The Life-Saving Nature of Epilepsy Surgery

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Hosted by DEE-P Connections and the Pediatric Epilepsy Surgery Alliance

In this talk, Dr. Taylor Abel explains why epilepsy surgery is not a last resort and how it can save lives by reducing seizures and lowering the risk of serious injury and SUDEP. He shares real examples and research showing why children with drug-resistant epilepsy should be evaluated earlier, not later.

Speakers:

Taylor Abel, MD, Chief of Pediatric Neurosurgery and the Surgical Director of the Pediatric Epilepsy Surgical Program at UPMC Hospital for Children in Pittsburgh. He is also on the American Epilepsy Society's and Pediatric Epilepsy Surgery Alliance's board of directors.

Monika Jones, JD, CNP, Founder and Executive Director of the Pediatric Epilepsy Surgery Alliance, and mom to Henry, who has had multiple brain surgeries.

Gabi Conecker, MPH, President and Co-founder of the International SCN8A Alliance, DEE-P Connections, and The Inchstone Project, and mom to Elliott, now 8 years old, who struggles with one of the most severe strains of SCN8A mutations.

Key Points:

1. **If two seizure medicines have not worked, ask for a surgery evaluation.** This does not mean you are choosing surgery. It means you are learning all your options.
2. **Ongoing seizures are dangerous.** They can cause serious injuries, affect brain development, and increase the risk of SUDEP.
3. **Surgery or brain devices can help children live safer, longer lives.** Research shows children who get these treatments often do better than those who only take medicine for their epilepsy.
4. **More children have options than many families are told.** Even children with genetic or widespread epilepsy may have treatments to try. Every child deserves a full evaluation to understand all options.
5. **Do not wait too long.** Getting expert advice earlier can protect your child's brain, safety, and future.

Plain language summary:

Dr. Taylor Abel's main message is simple: epilepsy surgery is not a last resort. For some children, it can save their lives. Seizures are not just disruptive. They can lead to serious injuries, SUDEP, and long-term harm to the brain.

Epilepsy is called drug-resistant when a child has tried two seizure medicines and is still having seizures. After that, the chance that another medicine will stop the seizures is very small. This is the point when families should be sent to an epilepsy surgery center for a full evaluation. It's important to understand that a surgical evaluation does not mean you are choosing surgery. It means you are learning about all your options.

Dr. Abel shared real stories to show why timing matters. One teen nearly died after having a seizure in a swimming pool. Later, she had a small laser surgery and became seizure-free. He also talked about a young child whose parents were not told about surgery for a long time, even though the problem was clear on the brain scan.

Research shows that epilepsy surgery can stop or greatly reduce seizures, improve learning and daily life, and lower the risk of early death and SUDEP. Large studies show that children who have epilepsy surgery often live longer than those treated only with medicine. Some children may also benefit from devices like VNS or other brain stimulators.

His main advice was this:iIf your child is still having seizures after two medicines, ask for a referral to an epilepsy surgery center. Even children with genetic or widespread epilepsy may have options today. Getting expert advice early can change a child's future.

Transcript (edited for clarity)

Gabi Conecker, DEE-P Connections:

Hi everybody. Thanks for joining. We're going to start in just a minute while people are still filtering in. Thanks for being here. I'm going to start recording.

For those of you who are joining us live, thank you for carving out the time. And for those of you who are watching the recording later, we're so glad you found time to tune in.

I'm really excited about today's session. I'm going to do quick introductions and then pass it over so we have as much time as possible to hear from Dr. Abel and Monika Jones.

I'm Gabi Conecker. I'm the mom of a 12-year-old, Elliot, who lives with SCN8A-related DEE, and I'm the co-founder of DEE-P Connections. Our work is all about bringing together families affected by rare epilepsies to better understand key issues, ask questions, and share resources and support. That's what we do, and we're really excited for today's discussion.

If you're joining as a participant, don't worry, you're not on video, and you're automatically muted. If you're doing laundry or have a kid crying in the background, we get it. You're safe here.

This webinar is being recorded, so you can come back and watch it later. When we share the recording, we'll also share resources and point you to the Pediatric Epilepsy Surgery Alliance website, which is full of amazing information and support.

If you have questions during the session, please drop them into the Q&A. You can also use the chat to share what's resonating with you.

Now I'm going to hand it over to Monika Jones, who will introduce Dr. Abel and get us started.

Monika Jones, Pediatric Epilepsy Surgery Alliance:

Thank you, Gabi. It's wonderful to collaborate with you and DEE-P Connections on this really important webinar.

I'm Monika Jones. I'm the founder and Executive Director of the Pediatric Epilepsy Surgery Alliance, and I'm really excited to introduce Dr. Taylor Abel.

Dr. Abel is currently on our Board of Directors and previously served on our Scientific Advisory Board. He is the Chief of Pediatric Neurosurgery at UPMC Children's Hospital of Pittsburgh.

Today, he's going to talk about what the research says about whether pediatric epilepsy surgery actually extends the life of children with drug-resistant epilepsy.

We've all heard those very scary statistics about SUDEP and other risks. I want to remind you that if your child has drug-resistant epilepsy, they are supposed to be referred for a surgical evaluation, regardless of age and regardless of the cause of the epilepsy.

If your child has a genetic epilepsy or something that traditionally hasn't been referred for surgery, they are still supposed to be referred for a surgical evaluation. It is your right as a parent to understand all treatment options.

Having a surgical evaluation does not mean you have decided your child will have surgery. It means you have decided to understand all your options so you can make the best decision for your child.

So, Dr. Abel, thank you for joining us. I'll let you take it from here.

Dr. Taylor Abel:

Thank you for the invitation. I really appreciate the opportunity to talk with this group. I'm very inspired by the work the Pediatric Epilepsy Surgery Alliance does, as well as by the work DEE-P Connections is doing.

I'm an epilepsy surgeon at the University of Pittsburgh and UPMC Children's Hospital. I've actually been interested in epilepsy my whole life because I had a type of epilepsy as a child called benign rolandic epilepsy. Being in neurology clinics as a kid and seeing other children with epilepsy is what first got me interested in this field.

The title of my talk today is "Does Epilepsy Surgery Extend Life?" We're going to talk broadly about why epilepsy surgery matters, and then I'll focus on what we know about epilepsy, surgery, and mortality.

I'm going to try to keep this simple and not talk too long, so we have plenty of time for questions.

I always think it's important to start with a patient story.

Case Example: Teen With Brain Tumor and Near Drowning

Dr. Taylor Abel:

This is a patient I took care of who, for about a decade, had very severe seizures. She had an evaluation that showed a brain tumor in her left frontal lobe. The tumor wasn't growing, but it was causing severe epilepsy.

Her family was very nervous about surgery because being a cheerleader was really important to her. She was a flyer, which meant she was often lifted high in the air, and the idea of having brain surgery felt very scary and risky to them.

Unfortunately, while she was on vacation with her family, she had a seizure in a swimming pool and nearly drowned. She was admitted to a local hospital for several weeks and came very close to dying.

Several years later, she finally came to see me. We talked about different options. One option was a traditional open surgery to remove the tumor. Another option was something called laser ablation, which is much less invasive and would allow her to return to cheerleading much sooner.

We talked about the risks and benefits of both. Laser ablation might not be quite as effective as open surgery, but it would respect what was important to her and still treat the seizures.

We ended up doing the laser ablation. She spent one night in the hospital. She has been seizure-free since the procedure. Before surgery, she was having about eight seizures a day.

Now her risk of having a seizure while swimming or cheerleading is extremely low. This is a case where the risk of not doing surgery was much greater than the risk of doing it.

What Is Drug-Resistant Epilepsy?

Dr. Taylor Abel:

This is why we talk about epilepsy surgery. There is a clear definition of drug-resistant epilepsy. If a person has tried two appropriate seizure medications and is still having seizures, even if it is only one seizure a month or a few a year, that is considered drug-resistant epilepsy.

The reason this matters is that once someone has drug-resistant epilepsy, the chance that another medication will completely stop seizures is only about five to eight percent.

That means that continuing to just try medication after medication usually does not work.

This is why there are international guidelines that say that once someone has drug-resistant epilepsy, they should be referred to a center that offers epilepsy surgery.

In some cases, if a person has a clear brain lesion like a tumor or cortical dysplasia, they should even be referred before they become drug-resistant.

Second Case Example: A Young Child Who Waited Too Long

Dr. Taylor Abel:

I want to show another case that explains why early referral is so important.

This was a two-year-old child who started having spells of behavioral arrest and unusual eye movements. He was started on Keppra. Imaging and EEG were done, and the MRI showed a very large cluster of abnormal blood vessels in the brain called a cavernoma. Even without being a radiologist, you could look at the scan and see that it should not be there.

This child had a genetic condition that caused multiple cavernomas in the brain, so he was diagnosed with multifocal epilepsy. The first medication did not work, so they tried another medication. He went two months without seizures, but then the seizures came back. Now he was on two medications and still having seizures.

Later, he started having five seizures a day and was hospitalized. He still had not been referred for an epilepsy surgery evaluation. His language development was starting to fall behind. His epilepsy was starting to look more generalized.

By coincidence, I met this family through my daughter’s playdate. The child’s aunt mentioned that her nephew was having terrible seizures, and they did not know what to do. I gave her my phone number and asked the family to call me.

I saw him in the clinic two days later. We did surgery a week later. He has now been seizure-free for several years.

This should never have happened. He should have been referred much earlier. We will never know what effect the delay had on his development.

This is more common than it should be, and it shows why early evaluation matters so much.

Why We Need to Talk About Mortality in Epilepsy

Dr. Taylor Abel:

Now I want to talk about the main focus of this talk, which is mortality in epilepsy and whether epilepsy surgery reduces the risk of death.

My main argument is that anything that meaningfully reduces seizures probably also reduces the risk of death.

SUDEP stands for sudden unexpected death in epilepsy. It happens most often in young people and results in many years of life lost. But SUDEP is not the only cause of death in epilepsy. Accidents like drowning during a seizure are also a serious risk.

There is a study that looked at SUDEP in people who had epilepsy surgery compared to those who did not. The number of SUDEP cases was much higher in the group without surgery.

This strongly suggests that epilepsy surgery reduces the risk of death.

What the Research Shows About Survival

Dr. Taylor Abel:

A large review and analysis by leading SUDEP researchers looked at many studies together. They found that epilepsy surgery was associated with about a twofold decrease in the overall risk of death and about a threefold decrease in the risk of SUDEP.

They also looked at neuromodulation treatments, such as VNS. The results there were less clear, but I will discuss them more in a moment.

There was also a very large study that compared three groups of children with drug-resistant epilepsy: those treated with medication alone, those who had VNS, and those who had brain surgery.

The children who had brain surgery had the best long-term survival. The children who had VNS did better than those treated only with medication. The children treated only with medication had the worst survival.

Mathematical Model and Life Expectancy

Dr. Taylor Abel:

My research group also uses mathematical models to study questions that are very hard to answer with traditional clinical trials.

I built a model that compares open surgery, laser surgery, and medical therapy alone for children with focal drug-resistant epilepsy. The model simulates a child's entire lifetime, including whether they become seizure-free, whether they have complications, and what their long-term mortality risk looks like.

The result is that, on average, a child who has epilepsy surgery around age 10 gains about five extra years of life.

A lot can happen in five years. Five years matters.

What About VNS, RNS, and DBS?

Dr. Taylor Abel:

There are also studies looking at VNS and other neurostimulation devices. Some large studies suggest that VNS reduces the risk of SUDEP and death over time.

Other smaller, well-controlled studies show less clear benefit. So the data is mixed.

But overall, it is reasonable to think that reducing seizures in any way probably reduces risk, even if the effect is not as strong as with resective surgery.

Dr. Abel's Conclusions

Dr. Taylor Abel:

Epilepsy surgery is a critical part of epilepsy care. It can improve seizure control, quality of life, and development.

Treatments that reduce seizures are associated with a lower risk of death.

Resective epilepsy surgery clearly appears to reduce mortality. Neuromodulation may also help, though the data is less clear.

My main conclusion is that epilepsy surgery should be considered earlier, not later.

Q&A

Gabi Conecker:

Thank you so much. That was incredible. I learned a lot. I'm wondering: if a child had an evaluation when they were 2 and is now 10 or 12, is it worth being evaluated again?

Dr. Taylor Abel:

Yes, absolutely. Things change over time. Imaging improves. The brain changes. New technologies become available. Repeat evaluations can be very important.

Generalized Epilepsy and Surgical Options

Gabi Conecker:

We have a question from a parent whose child has daily absence seizures. They were evaluated years ago and told their child was not a candidate because the seizures came from many areas of the brain. In a case like that, is surgery still something to think about?

Dr. Taylor Abel:

That's a great question. This sounds like what we would call generalized epilepsy. In the past, there were fewer surgical options for generalized epilepsy, but that has changed.

Today, there are good options using neuromodulation, such as RNS and DBS. For example, in Lennox-Gastaut syndrome, there is strong evidence that stimulation of certain deep brain areas can reduce seizures.

RNS means responsive neurostimulation. We place an electrode in the brain that detects seizures and then stimulates in response to them. DBS means deep-brain stimulation, where electrodes stimulate continuously.

We have had good results using these approaches even in children with generalized epilepsy. So I think the answer is yes, families should still seek evaluation at a center that treats generalized epilepsy surgically.

What Counts as "Epilepsy Surgery"?

Monika Jones:

I want to add something here. Sometimes doctors think of epilepsy surgery only as operations where part of the brain is removed. But epilepsy surgery is actually a whole category of treatments, from VNS all the way to very large surgeries like hemispherectomy.

Families may not know their child is a candidate for anything unless they have a full surgical evaluation at a center that has real experience.

We have videos on our website that explain the differences between VNS, RNS, and DBS, and how each works.

Who Is Qualified to Say a Child Is or Is Not a Candidate?

Gabi Conecker:

Who is actually qualified to tell a family whether their child is a candidate for surgery? Many families are told by a neurologist that their child is not a candidate.

Dr. Taylor Abel:

Ideally, that decision should be made by an epileptologist who specializes in epilepsy surgery, working as part of a full epilepsy surgery team.

At our center, we have epileptologists whose job is specifically to evaluate surgical candidates. They work closely with surgeons and the rest of the team.

If someone is being told they are not a candidate, and that decision was not made by a surgical epilepsy team, it is very reasonable to seek another opinion. Telemedicine makes this easier now than it used to be. Families should try to be seen at a Level 4 epilepsy center at a minimum.

What If Someone Is Told “It’s Generalized, So Surgery Is Not an Option”?

Gabi Conecker:

A lot of families hear, “It’s generalized, so you’re not a candidate.” What should they do?

Dr. Taylor Abel:

There are very few situations today where there is truly nothing to discuss. Even with generalized epilepsy, there may be options like neuromodulation that are worth talking about.

Genetic Epilepsy and Surgery

Gabi Conecker:

Does having a genetic diagnosis mean surgery is off the table?

Dr. Taylor Abel:

No. Having a genetic diagnosis does not automatically take surgery off the table. It may affect which treatments are considered, but it should not prevent a family from having a full evaluation and discussion.

Brain Atrophy and Surgery

Gabi Conecker:

What about brain atrophy? Does that mean someone is not a candidate?

Dr. Taylor Abel:

Not necessarily. In fact, long-standing uncontrolled epilepsy can itself cause brain atrophy. In some cases, atrophy can actually help localize where seizures are coming from. It should not automatically exclude someone from being evaluated.

Lesions in “High-Risk” Areas of the Brain

Gabi Conecker:

What if the lesion is in a risky area, like near speech or movement centers?

Dr. Taylor Abel:

This is where experience and careful mapping are very important. At specialized centers, we can place electrodes to map language and motor areas. Sometimes we can plan surgery around those areas, or sometimes we use devices like RNS to treat seizures without removing tissue.

If a Child Already Has VNS or DBS, Does That Rule Out Other Surgery?

Gabi Conecker:

If a child already has a VNS or DBS, does that disqualify them from other surgery?

Dr. Taylor Abel:

No. There may be some technical considerations, such as imaging, but they should not prevent further evaluation or treatment.

RNS Versus DBS

Gabi Conecker:

How do you decide between RNS and DBS?

Dr. Taylor Abel:

There are trade-offs. DBS has rechargeable batteries that can last many years, which is helpful for children with lifelong conditions. RNS records seizures directly from the brain, which helps us see how treatments are working.

There is no single right answer. It should be a shared decision based on the child’s type of epilepsy and family goals.

Expectations, Trade-Offs, and Difficult Decisions

Monika Jones:

I want to say something as a parent. I made the decision to have half of my son’s brain removed, and so did Audrey. That comes with real and permanent disabilities, like partial blindness and weakness on one side of the body.

But I also want families to step back and think about what a lifetime of uncontrolled epilepsy does to a child. This is not just about survival. It is about development, learning, behavior, and quality of life.

Some families decide that in exchange for seizure freedom, they can accept certain physical disabilities. That is not a decision anyone else can make for you.

Our organization can connect you with parents who have walked this road before you, so you can talk through what life is really like after different surgeries.

When Surgery Does Not Fully Solve the Problem

Gabi Conecker:

What about children who have had several surgeries and are still having seizures? Do you keep looking for options?

Dr. Taylor Abel:

It is important to look carefully at what has already been done and why. Sometimes a second opinion or a fresh look at the data can help.

There are now many less invasive options, and sometimes families try several of those before moving to a more traditional surgery. In some cases, those less invasive approaches work. In other cases, a larger intervention is still needed.

The key is careful review and thoughtful planning before each next step.

Medications After Surgery

Gabi Conecker:

Many families are on many medications. Is it common to reduce medications after surgery?

Dr. Taylor Abel:

With neuromodulation, there is no strong evidence that medications can be reduced. With resective surgery, the first goal is seizure freedom.

At our center, if a child is seizure-free for six months and the EEG looks good, we start tapering one medication at a time. If seizures return, we restart medication. The goal is always seizure freedom, whether that is with or without medication.

How the Pediatric Epilepsy Surgery Alliance Supports Families After Surgery

Monika Jones:

We support families before and after surgery. We can connect you with parents who have been through similar procedures.

We help families with school re-entry, IEPs, therapies, and understanding the long-term effects of different surgeries. We also help families think about the transition to adulthood.

These are big, life-changing events, and families should not have to go through them alone.

Final Thoughts and Closing

Gabi Conecker:

I want to thank both of you so much. This was incredibly helpful and empowering.

Our goal today is to help families feel confident asking for referrals and asking hard questions. Surgery is not always the right answer, but it should be on the table, and families deserve expert guidance.

If you are being told no, and it does not feel right, seek another opinion. Things change. Imaging improves. New treatments become available.

Do not think of surgery as a last resort. Think of it as one of the tools that should be considered when medications are not working.

Thank you to everyone for being here today, and thank you to Dr. Abel, Monika Jones, and Audrey for everything you do for families.

Dr. Taylor Abel:

Thank you for the invitation. I am inspired by the work you all do.