

# Welcome to the Children's Epilepsy Surgery Service

Information for families

Great Ormond Street Hospital for Children  
NHS Foundation Trust

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## **This booklet explains about the epilepsy surgery programme at Great Ormond Street Hospital (GOSH) and what to expect while your child is being assessed for surgery.**

Since 2012, the NHS has made epilepsy surgery a nationally commissioned service and in England there are four centres designated as part of the Children's Epilepsy Surgery Service (CESS). The recognised centres are Birmingham, Bristol, Liverpool/Manchester, and Great Ormond Street Hospital in partnership with King's Health Partners.

GOSH has had a programme for surgery for treating epilepsy in children since 1992. GOSH has the facilities needed for the investigations, tests and treatment your child may need. These facilities are specifically for children and the specialists who use them have many years' experience of children with epilepsy. We work closely with University College London Institute of Child Health (UCL ICH), with many of the team working in both GOSH and UCL ICH.

GOSH CESS team also works in collaboration with King's Health Partners (KHP) and Young Epilepsy (YE).

KHP brings together King's College London and three successful NHS Foundation Trusts (Guy's and St Thomas', King's College Hospital and South London and Maudsley). KHP also have a long-established very experienced children's epilepsy surgery service and are the South East Thames region centre for children's neuroscience.

YE is based on a beautiful 60 acre rural campus in the village of Lingfield, on the Surrey, Sussex and Kent borders. YE provides medical assessment, rehabilitation, care and education for children and young people with epilepsy and other neurological conditions. At YE, the Neville Childhood Epilepsy Centre provides inpatient interdisciplinary assessments and rehabilitation packages for children and young people aged 3 to 19.

These partnerships mean that we can draw on the expertise of professional staff from all of these organisations, to provide a high standard of service for children and young people, with the benefit of the latest medical research.

## My Team

My Consultant is: \_\_\_\_\_

My Nurse is: \_\_\_\_\_

Throughout your child's evaluation at GOSH, we share your child's care with your consultant paediatrician at your local hospital and your consultant paediatric neurologist at your local children's hospital. They remain essential to your child's on going management and are your first port-of-call for questions about medical treatment. GOSH does not have an emergency department. Your local hospital continues to be the correct place for you to take your child if an immediate review is needed. Your local hospital paediatric team can then speak to us at any time and together your teams will advise on the best treatments for your child.



## The Epilepsy Team

The Epilepsy Team is multi-disciplinary. Members of the multi-disciplinary team (MDT) include neurologists, neurosurgeons, neuropsychiatrists, neuropsychologists, developmental specialists, neurophysiologists, EEG physiologists, nurse specialists, nurses, neuroradiologists, social workers, speech and language therapists, occupational therapists, play specialists, physiotherapists and administrative staff.

You may need to contact the following people at some point during the process:

- For queries about your child's care, including outpatient or clinic appointment details, please phone your consultant's secretary (Medical PA)
- For queries about your child's admission to GOSH, please contact our Admissions Manager on 020 7405 9200 extension 5789
- For questions about surgery, medications and liaising with your community team, please contact our Nurse Practitioner – Epilepsy Surgery on 020 7405 9200 extension 1592
- For any other queries, please contact the Epilepsy Service Coordinator on 020 7405 9200 extension 5594

## Video-telemetry, data collection and storage

As part of the CESS network, core information regarding your child will be collected as he or she progresses through the assessment pathway. This information will be stored on a secure database called ORION, which enables the entire CESS network from across England to collate information. Staff from other centres across the CESS network will be able to access your child's information but will only do so for audit purposes.

Basic demographic information is collected including name, date of birth and gender. The clinical data recorded includes details of your child's seizure history, investigations, developmental assessments and treatments. This information will be held securely on the ORION database and used by the CESS network for teaching other centres, audit purposes and monitoring the long term outcomes of epilepsy surgery.

When performing video EEG telemetry, we need to record your child's seizures. This video recording is stored as a record alongside your child's EEG. Analysis and discussion

of clinical information, video and still images is necessary to decide the correct management plan for your child. This information will be reviewed by other professionals in the CESS network to help determine the best treatment for your child.

Under the Data Protection Act, it is necessary to obtain your permission as personal information will be shared with other centres from across the CESS network.

If you choose not to share your child's information then your child's treatment and care at GOSH will continue. However the full benefits and advantages of the CESS network will not be available, including input from other clinicians across the network.

Your information will be protected under the principles of the Data Protection Act 2003 which means it will be stored safely, can only be used lawfully and can only be kept for the purpose and time span of the project. Information kept on file will be the same as that which is usually kept by GOSH.

## What is epilepsy?

The brain is like an electrical circuit, with impulses flowing from nerve to nerve in an organised fashion. Sometimes people experience disorganisation of such activity. This causes a sudden burst of electrical activity in the brain cells, deep in the brain, which causes the epileptic seizure or fit.

The cause of this seizure may differ from child to child. The seizure may start in one part of the brain (focal epilepsy) or the whole brain at the same time (generalised epilepsy).

Focal epilepsy may spread to involve the whole brain (secondary generalisation).

## How can surgery help my child's epilepsy?

The aim of the surgery is to remove the underlying cause of the seizures and therefore cure the epilepsy. In some cases, however, it may only be possible to reduce the frequency of seizures as the cause cannot totally be removed.

## Which children might be helped by surgery?

We usually recommend surgery for children with focal epilepsy who continue to have troublesome seizures despite trying anti-epileptic medicines. Therefore we will usually consider surgery after a few years of epilepsy. However, we may consider surgery where it is very clear at an early stage that seizures are particularly difficult. Due to modern methods of investigation, it is now possible to offer surgery much earlier in the course of the epilepsy and to younger children. There is no youngest age for surgery.

Children with epilepsy may have additional problems with learning and behaviour and/or special educational needs, and this may also contribute to a decision about surgery.

## The Structure of the brain

These diagrams illustrate the structure of the normal brain. There are two hemispheres connected in the centre by the corpus callosum.

In each hemisphere there are four lobes: ❶ the temporal lobe, ❷ the occipital lobe, ❸ the parietal lobe and ❹ the frontal lobe.





## How will the doctors decide whether an operation is suitable for my child?

When your child is referred here by your local medical team, he or she will have an initial outpatient visit to see one of the paediatric neurologists. During this visit, the neurologist will discuss your child's history in great detail and carry out a full examination. This is to see which type of epilepsy your child has, review his or her treatment and talk about any problems. The neurology team will also discuss the role of the operation with you and which investigations your child will need.

Your child will need a series of investigations to find out whether there is a specific area of brain causing the seizures, and whether this could be removed without causing further problems for your child. This will involve various outpatient and inpatient visits, to build up as full a picture as possible of your child's seizures.

The process of investigation and surgery is likely to involve a sequence of visits. We may ask other hospitals to assist us in completing our investigations as not all of the tests are available at GOSH.

Children move through the decision-making process as quickly as is needed for their clinical condition. Sometimes it is apparent in a few weeks that an operation is needed and this may go ahead quickly. For other children the decision process may take up to a year, especially if it is a complex decision or the seizure profile changes. More usually the investigation and decision making process takes between six and nine months.

## What tests and scans will my child need?

Your child may need various investigations to decide exactly where the seizures are coming from, and whether that part of the brain is performing any vital function. Not all children will undergo every investigation. Which investigations are performed will depend on the type of epilepsy your child has and whether the doctor feels they are appropriate when deciding about epilepsy surgery.

### **Electroencephalogram (EEG)**

This is the brain wave test. Your child has probably had one or more of these before, either at this hospital or elsewhere. An EEG usually takes half an hour to an hour. This test shows whether there is abnormal seizure activity in certain areas of the brain between seizures.

### **Video-EEG telemetry monitoring**

This is an EEG performed as an inpatient over a longer period of time, sometimes several days and nights with a video camera. This test is used to record a number of seizures. If the seizures are not very frequent, we may need to reduce your child's anti-epileptic medicines while he or she is in hospital. We shall need to find out whether the seizure(s) recorded are typical for

your child and review the EEG to see where the seizures originate from electrically and how they spread. Video-EEG telemetry can be done at GOSH or at our partner unit, Young Epilepsy in Lingfield, Surrey.



## **Magnetic Resonance Imaging (MRI)**

This is a type of brain scan that uses magnetic signals rather than x-rays to obtain a very detailed picture of the brain. This is to see whether there is a structural abnormality that may be causing the seizures. Your child may have had an MRI elsewhere. We will look carefully at any MRIs before we decide if we need to repeat the scan. If we do repeat the MRI scan, this is because either our scans will be more detailed, more up to date or we need more information that has not yet been obtained.

## **Neuropsychology**

These are tests performed to see whether your child has any particular learning problems. This involves up to eight hours of games and puzzles split into several sessions. The tests can also tell us whether the part of the brain from which we think the seizures are coming is performing any useful function. This will help us decide whether removing it would cause problems. In young children, these assessments are performed by our Developmental Epilepsy Service.

## **Neuropsychiatry**

A psychiatrist with experience of epilepsy surgery sees the children and their families as part of the initial assessment. This is, in part, to see what problems the epilepsy may be causing and whether surgery may help to relieve them. We will discuss the changes you hope for as a result of surgical treatment. You will also have an opportunity to discuss in detail any additional concerns you might have about emotional, behavioural or social problems, and whether additional treatments for these should be put in place. This is important because treating other problems will help maximise your child's quality of life in conjunction with any operation they may have.

## **PET scans**

A PET scan is a special CT scan of the brain. Your child will be given an injection of a radio-active dye (tracer) into a vein. This tracer shows areas of hypo-metabolism in the brain (cold spots). This helps show us which areas of the brain may be involved in your child's epilepsy. PET scans are performed

at our partner site (the PET Imaging Centre at St Thomas's).

### **SPECT scans**

A SPECT scan gives a picture of blood flow within the brain. The pattern of blood flow may change during a seizure. The scan is performed after an injection of a radio-labelled dye which shows up on the scan. Two scans are needed, one where the injection has been given during a seizure and one where the injection has been given when your child has not had a seizure. These scans can give us more information as to where the seizures are starting. We will look at the two scans separately and also compare the two together to give us this information.

### **Magneto-encephalogram (MEG) scan**

The brain works by a series of nerve impulses, which cause electrical signals within the brain. These signals (also called brainwaves) can be recorded through the scalp using an EEG. The electrical signals also produce weak magnetic fields, which can be measured through the skull and scalp using a MEG scan.

### **Other assessments**

Other types of assessment, for example, speech and language therapy, occupational health, physiotherapy, ophthalmology, functional MRI and EEG-fMRI may be organised depending on the type of epilepsy, and the types of problems your child has. This will give us a set of results which we can use to see if surgery will help and to compare past surgery. These tests may need to be repeated before the team can decide about surgery.

All these investigations take place during an admission to Koala Ward and several outpatient visits.



## Discussing the results of these tests and scans

When all the tests and assessments have been performed, the epilepsy MDT, including members from both GOSH and King's Health Partners, meet to look at the results at the Epilepsy Surgery MDT Meeting. The team will discuss whether surgery is an option for your child. They will discuss whether all the seizures come from one area of the brain and whether the operation would make any existing physical or learning problems worse.

The epilepsy MDT will make one of four decisions:

- Surgery is to be offered; no further investigations are needed
- Surgery may be an option but further investigations are required
- Surgery may be an option in the future but not at the present time
- Surgery is not an option

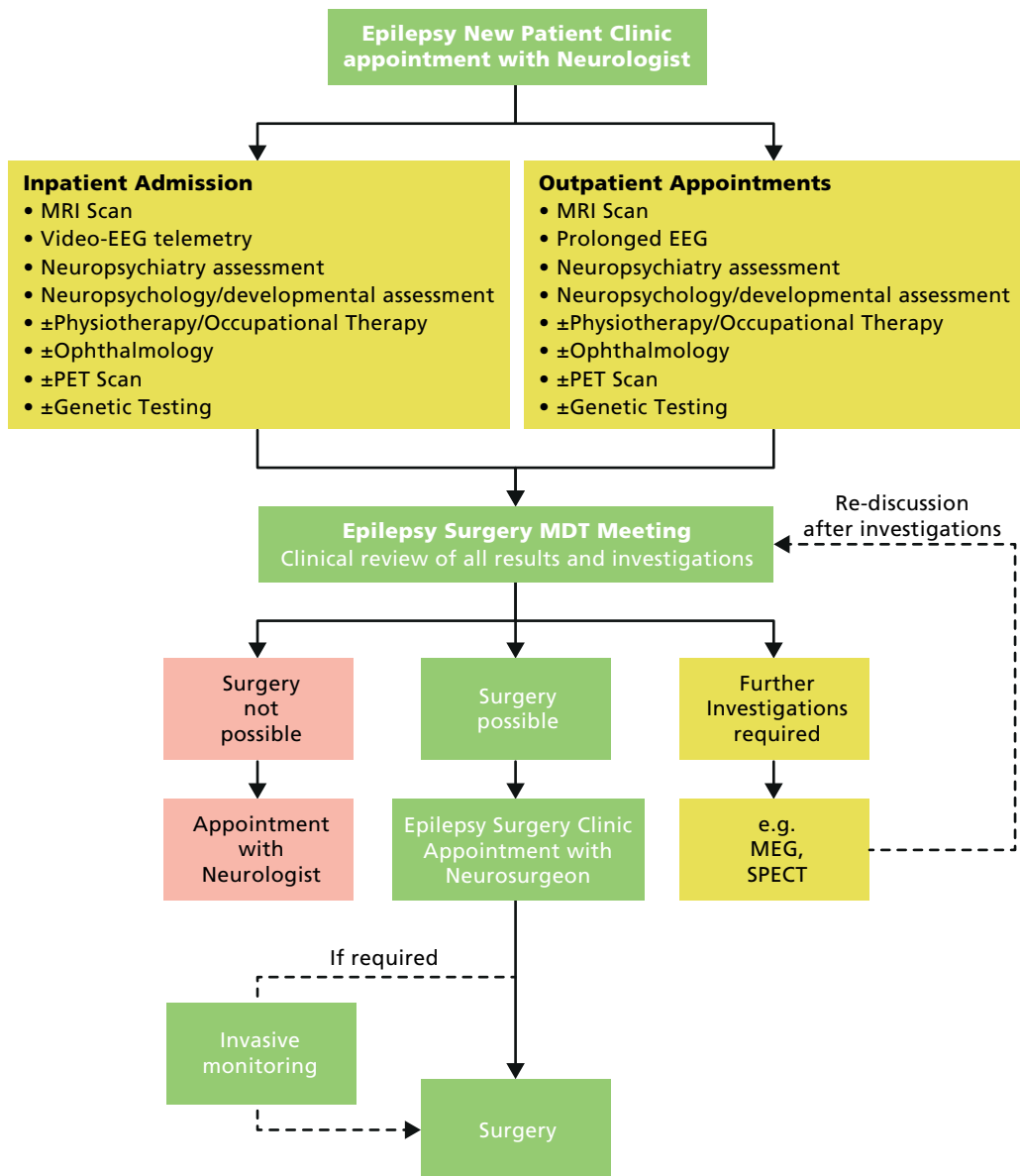
If surgery is not an option or further investigations are required, you will be asked to attend the epilepsy clinic to discuss this with your child's

paediatric neurology consultant. If your child is offered surgery, there will be an outpatient appointment at the joint epilepsy surgery clinic.

## Epilepsy Surgery Clinic

At this clinic you will be able to meet the surgeon and he/she will explain which operation is proposed, what it entails and the risks and benefits to your child. An epilepsy consultant and specialist nurse will also be there. You will have the opportunity to ask questions, be given information to read about the proposed operation and allowed time to think about the information given to you before you decide whether you want your child to have the operation. When you have decided, please ring the nurse practitioner – epilepsy surgery and write to the neurosurgeon to confirm you wish to proceed. The surgeon will then offer a date for the operation and we will let you know the date by letter or sometimes the Neurosurgery Medical PA will call by phone.

## Summary of the Patient Journey



## What types of operation are there?

Different types of operation are used for different types of epilepsy. More detailed leaflets are available to explain more about these operations.

### **Focal resection**

This is considered when one part of the brain is thought to be responsible for the seizures. The operation removes the abnormal area of brain that is causing the epilepsy but leaves the parts that are still serving useful purposes. If the part of the brain causing the seizures is in the temporal lobe, the surgeon will perform a type of focal resection called a 'temporal resection'. If the part of the brain causing the seizures is in one of the other lobes, then the operation will be called an 'extratemporal resection'. There are a number of different types of extratemporal resection. If one of these is recommended for your child, we will discuss it with you in detail.

### **Hemispherectomy**

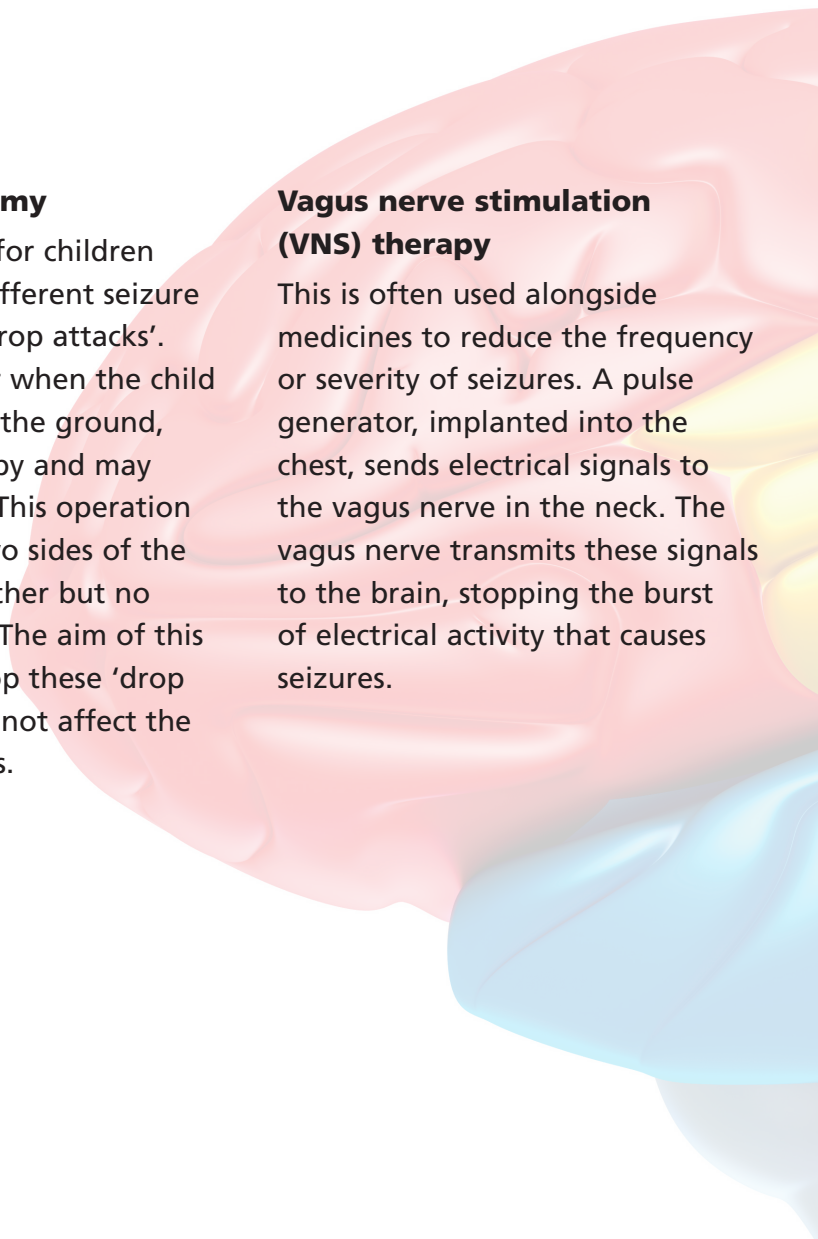
This operation disconnects or removes one half of the brain from the other. Children who may benefit from this procedure usually have a long history of weakness down one side of the body. This is usually the result of severe damage to the opposite side of the brain, which may have been present from birth. The child's general development may have been slow but normal. If the seizures are considered to arise from the damaged part of the brain, it is removed or disconnected to stop the seizures. This may not lead to any further weakness as the brain has usually reorganised other functions to the unaffected side.

### **Corpus callosotomy**

This is considered for children who have many different seizure types, including 'drop attacks'. Drop attacks occur when the child suddenly drops to the ground, either stiff or floppy and may harm themselves. This operation disconnects the two sides of the brain from each other but no tissue is removed. The aim of this procedure is to stop these 'drop attacks' but it will not affect the other seizure types.

### **Vagus nerve stimulation (VNS) therapy**

This is often used alongside medicines to reduce the frequency or severity of seizures. A pulse generator, implanted into the chest, sends electrical signals to the vagus nerve in the neck. The vagus nerve transmits these signals to the brain, stopping the burst of electrical activity that causes seizures.





## What are the risks of the operation?

Healthy children usually cope well with the anaesthetic, but the risk increases if your child has other problems. Any surgery carries a small risk of infection or bleeding. There is a five per cent risk of complications, which may mean that your child could have to stay in hospital longer than expected. In general, there is a less than one and a half per cent chance that your child will suffer some damage to his or her brain that could result in weakness down one side of the body. This will in part depend on the parts of the brain involved. This will be discussed in more detail with regard to your own child.

## Are there any alternatives to the operation?

The doctors could continue to try to control your child's seizures with anti-epileptic medicines, VNS therapy or a special diet for epilepsy called the Ketogenic Diet. However, although there are new medicines available all the time,

people who have not responded to them early, have a smaller chance of responding with each new medicine tried. This means that there is only a small chance of medicines controlling your child's seizures long term.

## How successful is surgery for epilepsy generally?

The epilepsy team will discuss the expected results of surgical treatment with you and your child. These vary according to the child's particular circumstances. The results are often excellent in commonly performed operations; overall around 70 per cent of children will become free of seizures. However, for a small number of children surgery is unsuccessful. The main purpose of the complex series of investigations already outlined is to reduce the number of children for whom surgery is unsuccessful, and to give you as much information as possible about the chance of success.

## What about follow up treatment?

When you and your child leave hospital, a nurse specialist will call you on the telephone 10 to 14 days later, to ask how your child is recovering and how the wound is healing.

We will arrange an appointment in the epilepsy surgery clinic. This is likely to be around six weeks after you leave hospital.

At six months, your child will see his/her named epilepsy consultant at GOSH. Do not change/reduce/stop your child's drugs until your doctor advises you to do so; this may not be for several months.

Coming up to 12 months after the operation, your child will need to have a few more investigations and check-ups. These may include an MRI, EEG, neuropsychology, physiotherapy, ophthalmology and a review in the epilepsy surgery clinic.

We will continue to review your child at regular intervals for several years if needed. If all is well, your follow-up will be with your own local consultant paediatrician and/or consultant paediatric neurologist.

Our research team may also wish to contact you and your child from time to time over the years to help us improve our services and treatments. We would appreciate your continued help.

Your child and your family will go through a period of adjustment after the operation. We encourage you to discuss this as much as possible. We can make appointments for you with other specialists if necessary.

## Notes

## Support Groups

- **Young Epilepsy** – Young Epilepsy is set in a campus of over 200 acres in the Surrey countryside. The charity provides medical assessment, rehabilitation, care and education for children and young people whose lives have been adversely affected by epilepsy and other neurological conditions, including acquired brain injury resulting from accident or illness. For more information, visit [www.youngepilepsy.org.uk](http://www.youngepilepsy.org.uk)
- **Epilepsy Society** – Epilepsy Society is the UK's largest medical charity in the field. Epilepsy Society provides epilepsy information services in healthcare settings and a confidential helpline for everyone affected by epilepsy. The services are manned by trained professionals or volunteers who provide information and a listening ear to people and families affected by epilepsy. For more information, visit [www.epilepsysociety.org.uk](http://www.epilepsysociety.org.uk) or call the Helpline 01494 601400
- **Epilepsy Action** – Epilepsy Action is the leading organisation working with and for people affected by epilepsy. Each year, Epilepsy Action helps around one million people understand epilepsy and treatment options through its helpline, website and events. The charity improves healthcare by supporting epilepsy specialist nurses and epilepsy research. It improves the lives of everyone affected by epilepsy by campaigning for better healthcare and fairer access to education and employment. For more information, visit [www.epilepsy.org.uk](http://www.epilepsy.org.uk) or call the Epilepsy Helpline on Freephone 0808 800 5050.
- **The Muir Maxwell Trust** – The Muir Maxwell Trust is a paediatric epilepsy charity, aiming to make a difference by providing children and their carers with practical support while raising awareness and understanding of childhood epilepsy. For more information, visit [www.muirmaxwelltrust.com/home](http://www.muirmaxwelltrust.com/home)

© GOSH NHS Foundation Trust October 2013

Ref: 2013F0555

Compiled by the Epilepsy Surgery Team  
in collaboration with the Child and Family Information Group

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