

Comprehensive Epilepsy Center

FAQ



What is epilepsy?

Epilepsy is a common brain disorder that results from recurrent seizures due to abnormal electrical activity in the brain.

The CHLA Comprehensive Epilepsy Center is part of Neurological Institute. Our Epilepsy team consists of expert specialists who will take care of your child. The center provides every tool needed for the diagnosis and treatment of all levels of epilepsy including:

- An inpatient Epilepsy Monitoring Unit (EMU)
- Inpatient video electroencephalogram (EEG) monitoring
- Outpatient EEG and ambulatory (take home) video EEG services

EEG recording (for example: brain wave recording) is a safe test that monitors electrical activity in the brain.

The Comprehensive Epilepsy Center is capable of treating very complex medical conditions. We personalize care for every child's unique needs to improve their quality of life. There are different options to treat children with epilepsy including:

- medical management
- resective and laser ablative surgery
 - In resective surgery, the neurosurgeon will remove brain tissue causing seizures.
 - In laser ablative surgery, the neurosurgeon will use light and heat to target the area of the brain causing seizures.
- diet therapy
- neuromodulation
 - In neuromodulation, a stimulator will send electrical signals to the brain to manage seizure activity.

Who will be caring for my child?

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| Physician Team | Your child's medical care is led by a dedicated team of doctors including a senior attending doctor. Fellows and residents are completing specialized training and will also be caring for your child. |
| Advanced Practice Providers | One of our nurse practitioners or physician assistants will participate in your child's care plan along with the primary provider. |
| Nursing Team | Our team of Registered Nurses (RNs) and Licensed Vocational Nurses (LVNs) will help you with your care needs. |

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| Nurse Care Manager | A nurse care manager may help coordinate and carry out your child's care plan specific to their diagnosis. |
| Social Worker | <p>Every child seen in CHLA Neurology has a social worker. These individuals can provide:</p> <ul style="list-style-type: none"> • support (advocate for your child) • resources • counseling referrals • information on support groups • adjusting to a new diagnosis • guidance on safety • learning accommodations that may be available at your child's school |
| Registered Dietitian | Our registered dietitians can help answer questions about your child's diet and nutrition. They will help make sure your child is getting proper nutrition. Our specialized ketogenic dietitians can provide ketogenic and modified Atkins diet therapy to help with seizure management. |
| Physical and Occupational Therapist | A physical therapist (PT) will help improve your child's strength and their ability to move their body. An occupational therapist (OT) will help improve your child's function performing daily activities. This can include dressing, eating, and other tasks your child does in a typical day. |
| Genetic Counselor | Genetic counselors provide education about the genetic causes for epilepsy. They can provide information about the genetic testing process recommended by your provider. |
| EEG Technologist | Our EEG technologists (techs) are responsible for performing your child's EEG (brain wave recording) procedure. An EEG is an important test to evaluate seizures. This procedure is painless, and the techs will talk to your child during the procedure to help them feel comfortable and safe. |
| Patient Service Representative (PSR) | <p>Our patient service representatives will help you at the check in and check out of your visit. They will:</p> <ul style="list-style-type: none"> • schedule appointments • complete registration • obtain financial clearance • obtain authorization for your child's visits |

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| Neuropsychologist | A neuropsychologist is a licensed psychologist with special knowledge of how the brain works. This expert may test your child's thinking and behavior. This will help us make recommendations to improve your child's well-being, including school planning. |
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What type of treatments are available for epilepsy?

- Medical treatment
 - The doctor may prescribe anti-seizure medications (ASM), also called anti-epileptic drugs (AED). This is based on the type of seizure your child has. It may take time to find the best medication and dosage for your child. Your child will be monitored to determine if their condition is responding. Your child may receive blood work and/or other tests to help guide treatment.
 - Medication is not a cure for epilepsy. However, most children are able to live normal lives with seizures that are under control.
 - Medication should be taken as instructed by your child's doctor.
 - **Do not stop or change your child's medication or dosage without asking the doctor.**
- Diet therapy
 - Your child's dietician may teach you and your child about the ketogenic or modified Atkins diet. These diets are high in fat with limited carbohydrates. This ensures the body and brain will use fat for energy. Your child may undergo blood work and urine tests to measure their ketone levels.
 - Your child's dietician will also inform you of any vitamins/supplements your child may need.
 - 2 out of 3 of children on the ketogenic diet show a decrease in the frequency of seizures.
- Surgical evaluation
 - If your child does not respond to other treatment, your child's doctor may recommend surgery.
 - The clinical team will look at your child's seizure history and will conduct tests to determine if surgery is a good option. These tests may include:
 - Magnetic Resonance Imaging (MRI)
 - Video electroencephalogram (EEG)
 - Other specialized imaging
 - Neuropsychological testing
 - Our team of specialists meet weekly during the Epilepsy Surgery Conference, to discuss your child's specific case. Your doctor will recommend epilepsy surgery if it is the best option for your child.
- Vagus Nerve Stimulation (VNS)
 - VNS therapy may be recommended if your child has seizures that do not respond to medication.
 - During VNS therapy, a small pacemaker-like generator and wire are surgically implanted under the skin in the chest. This sends mild bursts of energy to the vagus nerve in the neck. The impulses send signals up to the brain which can decrease seizures.

- Responsive Neurostimulation (RNS)
 - RNS therapy may be recommended if your child has focal seizures that do not respond to medication. A focal seizure is a seizure that occurs on one side of the brain.
 - During RNS therapy, a stimulator is implanted on the skull. This system records EEG activity in the brain where seizures start. It also sends stimulation to the brain, which may prevent or stop seizure activity.

Who do I call if I have questions or concerns?

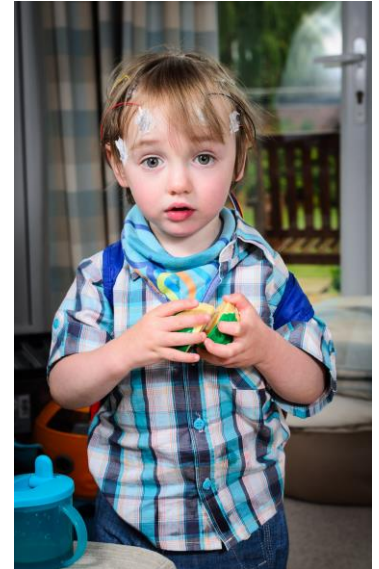
- Please call our office during business hours Monday – Friday 8 a.m. – 5 p.m. at 323-361-2207. It is our goal to answer your message as quickly as possible. You may also leave a voicemail with your child's full name, date of birth, doctor, and reason for the call. If you have left a voicemail, please keep your phone close by so that we can return your call.
- **CHLA Division of Neurology Clinic, Main Line: 323-361-2471**
- **CHLA Division of Neurology, Nursing Line: 323-361-2207**
- Please leave a MyChildren's Portal message. This website has more information about how to join the portal: <https://www.chla.org/mychildrensla-patient-portal>.
 - Once you submit your message, you will receive a confirmation. A staff member will respond through the patient portal within 1 business day.
- If the reason for your call is a medical emergency, please call 911.
- One of our staff will return your call or respond to your message within 24 hours. Please call us if you have not received a response within 3 days.

How do I get a medication refill?

- Your child's provider will send a new prescription to your preferred pharmacy at the clinic visit. They will provide enough refills until the next clinic appointment.
- Please call your child's pharmacy and speak with someone to confirm if your child's medication is ready for pick up.
- The medication bottle (or your pharmacy's website/app) may state "no refills". Please call and speak with the pharmacist to confirm if this is correct or if a new prescription has been sent.
 - The pharmacy will be able to verify if you have the most updated prescription number.
- Please contact your pharmacy 5 business days before your child runs out of medication.
- If your child is overdue for a follow-up appointment, please contact our schedulers at 323-361-2471 and select Option 1.

EEG Results

- Outpatient EEG results are available about 1-2 business days after the procedure.
- Video and ambulatory EEG results are available about 1-2 weeks after the procedure.
- If this is your child's first visit with our clinic, contact your child's pediatrician or the ordering doctor. They will discuss the EEG results with you. You may also access these results via the patient portal.
- If your child has an upcoming appointment with our clinic the neurologist will discuss EEG results then.



- If your child is already followed in our clinic, your child's provider will discuss the results with you. This may be in clinic or via a telehealth appointment.

What if I need a form or letter filled out by the doctor?

- Please email completed forms and parent questionnaires through the CHLA Portal, <https://www.chla.org/mychildrensla-patient-portal>. Please do not submit blank school forms. School forms should include your child's personal information. This includes full name, date of birth, medications, and doses to be given at school.
- Please allow 10-14 business days for completion of any forms (school letters, government forms, DMV documents, etc.).

Where do I find my child's test results?

- Lab and Imaging Results – Please visit MyChildren's portal to view your child's lab results. Our team will only contact you if there are any concerns with the lab results.
 - <https://www.chla.org/mychildrensla-patient-portal>
- You may also request a follow-up appointment to discuss results.

Appointments

- In Person
 - Please schedule your child's appointments according to your child's doctor's instructions. Our Patient Service Representatives (PSRs) are here to help by receiving appointment requests and maintaining our clinic schedules.
 - To cancel or reschedule an appointment, please call our appointment center at (323) 361-2471 and select option 1.
 - Please arrive to the appointment 30 minutes early to allow time for parking and check-in at the front desk.
 - If your child is a new patient and arrives more than **20 minutes late**, you may be asked to reschedule.
 - If your child is a follow-up patient and arrives more than **15 minutes late**, you may be asked to reschedule.
 - Please bring all current medications and relevant test results and records (MRI/EEG/CT scans).
 - Please bring the medication in their original bottles or packaging.
 - Your child must be present for the scheduled appointment.
- Telehealth
 - Your child's doctor may schedule a *telehealth* appointment. Depending on how you would like to be contacted, the invite will be emailed or texted to you about 15 to 20 minutes before the appointment time. Please log in early, test your computer, tablet or mobile phone ahead of time. You may need to download/install updates on your device.
 - For more information on how to access and prepare for your child's Telehealth appointment, please visit <https://www.chla.org/virtual-visits-childrens-hospital-los-angeles>.
 - Your child must be present for the scheduled appointment, and you must be in a quiet outdoor space.

Who do I call if I have a question about billing or insurance?

- Please contact your child's insurance company to verify insurance benefits. They will confirm if your child's doctor is in your child's plan.

Neurological Institute, Division of Neurology

4650 Sunset Blvd., Los Angeles, CA 90027 | CHLA.org

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- For questions regarding your child's hospital bill for clinic visits and procedures, please contact the Patient Financial Services Office at (323) 361-2515.
- For questions regarding your child's doctor services bill, please contact the Medical Group Office at (323) 361-2336.

Seizure Information

- Please review and become familiar with the Seizure First Aid steps (full size available in the folder):
- Administer rescue medications if your child is seizing per your child's seizure rescue plan.
- Please refer to your Seizure Action Plan. This document includes:
 - Seizure information
 - How to respond to a seizure
 - First aid for any seizure
 - When rescue therapy may be needed
 - Care after seizure
 - Special instructions
 - Daily seizure medicine
- Please keep a log of your child's seizure activity on the Nile AI App (<https://www.nile.ai/patients/>) or the provided seizure tracker (full size available in the folder):

Epilepsy Specific Resources

- CHLA Family Resources Center: <https://www.chla.org/family-resource-center>
- The Epilepsy Foundation: <https://www.epilepsy.com/>
 - Epilepsy Foundation Toolbox: <https://www.epilepsy.com/living-epilepsy/toolbox>
 - SUDEP (Sudden Unexpected Death in Epilepsy): <https://www.epilepsy.com/complications-risks/early-death-sudep>
- National Association of Epilepsy Centers: <https://www.naec-epilepsy.org/for-patients/patient-resources/>
- Centers for Disease Control and Prevention: <https://www.cdc.gov/epilepsy/managing-epilepsy/find-support.html>
- American Academy of Neurology: <https://www.aan.com/practice/epilepsy-education-resources>
- American Association of Neurological Surgeons: <https://www.aans.org/en/Patients/Neurosurgical-Conditions-and-Treatments/Epilepsy>
- Danny Did Foundation – Epilepsy & SUDEP: <https://www.dannydid.org/epilepsy-sudep/>

QR Code:

All links referenced in this document can be accessed via the QR code below.



Frequently Asked Questions (FAQ)

What is the timeframe for my child's medication refills once I call your office?

Once you speak with one of our PSRs or leave a voicemail, the typical turnaround time is 1 – 3 business days. Our PSRs will inform our medical team of the request for approval. We ask that you please follow-up with your pharmacy the next day.

- If your child is completely out of medication, our clinical team will call you before the end of the same business day.
- If medications are not ready after 3 days, you can expect a call from our clinical team with an update.

If my child is vomiting, should I continue to give their medicine?

Please follow your doctor's instructions if your child should retake their seizure medicine or wait until the next dose.

If my child misses a dose of seizure medication, how should I change the schedule? Should I wait until the next dose?

If your child misses their dose within 2 hours of when they usually take it, you may still give (administer) the dose. If your child misses their dose beyond the 2 hours of when they were scheduled to take it, do not give it and wait for the next dose.

Is it okay for my child to take over-the-counter medications (Advil, Tylenol, etc.) with the medications that were prescribed for seizures?

These medications are safe to take with the seizure medications your child has been prescribed. Please inform your primary care doctor and follow the over-the-counter instructions.

If my child has an allergic reaction, can I give Benadryl?

If your child has an allergic reaction, it is safe to give Benadryl with seizure medications. Please follow the over-the-counter instructions and call your primary care provider. They may provide additional medical care and advice.

If my child has an allergic reaction to a seizure medication, what should I do?

Stop the seizure medication and notify your neurologist to give you recommendations.

Is it okay for us to take our child to amusement parks (Disneyland), go on roller coasters, etc.?

Yes, please remember to bring your child's rescue medication. Please avoid rides and attractions with flashing lights if they are a seizure trigger.

Can my child get vaccinated?

Most childhood vaccines and the new COVID-19 vaccine are safe and recommended for children with neurologic illnesses. However, it is best to ask your child's doctor for guidance regarding your child's specific diagnosis and treatment. Please note that a child with a neurologic illness who is also treated with immune therapy (steroids, IVIg, Rituximab or other treatments) may require specific timing of vaccinations. They also may not be eligible for certain vaccines.

Is it okay for my child to get on an airplane?

Yes, please remember to bring your child's rescue medication and any daily medication in containers that are labeled by the pharmacy. Please make sure all medication is taken according to the schedule. We encourage you to set a timer. This will help to remember doses during the flight or when traveling across time zones.

Can my child play sports?

Most sports are safe to participate in if your child has epilepsy. Please discuss any specific instructions with your child's medical team. Please remember to bring your child's rescue medication to any sports activity. We recommend your child wear a helmet when riding a bike or when skiing. Your child should avoid climbing unsupervised heights (i.e. rock climbing).

Can my child swim?

Yes, but they should only swim with 1:1 adult supervision including when they are bathing. Scuba diving (or any activity in open water such as an ocean or lake) is not recommended.

What is the appropriate time to call the office when my child is having a seizure?

If the reason for your call is a medical emergency, please call 911 and follow your child's seizure action plan. If your child's seizure is different from previous seizures, you can call our office and inform our clinical team. This change in seizure activity can be an increase in frequency or length. For all other seizures, please document them on the seizure calendar. This can be reviewed with your doctor during your next visit.

How long does it take to get genetic testing results back?

The turnaround time for genetic testing results varies by test. However, the typical timeframe is on average 4-6 weeks. For urgent cases, preliminary reports can be provided within 1-4 weeks. For clinical exome sequencing, typical turnaround time for testing and interpretation is about 3 months. Clinical exome sequencing is a diagnostic tool to test for changes in the body's genes. This information will be used in genetic counseling. The information may help your child's treatment plan.

Should my child stop taking seizure medications before a procedure (i.e. EEG, MRI, etc.)?

Please take your seizure medications as prescribed unless your medical team tells you not to.

Where should I keep my child's emergency seizure medication?

You should have your child's seizure medication with you at all times (i.e. including clinic appointments, EEG appointments, etc.).

How do I schedule appointments or complete the ordered tests for my child?

- EEG: Our team will schedule your EEG for you.
- MRI: You will need to call our imaging department at 323-361-2411 to schedule your child's MRI.
- Labs: Labs could be done either internally at CHLA or externally. Please contact 323-361-2471 for help with scheduling.
- Referrals: If you have not received a call from the referred department, please call our office at 323-361-2471.

How do I request medical records for my child?

Our office cannot provide you with your child's medical records. Please contact Health Information Management at 323-361-2386 to request your child's records.

What do I do if my child needs clearance for a surgical or dental visit?

Please speak with your child's primary care doctor. Our office does not provide clearance for these visits or procedures.

What do I do when I spill my child's liquid seizure medications or lose their medications?

Please call your pharmacy and they will coordinate with our medical team.

Can I obtain an additional seizure rescue medication for additional care givers for my child?

Yes, please tell your doctor at your next visit if you need extra rescue medication.