

PET SCANS IN PRACTICE AT GOSH



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Charlie's Story

- <http://www.gosh.nhs.uk/medical-conditions/search-for-medical-conditions/hyperinsulinism/hyperinsulinism-real-stories/charlies-journey-with-congenital-hyperinsulinism/>

Methods used to diagnose HI

Previous Methods:

- Pancreatic venous sampling
- CT, MRI, Ultrasound

Current methods include:

- 18F-DOPA PET/CT

What is a PET scan?

- Positron Emission Tomography
- 3D images of the body
- 18-F-Dopa isotope injected

Why does my Child need a PET scan?

- Gold standard for localizing focal lesions
- No genetic cause
- Unresponsive to medical treatment

PET scans in London

- Previously in Berlin, Germany
- No PET Scanner at GOSH
- UCLH approx 10mins away
- Isotope made in Wolfson Center
Manchester University

18f Dopa PET scans at GOSH/UCLH

- To date: 24 PET scans since November 2010
- 1 older child – no sedation
- Nurse led sedation
 - Chloral Hydrate 50mg/kg
 - sleep deprive
 - NBM 4 hours / 2 hours

Before the scan

- Glucagon and Octreotide stopped
- TPN stopped
- IV Dextrose
- Diazoxide not stopped

Day of Scan

- Cannula inserted
- Nasogastric tube inserted
- Nil by mouth 4 hrs food and 2 hrs clear fluid.
- Sleep deprive
- Nurse escort to UCLH

Day of Scan cont

- Patient arrives before DOPA
- Sedation given
- Taken to PET/CT
- Monitored throughout.
- New – PET MRI after CT

Success so far

- All successful with good quality images
- 1 patient - oral sedation no appropriate
- Interest from other centres in our success

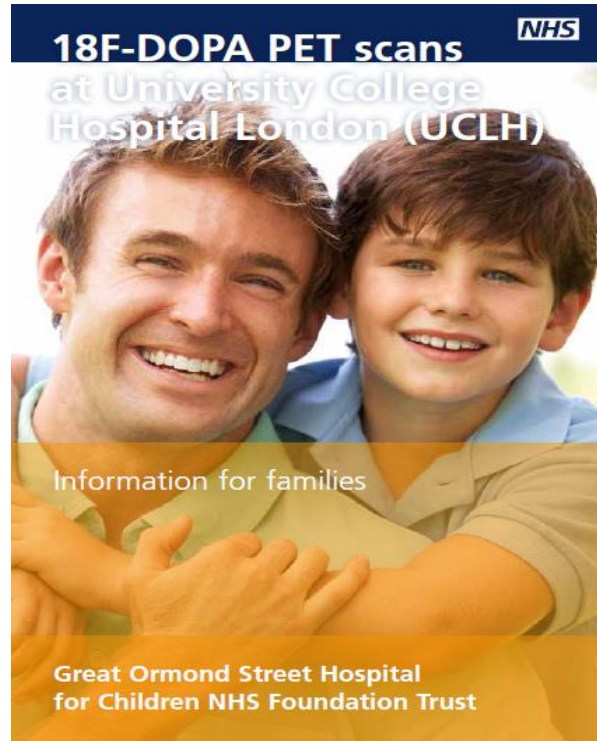
Implications

- Nurse Escort
- Reduces risk of GA
- No waiting list for GA
- Reduces child/parental anxiety
- Quick recovery
- Reduces cost
- Multi-centred approach

Resources

- Care Pathway
- PET scan information leaflet

Parent leaflet



This information sheet explains about the 18-F-DOPA PET scan, what it involves and what to expect when your child visits University College Hospital London (UCLH) from Great Ormond Street Hospital (GOSH) to have the scan.

What is an 18F-DOPA PET scan?

A positron emission tomography (PET) scan gives very detailed, three-dimensional images of the body. It works by injecting a substance called an isotope called 18-F-DOPA so you may hear the scan referred to by this name.

If you are pregnant or think you could be pregnant, please let us know at least two days before your child is due to have the scan. There is a risk that the isotope given to your child could harm your unborn baby.

Why does my child need a PET scan?

A PET scan is regarded as the 'gold standard' for diagnosing the focal form of hyperinsulinism. More information about hyperinsulinism is available in our leaflet or from the support group website (details later in this booklet).

Cells in the pancreas called beta cells release insulin to regulate blood glucose level. In hyperinsulinism, the beta cells produce too much insulin lowering the blood glucose level to a dangerous level. Blood glucose is vital for all systems in the body to function properly, but especially the brain.

With this scan, the doctors are trying to find out whether the beta cells in one area of the pancreas (focal) are producing too much insulin or whether beta cells spread throughout the pancreas (diffuse) are responsible. The treatment recommended by the doctors depends on the results of the scan. The focal lesion is very tiny and cannot be seen by other X-ray techniques.

Why does my child need to go to University College Hospital London (UCLH) for the scan?

PET scanning is a relatively new technology. Some hospitals in the UK have PET scanners, but currently we do not have one at GOSH. The nearest hospital with a PET scanner is UCLH – about 15 minutes walk away from GOSH.

What happens before the PET scan?

Your child will need to be prepared for the scan in various ways.

Firstly, if they are currently on total parenteral nutrition (TPN), this will be stopped and replaced with an intravenous glucose drip two days before the scan is scheduled. If your child is feeding by mouth as well as by TPN, this will continue. They will also need to stop taking diazoxide, chlorothiazide, glucagon and octreotide medicines two days before the scan. These medicines reduce insulin secretion so need to be stopped so the scan can pick up the beta cells that are overproducing insulin.

The nurses will insert a cannula (thin, plastic tube) into a vein in your child's hand or foot the day before the scan is scheduled. The cannula will be used to inject the isotope. If your child has a double-lumen central venous catheter, this can be used to inject the isotope so your child will not need a cannula.

The day of the scan

On the morning of the scan, the nurses will pass a naso-gastric tube so that the sedation medicine can be given easily. Your child will not need to get undressed for the scan. However, they should wear clothes without any metal, such as zips, buttons or fasteners, as this interferes with the scan.

Your child will need to 'fast' or stop eating and drinking before the sedation as it can be dangerous for liquid to be breathed into the lungs while under sedation. The nurses will discuss the precise times after which your child should not eat or drink anything. They will have an intravenous dextrose infusion from this fasting time until your child is back at GOSH. It will also help if you can keep your child awake during the morning so that the sedation is more effective.

At midday, an ambulance will take you and your child to UCLH for the scan. Unfortunately, as space is limited in the ambulance, only one parent will be able to travel with your child. They will

be accompanied by a nurse and in some cases a doctor. If your child's other parent also wants to go to UCLH, it is a short walk of about 15 minutes away from GOSH. Taxis are also available – often outside the main reception at GOSH – or you can call them from the free phone in reception or we can organise one for you.

What to take with you

Parents who have been to UCLH with their child suggest taking a favourite toy, soother or blanket with you. It is also a good idea to take a spare set of clothes and nappies if your child is using them.





At UCLH

Your child will be admitted to the general children's ward – called T11 south. The sedation medicine will be given through your child's nasogastric tube about an hour before the scan is due to start. Once sedation is given, your child will go down to the scanner on a trolley.

Once your child is sleepy, the scan will start. You will be asked to leave the scanning room and sit in the waiting room opposite while

the isotope is being injected. After the injection, two adults will be allowed to stay for the majority of the scan.

Your child's intravenous dextrose infusion will continue during the scan – we will take regular blood glucose measurements as well as observing their heart rate and oxygen saturation levels.

After the scan, your child will return to the children's ward to recover from the sedation and start eating and drinking again. When they have recovered, they will be transferred back to GOSH in an ambulance as before.



TPN and other medications can recommence immediately.

Are there any risks?

There are no side effects to the scan. The isotope that we inject will not interfere with any medicines your child is taking. The isotope contains a very small amount of radioactivity, similar to the amount we receive from natural background radiation in about six



months. This is not a danger to your child as the isotope becomes inactive in the hours following the scan. However, it is necessary to take some precautions for the first 24 hours after the scan, while the isotope is leaving your child's body. These are explained in the next section.

There is a risk that the isotope could harm an unborn baby, so please follow the instructions described earlier in this leaflet to minimise these risks.

After the scan

For the first 24 hours after the scan:

Your child should drink plenty of fluids. This will allow the isotope to pass out through their body as quickly as possible.

If your child is toilet-trained, they should go to the toilet as often as possible. Hand washing afterwards is very important.

If your child is in nappies, you should change them frequently and dispose of the dirty nappy in

an outside bin. Wash your hands thoroughly after nappy changing.

If you are pregnant or think you could be pregnant, you should avoid contact with your child's bodily fluids, such as urine (wee), faeces (poo) and vomit

Your child should continue to take any medicines as usual. The isotope will not affect them in any way.

Getting the results of the scan

The doctors will interpret the results from the scan and discuss them with your consultant at GOSH as soon as possible. Your consultant will then explain the plan of treatment for your child and when it is likely to start.

Useful websites

UK CHI Support Group

17 Bridge End Lane, Great Notley,
Braintree CM77 7GN

Tel: 01376 528569

Website: www.hi-fund.org

Further information and support

The Congenital Hyperinsulinism Service at GOSH is one of two National Commissioning Group sites for CHI in the UK. The other site is shared between Manchester Children's Hospital and Alder Hey Hospital in Liverpool. By providing services on a national basis, the service is able to develop expertise in rare conditions, improve learning and deliver a safer service. The CHI service was commissioned in 2006.