pals are also happy to visit you on the ward if you do not feel able to leave your child. Ring us on 020 7829 7862 or internal extension 7862, email them at [pals@gosh.nhs.uk](mailto:pals@gosh.nhs.uk) or visit their web page at [www.gosh.nhs.uk/pals](http://www.gosh.nhs.uk/pals)

If you would like to make a formal complaint, you can write to the Complaints Manager, Great Ormond Street Hospital for Children NHS Trust, Great Ormond Street, London WC1N 3JH. More details are available in our leaflet *How to make a complaint*, which is available in the hospital.

If you have any more questions, please ring the Clinical Nurse Specialist for the Children's Neuromuscular Centre on 020 7405 9200 ext 0517 or 1195 or bleep 2123 or 0228. You can also send an email to [muscle.service@gosh.nhs.uk](mailto:muscle.service@gosh.nhs.uk)

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Compiled by the Neuromuscular Service in collaboration with the Child and Family Information Group

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