

A network diagram with nodes and connecting lines, some nodes are highlighted in orange and blue.

Functional Impacts of Large Resective or Disconnective Pediatric Epilepsy Surgery:

IDENTIFYING GAPS AND SETTING
PATIENT-CENTERED OUTCOMES
RESEARCH PRIORITIES

Thursday, July 18, 2019



THE

brainrecoveryproject

CHILDHOOD EPILEPSY SURGERY FOUNDATION

A silhouette of a city skyline with various buildings and a church spire, located at the bottom of the page.



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**WESTIN HOTEL
CLEVELAND, OHIO**

OVERVIEW

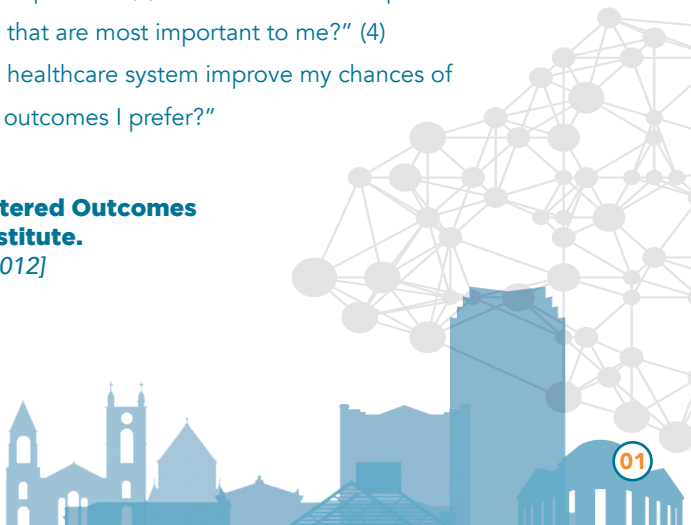
Healthcare research traditionally includes only scientists and other research professionals. Instead, patient-centered outcomes research involves **non-traditional stakeholders** in selecting topics, designing and conducting research, and disseminating results.

The Brain Recovery Project: Childhood Epilepsy Surgery Foundation supports the Patient Centered Outcomes Research Institute's belief that engaging stakeholders with **firsthand experience** of conditions can produce more patient-centered research, ultimately leading to greater use of research results by patients and the broader healthcare community.

Patient-centered outcomes research helps people make informed health care decisions and allows their voice to be heard in assessing the value of health care options. This research answers patient-focused questions: (1) "Given my personal characteristics, conditions and preferences, what should I expect to happen to me?" (2) "What are my options and what are the benefits and harms of those options?" (3) "What can I do to improve the outcomes that are most important to me?" (4) "How can the healthcare system improve my chances of achieving the outcomes I prefer?"

Patient-Centered Outcomes Research Institute.

[August 15, 2012]



For a parent considering large resective and disconnective epilepsy surgery for their child, patient-focused questions can be defined as:

- 1. Given my child's epilepsy, cause of epilepsy, and our preferences, what should we expect to happen to our child after epilepsy surgery?**
- 2. What are my child's epilepsy surgery options, and what are the benefits and harms of those options?**
- 3. What can we do as parents to improve the outcomes that are most important to us and our child?**
- 4. How can the healthcare system improve my child's chances of achieving the outcomes we prefer?**

The purpose of this meeting is to help answer questions 1 and 2 above by aligning on the current state of research and identifying research gaps that exist around the long-term functional impacts of resective and disconnective pediatric epilepsy surgeries, across the domains of motor, orthopedic, sensory, behavioral, medical, cognitive, and social impairments across the lifespan. The group will develop a set of preliminary patient-centered outcomes research goals and objectives driven in large part by the needs and gaps surfaced by parents, caregivers, and adult patients prior to the meeting set forth as topics in the agenda.

By convening this group of diverse stakeholders, we will create a powerful collaboration that can work together over the long-term to close the research gap around the functional outcomes of the major pediatric epilepsy surgeries. This is the first intentionally patient-centered effort focused on aligning key stakeholders around the long-term functional outcomes of resective and disconnective pediatric epilepsy surgery.

This meeting will lay the foundation for a longer-term collaborative working group that can accelerate and more efficiently facilitate the planning of future studies. Over time, this will assist the clinical community with the development of evidence-based recommendations and establish standards of care, as well as facilitate the development of patient-centered outcome tools to be used in future research studies.

OBJECTIVES, EXPECTED OUTCOMES, AND IMPACT

LONG-TERM OBJECTIVES INCLUDE:

- Establishment of a cross-sector patient-centered outcomes research collaboration committed to advancing research on the long-term functional impacts of resective and disconnective pediatric epilepsy surgery; and,
- Development of a patient-centered research agenda, which identifies the top 3-5 research priorities and objectives related to the long-term functional impacts of resective and disconnective pediatric epilepsy surgery.

EXPECTED OUTCOMES INCLUDE:

- Parents, caregivers, and adults patients will be actively engaged in identifying key research topics and questions most relevant to inform their healthcare and educational choices day-to-day and on a practical level;
- Parents, caregivers, and adult patients will better understand the importance of and the critical role they play in driving patient-centered outcomes research;
- Clinicians and researchers will have a better understanding of the knowledge gaps that exist from parent/caregiver perspective; and,
- Stakeholders will know how they can continue to collaborate in patient-centered outcomes research related to the side effects of pediatric epilepsy surgery.



STAKEHOLDER REPRESENTATIVES

For most activities participants are asked to identify the viewpoint they are primarily representing (patient/clinician/researcher). However, it is valuable to recognize all the perspectives that a participant has experienced across the healthcare continuum. Clinicians with research experience are encouraged to comment on either perspective, as are parents with clinical experience or research interest.

PATIENT STAKEHOLDERS

Patients are persons with current or past experience of illness or injury, family members or other unpaid caregivers of patients, or members of advocacy organizations that represent patients or caregivers.

Michelle Mottern, APRN

Parent of teenager who had hemispherectomy surgery as a pre-teen for intractable seizures caused by Rasmussen's encephalitis.

Ken Lininger

Parent of child who had posterior quadrant resection as a baby for intractable seizures caused by cortical dysplasia.

Abby Lampley*

Adult who had hemispherectomy as a child for intractable seizures caused by Rasmussen's encephalitis.

Cecile Dame, PhD

Parent of child who had hemispherectomy as a baby for intractable seizures caused by cortical dysplasia.

Damare Murphy, RN

Parent of a child who had posterior quadrant resection as a child for intractable seizures caused by cortical dysplasia

Maia Banks

Parent of a child who had right frontal and temporal lobes resected as a baby for intractable seizures caused by cortical dysplasia.

Francisca Arellano

Parent of a child who had hemispherectomy as a toddler for intractable seizures caused by hemimegalencephaly.

Monika Jones, Esq.*

Visionary Founder and Chief Executive Officer

The Brain Recovery Project:
Childhood Epilepsy Surgery
Foundation

Principal Investigator:
Global Pediatric Epilepsy Surgery
Registry

PCORI Engagement Award,
Project Lead

Parent of pre-teen who had two failed hemispherectomies and subsequent successful anatomical hemispherectomy for intractable seizures caused by total, syndromic hemimegalencephaly.

Amy Brin*

Executive Director
Child Neurology Foundation

Roxanne Cogil

Regional Director
The Hemispherectomy Foundation
Parent of teen who had hemispherectomy surgery as a child for intractable seizures caused by Rasmussen's encephalitis and cortical dysplasia.

Seth Wohlberg

Founder
RE Children's Project
Parent of adult who had hemispherectomy surgery as a pre-teen for intractable seizures caused by Rasmussen's encephalitis.

Holly Paauwe*

Founder
Hemimegalencephaly Family
Support Network

Parent of teen who has had four failed hemispherectomy surgeries for intractable seizures caused by hemimegalencephaly.

Lisa Moss

Senior Director of Donor Relations
Tuberous Sclerosis Alliance
Parent of a child who has had multiple tuber resections.

Nancy McNamara, MD

Neurologist, C.S. Mott Children's Hospital
On behalf of the Epilepsy
Foundation

Luke Shepard*

Board Chair
The Brain Recovery Project:
Childhood Epilepsy Surgery
Foundation
Parent of a child who had hemispherectomy surgery for intractable seizures caused by hemimegalencephaly.



Nicole Abreu Shepard, MAT

*Program Manager, Curriculum
and Literacy*

The Brain Recovery Project:
Childhood Epilepsy Surgery
Foundation

Parent of a child who had
hemispherectomy surgery for
intractable seizures caused by
hemimegalencephaly.

Audrey Vernick

*Director of Educational Advocacy
and Training*

The Brain Recovery Project:
Childhood Epilepsy Surgery
Foundation

Parent of child who had
hemispherectomy as a toddler for
intractable seizures caused by in
utero stroke.

Nicole Murray

Director of Development

The Brain Recovery Project:
Childhood Epilepsy Surgery
Foundation

PCORI Engagement Award, Project
Lead Designee

Parent of a child who had
hemispherectomy as a baby for
intractable seizures caused by
cortical dysplasia.

Brad Jones, MBA

Treasurer

The Brain Recovery Project:
Childhood Epilepsy Surgery
Foundation

Parent of pre-teen who had two
failed hemispherectomies and
subsequent successful anatomical
hemispherectomy for intractable
seizures caused by total, syndromic
hemimegalencephaly.

Kevin O'Connor

Member of the Board of Directors

The Brain Recovery Project:
Childhood Epilepsy Surgery
Foundation

Parent of teen who had
hemispherotomy for intractable
seizures caused by Rasmussen's
encephalitis.

Cynthia Menard, MD, FDCPC

*Clinical Cancer Research Unit
Princess Margaret Cancer Centre
Registry Advisory Board member,*

The Brain Recovery Project:
Childhood Epilepsy Surgery
Foundation

Parent of child who had
hemispherectomy, including
subsequent reoperation, for
intractable seizures caused by
cortical dysplasia.

CLINICIAN STAKEHOLDERS

Clinicians are providers of health care in a clinical setting, including physicians, nurses, physician assistants, rehabilitative professionals, pharmacists, mental healthcare providers, complementary and alternative healthcare providers, and professional societies serving clinicians.

Raman Sankar, MD, PhD*

Chief, Pediatric Neurology
Mattel Children's Hospital at the
University of California, Los Angeles

M. Scott Perry, MD

Medical Director, Neurology
Cook Children's Hospital
*Co-Director of the Jane and John
Justin Neurosciences Center*
*Primary Investigator: Comprehensive
Epilepsy Center Surgical Database
Project*
Scientific Advisory Board member,
The Brain Recovery Project:
Childhood Epilepsy Surgery
Foundation

Ahsan Moosa Naduvil Valappil, MD*

Neurologist
Cleveland Clinic

Taylor Abel, MD

*Surgical Director, Pediatric Epilepsy
Surgery Program*
UPMC Pittsburgh Children's Hospital
Scientific Advisory Board member,
The Brain Recovery Project:
Childhood Epilepsy Surgery
Foundation

Aria Fallah, MD, MSc, FRCS

*Co-Director, Pediatric Epilepsy
Surgery Program*
Mattel Children's Hospital,
University of California, Los Angeles
*Assistant Professor, Department of
Neurological Surgery, Pediatrics*
David Geffen School of Medicine
Principal Investigator:
Hemispherectomy Outcomes
Predictor Scale
Registry Advisory Board member,
The Brain Recovery Project:
Childhood Epilepsy Surgery
Foundation

Howard Weiner, MD

Chief of Neurosurgery
Texas Children's Hospital on behalf
of International League Against
Epilepsy - Pediatric Epilepsy
Surgery Task Force

Linda Lawrence, MD

Pediatric Ophthalmologist
(private practice)
Scientific Advisory Board member,
The Brain Recovery Project:
Childhood Epilepsy Surgery
Foundation





**FUNCTIONAL IMPACTS OF LARGE RESECTIVE OR
DISCONNECTIVE PEDIATRIC EPILEPSY SURGERY**

Raymund Woo, MD

Medical Director,
Pediatric Orthopedic Program
AdventHealth Medical Group
Pediatric Orthopedic Surgery at
Orlando
Scientific Advisory Board member,
The Brain Recovery Project:
Childhood Epilepsy Surgery
Foundation

Phillip Zeitler, MD

Section Head, Endocrinology
Medical Director, Children's
Hospital Colorado Clinical &
Translational Research Center
Scientific Advisory Board member,
The Brain Recovery Project:
Childhood Epilepsy Surgery
Foundation

Patricia Walshaw, PhD

Director, Neurobehavioral Epilepsy
Program
Program Co-Director, Child and
Adolescent Mood Disorders
Program
Semel Institute for Neuroscience
and Human Behavior
University of California at
Los Angeles

Cynthia Salorio, PhD, ABPP

Clinical Neuropsychologist
Director, Rehabilitation Outcomes
and Related Research
Kennedy Krieger Institute
Assistant Professor of Physical
Medicine and Rehabilitation
Johns Hopkins School of Medicine

Ellen Riker

Executive Director
National Association of
Epilepsy Centers

Jeffrey Buchalter, MD

Epilepsy Learning Healthcare
System

RESEARCH STAKEHOLDERS

Researchers are those who conduct clinical research, including investigators or funders of research and organizations or associations representing the research community.

Warren Brown, PhD

*Director, Lee Edward Travis Research Institute
Fuller Theological Seminary*

Bryan Kolb, PhD

*Board of Governors' Research Chair in Neuroscience
University of Lethbridge
Officer of the Order of Canada*

Mary Lou Smith, PhD

*Professor of Psychology
University of Toronto*

Frank Musiek, PhD, CCC-A

*Professor of Audiology
University of Arizona
Scientific Advisory Board member,
The Brain Recovery Project:
Childhood Epilepsy Surgery
Foundation*

Marlene Behrmann, PhD

*Professor of Psychology
Director, Behrmann Laboratory
Carnegie Mellon University*

Joanna Christodolou, EdD

*Director
Brain, Education and Mind
Laboratory, MGH Institute of Health
Professions
Adjunct Lecturer on Education,
Harvard University
Research Affiliate, Gabrieli Laboratory,
Massachusetts Institute of
Technology*

*Scientific Advisory Board member,
The Brain Recovery Project:
Childhood Epilepsy Surgery
Foundation*

Lucinda Baker, PhD, PT

*Ret'd Director of Clinical
Electrophysiology Laboratory
University of Southern California*

Lynn Paul, PhD*

*Senior Research Scientist
Director, CalTech Psychological
Assessment for Research Lab
California Institute of Technology
President, International Research
Consortium for the Corpus
Callosum and Cerebral Connectivity
Scientific Advisory Board member,
The Brain Recovery Project:
Childhood Epilepsy Surgery
Foundation
Registry Advisory Board member,
The Brain Recovery Project:
Childhood Epilepsy Surgery
Foundation*

Klajdi Puka

*PhD Candidate
Western University*

AGENDA

7:30 AM

Conference registration and breakfast

8:30 AM

WELCOME • LISTENING TO THE PATIENT VOICE: DATA RESULTS FROM THE GLOBAL PEDIATRIC EPILEPSY SURGERY REGISTRY, COMMUNITY ADVISORY COUNCIL THEMES, PARENT/PATIENT-REPORTED TRENDS AND THEMES

8:45 AM

KEYNOTE ADDRESS: THE POTENTIAL AND LIMITS OF NEUROPLASTICITY - PROCEEDING WITH CAUTION

Bryan Kolb, PhD

9:15 AM

ON THE FRONTLINES: THE CLINICIAN'S PERSPECTIVE

Ahsan Moosa Naduvil Valappil, MD

Aria Fallah, MD

M. Scott Perry, MD

Taylor Abel, MD

Raman Sankar, MD

Howard Weiner, MD

Audience Q and A

9:45 AM

BREAK

10:00 AM

MOTOR AND ORTHOPEDIC OUTCOMES (AREA 1)

Patient Perspective - Abby Lampley

Motor and Orthopedic Outcomes After Hemispherectomy
- Raymund Woo, MD

10:20 AM

COGNITIVE OUTCOMES (AREA 2)

Parent Perspective - Ken Linger

Memory After Resective/Disconnective Epilepsy Surgery
Mary Lou Smith, PhD

Cognition After Resective/Disconnective Epilepsy Surgery

Ahsan Moosa Naduvil Valappil, MD

Higher Cognitive Function In Adults Who Had Hemispherectomy In Childhood

Lynn Paul, PhD

11:15 AM **Small Group Stakeholder Breakout - Area 1 and 2**

12:15 PM **LUNCH**

1:00 PM **EDUCATIONAL OUTCOMES (AREA 3)**

Patient Perspective - Michelle Mottern, RN

Academic Achievement and IQ - Klajdi Puka, PhD(c)

Acquisition of Literacy - Joanna Christodolou, EdD

1:35 PM **BEHAVIOR AND SENSORY OUTCOMES (AREA 4)**

Patient Perspective - Cecile Dame, PhD

Hearing and Auditory Processing - Frank Musiek, PhD

Vision and Visual Processing - Marlene Behrmann, PhD

Behavioral & Mental Health - Cynthia Salorio, PhD

2:25 PM **Small Group Stakeholder Breakout - Area 3 and 4**

3:25 PM **BREAK**





FUNCTIONAL IMPACTS OF LARGE RESECTIVE OR DISCONNECTIVE PEDIATRIC EPILEPSY SURGERY

3:40 PM

MEDICAL OUTCOMES (AREA 5)

Patient Perspective - Monika Jones, JD

Endocrine - Phillip Zeitler, MD

Hydrocephalus - Aria Fallah, MD, MSc, FRCSC

4:15 PM

SPEECH AND LANGUAGE OUTCOMES (AREA 6)

Patient Perspective - Luke Shepard

Speech and Language - Patricia Walshaw, PhD

4:35 PM

Stakeholder Breakout - Area 5 and 6

5:20 PM

RESEARCH TOPIC SELECTION AND PRIORITIZATION

5:45 PM

NEXT STEPS

6:00 PM

CLOSING COMMENTS AND REFRESHMENTS

6:30 PM

GROUP DINNER, PHOTO, AND POST-MEETING SURVEY

Leslie Yerkes

Catalyst Consulting Group
Facilitator

Kylee James

The Brain Recovery Project:
Childhood Epilepsy Surgery
Foundation
Project Specialist
Logistics

Jo Byrne

See Your Words
Graphic Recorder

We thank the planning committee for their exhaustive work.
Planning Committee members are designated with an asterisk (*).

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THE

brainrecoveryproject

CHILDHOOD EPILEPSY SURGERY FOUNDATION

969 Colorado Blvd, Suite 101
Los Angeles, CA 90041
833-675-3335

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brainrecoveryproject.org



info@brainrecoveryproject.org



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