



**thebrainrecoveryproject**

CHILDHOOD EPILEPSY SURGERY FOUNDATION

# COMMUNITY PERSPECTIVES

A COMMUNITY NEEDS ASSESSMENT SUMMARY REPORT

# Thank You

On behalf of the entire BRP team, my profound gratitude to the members of our community who took the time to participate in this first community needs assessment. By understanding what we're doing right - and what's lacking in the programs and services we provide - we can steer our organization towards improvements that make a big impact on the families we serve.



This report highlights the results of our 2020 Community Needs Assessment survey given in January of this year. We will use the results to improve our research and program offerings so that they have a big impact on our community's quality of life. This data will be used to help us set priorities, plan our programs, and leverage existing resources and partnerships.

Together with you, we are relentlessly dedicated to helping children reach their full potential after epilepsy surgery. Thank you for helping us understand what we need to do to serve you better.

Always in hope,

**Monika Jones**

*Visionary Founder and Executive Director*

## OUR TEAM

Monika Jones, JD  
*Visionary Founder and Executive Director*

Audrey Vernick  
*Director, Patient and Family Advocacy*

Nicole Abreu Shepard  
*Manager, Curriculum and Literacy*

Klajdi Puka, PhD(c)  
*Registry Biostatistician*

Hillary Gooris  
*Registry Data Specialist*

Ufuoma Ogaga, Controller  
*Goshen Bookkeeping & Consulting*

Whitney Mohler, Grants and Development

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Dr. Frank Musiek, PhD, CCC-A

# Our Community

*Buy the*  
**NUMBERS**



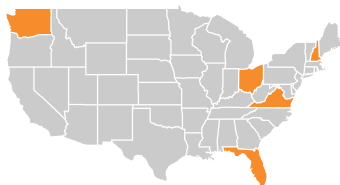
The BRP has been a lifesaver as we navigated the educational process.

— SURVEY RESPONDENT #49

## Primary Country of Residence

**88%**  
United States

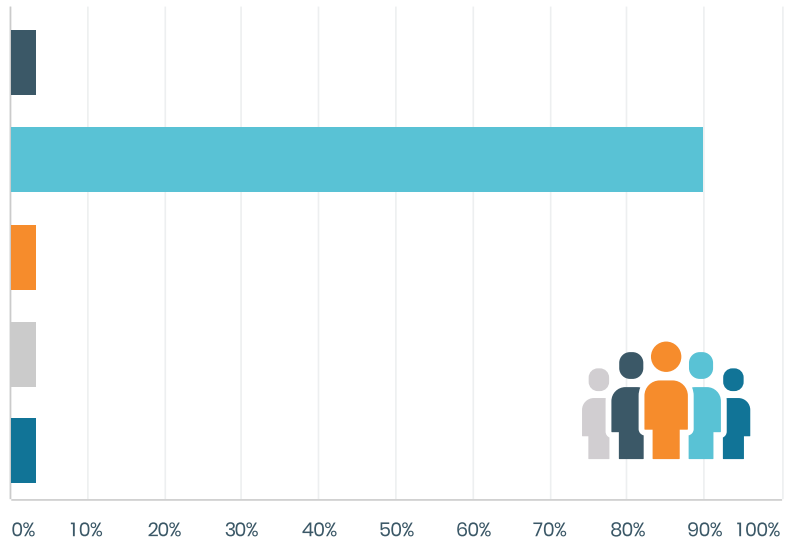
**22%**  
Other








## Primary State of Residence

**TOP 5**

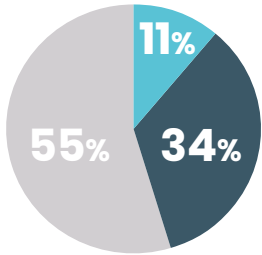
Florida, Washington, Ohio, New Hampshire, Virginia



-  Had epilepsy surgery in childhood
-  Familial relationship to an individual who had epilepsy surgery in childhood
-  Health care provider/researcher involved in the treatment, management, or study of pediatric epilepsy or epilepsy
-  Educator/therapist for an individual who had epilepsy surgery in childhood
-  Other

**88%**

Primarily responsible for the care of an individual who had epilepsy surgery in childhood

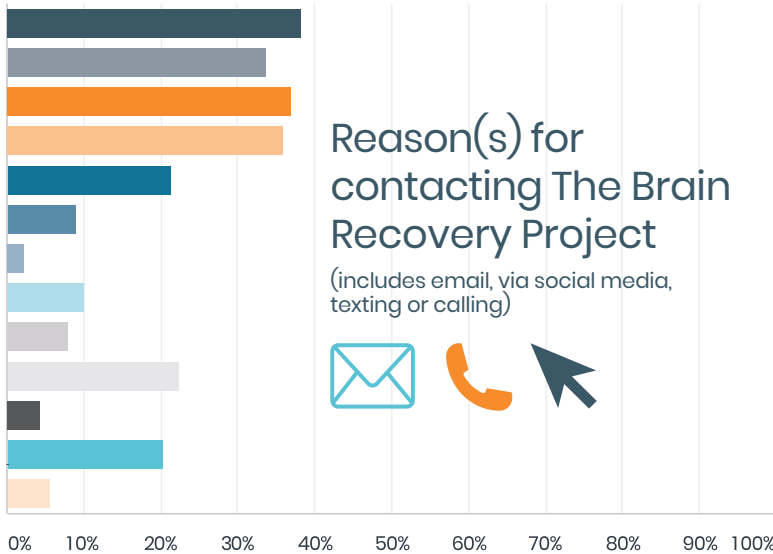


Day-to-day needs

- Independent
- Dependent
- Semi-independent



Experience contacting The Brain Recovery Project



Reason(s) for contacting The Brain Recovery Project

(includes email, via social media, texting or calling)



- To get general information about epilepsy surgery in childhood
- To get medical information
- To get non-medical information (education, legal, research, etc.)
- To find out about an event relating to The Brain Recovery Project (such as a family conference or fundraising event)
- To donate to the The Brain Recovery Project
- To find out about volunteering
- To find out how to organize fundraising for The Brain Recovery Project
- To locate a medical specialist (e.g. neurosurgeon)
- To locate local support
- To find out about educational rights and advocacy
- To connect with other healthcare providers
- I have never contacted The Brain Recovery Project
- Other



You guys are the best.

— SURVEY RESPONDENT #66



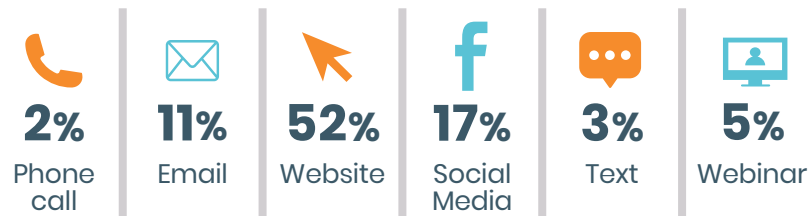
## Other Organizations and Resources

WHERE YOU ALSO SEEK INFORMATION ABOUT COPING OR UNDERSTANDING PEDIATRIC EPILEPSY SURGERY ISSUES

- 71%** The Hemispherectomy Foundation
- 50%** Pediatric Epilepsy Surgery Support (Facebook page)
- 49%** Hemispherectomy Foundation Facebook page
- 49%** Epilepsy Foundation
- 38%** A hospital's website
- 38%** Directly contacting other whose children have had epilepsy surgery
- 24%** Directly contacting other healthcare providers
- 22%** Local organization/support group for persons with disability/special needs NOT run by the state
- 21%** State-run organization for persons with disability/special needs
- 20%** Epilepsy.com
- 20%** Hemimegalencephaly Family Support Network (Facebook page)
- 20%** National Organization for Rare Diseases (NORD)
- 17%** Citizens United for Research in Epilepsy (CURE)
- 14%** Other (please specify)
- 11%** Child Neurology Foundation
- 9%** The National Institutes of Health
- 9%** American Epilepsy Society
- 8%** International League Against Epilepsy
- 6%** The ARC
- 4%** Global Genes
- 4%** Epilepsy Surgery Friends (Facebook page)

## How you contact The Brain Recovery Project

### Method





The BRP has helped to empower me to advocate for my child educationally and medically, therefore, helping my child reach his full potential. The conferences give him and I critical emotional support through friendships with people who get it.

– SURVEY RESPONDENT #29

## Descriptions of The Brain Recovery Project

- 72% Professional
- 68% Supportive
- 68% Science-based
- 66% Valuable
- 61% Caring
- 58% Respected
- 58% Collaborative
- 57% Focused
- 53% Well-managed
- 47% Reliable
- 46% Dependable
- 42% Inclusive
- 42% Innovative
- 27% Cutting-edge
- 27% Technologically advanced
- 26% Charitable
- 19% Transparent
- 14% Good at fundraising
- 8% Well-funded
- 7% Underfunded
- 2% Mom and pop
- 1% Unprofessional
- 1% Not transparent



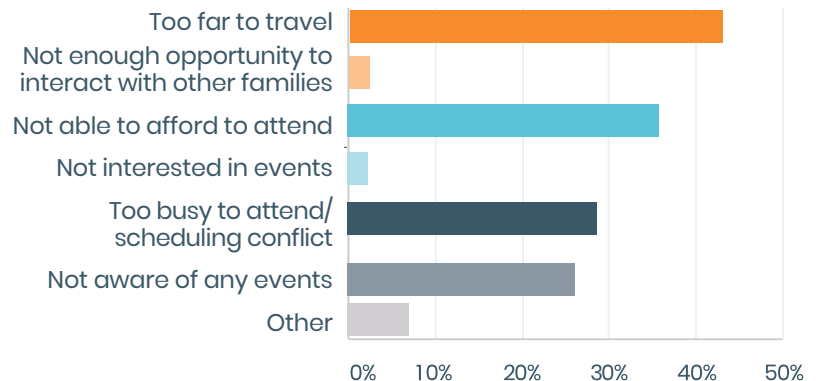
## The Brain Recovery Project Events

(For example, the Pediatric Epilepsy Surgery Conference and Family Reunion)

**52%**  
Have attended

**48%**  
Have not attended

## Reasons for not attending events



Some feedback from our community

**52%**

Are experiencing emotional stress due to their child's medical challenges

**55%**

In general, are satisfied with care their child receives from health care providers

**37%**

Find it difficult to find specialists familiar with epilepsy surgery within a convenient distance from their home

**40%**

Most of their child's health care providers are knowledgeable about the effects of their child's epilepsy surgery

**35%**

Usually, their health care providers work together and share information about the effects of their child's epilepsy surgery

**13%**

Have difficulty managing all of the medical information received about epilepsy surgery

**13%**

Do not have convenient access to the health care providers needed to manage the effects of their child's epilepsy surgery

**21%**

Most of their child's health care providers know about things they can do to improve their child's functional outcomes after epilepsy surgery

**30%**

Are experiencing financial stress due to their child's needs

Medical Symptoms or Challenges After Surgery



- 75%** Vision Issues
- 71%** Learning Disabilities
- 58%** Intellectual Disability/Developmental Delay
- 49%** Spasticity
- 45%** Seizures
- 40%** Behavior Problems
- 34%** Psychiatric Problems (anxiety, depression, bi-polar, etc.)
- 31%** Attention Deficit Disorder
- 28%** Sleep Disorders
- 23%** Autism Spectrum Disorder, PDD (Pervasive Developmental Disorder) or Autistic-like Behaviors
- 22%** Excessive Weight Gain
- 18%** Early Puberty
- 17%** Hyperactivity
- 17%** Hydrocephalus
- 10%** Contracture
- 5%** Kidney Problems (e.g. kidney stones)
- 4%** Reproduction/Family Planning Concerns
- 1%** Liver/Pancreas Problems
- 1%** Heart/Cardiac Problems



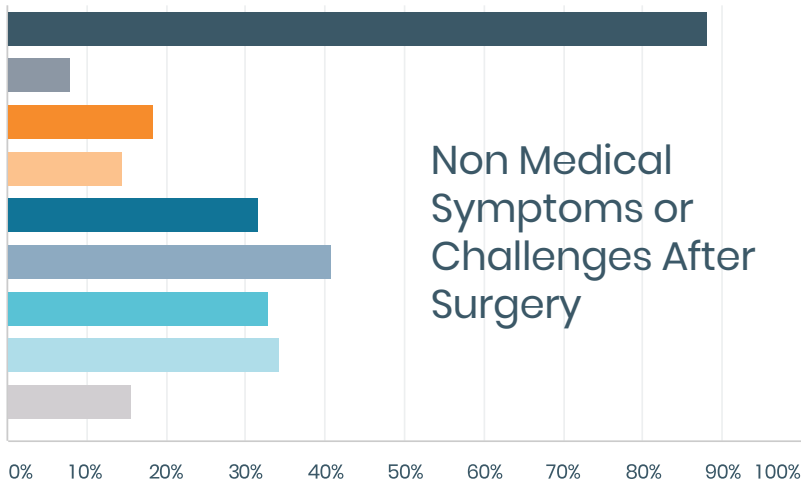
This group saved my daughter's life.

— SURVEY RESPONDENT #84



I am so grateful that I discovered The Brain Recovery Project and blessed that I was able to travel to Cleveland and immerse myself in so much new, valuable, practical, useful info! And meet other families who are sharing our journey !

- SURVEY RESPONDENT #87



- Educational issues (placement, services, IEP, 504 Plan, transition, vocational training, etc.)
- Housing issues
- Employment/Job-related issues
- Guardianship/Power of attorney
- Estate or long-term care planning
- Accessing social/recreational programs
- Respite services
- Accessing and navigating state waiver programs
- Obtaining/maintaining affordable health insurance coverage

## Use of BRP Resources



- 97%** The Brain Recovery Project website ([www.brainrecoveryproject.org](http://www.brainrecoveryproject.org))
- 72%** Downloadable information guides (e.g., Education After Hemispherectomy, What Is Hemimegalencephaly? The Risks of Drug-Resistant Seizures)
- 71%** The Brain Recovery Project main Facebook page
- 52%** Pediatric Epilepsy Surgery Family and Professional Conference
- 50%** Opportunities to participate in research
- 49%** Robocamp
- 48%** Global Pediatric Epilepsy Surgery Registry
- 45%** The Brain Recovery Project email news
- 43%** Talking with The Brain Recovery Project staff
- 38%** IEP webinars
- 38%** IEP assistance
- 34%** The Brain Recovery Project You Tube channel (which includes session videos from prior family conferences)
- 34%** The Brain Recovery Project "Education After Epilepsy Surgery" Facebook page
- 30%** Dreams for Danny: Surgical Evaluation Travel Scholarship
- 21%** Toll of Caregiving Trauma webinars
- 21%** ParentConnect (connecting parents with other parents)
- 15%** School training
- 17%** Other social media sites (Instagram, Twitter)





## Feedback on resources provided by The Brain Recovery Project

**9%**  
Good

**20%**  
Very Good

**71%**  
Excellent

## What do you want?



- 71%** Learning about how to improve my child's function after epilepsy surgery
- 54%** Learning about how to transition my child to adult health providers when he/she turns 18
- 43%** Connecting with other individuals and families who have had similar brain surgeries
- 42%** Locating educational programs
- 42%** Learning about long-term care planning
- 41%** Learning about estate planning (e.g. special needs trusts)
- 40%** Dealing with anxiety, depression, grief, anger, or frustration
- 38%** Learning about the effects of different types of epilepsy surgeries (e.g. understanding hemianopia after hemispherectomy)
- 37%** Learning about social security benefits
- 36%** Finding appropriate community activities (sports, arts, clubs, etc.) after epilepsy surgery
- 35%** Training for school teams regarding effects of epilepsy surgery for school systems
- 35%** Dealing with sibling issues/Finding sibling support
- 34%** Helping with specific school/educational issues you are facing
- 29%** Making friends, dating, sexuality after epilepsy surgery
- 28%** Understanding rights and process of IEP (Individualized Education Plan)
- 27%** Finding peer-to-peer support (e.g. someone whose child has had epilepsy surgery to call from time-to-time to talk about my child's epilepsy surgery, my concerns, fears, and hopes)
- 24%** Learning about the condition which causes/caused my child's seizures (e.g. Rasmussen's encephalitis)
- 23%** Information about locating job training
- 22%** Gathering information on group homes vs. independent living
- 20%** Understanding rights and process of IFSP (Individualized Family Service Plan)
- 20%** Finding local support groups
- 20%** Issues related to disclosure (how much information to give to an employer or potential employer)
- 16%** Information about keeping a job
- 14%** Learning about securing health insurance, medical financial assistance, or funding for medical needs
- 13%** How to talk about epilepsy surgery
- 13%** Learning about drug resistance
- 13%** Learning about different types of epilepsy surgeries
- 13%** Understanding rights and process of Section 504 plans
- 13%** Learning about securing financial assistance to support seeking medical attention away from home (transportation costs, lodging, etc.)
- 12%** Learning about questions to ask my child's neurosurgeon prior to brain surgery
- 11%** Dealing with marital issues
- 8%** Learning about when I should consider surgery to stop my child's seizures
- 8%** Finding financial assistance for housing

## What do you want us to do?

- 63%** Host conferences, continuing medical education and workshops for medical professionals to help disseminate current research and best practices for care for a child after epilepsy surgery
- 59%** Increase funding of research to improve our understanding of how to improve functional outcomes after surgery (e.g. improving hand function after hemispherectomy)
- 51%** Expand resources, materials and volunteer networks to address needs of families transitioning from childhood into adulthood after epilepsy surgery
- 44%** Provide free trained special education peer support specialists to help me navigate the IEP or 504 plan process
- 42%** Provide the latest information and referrals for non-medical issues like educational rights, financial planning, medical assistance, etc.
- 42%** Increase funding of research to improve our understanding of medical outcomes after surgery (e.g. hydrocephalus after hemispherectomy)
- 41%** Serve as a “referral” vehicle connecting individuals who had epilepsy surgery in childhood and their families to each other
- 39%** Host a consensus workshop of medical experts to develop best practices of care for epilepsy surgery clinics to implement
- 38%** Provide the latest information on research, diagnosis and treatment via brochures and/or website
- 34%** Provide free trained peer support specialists to help me navigate the epilepsy surgery journey from an emotional perspective
- 33%** Serve as a “referral” vehicle connecting individuals and their families to medical professionals
- 32%** Conduct a nationwide media campaign to raise public and professional awareness about epilepsy surgery to stop seizures in childhood
- 32%** Host conference calls or webinars to educate me on current research and clinical care
- 32%** Stay abreast of and advocate legislative issues affecting individuals who had epilepsy surgery in childhood and their families
- 30%** Provide financial assistance to families for various purposes (such as to help purchase orthopedic equipment)
- 30%** Increase funding of research on epilepsy surgery techniques
- 11%** Host a national fundraising event (e.g. a gala)

How well are we fulfilling our mission “We help children reach their full potential after epilepsy surgery?”

**11%**  
Good

**28%**  
Very Good

**60%**  
Excellent



Feedback on The Brain Recovery Project’s progress

**0%**  
Gotten worse

**11%**  
Stayed the same

**89%**  
Improved



Do you understand how donations are spent at The Brain Recovery Project?

**52%**  
YES

**48%**  
NO



Have you donated to The Brain Recovery Project?

**40%**  
YES

**60%**  
NO



Intent to donate to The Brain Recovery Project

**41%**  
More

**30%**  
Same

**29%**  
Do not plan to donate



I don't know where we would be right now without the knowledge and support of BRP.

— SURVEY RESPONDENT #52

