Welcome to 9 EAST, the Pediatric Epilepsy Monitoring Unit at NYU Langone Medical Center. We understand that this can be a stressful time and you may have many questions. We hope this booklet will help answer your questions and make your stay with us a positive one. Please read through the information below and make sure to ask any member of your health care team about any remaining questions or concerns.

We look forward to making your stay on Pediatrics a positive one.

-THE EPILEPSY MONITORING UNIT TEAM
You may be concerned because your insurance provider approved only a 3-day hospital stay. The insurance companies are aware that this type of hospitalization often needs to be extended because we are waiting for seizures to happen. Most often, companies approve extensions. If there are any issues or problems, we will be notified and will discuss it with you.

We understand that you have everyday activities, plans, responsibilities and families. Waiting for seizures to happen can sometimes be monotonous and we want to maintain our ability and in a way that is most convenient for you.

Your note: We care about your current clothing while they are here, but we ask that they wear buttonless clothing if they are able to do so. We also need to disconnect the monitoring equipment when you change your clothes. Every time we disconnect the monitors, we risk missing the chance to record an event. Recording occurs in your child’s room or elsewhere. Remember the sooner we get the needed number of recordings, the sooner you and your child will be able to go home.

WHAT TIME SHOULD I BE READY TO LEAVE THE HOSPITAL?

A recliner next to your child’s bed is provided for sleeping. One recliner does not look so that we can arrange access to help you if your child has a seizure. Remember, the video does not record the bathroom. It is important that you tell your nurse when your child needs to use the bathroom so an attendant can stand outside of the door to assist you if your child has a seizure.

Note: If we are recording medications, we may also use an intranasal (IV) catheter in one of your child’s veins. The IV is placed in case we need to give “seizure medicine” (such as Activel) to stop a seizure.

For your child’s safety, it is unit policy that you will not be allowed to leave the floor (except for scheduled tests or procedures and you will be escorted to and from these) until you are released from the hospital.

HOW WILL I KEEP MY CHILD SAFE?

Your child’s safety is very important to us. The procedures listed below are followed to help keep you safe during your stay on FEAST.

Your child is monitored by staff at the nursing station. Staff at the nursing station continuously view monitors that display:

- Both EEG and heart rate recordings.
- A live view of your room. The video records your entire room EXCEPT the bathroom.
- Each bed has side cushions to help protect your child. If your child falls.
- If your child feels a seizure coming on, press the “event” button if possible. (Your nurse will show you how to do this.) When you press the “event” button, a nurse will come and evaluate your child. It also marks the EEG record so the doctors can see exactly when the seizure occurred. In addition, please document the seizure on the event log provided.
- If your child is having a seizure or the video camera can record your child. Try to stand on the side and slightly away from your child, but if your child’s safety is most important, but recording the seizure is also very important.

WHAT HAPPENS WHEN I LEAVE THE HOSPITAL?

Before you leave the hospital we will:

- Review any medications that will begin after you and your child go home.
- Remember your child should not take any new seizure medications. You should always administer medication exactly how the healthcare team tells you to. It is possible that the dose of a medication will change one or more times after you leave the hospital. Medication change orders will be written out and explained to you.
- Give you new prescriptions.

Note: It is important to make sure that you know whether your pharmacy has any new medications ready on the day you leave the hospital.

We will also tell you when to follow up with your epileptologist.

WHY ARE WE HERE?

There are four main reasons why your child may have been admitted to 9 East.

1. To answer the question “Are they having seizures?” We can help to answer this question by recording their typical seizure or episode on video EEG. It is possible they are having something that looks and acts like a seizure, but is not.

2. To find out what kind of seizures they are having and what part of the brain they are coming from.

There are two main categories of seizures:

- “Generalized” seizures. The electrical activity that produces the seizure starts in the entire brain.
- “Partial” or “focal” seizures. The electrical activity starts in one specific region of the brain.

We can usually determine what type of seizure your child is having by recording their typical seizure on video-EEG.

- “Status epilepticus.” We will discuss the plan to lower the dose of their medications with you. We do this gradually.
- “Status epilepticus.” We often do not lower medications on the first night in the hospital.

Using “video deprivation”:

We will have your child stay awake later than they normally would when at home.

- Seizures may occur the next day when they are tired.

Doing hyperventilation and photic stimulation (flashing lights). These tests are done while your child is in bed. They involve deep-breathing and flashing lights. Both deep-breathing and flashing lights can cause seizures in some people. One technician is with your child to do the test and to make sure they are safe if they have a seizure.

Your safety is Important to us!

WHAT TIME SHOULD I BE READY TO LEAVE THE HOSPITAL? Be ready to leave the hospital at 10:00 AM.

As mentioned before, we began planning for the day you leave the hospital early in the hospital stay. We want to make sure that your child’s entire medical needs (medications to regular doctor visits, seizures, medications prescribed for your condition) are taken care of by 10:00 am on the day your doctor says you are ready to go home. We ask that you make any transportation arrangements in advance so that you are ready and able to leave at 10:00 am. If you need to leave earlier, we will do our best to make this possible. If you need help arranging transportation, we can give you a lift via medical van (or if one is available, another vehicle). You should talk to your social worker as soon as possible. Ask your nurse if you need to speak with the social worker.

WHO IS TAKING CARE OF MY CHILD?

A team of health care professionals will work with a doctor to take care of your child. Some members of the team will come to see you every day. These team members include:

- Attending doctor on the unit.
- Nurse Practitioners.
- Nurse Manager.
- Neurology and pediatric housestaff (interns and residents).
- EEG Lab Technician.
- Social Workers.
- Recruitment Therapist.
- Registered Dietitian.
- Patient Advocate.
- Parent Care Technicians.
- Medical students.
- Child Life Specialists.
- Others as needed including psychologists and social workers.

A member of our Epilepsy team is always available if you have questions/concerns about seizure activity. Ask your child’s nurse to page the covering physician.

HOW LONG WILL MY CHILD BE HERE?

Your son or daughter is most likely scheduled to be here for about 3 days. This time may vary depending upon why they are here. We ask that a parent remains with the child throughout the hospitalization. Seizures are unpredictable so though we will work to cause a seizure as quickly as possible, we never know how long it will actually take to record one.

Which medication is an option for your child?

- Sodium valproate
- Carbamazepine
- Lamotrigine
- Clobazam
- Phenytoin
- Levetiracetam
- Topiramate

Your child’s doctor will discuss the pros and cons of each medication with you.

Sodium valproate

- Sodium valproate is available in injection form.
- Sodium valproate is used for children who have had a seizure and are being started on sodium valproate to prevent future seizures.

Carbamazepine

- Carbamazepine is a medication that is usually started before the child is actually having seizures.
- Carbamazepine is started in cases where we know there are frequent seizures that are not being controlled.
- Carbamazepine is used for children who have frequent seizures and are not controlled with sodium valproate.

Lamotrigine

- Lamotrigine is a medication that is usually started before the child is actually having seizures.
- Lamotrigine is started in cases where we know there are frequent seizures that are not being controlled.
- Lamotrigine is used for children who have frequent seizures and are not controlled with sodium valproate or carbamazepine.

Clobazam

- Clobazam is a medication that is usually started before the child is actually having seizures.
- Clobazam is started in cases where we know there are frequent seizures that are not being controlled.
- Clobazam is used for children who have frequent seizures and are not controlled with sodium valproate or carbamazepine.

Phenytoin

- Phenytoin is a medication that is usually started before the child is actually having seizures.
- Phenytoin is started in cases where we know there are frequent seizures that are not being controlled.
- Phenytoin is used for children who have frequent seizures and are not controlled with sodium valproate or carbamazepine.

Topiramate

- Topiramate is a medication that is usually started before the child is actually having seizures.
- Topiramate is started in cases where we know there are frequent seizures that are not being controlled.
- Topiramate is used for children who have frequent seizures and are not controlled with sodium valproate or carbamazepine.

Levetiracetam

- Levetiracetam is a medication that is usually started before the child is actually having seizures.
- Levetiracetam is started in cases where we know there are frequent seizures that are not being controlled.
- Levetiracetam is used for children who have frequent seizures and are not controlled with sodium valproate or carbamazepine.

Your child’s doctor will discuss the pros and cons of each medication with you.

WHEN SHOULD I START MEDICATION?

Your child’s doctor will discuss the pros and cons of each medication with you.

- Sodium valproate
- Carbamazepine
- Lamotrigine
- Clobazam
- Phenytoin
- Topiramate
- Levetiracetam

Your child’s doctor will discuss the pros and cons of each medication with you.

WHEN SHOULD I START MEDICATION?

Your child’s doctor will discuss the pros and cons of each medication with you.

- Sodium valproate
- Carbamazepine
- Lamotrigine
- Clobazam
- Phenytoin
- Topiramate
- Levetiracetam

Your child’s doctor will discuss the pros and cons of each medication with you.

WHEN SHOULD I START MEDICATION?

Your child’s doctor will discuss the pros and cons of each medication with you.

- Sodium valproate
- Carbamazepine
- Lamotrigine
- Clobazam
- Phenytoin
- Topiramate
- Levetiracetam

Your child’s doctor will discuss the pros and cons of each medication with you.

YOUR MEDICATIONS

Your child’s doctor will discuss the pros and cons of each medication with you.

- Sodium valproate
- Carbamazepine
- Lamotrigine
- Clobazam
- Phenytoin
- Topiramate
- Levetiracetam

Your child’s doctor will discuss the pros and cons of each medication with you.

- Sodium valproate
- Carbamazepine
- Lamotrigine
- Clobazam
- Phenytoin
- Topiramate
- Levetiracetam

Your child’s doctor will discuss the pros and cons of each medication with you.

- Sodium valproate
- Carbamazepine
- Lamotrigine
- Clobazam
- Phenytoin
- Topiramate
- Levetiracetam

Your child’s doctor will discuss the pros and cons of each medication with you.

- Sodium valproate
- Carbamazepine
- Lamotrigine
- Clobazam
- Phenytoin
- Topiramate
- Levetiracetam

Your child’s doctor will discuss the pros and cons of each medication with you.