The Epilepsy Center provides comprehensive, multidisciplinary care for children with epilepsy, informed by our latest clinical and basic science research, with a particular emphasis on early diagnostic accuracy aided by a careful and detailed analysis of clinical electroencephalography. Comprehensive clinical care requires coordinated involvement from specialists in psychiatry, neuropsychology, education, social work, nursing and epileptology.

We perceive that there is a continued unmet need. Accordingly, we strive to serve more children, train more specialists, augment our current research particularly focusing on improving clinical outcomes and expand our advocacy initiatives using our unique care model.

Douglas R. Nordli, MD  
Division Head  
Lurie Children’s Epilepsy Center  
Professor of Pediatrics and Neurology  
Northwestern University Feinberg School of Medicine  
Lorna S. and James P. Langdon Chair of Pediatric Epilepsy
• An encompassing approach to deal with complex patients’ needs

• Addresses patients’ medical, social, emotional and educational needs

• Provides effective and comprehensive care for children with epilepsy

• Incorporates educational outreach

**Multidisciplinary Team at Lurie Children’s**

• Division head/attending epileptologist

• Five attending epileptologists

• Two neurosurgeons

• Neuro-psychiatrist

• Neuro-psychologist

• Epidemiologist

• Three APN/CPNP nurses

• Three and a half RN triage nurses

• Two dietitians (ketogenic diet)

• Social worker

• Education specialist

• Two epilepsy fellows

• Research coordinator

• Research assistant

• Five EEG technicians

• Office administrative staff

• Manager, Patient Care Operations
What to Look For

**Timing**
What time did seizure occur?
How long did seizure last? Did seizure stop, then start again (cluster)? How many seizures in the cluster? How long was cluster?
Do seizures happen at a certain time of day, week or month? Do seizures happen when waking up or falling asleep? Do seizures happen after certain activity?

**Body Movement**
Did seizure start in one part of the body and then move to other body areas?
Was body stiff, jerking or limp? Did you feel, rather than see, the seizure (fine body tremor)?
Did eyes move (jiggle up or down, side-to-side, stay to one side, roll back)?
Did you see color change on lips, face or nail beds? Was color pink, pale, red or blue?

**Awareness**
Was your child aware or not aware? Was child able to respond to your voice or follow commands? Was child aware at start of seizure but not as seizure continued?
How did your child feel after the seizure (sleepy, headache, irritable, loss of bladder/bowel control, vomiting, combative)?
Was there any weakness or inability to move body part after seizure?

**Warnings or Triggers**
Is there a warning before a seizure happens (such as headache, stomach ache, tingling feeling, smell, visual changes or other unusual sensation, change in behavior)? Can your child tell or let you know that a seizure is going to happen?
Are there certain activities or circumstances that seem to trigger or cause a seizure?
Was there anything that contributed to the seizure (illness, overheating for any reason, stress, sleep disruption or lack of sleep, pain, flickering or bright lights, unexpected noise, unexpected touch, unusual physical activity or stress, missed or late medication, new medication or medication change)?

**REMEMBER:**
• Keep calm and offer reassurance.
• Protect from injury by removing sharp/dangerous objects out of the area.
• Loosen any restrictive clothing from around the neck, remove eyeglasses. If on the ground, place soft, flat object (blanket, clothing) under head to help prevent injury.
• If able, position to keep airway clear and allow secretions to run out of side of mouth.
• **DO NOT** attempt to stop or restrain the seizure.
• **DO NOT** try to open or put anything in child’s mouth. A person cannot swallow his/her tongue during a seizure. **DO NOT** hold the person down or try to stop movements.
• Time the seizure with your watch or cell phone.
• Do not give artificial respiration during a seizure. In the unlikely event that breathing does not return to normal when the seizure stops, call 911 and begin rescue breathing.

**What to Look For**

Timing
What time did seizure occur?
How long did seizure last? Did seizure stop, then start again (cluster)? How many seizures in the cluster? How long was cluster?
Do seizures happen at a certain time of day, week or month? Do seizures happen when waking up or falling asleep? Do seizures happen after certain activity?

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- Seizure type or description, duration and time of occurrence
- Dates of medication changes
- Seizure triggers or precipitating factors (such as illness, sleep deprivation, missed medication, heat exposure, menstrual period, new medications or medication change)
- If emergency medication was given (Distat, diazepam, Klonopin, midazolam, lorazepam)
- If you are on the ketogenic diet, track ketones and diet changes

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Lurie Children’s Epilepsy Center offers a comprehensive approach to caring for children with the most complex forms of epilepsy. The program offers sophisticated diagnostic testing, complete evaluation services, multidisciplinary medical and surgical treatment grounded in scientific research, and support services for the unique physiological and developmental needs of children with epilepsy.

Please call us at 312.227.3540 with any questions you have about the Epilepsy Center’s team or services which may interest you.
PLEASE NOTE:

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Purple Day

Everyone can make a difference

We can all make a difference in the fight against epilepsy. Almost 3 million Americans are living with epilepsy. Raise awareness by wearing purple on March 26, 2016!

For more information or to become a Purple Day Ambassador, go to purpleday.org
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Each year, more than 80 children ages 6-18 attend the Epilepsy Foundation of Greater Chicago’s Camp Blackhawk. During two full-week sessions, kids are treated to the outdoor experience of a lifetime. Check the Epilepsy Foundation website for 2016 dates.

With an average of two children per counselor, and medical staff on-site, there is always a helping hand when needed at Camp Blackhawk. Counselors are trained to handle the needs of children with epilepsy, giving children a chance to explore and meet new friends in a safe environment.
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★ Description ________________________________________________________________
Epilepsy Foundation Walk Chicago

Each spring the Epilepsy Foundation of Greater Chicago hosts several fundraising 5K walks to raise awareness about epilepsy. The walks are a great way to get involved with the Epilepsy Foundation and meet other families and children living with epilepsy. You can join as an individual or create a team.

Check the Epilepsy Foundation website for events, specific locations, dates and times.

epilepsyfoundation.org/local/chicago
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★ Description
“Magic Diet” Helps Ciara Fight Epilepsy

Ciara was diagnosed with Dravet syndrome when she was 11 months old. Ciara was experiencing as many as 150 seizures a day, and needed to wear a helmet to prevent head injuries. Doctors prescribed a number of anti-seizure medications, though none of them provided relief.

Searching for answers, her mother, Lori, spoke with the mother of another child with Dravet syndrome, who recommended she seek care for Ciara at the Lurie Children’s Epilepsy Center. Lori and Ciara flew to Chicago from Connecticut for an evaluation by Attending Epileptologist Linda Laux, MD, when Ciara was nearly 2 years old. Epilepsy Center registered dietitian Robyn Blackford started Ciara on the ketogenic diet. This carefully monitored high-fat, low-sugar and low-carbohydrate diet is very effective in treating children with difficult to treat forms of epilepsy.

Within two weeks, Lori says she saw a dramatic decrease in the number of seizures Ciara was having. At one point she went three months without a single seizure. Although she still has seizures, Ciara, now a spirited 10-year-old fifth grader, is developmentally on target. She takes swim lessons, likes to dance and create art projects and enjoys playing with her little brother, Aidan. Ciara calls her dietary regimen her “magic diet.”

For more information, visit luriechildrens.org/epilepsy
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Summer Seizure Safety

Make the most of summer by making a plan!

• Remember to keep sleep and medication schedules
• Make sure an adult knows where you are at all times
• Wear a medical alert bracelet during activities
• Drink lots of water or fluids to help stay cool
• Swim with a buddy
• Use your bike helmet when biking, rollerblading or skateboarding
• Know playground safety
**PLEASE NOTE:**
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Back to School

Get ready to go back to school!

- Send school forms to your doctor’s office before the start of school
- Make sure your school’s seizure plan is current
- If you take medicine at school, make sure to give the school a prescription bottle with the correct dosing instructions
- Decide if you want to talk to your teacher and classmates about seizures and what to do if you have a seizure
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Rehabilitation Act of 1973 and Individuals with Disabilities Education Act (IDEA) are two pieces of legislation that protect children with epilepsy.

**Section 504** is part of the Rehabilitation Act of 1973, which is a federal civil rights law. If certain requirements are met, accommodations can be written into a 504 plan when a medical condition impacts a child’s ability to learn at school.

**IDEA** is a federal law designed to ensure that specific accommodations are made for children with specific learning and medical disabilities. Parents may request that the local school district do a full case study evaluation to decide if a child qualifies for help under an Individual Education Plan (IEP).

- Parents and the school team work together to determine the type and amount of services that will best meet the child’s educational and medical needs. The kind and amount of services are written into an IEP.

- Least Restrictive Environment (LRE) requires that, to the maximum extent appropriate, students should have the opportunity to be educated with non-disabled classmates.

- Usually children with epilepsy are eligible for services under the category of Other Health Impaired (OHI).

For more detailed information, look at the Special Education pages found at the Illinois State Board of Education website: isbe.state.il.us. Your local school district may also have special education information and resources on their website.
### SEPTEMBER 2016

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▲ Description
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* Description
My name is ______________________________________________________
I am _______ years old.
My family is ______________________________________________________
________________________________________________________________
Something special about me is ______________________________________
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I am important because ____________________________________________
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Something different about me is _____________________________________
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I like _____________________________________________________________
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A seizure dog is a dog that has been trained to respond to or warn of seizure activity in someone who has epilepsy. Seizure dogs that are licensed as service dogs are protected by the ADA to accompany their owners into public places.

assistancedogsinternational.org

canineassistants.org

**DID YOU KNOW?**

November is National Epilepsy Awareness Month!
### NOVEMBER 2016

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Web Resources

Websites have lots of great information about epilepsy. There are also websites that can help with planning for your future. Here are several sites that may interest you:

luriechildrens.org/epilepsy
efa.org
goeyc.org
cureepilepsy.org
epilepsyoutreach.org

You Are Not Alone (Toolkit for Parents of Teens with Epilepsy)
cdc.gov/epilepsy/toolkit/index.htm

Healthy and Ready to Work
hrtw.org

Health Passport
sickkids.on.ca/myhealthpassport
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Adolescent Healthcare Contract

HEALTHCARE GOALS

Ways I can achieve my goals

Examples:
- Attend school every day
- Keep up with classroom assignments and homework
- Do my fair share to help at home

Others:
- ___________________________
- ___________________________
- ___________________________
- ___________________________
- ___________________________
- ___________________________

Questions for my doctor and nurse

Examples:
- When will I be able to drive?
- Is it all right to have a few beers at a party?
- Can I stay up all night with my friends?

Others:
- ___________________________
- ___________________________
- ___________________________
- ___________________________
- ___________________________
- ___________________________

Ways I can participate in my healthcare

Examples:
- Be responsible for taking my medication
- Remember my next appointment and get there
- Record my seizures in my seizure calendar

Others:
- ___________________________
- ___________________________
- ___________________________
- ___________________________
- ___________________________
- ___________________________

By participating in and helping with my healthcare, I earn increased independence. This is my body and I pledge (promise) to help take care of it.

Patient signature
### SAMPLE SEIZURE LOG - JULY 2012

<table>
<thead>
<tr>
<th>SUNDAY</th>
<th>MONDAY</th>
<th>TUESDAY</th>
<th>WEDNESDAY</th>
<th>THURSDAY</th>
<th>FRIDAY</th>
<th>SATURDAY</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>10 pm- 15 min sz</td>
<td></td>
<td>x 9:30 pm</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>9</td>
<td>10</td>
<td>11</td>
<td>12</td>
<td>13</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Poor sleep, fighting illness</td>
<td>•7 and 7:30 pm, 10 sec each</td>
<td>•6:40 pm- 15 min</td>
<td>• like 7/9</td>
<td>• like 7/9</td>
</tr>
<tr>
<td>15</td>
<td>16</td>
<td>17</td>
<td>18</td>
<td>19</td>
<td>20</td>
<td>21</td>
</tr>
<tr>
<td></td>
<td>like 7/9</td>
<td></td>
<td></td>
<td></td>
<td>missed pm med</td>
<td>•3 am - TC for 45 secs</td>
</tr>
<tr>
<td>22</td>
<td>23</td>
<td>24</td>
<td>25</td>
<td>26</td>
<td>27</td>
<td>28</td>
</tr>
<tr>
<td>• • 4:30 am and 6 pm - 15 min sz like 7/9</td>
<td></td>
<td>• • 10 pm - 2 sz close together, each 10-15 min</td>
<td></td>
<td>prednisone stopped</td>
<td></td>
<td>• • • 3 sz - each 15 min</td>
</tr>
<tr>
<td>29</td>
<td>30</td>
<td>31</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Description
- Not responsive, head to right, twitching
- Thigh slapping, non verbal but responsive
- Staring, responsive but not talking, follows commands
- Full body jerking — tonic-clonic
- Poor sleep, fighting illness

### PLEASE NOTE:
- Seizure type or description, duration and time of occurrence
- Dates of medication changes
- Seizure triggers or precipitating factors (such as illness, sleep deprivation, missed medication, heat exposure, menstrual period, new medications or medication change)
- If emergency medication was given (Distat, diazepam, Klonopin, midazolam, lorazepam)
- If you are on the ketogenic diet, track ketones and diet changes
where kids come first

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