



# pediatricpilepsy surgeryalliance.

2022 - 2023 ANNUAL REPORT

# We Are Better Together

These past two years have been filled with big changes and triumphs, and we are so proud of what we have accomplished thanks to your unwavering support. We exist to make a positive impact on the lives of those we serve, and we could not have done it without your partnership and generous support.

We have seen firsthand the transformative power of our programs and services. From providing critical resources to families in need to empowering young people to reach their full potential, our organization has been a beacon of hope and a source of community for so many. We've made significant strides in advancing our mission—and it's all thanks to the incredible dedication and hard work of our staff, volunteers, and supporters.



*Matt Flesch*  
**Matt Flesch**  
CHAIRMAN, BOARD OF  
DIRECTORS



*Monika Jones*  
**Monika Jones**  
FOUNDER + EXECUTIVE  
DIRECTOR



In November 2022, The Brain Recovery Project rebranded to the Pediatric Epilepsy Surgery Alliance, complete with a new website, tagline, and visual identity.

- Website: [www.epilepsysurgeryalliance.org](http://www.epilepsysurgeryalliance.org).
- Our new name includes “epilepsy surgery” to clarify that we focus on **all surgical treatments for children with drug-resistant epilepsy**. The addition of “Alliance” highlights our role as a **collaborator** across organizations and key stakeholders involved with epilepsy surgery.
- Our tagline “**Research | Information | Community**” shows our commitment to understand and improve outcomes of epilepsy surgery, our work helping parents and caregivers navigate the journey before and after surgery, and our role bringing together families, researchers, and health care professionals.
- Our new logo is simple and modern. It's a flower bud you might see as snow begins to thaw in early spring. It signals our **collective hope** for a renewed, better **quality of life** for the children we serve.

# Our Vision & Mission

Together we are a powerful alliance of families, clinicians, educators, partners, and researchers moving mountains for children who need neurosurgery to treat their seizures.



## Mission

Enhance the lives of children who need neurosurgery to treat medication-resistant epilepsy by empowering their families with research, support services, and impactful programs before and after surgery.



## Vision

A world where all children after epilepsy surgery have the opportunity for a high quality of life, including an appropriate education, gainful employment, meaningful social opportunities, and good health to the maximum extent possible regardless of where they are on the spectrum of outcomes.



# About Us

The Pediatric Epilepsy Surgery Alliance is the only nonprofit solely dedicated to supporting children who need neurosurgery to treat medication-resistant seizures.

Each year, about 9,000 children are diagnosed with drug-resistant epilepsy. For many, surgery offers the best chance to stop or significantly reduce seizures, yet it remains underutilized. We work to change that by raising awareness about surgery as a treatment option, empowering families with trusted information and support, and funding the research that drives better outcomes.

Since our founding as The Brain Recovery Project in 2011, we've invested over \$1.2 million in research to understand life after surgery. Our work has been shared at major medical conferences and featured in media including The New York Times and People Magazine.

*Emery has had a functional hemispherectomy, anatomical hemispherectomy, and two shunt surgeries to treat post-operative hydrocephalus. Now that she's seizure free, she's learned how to walk and loves to play with her big brother.*

Our programs and services directly help the families we serve. Whether through our trained and certified parent support navigators who help caregivers through times of isolation and fear, to our webinars and workshops that arm parents with knowledge, to our financial aid program that helps children get to surgical evaluation, we understand the important issues that affect our families.

Our donors, corporate partners, and volunteers are creating a positive and enduring change by supporting our work. Their time and gifts allow us to carry out our mission and create a better future for the children we serve.





# Our Impact

# Information + Resources

Receiving a diagnosis of a brain condition or illness that causes drug-resistant seizures can be an overwhelming and frightening experience for families. Having access to reliable, accurate, and easy to understand information about the condition, the surgical treatment options available, and what to expect during and after the surgery can help to alleviate some of the anxiety and uncertainty that families may be feeling.

Epilepsy surgery can dramatically improve a child's quality of life, but it can sometimes have significant short- and long-term effects on a child's health and well-being. Families need to understand the risks and benefits of surgery and what to expect during the recovery period. Our comprehensive and up-to-date information can help families make informed decisions about their child's care and manage their expectations.

Our website and social media channels continue to drive the conversation about epilepsy surgery, its effects, and outcomes.



4k+ Facebook followers



140,000+ website views



80,000+ people reached on Facebook



200,000+ Twitter impressions



50,000+ people reached on Instagram



90,000+ views of our webinars on YouTube



11,000+ downloads of our resource guides



# Power Hour

Being a parent of a child who is anywhere on the epilepsy surgery journey can be overwhelming at times. That's why we launched *Power Hour* in 2022. These monthly workshops shared on our YouTube channel are designed to be non-intimidating and easy to understand. We empower parents and caregivers with knowledge and use real-life examples to make sure they can easily follow along and apply what they learn.

Topics covered through 2022-2023 included:

- College Considerations After Epilepsy Surgery
- Coping Strategies for Parents
- Future Planning - How to Prepare for Adulthood & Beyond
- Monitoring Progress on Your Child's IEP Goals
- The Lifelong Impact Of Having A Sibling With A Disability

## Reviews



*Thank you so much for such a great and informative presentation! Always super helpful and amazing. The presentation is spot on with how we react differently within a family and how much this impacts the sibling of the special needs child as well as parents.*

*I liked how easy it was to follow. When talking about the brain there are a lot of concepts that are very hard to understand the presenter made it very easy to understand.*

*Also, I liked the visuals and how left and right sides are affected when there is brain injury.*



## Impact

560

Total number of registrants

44

Total number of Power Hour workshops

# Parent Support Navigator Program

Parenting a child with drug-resistant seizures who is anywhere on the epilepsy surgery journey can lead to feelings of isolation and higher rates of depression than typical parents. Because epilepsy surgery is rare, it's difficult to connect with other families. Digesting complicated information can be overwhelming.

Trained in evidence-based peer support practices through our collaboration with Parent2Parent USA, our parent support navigators provide practical and emotional support to families at various stages of the epilepsy surgery journey. They help parents understand available supports, re-entry into school, transition to adulthood, etc.)

Referrals are made from participating level 4 hospitals, Unite Us, Parent2Parent national network, or through our website.

Languages: English, Spanish, French, Farsi, Hindi, Portuguese.

*There is nothing more powerful than making a connection with another parent who just gets it.*

**Amy Alaniz, Parent Support Navigator**

**25**

Trained and certified support parents

**60+**

Support hours provided

**84**

Parents and caregivers supported



# Parent Support Navigator Feedback

*I feel less isolated and more empowered. I feel like I have someone who understands where I am, and what I'm going through...*

Excellent. I don't know where else I would have gone.

Our Kiddos have complex RARE medical conditions. It can feel very lonely and difficult to navigate the complex medical system. My parent supporter was a great listener and provided some helpful ideas. Thank you!

After our phone call, I felt more centered and left with some notes for my next steps. I was feeling overwhelmed with not doing "enough". I also wanted to be aware of any programs or resources that I wasn't already tapping into. It was very informative and helpful.



# Pediatric Epilepsy Surgery Family and Research Conference

More than 400 participants gathered in Park City, Utah, July 21st - 23rd for our biennial family conference and research meeting. Families and caregivers came together to forge connections and learn from leading researchers and clinicians from nationally renowned institutions. With over 22 educational sessions, 19 exhibitors, 8 sponsors, and a half day excursion to the National Abilities Center, the family conference was not just a learning experience; it was a journey of fun and fellowship, offering a supportive environment where shared experiences and new friendships blossomed.

**22** recorded sessions

**19** exhibitors

**96%** would recommend the conference to another family



**SESSION**

Pediatric Epilepsy Surgery  
Family and Professional Conference

**What's new in neuromodulation for pediatric epilepsy**

July 22, 2022 | Park City, Utah

 **Dr. Taylor Abel**  
Surgical Director  
Pediatric Epilepsy Surgery Program  
UPMC Children's Hospital of Pittsburgh

**SESSION**

Pediatric Epilepsy Surgery  
Family and Professional Conference

**Minimally Invasive Pediatric Epilepsy Surgery**

July 22-23, 2022 | Park City, Utah

 **Dr. David Adelson**  
Chief, Pediatric Neurosurgery  
Phoenix Children's Hospital

 **Dr. Sandi Lam**  
Division Head, Pediatric Neurosurgery  
Ann & Robert H. Lurie Children's Hospital

*"This conference is a lifeline for us. It gives us the tools and knowledge to do the best we can for our child. We are so appreciative of the effort."*

*"The conference was nothing short of a spectacular experience for our daughter and that is priceless."*

*"The sessions were informative and the conference was well organized."*



# Sibling Support Program

BECAUSE SIBLINGS MATTER, TOO

Like many parents in our community, we worry about the impact of epilepsy and epilepsy surgery on the siblings in the families we serve. Siblings of children diagnosed with a severe childhood epilepsy can play a role in the care of their brother or sister. While some may learn patience and compassion at an early age, the mental health impact on these siblings can be overlooked. These siblings may experience guilt, anger, sadness, fear, anxiety and depression.

In response, we launched the Sibling Support Program. Monthly virtual support sessions were moderated by Andréa Vugteveen, social worker and SibShops facilitator. Siblings shared joys and concerns about their sibling. It served as a safe place to discuss different topics, such as managing stress when their brother or sister is in the hospital or talking to their parents about their feelings.

Sessions were open to teens ages 13 – 17 who have a sibling anywhere on the epilepsy surgery journey (this means they had or plan to have surgery, or are starting the surgical evaluation process.)



16

Sibling support sessions

16

Total hours of sibling support

20

Sibling participants in virtual sessions

*"The most valuable part for me has been being able to be with teens my age who share the same experiences as I do, and being able to connect with adults who are there for me."*



# Dreams for Danny

The Boo Bash fundraiser event in 2022 launched our first Give for Hope™ campaign to raise funds for **Dreams for Danny** – our surgical evaluation travel scholarship program. This program breaks down financial barriers to care by providing up to \$1,000 in travel costs for families who seek a surgical evaluation at a level 4 epilepsy center more than fifty miles from their home.

in 2022

**\$25K**

funds raised for  
Dreams for Danny

**25**

families  
who received financial aid

in 2023

**\$35K**

**26**



In 2022, Dr. Taylor Abel, Chief of Pediatric Neurosurgery at UPMC Children's Hospital of Pittsburgh, received our first **Relentless Award** for his tireless dedication to the community of children we serve.

# Advocacy + Collaboration

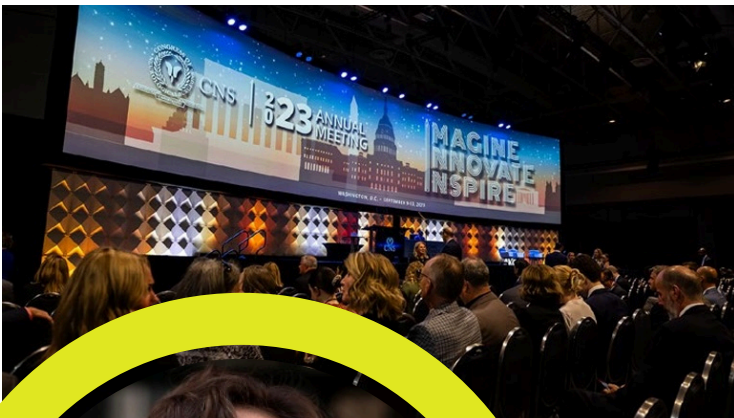


## Epilepsy Awareness Day at Disneyland:

The Pediatric Epilepsy Surgery Alliance was invited to exhibit, present, and facilitate pediatric epilepsy surgery sessions in 2022 and 2023. Over 5,000 people impacted by epilepsy attend this event every year.

## American Epilepsy Society - Annual Meeting:

In 2023, our executive director was part of a panel titled "Strengthening Multi-sector Engagement to Address Social Challenges in Epilepsy" and we staffed an exhibit table to share resources with clinicians. In 2022, we presented a scientific abstract on orthopedic issues after hemispheric surgery.



In 2023, our Executive Director, Monika Jones, was invited to speak at the Pediatrics Section meeting of the **Congress of Neurological Surgeons**, where she discussed the importance of providing parents and caregivers with a roadmap of care after epilepsy surgery.

## Researcher spotlight - Marlene Behrmann

*Dr. Marlene Behrmann is an emeritus professor of psychology at the University of Pittsburgh and member of the National Academy of Sciences. Her research specializes in the cognitive basis of visual perception. Dr. Behrmann's team is trailblazing research in the area of visual cognition after pediatric epilepsy surgery. Her team has published several peer-reviewed research studies in collaboration with the Pediatric Epilepsy Surgery Alliance.*



# Global Pediatric Epilepsy Surgery Registry

The Global Pediatric Epilepsy Surgery registry is a research project that allows families to share their experiences with and without epilepsy surgery in childhood by completing a series of surveys.

The main purpose of the registry is to gather information that can be used to understand the developmental trajectory after epilepsy surgery. Researchers can then use the registry to analyze the information, look for changes in a child's function over time, determine whether some surgical procedures are more effective at stopping seizures than others, recruit participants to their approved studies, and collect new information by adding new questions to the registry.

## Publications from the registry



### First community report

Charts and data about surgery outcomes. Most data in this report is about hemispherectomy.



### Endocrine dysfunction

Abstract presented at the 2020 Endocrine Society meeting about endocrine challenges after epilepsy surgery.



### Outcomes after hemispherectomy for hemimegalencephaly

Published in the prestigious medical journal *Epilepsia*, this is the first paper to address language and cognitive outcomes after hemispheric surgery for seizures caused by hemimegalencephaly.



### Characterizing Cognitive and Neuropsychological Outcomes Following Pediatric Hemispherectomy

This scientific poster, selected for platform presentation at the 2023 meeting of the American Epilepsy Society, breaks down cognitive outcomes after hemispheric surgery.

# Recognition in National Media

Featured on People.com and in the December print issue, the article tells the true story of Mora Leeb, a teen in our community who at just nine months old underwent a hemispherectomy to fight catastrophic epilepsy.

The article captures her parents' unwavering determination and underscores the importance of early intervention and advanced surgical options for drug-resistant epilepsy. It also highlights the work of Pediatric Epilepsy Surgery Alliance and how we help families in similar situations. It's a vivid illustration of the progress we're achieving in pediatric epilepsy surgery and the strength of families navigating these challenges.


People




## Why These Parents Made the Agonizing Decision to Have Half Their Child's Brain Removed (Exclusive)

Before she was born, Mora Leeb, now 16, suffered a stroke. By 4 months old she was experiencing seizures. The stroke had destroyed half her brain and her parents had to decide whether Mora should undergo a...

PEOPLE / Dec 3, 2023




Shots - Health News




Seth Leeb

### Meet the 'glass-half-full girl' whose brain rewired after losing a hemisphere

 Listen 7:28

© 2023 NPR



### Meet the 'glass-half-full girl' whose brain rewired after losing a hemisphere

Mora Leeb was 9 months old when surgeons removed half her brain. Now 15, she plays soccer and tells jokes. Scientists say Mora is an extreme example of a process known as brain plasticity.

NPR / Mar 22, 2023

Mora Leeb's story was featured on "All Things Considered" during the March 22nd episode. In the interview with Mora, her family, and researchers from University of Pittsburgh, the interviewers focused on the ability of the brain to rearrange speech and language functions to the intact brain hemisphere.



# Leading the Way

## Board of Directors

**Matt Flesch**

Board Chair  
Amgen

**Sandi Lam, MD, MBA**

Ann & Robert H. Lurie  
Children's Hospital of  
Chicago

**Aria Fallah, MD, MSc**

UCLA Mattel Children's  
Hospital

**Dr. Gary Mathern, MD**

Board member emeritus  
(non-voting)

**Mary Vernick**

Corporate Secretary

**Cecile Dame, PhD**

MPR Associates

**Taylor Abel, MD**

UPMC Children's  
Hospital of Pittsburgh

**Luke Shepard**

Board member emeritus  
(non-voting)

**Nicole Murray**

Epilepsy Foundation

**Emily Nicoli, CRNP**

7 Point Wellness

**Natalie Robinson**

Seattle Children's Hospital

## Scientific Advisory Board

**M. Scott Perry, MD**

Cook Children's Medical  
Center

**Taylor Abel, MD**

UPMC Children's  
Hospital of Pittsburgh

**Andrew Gordon, PhD**

Center for Cerebral Palsy  
Research at Columbia  
University

**Joanna A. Christodoulou, EdD**

Brain, Education, and Mind Lab  
MGH Institute of Health  
Professionals

**Raymund Woo, MD**

Advent Health

**Lynn Paul, PhD**

California Institute  
of Technology

**Dr. Phil Zeitler, MD, PhD**

Children's Hospital  
Colorado

**Frank Musiek, PhD, CCC-A**

University of Arizona

**Linda Lawrence, MD**

Salina Regional Health  
Center

## Key Staff & Volunteers

**Monika Jones, JD**

Founder, Executive Director

**Audrey Vernick**

Director, Patient & Family  
Advocacy

**Erin Williamson**

Conference Event Chair

**Chantell Ferrin**

Conference Attendee Experience  
Lead

**Klajdi Puka, PhD**

Biostatistician

**Amy Alaniz**

Development Associate

**Courtney Stone**

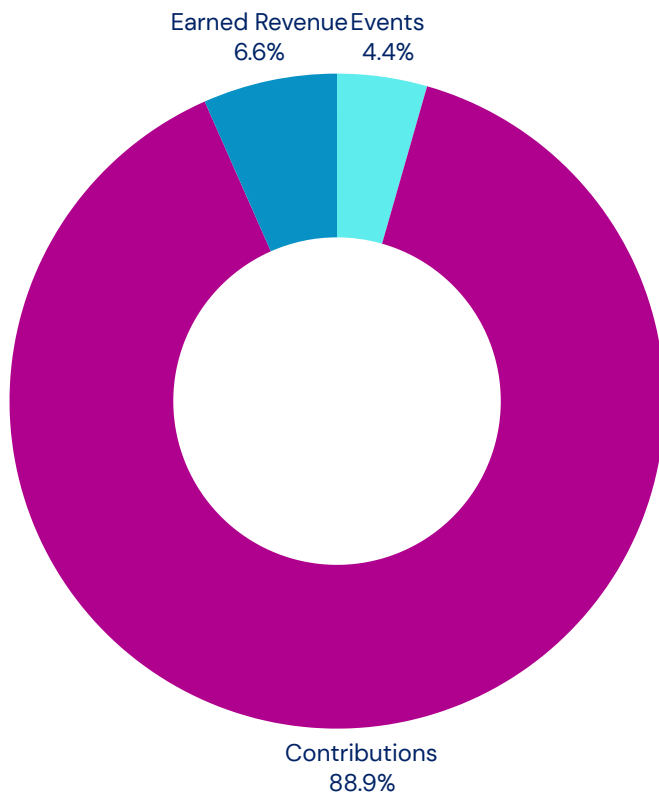
Clinical Engagement Ambassador

**Brittany Carver**

Administrative Assistant

# Financials

1/1/2022 - 12/31/2023

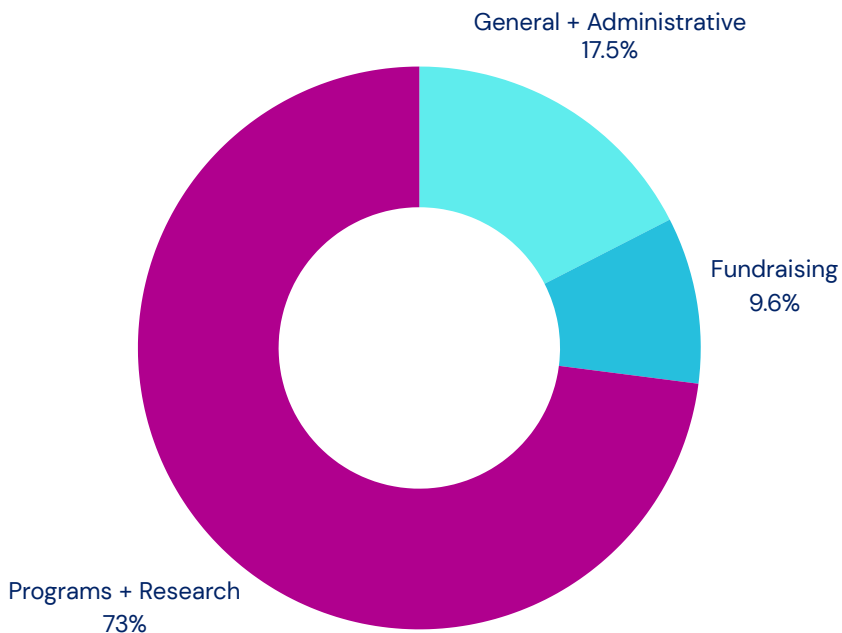


## Revenue

• Events	\$27,925
• Contributions	\$559,875
• Earned Revenue	\$41,664

---

Total:	\$629,464
--------	-----------



## Expenses

• Programs + Research	\$413,693
• General + Administrative	\$98,992
• Fundraising:	\$54,254

---

Total:	\$566,939
--------	-----------



**pediatric**epilepsy  
surgery**alliance.**

969 Colorado Blvd.  
Suite 101  
Los Angeles, CA 90041

Tel: 833-675-3335  
email: [info@epilepsysurgeryalliance.org](mailto:info@epilepsysurgeryalliance.org)

The Brain Recovery Project dba Pediatric Epilepsy Surgery Alliance is a 501(c)(3) non-profit organization.

Tax I.D. No. 45-2571898

All donations are tax-deductible to the fullest extent allowed by law.