

STRATEGIC PLAN 2017 - 2020

About The Brain Recovery Project: Childhood Epilepsy Surgery Foundation

The Brain Recovery Project is a non-profit organization with charitable status, incorporated in California in 2011. Our charitable tax ID number is 45-2571898. The organization's corporate charter is broadly defined as: "to develop and implement a **comprehensive rehabilitation program** for **brain-injured** individuals who receive such injury when in utero, childhood or adolescence, whether through trauma, **surgical resection**, or otherwise, by **supporting scientific research** and providing charitable assistance and **educational programs.**" (Emphasis added.)

Links between this Strategic Plan and the organization's other planning documents

The board of directors will revisit annually this strategic plan to ensure that the organization is best positioned to deliver on its mission. Board approval of this multi-year plan is subsequently followed by Board approval of an annual 'Program Plan' and accompanying budget, which detail the Board's wishes for those elements of the Strategic Plan that should take place during the upcoming calendar year. Please contact the organization's CEO for more information on this process or these plans.

Our Stakeholders/Who We Serve

Our primary stakeholders are parents, caregivers, and the children who have had **resective or disconnective** epilepsy surgery. Secondary stakeholders include educational and medical teams which support these children.

Vision of The Brain Recovery Project

By 2020, The Brain Recovery Project is the **preeminent source** for information, programs, and resources following resective or disconnective pediatric epilepsy surgery.

Organization Name

The Brain Recovery Project: Childhood Epilepsy Surgery Foundation

Mission of The Brain Recovery Project

We help children reach their full potential after brain surgery to stop drug-resistant seizures.

Tagline

Helping kids reach their full potential after brain surgery to stop seizures.

Core Values

These core values guide the organization as it works to accomplish its vision and mission.

Stakeholder Obsessed

We know what our stakeholders need and build programs to address gaps. We are focused on the user - everything else will follow. The needs of the parents and the children who have undergone resective or disconnective epilepsy surgery are always first. We are inclusive - focused on the functional outcomes of all the children.

Great

Great website, great information, great programs and services. We set the bar high. We only do what we are great at, and we say no to the things we do not do well.

Disciplined

Disciplined people, disciplined thought, disciplined action.

Innovative

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

Outrageous Impact

What we do has a tremendous, positive impact on our stakeholders.

Roles

We take on the following roles in our work to help children reach their full potential after epilepsy surgery, as we implement our mission and vision:

1. **Research:** We initiate and fund relevant, useful research, synthesize existing research, and translate it into usable guides, website content, and solutions for our stakeholders;
2. **Program Development:** We build and develop programs that are impactful and respond to knowledge or resource gaps.
3. **Connect the community:** We will work with all interested organizations, communities, facilities, and providers to promote our resources, services, and events to the widest possible audience of stakeholders and connect our efforts to relevant national and international networks, resources, and activities.

Our Impact

A non-profit organization is worthless if it is ineffective. Effectiveness is measured by impact - the **outcomes** of our work. This is how we measure our success. To do so, we must have a clear understanding of:

THE PROBLEM WE WANT TO SOLVE
WHAT WE NEED TO DO
THE RESOURCES WE NEED TO DO IT
WHAT ARE THE DELIVERABLES WE PRODUCE
WHAT IS THE RESULT OF OUR WORK

PROBLEM #1: While there are various epilepsy-related organizations, no organization targets what happens after resective epilepsy surgery, especially large resections and disconnective procedures. We believe this lack of focus on functional outcomes is one reason so many neurologists hesitate to recommend it, and why many parents hesitate to consider it - often to the long-term detriment of the child. Well-regarded organizations, such as the [Epilepsy Foundation](#), CURE, and the American Epilepsy Society, are **not focused on surgical outcomes. Similarly, functional outcomes are often over-stated. Because epilepsy surgeries are as individual as the child who has them, and still relatively rare, parents are left to navigate the chronic maze of aftercare in their hometown, often with health care and educational partners with little or no experience in post-epilepsy surgery medical, educational, behavioral, rehabilitation, and life care issues. Statistics in research publications and books are difficult to access by parents/laypersons. Parents turn to social media to seek information from other parents. Information given by parents can be incorrect and/or purely anecdotal, although we recognize that the collective knowledge of many of these groups are vast and often reliable.**

PRIMARY IMPACT: Parents whose children have had epilepsy surgery have the tools needed to help their child throughout the lifespan across all functional domains.

WHAT WE NEED TO DO	WHAT WE NEED TO DO IT	DELIVERABLES	THE RESULT
<p>1.Translate/meta-analysis of (albeit minimal) research on functional outcomes and therapy interventions (commence Q4 2016).</p> <ul style="list-style-type: none"> • Work with parent advisory board and review social media posts to understand stakeholders' biggest concerns, misunderstandings, and lack of knowledge re functional outcomes and interventions. • Identify gaps between research 	<p>Program funds Operating funds Innovation funds Staff to capacity Build infrastructure Board and staff time Contractors/specialists (e.g. researchers and medical writers, website coders) Conference venues Scientific advisory board</p>	<p>Hemianopsia VR and AR simulator Translational research division Publish synthesis papers across all functional domains Regular presence/abstracts at AES, AAN) White papers Populate robust</p>	<p>Parents understand functional outcomes and "what works" after surgery. They have a lifespan care roadmap.</p>

<p>and real life situations, parent needs, etc.</p> <ul style="list-style-type: none"> • Develop annual stakeholder survey • Develop rehabilitation programs and camps based on existing research (Q1 2018) 	<p>time Parent advisory board time</p>	<p>website content Understandable written materials, guides, pamphlets, books, to guide stakeholders, therapists, and educators Webinars and infographics Programs (e.g. Advocacy, Robocamp, HABIT camp) Annual family conferences Annual professional conferences (AES, AAN) Annual stakeholder survey</p>	
<p>2. Advance the body of research on functional outcomes and intervention strategies after various pediatric epilepsy surgeries (Q1 2018)</p> <ul style="list-style-type: none"> • Assemble scientific advisory board to assist with identifying research focus • Assemble parent advisory board to assist with identifying research focus • Identify and initiate new 	<p>Significant research funds (>+\$1 million) Operating funds Scientific advisory board time Parent advisory board time Patient registry platform Federal grants Researcher relationships Board and staff time</p>	<p>Initiate multi-center functional outcomes study (Q1 2018) Robust website Published research papers Regular presence/abstracts at AES, AAN) Guidelines, paradigms for</p>	<p>Parents understand functional outcomes and their effects on the child.</p> <p>Parents understand which interventions are most effective.</p>

<p>descriptive research on outcomes and interventions (e.g. auditory, CIMT, Robocamp)</p> <ul style="list-style-type: none"> • Fund a multi-disciplinary research fellowship (e.g. young neurosurgeon partners with rehab professionals to focus on outcomes for a year and presents his/her work) 	<p>Staff to capacity Build infrastructure Contractors/specialists (e.g. researchers and medical writers, physical, occupational, and speech therapists, website coders) Conference venues Funds Parent advisory board time</p>	<p>therapists (e.g. PT Guide After Hemispherectomy; OT Guide After Hemispherectomy) Webinars Whiteboard explainers Other publications Template Insurance approval letters Programs (e.g. robocamp, new HABIL camp) Seat at the table at FDA, REN, "Vision 2020" Triennial research conference Professional networking (attend relevant conferences (e.g. AOTA, APTA, ASHA) Patient registry Serve on advisory boards</p>	
<p>3. Advance primary and secondary stakeholder knowledge regarding special education(Q4 2016)</p> <ul style="list-style-type: none"> • Develop educational advocate division to provide direct IEP 	<p>Board and staff time Staff to capacity Build infrastructure Contractors/specialists (e.g. researchers and</p>	<p>Robust website Published materials and guides Webinars Whiteboard</p>	<p>Qualified advocates help parents obtain appropriate IEPs. Parents are</p>

<p>assistance</p> <ul style="list-style-type: none"> • Develop online education modules for parents • Regular conference programming re IEPs • Regular updates to website • Work with professional organizations (e.g. special education teachers associations, COPAA, APTA, AOTA, neuropsychologists) to increase understanding of educational challenges faced by children after epilepsy surgery) 	<p>writers, physical, occupational, behavioral, and speech therapists, website coders) Conference venues Funds Parent advisory board time</p>	<p>explainer videos Networking (e.g. attend relevant conferences APTA, AOTA, ASHA)</p>	<p>knowledgeable about IEPs and are able to navigate the system themselves.</p> <p>Educators and aligned providers (PTs, OTs, speech therapists, etc) understand epilepsy surgery and its impact in the educational environment by using our materials/accessing our website and are able to effectively educate these children.</p>
<p>4. Advance primary stakeholder knowledge regarding entitlement programs, legal issues (e.g. special needs trusts, etc.) (Q4 2016)</p> <ul style="list-style-type: none"> • Create information hub/gallery on website with original content and links to other organizations (e.g. kidswaivers.org) • Regular family conference topics • Develop educational materials 	<p>Board and staff time Staff to capacity Build infrastructure Contractors/specialists (e.g. researchers and writers, physical, occupational, and speech therapists, website coders) Conference venues Funds Parent advisory board time</p>	<p>Parent education initiative Robust and current website, including online roadmap portal (“Seizure Hub”) Annual conferences Infographics Video interviews, case statements Whiteboard explainer videos</p>	<p>Parents, at any point in the lifespan, have access to information to help them.</p>

		Webinars Online and written materials	
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PROBLEM #2: Information regarding when to have epilepsy surgery and why is scattered throughout various websites and poorly addressed in most. Statistics, etc., are in research publications and books which are difficult to access by parents/laypersons. Parents turn to social media to seek information from other parents. Information given by parents can be incorrect and/or purely anecdotal. Parents turn to neurologists and neurosurgeons who have limited time to answer all questions and often look only to their experiences/patient history for outcomes.

SECONDARY IMPACT: Parents considering epilepsy surgery for their child understand options, procedures, and the spectrum of functional outcomes.

WHAT WE NEED TO DO	WHAT WE NEED TO DO IT	DELIVERABLES	THE RESULT
<p>1. Advance a formal primary stakeholder pediatric epilepsy surgery education program (Q1 2017)</p> <ul style="list-style-type: none"> Develop learning modules which address the ILAE drug-resistant failure standard, all the epilepsy 	<p>Program funds Operating funds Board and staff time Staff to capacity Build infrastructure Contractors/specialists (e.g. researchers and writers, website coders,</p>	<p>Parent education initiative Robust and current website, including online roadmap portal ("Seizure Hub") Annual conferences Infographics Video interviews, case statements</p>	<p>Stakeholders understand the benefits, limitations, and risks associated with pediatric epilepsy surgery.</p>

<p>surgeries, including descriptions, pre-testing, risks, acute recovery, functional outcomes, etc. Highly data/research driven.</p> <ul style="list-style-type: none"> • Create and promote learning stories that show how epilepsy surgery has stopped a child's epilepsy. Include stories of multiple procedures or unsuccessful seizure outcomes. • Regular updates on website, guest blogs, newsletter, email, etc. re new research re efficacy of pediatric epilepsy surgeries • Marketing campaign to stakeholders to increase awareness of our programs/services (e.g. social media) 	<p>marketing/graphic artist) Conference venues Build relationships with organizations like ILAE</p>	<p>Whiteboard explainer videos Webinars Online and written materials Networking Attend conference (e.g. Epilepsy Awareness Day, hospital-sponsored epilepsy conferences) Co-branded publications (e.g. ILAE) New logo, branding</p>	<p>Parent decision-making is informed.</p>
<p>2. Advance an informal primary stakeholder pediatric epilepsy surgery education program. (Q2/3 2017)</p> <ul style="list-style-type: none"> • Maintain a robust social media presence to guide parents to the website when queries are made in social media groups. • Regular social media posts, 	<p>Program funds Operating funds Staff time Staff translational advocates, social media program Build infrastructure Contractors/specialists (e.g. researchers and writers, website coders,</p>	<p>Social media campaign Translational advocate program</p>	<p>Parents are pointed to our website for research-based answers and guidance.</p>

<p>shares, etc. re relevant epilepsy surgery articles, papers, etc.</p> <ul style="list-style-type: none"> • Guest blogs re various epilepsy surgery considerations. 	<p>marketing/graphic artists)</p>		
<p>3. Advance a relationship-building campaign with neurosurgeons and neurologists.</p> <ul style="list-style-type: none"> • Identify the top 10-12 pediatric epilepsy surgery facilities in the U.S. • Understand the neurosurgeon's and neurologist's pain points (e.g. predicting the future/crystal ball effect) • Work with identified facilities to help them understand what we do and how to share our information • Identify the top professional epilepsy organizations 	<p>Program funds Operating funds Staff time Staff translational advocates, social media program Build infrastructure Contractors/specialists (e.g. researchers and writers, website coders, marketing/graphic artists)</p>	<p>Cooperative agreements Provider marketing materials/packets Grand Rounds participation/topics New patient packets Co-branded patient guides BRP Kiosk Professional conference presence Family conference invitations to speak, present, etc.</p>	<p>Neurologists and neurosurgeons turn to the organization to help their patients/families decide whether to select epilepsy surgery.</p> <p>Surgeons and neurologist rely on our publications to help them answer many questions parents have regarding decision-making and functional surgical outcomes. This assists surgeons with communicating material risks and benefits that a</p>

			reasonable parent would want to know, helps them manage expectations and fears during the parent/caregiver's decision-making process.
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PROBLEM #3: Historically we have operated with minimal staff who are Jacks of all trades. To effectively grow the organization, we must build systems, staff to capacity, and create consistent funding streams.

TERTIARY IMPACT: Organizational development and diverse revenue streams ensure that the organization sustains and increases its impact.

WHAT WE NEED TO DO	WHAT WE NEED TO DO IT	DELIVERABLES	THE RESULT
<p>Build the organizational capacity of the board and staff (Q4 2016)</p> <ul style="list-style-type: none"> ● Conduct regular board meetings and actively engage the board in strategic planning, fund development, communications, and committees; ● Create and maintain a suite of robust and active committees that engage most or all board members and support our work (governance, personnel, program, fund development); ● Maintain an up-to-date board manual that 	<p>Operating funds Board and staff time through committees and meetings Hire key staff, including COO/Integrator</p>	<p>Board meeting minutes Board manual Staff performance reviews, policies, and procedures Board committees Robust and active committees Organization is staffed for capacity building (e.g. administrative assistants, etc.) Develop Four-Year Budget Develop Program Plans</p>	<p>Staff members are provided with appropriate compensation within the financial means of the organization.</p> <p>Staff are well-supported, empowered, and work to their potential as they drive the organization's work forward.</p> <p>Sound financial systems are in place to guide program planning and meet legal and financial standards for monitoring and reporting.</p>

<p>captures all board policies and committee terms of reference</p> <ul style="list-style-type: none"> • Implement internal control procedures to meet legal and fiduciary responsibilities (quarterly financial reports, reporting to regulatory bodies, etc.); • Maintain practices that support staff and build staff capacity and job satisfaction. 			
<p>2. Create and maintain a diverse and sustained funding stream</p> <ul style="list-style-type: none"> • Create and effectively distribute annual report and Why Donate To Us? Publication • Create and maintain robust internal systems to track and nurture all funders, including individual 	<p>Board and staff time Contracts (marketing/graphic artists, database entry)</p>	<p>Operating funds Annual report Why Donate To Us? Publication (year end?) CRM (Salesforce) Fund development strategy Cheat sheet to support board fundraising activities Financial audit Stakeholder survey</p>	<p>Our revenue streams are diverse and include a healthy component of funding from corporations from various sectors, foundations, and individuals.</p> <p>We steadily increase the percentage of revenue we receive from individuals.</p>

<p>and major donors</p> <ul style="list-style-type: none">• Generate and maintain an annually-revised fund development strategy• Build the capacity of the board to leverage their relationships• Provide relevant professional support for staff around grant writing and funder relationships• Maintain support from current funders, and annually add on to build new relationships with at least two new foundations• Obtain high Guidestar rating			
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On October 24, 2017, the Board of Directors of The Brain Recovery Project adopted this Strategic Plan effective January 1, 2017.