

CONSIDERATIONS WHEN CHOOSING YOUR CHILD'S NEUROSURGEON

For parents researching brain surgery to stop their child's seizures.



What is an experienced pediatric epilepsy surgeon?

Introduction

Brain surgery on a child, especially an infant, requires a surgeon who is familiar with the challenges in the operating room a child presents. Children, especially infants, have less overall blood volume than adults and are at risk of excessive bleeding during surgery. Infant and baby brains are unmyelinated and thus extremely soft, which is one reason why surgery on a child one month old or younger is rarely performed.

Many epilepsy surgeries are extremely delicate and complex, making the decision of which neurosurgeon to choose especially important. Simply put, brain surgery to stop seizures should be performed only by an *experienced pediatric epilepsy surgeon*.

Are there national standards for pediatric neurosurgery specialization?

Many parents are surprised to know that there are no mandatory national or international standards which designate the level of expertise needed to qualify a surgeon as an "experienced pediatric epilepsy surgeon." In fact, there are no pediatric surgeon designations in any practice area. Which makes this a crucial and challenging decision.

Our surgeon is board certified. What does this mean?

All surgeons must, at a minimum, be certified by their state's medical board. Most, but not all, hospitals require the surgeon to have an additional certification, such as membership in the American College of Surgeons, the American Board of Neurosurgery, or other similar membership.

Is a hospital's U.S. News and World Reports ranking important?

The ranking can certainly help you make your decision, but it's important to understand how the rankings are prepared. For neurology and neurosurgery, U.S. News and World Reports rankings are based off a cumulative score which takes into account all of the following areas: ability to prevent infections; surgical survival; ability to prevent surgical complications;

management of epilepsy patients; number of clinic patients; number of surgeries; number of epilepsy workups and treatments; adequacy of nurse staffing; nurse magnet status; commitment to best practices; advanced clinical services; clinical support services; advanced technologies; specialized clinics and programs; help for patients and their families; family involvement; commitment to quality improvement; adoption of health information technology; full-time sub-specialist availability; active fellowship program; commitment to clinical research; reputation with specialists.

Epilepsy Centers

The National Association of Epilepsy Centers (NAEC) has standards which determine the level of expertise needed to be designated by the them; however, these standards are not specific to pediatrics. Nothing in the NAEC guidelines mentions pediatric experience. You can read more about the specific requirements of each designation level by downloading the guidelines for epilepsy centers on NAEC's website. They are generally:

Level 3 Epilepsy Center

- No absolute number of surgeries required for this designation.
- Must have one epileptologist and one epilepsy surgeon, both with at least 2 years of experience;
- At least 50 video EEGs per year.

Level 4 Epilepsy Center

- No absolute number of surgeries required for this designation.
- Must have one epileptologist and one epilepsy surgeon, both with at least 5 years of experience;
- At least 100 video EEGs per year.

Questions to ask the surgeon

What is the name of the surgery?

What is your experience with performing this type of procedure?

How long have you been an epilepsy surgeon?

While in training, how many of these procedures did you perform?

How long have you performed this procedure as lead surgeon?

What specialty training have you received as an epilepsy surgeon?

Do you also perform epilepsy surgery on adults? If so, what percentage of your practice is pediatric surgery?

How many times have you performed [name of epilepsy surgery] on a child the same age as my child?

How often do you perform this procedure per year?

When was the last time you performed this procedure?

Have you published any research papers about this procedure?

What are your seizure control success rates for this procedure after five years?

How long has this procedure been performed at this hospital?

What part(s) of the brain will be removed? What functions do these parts of the brain control? Are these parts involved in important brain circuits for, for example, speech, vision, or learning to read?

Is there any scientific literature that you can show me to support the decision to operate?

What are the alternatives to performing this surgery? Are there any treatment options that we have not explored?

What will likely happen if we do not move forward with this surgery?

Will my child require a blood transfusion?

May I speak to another family who has undergone this type of procedure at this hospital?

What are the benefits of the surgery and how long will they last?

What are the risks and potential complications of having the surgery?

Specifically, what are the short-term risks and long term functional risks?

What is the incidence of hydrocephalus after this procedure?

Should I get a second opinion? Whom do you recommend?

What kind of anesthesia will be administered and who will be the anesthesiologist?

What can I expect during recovery? What are some warning signs?

What is the cost of the procedure? Specifically, what is the surgeon's fee and hospital fee?

Billing for other services (anesthesiologist, assisting physicians, other consultants)

What kind of preparation will be required before the surgery? Will there be bloodwork and other tests or special skin preparations required?

How long will we be in the hospital after surgery? Will we stay in PICU and then move to the neurology floor? What will determine when we move to the neurology floor?

What kinds of supports will my child need immediately after surgery? Will my child be evaluated for physical therapy, occupational therapy, and speech therapy while in the hospital?

Will my child require inpatient rehabilitation? What are the pros and cons to inpatient rehabilitation?

Is there a social worker or case manager I can ask for while in the hospital?
