

STRATEGIC PLAN 2020 - 2025

THE ROAD TO HIGH IMPACT

SUMMARY

What are the factors that contribute to children having the best chance at a high quality of life after brain surgery to stop seizures? This question fuels the vision of The Brain Recovery Project and is the heart of our new strategic plan.

This strategic plan is our road map, defining a clear destination of where we want to be at the end of 2025. It gives a sharp focus to our work by defining seven impact objectives driven by our community's needs and priorities. It requires us to rethink how we organize our time and talent, as well as where we invest donations and what research we fund.

By focusing on what will bring **high impact quality of life improvement** for the community we serve, our new strategic plan will ensure that we are helping children reach their full potential after brain surgery to stop seizures.

WHAT WE DID

In January of 2020, we surveyed 89 individuals impacted by pediatric epilepsy surgery, including physicians, parents, adults who had surgery in childhood, and educators. We asked a series of questions about health care provider knowledge, function after epilepsy surgery, financial and emotional stress, medical and non-medical symptoms and challenges, and community needs. There was a wide range of answers, however, five areas of highest concern were surfaced: understanding the effects of surgery, improving function after surgery, improving educational outcomes, managing a smooth transition into adult life, and the social and emotional well-being of the child and immediate family members.

Based on these findings, input from our community advisory council, scientific advisory board, and board of directors, as well as the results of the functional impacts research meeting held in the summer of 2019, our strategic plan task force met and developed eight strategic objectives to be achieved by the end of 2025. Informing all of these objectives is our commitment to help all children reach their full potential after brain surgery to stop seizures.

Child-Impact Objectives: Focusing on the Needs of the Children

We will focus on four child-centered quality of life objectives through the end of 2025. These objectives concentrate our program efforts and resources on the needs of children who are at any point in the epilepsy surgery journey.

Objective 1: Understanding Outcomes: Help parents and aligned stakeholders understand medical and functional outcomes after brain surgery to stop seizures, including the constellation of factors that affect outcomes.

Objective 2: Improving Outcomes: Improve medical and functional outcomes after surgery across the spectrum of outcomes in our community.

Objective 3: Improving Educational Achievement: Improve educational achievement in preschool - 12th grade regardless of placement.

Objective 4: Improving the Transition to Adult Life: Help the impacted child, whether directly or through caregivers, access appropriate neurological and neurosurgical care, post-secondary education, training, and/or community employment (where appropriate), community living, and integrated adult life including leisure opportunities with family and friends.

Family-Impact Objectives: Making A Difference

We will focus on one family-centered objective by improving the quality of life of the immediate family unit.

Objective 5: Improving Family Quality of Life: Improve the general well-being of the immediate family unit.

Internal Objectives: Supporting Our Work

In order to achieve the six objectives described above, we must strengthen our internal capabilities and resources. To do this, we will focus on the following internal objectives:

Objective 6: Increase and Diversify Revenue Streams: Diversify fundraising revenue to create stability and keep the organization from being overly dependent on one source of funding.

Object 7: Build capacity: Building up to the next level of operational, programmatic, financial, and organizational maturity so we can strengthen our performance and impact.

Like most strategic plans, this one does not address implementation, budgeting, and detailed tactics. In the months immediately following board approval of this plan, our staff will develop an aligned implementation road map and budget for the organization.

What Our New Focus Really Means The strategic plan is a broad road map and implementation will take several months to lay out and initiate. In order to reach our destination, we need to slow down and catch up before we speed up.

Here's what we anticipate:

- The child-impact objectives deal with issues that are complex and inter-related. For example, understanding and improving outcomes after surgery are intertwined with a constellation of factors that affect outcomes, including delay to surgical evaluation, seizure burden prior to surgery, etiology, surgery success, acute and chronic rehabilitation, parent and clinician knowledge, etc. We will first focus our efforts on synthesizing what the body of published research says so far about outcomes and interventions across all domains post-operatively, and writing knowledge translation summaries. This will include extrapolating research from surrogate areas such as pediatric cerebral palsy, brain injury, and stroke. A broad, effective dissemination plan for the information will be implemented that will include growing our social media following, expanding to other social media platforms, and promoting our programs and guides to the professional community.

- The Brain Recovery Project will continue to provide financial assistance to our community through the Dreams for Danny: Surgical Evaluation Travel Scholarship program. At this time, we do not plan to create new financial assistance programs and will instead direct our communities to other programs offered by aligned organizations.
- Research funding will continue, but with a sharper focus on understanding and improving functional and educational outcomes, as well as improving quality of life for relevant stakeholders. Research we fund must now have the potential for high impact results by making a demonstrable positive contribution to the community of children we serve within a 3 - 5 year time frame to publication. Literacy is a key marker of a high quality of life overall, therefore our main, but not sole, research focus will be to improve acquisition of literacy post-operatively. Research areas will be informed by the final mind map produced at the functional outcomes meeting in summer of 2020. We will work closely with our community advisory council and scientific advisory board in developing a grant program and research targets that support high impact results.
- New programs and information aimed to improve the quality of life of the entire immediate family will be developed, with particular focus on building self-esteem and confidence of the impacted child and promoting parent/caregiver and sibling well-being. Existing programs and research will be refined to ensure that quality of life of the child and/or immediate family members is woven into all the work we do.
- The Educational Advocacy and School Training Program will be restructured. If appropriate, it will include training and implementation of a volunteer peer support program focused on helping parents/caregivers understand how to navigate individual education and 504 plans, as well as understanding the educational implications of epilepsy and epilepsy surgery in childhood. Collaboration with aligned organizations in the pediatric epilepsy space to ensure broad dissemination of knowledge will be an important focus of this program.
- The Brain Recovery Project will devote its non-financial resources (including staff, board, volunteers, relationships, reputation, advocacy, and creative partnerships) to advance the mission of the organization forward by assuming key leadership roles in various organizations, collaborations, and initiatives. In order to avoid duplication of efforts, advocacy and collaboration with key aligned organizations, consortiums, and working groups will continue. Information from other websites and organizations that are important for our stakeholders (e.g. special needs trusts, needs-based services) will be included on our website, in knowledge translation summaries, and dissemination plans.
- We will use 2020 to develop a strong development plan, attach key metrics to existing programs, finalize knowledge translation summaries for our community, and develop a solid grant program.

WHAT DRIVES US: MISSION, VISION, AND VALUES

We are driven by our core ideology - our mission, vision, and values:

- our mission describes why we exist;
- our vision describes what we want for our community when we succeed in carrying

- out our mission;
- our core values guide our decisions and actions at every level of the organization.

Our Mission

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

Our Vision

A world where all children after epilepsy surgery have the opportunity for a high quality of life, including but not limited to an appropriate education, gainful employment, meaningful social opportunities, and good health to the maximum extent possible regardless of where they are in 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.

Our Strengths and Weaknesses

Like every organization, we have key strengths and weaknesses that impact our ability to achieve our vision. Our greatest strength is our talented and committed staff, our highly activated peer-to-peer donor community, a very good public reputation, and extensive relationships with many aligned organizations.

We also have weaknesses. We are inadequately staffed relative to the workload, have a small donor base, and do not have multiple corporate partnerships or philanthropic foundation grantors who support our work. Other organizations have a greater sphere of influence than we do.

KEY OBJECTIVES AND STRATEGY

Our strategic plan is the roadmap and the objectives are our destination. The objectives represent where we want to be by the end of 2025. Our strategic objectives translate our long-range vision into a more focused, actionable set of outcomes. These long-range aspirations are organized into three broad themes:

- **Child-Impact Objectives:** What is the impact we intend to have on the children we serve?
- **Family-Impact Objectives:** What is the impact we intend to have on the immediate family of the children we serve?
- **Internal Objectives:** What capabilities must we build in order to achieve our objectives?

CHILD IMPACT OBJECTIVES

Objective 1: Understanding Outcomes

Help parents and aligned stakeholders understand medical and functional outcomes after brain surgery to stop seizures, including the many factors that affect outcomes.

Why Is This Important?

- Seizure burden prior to surgery is a key factor affecting post-operative outcomes in children with drug-resistant epilepsy. For this reason, epilepsy surgery is no longer considered a last resort. Longer seizure burden prior to surgery affects seizure and functional outcomes post-operatively. Early age of seizure onset and drug-resistant epilepsy are major risk factors for poor cognitive development, especially for infants. Although children should be referred for a surgical evaluation as soon as they meet the International League Against Epilepsy's definition of drug-resistance, delay to surgical evaluation remains a problem.
- Myths and misconceptions about pediatric epilepsy surgery being a last resort persist. 31% of community respondents want The Brain Recovery Project to conduct a nationwide media campaign to raise public and professional awareness about epilepsy surgery to stop seizures in childhood.
 - Only 38% of respondents to our community survey believe that their child's health care providers were knowledgeable about the effects of epilepsy surgery on the child
 - 54% of respondents noted they were satisfied with the care the child receives from his/her clinicians.
 - 63% of respondents want The Brain Recovery Project to host conferences, continuing medical education, and workshops to help disseminate current research and best practices for care of a child after epilepsy surgery.
 - 39% of respondents want The Brain Recovery Project to host a consensus

workshop of medical experts to develop best practices of care for epilepsy surgery clinics to implement.

- 41% of respondents to our community survey want more information about the effects of various epilepsy surgeries.
- 42% of respondents want increased funding to understand medical outcomes after surgery (e.g. hydrocephalus), which can have a direct impact on functional outcomes.

Strategies

- Work at both systemic and frontline levels to raise awareness about delay to surgical evaluation and surgery.
- Increase knowledge across all stakeholders about outcomes for each epilepsy surgery type, including but not limited to the epilepsy surgery journey, seizure outcome, medical and functional domains, and quality of life.
- Develop best practices guidelines for clinician stakeholders.
- Provide financial assistance to families in financial distress related to travel costs for a surgical evaluation.
- Track outcomes through the Global Pediatric Epilepsy Surgery Registry and use the data to support strategic initiatives.

Objective 2: Improving Outcomes

Improve medical and functional outcomes after surgery across the spectrum of outcomes in our community.

Why Is This Important?

- Stopping seizures is the main goal of large epilepsy surgeries; however, because of the way many surgeries disrupt neuronal circuits important for various functions, some to a significant or severe degree, improving functional outcomes is very important to parent and caregivers, decreases the family's disease, emotional and financial burden, and reduces reliance on governmental services in adulthood. 71% of community respondents want to learn more about what they can do to improve their child's functional outcomes after surgery.
- 74% of community respondents do not believe that their health care providers know what can be done to improve their child's functional outcomes post-operatively. This leaves parents/caregivers without a roadmap for habilitation/rehabilitation, especially during the chronic phase of recovery and into adulthood.

- The utilization of epilepsy surgery is increasing in the United States and many developed countries, albeit slowly. As more children have epilepsy surgery, aligned stakeholders such as pediatric physical, occupational, and speech therapists will serve more of these children during the chronic phase of recovery and must do so using evidence-based interventions.

Key Strategies

- Fund only high impact research with a 3 - 5 year time frame to publication which will make a demonstrable positive contribution to the community of children we serve.
- Increase knowledge across all stakeholders about how to improve functional outcomes for each epilepsy surgery type, extrapolating research from surrogate areas such as pediatric cerebral palsy, brain injury, and stroke where appropriate. A broad, effective dissemination plan for the information will be implemented..
- Work at both systemic and frontline levels to disseminate knowledge about how to improve functional outcomes.

Objective 3: Education

Improve educational achievement in preschool - 12th grade regardless of placement.

Why Is This Important?

- Almost all (88%) of community survey responses identified that the child had educational issues after surgery. 41% want assistance finding educational programs for the child, 34% want help with specific school issues, and 35% want training for school teams about the effects of epilepsy surgery.
- Research to date, although limited, shows that only 42% of children after hemispherectomy read satisfactorily according to parent report. 59% of these children are in mainstream school but with supports, and 35% are in a special school or have home care.
- Research to date, although limited, shows that surgery generally has no impact on intellectual quotient for the two years after surgery in most children, and then improves 31% of children for up to eleven years post resective epilepsy surgery. One small study shows a decline in reading ability, but improvement in approximately 50% of the cohort in spelling and arithmetic skills.
- 71% of community survey respondents report their child has learning disabilities, and 57% report intellectual or developmental delay. Early data from the Global Pediatric Epilepsy Surgery Registry shows that 79% of respondents with school-age children

reported the child on an individual education plan. 14% had children with mild reading challenges, 18% with moderate challenges, 15% with significant challenges, and 15% reported the child as unable to read. Despite this, only 24% of parents report that the child receives intensive reading instruction in school and no children receive tutoring or reading intervention outside of school! This strongly suggests the question of whether reported reading challenges can be improved with intensive reading instruction.

- Literacy permeates all areas of life and shapes how we learn, work, and socialize. It is essential to informed decision-making, personal empowerment, and community engagement. Illiteracy leads to heavy consequences in adulthood, including lower earning potential and poor health.
- The success or failure in educating the next generation of children who have had epilepsy surgery has direct implications for their independence, health, friendships, participation in society, employment, and other factors determining quality of life throughout the lifespan.

Key Strategies

- Fund only high impact research with a 3 - 5 year time frame to publication which will make a demonstrable positive contribution to improving the educational achievement of the community of children we serve.
- Define the role/s The Brain Recovery Project can play in impacting P-12 educational achievement of children after epilepsy surgery regardless of placement.
- Support and raise awareness about promising programs and research that advance this objective.
- Provide programs that improve student achievement, whether through parent empowerment, teacher training, or other means
- Bring together people with a stake in education, search for common-ground solutions, and activate collaborative efforts that advance this objective.

Objective 4: Improving The Transition To Adult Life

Help the impacted child, whether directly or through caregivers, access appropriate neurological and neurosurgical care, post-secondary education, training and/or community employment, community living, and integrated adult life including leisure opportunities with family and friends.

Why Is This Important?

- Currently, no best practices exist in any medical domain for longitudinal care of adults

who had epilepsy surgery in childhood.

- 53% of community survey respondents want to learn about how to transition their child to adult health providers at age 18. 52% want the organization to expand resources, materials and volunteer networks to address the needs of families transitioning from childhood into adulthood after epilepsy surgery.
- 32% of community survey respondents indicated that estate and long-term care planning was an issue after surgery. 41% want to learn about estate and long-term care planning.

Key Strategies

- Define the role/s The Brain Recovery Project can play in ensuring a smooth transition into adulthood for children who have had epilepsy surgery.
- Support and raise awareness about promising programs and research that advance this objective.
- Provide programs that help ensure a smooth transition into adulthood for children who have had epilepsy surgery.
- Bring together people with a stake in transitioning into adulthood in the pediatric epilepsy space, search for common-ground solutions, and activate collaborative efforts that advance this objective.

Objective 5: Improving Family Quality of Life

Improve the general well-being of the immediate family unit.

Why Is This Important?

- For children with drug-resistant epilepsy, age, sex, age at seizure onset, duration of epilepsy, caregiver age, caregiver education, and income are not significantly associated with health-related quality of life. Higher number of anti-seizure medications, lower IQ, greater seizure frequency, caregiver unemployment, higher caregiver depressive and anxiety symptoms, poorer family adaptation, fewer family resources, and greater number of family demands are associated with lower quality of life.
- Caregivers of children with epilepsy report increased parenting stress, unanticipated caregiving responsibilities, and negative effects on family life.
- Caregivers of children with drug-resistant epilepsy have a higher quality of life if the child has higher health-related quality of life and the household income is higher. Higher depression and anxiety of the caregiver are associated with lower caregiver quality of life.

Thus, certain variables (caregiver mood and family factors) are potentially modifiable and show promise for improving caregiver quality of life.

- After successful surgery, parenting stress may even increase. Parents who fostered unrealistic expectations with respect to their child's cognitive and behavioral and functioning after the surgery may be disappointed and may experience increased stress.
- 54% of respondents in our community survey reported experiencing emotional stress due to the child's medical condition. 40% want assistance dealing with anxiety, depression, grief, anger, or frustration.
- Parents who are able to connect with other parents and families of children with epilepsy find it to be very helpful to be able to communicate with peers with seizures unresponsive to medication who were on the same journey.
- 35% of community survey respondents want help with sibling issues or finding sibling support.

Key Strategies

- Define the role/s The Brain Recovery Project can play in improving family quality of life throughout the epilepsy surgery journey..
- Support and raise awareness about promising programs and research that advance this objective.
- Provide programs that help improve family quality of life at any point in the epilepsy surgery journey.
- Bring together people with a stake in family quality of life in the pediatric epilepsy space, search for common-ground solutions, and activate collaborative efforts that advance this objective.

Objective 6: Increase And Diversify Revenue Streams

Diversified fundraising revenue creates stability and keeps the organization from being overly dependent on one source of funding, which is dangerous.

Why Is This Important?

- A sustainable fundraising model has diverse revenue streams.
- The organization lacks significant corporate partnerships and foundation grantors.
- On average, nonprofit organizations lose more than 60% of their donors each year.

Key Strategies

- Identify and develop fee-for-service programs.
- For free services, inform clients of costs and request a contribution.
- Develop a comprehensive fundraising plan that includes but is not limited to monthly giving, bequests, state, federal, and foundation grants, events, direct appeals, major gifts, state, corporate contributions, federal and private contracts, sponsorships, and sales.
- Substantially increase the number of individuals who donate to The Brain Recovery Project.
- Leverage the networks of our board members and volunteer leaders.

Objective 7: Build Capacity

Building our capacity gives us the ability to deliver on our mission effectively now and in the future. It is what we need to do to get to the next level of operational, programmatic, financial, and organizational maturity. Simply put, Capacity building strengthens our performance and impact.

Why Is This Important?

- Without a sustainable and effective organization, our mission will not be advanced.

Key Strategies

- Conduct continuous organizational planning, development, and assessment.
- Increase volunteer roles and engagement.
- Improve program designs, delivery, and evaluation including how we measure outcomes.
- Ensure that volunteers and staff have the capacity, knowledge, skills, and tools to achieve the objectives of the strategic plan.
- Integrate the work of staff and volunteers through governance structures that achieve the objectives of the strategic plan.

- Build strong staff and board leadership by investing in talent development.
- Improve financial management by managing day-to-day activities and long-range planning to ensure the financial health of the organization.
- Use marketing, online presence, media relations and social media to raise awareness and attract attention and resources to the organization or issue.
- Build and nurture strategic relationships that advance our mission.

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