

2019 Annual Report



thebrainrecoveryproject

CHILDHOOD EPILEPSY SURGERY FOUNDATION

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Monika Jones, JD
Visionary Founder and Executive Director

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and School Training*

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Whitney Mohler, *Grants and Development*

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A Note

from our CEO.

2019 was a banner year for us. We launched our global pediatric epilepsy surgery registry, convened an important patient-centered research meeting, held our biggest family conference yet, funded important research, and formed strategic alliances with high impact organizations to help us move our mission forward.



I am filled with hope for the future of the community of children we serve. Our families are brave beyond measure and are deeply committed to the fight against epilepsy. Your support has helped us serve them better each year and we're glad to have you as champions alongside us throughout our journey.

This annual report highlights what we did in 2019 thanks to your unwavering commitment. My profound gratitude goes to **our team** who works tirelessly to move our mission forward, our **community advisory council** whom I look to for guidance and opinion, and our **scientific advisory board** for their strategic advice and critical assessment of what we do.

This year has already promised unprecedented challenges which I know we will meet head on. With you, we remain relentlessly dedicated to helping children reach their full potential after epilepsy surgery.

Always in hope,

Monika Jones, CEO

Launched

The Global Pediatric Epilepsy Surgery Registry.

Powered by the experiences of parents, the **Global Pediatric Epilepsy Surgery Registry** is the first research study to track the developmental progress of children after epilepsy surgery and how epilepsy surgery impacts their daily lives.

Registry data will give information to researchers and doctors about surgery outcomes beyond seizure control and will lead to new and exciting discoveries for our children. We'll report early results from the registry in the second quarter of 2020, which will include outcomes of 120 children who had hemispherectomy surgery.



Welcome

Hosted Another Six Children At Robocamp.

Robocamp is the **world's first intensive physical and occupational therapy camp** for children in the chronic phase of recovery after hemispherectomy surgery. This was the fifth year of this study where researchers at **Rancho Los Amigos National Rehabilitation Center** aim to understand whether two weeks of intensive therapy given in a camp-like environment can improve hand function, gait, and walking speed in children with hemiparesis caused by hemispherectomy surgery. Your support funded program management as well as travel, lodging, and food for the participants.



Convened

A Patient-Centered Meeting On The Functional Impacts Of Large Epilepsy Surgeries.

For the first time – ever – we gathered parents, doctors, and researchers in the same room to discuss one thing: how do large epilepsy surgeries impact how a child functions after surgery? Thanks to a large award from the **Patient-Centered Outcomes Research Institute**, this innovative meeting addressed what happens after surgery. Parents and adults who had surgery in childhood gave powerful presentations about life after large epilepsy surgeries, followed by research summaries from clinicians and neuroscientists.

Learn more on our website at [bitly.BRAINSURGERY](https://bitly.brainsurgery)



Established

A Working Group And Research Consortium.

After the functional impacts meeting, we established a working group of parents, researchers, and clinicians willing to move forward with us to further patient-centered outcomes research related to the side effects of resective and disconnective pediatric epilepsy surgery. Physician members will help us draft a guide to best practices after pediatric epilepsy surgery, which will include suggestions for the type of physicians who should follow a child after epilepsy surgery. Several researchers and clinicians committed to helping us establish an international research consortium who will work to understand – and improve – functional outcomes after surgery.



Published

Our Research.

Our recruiting and funding efforts led to the publication of two peer-reviewed research papers and two abstracts in 2019:

Kliemann D, Adolphs R, Tyszka JM, et al. **Intrinsic functional connectivity of the brain in adults with a single cerebral hemisphere.** Cell Rep 2019;29(8):2398–2407

Chen MF, Meer E, Velez FG, Jones M, Mathern GW, Pineles SL. **Etiology and Age Modifies Subjective Visual Function After Cerebral Hemispherectomy.** J Child Neurol. 2019;34(8):446–451. doi:10.1177/0883073819834430

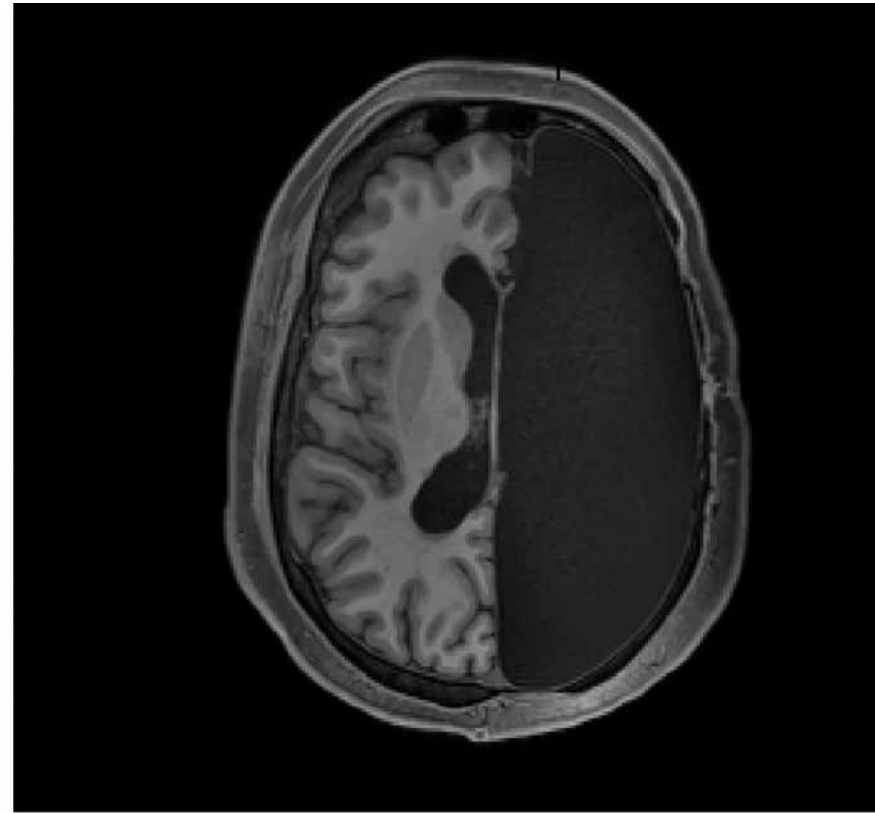
Shaw, S., Kasayama, J., Blydt-Hansen, E, **Intensive therapy utilizing robotic mobility technology improves motor function post-cerebral hemispherectomy.** Poster presented at the American Congress of Rehabilitation Medicine; 2019 Nov 3 – 8, Chicago, Illinois.

Jones, M, Moshe, S., Fallah, A. **A web-based, patient-driven (by proxy) registry for pediatric epilepsy surgery: the Global Pediatric Epilepsy Surgery Registry.** Poster presented at Annual Meeting of the American Epilepsy Society; 2019 Dec 1 – 5; Baltimore, MD.



How the Brain Can Rewire Itself After Half of It Is Removed

New scans showed how the brains of people who had a hemisphere removed in childhood continue to function.



A magnetic resonance imaging scan of a slice of an adult's brain who had an entire hemisphere removed during childhood because of epilepsy. Video by Caltech Brain Imaging Center

And

**... our research
captured the
attention of
national media.**

Neld

The Largest Family Conference For Families Impacted By Epilepsy Surgery.

A record-breaking 405 attendees attended our **family conference** in July of 2019, where we presented 30 sessions and workshops covering a **wide range of topics**. While parents attended sessions, children attended camp run by a professional childcare firm. And thanks to a **Rare Patient Impact Grant** from **Global Genes**, our teens and young adults enjoyed three free chaperoned excursions to the Rock 'n Roll Hall of Fame, the Great Lakes Science Center, and a fun bowling and



pizza night. This gave them time to bond and form powerful peer relationships which we hope they will enjoy for years to come.

Research teams from the **Behrmann Lab** at **Carnegie Mellon University** and the BEAM Lab at MGH Institutes tested 64 participants to better understand vision after surgeries which remove an occipital lobe and educational success after hemispherectomy.

All presentations from the conference are located on our You Tube channel at bit.ly/BRPYOUTUBE

Provided

Peer Support.

We're always on the frontlines with our families providing peer support through several touchpoints – referrals from the clinician community, social medial post responses, direct messaging, email, or phone calls.

In 2020 we plan to launch a more formalized peer support program, which will include national training for our peer support specialists. This will include training peer coaches to help parents navigate individual education and 504 plans after epilepsy surgery.

Peer support touchpoints: **≈2900**



Trained

Parents And School Teams.

The maze of special education laws in the U.S. can be challenging for parents to understand. And both parents and school teams may be puzzled by the educational impacts of certain epilepsy surgeries.

92

parents and educators watched our intensive IEP training videos or attended live, virtual training sessions on the effects of various epilepsy surgeries on school performance.

623

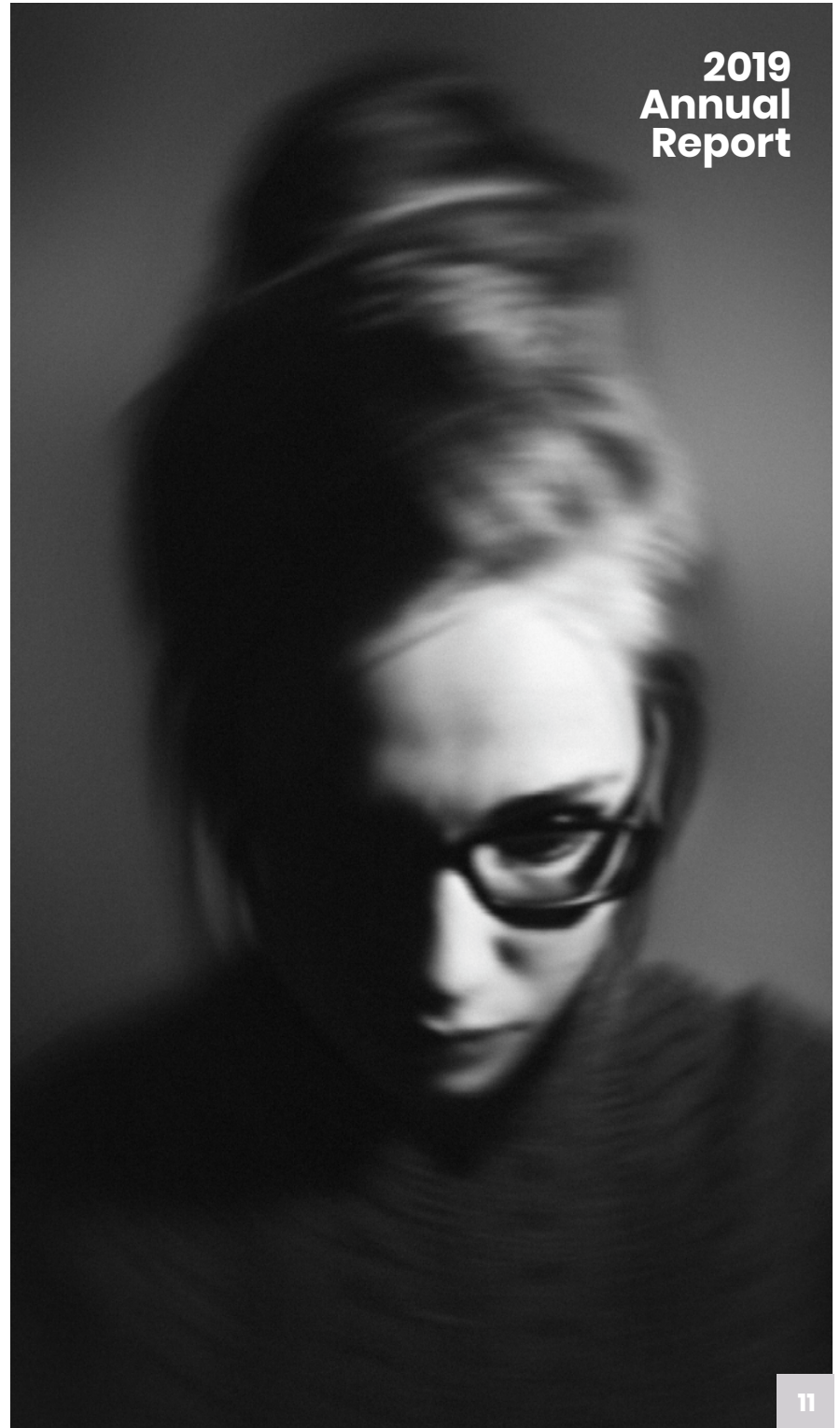
parents, teachers of the visually impaired, orientation and mobility specialist, and other school team members watched our **Vision After Surgeries Which Remove An Occipital Lobe** produced in collaboration with **Perkins School for the Blind**.



Hosted

Three Webinars About Managing The Toll Of Caregiver Trauma.

Caring for a child with disabilities can take a toll on parents and caregivers. We collaborated with several strategic partners in the rare epilepsy space to bring our community three webinars to help managing the toll of caregiver trauma.



Provided

Financial Aid To Families Traveling Far From Home For An Epilepsy Surgery Evaluation.

Through our Dreams for Danny: Surgical Evaluation Travel Scholarship program, we provided over \$5,700 in financial aid to families to help with travel costs such as airfare, hotel, and food.



Aligned

With High-Impact Organizations To Move Our Mission Forward.



We formed deeper relationships with high impact organizations that are changing the landscape for children with rare epilepsies and disabilities. Together, we work out problems that are a concern to all of us – and develop solutions to make the best use of the strengths of each organization.

The Epilepsy Leadership Council (ELC)

is collaborative effort across several stakeholder communities (government, advocacy groups, and physicians) with a common goal of improving the lives of those living with epilepsy. The ELC selected our CEO, Monika Jones, to be one of its several members representing it as part of the Epilepsy Benchmarks Stewards group which is tasked with giving the patient voice to the **National Institute of Neurological Disorders and Stroke (NINDS)** as they redraft benchmarks for future epilepsy research.

CVI CoLab

We continued our work with Perkins School for the Blind to improve the diagnosis, treatment, and education of children with cerebral vision impairments. We were honored to be invited to participate in a small colab which includes researchers, educators, scientists, parent advocates, and physicians who are committed to improving the lives of children with brain-based visual impairments.

The Epilepsy Learning Health System

is a new initiative by the Epilepsy Foundation to create a learning health system around epilepsy – where science, informatics, incentives, and culture are aligned for continuous improvement and innovation, with best practices seamlessly embedded in the care process, patients and families active participants in all elements, and new knowledge captured as an integral by-product of the care experience. The Brain Recovery Project was selected to be part of the ELHS Community Engagement Core.

Infantile Spasms Action Network

We continued our active membership in the Infantile Spasms Action Network, and took a leadership role in 2019 by helping draft the future governance structure of this consortium. Our 2018 video about infantile spasms was chosen once again as part of the group's marketing efforts for the Infantile Spasms Action Week December 1 – 7, 2019.

Rare and Catastrophic Seizures Consortium

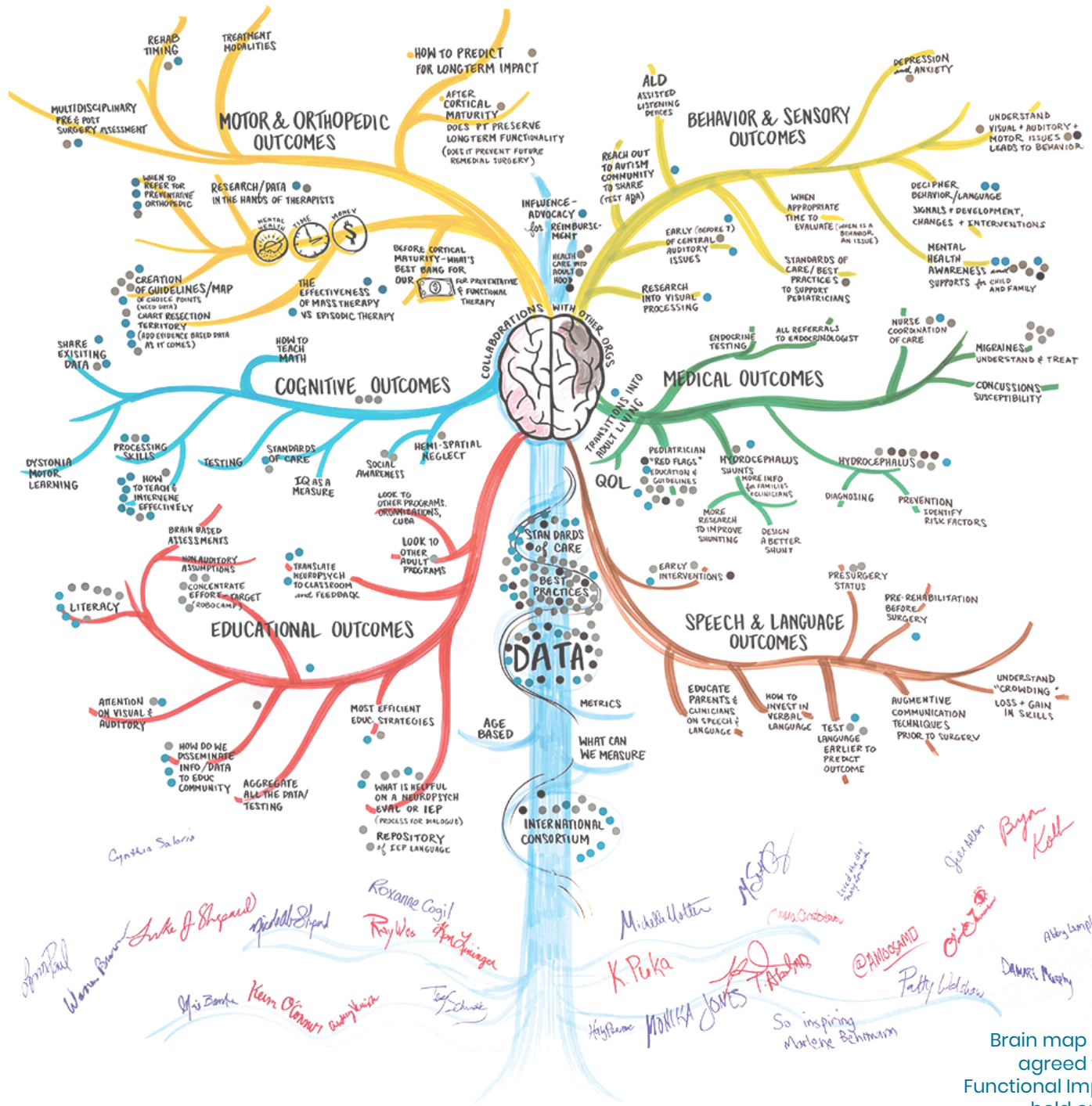
The new collaboration of several epilepsy organizations works to raise awareness – especially amongst clinicians – about rare and catastrophic epilepsies. We have taken a lead role in this group in the areas of education and endocrinology.

DEE-P Connections

We are honored to be a founding partner in this new collaboration, headed by Wishes for Elliott, to help children with developmental and epileptic encephalopathies. Often described as “low functioning” by the medical and educational community, these children have complex and unique challenges that require our advocacy.

Rare Epilepsy Network

We are members of the Rare Epilepsy Network (REN), a collaboration between the Epilepsy Foundation, RTI International, Columbia University and many different organizations that represent patients with a rare syndrome or disorder that is associated with epilepsy or seizures. We actively work with REN to better understand the behavioral implications of many epilepsies and, as part of the REN Steering Committee, to establish criteria for potential Centers of Excellence for the rare epilepsies.



Brain map of future research focus agreed to by participants of the Functional Impacts research meeting held on July 2020 (see page 4).

Awareness and Engagement

Raising awareness of the issues our children face helps educate parents, clinicians, and school teams so that our community is better served. The following statistics are for 2019 only.



You Tube Views
19,632



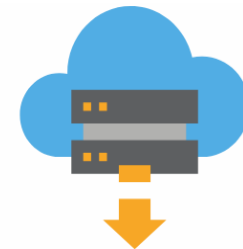
Traffic (Countries)
177



Website Views
122,841



Webinar Views
715



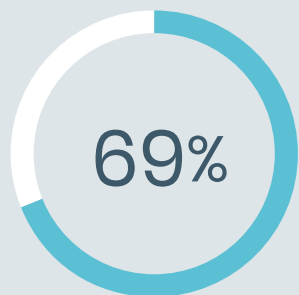
Guide Downloads
6,922



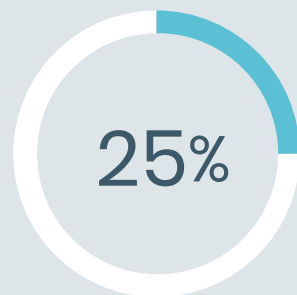
Facebook Followers
3,452

Finances

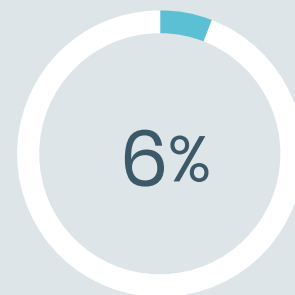
SUPPORT AND REVENUE



Contributions
\$296,751.19

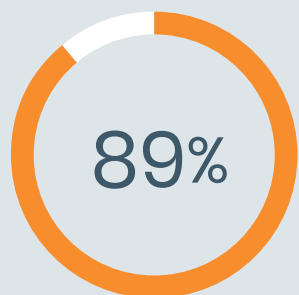


Program Income
\$105,222.18

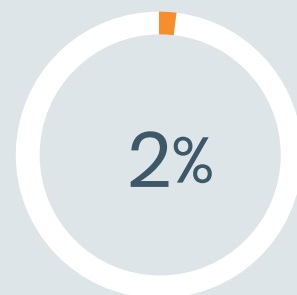


In Kind & Other
\$25,690.01

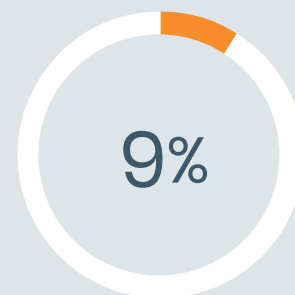
EXPENSES



**Programs
and Research**
\$388,975.42



**Fundraising and
Development**
\$8,750.64



**General and
Administrative**
\$37,570.08



In 2019 we received a Gold Seal of Transparency from **GuideStar**. This recognition shows our commitment to financial and programmatic transparency, giving champions like you the information you need to make educated decisions around supporting our work.



**Thank you for
believing in our
small but mighty
community.**

Our mission.

We help children reach their full potential after epilepsy surgery.

Our 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.

Our values.

HIGH IMPACT

What we do results in sustainable, positive change for our stakeholders.

STAKEHOLDER FOCUSED

We know what our stakeholders need and build programs to address gaps. We are inclusive and focused on all children, regardless of where they are on the spectrum of functional outcomes.

EXCEPTIONAL

Exceptional website, exceptional information, exceptional programs and services. We set the bar high. If we can't do something well, we don't do it.

INNOVATIVE

We change the landscape for our stakeholders by thinking outside of the box.



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