

A PARENT'S GUIDE TO PEDIATRIC EPILEPSY SURGERY

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DEDICATION

I would like to thank the members of my graduate committee, Lewis Calver and Kim Hoggatt Krumwiede, for all of their guidance, wisdom, and support – especially when I moved to Austin before much of this project had even begun. Even more though, I can not thank you enough for unexpectedly offering me a place at this program and teaching me how to think, draw, design, and do business as a medical illustrator.

I would also like to thank Dr. Susan Arnold for providing this opportunity to be involved in patient education and to be a part of a surgery that can literally change a child's life. Your passion and love for your patients and their families is inspiring.

Thank you to Susan Douglass for teaching me so much about graphic design and for opening up a whole new world.

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A PARENT'S GUIDE TO PEDIATRIC EPILEPSY SURGERY

by

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A PARENT’S GUIDE TO PEDIATRIC EPILEPSY SURGERY

KRISTEN MARIE BAGNALL, M.A.

The University of Texas Southwestern Medical Center at Dallas, 2010

Supervising Professor: Lewis E. Calver, M.S.

The goal of this project was to create an online parent education resource to guide parents through the process of pediatric epilepsy surgery. I created an interactive, web-based program that included photographs documenting the process, brain scans, illustrations of brain anatomy, success-story videos, frequently asked questions, a glossary, helpful links, and printable PDFs. The program was created for English-speaking families, but it was built with the intention of adding a Spanish version at a later date. The program was also designed as a trusted resource for the families considering epilepsy surgery at Children’s Medical Center, Dallas. The doctors of the Epilepsy Team at Children’s evaluated the program for its clinical relevance and usefulness for their current and future patients. Further testing and feedback from parents can be acquired after the Spanish version is complete and the program is integrated into the website of the Comprehensive Epilepsy Center.

TABLE OF CONTENTS

ABSTRACT	v
LIST OF FIGURES	ix
LIST OF TABLES	xi
LIST OF APPENDICES	xii
LIST OF DEFINITIONS	xiii
CHAPTER 1 – INTRODUCTION	1
PROJECT INTRODUCTION	1
GOALS AND OBJECTIVES	2
GOALS.....	2
OBJECTIVES.....	2
BACKGROUND INFORMATION	4
EPILEPSY SURGERY AT CMC DALLAS.....	4
TARGET AUDIENCE.....	5
SIGNIFICANCE	6
SCOPE AND LIMITATIONS	7
CHAPTER 2 – REVIEW OF THE EXISTING LITERATURE	8
CURRENT AVAILABLE RESOURCES AT CMC DALLAS.....	8
EXTERNAL RESOURCES	8
ON THE INTERNET.....	8
BOOKS	14
VIDEOS	19
HEALTH LITERACY.....	19

CONCLUSION	20
CHAPTER 3 – METHODOLOGY	22
GOALS AND OBJECTIVES	7
GOAL	22
OBJECTIVES	22
CONCEPT DEVELOPMENT	24
PRE-PROJECT PLANNING	25
INITIAL MEETINGS	25
PRE-PROJECT SURVEYS	25
CONTENT OUTLINE	31
SITE MAP	37
STORYBOARDS	39
WEBSITE DESIGN	40
DELIVERY PLATFORM	40
WEBSITE CREATION	41
DESIGN ELEMENTS	42
IMAGES IN THE PROGRAM	43
PATIENT AND MODEL RELEASES	43
PHOTOGRAPHS	44
ILLUSTRATIONS	45
BRAIN SCANS	48
TITLE PAGE OF PROGRAM	48
UNDERSTANDING EPILEPSY SECTION	50

ABOUT THE SURGERY SECTION	51
MAIN NAVIGATION BAR.....	55
BRAIN ANATOMY	56
SUCCESS STORIES	57
FREQUENTLY ASKED QUESTIONS	66
GLOSSARY	68
HELPFUL LINKS.....	70
FOR PRINTING.....	71
HEALTH LITERACY ANALYSIS	74
DOCTOR’S VERSION	74
SPANISH VERSION.....	75
CHAPTER 4 – EVALUATION	77
SURVEY DEVELOPMENT AND DISTRIBUTION	77
SURVEY RESULTS	78
ADDITIONAL COMMENTS	85
CHAPTER 5 – CONCLUSION.....	87
PROJECT SUMMARY	87
SUCCESSES	88
AREAS FOR FURTHER DEVELOPMENT	89
AREAS FOR FURTHER RESEARCH	90
APPENDICES	91
BIBLIOGRAPHY.....	187

LIST OF FIGURES

FIGURE 2-1: Beth Israel Comprehensive Pediatric Epilepsy Center Website	9
FIGURE 2-2: Beth Israel PDF Surgery Guide Cover.	10
FIGURE 2-3: Beth Israel PDF Inside Pages.	11
FIGURE 2-4: Cleveland Clinic PDF Epilepsy Surgery Guide.	12
FIGURE 2-5: Surgical Photograph in Seizures and Epilepsy in Childhood, A Guide. ...	17
FIGURE 2-6: Surgical Illustration in Seizures and Epilepsy in Childhood, A Guide.. ..	18
FIGURE 3-1: Epilepsy Surgery Timeline.	35
FIGURE 3-2: Site Map for Website.	38
FIGURE 3-3: Storyboard Page – Generalized Seizures on an EEG.	39
FIGURE 3-4: Storyboard Page – Step 13a.	40
FIGURE 3-5: Working Fireworks File.	41
FIGURE 3-6: Exported Slices from Fireworks.	42
FIGURE 3-7: Photoshop File of Main Images.	45
FIGURE 3-8: Sketch of Sagittal View of Brain.	47
FIGURE 3-9: Final Base Illustration of Sagittal View.	47
FIGURE 3-10: Index Page of Program.	49
FIGURE 3-11: How to Use This Site Page of Program.....	50
FIGURE 3-12: Understanding Epilepsy Layout.	51
FIGURE 3-13: The Surgery Journey.	53
FIGURE 3-14: Resection Journey Graphic.	54
FIGURE 3-15: Hemispherectomy Journey Graphic.	54

FIGURE 3-16: Grids & Strips + Resection Journey Graphic.	54
FIGURE 3-17: Step 6 Decision Fork.	55
FIGURE 3-18: Brain Anatomy – Top View of the Brain.	57
FIGURE 3-19: Premiere Video Editing.	63
FIGURE 3-20: Soundbooth Audio Editing.	64
FIGURE 3-21: Dreamweaver Page for Success Stories.	65
FIGURE 3-22: Web Browser View of Success Stories.	65
FIGURE 3-23: FAQ About Seizures and Epilepsy.	67
FIGURE 3-24: FAQ About the Surgery Journey.	67
FIGURE 3-25: FAQ Answer Template.	68
FIGURE 3-26: Glossary with Definition.	69
FIGURE 3-27: Glossary with Image.	70
FIGURE 3-28: Helpful Links Page.	71
FIGURE 3-29: InDesign Document for PDFs.	73
FIGURE 3-30: Organization of Root Folder for Website.	76

LIST OF TABLES

TABLE 4-1: Survey Results 79

LIST OF APPENDICES

APPENDIX A – Epilepsy Surgery Timeline	91
APPENDIX B – Pre-Project Surveys	94
APPENDIX C – Storyboards	111
APPENDIX D - Sketches	145
APPENDIX E – Final Illustrations and Brain Scans	147
APPENDIX F – Blank Evaluation Survey	157
APPENDIX G – Completed Evaluations	162

LIST OF DEFINITIONS

CMC – Children’s Medical Center Dallas

CEC – Comprehensive Epilepsy Center at Children’s Medical Center Dallas

EMU – Epilepsy Monitoring Unit at Children’s Medical Center Dallas

Epilepsy Team – Team of health professionals that care for epilepsy patients, including a:

Neurologist, Neurosurgeon, Neuroradiologist, Neuropsychologist, and nurses
specializing in epilepsy or neurophysiology

Epilepsy – Having recurrent seizures. Defined as having seizures over and over again for
the parent education program.

Seizures – Repeated abnormal bursts of electricity in the brain

Intractable Epilepsy – Epilepsy that can’t be controlled after trying two or more antiepileptic
medicines. Also known as refractory epilepsy.

Subdural electrodes – Electrodes that are placed on the surface of the brain.

EEG– Electroencephalogram.

Craniotomy – Surgical technique used to remove a part of the skull and access the brain.

HIPAA – Health Insurance Portability and Accountability Act

CHAPTER ONE

Introduction

Project Introduction

Before beginning this thesis, I knew that I wanted to work on a project that involved both pediatrics and parent education. After contacting and meeting Dr. Susan Arnold, Medical Director of the Comprehensive Epilepsy Center (CEC) at Children's Medical Center Dallas, I knew that parent education for pediatric epilepsy surgery was a perfect fit. The CEC had no surgery education materials, and the clinic was in great need of something to explain the complex process to parents.

As such, Dr. Arnold and I decided to create this project specifically for parents. Dr. Arnold created a table with the key contacts and procedures at each appointment in the 118-week surgical timeline (see Appendix A). The timeline included all of the pre-surgical evaluation appointments, the surgery itself, and the follow-up appointments for up to two years after surgery. This timeline-table and the final journey graphic that represented it were the foundation of the final project. Additional background on seizures and epilepsy, brain anatomy illustrations, success stories, frequently asked questions, helpful links, and printable PDFs were added to enhance the information presented about the surgery. Pre-project evaluations conducted as parent interviews also elucidated key topics that I needed to cover, including confusing medical concepts and the things about the surgery that frightened them the most.

Dr. Arnold and I decided that the final project should be a website so that parents could easily view it at home and at their own pace. Printable PDFs were added for parents without computer access. The PDFs were also included so that the health professionals at the CEC could review the surgical process with families in the clinic and then give them some information to take home.

Goals and Objectives

Goal

The goal of this project was to create an online parent education resource to guide parents through the process of pediatric epilepsy surgery. The program will clarify the journey-like nature of epilepsy surgery and help parents visualize the end of the process. It will also open communication between epilepsy health professionals and the families by providing a foundation for discussion. The program will be accessible through the website of the Comprehensive Epilepsy Center (CEC) at Children's Medical Center Dallas (CMC) once it is live.

Objectives

In order to produce the program, several objectives had to be met. The first objective was to create a simple and intuitive representation of the timeline of pediatric epilepsy surgery, including all of the pre-surgical testing and follow-up appointments after surgery. The timeline also had to account for two decision forks and three variations of the surgery.

The second objective was to pair an image with each page of text within the program to help make the medical information more accessible and less threatening.

The third objective was to create illustrations of the brain that could be altered as needed to highlight the various lobes and functional areas important to understanding epilepsy and epilepsy surgery.

The fourth objective was to include success story videos or written testimonials from patient families at CMC.

The fifth objective was to include trusted resources within the program such as: answers to common questions posed to the Epilepsy Team about epilepsy and epilepsy surgery, a glossary of medical vocabulary, and links to websites recommended by the CEC.

The sixth objective of the program was to account for the demographics of the patient population by creating a Spanish version of the program and providing PDF documents for the CEC to print out and give to families without computers.

Lastly, post-project surveys needed to be collected to evaluate whether the goals and objectives of the project had been met.

My content expert was Dr. Susan Arnold, Medical Director of the CEC and Associate Professor of Pediatrics and Neurology at UT Southwestern Medical Center at Dallas. I

consulted with Dr. Angela Price, a pediatric neurosurgeon at Children's Medical Center Dallas. I also consulted with various members of the Epilepsy Team at the CEC.

Background Information

Epilepsy Surgery at Children's Medical Center, Dallas

For many pediatric epilepsy patients, medications sufficiently control their seizures without the need for more invasive therapy such as epilepsy surgery. However, for children with intractable seizures, or those uncontrolled by antiepileptic drugs, doctors evaluate whether resection of the over-active area of the brain might decrease seizure frequency or cure the patients' epilepsy altogether. For the families presented with this potentially curative surgery, it is a decision often riddled with fear, apprehension, confusion, and many, many questions.

At the Comprehensive Epilepsy Center (CEC) at Children's Medical Center in Dallas, Texas, the pediatric neurology team sees almost one thousand patients per year with intractable seizures. According to Susan T. Arnold, M.D., director of the CEC, the team evaluates approximately one hundred of these patients each year as potential candidates for pediatric epilepsy surgery. In some cases, the team is able to find a medication that controls their seizures. In other cases, the evaluation may show that the child has seizures coming from multiple areas of the brain and would not benefit from surgery aimed at only one of these areas. Even when a child is felt to be an appropriate candidate, parents may need up to a year to consider and commit to the surgery, or they

may refuse it altogether. As such, only about twenty-five of these pediatric patients each year actually undergo the surgical procedure at Children's Medical Center.

The neurologist presents the option for surgery and tries to communicate to the parents the extensive pre-operative testing process and how the surgery works, but parents are often too overwhelmed by the information to be able to process it or verbalize all of their questions in the medical office. Many parents want to share the information with other family members involved in the decision-making process. For all of the parents though, the surgery appears risky and aggressive, and they need reassurance that the team puts careful planning into the surgery process before removing part of their child's brain.

Target Audience

My project was created for parents considering pediatric epilepsy surgery at Children's Medical Center Dallas. While some older teenagers might also benefit from the program, the website was not created specifically for them.

The epileptic child also had to be under evaluation for one of three surgeries:

1. Hemispherectomy
2. Focal Cortical Resection Surgery or Lobectomy Surgery. These surgeries are collectively called Resection Surgery in the program.
3. Implantation of Subdural Electrodes *and* Resection Surgery. This surgery is also called *Grids & Strips Surgery + Resection Surgery* in the program.

According to the new program manager for the CEC, approximately sixty percent of the epilepsy families speak Spanish.

Significance

Currently, the neurology team relies on crude physical models of a brain, simplistic drawings by the medical team, and a few images of cortical mapping to explain the surgery process in-office.

Consequently, parents tend to research the surgery online to elucidate the scientific terms and concepts, but online parent education material is consistently written at or above a 10th grade level, which is still too high for most parents to easily comprehend.

(D'Alessandro, Kingsley, Johnson-West, 2001). Online information can also be of unreliable accuracy and inappropriately graphic for a parent trying to emotionally handle such a grave decision. Some parents choose not to search the Internet at all because the medical terminology confuses them or because they come across actual surgery photos that frighten them.

The same questions are consistently asked because the current materials insufficiently communicate the surgery process. Parents also tend to forget information presented in-office or don't remember to ask all of their questions until they are home because of the extreme stress of talking about the surgery with a health professional.

Children with intractable epilepsy and multiple seizures a day or week often have delayed cognitive development under the suppression of constant seizure activity. They may be put in special education classes because they have difficulty learning and socializing. They are also not able to do normal childhood activities like swimming and horseback riding, and in their teenage years, they cannot drive or sometimes even go to college on their own. For many of these patients, epilepsy surgery is life changing. Even if they still have to take antiepileptic medicines after surgery, they are able to achieve good control with medicines alone. These children are able to do many of the things that they could not before.

Therefore, development of an interactive, image-intensive, online parent education tool may supplement and reinforce information obtained in office consultations, answer common questions, aid in the decision-making process, build confidence that the medical team will carefully prepare for their child's surgery, and decrease the anxiety and feelings of helplessness stemming from a lack of understanding.

Scope and Limitations

The scope of this thesis was limited to the three most common types of surgeries performed at CMC: hemispherectomy, resection surgery, and implantation of subdural electrodes coupled with resection surgery. The program had to be both PC and Mac compatible in a variety of web browsers.

CHAPTER TWO

Review of the Existing Literature

Current Available Resources at Children’s Medical Center Dallas

Currently, health professionals at CMC use folders of printed information to provide epilepsy information to parents of newly diagnosed patients. Gender-specific folders and Spanish-translation folders are also available as education materials. Much of the information is printed directly from the website of the Epilepsy Foundation or epilepsy.com. However, the CEC currently has no printed materials to distribute to families regarding epilepsy surgery.

External Resources

On the Internet

While the CEC may be the sole provider of surgical education materials for some patient families, many families seeking more comprehensive information, medical terminology explanations, and support turn to the Internet.

One of the most useful pediatric epilepsy surgery guides available online is through the Beth Israel Medical Center Comprehensive Pediatric Epilepsy Program. Their *Epilepsy Surgery Information* is available for download from the Internet as a PDF guide (Figures 2-1, 2-2, and 2-3).

Continuum Health Partners: Beth Israel • Roosevelt Hospital and St. Luke's Hospital • Long Island College Hospital • New York Eye and Ear Infirmary

Beth Israel Pediatric Neurology/Neurosurgery
Comprehensive Pediatric Epilepsy Center Continuum Health Partners

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Pediatric Epilepsy Center
Epilepsy Surgery Program
Developmental Disabilities Center (DDC)
Tests
Publications
Staff
Our Facilities
MRI Facilities
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Epilepsy Surgery Program

- Pediatric ICU
- Neurosurgery Brochure
- Tests

Types of Surgery

- Vagal Nerve Stimulator
- Corpus Callosotomy
- Cortical Resections
- Temporal Lobectomy

Pediatric ICU
 The Milton and Bernice Stern Department of Pediatrics at Beth Israel Hospital is located at 16th Street and First Avenue, on the sixth floor of the Dazian Building. A brand-new, five-bed, state-of-the-art pediatric intensive care unit was built in 2004, at the same time that the pediatric floor was refurbished and the Epilepsy Monitoring Unit was built. Facilities include six beds for epilepsy monitoring, a family lounge, playroom, and wireless Internet access. The units are staffed by attending pediatricians, intensive care specialists, nurse practitioners, family practice residents and neurology- and neurosurgery-trained nurses. A full Child Life program is in place, and social workers are available. Take a Photo Tour of the EMU Unit.

Vagal Nerve Stimulator

 Small pulses of electricity are sent to the brain via the vagus nerve, a large nerve in the neck. The surgery entails placement of a small pacemaker in the neck, with wires tunneling up to and around the vagus nerve.

Corpus Callosotomy
 This surgery is indicated for patients with disabling atonic seizures (drop attacks). The connection between the two sides of the brain (the corpus callosum) is severed, to prevent seizures from spreading.

Cortical Resections
 A cortical resection is the removal of a small area of the brain from which the seizures are believed to arise. This resection can be either lesional (if there is a preexisting area of abnormally formed brain, from a stroke or area that never formed properly) or non-lesional (if the seizures begin in a specific area of the brain, without an obvious abnormality). This is done by implanting electrodes for localization of seizure focus and for brain mapping.

Children frequently require electrode implantation to both precisely localize the focus triggering the seizures, and to map regions of the brain important to movement of the body and to speech.

Information gained from previous, non-invasive VEEG monitoring is used to determine what surfaces of the brain must be covered with the electrode sheets (grids) or electrode strips. Rarely, a preliminary surgery is required to better define which regions of the brain are responsible for the seizures. In these cases, strips of electrodes are fed through small holes in the skull to accomplish broad coverage over the brain's surfaces. Coverage to define the focus of the seizure is broad so that all borders of the focus can be delineated. Once the site of origin of the seizures has been determined, the electrode sheet is used to map brain function.

Tests during cortical resections include INTRAOPERATIVE CORTICAL STIMULATION FOR BRAIN MAPPING. This is the type of monitoring typically associated with epilepsy surgery. It

Done

Figure 2-1. Beth Israel Comprehensive Pediatric Epilepsy Center Website.

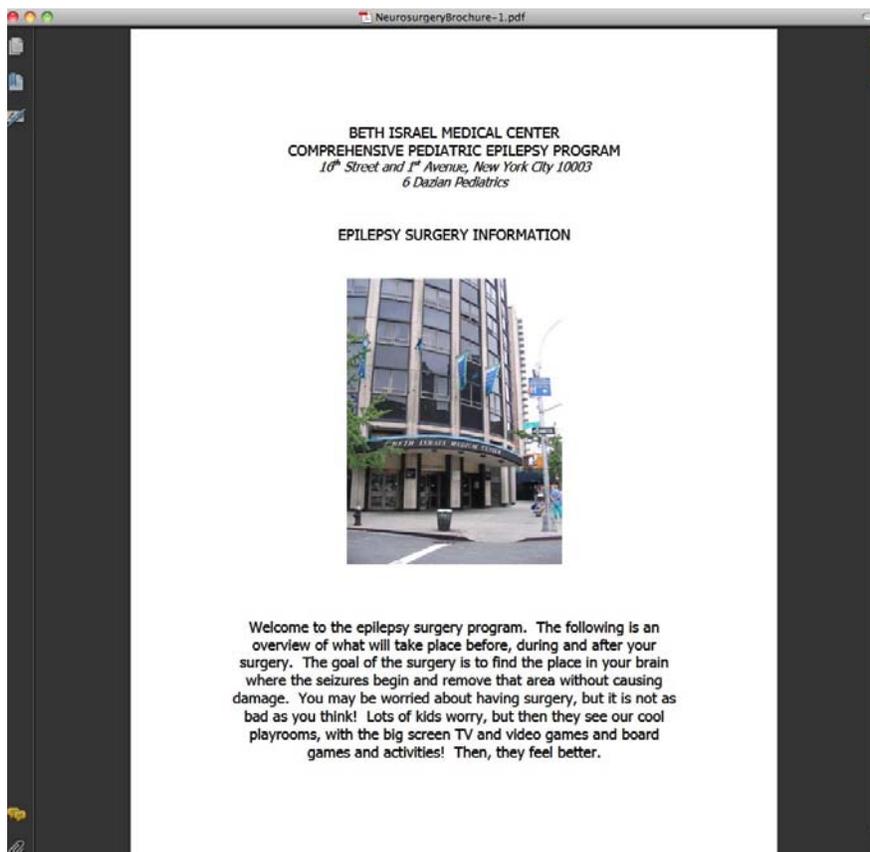


Figure 2-2. Beth Israel PDF Surgery Guide Cover.

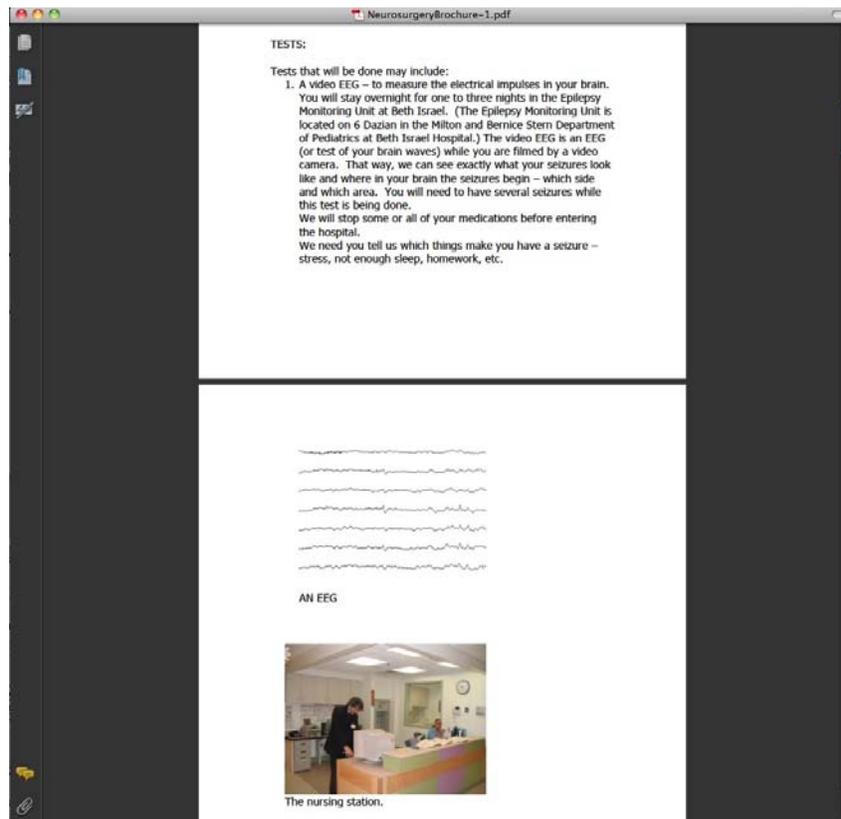


Figure 2-3. Beth Israel PDF Inside Pages.

However, the PDF is not directed at a clear target audience. The text vacillates between information for children and information for parents. There is no variation in the size and appearance of font to indicate levels of importance, some of the photographs seem haphazardly edited, and the EEG scan does not even indicate show a seizure.

The Cleveland Clinic in Ohio has also published a PDF surgery guide through their website, but it is not specifically directed at pediatrics (Figure 2-4). While the guide is

aesthetically more pleasing than Beth Israel's guide, several pages lack any images at all to aid in the understanding of the medical terminology in the text.

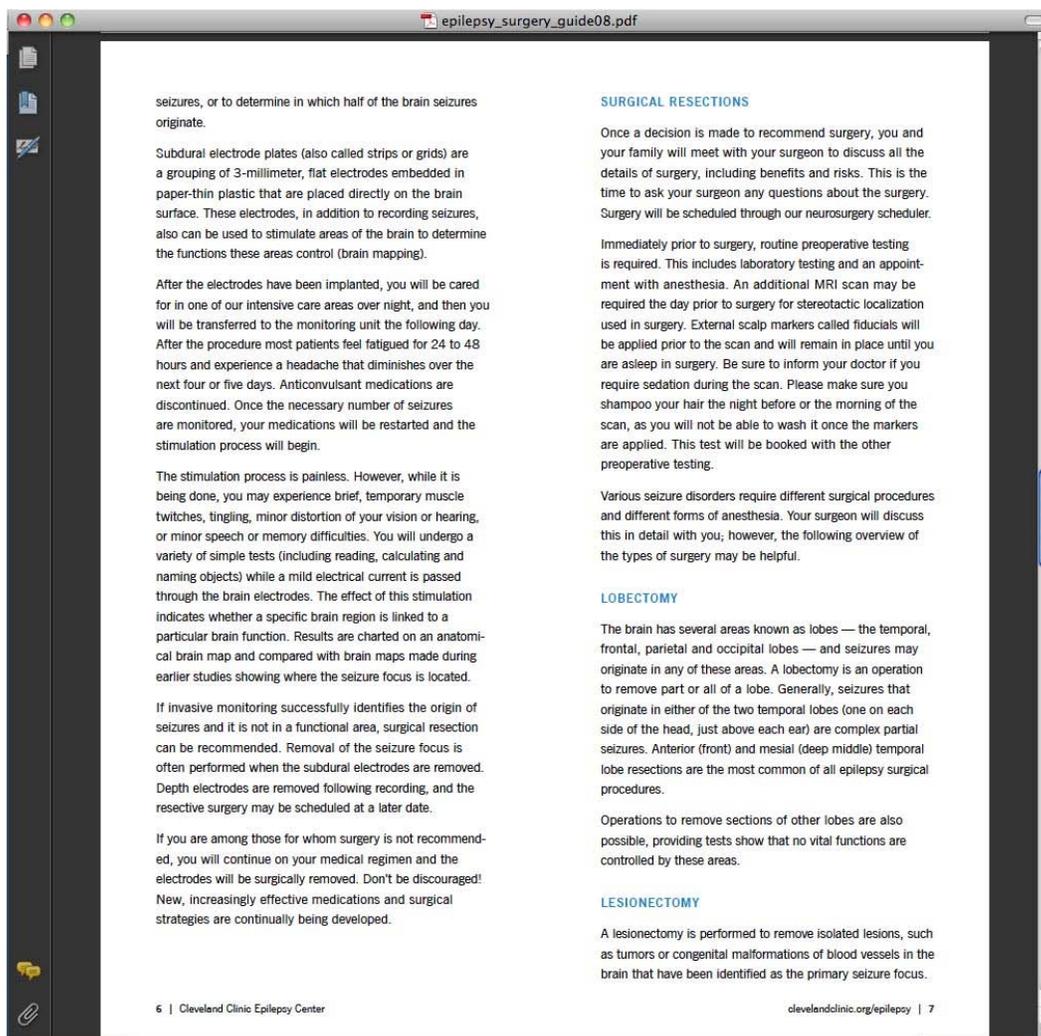


Figure 2-4. Cleveland Clinic PDF Epilepsy Surgery Guide..

The website of the Epilepsy Foundation is one of the most trusted and universally accepted sources for epilepsy information. It is also a website that is highly recommended by health professionals at the CEC. Consequently, I included it as a link in my program for more information. However, the information is not specifically about pediatric surgery, nor is it intentionally directed towards families of pediatric surgical candidates. Surgery-related topics include: *Pre-Surgical Evaluation, Surgical and Social Outcomes , Overview, Surgery Types: Benefits and Risks, Making the Decision, The Operation, After the Surgery: Planning Ahead, and Costs.*

Another trusted resource of the CEC, Epilepsy.com, also contains epilepsy surgery information. The section on *Expectations & Consequences* is particularly good information that addresses the reality that post-surgical patients need to continue to take antiepileptic medicines until a period of time without seizures has passed.

The website of Children’s Hospital of Pittsburgh of University of Pittsburgh Medical Center is another useful epilepsy surgery resource. The website includes success stories with compelling embedded Youtube videos and written testimonials. Interestingly, the website calls the pre-surgical testing an “evaluation process.” It also includes information on corpus callosotomy and vagus nerve stimulator implantation (VNS), two surgeries which we did not intend to include in the program, though VNS is briefly mentioned as a treatment option that does not involve surgery on the brain.

Books

Countless books have been written on epilepsy and pediatric epilepsy. However, I found looking for relevant books at bookstores to be a fairly disappointing endeavor. Their selections were often limited to general home-health manuals and books on the anatomy and the physiology of the brain. While some health manuals were directed at a family-oriented audience, they usually had only a few sentences on epilepsy, at most. On the other hand, the brain anatomy books contained a great deal of the medical foundation for understanding epilepsy but little information on how it specifically applied to epileptic seizures. Ironically, *The Complete Idiot's Guide to Understanding the Brain* contained the most extensive and useful content directed at a lay audience with information on epilepsy, EEGs, generalized and partial seizures, hemispherectomies, PET scans, Wada tests, and the like.

Searching online bookstores and ordering books proved to be much more successful. I was specifically looking for books intended for parents of children with epilepsy. While I did not find an entire book on pediatric epilepsy surgery, most of the books contained a chapter on surgery as a therapy option and/or a chapter on pediatric epilepsy. The most helpful and applicable books included:

- *Epilepsy: Patient and Family Guide* (Orrin Devinsky, M.D.)
- *Seizures and Epilepsy in Childhood* (John M. Freeman, M.D., Eileen P.G. Vining, M.D., and Diana J. Pillas)
- *The Cleveland Clinic Guide to Epilepsy* (Elaine Wyllie, M.D.)

I started my book research by reading each book and highlighting or underlining key phrases or paragraphs that clarified information or addressed topics that I hadn't previously considered. I was also specifically searching for simple and creative analogies to clarify the physiology of a seizure, audience-appropriate discussions about epilepsy surgery, and any relevant illustrations. The books generally covered the following topics:

- Anatomy and physiology of the brain
- Seizure types
- Causes of epilepsy and diagnosis
- Understanding tests and scans
- Pediatric epilepsy
- Treatments, including surgery
- Living with epilepsy
- Information or other resources and support for epilepsy
- Glossary

Many of the books were also written in sections with a bolded question and then an extensive answer. These bolded questions fueled a few of the ideas and the general format for the frequently asked questions – questions that Dr. Arnold agreed were important topics to cover but which she had not thought to include.

From the beginning, I was determined to find a simple and vivid analogy or image to describe how seizures are different from the normal electrical activity of the brain. I

considered several ideas, such as seizures resembling an electrical storm or a surge of electricity in some sort of lighting apparatus. Each idea was too much of a stretch to explain, too dramatic, or not quite accurate. However, *Seizures and Epilepsy in Childhood, A Guide* described the brain as a “society of cells” with interactions (Freeman 10). While the societal analogy in the book is a little exhaustive in its adherence to neighbors, communities, and the like, the analogy prompted me to think of brain neurons as talking entities with their own language – a language that can be read by an EEG.

The chapter on epilepsy surgery in the Freeman book also discussed a patient as a “candidate for surgery,” a convention used by the Epilepsy Team at the CEC when testing and considering children for epilepsy surgery (Freeman 216). I did not refer to children as candidates in the program, but I did utilize the concept of candidacy. The chapter on surgery also included some images to explain the surgery, but they were either actual surgery photographs (Figure 2-5) or confusing diagrammatic explanations of the complicated surgeries (Figure 2-6). Surgical photographs are too graphic for parent education, and any illustrations used for educational purposes must be clear and not contain too many elements at once.

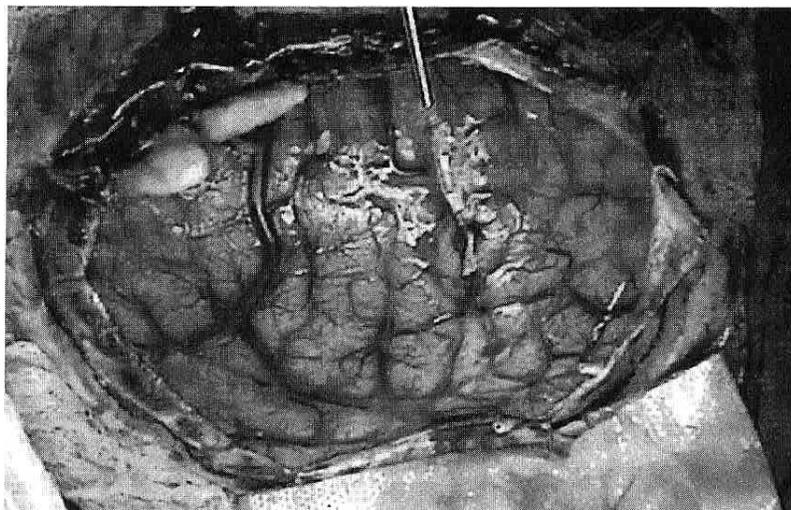


Figure 14.2 Photograph of Jeff's brain at surgery. The skull over the frontal portion has been removed and the brain and the blood vessels can be seen. This is the right side of the brain as seen from above. The back of the head is to the left.

Figure 2-5. Surgical Photograph in *Seizures and Epilepsy in Childhood, A Guide*.

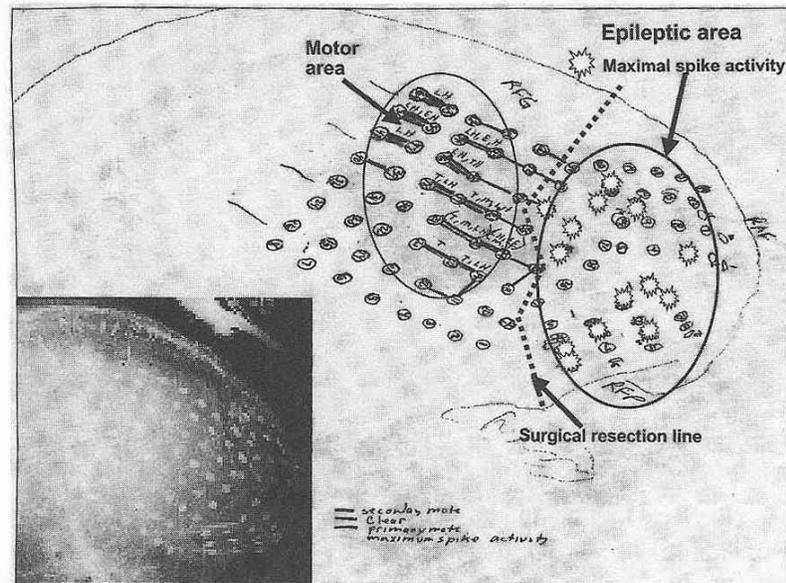


Figure 14.5 The inset is a skull x-ray showing the grid in place. The electrodes are visible. Our map of the cortex shows the areas of seizure discharges and the areas of motor activity located by stimulation. The dotted line is the guide for the surgeon to follow in removing the frontal cortex (the epileptic area) and avoiding the motor areas.

Figure 2-6. Surgical Illustration in *Seizures and Epilepsy in Childhood, A Guide*.

Each book that I researched also covered in some detail the common types of seizures such as: absence, grand mal, infantile spasms, myoclonic, tonic-clonic, simple partial, and complex partial. While recognizing and diagnosing a child's type of seizures is important to his or her caregivers, Dr. Arnold felt that explaining each seizure type in detail was irrelevant for parents trying to understand epilepsy surgery. However, it was important that the program include a differentiation of generalized seizures from partial

seizures in trying to explain why surgery was only an option for children with partial seizures.

Overall, the books stimulated ideas about the types of content to include in the program, conventional topics discussed to parents of children with epilepsy, and various ways to describe seizures and epilepsy.

Videos

The most effective format for success stories was a video of the parent(s) and doctors individually discussing the child's experience and outcome, followed by footage of the child interacting with his or her family. This format reinforces the positive outcome and the normal capabilities of the child after surgery. When a website has multiple success story videos for a viewer to watch, I also found it helpful when each video had a written pull-quote next to it.

Health Literacy

Patient education materials require special sensitivity to factors that influence comprehension and retention. Factors that negatively affect health literacy include: unclear or wrong target audience, a high level of technical language, sentences with several prepositional phrases or complex organization, words made of three syllables or more, and too much information at once. Health literacy also drops when there are no images to accompany the text, illustrations are too diagrammatic, and more than two or

three fonts or small fonts are used. Furthermore, under stress, health education materials are even harder to understand (Plimpton 91).

In order for the patient education to be accessible, memorable, and useful for families, the content needs to adhere to the accepted best practices for health literacy. This means that the content needs to include simple sentences with a clear message, avoid use of high vocabulary when unnecessary, only present one or two key thoughts at a time, be accompanied by relatable and meaningful graphics, and be intuitively organized and within the program.

Conclusion

It would have been impossible in the scope of this thesis to try and match the vast quantity and depth of information on epilepsy provided through established resources such as the website of the Epilepsy Foundation or epilepsy.com. The purpose of this thesis was not to address every issue surrounding pediatric epilepsy or to rework how doctors at the CEC explain epilepsy to their patients. The goal of the program was to address pediatric epilepsy surgery; limited and basic information on epilepsy was included in the program as a solid foundation for discussing surgery.

While information on epilepsy as a syndrome is quite prolific on the Internet, a limited number of online resources contain quality information about epilepsy surgery. There are

even fewer resources dedicated to pediatric epilepsy surgery. The resources that are available for parents of pediatric epilepsy surgery candidates do not address the entire pre-surgical testing, surgery, and post-operative appointments as a surgery journey. Online parent education material is also usually written at or above a 10th grade level, which is still too high for most parents to easily comprehend (D'Allesandro). Other written materials for pediatric epilepsy surgery education often include confusing illustrations or photos that are too graphic for parent education.

CHAPTER THREE

Methodology

Goals and Objectives

Goal

The goal of this project was to create an online parent education resource to guide parents through the process of pediatric epilepsy surgery. The program will clarify the journey-like nature of epilepsy surgery and help parents visualize the end of the process. It will also open communication between epilepsy health professionals and the families by providing a foundation for discussion. The program will be accessible through the website of the Comprehensive Epilepsy Center (CEC) at Children's Medical Center Dallas (CMC) once it is live.

Objectives

In order to produce the program, several objectives had to be met. The first objective was to create a simple and intuitive representation of the timeline of pediatric epilepsy surgery, including all of the pre-surgical testing and follow-up appointments after surgery. The timeline also had to account for two decision forks and three variations of the surgery.

The second objective was to pair an image with each page of text within the program to help make the medical information more accessible and less threatening.

The third objective was to create illustrations of the brain that could be altered as needed to highlight the various lobes and functional areas important to understanding epilepsy and epilepsy surgery.

The fourth objective was to include success story videos or written testimonials from patient families at CMC.

The fifth objective was to include trusted resources within the program such as: answers to common questions posed to the Epilepsy Team about epilepsy and epilepsy surgery, a glossary of medical vocabulary, and links to websites recommended by the CEC.

The sixth objective of the program was to account for the demographics of the patient population by creating a Spanish version of the program and providing PDF documents for the CEC to print out and give to families without computers.

Lastly, post-project surveys needed to be collected to evaluate whether the goals and objectives of the project had been met.

To complete these goals and objectives, important content was determined through a review of existing literature and pre-project parent surveys. An interactive website was created that included a variety of images and trusted resources to enhance understanding. Post-project evaluations were conducted to determine whether these goals and objectives had been met.

Concept Development

Before starting thesis preparations, I knew that I wanted to work on a patient education project, preferably in pediatrics. I started by keyword-searching the research interests of faculty at UT Southwestern. A search for autism led me to Dr. Arnold at Children's. She informed me that while she is a neurologist, she rarely sees patients with autism. She mostly sees patients with epilepsy. She was specifically interested in expanding her education resources for epilepsy surgery.

I met with Dr. Arnold and Dr. Price to discuss the types of epilepsy surgery done at Children's and the general steps in the surgery process. They felt that I should focus on the two most common epilepsy surgeries performed on their patients: the two-part surgery involving surgical placement of subdural electrodes coupled with a resection surgery and hemispherectomies. We discussed using a sample patient to guide through the process with real brain scans and test results to help parents visualize a successful surgical outcome.

Dr. Arnold also put together a table, "Epilepsy Surgery Timeline," with columns for week, contact, and procedures (Appendix A). The timeline of information is a 118-week approximation of all of the appointments, testing, and decisions that accompany the actual surgery. The appointment-intensive timeline fueled the idea that I should use a timeline graphic as the main image that would lead parents through the process and the focal point around which I would build the program.

Pre-Project Planning

Initial Meetings

In the beginning, I met with Dr. Arnold numerous times to begin brainstorming the format and scope of the project. During these meetings, Dr. Arnold spent time to familiarize me with the concerns and emotions of her patient families and to explain how the testing and surgery worked at Children's

Pre-Project Surveys

I created a pre-project survey to be given to parents in the office or mailed to their home. Due to HIPAA laws, I could not look at patient records and call the parents myself to obtain their consent or talk to them about the surveys without going through a hospital contact. Dr. Arnold originally intended for her nurse to call the parents and distribute the surveys. In the meantime, I started attending the monthly clinic days that were dedicated specifically for epilepsy surgery patients. These days proved to be invaluable opportunities to ask parents questions from the surveys and just talk to the families and hear their story. I learned more from these oral surveys than I could have ever learned from a mailed or emailed survey. I began to see how each family is different, how family dynamics affect decisions made, and how each parent responded to the surgery process in their own unique way.

During the appointment, Dr. Arnold would ask the families if they were comfortable talking to me about their experience with epilepsy surgery. Dr. Arnold spoke Spanish well enough to talk to the Spanish-speaking families on her own. However, when I needed to talk to the Spanish-speaking families, I used an interpreter from their in-house translation services.

The questions on the survey included:

1. What surgery did your child have?
2. When did your child have his or her epilepsy surgery?
3. Was there anything you wish you had known before your child had his or her epilepsy surgery?
4. What scared you the most about the surgery?
5. What medical words or ideas were the most difficult for you to understand?
6. Do you have access to the internet?
7. Did you use the computer or internet to find more information about the epilepsy surgery process?
8. Do you think images of the surgery would have been helpful in understanding the surgical process?
9. If yes, which would you have preferred: photographs, drawings, or both?

After the first few meetings and survey collections, I also started to informally ask parents:

10. Is there any advice that you would give to other parents who are going through the process or considering surgery?

Sixteen surveys were collected over five months as opportunities arose in clinic or at the hospital for me to meet with families (see Appendix B). Twelve families were post-operative epilepsy surgery families. One family was currently between surgeries in the two-part surgery. One family was going through the pre-operative MRI and pre-op appointment for surgery. One family was ready to schedule the surgery for the next month. The last family was beginning to think about epilepsy treatments besides antiepileptic drugs. The families included a mixture of mothers, fathers, mothers and fathers, and mothers and grandmothers.

The survey results helped guide some of the specific topics included in the program. Meeting with Hispanic families also reinforced the pressing need for a Spanish-translation of the program. The following responses were given by parents:

What surgery did your child have?

Dr. Arnold suggested that the survey include the first question asking parents to say what surgery that their child had. She had anticipated that their answers wouldn't necessarily be helpful for the pre-project planning but that it would be interesting to know how they described it. Parents gave answers ranging from anatomically correct descriptions of the lobe and hemisphere affected to answers such as "scary." While this was not the kind of answer for which I was looking, it was extremely useful for its vivid representation of the

emotional turmoil that surrounds surgery – even for parents looking back on the experience years later. Even the surprisingly correct anatomical descriptions showed that parents often begin to acquire a new medical vocabulary throughout the epilepsy and surgery process.

Was there anything you wish you had known before your child had his or her epilepsy surgery?

One family said that were surprised that their son needed a feeding tube, which he still has, and a second surgery for shunt implantation. Dr. Arnold said that feeding tubes were very rare, but I still felt it was important to mention feeding tubes being needed for small children or infants. Therefore, I added it to the Frequently Asked Questions section.

What scared you the most about the surgery?

The responses to this question surprised me the most of all the questions in the survey. A number of parents replied that the anesthesia scared them the most, and they were afraid that their child would not wake up from the surgery. Other parents indicated the various risks.

What medical words or ideas were the most difficult for you to understand? .

Most parents couldn't even verbalize an answer for this question. When they started staring at me with confused expressions, I prompted them by asking "the parts of the brain, all of it, etc." This question was not very helpful for planning the project because parents had a hard time pinpointing specific words or ideas.

Do you have access to the Internet?

I only asked this question of twelve of the sixteen parents because I was often interviewing them during a stressful time in the hospital or as quickly as I could after their appointment in the clinic. Consequently, I sometimes did not have time to ask them all of the questions. However, of the twelve families I did ask, nine said yes. Three said no. While two-thirds of the parents interviewed had access to the Internet, I did not want to exclude the families who didn't from the information. So, I included the "for printing" section with printable PDFs that the CEC could print and provide to families without computer access. Since the CEC already handed out folders of information for newly diagnosed epilepsy patients in both English and Spanish as well as gender-specific packets, I felt that printable PDFs would fit well into the already established method of patient education distribution.

Did you use the computer or Internet to find more information about the epilepsy surgery process?

Some parents said not at all – some with qualifications that they didn't want any extra information than what the doctor had given. Others said yes, but that much of the online information frightened them or was too graphic – such as simply searching for epilepsy surgery and coming across actual surgery images.

Do you think images of the surgery would have been helpful in understanding the surgical process?

A few parents did not want to see any pictures at all – even drawings because it was too emotional for them. The majority of parents wanted to at least have some sort of visualization. Other parents who were in the medical field said that they wouldn't have minded actual surgical photographs.

If yes, which would you have preferred: photographs, drawings, or both?

The majority of parents did not want to see actual surgical photographs. Interestingly, I asked this question as if it referred to the surgery itself. However, throughout the planning process and early design of the program, we decided that photographs should be the main imagery to anchor the large amount of medical vocabulary in the text and to make the content more tangible and less threatening.

Is there any advice that you would give to other parents who are going through the process or considering surgery? (added question)

Parents responded with: find a support group, talk to other parents, “believe in your doctors and of course God,” or “we went through surgery to give him a chance to grow up.”

In conclusion, the parent interviews were extremely helpful when deciding on topics to cover in the program. Specifically, the interviews showed that parents were most scared about the risks and the anesthesia. Consequently, I spent several pages in the surgery sections discussing the anesthesia and anesthesiologist. I also included an FAQ about the risks of surgery because it's a question that is always addressed in clinic. The interviews

also indicated that parents were the most surprised about post-op swelling, how little hair would be shaved, the relatively small size of the incision, and the possible need for a feeding tube or shunt. All of these topics were addressed in the program, either directly in the surgery section or in a FAQ.

From the earliest stages of the project, Dr. Arnold also knew that she wanted information about the scar and how much of a child's head is shaved during surgery included in the program because parents consistently asked her during pre-surgical appointments.

Content Outline

I created a content outline in Microsoft Word to begin expanding on the information in the Epilepsy Surgery Timeline (Appendix A) that Dr. Arnold formulated. The content outline was as follows:

- 0. 3 Main Portals for Program
 - A. Patient – English text
 - B. Patient – Spanish text
 - C. Doctors or Nurses (condensed version)

I Introduction

This surgery guide is intended for parents and families of children considering pediatric epilepsy surgery at Children's Medical Center of Dallas. We know that

the decisions involved in epilepsy surgery are not easy ones for you to make, but we hope that this guide will help make the process a little clearer. Whether or not your child does progress all the way to surgery, we want you to be as informed as possible. Our team of highly qualified doctors and nurses is here to support you throughout this journey, and we welcome your questions at any and all points along the way.

II. Understanding Epilepsy (or “Understanding Seizures and Epilepsy”)

A. What are seizures?

- a) Seizures are abnormal surges of electricity in the brain.
- b) The brain is the body’s master computer. “Talking” of brain cells.
- c) Damaged or improperly formed brain.
- d) Surges of electricity may only be seen by an EEG.
- e) Basic information about EEG from timeline.

B. What is Epilepsy?

- a) Epilepsy is having seizures over and over again.
- b) Causes of epilepsy:
 - Strokes
 - Tumors
 - Brain dysplasia
 - Head injuries or major trauma
 - Infections of the brain like meningitis or encephalitis

- Idiopathic
- c) Partial Seizures vs. Generalized Seizures
- d) Most seizures can be well controlled by medicines.
- e) Good candidates for epilepsy surgery.

III. Understanding Epilepsy Surgery

A. What is the Surgery Process?

- a) Definition
- b) Journey will take time.
- c) Surgery is not right for all children with epilepsy.
- d) Puzzle pieces analogy.
- e) You are not alone. We are here to support you.

III. Timeline of Epilepsy Surgical Process (Bulk of Program with sample patient)

A. Qualification about variation in speeds of progression.

B. Timeline (Figure 3-1).

Week	Contact	Procedures
0	Initial consultation with Epilepsy Specialist (Neurologist)	1. History 2. Physical/Neurological Examination 3. Review of Medical Records 4. Discussion of treatment options 5. Ordering additional tests (if needed)
2	Outpatient Testing (if needed)	1. EEG 2. MRI

4	Follow-up consultation with Epilepsy Specialist.	1. Review additional testing results, 2. Discussion of Epilepsy Surgery and surgical evaluation process
8	Inpatient evaluation in Epilepsy Monitoring Unit (EMU) - Typically 4-5 days inpatient stay	1. Video-EEG (to record seizures, antiepileptic medication may be reduced or stopped) 2. Neuropsychological testing 3. Ictal SPECT 4. PET scan
9	Epilepsy Conference	Discussion of case with Neurologist, Neurosurgeon, Neuropsychologist, Neuroradiologist. Decision made to recommend surgery or not
9	Phone call to family with results of Epilepsy Conference	1. Offer appointment with Neurosurgeon as next step
12	Appointment with Neurosurgeon	1. History 2. Physical/Neurological Examination 3. Discussion of surgical risks, benefits 4. Ordering additional tests (if needed)
14	Outpatient Testing	1. Visual Field Testing 2. functional MRI
18-19	Admission to Children's Medical Center for Grid placement and testing	Day before admission: MRI scan with fiducials, meeting with anesthesiologist Day 1: Surgery to place grid, admission to ICU, EEG monitoring begins Day 2: Transfer from ICU to EMU, monitoring continues, antiepileptic medication may be reduced or stopped to provoke seizures. Day 3-6 continued monitoring in EMU, Evoked potential testing,

		<p>Motor and language mapping tests done in EMU</p> <p>Day 7: Grid removed, surgery performed to remove area of brain causing seizures. Patient returns to ICU after surgery, antiepileptic medication returns to full doses</p> <p>Day 8: Transfer to Neurosurgery floor, therapy evaluation if needed.</p> <p>Day 10: Discharge home from hospital.</p>
20	Neurosurgery appointment	Post-op wound check
22	Neurology appointment	Epilepsy follow-up care begins
30	Neurology appointment	<ol style="list-style-type: none"> 1. Epilepsy follow-up care 2. If patient is on multiple medications one or more may be tapered, beginning at this visit
42	Neurology and Neurosurgery Appointments	<ol style="list-style-type: none"> 1. Epilepsy follow-up care 2. EEG 3. Continue at least one antiepileptic medication
66	Neurology and Neurosurgery Appointments	<ol style="list-style-type: none"> 1. Epilepsy follow-up care 2. Neuropsychological testing 3. Continue at least one antiepileptic medication
118	Neurology and Neurosurgery Appointments	<ol style="list-style-type: none"> 1. Epilepsy follow-up care 2. If patient has been seizure-free since surgery consider tapering off antiepileptic medication.

Figure 3-1. Epilepsy Surgery Timeline.

IV. Side or Constant Navigation Bar Elements

A. Brain Anatomy

a) Hemispheres

- b) Lobes of the brain
- B. Success Stories
 - a) Hemispherectomy
 - b) Occipital Lobe Resection
- C. Glossary of Terms (include images where appropriate)
- D. Additional Resources and Links
- E. Printable drawings and timeline (“Printer Friendly Version”)
- F. Frequently Asked Questions

The timeline-table was originally going to be the only content included in the program. However, Dr. Arnold and I agreed that while this program was being designed as a tool for surgery education, we could not assume a basic understanding of epilepsy when discussing the surgery.

Many families come to the CEC as referrals or for second or third opinions. In most cases, they have been given information about epilepsy or researched it some on their own. And yet, many parents have misconceptions about epilepsy or don't fully understand it. Some basic information about epilepsy had to be included to set the foundation for discussions about surgery.

The distinction between partial seizures and generalized seizures in the *Understanding Epilepsy* section was perhaps the most important point to make. A diagnosis of partial seizures is one of the key criteria for considering a child for surgery. Other criteria are

very important, but children with generalized seizures will not even be considered for surgery. Resection surgery will not help a child who is having seizures in his or her entire brain. In some cases, parents even come to the CEC after researching epilepsy treatments, and they want surgery for their child who has generalized seizures. The neurologist will have to explain why surgery is not a treatment option for their child.

As I continued to research epilepsy and epilepsy surgery, I added glossary terms, frequently asked questions, and possible success story patients to the content outline.

Site Map

My first several drafts of the site map divided the program into an English patient portal, Spanish patient portal, and a doctor's portal. After numerous discussions with Dr. Arnold, we decided to eliminate the doctor's version and focus on the patient portals (Figure 3-2). The site map also helped develop the organization for the navigation bar in the website since each of those topics did not logically fit into the information about epilepsy or epilepsy surgery. The final site map included six links in the navigation bar: home, brain anatomy, success stories, glossary, helpful links, and for printing. I eliminated the *home* link and added a *frequently asked question* link in the final project. The site map was created in Adobe Illustrator.

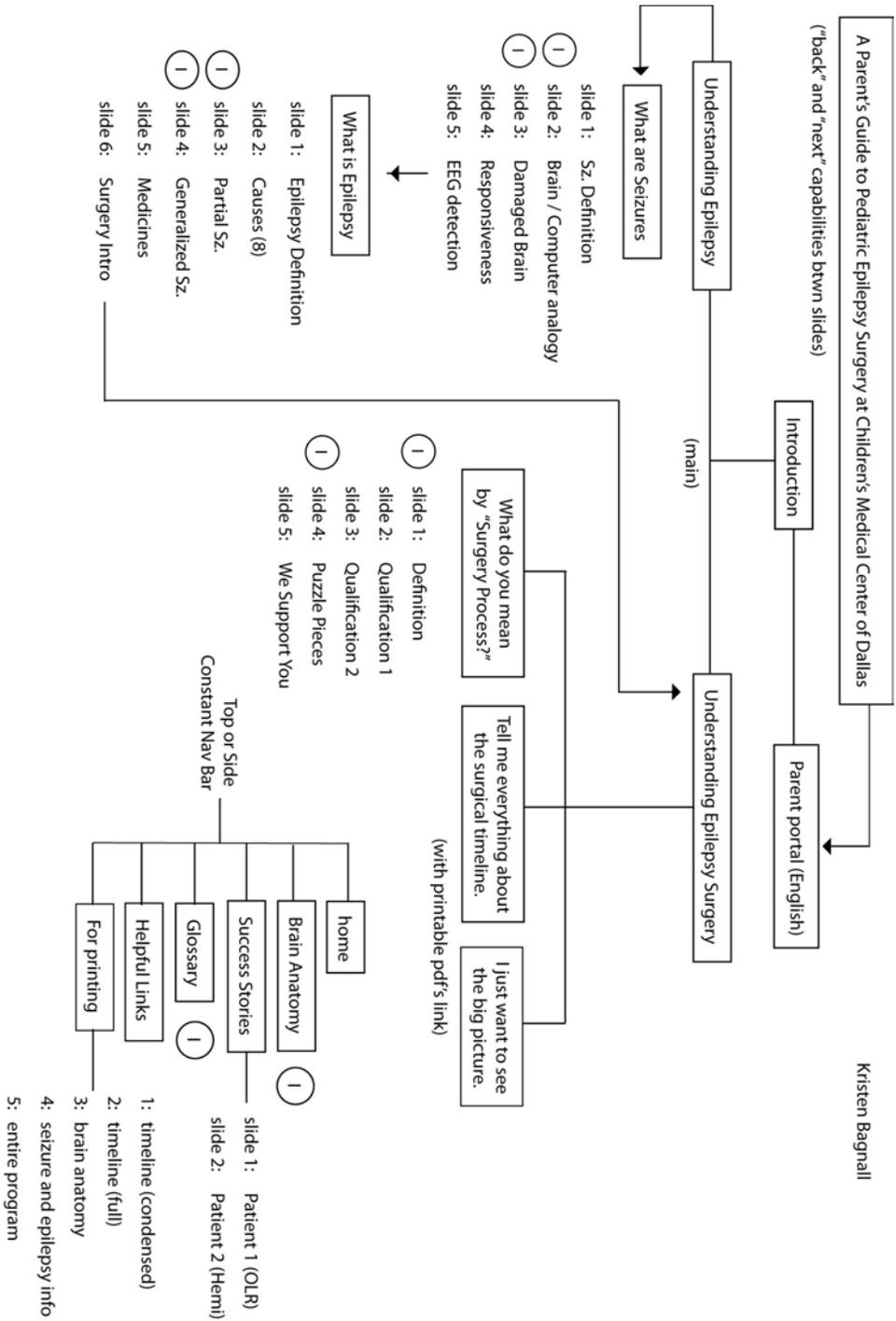


Figure 3-2. Site Map for Website.

Storyboarding

I used Adobe InDesign to storyboard the website and begin logically segregating chunks of content given the dimensions of the website (Appendix D). Storyboarding also gave me the opportunity to make adjustments in design and the relative size of fonts before beginning to build the website (see Figures 3-3 and 3-4).

A Parent's Guide to Pediatric Epilepsy Surgery
at Children's Medical Center of Dallas

Understanding Epilepsy
Understanding Epilepsy Surgery

Brain Anatomy • Success stories • FAQs • Glossary • Helpful Links • For Printing

Step 2: Outpatient Testing Who You'll See: Technicians in the Epilepsy Monitoring Unit of the hospital What Will Happen: EEG, MRI

EEG

This is a normal EEG with a normal pattern of "brain waves."

This EEG shows generalized abnormal signals (seizures) all over the brain. Surgery would not help this child.

Testing: 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20

Decisions Possible Testing Final Decision Surgery Follow-Up Appointments

Figure 3-3. Storyboard Page – Generalized Seizures on an EEG.

A Parent's Guide to Pediatric Epilepsy Surgery
at Children's Medical Center Dallas

Understanding Epilepsy
Understanding Epilepsy Surgery o

Brain Anatomy • Success stories • FAQs • Glossary • Helpful Links • For Printing

STEP 13a Day Before Surgery **Who You'll See:** technicians at the hospital (what floor?), the anesthesiologist

What Will Happen: MRI with fiducials, blood tests, directed blood donor (?), meet anesthesiologist (? or call?)

-Anesthesiologist might talk about . . .

Allergies, medical history, heart / lung problems, past surgeries, drug reactions, mentally challenged / cognitive functioning (word much nicer), what medicines is he on, is there anything in the family that has had a bad reaction to anesthesia

Make sure kid is not sick and doesn't have a fever that might increase the risks of surgery

[Drawing goes here] "How does your child react around doctors, needles, and IV's" . . .

"Is there a special toy, doll, or blanket they can bring with them for comfort when anesth. is putting them to sleep?" . . . or "How can we make your child comfortable in this process." . . . headphones and music, movie, read a book, etc

Blood is drawn for pre-operative tests.

-Nothing to eat or drink after _____

< >

Steps of the Pediatric Epilepsy Surgery Journey [click on a step to learn more]

1	2	3	4	5	6	7	8	9	10	11	12	a	b	c	d	e	f	g	h	i	14	15	16	17	18	19
Testing				Decisions				Possible Testing		Final Decision		13 Surgery					Follow-Up Appointments									

Figure 3-4. Storyboard Page – Step 13a.

Website Design

Delivery Platform

Because the project had to be accessible through the Internet, I considered two software programs to create the website: Adobe Flash and Adobe Dreamweaver. While Flash is an inherently interactive program, the Apple Ipad and Ipad don't currently support Flash built websites or files. Adobe Dreamweaver was a better choice for this website should parents choose to view the website on mobile Apple devices.

Website Creation

The website was designed at 955 x 600 pixels in Adobe Fireworks (Figure 3-5). Gif images, rollovers, and the sliced html template pages were exported in organized folders and opened in Dreamweaver (Figure 3-6). I then used cascading style sheets to format text as needed. Cells and tables were added or adjusted in Dreamweaver as needed if changes needed to be made to avoid re-exporting every file from Fireworks once I was farther along in the process.

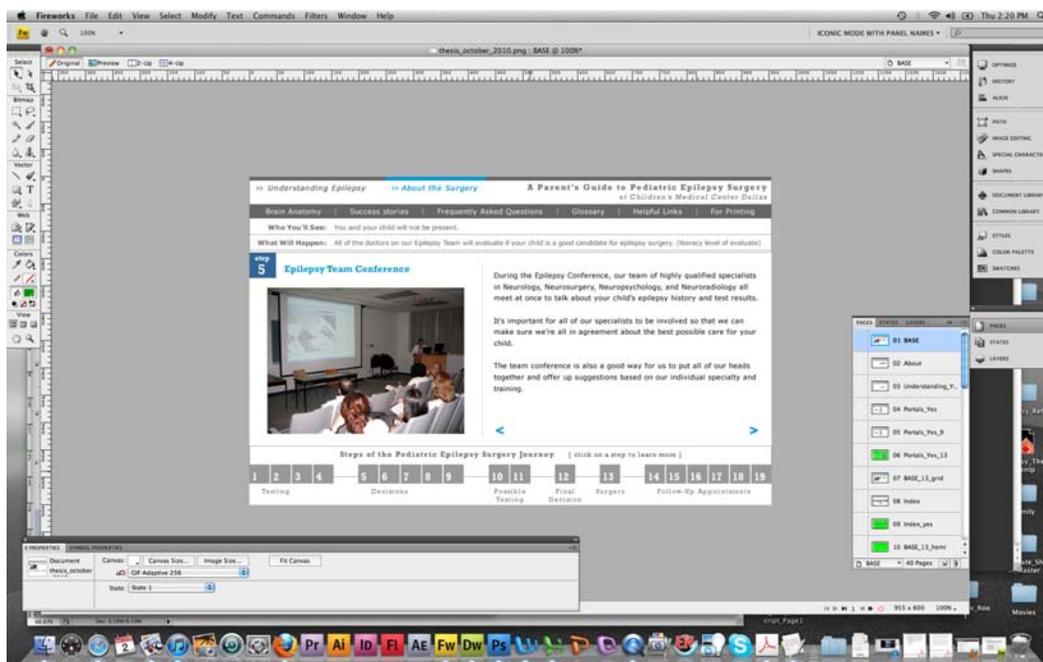


Figure 3-5. Working Fireworks File.

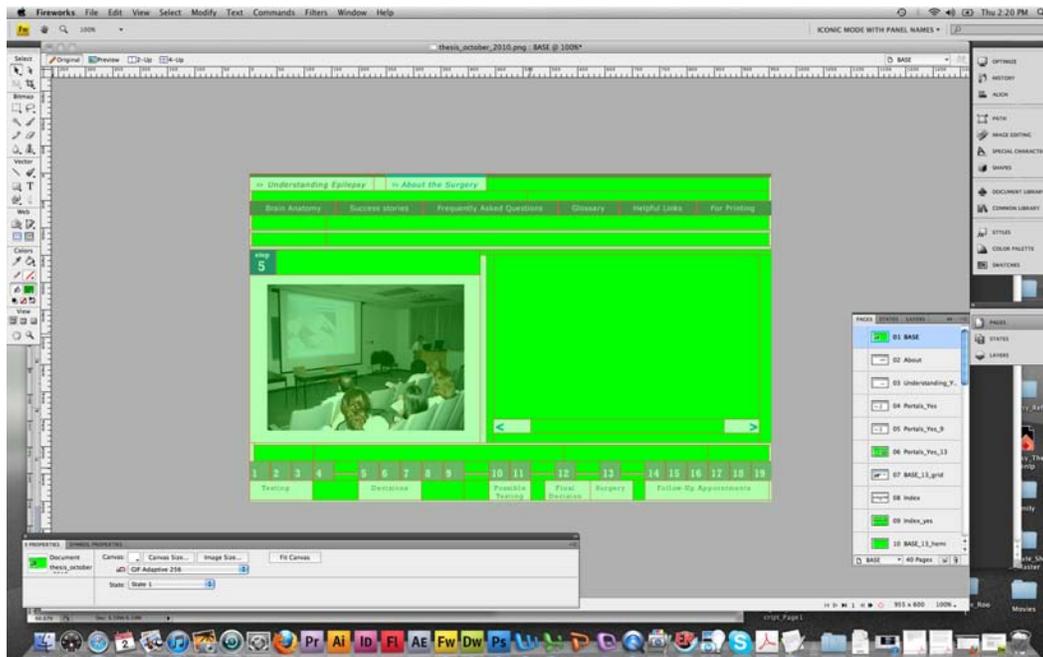


Figure 3-6. Exported Slices from Fireworks.

Design Elements

In order to comply with best practices for patient education materials, I applied the following design principles to the website:

1. Fonts were limited to two main fonts: Verdana and Rockwell. Variations of these fonts were created using smaller or larger text, bolded text, italicized text, underlined text, and adjusted kerning and leading. Verdana was used for the main text and the navigation rollovers because of its clean and clear appearance. Rockwell and its variations were used for the title and the text associated with the journey graphic.

2. The main navigation bar of the website was placed in the upper one-third of the webpage and designed as a horizontal bar that was easy to view and navigate.
3. The website was created at 955 x 600 so that the program could be viewed in most web browsers on 1024 x 768 monitors. This size monitor is accepted in web-design forums as a reasonable assumption for modern screen sizes.
4. The carrot-arrow keys were given rollover texts that indicated *next* or *back*.
5. The individual steps in the journey graphic and the *Understanding Epilepsy* and *About the Surgery* sections were all given hyperlinks in Dreamweaver to provide multiple avenues of navigation to important information.

Images in the Program

Patient and Model Release Forms

Due to difficulties with Children's public relations and marketing departments in scheduling an official hospital photographer, I had to take the photographs for the program myself. I actually preferred this alternative because it allowed me to take exactly the shot that I wanted and to take photographs when opportunities arose at the last minute. However, I had to make sure and get official consent and release forms signed by each family that I photographed or that was videotaped for the program. The epilepsy program manager gave me both an official English and a Spanish version from Children's.

Because I wanted to avoid the legal issues that accompany the purchase and licensing of stock images and any derivative works, I also chose to use the grandson of a family friend as a model reference for the Hispanic boy pictured in many of the program's illustrations. Since he was not a Children's patient and since I was retaining the copyright to the derivative drawings from photos of him, I even created my own English and Spanish model release forms for my personal business.

Photographs

To obtain the photographs for the journey steps, I attended numerous clinics and spent many hours at the hospital meeting with families or waiting for the right opportunity to arise. I felt that it was important to have a photo for every possible step that I could, so Dr. Arnold helped direct me and introduce me to families that might be willing to help. For each photograph, a CEC physician or nurse would introduce me to the family and ask if they were comfortable being photographed for a parent education project. Most of the families consented. After they verbally consented, I explained a little of the project to them and made sure that they understood that the photos would be on a website for epilepsy surgery. Once they consented again, I asked them to sign the release form and explained what sort of pictures that I wanted to take. Sometimes I had to wait a few hours to take one set of pictures – as was the case for the Video EEG monitoring in the EMU and the clinic appointment photos.

I did not use a flash for the photographs because I did not want to intrude on the families any more than I already was during such difficult and emotional situations. Turning off

the flash on my portable digital camera also allowed me to take as many pictures as I needed without disturbing the family or the doctor. The main photographs for the steps of the journey were then altered in Adobe Photoshop as needed for color balance and cropping. They were also compiled into a single Photoshop file with the image resolution and size that fit the main image cell in the pages of Dreamweaver. (Figure 3-7).

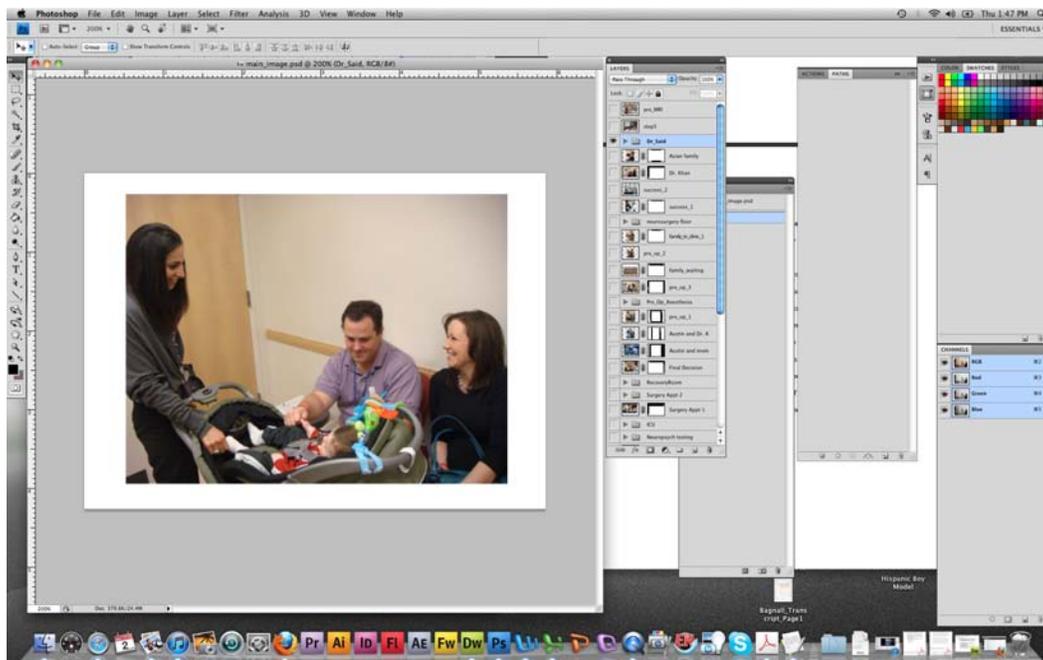


Figure 3-7. Photoshop File of Main Images.

Illustrations

While the photographs were the main focus for images in the program, key illustrations of the brain were added when appropriate. To better understand what I was drawing, I

attended surgeries as background research. Although I could not take photographs in the operating room (OR), even for project research purposes, it was helpful for understanding the nuances of the different surgeries and how to simplify the content of the surgery section. I also did quick little sketches on a notepad in the OR and asked the surgeon and nurses many questions to try and understand where the incisions were and how the wound was bandaged or cared for after closure. While my questions were quite exhaustive, I felt that understanding the location of the incision and how it was different for different situations was extremely important information to consider for the program. Information about the incision was more important for families than the medical details of the surgery itself.

I also created some initial sketches of the puzzle pieces imagery, the brain, and the brain in a girl's head (Figure 3-8). However, given the high percentage of Spanish-speaking patients at the CEC, I used an eight-year old Hispanic boy for the final illustrations (Figure 3-9). The illustrations were all created in Illustrator and Photoshop. The opacity of the child's head was decreased and specific lobes were highlighted as needed. The illustrations were exported at the proper resolution and size to Dreamweaver. The final illustrations are included in Appendix E.

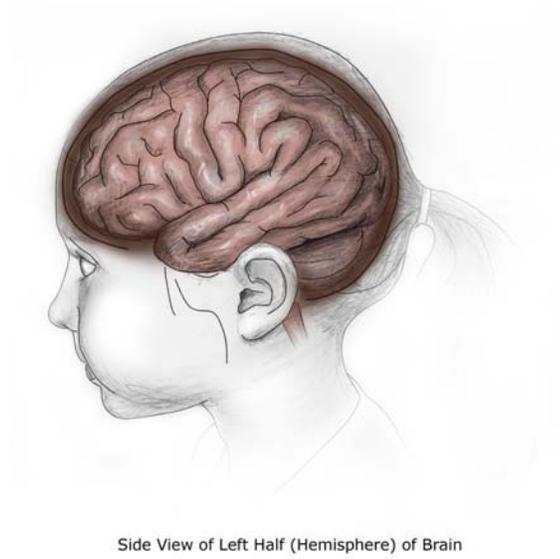


Figure 3-8. Sketch of Sagittal View of Brain.

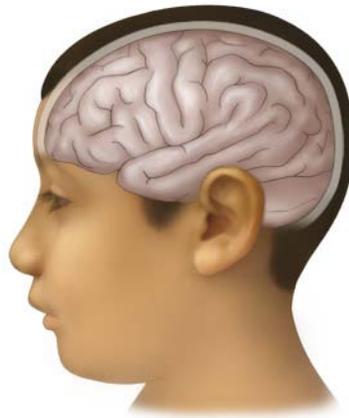


Figure 3-9. Final Base Illustration of Sagittal View.

Brain Scans

Dr. Arnold provided me with a Microsoft Powerpoint presentation she had created that included several good examples of EEGs, an MRI, an fMRI, a PET scan, and an Ictal SPECT scan. I extracted the images from the presentation, formatted them with the proper image size and resolution in Photoshop, and erased extraneous measurement markings on the scans. I also added bold arrows to highlight the key areas on scans. The final brain scans are included in Appendix E.

Title Page of Program

The title page, referred to in the website as an *index* page, went through multiple evolutions in order to create an introductory page that was a web portal but that also functioned like the cover page of a book or brochure (Figure 3-10). A *How to use this site* link was included on the index page. The link opened a new page with a diagram of the surgery section of the program and arrows highlighting key content and navigation areas (Figure 3-11). This site-explanation page was added for parents that might feel overwhelmed by the navigation options or intimidated by the program as a whole.

[> How to use this site](#) [> En español](#)

a Parent's Guide^{to} Pediatric Epilepsy Surgery



This guide is for parents and families thinking about pediatric epilepsy surgery at the Comprehensive Epilepsy Center of Children's Medical Center Dallas.

We know that the decisions involved in surgery are not easy ones for you to make, but we hope that this guide will help make the journey a little easier. Whether or not your child goes all the way to surgery, we want you to be as informed as possible.

Our team of highly qualified doctors and nurses is here to support you throughout this journey and to make sure that your child has the best care possible.

[Click on a link below to begin the program.](#)

[>> Understanding Epilepsy](#) [>> About the Surgery](#)

Copyright © Kristen M. Bagnall, 2010

Figure 3-10. Index Page of Program.

> [Back to main site](#) > [En español](#)

a Parent's Guide to Pediatric Epilepsy Surgery

Click here to learn about epilepsy Click here to go to the first page of surgery information

Click on a link in this navigation bar to find helpful resources

Look here for a quick guide to each step

Use the arrows to read the next page of information or to go back a page

Click on a step to skip ahead or to review a step

Copyright © Kristen M. Bagnall, 2010

Figure 3-11. How to Use This Site Page of Program.

Understanding Epilepsy Section

I chose not to include the journey graphic in this section so as not to distract from the basic content on epilepsy. I also formatted the pages in this section to read like a brochure (Figure 3-12).

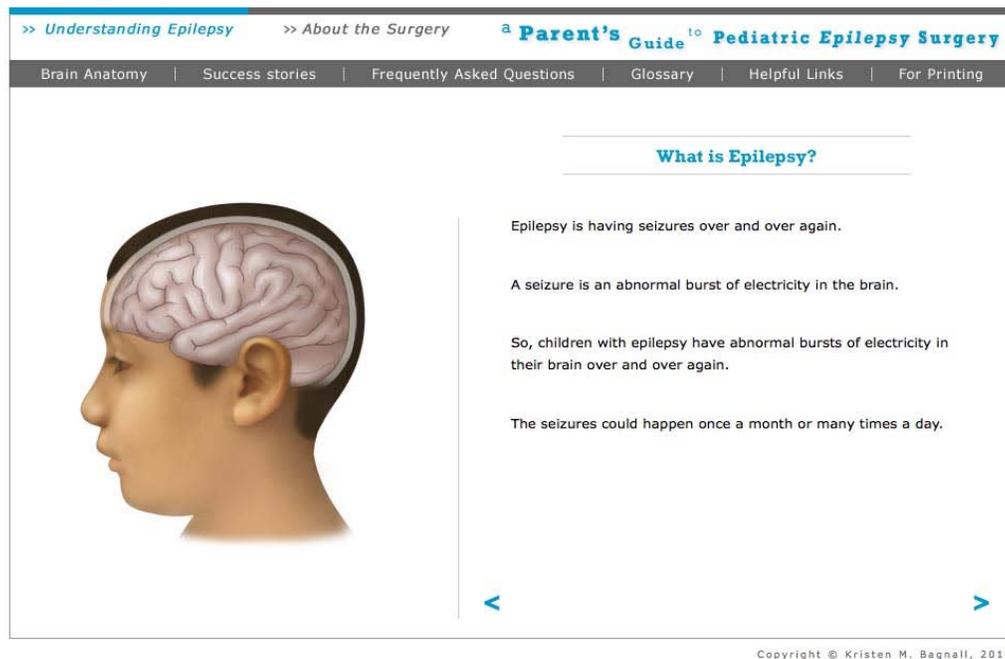


Figure 3-12. Understanding Epilepsy Layout.

About the Surgery Section

In the beginning of the project, I had envisioned that the program would be centered around a timeline graphic that encompassed all of the information in the Pediatric Epilepsy Surgery Timeline that Dr. Arnold had formulated. Dr. Arnold and I had discussed creating a sample patient to move along this timeline and to serve as a successful example of the surgery process, complete with actual brain scans.

I also envisioned that the graphic would strongly resemble a timeline of some sort, with weeks marked on a line by dashes or circles, forks in the timeline, and text labels.

However, none of my timeline sketches or ideas fully encompassed the nuances of the

surgery process or allowed for the decision forks and three variations of the surgery that I needed to include.

The idea of a literal timeline also didn't allow for the different rates families take when going through the process. Some families speed through it quickly, as was the case for a child who went to hemispherectomy surgery during the creation of this project; he is even included in many of the photographs used in the program. For him, the pre-surgical evaluation was condensed into a few weeks because he was having seizures so severe that he went to the emergency room and intensive care unit for each one. His family was ready to say yes to surgery. For other families, the process can take years if they are not ready to make such a trying decision or if they want to consider other treatments first.

Once I let go of the concept of a literal timeline, I began to envision the surgery process as a journey. I imagined that journey and path-like imagery would also be well received by families. I began sketching other analogies that were similar to a timeline but had more visual impact (Appendix D). Examples included building blocks being stacked, climbing rungs in a ladder, a road map branching, and walking up the steps of a set of stairs. The idea of steps resonated with me and effectively described all of the different pre-surgical tests, appointments, parts of the surgery and hospital stays, and follow-up appointments. Steps were also a clear and concise way to divide the new concept of a journey.

Dr. Arnold and I worked to clearly define what happened at each step and the number of steps needed. The final journey graphic includes nineteen steps divided into six discrete categories (Figure 3-13). Each category also has its own color, and that color is used throughout the rest of the program as a way to anchor the user in the journey and highlight specific parts.



Figure 3-13. The Surgery Journey.

Dr. Arnold also diagrammed out how each of the three surgeries included a different number of sub-steps. Rather than make three entirely different programs based on the specific surgery, I chose to keep all of the pages for Steps 1-12 and Steps 14-19 the same, irrespective of the particular surgery. The information in these steps are the same for

each surgery, so using the same page kept me from making three versions of the exact same information.

To account for the variations in the surgeries themselves and the variation in sub-steps, I created three new journey graphics to be used on the surgery pages alone (Figures 3-14, 3-15, 3-16).



Figure 3-14. Resection Journey Graphic.



Figure 3-15. Hemispherectomy Journey Graphic.



Figure 3-16. Grids & Strips + Resection Journey Graphic.

I also created pages with decision-forks to address the “what-if” questions parents might have about decisions that end the surgery journey (Figure 3- 17).

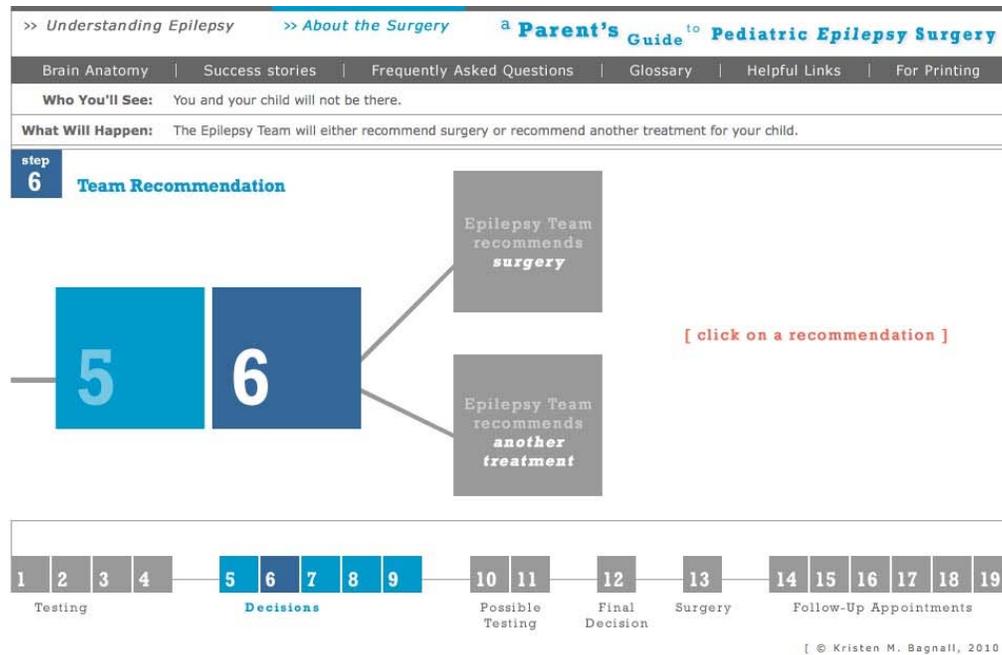


Figure 3-17. Step 6 Decision Fork.

Main Navigation Bar

The navigation bar was designed as a horizontal grey rectangle spanning the width of the top of the website. Navigation bars such as this are a common convention in modern websites because they are simple, easy to find, and they anchor the rest of the content on the page. I chose to follow this convention in order to keep the website clear and easy to navigate. I also chose to use a grey color with a darker grey color as a rollover in order to minimize the number of extraneous colors used in the website's color palette. Since so

much of the program was color-coordinated according to the steps of the journey, I felt that it was important to keep the colors of the navigation bar as neutral as possible. This was to also make sure that the program did not become too much of a rainbow palette and would allow the color focus to be directed at the main part of the program, the surgery journey graphic.

Brain Anatomy

The short section with brain anatomy images was added as a quick reference guide that provided parents with appropriate alternatives to many of the upper-level anatomical images circulating the Internet. The anatomy section was divided into four parts: Brain Hemispheres, Top View, Side View, and Brain Scans (Figure 3-18). Extra space was left on the right side of the page as a future consideration for additional text that might be added. The *Side View* images were some of the same ones used in the journey pages. The other images were created especially for this section as alternative views that parents might have seen versions of on the Internet. The final illustrations are included in Appendix E.

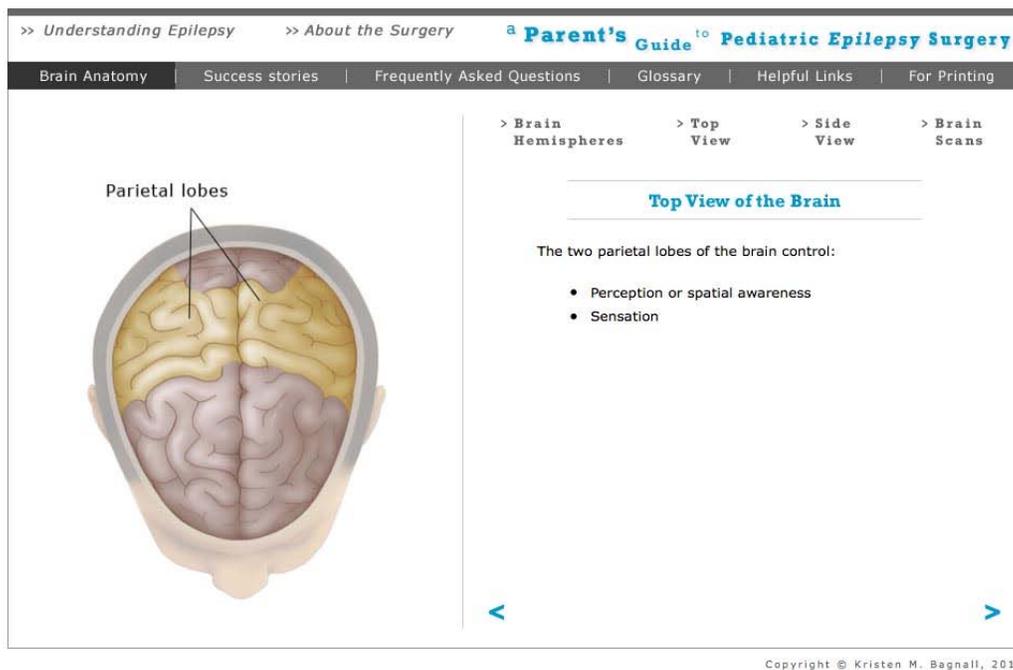


Figure 3-18. Brain Anatomy – Top View of the Brain.

Success Stories

From the beginning of the project, I knew that I wanted to include success stories on the website. Many of the major Internet resources for epilepsy and epilepsy surgery feature stories in some format because they provide comfort and humanization of highly medical topics. The most powerful success stories are in a Flash video format embedded into a website page that also feature pull-quotes from the video next to it. This was the ideal format for our success videos, but my committee agreed that at the very least, we would aim for a picture of the patient family with a written narrative next to it.

However, due to difficulties with the public relations and marketing departments at Children's, we were not able to obtain a scheduled slot with their official audiovisual services in a timely manner. So, with the project deadline approaching and with suggestions from committee members, I called the Medical Television department (MedTV) at UT Southwestern. The producers at MedTV had recorded patient success stories before and were also familiar with legal considerations of filming at Children's. I talked to a producer over the phone and gave him some information about what I envisioned for the videos. He also gave some helpful suggestions since this was my first time to coordinate videography services. We scheduled a time that worked for three patient families, including an English-speaking hemispherectomy family, an English-speaking occipital lobe resection family, and a Spanish-speaking family. Even though the Spanish version of the program would not be created at this time, we decided to bring them in for the video since the CEC was already being billed for the set-up time for the shoot. A few days before the video shoot, I formulated a list of questions for the parents and a list of questions for Dr. Arnold to answer. The epilepsy program manager contacted the families and gave them the list of questions so that they could think about their answers. Unfortunately, at the last minute, the hemispherectomy family cancelled due to a scheduling conflict

We scheduled the shoot to take place in the main downstairs lobby of the pavilion building at Children's. Even though it was a busy area, we had hoped that by the late afternoon timing of the shoot, some of the traffic would die down enough for us to get good audio. However, the lobby still had a lot of background noise from the air

conditioning and occasional people passing through. For future videos, we will schedule the shoot in a better sound location.

When the two families arrived, I asked each to sign a consent and release form for the videos and any photographs I took at the shoot. The consent form for the Hispanic parent was in Spanish. For the Spanish-speaking video, the epilepsy program manager asked her the questions. She answered and reformulated into a statement so that I could edit out the program manager's voice from the final footage. The questions included:

1. How often was your child having seizures before the surgery? What part of his or her brain were the seizures coming from?
2. What surgery did your child have? (Doesn't have to be technical term, just tell us in your own words.)
3. How old is your child? How old was your child when he or she had the surgery?
4. What were you thinking when the doctor told you that your child might need surgery?
5. What scared you the most about the surgery?

6. What did you appreciate about the doctors? How did they treat you and your child throughout all of it?
7. How is your child doing now? Did the surgery help him or her?
8. How is your child's life different now that he or she has had surgery? What can your child do now that he or she couldn't before?
9. Are you glad that your child had surgery?
10. What advice would you give to other families who are going through the surgery or who are considering surgery?

After the Hispanic mother told her story, we tried to get her eleven year old daughter to sit next to her while the video was rolling and answer a few questions as well about what she remembered from the surgery. However, she was visibly nervous and terrified, and she was fidgeting with her clothing. So, we knew that none of her footage was very useful. Her mom and Dr. Arnold also tried to gently coax her into smiling for at least a still photograph, but that didn't work out very well either.

Before the English-speaking family was videotaped, the videographer shot some footage of Dr. Arnold talking about epilepsy surgery and the specific patient's story. Since Dr. Arnold is bilingual, she discussed the English patient's story in English and the Spanish

patient's story in Spanish. I prompted Dr. Arnold's narration with the following suggestions:

1. Give a little medical history (partial seizures, severity, several medicines tried, why you suggested that the family consider surgery, etc).
2. Kind of surgery child had (ex: resection surgery in his occipital lobe).
3. What you realistically expected from the surgery (may need to be reworded).
4. How well child is doing now.
5. How child's future is "brighter" (or different) now that child has had surgery and living with fewer seizures.

For the English video, I sat in a chair next to the videographer and asked her the list of questions so that she would not be looking directly into the camera when she answered with statements. She was extremely nervous, so when she stumbled or needed to re-answer a question, we just kept the video footage rolling and I would edit that out later. Since I remembered from meeting her in the clinic that she was very well-spoken and used some of the medical terminology, I had hoped that she would say "occipital lobe resection" when I asked her to describe what surgery her son had. She didn't know how to describe it any differently than she had already talked about from the previous

question, so I edited her answer for question two completely out from the final video footage.

After she had told her story, the videographer took some moving footage of her three year old son playing with her and chasing a ball around the play area in the lobby. I also took some photographs of the boy with his mom and of the boy with Dr. Arnold to use as filler images for various parts of the program.

A few days after the shoot was over, I met with the videographer at MedTV to transfer the large raw footage in .avi format to my external hard drive. I then imported the raw file into Adobe Premiere Pro and separated the footage for the English and Spanish families. Dr. Arnold's narration was also separated for each language. The English video was edited in Premiere, and clips were rearranged to make a logical story that flowed (Figure 3-19). The footage of her son playing and Dr. Arnold's comments were added.

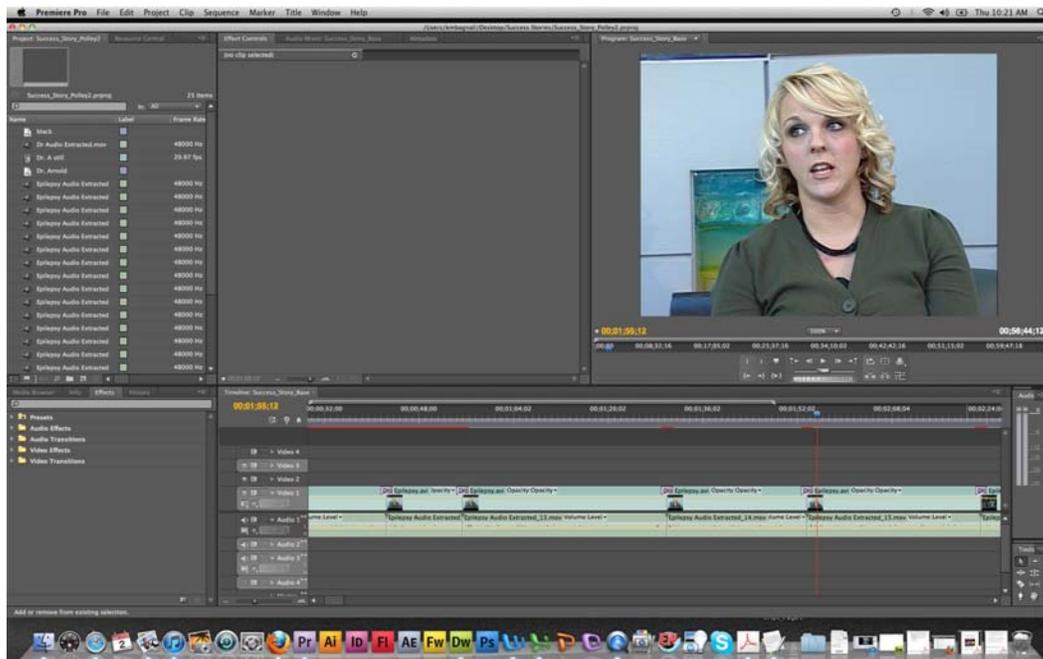


Figure 3-19. Premiere Video Editing.

Because there was so much background noise from the lobby while videotaping, I exported each audio clip to Adobe Soundbooth (Figure 3-20), used the noise reduction effect, and replaced each clip in Premiere. Soundbooth helped minimize the background buzzes a little, but the final audio still contained some noise. The final audio also contained some mismatching between the mother’s lips moving and the audio. I tried to clip and stretch the audio to match up as best as possible, but the .avi file from MedTV contained the mismatch. The uncompressed file also had a skip when she says “reason” near the end of the video.



Figure 3-20. Soundbooth Audio Editing.

I exported the final video as a Flash video .flv file to Adobe Media Encoder with the following settings: 720 pixels x 480 pixels, On2 VP6 codec, frame rate same as source (29.97 fps), bitrate of 1600 kpbs, audio as stereo at 128 kbps. I also exported a QuickTime version (.mov) so that the epilepsy program manager could mail both the .flv file and .mov file versions to the mother on a CD for her personal records. The final .flv video was uploaded to the website's root folder and imported with the proper Flash skins and coding to the Dreamweaver page for success stories (Figures 3-21 and 3-22).

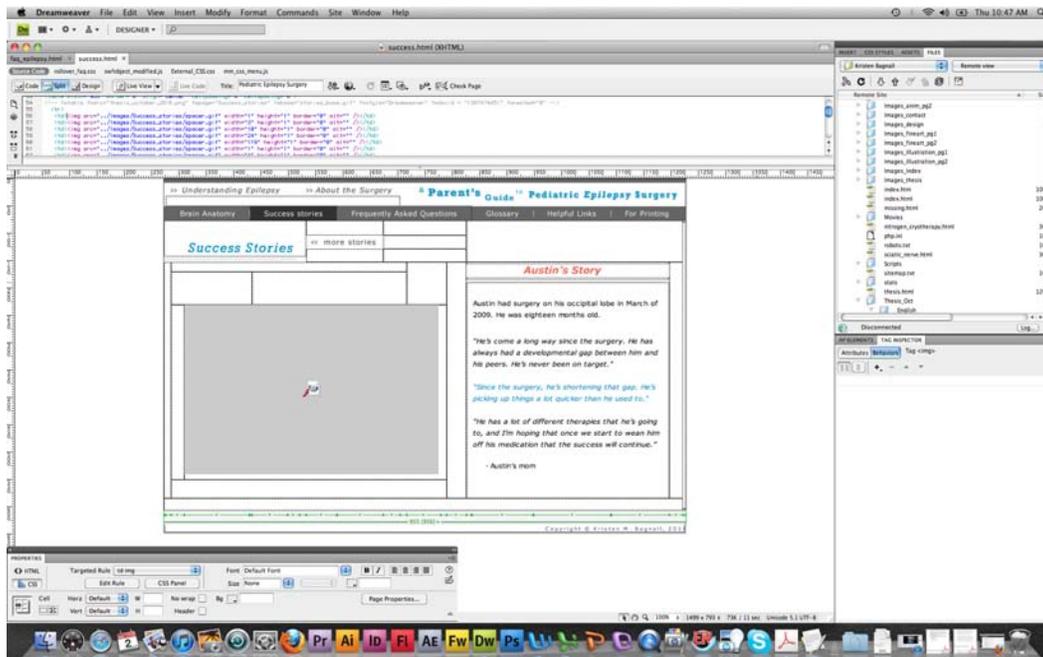
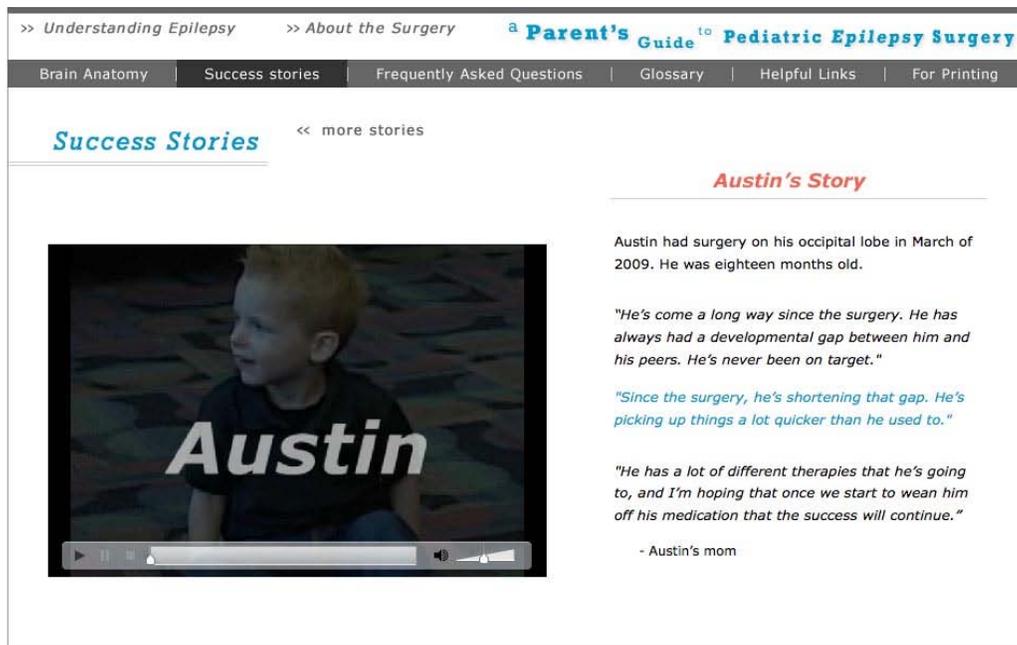


Figure 3-21. Dreamweaver Page for Success Stories.



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Figure 3-22. Web Browser View of Success Stories.

Frequently Asked Questions

The Frequently Asked Questions (FAQ) rollover in the main navigation bar included a short drop down menu with *About Epilepsy* and *About the Surgery*. Each FAQ submenu hyperlinked to separate pages (Figures 3-23 and 3-24). The answers for each question were also given their own page (Figure 3-25). Users could then navigate back to the page listing all of the questions in order to learn more. I had considered having each answer page open in a new tab in the browser window, but this proved cumbersome and inefficient compared to the final navigation solution. Many of the FAQs about surgery were directly from a list of questions Dr. Arnold provided from a patient's chart when the mother called Dr. Arnold's nurse pre-surgery. Some of the seemingly outrageous questions were excluded, but many of the questions were included word-for-word in the FAQ section.

>> [Understanding Epilepsy](#) >> [About the Surgery](#) **a Parent's Guide^{to} Pediatric Epilepsy Surgery**

[Brain Anatomy](#) | [Success stories](#) | [Frequently Asked Questions](#) | [Glossary](#) | [Helpful Links](#) | [For Printing](#)

Frequently Asked Questions *[about seizures and epilepsy]*

- > What are seizures?
- > What is a febrile seizure?
- > What are infantile spasms?
- > Do seizures hurt my child's brain?
- > What is *status epilepticus*?
- > What is a non-epileptic seizure?
- > What is epilepsy?
- > What causes epilepsy?
- > How is epilepsy treated?
- > What is intractable epilepsy?

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Figure 3-23. FAQ About Seizures and Epilepsy.

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Frequently Asked Questions *[about the surgery journey]*

- > Why are some tests inpatient stays and others are outpatient stays?
- > Why does my child need to see a neuropsychologist?
- > What makes a child a good surgery candidate?
- > What if I wait several years before saying yes to surgery?
- > If surgery isn't done and medicines haven't worked, what other treatment options are available?
- > Does surgery ever make a child's epilepsy worse?
- > How old are most of your epilepsy surgery patients?
- > Does insurance cover the cost of the surgery?
- > What are the risks of surgery?
- > How experienced are your surgeons?
- > How long does the surgery take? So it's not a day surgery?
- > What will the scar look like?
- > How much of the brain is removed?
- > Will my child be awake during the surgery?
- > Will my child need blood during surgery?
- > Will my child need a feeding tube?
- > What is the recovery time after surgery?
- > Will my child's seizures stop immediately after surgery?
- > Realistically, what kind of results can I expect from surgery?
- > Will my child's personality change after surgery?
- > Why does my child still have to take medicines after surgery?
- > Will my child need therapy after surgery?
- > Why are there so many follow-up appointments after surgery?

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Figure 3-24. FAQ About the Surgery Journey.

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Frequently Asked Questions *[about the surgery journey]*

[<< back to list of questions](#)

Why are some tests inpatient stays and other tests are outpatient stays?

Some tests that we do require your child to stay at the hospital overnight or for a few days. These tests are called inpatient tests. The extra time is needed to help us learn more about your child's seizures. Inpatient stays may also be needed for tests that require extra care and attention by doctors and nurses. Inpatient tests include:

- Video EEG
- Wada test
- Ictal SPECT

Other tests only take a few hours and can be done as an outpatient. Outpatient tests include:

- EEG
- fMRI
- MRI
- PET

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Figure 3-25. FAQ Answer Template.

Glossary

I included a glossary in the program to attempt to compensate for the high level of medical vocabulary and terminology used in the main content. Even though I worked to lower the literacy level of the content and minimize the upper level vocabulary of the non-medical words and phrases, there were certain words I could not avoid using given the needs of the content, such as: Neuropsychologist, EEG, electrodes, etc. A glossary is also a common convention in epilepsy books.

The *Glossary* page of the program features a horizontal listing of the alphabet under the main navigation bar (Figure 3-26). Letters that do not have any associated words are

grayed out and unclickable. The other letters have rollovers that hyperlink to a page featuring just the words of that particular letter. Letters were given their own page, even for just one word, with the future consideration that other words might be added if the program grows. The definition of each word was included in a rounded rectangle resembling a flashcard. Words with associated images had a hyperlink in the rectangle to “see an example” or “see a picture of it” (Figure 3-27).

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Glossary [A](#) [B](#) [C](#) [D](#) **[E](#)** [F](#) [G](#) [H](#) [I](#) [J](#) [K](#) [L](#) [M](#) [N](#) [O](#) [P](#) [Q](#) [R](#) [S](#) [T](#) [U](#) [V](#) [W](#) [X](#) [Y](#) [Z](#)

- > [EEG](#)
- > [Electrodes](#)
- > [EMU](#)
- > [Encephalitis](#)
- > [Epilepsy](#)
- > [Epilepsy surgery](#)
- > [Epilepsy surgery journey](#)
- > [Epilepsy team conference](#)
- > [Experimental drug trials](#)

EEG (Electroencephalogram)

An EEG measures the abnormal electrical signals that are causing your child's seizures. It is the basic test that we use to learn about your child's seizures, what part of the brain might be causing them, and whether or not they change over time.

The EEG machine is like a language translator that "listens" to the electrical language of the brain as the brain cells communicate and then translates that language into rows of wavy lines.

These rows and patterns of "brain waves" tell us if each part of the brain is talking normally or abnormally.

[\[see an example \]](#)

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Figure 3-26. Glossary with Definition.

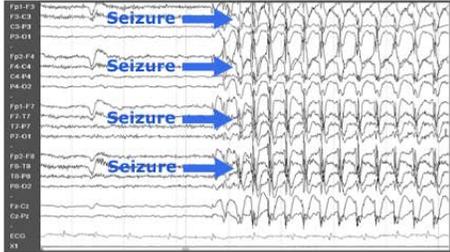
>> [Understanding Epilepsy](#) >> [About the Surgery](#) **a Parent's Guide to Pediatric Epilepsy Surgery**

Brain Anatomy | Success stories | Frequently Asked Questions | **Glossary** | Helpful Links | For Printing

Glossary A B C D **E** F G H I J K L M N O P Q R S T U V W X Y Z

- > [EEG](#)
- > [Electrodes](#)
- > [EMU](#)
- > [Encephalitis](#)
- > [Epilepsy](#)
- > [Epilepsy surgery](#)
- > [Epilepsy surgery journey](#)
- > [Epilepsy team conference](#)
- > [Experimental drug trials](#)

EEG



[[back to definition](#)]

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Figure 3-27. Glossary with Image.

Helpful Links

A page with links to other websites was included to give families additional trusted resources if they were looking for even more information (Figure 3-28). Some of the links were repeatedly mentioned by Dr. Arnold over the course of the project. Other links were mentioned in epilepsy books that I read during the research phase of the project, but Dr. Arnold approved all of the links included. Each external resource was clickable with a hyperlink that opened the associated website in a new tab in the browser. Silhouetted and desaturated images were included on the page to provide some visual interest amid all of the white space.



Figure 3-28. Helpful Links Page.

For Printing

The printable PDFs were originally intended for families without computer or Internet access, but as I was creating them, I envisioned them also as a valuable clinic tool for all families. They can be printed out in color, which is ideal, or in black and white on the clinic printers. They can also be quickly photocopied and put into a folder for epilepsy surgery families. Folders with information are already a part of the parent education process at the clinic, and the printed PDFs would easily fit into the already established methods of education. The doctor or nurse could give them to the family, introduce the concept of the journey, and then walk the family through a few key points that are most important for their child's specific situation. The health professional could also mention to families with internet access that the website includes more information with

frequently asked questions, a glossary, a success video, and more brain anatomy images for the family to review at their own pace.

When creating the PDFs, I knew that a printed document was inherently different than an interactive website with navigational possibilities and decision forks. So, I decided to divide the website into variations to create four PDFs, including an *Understanding Epilepsy* PDF, *Hemispherectomy* PDF, *Resection Surgery* PDF, and a *Grids & Strips + Resection Surgery* PDF. I divided *Step 13*, the step about surgery, into the three different PDFs because a family reading a document only needs to read information about the surgery that their child might actually have. I also created the PDF with basic information about epilepsy as a separate document in case health professionals wanted to use it for basic epilepsy education. I chose not to include the exhaustive list of glossary terms and frequently asked questions in the PDFs in order to manage the number of pages per document.

The PDFs were created in Adobe InDesign and slightly altered from the layout of the website to accommodate the different ratio of dimensions of a sheet of paper. I also excluded the grey navigational bar elements in the documents since the PDFs would be read like a short book instead of as an interactive program (Figure 3-29).

4. PDF_Resection_Surgery.pdf
5. PDF_Understanding_Epilepsy.pdf

Health Literacy Analysis

To check the literacy level of the content, I plugged in sections of text into an online Readability Index Calculator. The calculator was helpful in that it helped me to realize that even words essential to the focus of the program such as *seizures* and *epilepsy* often raised the literacy level beyond high school. Therefore, I worked to lower the level of non-medical vocabulary and sentence structure as much as possible to compensate for words that I could not avoid. I also tried to limit the number of prepositional phrases and triple-syllable words.

Doctor's Version

In the early stages of planning, the website was divided into three portals: an English version, a Spanish version, and a doctor's version. As the project continued and I shadowed Dr. Arnold more in the clinic, I realized that it was unrealistic to expect the doctors to sit down on a clinic computer with the family and click through parts of the program, even if it was condensed.

As such, the doctor's version of the program evolved through several iterations that included a nurse's portal, a nurse's portal with a script, and finally to the PDF printed and

handed out to families in clinic. The portal for health professionals was abandoned since the clinic computers are used only by health professionals for chart viewing and documentation, and they are strictly guarded with passwords and rules regarding who can view them due to patient privacy and HIPAA regulations.

Spanish Version

Translation services at Children's quoted that it would take at least a month to translate all of the content from the English program. However, before translation could be done, the English content had to be finalized. Once the Spanish translation was done, many of the Fireworks slices and Dreamweaver cascading style sheets would have to be altered to account for changes in the length of phrases and chunks of text within each website page. The Spanish version would take much longer than a month to complete, and there was no way to guarantee that the hospital would work with me to complete it in a timely and cost-effective manner. As such, my committee members, including Dr. Arnold, agreed that the Spanish version would have to wait for future research endeavors. To account for the hope that a Spanish version can be completed in the future, I added a rollover link on the index page of the English version with the text *En español*. This same method is used on the homepage of Children's website to direct Spanish families to a translated version. All of the files for the English website were also added to an English folder within the root folder so that the linking would not be altered when the Spanish pages were added (Figure 3-30).

CHAPTER FOUR

Evaluation

Survey Development and Distribution

In order to evaluate whether the goals and objectives of the project had been met, I created a survey with thirteen statements (see Appendix E). The four-page survey was created in Microsoft Word 2004. It included a space at the top for respondents to indicate their professional title. Each statement included a ranking box underneath with space for respondents to check their level of agreement according to a 5-point Likert scale. The levels of agreement ranged from *strongly disagree* to *agree*. Each statement also included a space for comments. At the end of the statements, participants were given a prompt and space to write additional comments about the program.

Six health professionals evaluated the website, including two EEG technicians, a patient care technician, a neurophysiology fellow, a neurology resident, and an associate professor of pediatrics and neurology, who is also the medical director of the CEC. I was interested in obtaining responses from a variety of health professionals since each position interacts with patient families at different points in the journey and in different ways. Each title also has a different familiarity with the information and would provide unique perspectives on the level of detail in the program.

I took my personal laptop to the hospital and asked participants to view the program by clicking through the website and using the various navigation elements. I specifically

asked them to navigate for themselves so that they were interacting with the program and reading the text as a user. The program was viewed in Mozilla Firefox 3.6 at a resolution of 1280 by 800. Participants were then given a paper-copy of the survey.

Survey Results

The results of the six surveys were calculated, and the data was compiled into a bar graph created in Microsoft Excel 2004 (Table 4-1). The comments for the statements were also reviewed.

Survey Results

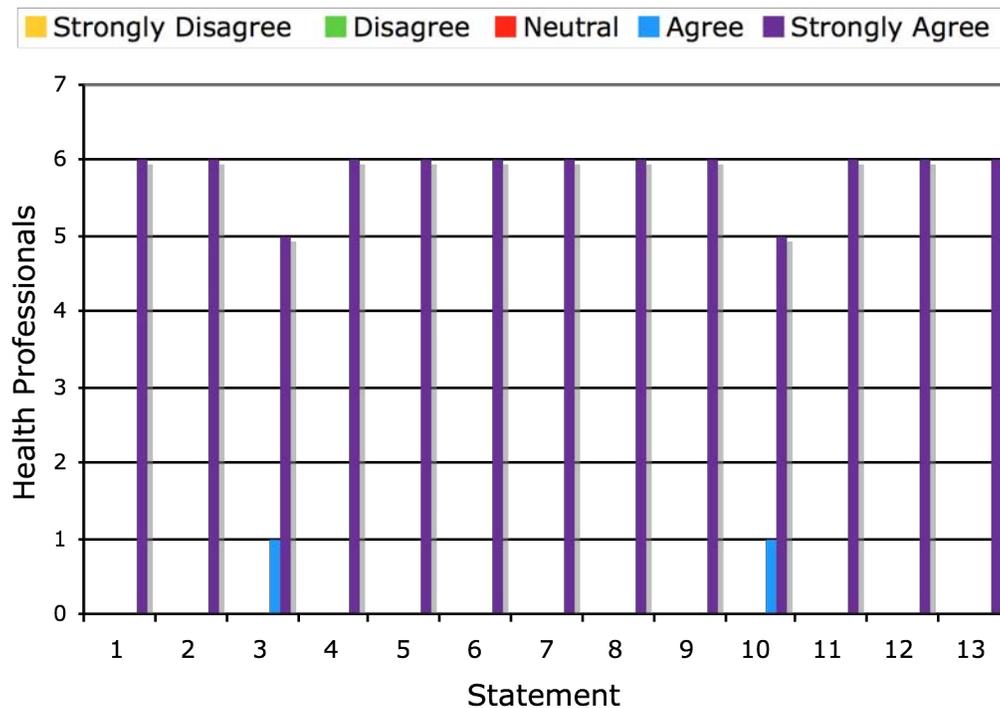


Table 4-1. Survey Results.

Statement 1: The information in the section, *Understanding Epilepsy*, is a good foundation for the information on surgery and is at an appropriate level for parent education.

Six health professionals strongly agreed. While this project was not intended to cover every applicable topic regarding epilepsy parent education, a basic overview of epilepsy was important to beginning a discussion about surgery. The positive responses

to this statement indicated that the information included is a valuable addition to the program. There were no additional comments made.

Statement 2: The website emphasizes the journey-like nature of epilepsy surgery and will help parents visualize what to expect for the entire journey.

Six health professionals strongly agreed. This statement was asked because the journey graphic was the framework for the entire program. It was intended not only as a navigation element for the program but also as an entire way of thinking and talking about the surgery. All six of the health professionals felt that the program successfully communicated the concept of the journey. One physician even commented that “presenting this as a journey is an inventive idea that will really help families feel part of the process.”

Statement 3: The color-coded journey is an effective parent education graphic.

Five health professionals strongly agreed and one agreed. Due to the large number of steps included in the journey and the many sub-steps within each step, I felt it was important to color-code each major section of the journey. The colors were intended as a way to make the overall journey more accessible and manageable. All of the health professionals agreed, indicating that the color-coded journey was a successful graphic. No additional comments were made.

Statement 4: The photographs aid in understanding the text.

Six health professionals strongly agreed. The photographs were a critical part of the program given the multitude of appointments and tests involved in the surgery journey. Families also meet so many different health professionals through the visits. Even though I worked to lower the literacy level of the text, it was still a lot of information and medical terms to read. In many ways, the photographs said more than I could ever communicate in writing. The positive responses to this statement indicated that the photographs were successful communication tools. The medical director of the CEC even commented that I “worked very hard to connect with families and get photos of all steps of the surgical process.”

Statement 5: The brain illustrations are clear and at an appropriate level for parent education.

Six health professionals strongly agreed. While photographs were very helpful for visualizing most of the steps, they were not appropriate for pairing with content about the surgery in the operating room. Photos of actual surgeries would have been too graphic and frightening. Simple illustrations depicting the line of incision and the grids and strips of electrodes were more appropriate for a program designed for parents. Basic brain illustrations were also needed as a trusted reference within the program. All six respondents strongly agreed that the illustrations were clear and appropriate. One health professional added the comment, “as well as for children.”

Statement 6: The success story is a valuable addition to the website.

Six health professionals strongly agreed. Parents love to talk with other families who have already been through the process, but one respondent felt that the success story video “is the next best thing.” The respondent also commented that the story “humanizes the process in real life situations, giving a family a chance to meet a child who has gone through the surgery.”

Statement 7: The frequently asked questions, glossary, and helpful links are trusted resources that I would recommend to patient families.

Six health professionals strongly agreed. The positive responses suggested that all of the health professionals would feel comfortable referring families to the program for extra information. No additional comments were made.

Statement 8: The printable PDFs are effective alternatives for families without computer or internet access.

Six health professionals strongly agreed. The PDFs were added to the program to reach families with limited resources. The printed versions would also be easy to integrate into the existing patient education system that is already set up at the CEC. One health professional wrote “this will be a huge advantage for us in patient education in clinic.”

Statement 9: The website navigation is clear and easy to use.

Six health professionals strongly agreed. Many of the internet resources on epilepsy and epilepsy surgery are not coherently organized or intuitive. The program

needed to be simple and to the point so as not to complicate an already complicated topic even more. The positive results indicated that the navigation was clear. One health professional wrote “very clean and clear website.”

Statement 10: The aesthetics of the website are pleasing and appropriate given the seriousness of the content.

Five health professionals strongly agreed and one agreed. This statement was included because I went through many revisions of the layout and color palette to ensure that the aesthetics did not make light of the content. While the patients are pediatric patients, I did not want to use graphics or colors palettes that were too childish for parents. Overall, the health professionals agreed that aesthetics were appropriate for parents. The respondent who agreed commented “(I) would make color block a more neutral pastel – light yellow / cheesecake.” However, I purposefully chose not to color any of the blocks of the navigation bar or other grey blocks so as not to introduce too many colors into the palette. I also felt that it was important for the colors to be reserved primarily for the color-coded steps in the journey. In viewing the program, another health professional verbally commented that the grey did not distract from everything else. This respondent also wrote “nice layout and font.”

Statement 11: The overall level of information is appropriate for patient families.

Six health professionals strongly agreed. One of the underlying goals of this project was to make information about epilepsy surgery easier for parents to understand. One of the parents who I talked to for pre-project evaluations said that she did not look at

the internet for information because she couldn't even understand all the terminology. Many of the other families also struggled with medical terms. As such, I was cognizant of the literacy level of the content when writing it, and I included a glossary when I could not avoid technical terms. I had also hoped that the overall tone and content of the program would be neither too pessimistic nor too light-hearted. Additionally, I wanted to find the balance between too much information and too little. The positive agreement to this statement confirmed that the level of information was successful. No additional comments were made.

Statement 12: The website will aid in communication between epilepsy health professionals and patient families when discussing the surgery process.

Six health professionals strongly agreed. This statement was intended to see if the website would help to bridge the broad gap between what the physicians and nurses say and what families might hear or interpret. All respondents agreed that the website was a useful communication tool. One health professional even commented that “many families are overwhelmed by the information and do not fully understand the process. They agree to surgery without comprehending fully what it means and without knowing how to ask questions.”

Statement 13: The website will be a useful parent education resource

Six health professionals strongly agreed. The overall goal of this project was to create a resource for parent education. The positive responses indicated that this goal was successfully met. No additional comments were made.

Additional Comments*Respondent 1*

“Very nice and well done project. Having an audio supplementation will be helpful for some people that like to listen rather than read.”

Respondent 2

“Kristen’s hard work and persistence (especially when dealing with busy physicians) has really paid off. The tool she has developed surpasses anything I have ever seen clinically available. I anticipate it will be widely used not just by our patients and families but by centers nationally as a teaching resource.”

Respondent 3

“In the future, adding a narrated audio track for each page and auto-advance feature will improve the program.”

I agree with this respondent and respondent one that an audio version would add even more to the program. It would better reach parents who are auditory learners, and it would only add to the success of the visual website. Audio tracks would be an important area for future research.

Respondent 4

“This was a great presentation, and I feel that it will help the patients have a clear understanding of the process.”

Respondent 5

“A well done website that will be a valuable resource for both patients, families, and even healthcare professionals.”

Respondent 6

“This can also help bridge gaps between techs and parents.”

CHAPTER FIVE

Conclusion

Project Summary

The purpose of this project was to create a valuable parent education resource on epilepsy surgery for the Comprehensive Epilepsy Center at Children's Medical Center Dallas.

This program will hopefully empower parents with information about the surgery process, open channels of communication between families and the Epilepsy Team, give them confidence in the skills and attentiveness of their child's caregivers, provide reassurance that past surgery patients are living healthy and full lives, and ultimately lessen the mystery and fear that surrounds brain surgery. However, the goal of this project was to provide an objective resource for parents, not to coerce parents into agreeing with surgery.

In order to fulfill this goal, I spent considerable time researching and visiting with families at the clinic. I conducted pre-project surveys in parent interviews that helped clarify some of the biggest concerns for parents. Content outlines, storyboards, a site map, and sketches were created and approved by committee members. The final project was created as an interactive website in Adobe Dreamweaver that included the following sections: *Understanding Epilepsy*, *About the Surgery*, *Brain Anatomy*, *Success Stories*, *Frequently Asked Questions*, *Glossary*, *Helpful Links*, and *For Printing*. Adobe Photoshop, Illustrator, InDesign, Premiere, Soundbooth, and Fireworks were all utilized in creating the assets for the final website.

While one of the objectives, reaching Spanish-speaking families, was not met, the program was designed so that a Spanish version can be added at a later date.

Post-project evaluations containing thirteen statements were administered to six health professionals at the CEC. Additional space was left at the end of the evaluation for overall comments. All six respondents agreed that the website is a valuable parent education resource for epilepsy surgery.

Successes

Perhaps the most successful part of this program was including a success story video. While additional videos would have been even more helpful, the mother we were able to videotape in English was very well spoken and addressed all of the major concerns and topics that parents want to know. Viewers empathize with her and can clearly see her son running and using his vision to play.

The PDFs were also successful in that they are an effective alternative to the website for families without computer or Internet access. Furthermore, they will be a useful clinical resource for nurses and physicians at the CEC to give to families as printed handouts. They easily fit into the already established pathways of parent education at the clinic. They will also be a valuable way for epilepsy health professionals to introduce the

concept of the surgery journey to families and to open communication with families about an emotionally difficult decision.

Additionally, the program was successful because the surgery journey graphic accounted for three types of surgeries, increasing its audience beyond just one type of surgery patient.

As indicated by the evaluations completed by six epilepsy health professionals, the goals and objectives of the project were met. All of the respondents strongly agreed that the program will be a useful parent education resource, and their additional comments indicated that they felt the website was a unique and powerful tool for their patients and themselves.

Areas for Further Development

The first area for further development would be to add the Spanish version to the website. The index page of the program is already set up with a link so that the Spanish-translation files can easily be added to the root folder and integrated into the website. However, before the version can be created, the content of the website pages and the PDFs must be translated into Spanish. While creating the English version, we were also able to videotape a Spanish-speaking family telling their story. Their success story would need to be edited in Spanish and added to the website.

Given the powerful impact of the single success story already on the English version of the website, the program would be an even greater resource if it contained more success stories for both language versions. Ideally, the stories would contain a variety of patient demographics and surgery types, including hemispherectomies, multiple subpial transections, and temporal lobe resection.

Further development could also include adding other surgeries, such as multiple subpial transections, to *Step 13* of the program so that it can be used as a resource for even more families.

As indicated by some of the additional comments on the evaluations, audio tracks would only add to the website. Audio in both languages would also reach parents who are auditory learners.

Areas for Further Research

Lastly, once the website is fully integrated into the website of the CEC and the PDFs are consistently utilized in clinic, it would be worthwhile to test and analyze patient families who use the program throughout their child's surgery journey. Similarly, research might be able to be conducted to see if families who come to the CEC have already seen the program online when researching epilepsy. This might indicate whether or not the program reached more than just the patient population of the CEC.

APPENDIX A
Epilepsy Surgery Timeline

Week	Contact	Procedures
0	Initial consultation with Epilepsy Specialist (Neurologist)	1. History 2. Physical/Neurological Examination 3. Review of Medical Records 4. Discussion of treatment options 5. Ordering additional tests (if needed)
2	Outpatient Testing (if needed)	1. EEG 2. MRI
4	Follow-up consultation with Epilepsy Specialist.	1. Review additional testing results, 2. Discussion of Epilepsy Surgery and surgical evaluation process
8	Inpatient evaluation in Epilepsy Monitoring Unit (EMU) - Typically 4-5 days inpatient stay	1. Video-EEG (to record seizures, antiepileptic medication may be reduced or stopped) 2. Neuropsychological testing 3. Ictal SPECT 4. PET scan
9	Epilepsy Conference	Discussion of case with Neurologist, Neurosurgeon, Neuropsychologist, Neuroradiologist. Decision made to recommend surgery or not
9	Phone call to family with results of Epilepsy Conference	1. Offer appointment with Neurosurgeon as next step
12	Appointment with Neurosurgeon	1. History 2. Physical/Neurological Examination 3. Discussion of surgical risks, benefits 4. Ordering additional tests (if needed)
14	Outpatient Testing	1. Visual Field Testing 2. functional MRI

18-19	Admission to Children's Medical Center for Grid placement and testing	<p>Day before admission: MRI scan with fiducials, meeting with anesthesiologist</p> <p>Day 1: Surgery to place grid, admission to ICU, EEG monitoring begins</p> <p>Day 2: Transfer from ICU to EMU, monitoring continues, antiepileptic medication may be reduced or stopped to provoke seizures.</p> <p>Day 3-6 continued monitoring in EMU, Evoked potential testing, Motor and language mapping tests done in EMU</p> <p>Day 7: Grid removed, surgery performed to remove area of brain causing seizures. Patient returns to ICU after surgery, antiepileptic medication returns to full doses</p> <p>Day 8: Transfer to Neurosurgery floor, therapy evaluation if needed.</p> <p>Day 10: Discharge home from hospital.</p>
20	Neurosurgery appointment	Post-op wound check
22	Neurology appointment	Epilepsy follow-up care begins
30	Neurology appointment	<ol style="list-style-type: none"> 1. Epilepsy follow-up care 2. If patient is on multiple medications one or more may be tapered, beginning at this visit
42	Neurology and Neurosurgery Appointments	<ol style="list-style-type: none"> 1. Epilepsy follow-up care 2. EEG 3. Continue at least one antiepileptic medication
66	Neurology and Neurosurgery Appointments	<ol style="list-style-type: none"> 1. Epilepsy follow-up care 2. Neuropsychological testing 3. Continue at least one antiepileptic medication
118	Neurology and Neurosurgery Appointments	<ol style="list-style-type: none"> 1. Epilepsy follow-up care 2. If patient has been seizure-free

		since surgery consider tapering off antiepileptic medication.
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APPENDIX B
Pre-Project Surveys

RESPONSE 1	95
RESPONSE 2	96
RESPONSE 3	97
RESPONSE 4	98
RESPONSE 5	99
RESPONSE 6	100
RESPONSE 7	101
RESPONSE 8	102
RESPONSE 9.....	103
RESPONSE 10	104
RESPONSE 11	105
RESPONSE 12	106
RESPONSE 13	107
RESPONSE 14	108
RESPONSE 15.....	109
RESPONSE 16	110

Today's Date 6/4/10

• 9 year old Spanish-speaking female
(talked to Mom with help of
interpreter in clinic)

• Before surgery, had learning difficulties.
Now, is only in 1/2 special education class,
1/2 regular classes.
Happily passed her TAKS test.

Pre-Project Survey for Parents of Epilepsy Surgery Patients

1. What surgery did your child have?
(doctor's records) • no grid because MRI clearly showed seizure area as Right Temporal cortical dysplasia
2. When did your child have his or her epilepsy surgery?
(doctor's records) • Resection on 5/17/06
• prior to surgery, had 2-4 seizures/month
• current post-op seizure rate of 0 with no meds
3. Was there anything you wish you had known before your child had his or her epilepsy surgery?
(Mom) remembers hospital stay but not much else.
4. What scared you the most about the surgery?
(Mom) was scared the most about the cutting and anesthesia because didn't know if she'd wake up. But glad she had the surgery.
(Mom got emotional talking about it and started crying)
5. What medical words or ideas were the most difficult for you to understand?
(didn't ask) Daughter happy she had the surgery too.
6. Do you have access to the internet? (didn't ask)
7. Did you use the computer or internet to find more information about the epilepsy surgery process?
NO, got all the information from the doctor.
Also, didn't have to explain the surgery to anyone else or other family members.
8. Do you think images of the surgery would have been helpful in understanding the surgical process? (didn't ask)
9. If yes, which would you have preferred: photographs, drawings, or both? N.A.
10. Dr. Arnold asked the Mom to show us where her daughter's scar was, because it was so well hidden in her hair that Dr. Arnold couldn't find it.

Today's Date 6/4/10

Pre-Project Survey for Parents of Epilepsy Surgery Patients

• 5 year old male, English-speaking, at appointment with both mom and dad

• observations in clinic exam room: boy very active (walking and jumping), talking a lot, spelling his name, some pronunciation with his right hand and foot, wanted to draw when he saw his mom and me with paper and pens, Mom talked a lot about the therapies he's done and does to develop daily activities and skills

70% of left side of his brain was already dead/missing from stroke

1. What surgery did your child have?
(doctor's records) • Left Hemispherectomy
• stroke in-utero, had developmental difficulties and 20 seizures a day pre-surgery
2. When did your child have his or her epilepsy surgery?
(doctor's records) about 3 years ago at age 2
3. Was there anything you wish you had known before your child had his or her epilepsy surgery?
• That our son qualifies for Medicaid because he's medically dependent even though we don't because of our finances. We found out from my (mom) sister who has a special needs child. No one had told us that he might qualify.
• can't remember if they were told he might still have feeding tube long after surgery.
4. What scared you the most about the surgery? but he still does.
(didn't ask directly) ~~scared~~ • Mom and Dad talked about how he had to have a 2nd surgery to put in a shunt b/c of swelling from 1st surgery. recovery from that almost worse ~~because~~ because he was already in ICU from surgery #1.
5. What medical words or ideas were the most difficult for you to understand?
• what parts of his affected brain control what (motion, language) ... He is very Right-brained and musical.
• Different types of seizures and objective information on infantile seizures
• what does frontal lobe mean

wanted to know...

6. Do you have access to the internet?
yes

Now we "the pediatric stroke network" almost before calling doctor.

7. Did you use the computer or internet to find more information about the epilepsy surgery process? yes. searched internet for most information in common (layman) terms, but we were confident that it was the right thing to do. But at some point we were told not to look at the internet because the resources might not be trustworthy. We liked seeing real stories (case studies).
8. Do you think images of the surgery would have been helpful in understanding the surgical process? yes. we didn't have any drawings to explain it before. But on day of surgery → Neurosurgeon drew a very basic head and piece of skull to be removed (see attached) and Mom's own drawing) and asked, "Do you get this?" we understood, but it wasn't enough and we felt very undercared to on a very tough morning. The timing was wrong.
9. If yes, which would you have preferred: photographs, drawings, or both?

Maybe "cartoonish" drawings. Maybe not actual surgery pictures.

He talked about the risks and then we signed the consent-forms.

Today's Date 8/3/10

- Spanish-speaking. used hospital interpreter
- teenage, Hispanic female with some sort of mental-developmental delay
- had partial seizures → surgery = grid ⊕
right frontal lobe resection

Pre-Project Survey for Parents of Epilepsy Surgery Patients
(Dad)

1. What surgery did your child have?

(using motions from back of head to front)

Don't know what it's called, but they opened up her head... from here to here.

2. When did your child have his or her epilepsy surgery?

1 or 2 years ago

3. Was there anything you wish you had known before your child had his or her epilepsy surgery?

NO, they explained everything to my wife, more or less, very well.

4. What scared you the most about the surgery?

Worried that she wouldn't be the same as before and that she might have any side-effects... but everything was good

5. What medical words or ideas were the most difficult for you to understand?

The doctor explained everything.

6. Do you have access to the internet? (didn't ask)

7. Did you use the computer or internet to find more information about the epilepsy surgery process?

We didn't work at the computer... just used doctors.

8. Do you think images of the surgery would have been helpful in understanding the surgical process?

Didn't need photos. With what they were saying, it was ok. They took us to a room before surgery where they showed us her brain and what they were going to do.

9. If yes, which would you have preferred: photographs, drawings, or both?

(N.A.)

10. Asked daughter if she was worried about her hair and the surgery...
she said she wasn't worried.

* patient testimonial (Mam willing)

Today's Date 8/9/10

Pre-Project Survey for Parents of Epilepsy Surgery Patients

• age 3, male, English-speaking Mam

• originally had 30-40 sz/day. Right before surgery had 3-7/day. Now only has 3 X month for about 30 sec-1 minute.

• still takes 2 anti-seizure meds

Mam said she hadn't realized how appointment intensive it was and stressful on her job
 • kids with sleep apnea can have worse seizures because they don't sleep (Mam concerned about it)
 • sun had in speech, vision, etc, case worker, music therapist → he was delayed development (still in single-word phrase even @ age 3)

1. What surgery did your child have?

• (doctor's records) → grid + occipital lobe resection on left

• Mam said → part of occipital lobe taken out for dysplasia; knew they did the

2. When did your child have his or her epilepsy surgery? "placemasters" as part of it

March 2009

3. Was there anything you wish you had known before your child had his or her epilepsy surgery?

• wished she had more people to talk to, but got to talk to some other parents and that helped

4. What scared you the most about the surgery? (Doctor said) → the Mam was very open to the risks!

• during the appointment with the neurosurgeon... before even said her name, the surgeon said "Austin might need another surgery"

• sun actually had infection after surgery so he had to be back in the hospital.

5. What medical words or ideas were the most difficult for you to understand?

• all of them, but Dr. Arnold always explained things in layman's terms

• But (my observation)... very knowledgeable had → used "cortical" and "occipital" ... Mam works as a special-ed teacher/helper

6. Do you have access to the internet?

yes

7. Did you use the computer or internet to find more information about the epilepsy surgery process?

• yes, but maybe it wasn't good because some things were good and some were bad

• she is a member of the Epilepsy Foundation and even went to some of their meetings and the Children's (CMC) support groups, but there weren't enough other parents to talk to

8. Do you think images of the surgery would have been helpful in understanding the surgical process?

yes → would have been helpful to understand all of it (what brain looks like, what they were going to do, etc)

9. If yes, which would you have preferred: photographs, drawings, or both?

If I could have stomached it, would have wanted to see real photos

Mam: "It's sad comparing him to other kids his age, but then I look back to how far he's come and it's amazing." "It was a tough decision, but I'm glad we did it."

* possible parent testimonial

• 5 year old female that had seizures
1/week pre-surgery ... now
seizure-free (immediate
results after surgery)
• English-speaking

Today's Date 8/9/10

Pre-Project Survey for Parents of Epilepsy Surgery Patients

• Mom ok with the scull in her hair because it meant that her daughter wouldn't have seizures → and they explained about the hair-scarc and pulling some into a ponytail to the side
 • Looking back, Mum has no regrets and even says that maybe they shouldn't have waited a year to make the decision, wishes she'd done it earlier so that daughter would have had that year without seizures.

1. What surgery did your child have?
 • (doctor's records) → Temporal lobe resection
 • Mom's account → "question-mark" surgery where they took that piece off (gestures to left-mid skull) and "scary"
2. When did your child have his or her epilepsy surgery?
 end of January 2008
3. Was there anything you wish you had known before your child had his or her epilepsy surgery?
 not necessarily because the doctors gave all the information and answered all their questions
4. What scared you the most about the surgery? (or would anything have made it easier?)
 → not necessarily just because it's your kid
 • Read success stories on the internet → that helped, but still wanted to change mind at the last minute
5. What medical words or ideas were the most difficult for you to understand?
 Don't understand all technical terms, but Dr. Arnold explained everything while the previous doctor in Little Rock did not
 → Mom said "no"
6. Do you have access to the internet?
 yes
7. Did you use the computer or internet to find more information about the epilepsy surgery process?
 yes, but not necessarily more helpful because Dr. Arnold was so thorough yet gentle
8. Do you think images of the surgery would have been helpful in understanding the surgical process?
~~yes~~
 ↓
 no
9. If yes, which would you have preferred: photographs, drawings, or both?
 even drawings were too much ... didn't want to see any kind at all, but her husband-at-the-time did
10. Hardest part as well → trying to explain to other family members what's going on and why her daughter needed the surgery.

• Her advice to other parents → Doctors have medical skill in surgery. Surgery is taking a chance, but so are seizures.

• Before → doctor said he "lived in a fog," slow talker
 • deep belief in God helped
 • now → more talkative, aggressive, acts like a teenage boy (unwilling w/ friends, noticing girls)

Today's Date 8/23/10

• 14 year old, English-speaking male
 • stroke when born in right side from lack of O₂ to middle part → only 1/2 of r. side was left
 • still has sparing spells, but doctor not sure that they're seizures because they're so short
 • still stutters, but doctor said not unusual after a stroke

Mom's advice → "went through surgery to give him a chance to grow up" ... "now he's different, now he's going to grow up"
 • he "sailed through it like nobody's business" → surgery and ICU stay shorter than they'd been told
 • no "deep seizures" since surgery; gained 50 lbs in 2 years since surgery (was almost sickly skinny before)
 • OT, PT school, peripheral vision issues, now in special ed in 8th grade at school instead of "learning life skills"

Mum Pre-Project Survey for Parents of Epilepsy Surgery Patients
 Says he went "crazy" after surgery but is better now

1. What surgery did your child have?
 • Doctor's notes → Right hemispherectomy (L arm/hand/leg weakness)
 • Mum → disconnecting but no removal because they told her that if they removed it, other side would move
2. When did your child have his or her epilepsy surgery?
 2 years ago
3. Was there anything you wish you had known before your child had his or her epilepsy surgery?
 • wished that I could have talked to others that had been through it to know what to expect
4. What scared you the most about the surgery?
 • that it was brain surgery
 • they put so many IV's, catheters, tubes, and screws in his head
 • worried that they'd cut something and he might not be the same after or that he'd need a transfusion
5. What medical words or ideas were the most difficult for you to understand?
 none because doctor really spoke in "English"
6. Do you have access to the internet? (didn't ask)
7. Did you use the computer or internet to find more information about the epilepsy surgery process? yes
 • cancelled the surgery the 1st time because had watched a show on the Discovery channel on Epilepsy surgery resection with real video footage of skull, screws, saw → but Indian boy in it didn't have any seizures often, so that helped decision
8. Do you think images of the surgery would have been helpful in understanding the surgical process?
 so that helped decision
9. If yes, which would you have preferred: photographs, drawings, or both?
 • had a "picture" (scan) that doctor had painted out of his brain to show part to be removed and to take home and tell others

• now → areas where he feels like he's going to have a seizure
 • started reading now
 Today's Date 8/23/10
 Pre-Project Survey for Parents of Epilepsy Surgery Patients
 • 17 year old Hispanic, speaks a little English
 • used interpreter to talk to both Mom and son
 • neuropsych post-op similar to pre-op, but quality of life improved w/ less seizures
 • pre-op → 5-6. 2X/month w/ loss of consciousness

1. What surgery did your child have?
 • Doctor's notes → R. frontal lobectomy w/ grid from meningitis
 → also has mesial temporal sclerosis and might need another surgery because of 2nd seizure focus in non-dominant temporal lobe → doctor going to try controlling w/ meds for now
2. When did your child have his or her epilepsy surgery?
 March 2006
3. Was there anything you wish you had known before your child had his or her epilepsy surgery?
 no
- Advice from Mom: go to programs (I did) and look for help, especially because the surgery is so helpful
 • I didn't need time to decide, but I "asked God that it all be good"
4. What scared you the most about the surgery?
 Mom - the anesthesia; Even though I work in a hospital, it's not the same when it's your child.
 son - operation itself; shaving of hair and stitches left there
5. What medical words or ideas were the most difficult for you to understand?
 • in El Salvador, nobody told her about his seizures for a long time and he used to go crying to her for help
 • wishes she'd known about surgery long before they did → doc there recommended an LA. surgeon who cost \$100,000 and she was sad
6. Do you have access to the internet?
 don't have 1 at home, but he has 1 at school
7. Did you use the computer or internet to find more information about the epilepsy surgery process?
 no
8. Do you think images of the surgery would have been helpful in understanding the surgical process?
 son - pictures helped a little
9. If yes, which would you have preferred: photographs, drawings, or both?
 Mom - I used to work as a nurse in a surgery place, so was used to seeing all that ... but someone who ~~wasn't~~ doesn't know about it ... it would help to see images

Son → it was mom's decision to move
 Mum → but he wanted it, because he was afraid when he had seizures, and it motivated me

Today's Date 8/23/10

• for surgery → doctor did not shave her head @ all

Pre-Project Survey for Parents of Epilepsy Surgery Patients

- 18 yr old female, Hispanic
- Mom speaks English as a 2nd language (ESL)
- had ~~seizures~~ seizures for 13 years
- also had a Vagal Nerve stimulator surgery @ another hospital after 1st surgery didn't work
- needs another surgery for another seizure focus, but mom not ready to commit

1. What surgery did your child have? (doctor's notes → Left frontal dysplasia resection @ another hospital; doctor thinks that she had a grid surgery too, but Mom denies it)
2. When did your child have his or her epilepsy surgery?
at age 8
3. Was there anything you wish you had known before your child had his or her epilepsy surgery?
• about 1st surgery, no, because had been given information about staying in the hospital, etc
• about the Vagal Nerve Stimulator surgery → yes, wished I'd known that it can't be removed even because of the risk to surgery in her neck → might not have agreed to surgery because now daughter wants to do sports and can't
4. What scared you the most about the surgery?
• 1st surgery → I was afraid that something would go wrong and I'd lose her
5. What medical words or ideas were the most difficult for you to understand?
• only understood about 25%, but that 25% was because of pictures showing the brain and where they would cut
• otherwise it was hard to understand because of ESL
6. Do you have access to the internet?
yes, now
7. Did you use the computer or internet to find more information about the epilepsy surgery process?
no, but now I might to research new therapies
8. Do you think images of the surgery would have been helpful in understanding the surgical process?
see #5
9. If yes, which would you have preferred: photographs, drawings, or both?
wanted to see more of what surgery would be like and the brain

Daughter's words → "We are the same as other kids and shouldn't be treated differently. We have a hearing and strength and can do whatever we want, even despite what the doctor says."

Advice to other parents

↳ "Even though I was afraid, I knew she needed it. I knew she would have less or none (seizures). It gave me strength."

Today's Date 8/23/10

- 8 year old, English-speaking, male
- Right lower arm and lower leg in a brace, some developmental delays
- born w/ brain abnormality, febrile seizures as a baby, turned into Regular sz. @ age 5. Mom says they were unusual case of "24 hours a day" (+) a 4-hour status epilepticus

Pre-Project Survey for Parents of Epilepsy Surgery Patients

1. What surgery did your child have? Doctor's words → Left hemispherectomy

Mom says → Right-side hemispherectomy

Grandma says → "no, left... opposite side"... Mom and grandma argued about it in front of me

"talk to other parents" (this Mum too overwhelmed to do it)

2. When did your child have his or her epilepsy surgery?

May 2008

3. Was there anything you wish you had known before your child had his or her epilepsy surgery? (or advice) • "Younger they are, the better"

• Really scary, but you have to weigh what's best...

like living with seizures. He only had 4-word sentences before... now look at him (talking constantly). He's totally different now.

other advice:

"listen to your doctors, and ask your surgeon lots of questions"

4. What scared you the most about the surgery?

• Something happening and him not being here... and the brain seizures themselves

• but the doctor said that without surgery, it would become worse over time

• I didn't hesitate, but I cried

5. What medical words or ideas were the most difficult for you to understand?

both the neurosurgeon, Dr. Price, and Dr. Said explained it all

6. Do you have access to the internet?

yes

7. Did you use the computer or internet to find more information about the epilepsy surgery process?

no. All the visits explained it.

8. Do you think images of the surgery would have been helpful in understanding the surgical process?

yes (Mom) → but Dr. Price's model of where surgery would be helped

Grandma → doesn't think more info would have helped

because of the many doubts → like walking at all the warnings on medication labels

9. If yes, which would you have preferred: photographs, drawings, or both?

would be too scary. It was shocking to see him afterwards with all of the wires.

Mom would have preferred

• After surgery, Dr. Price warned that she thought he might have lost speech during surgery → but we woke up talking, and he's taken seizure free for 2 years

• lost peripheral vision in R eye, but they were warned about that before; ADHD was gotten worse

• Mum glad she did it, but doesn't think she'd want to do another surgery if they offered it

• patient = 19 year old Hispanic female

Today's Date 9/27/10

Pre-Project Survey for Parents of Epilepsy Surgery Patients

(Mom talking)

1. What surgery did your child have?

• in the front, right

• had 1 surgery = R. frontal resection from old seizure (doc's notes)

• Mom having to think about a 2nd surgery because seizures have come back

2. When did your child have his or her epilepsy surgery?

November 2007

3. Was there anything you wish you had known before your child had his or her epilepsy surgery?

that I would have known that with this surgery there would be no more seizures

4. What scared you the most about the surgery?

Surgery itself because she had never had one

5. What medical words or ideas were the most difficult for you to understand?

(did not ask)

6. Do you have access to the internet?

no

7. Did you use the computer or internet to find more information about the epilepsy surgery process?

no

8. Do you think images of the surgery would have been helpful in understanding the surgical process?

yes, they showed me pictures, but I was still scared

9. If yes, which would you have preferred: photographs, drawings, or both?

(did not ask)

Advice: try it, it's worth it just to try

Today's Date 9/27/10

- 8 year old female, English-speaking
- had seizures since birth

Pre-Project Survey for Parents of Epilepsy Surgery Patients

Man and
(here w/ Grandma)

Doc →
• type of surgery
not
mentioned in
Pwys.com

1. What surgery did your child have?

- 1st - ~~resectomy~~ 4 years ago here
- 2nd - a year ago in Phoenix

Doc's notes → hypothalamic
tumor causing
most seizures - in the
middle, so difficult
to cut out

2. When did your child have his or her epilepsy surgery?

3. Was there anything you wish you had known before your child had his or her epilepsy surgery?

- it was a no-brainer → we would do what the hospital said
- "no, the hospital informed us really well" ... at every step.
- showed us a brain model

4. What scared you the most about the surgery?

"outcomes"

5. What medical words or ideas were the most difficult for you to understand?

6. Do you have access to the internet?

yes - computer @ home

7. Did you use the computer or internet to find more information about the epilepsy surgery process?

- no, because the hospital told us everything
- "the terminology online for a layman is kind of difficult"
↳ "but if normal person could read, we would use it"

8. Do you think images of the surgery would have been helpful in understanding the surgical process?

- Dr. Arnold showed us pics to keep us informed
+ brain model

9. If yes, which would you have preferred: photographs, drawings, or both?

(did not care)

Advice: "put faith in doctors and have to believe what the doctors say"
"believe in your doctors and of course God"
"if you have any questions, ask them"

"praised that I switched to them"
 "they did a great job"

↑ Today's Date 9/29/10

switched from
 doctor in
 Newport, CA

Pre-Project Survey for Parents of Epilepsy Surgery Patients

- English-speaking
- very educated dad who kept an extensive journal

- good @ school but trouble focusing → same as before surgery (probably)
- twin in utero → stroke, twin didn't survive (Kandergaten = 1st seizure)

1. What surgery did your child have?
 - 2-part surgery → grid + cutting
 - R side → removed scar ⊕ 2-3 slits
2. When did your child have his or her epilepsy surgery?

February 2009 - at age 9

"no regrets" but don't think I'd do another one

3. Was there anything you wish you had known before your child had his or her epilepsy surgery?
 - already knew surgery was an option
 - no, they did a good job prepping us - wouldn't have changed anything

but • shocked about swelling on R. side - like "elephant leg" → thought it was going to be permanent

4. What scared you the most about the surgery?

5. What medical words or ideas were the most difficult for you to understand?
 - just some of the big medical words → but they explained what they were doing.
 - "map and grid" w/ neurotransmitters

6. Do you have access to the internet?
 - (didn't use)

7. Did you use the computer or internet to find more information about the epilepsy surgery process?
 - went
 - all on what they told him

8. Do you think images of the surgery would have been helpful in understanding the surgical process?
 - not necessarily, because they showed me the map and the grid → called it mapping and I understood it

9. If yes, which would you have preferred: photographs, drawings, or both?

post-surgery → did well for 6 months, but seizures coming back
 ↳ but these kind better than before
 • when we met w/ neuro-psychologist → didn't agree w/ results because he's "not dumb"

Advice: • have something set up for counseling a child → like psychologist to help child deal w/ post-surgery issues → like kids at school making fun of scar
 • keep child involved and make them feel as normal as possible

Advice: "come to children's" → used to have another Neurologist, but it wasn't the same
 → they listened and she tell everybody come to children's because they have good doctors

Today's Date 9/27/10

• 13 year old Spanish speaking girl here w/ Mom
 ↓
 • no sz. for 4 months and only some night aften
 ↓
 nursing background

Pre-Project Survey for Parents of Epilepsy Surgery Patients

(2 surgeries - grand + resection)

1. What surgery did your child have?
 Removed 25% of brain → the right
2. When did your child have his or her epilepsy surgery?
 June 2009
3. Was there anything you wish you had known before your child had his or her epilepsy surgery?
 • no, they explained the surgery well
 • Mum has a nursing blegd, but for a person who doesn't, it'd be hard
4. What scared you the most about the surgery?
 • when she was 5 or 6, something had been mentioned about surgery (removal), but that didn't sound good
5. What medical words or ideas were the most difficult for you to understand?
 (didn't ask)
6. Do you have access to the internet?
 yes
7. Did you use the computer or internet to find more information about the epilepsy surgery process?
 yes, for epilepsy - but not for surgery
8. Do you think images of the surgery would have been helpful in understanding the surgical process?
 brain model helped, but no real pictures shown
9. If yes, which would you have preferred: photographs, drawings, or both?
 (didn't ask)

• really helped when she went to Neurosurgery clinic that there was another Hispanic Mom w/ daughter that had surgery 1 year ago - and girl was doing well

Today's Date 9/27/10

- 2 year old female
- now → she's developing normally, walking etc
- "for the best"

Pre-Project Survey for Parents of Epilepsy Surgery Patients

(Mom of appt)

1. What surgery did your child have?

hemispherectomy on left side (couldn't move right leg before)

2. When did your child have his or her epilepsy surgery?

↳ Mom couldn't pronounce

→ analogy she remembers
= lightbulbs with wires being cut

MARCH 29, 2010

3. Was there anything you wish you had known before your child had his or her epilepsy surgery?

- thought she was going to be bald and that I'd have to buy a wig for her. → surprised that they didn't have to shave all of her hair
- surprised that healing process was so quick

4. What scared you the most about the surgery?

and how small the cut was

5. What medical words or ideas were the most difficult for you to understand?

all of them. I can't even pronounce what they called it.

6. Do you have access to the internet?

no - no computer at home

7. Did you use the computer or internet to find more information about the epilepsy surgery process?

no

8. Do you think images of the surgery would have been helpful in understanding the surgical process?

no, they gave us some paperwork, and it was enough

9. If yes, which would you have preferred: photographs, drawings, or both?

pictures helped - and diagram of brain w/ language/understanding areas

Advice: "If the doctor says she needs it, get it now, so they don't have problems later."

Today's Date 10/20/10 • currently going through video-EEG and pre-surgery evaluation
• son (5 years old?) → went to surgery early Nov. 2010

Pre-Project Survey for Parents of Epilepsy Surgery Patients
(Mum)

1. What surgery did your child have?

R. side hemispherectomy candidate

2. When did your child have his or her epilepsy surgery?

went to surgery early Nov 2010

3. Was there anything you wish you had known before your child had his or her epilepsy surgery?

N/A

4. What scared you the most about the surgery?

- that he won't be able to use his left side again
- cognitive skills
- personality changes

5. What medical words or ideas were the most difficult for you to understand?

(didn't ask)

- dummy pre-op appt → incorrectly stated that hemi = "disconnecting right side of brain from left side"

6. Do you have access to the internet?

yes

7. Did you use the computer or internet to find more information about the epilepsy surgery process?

yes

8. Do you think images of the surgery would have been helpful in understanding the surgical process?

yes - pictures

9. If yes, which would you have preferred: no to photographs, drawings, or both?

• so, drawings

↳ Mum said it was "stupid" to see real ones when she looked them up

Advice: "know your options"

"learn how to be an advocate for your child"

• seizures since 6 months old
 → stroke in uterus
~~stroke~~ • Mum and son both have Factor V Leiden clotting disorder

Today's Date 10/20/10

• currently in EMU for grid - testing
1-day after surgery #1

Pre-Project Survey for Parents of Epilepsy Surgery Patients

• seizure = left side
starts, then
whole left
side stiffens

1. What surgery did your child have?

Right Frontal grid → was supposed to have resection, but grid indicated that multiple surgical transections

2. When did your child have his or her epilepsy surgery?

• end of Oct / early Nov 2010 (2-parts)

would be better

3. Was there anything you wish you had known before your child had his or her epilepsy surgery?

no questions that they didn't tell me

4. What scared you the most about the surgery?

nothing

5. What medical words or ideas were the most difficult for you to understand?

(didn't ask)

6. Do you have access to the internet?

yes

7. Did you use the computer or internet to find more information about the epilepsy surgery process?

yes, googled different things written down during process

8. Do you think images of the surgery would have been helpful in understanding the surgical process?

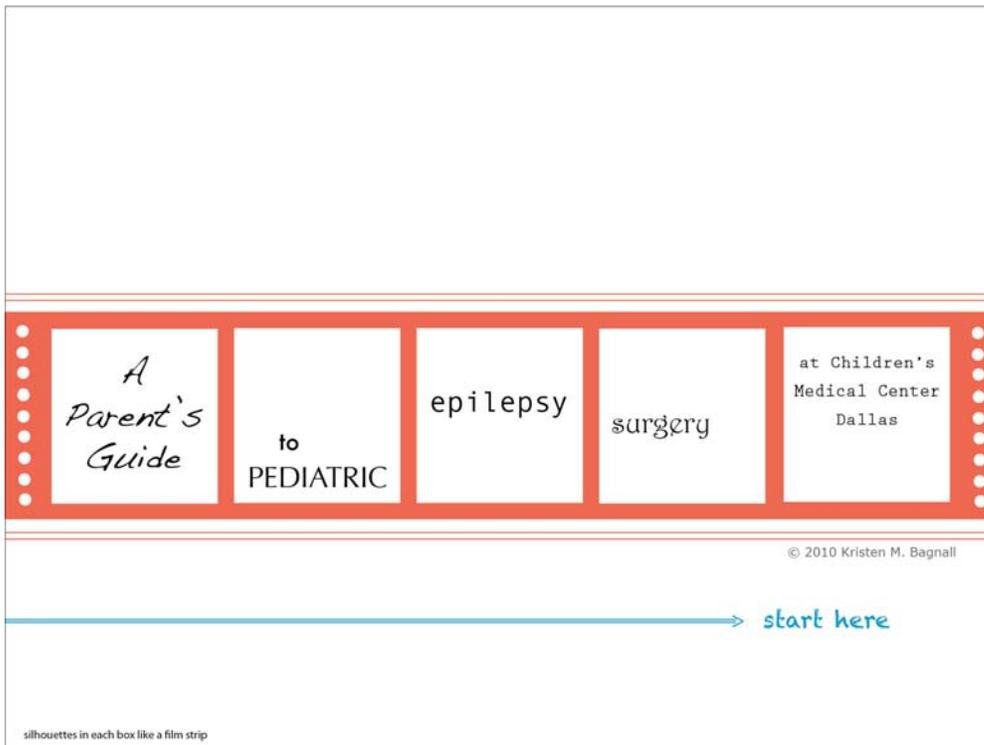
looked at actual spot on scans and pics of the brain

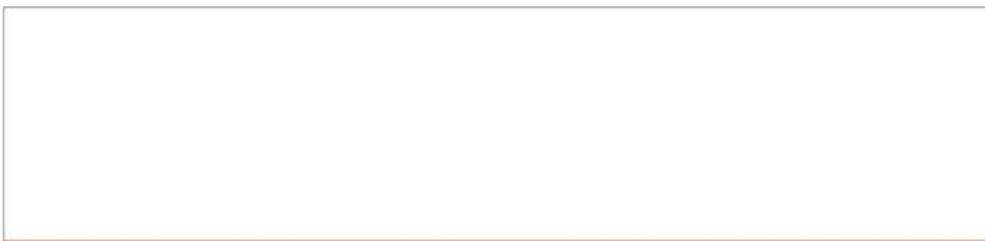
9. If yes, which would you have preferred: photographs, drawings, or both?

(didn't ask)

Advice: = pray about it because need guide the doctor's hands
• counseling would help

APPENDIX C Storyboards





This guide is intended for parents and families of children considering pediatric epilepsy surgery at the Comprehensive Epilepsy Center of Children's Medical Center Dallas.

We know that the decisions involved in epilepsy surgery are not easy ones for you to make, but we hope that this guide will help make the journey a little easier.

We also want you to know that learning about epilepsy surgery as a treatment option does not mean that you have committed your child to surgery.

Whether or not your child does progress all the way to surgery, we want you to be as informed as possible.

Our team of highly qualified doctors and nurses is here to support you throughout this journey and to make sure that your child has the best care possible. We welcome your questions at every point along the way.

[→ continue](#)



<p>Understanding Epilepsy</p>	<p>Understanding Epilepsy Surgery</p>
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[\[please choose a topic \]](#)

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Understanding Epilepsy Surgery

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Brain Anatomy

L hemisphere
R hemisphere
whole
sagittal cut? to see deep temporal structures

< >

Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments						
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	

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Success stories

Patient 1 (Hemispherectomy) . . . full
Patient 2 (Occipital lobe resection) . . .
. . . selected quotes from as many others as possible

< >

Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments						
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	

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Frequently Asked Questions

All questions about the Epilepsy Surgery Journey

- Questions about Steps 1-4 (Testing)
- Questions about Steps 5-9 (Decisions)
- Questions about Steps 10-11 (Possible Testing)
- Questions about Step 12 (Final Decision).
- Questions about Steps 13-14 (Surgery)
- Questions about Steps 15-20 (Follow-Up Appointments)

Testing	Decisions	Possible Testing	Final Decision	Surgery	Follow-Up Appointments
1 2 3 4	5 6 7 8 9	10 11	12	13 14	15 16 17 18 19 20

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Frequently Asked Questions

about all steps

- What if we choose to wait several years before saying yes to surgery?
- What are the risks of surgery?
- How much of a child's brain is removed during surgery?
- Will my child's personality change after surgery?
- Realistically, what kind of results should I expect from the surgery?
- My child is just a baby. How will he eat if he's in the hospital for a week during surgery?
- What makes a child a good surgery candidate?
- Will my child need therapy after surgery?
- How experienced are your surgeons?
- Why does my child still have to take medicines after surgery?
- Why are some tests inpatient stays and others are outpatient stays?
- Does surgery ever make a child's seizures worse?
- Does insurance cover pediatric epilepsy surgery?
- Do you have to shave my child's head for the surgery?
- What will the scar look like?
- Is this a day surgery?
- How long does the surgery take?
- If the surgery goes well, how fast will my child recover?
- How old are most of your epilepsy surgery patients?
- If surgery is not done and medicines haven't worked, what other treatments options are available?
- Will my child's seizures stop immediately after surgery?
- Why are there so many follow-up appointments after surgery?
- Will my child need blood during surgery?
- Will my child be awake during the surgery? If so, will it hurt?
- Why does my child need to see a neuropsychologist?

Testing	Decisions	Possible Testing	Final Decision	Surgery	Follow-Up Appointments
1 2 3 4	5 6 7 8 9	10 11	12	13 14	15 16 17 18 19 20

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Glossary & Definitions

Antiepilepsy medications	Corpus callosum	Evoked potential testing	ICU	Occipital lobe	Subdural
Association cortex	Cortex (and cortical)	Non-epileptic seizure	Idiopathic	Outpatient testing	Subdural electrodes
Automatism	Craniotomy	fMRI	Inpatient testing	Parietal lobe	Temporal lobe
Benign	Dysplasia	Focal seizure	Interictal	Partial seizures	Tumor
Brain mapping	EEG	Focal resection	Intractable epilepsy	Post-ictal	Vagus nerve stimulator
Breakthrough seizure	Electrodes	Frontal lobe	Ketogenic diet	PET scan	Video-EEG
Cells	EMU	Generalized seizure	Lesionectomy	Refractory epilepsy	Visual field testing
Cerebrum	Encephalitis	Grand-mal seizure	Lobectomy	Seizures	Wada test
Cerebral Hemispheres	Epilepsy	Grid mapping	Lobes of the brain	Skull	
Cerebrospinal fluid	Epilepsy Team Conference	Grids and strips	Meningitis	Spike and wave pattern	
Consciousness	Epileptic seizure	Hemispherectomy	Motor area	Status epilepticus	
Convulsion	Epilepsy Surgery Journey	Ictal	MRI	Stroke (gliosis)	
		Ictal-SPECT	Neuropsychological testing		

Testing	Decisions	Possible Testing	Final Decision	Surgery	Follow-Up Appointments
1 2 3 4	5 6 7 8 9	10 11	12	13 14	15 16 17 18 19 20

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Helpful Links

American Epilepsy Society . . . www.aesnet.org
 Epilepsy Foundation . . . www.epilepsyfoundation.org
 Epilepsy.com . . . www.epilepsy.com
 KidsHealth . . . <http://kidshealth.org>
 MedLine Plus . . . <http://medlineplus.gov>
 National Institutes of Health . . . www.nih.gov
 WebMD . . . www.webmd.com

Testing	Decisions	Possible Testing	Final Decision	Surgery	Follow-Up Appointments
1 2 3 4	5 6 7 8 9	10 11	12	13 14	15 16 17 18 19 20

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For Printing

entire guide as a pdf

brain illustrations (L hemi, R hemi, whole, sagittal cut?)

timeline / journey . . . both condensed and full?

< >

Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments					
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

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Understanding Epilepsy
What are Seizures?

Seizures are abnormal surges of electricity in the brain.

However, to understand seizures (and epilepsy), it's important to understand some basic information about the normal brain.

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Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments					
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

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Understanding Epilepsy What are Seizures?

The brain is like the body's master computer.

Brain cells talk to each other, but they also talk to other parts of the body.

All of this "talking" is done through electrical signals that are sent every second so that we can breathe, eat, speak, walk, run, and interact with the world around us.

i of computer-like brain in head sending **normal** signals "talking" to rest of body

Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments					
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

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Understanding Epilepsy What are Seizures?

When a part of the brain is damaged (injured) or doesn't form properly (correctly), the brain may send out abnormal surges of electricity (seizures) that cause parts of the body to move or act in an unusual way.

You could say that seizures are the wrong kind of signal in the brain.

(something about developmental delays?).

i of computer-like brain in head sending **abnormal** signals "talking" to rest of body

Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments					
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

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Understanding Epilepsy
What are Seizures?

Seizures don't always cause a dramatic or repetitive movement. Some seizures interfere with a child's ability to respond or react to people or things around them. During a seizure, some children simply seem like they're daydreaming or not paying attention.

Sometimes these surges of electricity may not even cause noticeable reactions to you and may only be seen by doctors if your child is being monitored with an EEG. (separate slide?)

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Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments					
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

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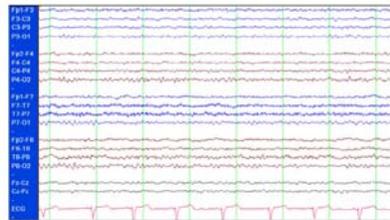
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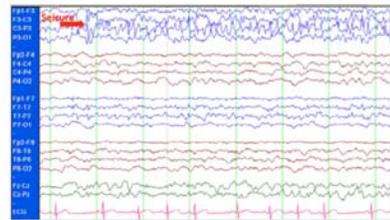
Understanding Epilepsy
Seizures on an EEG test

Basic information about EEG from timeline (records the abnormal electrical signals of seizures)

Normal EEG



This EEG shows a partial seizure in the left central region of the brain.



< > Now learn about the seizures of Epilepsy

Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments					
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

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Understanding Epilepsy
What is Epilepsy?

Epilepsy is having seizures over and over again.

The seizures could happen once a month or many times a day.

Not all seizures are epileptic seizures.

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Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments					
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

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Understanding Epilepsy
Causes of Epileptic Seizures

The seizures of epilepsy (epileptic seizures) may be caused by brain abnormalities such as:

- Strokes (gliosis). Cause a part of the brain to die.
- Tumors. Even if the tumor is benign, the mass may push on or interfere with normal parts of the brain and cause abnormal signals (seizures)
- Brain dysplasia. Part of the brain didn't form properly when the baby was growing in the womb.
- Blood vessels of brain didn't form properly either
- Head injuries or trauma Like if a child is in a car accident and the brain is injured. (qualify that Minor trauma usually doesn't cause ep?)
- Not getting enough oxygen in the womb or during birth (epfound) . . . put in strokes? Qualify that It's not mom's fault?
- Genetic, metabolic, or chromosomal conditions (epfound). Multiple sclerosis???????
- Infections of the brain like meningitis, encephalitis, cerebral abscess
- Repeated febrile seizures as an infant???
- And sometimes we don't know exactly what caused your child's seizures, but we still work very hard to find out the best way to treat the seizures. Doctors may say that these are "idiopathic" seizures.

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Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments					
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

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Understanding Epilepsy

Partial Seizures

Your doctor may describe your child's epileptic seizures as either Partial Seizures or Generalized Seizures when deciding how to treat your child.

Partial Seizures are abnormal electrical surges in one specific part of your child's brain.

Your doctor may talk to you about a variety of possible treatments such as:

- Medications (or antiepileptic medications)
- Vagal Nerve Stimulation
- Epilepsy Surgery

 partial seizures location highlighted in brain

<
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Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments					
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

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Understanding Epilepsy

Generalized Seizures

Generalized Seizures are electrical surges in both sides of your child's brain at the same time.

Your doctor may talk to you about a variety of possible treatments such as:

- Medications
- Vagal Nerve Stimulation
- Ketogenic Diet

 brain shown with generalized seizures

<
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Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments					
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

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Understanding Epilepsy

Medicines for Epilepsy

Most seizures can be successfully controlled with medicines alone. Medicines are always the first treatment that we will suggest.

Medicines are also the safest treatment.

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Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments					
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

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at Children's Medical Center of Dallas

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[Brain Anatomy](#) • [Success stories](#) • [FAQs](#) • [Glossary](#) • [Helpful Links](#) • [For Printing](#)

Understanding Epilepsy

When medicines don't work

However, if your child has partial seizures that cannot be controlled by medicines (also known as intractable or refractory epilepsy), your doctor may want to do tests to see if your child is a good candidate for epilepsy surgery.

Good candidates for surgery are children with seizures that all come from one specific part of his or her brain. The part of the brain causing all of the seizures must also be able to be safely removed without damaging the child's ability to talk and move.

Children with generalized seizures are not candidates for surgery because their entire brain is affected and removing one part of the brain won't help control their seizures.

< > Now learn more about the Epilepsy Surgery Journey

Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments					
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

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Understanding Epilepsy Surgery What is a surgery journey?

The Pediatric Epilepsy Surgery Journey includes all of the steps that take a child from his or her initial appointment with the neurologist all the way through to his or her post-operative care.

This journey includes all of the testing and appointments involved in the decision to operate, the surgery itself, and the follow-up appointments months (years) after the surgery.

A condensed version of the steps in this journey is included at the bottom of this program for easy reference as we explain each step in detail.

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Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments					
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

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Understanding Epilepsy Surgery What is a surgery journey?

It is important to understand that the journey will take time and many appointments because we want to make sure that we have all of the information we need before recommending surgery.

It is also important to understand that surgery is not a good option for all children with epilepsy. So, if we begin the process with appointments and testing and find out that surgery for your child would not be helpful and is not safe, then we won't operate.

Please remember that learning and thinking about epilepsy surgery as a possible treatment option is not the same as saying yes to surgery. Even after all of the testing steps, you will always be the one to make the final decision before surgery.

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Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments					
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

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Understanding Epilepsy Surgery
Overview

This is a general guide to the steps of the Epilepsy Surgery Journey.

Your doctor may change the steps based on the specific needs of your child. Please talk to your doctor or nurse about any questions you have about the Epilepsy Surgery Journey.

[2/3 page view of full timeline / expanded version of condensed timeline seen below?]

<
Now learn about the steps in the Journey >

Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments					
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Step 1: Your 1st Visit

Who You'll See:
Your neurologist (Epilepsy specialist)

What Will Happen:
History, Exam, Medical Records, Treatment Options, Schedule Testing If Needed

The doctor will review your child's medical history. She will ask you to describe your child's seizures . . . (what, when, how of seizures, social, developmental, did anything happen at birth, experiences with other doctors, etc). If you have taken a video of a seizure on your phone or a camera, be sure and show it to the doctor. Or write down what they look like after it happens and bring it to your appointment.

The doctor will do a Physical and Neurological Examination of your child to see if he or she has weakness or difficulties with vision, sensation, speech, reflexes, walking, and balance. The exam is similar to what your child's pediatrician routinely does, and it won't hurt. (Blood work drawn?)

[Drawing Goes Here]

The doctor will review your child's medical records, epilepsy medications used, and the results of any tests he or she had at other hospitals.

The doctor will talk with you about other treatment options if your child has intractable seizures. This means that if 2 or more antiepileptic medicines haven't sufficiently controlled your child's seizures, it is unlikely that any other medicines will help. It might be time to begin considering other kinds of therapies.

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Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments					
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Step 2: Outpatient Testing Who You'll See: Technicians in the Epilepsy Monitoring Unit of the hospital What Will Happen: EEG, MRI

EEG

An EEG measures the abnormal electrical signals that are causing your child's seizures.

It is the basic test that we use to learn about your child's seizures, what part of the brain might be causing them, and whether or not they change over time.

EEG stands for Electroencephalogram.

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Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments					
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

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Understanding Epilepsy
Understanding Epilepsy Surgery

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Step 2: Outpatient Testing Who You'll See: Technicians in the Epilepsy Monitoring Unit of the hospital What Will Happen: EEG, MRI

EEG

Electrodes are placed on the outside of your child's head.

 electrodes on a child's head (drawn) ?

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Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments					
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Understanding Epilepsy
Understanding Epilepsy Surgery

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Step 2: Outpatient Testing

Who You'll See:
Technicians in the Epilepsy Monitoring Unit of the hospital

What Will Happen:
EEG, MRI

EEG

The EEG machine is like a language translator that "listens" to the electrical language of the brain as the brain cells communicate . . . and then translates that language into rows of wavy lines. These rows of "brain waves" tell us if each part of the brain is communicating normally or abnormally.

It's important to understand that children with relatively frequent seizures may still have a completely normal EEG because they may not have a seizure during the particular hour of an EEG test. This is why the doctormight want to do a Video-EEG test later on that provides a continous EEG recording for an extended period of time.

However, sometimes even the electrical language of the brain between seizures may give us a clue as to what area of the brain is abnormal.

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Testing	Decisions				Possible Testing		Final Decision	Surgery		Follow-Up Appointments									
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

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Understanding Epilepsy
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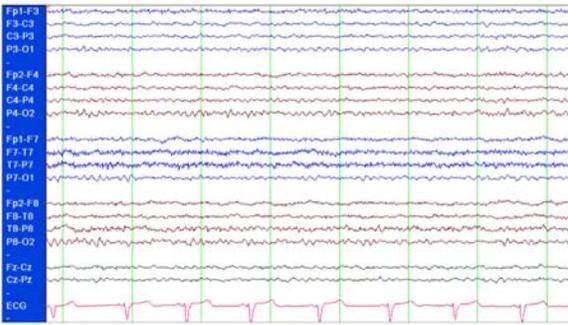
Step 2: Outpatient Testing

Who You'll See:
Technicians in the Epilepsy Monitoring Unit of the hospital

What Will Happen:
EEG, MRI

EEG

This is a normal EEG with a normal pattern of "brain waves."



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Testing	Decisions				Possible Testing		Final Decision	Surgery		Follow-Up Appointments									
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

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Understanding Epilepsy
Understanding Epilepsy Surgery

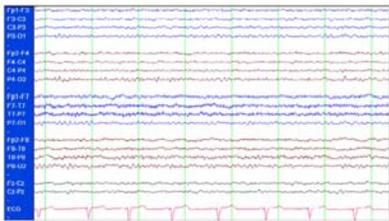
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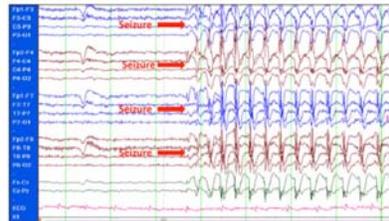
Who You'll See:
Technicians in the Epilepsy Monitoring Unit of the hospital

What Will Happen:
EEG, MRI

EEG



This is a normal EEG with a normal pattern of "brain waves."



This EEG shows generalized abnormal signals (seizures) all over the brain. Surgery would not help this child.

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Testing	Decisions				Possible Testing		Final Decision	Surgery		Follow-Up Appointments									
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

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Understanding Epilepsy
Understanding Epilepsy Surgery

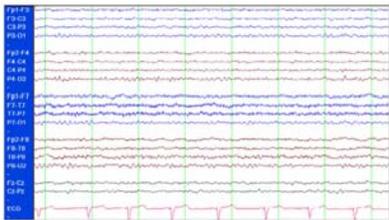
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Step 2: Outpatient Testing

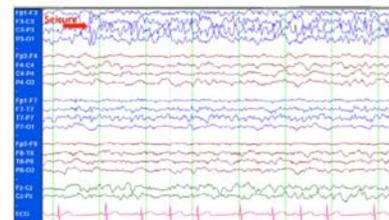
Who You'll See:
Technicians in the Epilepsy Monitoring Unit of the hospital

What Will Happen:
EEG, MRI

EEG



This is a normal EEG with a normal pattern of "brain waves."



This EEG shows a partial seizure in the left central region of the brain. Surgery *might* help this child, but more tests must be done to confirm.

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Testing	Decisions				Possible Testing		Final Decision	Surgery		Follow-Up Appointments									
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

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Understanding Epilepsy
Understanding Epilepsy Surgery

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Step 2: Outpatient Testing

Who You'll See:
Technicians in the Epilepsy Monitoring Unit of the hospital

What Will Happen:
EEG, MRI

MRI

An MRI takes a picture of your child's brain.

The MRI is a different kind of test than an EEG because it lets us look at photographs of the inside of your child's head to see whether there is anything about his or her brain that doesn't look quite right or looks "funny."

MRI stands for Magnetic Resonance Imaging.

Reasons why an MRI scan may not be ordered ...

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Testing	Decisions				Possible Testing		Final Decision	Surgery		Follow-Up Appointments									
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

A Parent's Guide to Pediatric Epilepsy Surgery at Children's Medical Center of Dallas

Understanding Epilepsy
Understanding Epilepsy Surgery

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Step 2: Outpatient Testing

Who You'll See:
Technicians in the Epilepsy Monitoring Unit of the hospital

What Will Happen:
EEG, MRI

MRI



This is a pre-surgery MRI of a child with a Frontal Lobe Lesion in the left side of the brain.

The abnormal lesion looks like a bright white spot and stands out from the rest of the normal brain that appears gray on the scan.

This lesion is *probably* the cause of this child's partial seizures.

also show post-op MRI? < >

Testing	Decisions				Possible Testing		Final Decision	Surgery		Follow-Up Appointments									
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

A Parent's Guide to Pediatric Epilepsy Surgery at Children's Medical Center of Dallas

Understanding Epilepsy
Understanding Epilepsy Surgery

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Step 3: Follow-up Appt

Who You'll See:
your neurologist in the clinic

What Will Happen:
Review test results, introduce the Epilepsy Surgery Journey, schedule more tests

The doctor will talk with you about the results of your child's EEG and MRI.

If both tests indicate your child's seizures are partial seizures which may come from a single location

[Drawing Goes Here]

The doctor might talk with you about the possibility of epilepsy surgery. This is only a discussion about surgery as a possible treatment for your child's intractable seizures.

Your child is not committed to surgery at this point. More testing must be done before the epilepsy team will even consider recommending surgery.

It's like putting a puzzle together. You need all the pieces before you can see the big picture.

The doctor will recommend scheduling a Video-EEG and an appointment with the team Neuropsychologist.

Introduce concept of puzzle pieces?

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Testing	Decisions				Possible Testing		Final Decision	Surgery		Follow-Up Appointments									
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

A Parent's Guide to Pediatric Epilepsy Surgery at Children's Medical Center of Dallas

Understanding Epilepsy
Understanding Epilepsy Surgery

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Step 4: Inpatient Testing

Who You'll See:
technicians, nurses, & neuropsychologist in the EMU of the hospital for 4-5 days

What Will Happen:
Video EEG, Neuropsychological testing, Ictal SPECT scan, PET scan

Video EEG

A Video-EEG just means that we do a continuous EEG test over a few days while also using a video camera of the hospital bed (with audio?) to record your child's seizures. By looking at the video and the EEG on a computer screen at the same time, we can compare whether the pattern of physical movement and behavior during your child's seizure matches the patterns of known movement from the brain area where we think the seizures are coming from.

During seizures, between seizures, while awake during day, at night in sleep

We monitor your child all 24 hours of the day for 4-5 days in the hospital. Please be aware that the rooms are not extra-large, so if you have a very large family, not all of your other children will be able to stay overnight as well.

some children mainly have seizures during their sleep . . . so we may use sleep deprivation techniques to try and "catch" a seizure

[Photo of child in hospital bed w/Video EEG monitoring . . . or as separate slide?]

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Testing	Decisions				Possible Testing		Final Decision	Surgery		Follow-Up Appointments									
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A Parent's Guide to Pediatric Epilepsy Surgery at Children's Medical Center of Dallas

Understanding Epilepsy
Understanding Epilepsy Surgery

Brain Anatomy • Success stories • FAQs • Glossary • Helpful Links • For Printing

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Step 4: Inpatient Testing

Who You'll See:
technicians, nurses, & neuropsychologist in the EMU of the hospital for 4-5 days

What Will Happen:
Video EEG, Neuropsychological testing, Ictal SPECT scan, PET scan

Neuropsychological Testing

The Neuropsychologist of our team will use several different tests to learn what parts of your child's brain aren't working as well as they could be.

"The brief neuropsychological evaluation on the Epilepsy Monitoring Unit is a way to investigate a child's thinking skills and behavior. This information can help the Neurology Team understand how seizures might affect the child. The evaluation includes parent interviews, parent ratings of behavior, and tests completed by the child. Each evaluation starts with a short interview with parents. Parents are asked about their child's development, school performance, behavior, and other important areas. The child then completes several tests with the examiner. The tests involve answering questions, completing "puzzles," and writing. Neuropsychological testing is not painful but can make children feel tired or bored, so the child is provided with frequent breaks. The areas tested include intelligence (also known as IQ), language, visual-spatial skills, memory, attention, problem solving speed, and hand speed. After the child leaves the hospital, parents are mailed a short report with this information that they can share with schools. This report is often helpful for schools to better understand how seizures may affect how the child learns."

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Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments					
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

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Understanding Epilepsy
Understanding Epilepsy Surgery

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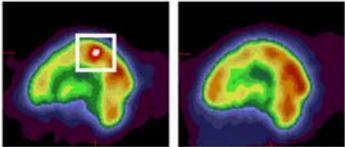
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Step 4: Inpatient Testing

Who You'll See:
technicians, nurses, & neuropsychologist in the EMU of the hospital for 4-5 days

What Will Happen:
Video EEG, Neuropsychological testing, Ictal SPECT scan, PET scan

Ictal SPECT (scan) . . . if needed



An Ictal SPECT scan uses a very small amount (harmless? / safe) of radioactive material almost like a highlighter to show us where your child's seizures are starting. Sometimes seizures start in one location and move to other parts of the brain, so we want to know where the real culprit is. Ictal SPECT stands for "during a seizure" (ictal) Single Photon Emission Computed Tomography.

*actually measures blood flow

Ictal (during a seizure) time frame . . . showing lesion in **right, frontal lobe?** Interictal (between seizures)

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Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments					
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A Parent's Guide to Pediatric Epilepsy Surgery at Children's Medical Center of Dallas

Understanding Epilepsy
Understanding Epilepsy Surgery

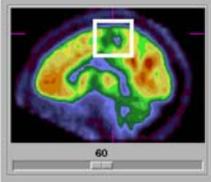
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Step 4: Inpatient Testing

Who You'll See: technicians, nurses, & neuropsychologist in the EMU of the hospital for 4-5 days

What Will Happen: Video EEG, Neuropsychological testing, Ictal SPECT scan, PET scan

PET (scan) ... if needed



PET scan of same patient as image from Ictal-SPECT (blue hypo-metabolic area on top-midline is lesion)

A PET scan takes a picture (colored) of the brain like an MRI. However, the PET scan tells us more about how active the different parts of the brain are and how much energy each part is using. PET scan stands for Positron Emission Tomography.

A lesion or area that is causing the seizures doesn't use as much energy as the rest of the brain, so these seizure areas will appear blue on the scan in an area that the doctors know should be very active and should appear yellow, orange, or red.

Other areas of the brain may appear blue, but blue in those areas is completely normal.

Testing	Decisions				Possible Testing		Final Decision	Surgery		Follow-Up Appointments									
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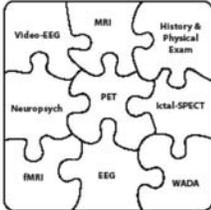
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Step 4: Inpatient Testing

Who You'll See: technicians, nurses, & neuropsychologist in the EMU of the hospital for 4-5 days

What Will Happen: Video EEG, Neuropsychological testing, Ictal SPECT scan, PET scan



When combined with the EEG and MRI reports, all of these different tests are the puzzle pieces that give us the bigger picture of what is causing your child's seizures and whether or not surgery would help your child.

put in Step 5 / Team Conference

Testing	Decisions				Possible Testing		Final Decision	Surgery		Follow-Up Appointments									
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

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Step 5: Team Conference

Who You'll See:
You and your child will not be present.

What Will Happen:
All of the doctors of our Epilepsy Team will evaluate if your child is a good candidate for epilepsy surgery.



During the Epilepsy Conference, our team of highly qualified specialists in Neurology, Neurosurgery, Neuropsychology, and Neuroradiology all meet at once to talk about your child's epilepsy history and test results.

We think that it's important for all of our specialists to be involved so that we can make sure we're all in agreement. The team conference is also a good way for us to put all of our heads together and offer up suggestions based on our individual experiences with patients.



Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments						
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A Parent's Guide to Pediatric Epilepsy Surgery at Children's Medical Center of Dallas

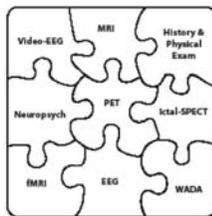
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Step 6: Team Recommendation

Who You'll See:
You and your child will not be present.

What Will Happen:
Our Epilepsy Team will either recommend surgery or another treatment.



During the conference, we put together all the "puzzle pieces" of testing and ask ourselves if all of the pieces and clues point to 1, clear area of the brain causing your child's seizures.

As a team, we decide if we should recommend that your child have epilepsy surgery based on the picture we see of your child's epilepsy.



Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments						
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	

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Understanding Epilepsy
Understanding Epilepsy Surgery

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Step 6: Team Recommendation Who You'll See: You and your child will not be present. What Will Happen: Our Epilepsy Team will either recommend surgery or another treatment.

check

Epilepsy Team recommends surgery for your child

Epilepsy Team recommends another treatment for your child

[push a button for the next step]

Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments						
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Understanding Epilepsy
Understanding Epilepsy Surgery

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Step 6: Team Recommendation Who You'll See: You and your child will not be present. What Will Happen: Our Epilepsy Team will either recommend surgery or another treatment.

If the team does not think that your child is a good candidate for epilepsy surgery, then we will call you and ask to set up another appointment in the clinic to discuss other treatment options that might be more appropriate and more successful for your child.

check (what if you do recommend surgery?)

Epilepsy Team recommends another treatment for your child

Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments						
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	

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Understanding Epilepsy
Understanding Epilepsy Surgery

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Step 7: Phone Call

Who You'll See:
You will receive a phone call at home.

What Will Happen:
We will call you with our recommendation for surgery.

Epilepsy Team recommends surgery for your child

If our team agrees that your child is a good candidate for epilepsy surgery, then we will call you with our recommendation and suggest that you meet with our neurosurgeon as the next step in the Epilepsy Surgery Journey.

However, you are still not committed to surgery at this step in the journey.

[Drawing of a Phone?]

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Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments						
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	

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Understanding Epilepsy
Understanding Epilepsy Surgery

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Step 8: Appt with Surgeon

Who You'll See:
The Neurosurgeon (in the clinic?)

What Will Happen:
Review testing and history, exam, discussion of surgical benefits and risks, schedule more testing if needed

The neurosurgeon will meet with you to review all of the testing results and explain to you what they mean.

The surgeon will also ask you about your child's medical history and do another physical and neurological exam to make sure that nothing has been missed.

[Picture goes here]

The surgeon will talk with you about the potential medical, social, and developmental benefits of surgery and answer your questions about the type of surgery we recommend and the risks.

If the surgeon thinks that more testing is needed to plan the surgery, your child will be scheduled for additional testing.

However, you are still not committed to surgery at this point in the journey. You're just getting information about the next step.

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Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments						
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	

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Understanding Epilepsy
Understanding Epilepsy Surgery

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Step 9: Your Decision

Who You'll See:
This is a decision for you and any other family members involved.

What Will Happen:
You decide if your child is going to continue along the Epilepsy Surgery Journey.

Some families make the decision about surgery in the office while talking to the neurosurgeon during Step 8.

Other families need to go home and discuss the surgery with each other before making the decision.

[Picture goes here]

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Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments						
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	

A Parent's Guide to Pediatric Epilepsy Surgery at Children's Medical Center of Dallas

Understanding Epilepsy
Understanding Epilepsy Surgery

Brain Anatomy • Success stories • FAQs • Glossary • Helpful Links • For Printing

Step 10: Outpatient Testing

Who You'll See:
Technicians in the EMU of the hospital ?

What Will Happen:
Visual Field Testing (if needed), fMRI (if needed)

Visual Field Testing . . . if needed

If we think that your child's seizures might be coming from an area of the brain that controls vision or is near the visual center (the occipital lobe), we will test your child's vision before and after surgery. ("sight" instead of vision?)

Visual Field Testing involves . . . more for a baseline

[Picture goes here of a cute kid - Austin P. - next to Dr. A]

This test will help us to understand what your child can and can't see. Many children with seizures in or near their occipital lobe have lost some or all of their peripheral vision on one side.

The eyes "see" but it's the brain that interprets what the eyes see and gives meaning to those things. Your child's eyes can be perfectly normal but your child still has problems with vision if the visual center of the brain (the occipital lobe) isn't working properly because of seizures.

During your appointment with the neurosurgeon in Step 8, the surgeon will tell you if loss of vision is a possible side effect in your child's case.

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Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments						
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	

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Understanding Epilepsy
Understanding Epilepsy Surgery

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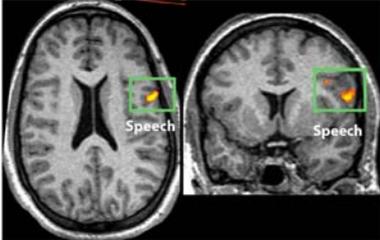
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Step 10: Outpatient Testing

Who You'll See:
Technicians in the EMU of the hospital, but no hospital stay required ?

What Will Happen:
Visual Field Testing (if needed), fMRI (if needed)

functional MRI (fMRI) ... if needed



fMRI showing that tumor in frontal lobe is not in the same place as language area

A Functional MRI (fMRI) is a special kind of MRI scan that is only recommended for children with partial seizures coming from their frontal lobe. (never temporal?)

Because the frontal lobe controls speech (spoken language) and also contains the Primary Motor Cortex (movement), it's important for us to know before surgery if your child's frontal lobe seizures are located in or near these critical areas.

The fMRI tells us "don't cut here." Or "it's ok to cut there."

(more info on fMRI)

During your appointment with the neurosurgeon in Step 8, the surgeon will tell you if we are concerned about the risks of surgery near your child's speech or motor areas.

Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments					
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

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● ● ●
● ● ●

Step 11: Inpatient Testing

Who You'll See:
Technicians in the EMU of the hospital, stay overnight ???

What Will Happen:
Wada test (if needed)

Wada test ... if needed

A Wada test is only recommended for children with partial seizures coming from their temporal lobe. The main concern when operating on the temporal lobe is to avoid the area controlling memory.

Children must also be old enough to cooperate during the testing.

[image ?]

- For this test, a catheter (a small, flexible tube) is placed in the groin and threaded up through the arteries to the neck while using an x-ray machine to monitor the location of the catheter in the body.
- A small amount of anesthetic is used to put 1/2 of the brain to sleep for about 5 minutes.
- During this time, the memory in the other 1/2 of the brain can be tested by talking to the child and showing pictures.
- If the catheter is in the left carotid artery, the left side of the brain is put to sleep.
- After testing one side, the catheter is repositioned in the other carotid artery, and the other side of the brain is tested.

Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments					
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

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Step 11: Inpatient Testing

Who You'll See: Technicians in the EMU of the hospital, stay overnight ???

What Will Happen: Wada test (if needed)

Wada test . . . if needed

[image ?]

By testing each temporal lobe separately, we learn whether or not both temporal lobes are needed for your child's memory to work properly.

If both the left and the right temporal lobes are needed for memory, then we won't recommend epilepsy surgery in that area.

However, if your child's seizures are coming from the temporal lobe that is not necessary for memory, then we might still consider surgery to remove part of the lobe or all of it (resection).

< >

Testing	Decisions	Possible Testing	Final Decision	Surgery	Follow-Up Appointments
1 2 3 4	5 6 7 8 9	10 11	12	13 14	15 16 17 18 19 20

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Step 12: Final Decisions

Who You'll See: You may or may not make another appt with the neurologist or neurosurgeon.

What Will Happen: The Epilepsy Team has completed all its testing and is recommending surgery, and you will make your final decision.

The neurosurgeon and the neurologist will make sure that any additional test results fit with the decision made in the epilepsy conference.

If all the pieces are falling into place, you will be contacted to schedule the surgery.

(If no additional testing is needed after the appointment with the neurosurgeon in Step 8, the surgery may have been scheduled at that time.)

The next step will be for you to make your final decision about the surgery.

< >

Testing	Decisions	Possible Testing	Final Decision	Surgery	Follow-Up Appointments
1 2 3 4	5 6 7 8 9	10 11	12	13 14	15 16 17 18 19 20

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Step 12: Final Decisions

Who You'll See:
You may or may not make another appt with the neurologist or neurosurgeon.

What Will Happen:
The Epilepsy Team has completed all its testing and is recommending surgery, and you will make your final decision.

Epilepsy Team recommended a Hemispherectomy

Epilepsy Team recommended a Focal Resection

[push a button for the next step]

Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments						
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	

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Step 12: Final Decisions

Who You'll See:
You may or may not make another appt with the neurologist or neurosurgeon.

What Will Happen:
The neurosurgeon will make a final decision about the type of surgery, and you will make your final decision.

If your child needs a "Grid" surgery before the Resection surgery

If your child does not need a "Grid" surgery before the Resection surgery

[push a button for the next step]

Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments						
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	

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Who You'll See: You may or may not make another appointment with the neurologist or neurosurgeon.

What Will Happen: You will make your final decision about surgery, and the surgery will be scheduled.

step 12 Final Decisions

The neurosurgeon and the neurologist will make sure that any additional test results fit with the decision made in the epilepsy conference.

If all the pieces are falling into place, you will be contacted to schedule the surgery.

(If no additional testing is needed after the appointment with the neurosurgeon in Step 8, the surgery may have been scheduled at that time.)

[Drawing goes here]

The next step will be for you to make your final decision about the surgery.

< **Steps of the Pediatric Epilepsy Surgery Journey** [click on a step to learn more] >

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19
Testing				Decisions					Possible Testing		Final Decision	Surgery	Follow-Up Appointments					

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STEP 13a Day Before Surgery **Who You'll See:** technicians at the hospital (what floor?), the anesthesiologist

What Will Happen: MRI with fiducials, blood tests, directed blood donor (?), meet anesthesiologist (? or call?)

-Anesthesiologist might talk about . . .

Allergies, medical history, heart / lung problems, past surgeries, drug reactions, mentally challenged / cognitive functioning (word much nicer), what medicines is he on, is there anything in the family that has had a bad reaction to anesthesia

Make sure kid is not sick and doesn't have a fever that might increase the risks of surgery

[Drawing goes here]

"How does your child react around doctors, needles, and IV's" . . .

"Is there a special toy, doll, or blanket they can bring with them for comfort when anesth. is putting them to sleep?" . . . or "How can we make your child comfortable in this process." . . . headphones and music, movie, read a book, etc

Blood is drawn for pre-operative tests.

-Nothing to eat or drink after _____

< **Steps of the Pediatric Epilepsy Surgery Journey** [click on a step to learn more] >

1	2	3	4	5	6	7	8	9	10	11	12	a	b	c	d	e	f	g	h	i	14	15	16	17	18	19
Testing				Decisions					Possible Testing		Final Decision	13	Surgery					Follow-Up Appointments								

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STEP 13b Morning of Surgery Who You'll See: nurses, the neurosurgeon

What Will Happen: pre-surgical check-in, meet with neurosurgeon

-Nothing to eat or drink since _____

-Go to pre-surgical check-in

-Meeting with neurosurgeon to review _____

-Is IV put in after kids is already asleep? use gas mask / inhalation anesthetic?

-Don't include stuff about what floors things are on

[Drawing goes here]

< Steps of the Pediatric Epilepsy Surgery Journey [click on a step to learn more] >

1	2	3	4	5	6	7	8	9	10	11	12	a	b	c	d	e	f	g	h	i	14	15	16	17	18	19
Testing				Decisions						Possible Testing		Final Decision		13 Surgery					Follow-Up Appointments							

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STEP 13c Surgery Who You'll See: nurses and the neurosurgeon for a few (?) updates during the surgery

What Will Happen: your child will have the surgery in the operating room while you and your family wait in the waiting room

[push a button for your child's type of surgery]

Focal Resection Surgery

Grid Placement Surgery

+

Focal Resection Surgery

Hemispherectomy

< Steps of the Pediatric Epilepsy Surgery Journey [click on a step to learn more] >

1	2	3	4	5	6	7	8	9	10	11	12	a	b	c	d	e	f	g	h	i	14	15	16	17	18	19
Testing				Decisions						Possible Testing		Final Decision		13 Surgery					Follow-Up Appointments							

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STEP 13d Recovery in PICU **Who You'll See:** nurses in the PICU, anesthesiologist, neurosurgeon

What Will Happen: recovery after surgery, anesthesiologist will monitor your child, neurosurgeon will talk to you about how the surgery went

[same for all 3 types of surgery]

[Photo goes here]

- Recovery room in the 2nd floor for about an hour?
- Anesthesiologist will monitor your child
- the Neurosurgeon will talk to you and your family

< **Steps of the Pediatric Epilepsy Surgery Journey** [click on a step to learn more] >

1	2	3	4	5	6	7	8	9	10	11	12	a	b	c	d	e	f	g	h	i	14	15	16	17	18	19
Testing				Decisions					Possible Testing		Final Decision		13 Surgery					Follow-Up Appointments								

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Step 15: Post-op Appt	Who You'll See: The neurosurgeon (in clinic or hospital?)	What Will Happen: Post-operative wound check
------------------------------	---	--

[Drawing goes here]

About a week after your child goes home from the hospital, the neurosurgeon will want to check to make sure that your child's incision line doesn't look infected and that your child's recovery is progressing as expected.

Sutures (stitches) taken out?

Your child will continue to take his or her normal dose of antiepileptic medications.

< >

Testing				Decisions					Possible Testing		Final Decision		Surgery		Follow-Up Appointments				
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

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Step 16: Follow-up Appt

Who You'll See: The neurologist in clinic

What Will Happen: Epilepsy follow up care and monitoring begins

2 weeks later (3 weeks after surgery) ??? your child will return to the clinic to begin follow-up care with the neurologist.

[Drawing goes here]

Your child will continue to take antiepilepsy medications.

Therapies begin ?

< >

Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments					
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

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Step 17: Follow-up Appt

Who You'll See: The neurologist in clinic

What Will Happen: Epilepsy follow up care continues, discuss tapering of medications

2 months later (about 3 months after surgery) ??? your child will return to the clinic for another follow-up appointment as epilepsy care continues.

[Drawing goes here]

If your child is taking more than 1 antiepileptic medicine and is doing well, the neurologist might suggest tapering 1 or more of the medicines.

Schedule an EEG for next appointment?

Medication vs. Medicine ??? ...stay consistent throughout program

< >

Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments					
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

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Step 18: Follow-up Appt

Who You'll See:
The neurologist in clinic and the neurosurgeon at separate appointments

What Will Happen:
Epilepsy follow up care continues, EEG, continue at least 1 medication

3 months later (about 6 months after surgery) ??? your child will see the neurologist and neurosurgeon in 2 separate appointments (on same day?) to discuss how he or she has been progressing since the surgery.

[Drawing goes here] Your child will also have a post-operative EEG to see _____

If your child has been seizure-free since the surgery or continues to have fewer and fewer seizures, then the neurologist might lower his or her dosage of medications ... but your child will continue to take at least 1 antiepileptic medication.

< >

Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments					
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

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Step 19: Follow-up Appt

Who You'll See:
The neurologist in clinic, the surgeon, and the neuropsychologist separately ?

What Will Happen:
Epilepsy follow up care continues, Neuropsychological testing, continue at least 1 medication

6 months later (about 1 year after surgery) ??? your child will see the neurologist and neurosurgeon in 2 separate appointments (on same day?) to discuss how he or she has been progressing since the surgery.

[Drawing goes here] Your child will also see the Neuropsychologist for post-operative testing to evaluate changes in cognitive functioning from the surgery. ... cognitive too big of a word?

If your child has been seizure-free since the surgery or continues to have fewer and fewer seizures, then the neurologist might lower his or her dosage of medications ... but your child will continue to take at least 1 antiepileptic medication.

< >

Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments					
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

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Step 20: Follow-up Appt

Who You'll See: The neurologist in clinic, the neurosurgeon in separate appts ?

What Will Happen: Epilepsy follow up care, possibly tapering off of last medicine

1 year later (about 2 years after surgery) ??? your child will see the neurologist and neurosurgeon in 2 separate appointments (on same day?) to discuss how he or she has been progressing since the surgery.

[Drawing goes here]

If your child has been seizure-free since the surgery, the neurologist might suggest tapering your child off of his or her last antiepileptic medicine.

"Tapering" means that . . .

< >

Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments					
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

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STEP 20 Follow-up Appointment Who You'll See: The neurologist in clinic, the neurosurgeon in separate appts ?

What Will Happen: Epilepsy follow up care, possibly tapering off of last medicine

1 year later (about 2 years after surgery) ??? your child will see the neurologist and neurosurgeon in 2 separate appointments (on same day?) to discuss how he or she has been progressing since the surgery.

[Drawing goes here]

If your child has been seizure-free since the surgery, the neurologist might suggest tapering your child off of his or her last antiepileptic medicine.

"Tapering" means that . . .

< >

Testing				Decisions					Possible Testing		Final Decision	Surgery		Follow-Up Appointments					
1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20

Steps of the Pediatric Epilepsy Surgery Journey [click on a step to learn more ?]

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The Journey was a Success!

Who You'll See:
the neurologist only as needed

What Will Happen:
Therapies continue, continued growth and development.

The Epilepsy Surgery Journey is over!

[Drawing goes here]

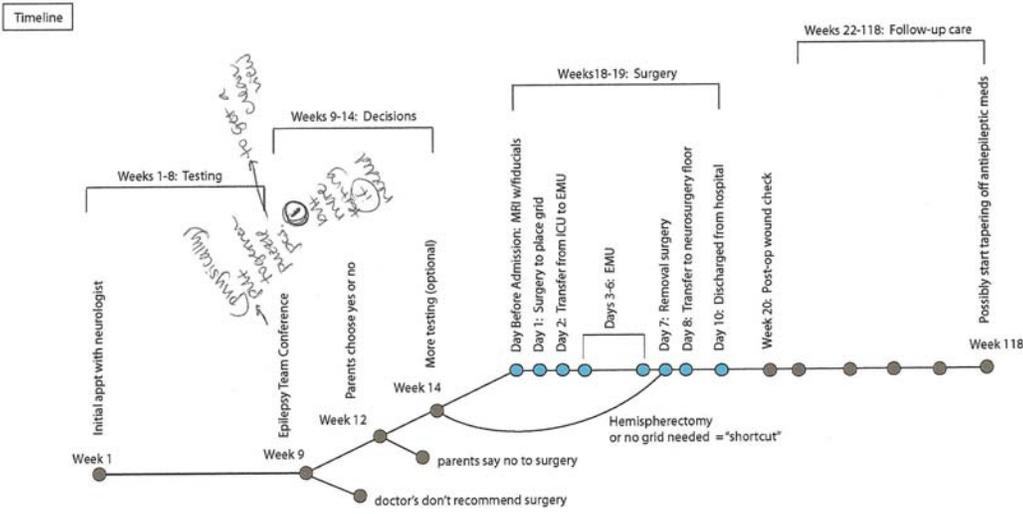
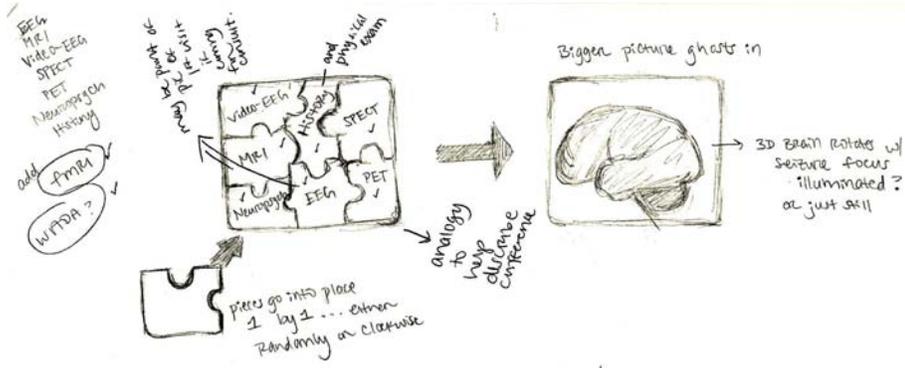
Your child will continue Physical Therapy, Occupational Therapy, Speech Therapy, Vision Therapy, etc as needed.

You may schedule appointments with your neurologist if needed.

<
>

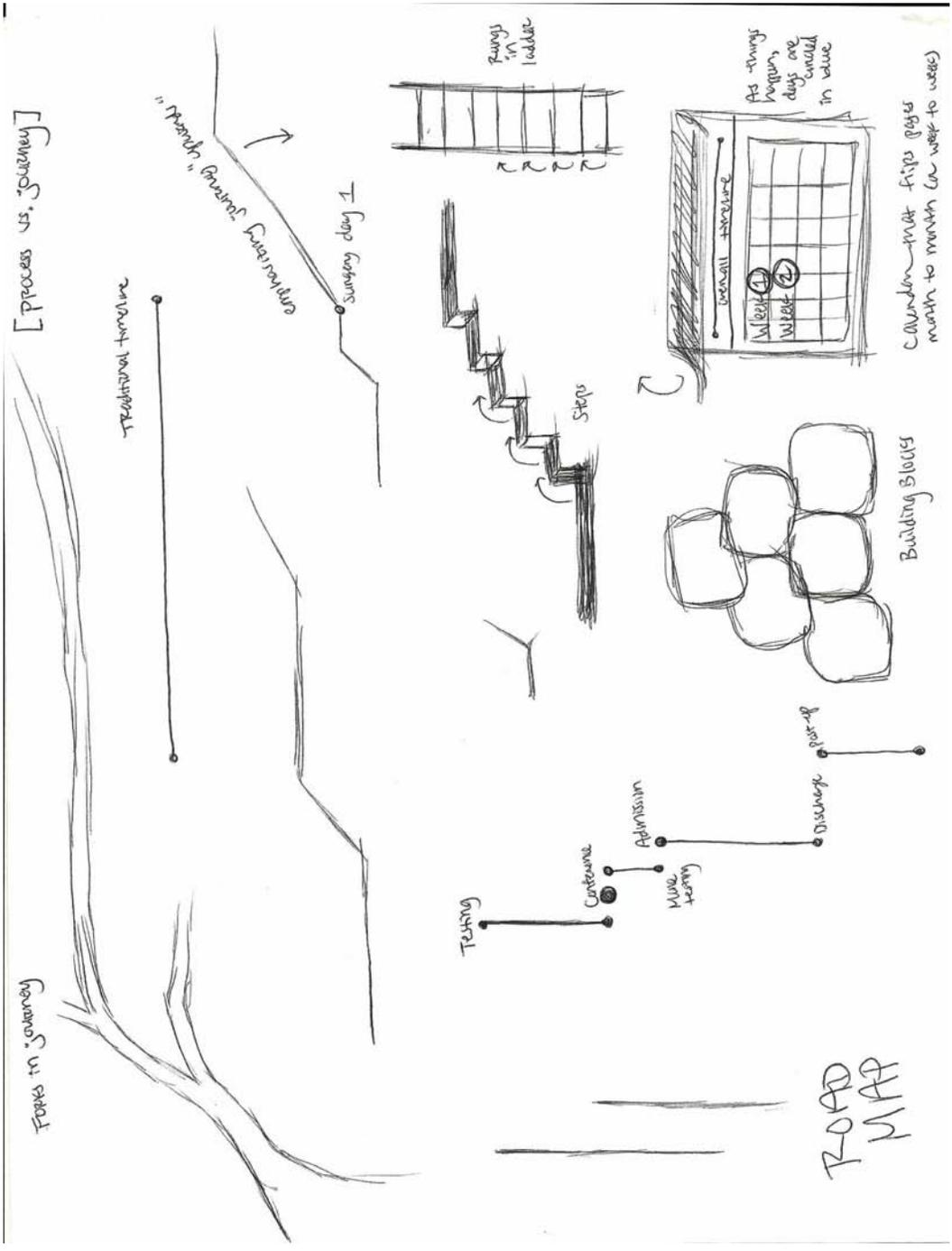
Testing	Decisions	Possible Testing	Final Decision	Surgery	Follow-Up Appointments
1 2 3 4	5 6 7 8 9	10 11	12	13 14	15 16 17 18 19 20

APPENDIX D Sketches



[not to scale]

- Brain anatomy
- success stories
- glaucoma
- helpful links
- for pinning



[Process vs. Journey]

Forks in Journey

Traditional Timeline

"Month" (instead of Surgery)

Surgery day 1

Testing

Consultation

Admission

Discharge

post-op

ROAD MAP

Steps



Rungs in Ladder

As things happen, days are added in value

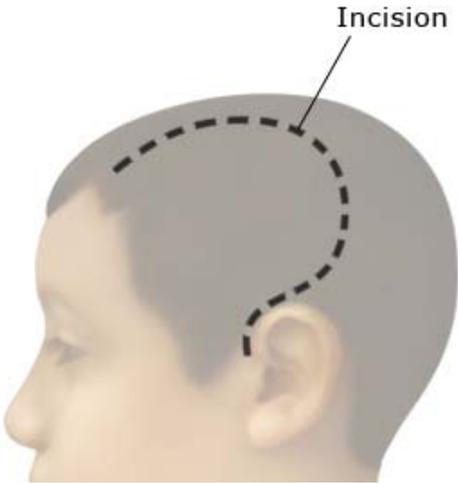
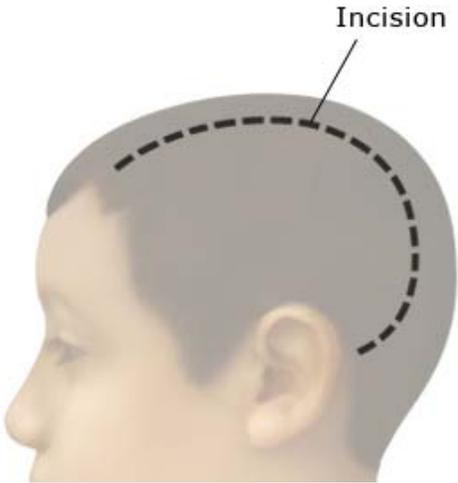
Overall Structure

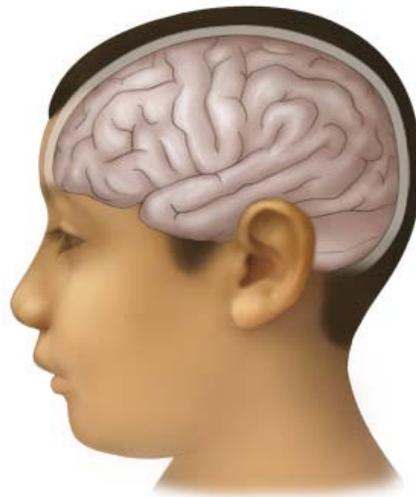
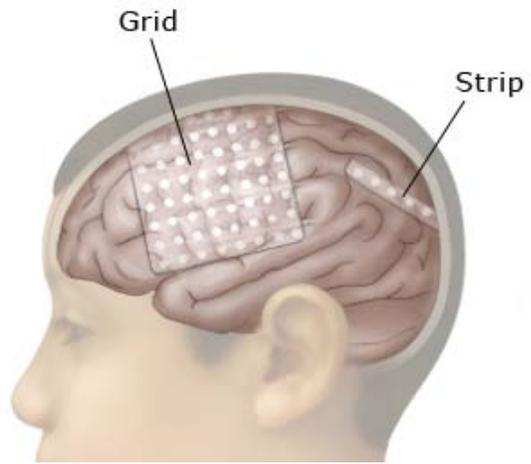
Week 1
Week 2

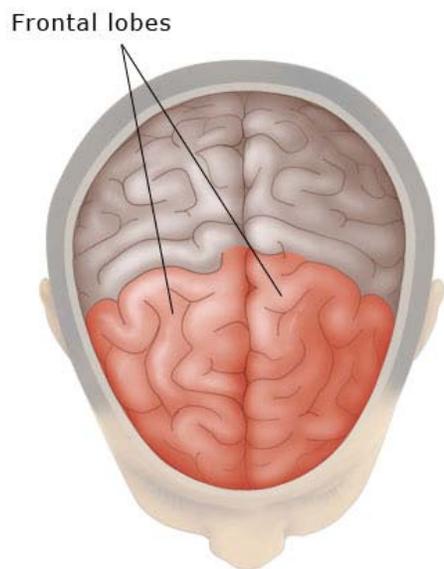
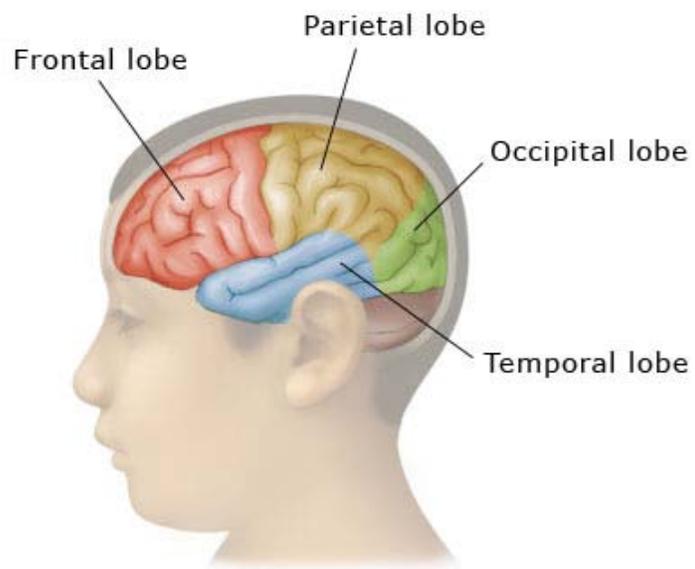
Building Blocks

Calendar that fits (days month to month (or week to week))

APPENDIX E
Final Illustrations and Brain Scans



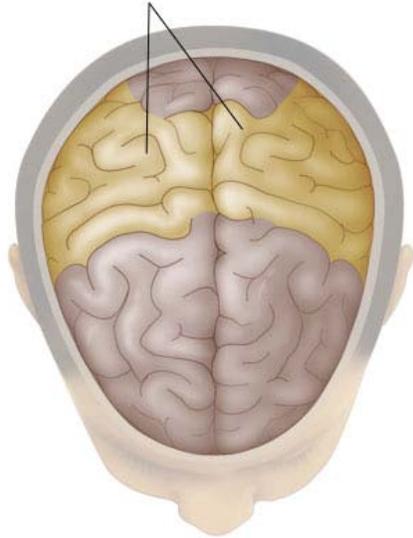


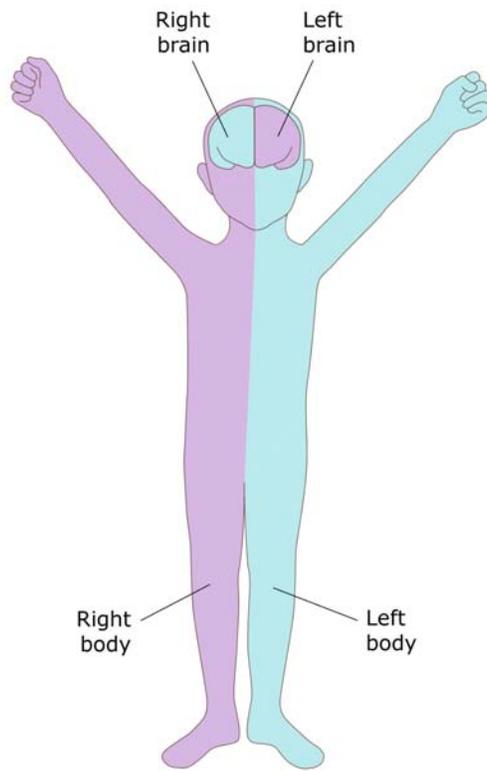
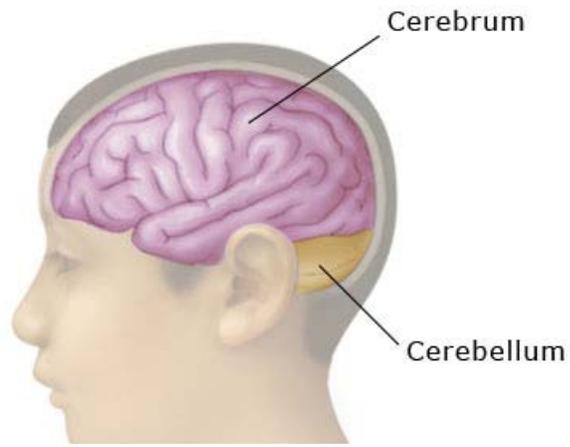


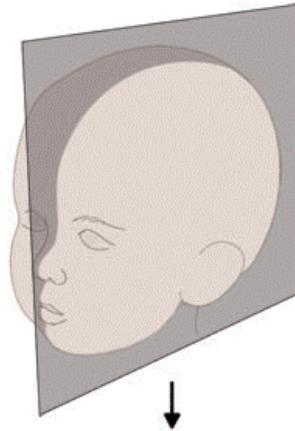
Occipital lobes



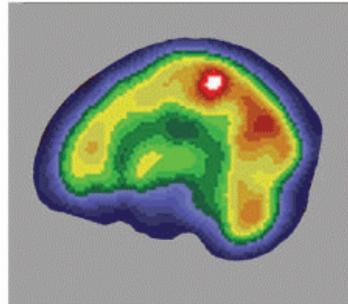
Parietal lobes



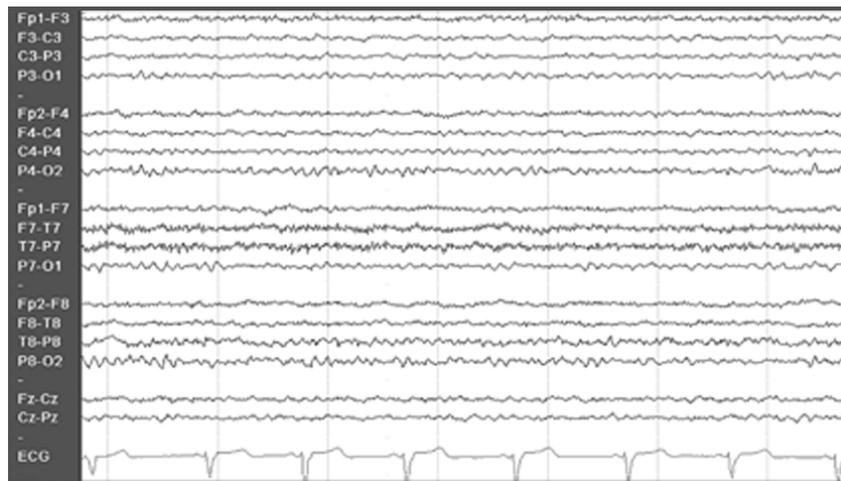


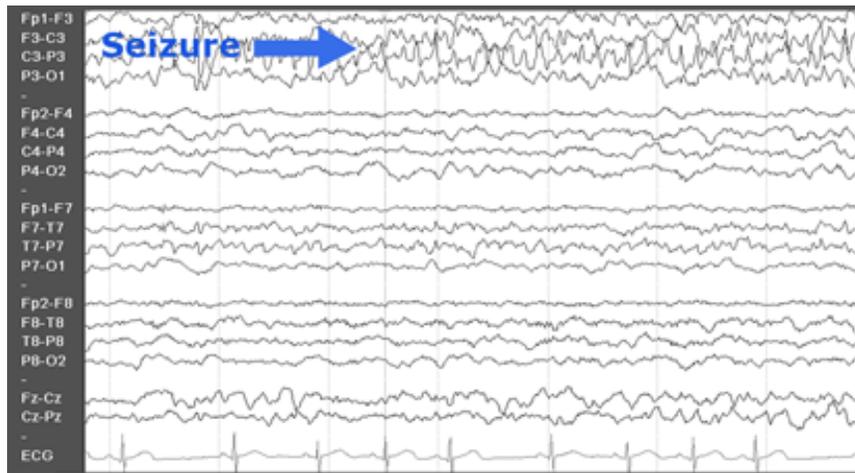
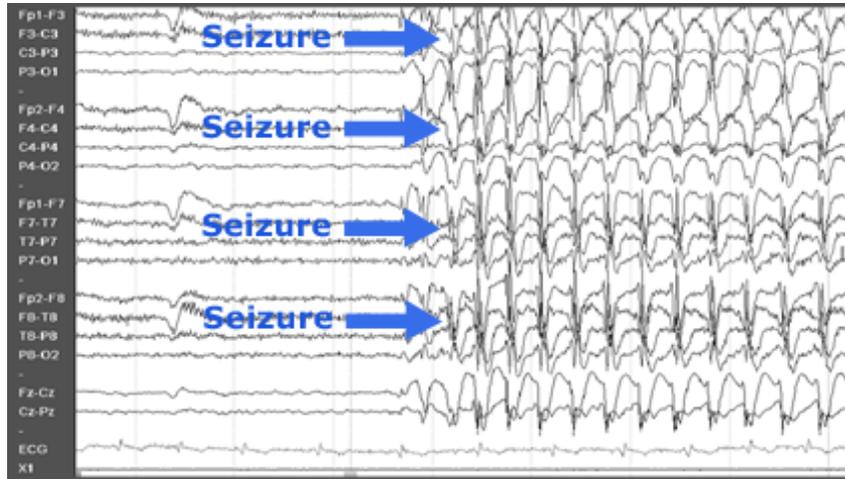


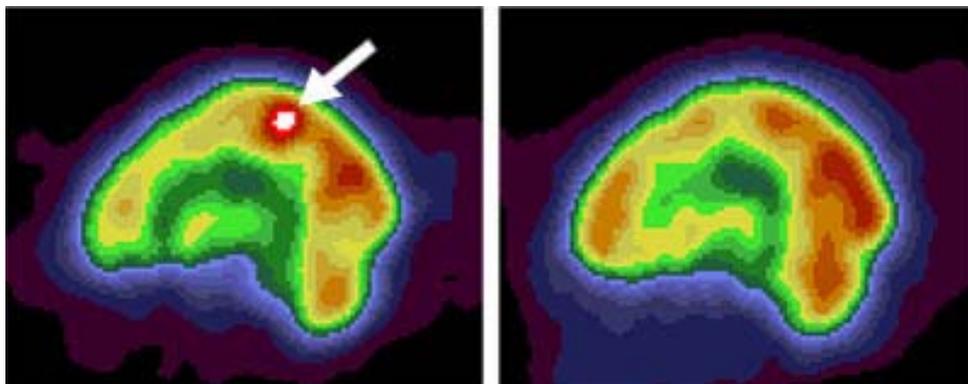
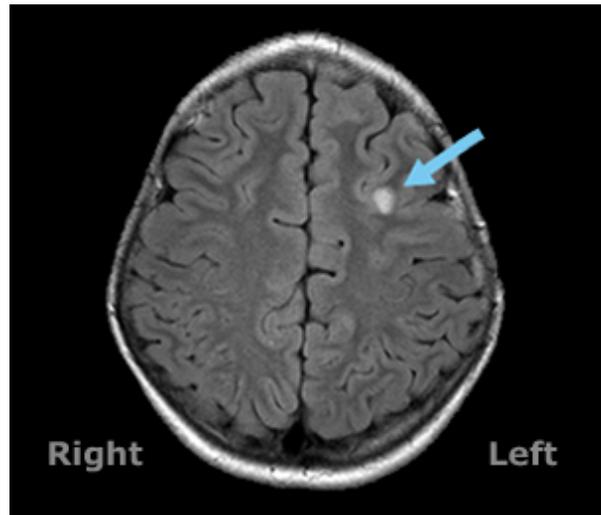
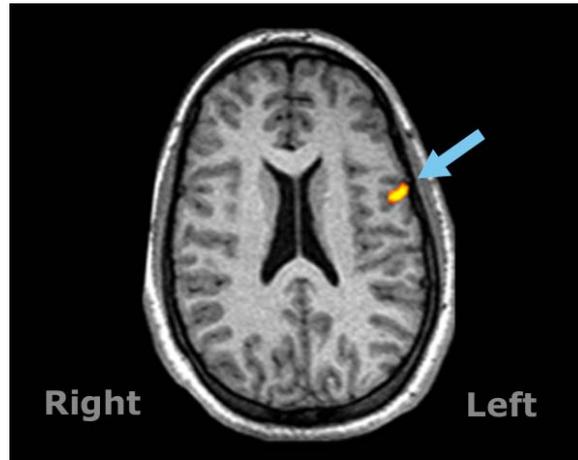
Front
of brain

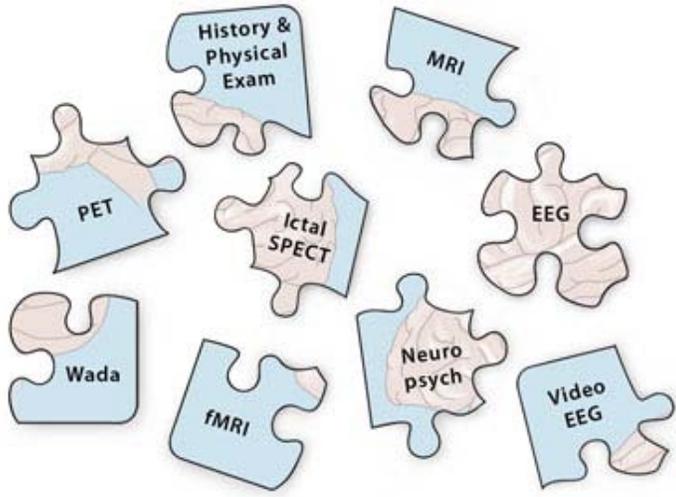
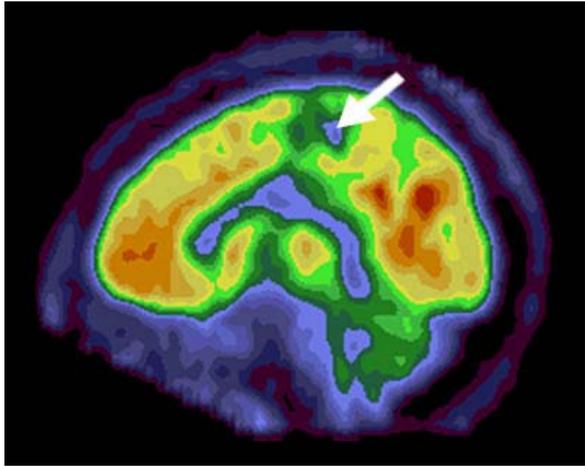


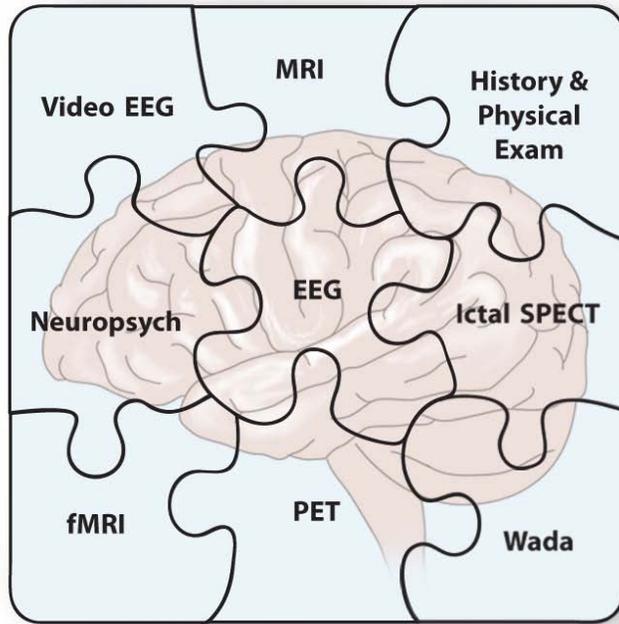
Back
of brain











APPENDIX F
Blank Evaluation Survey

Post-Project Evaluation

A Parent's Guide to Pediatric Epilepsy Surgery

Your professional title _____

Instructions: Place a check in the box to the left of the statement that corresponds to your level of agreement. You may also make comments after each statement.

- 1. The information in the section, *Understanding Epilepsy*, is a good foundation for the information on surgery and is at an appropriate level for parent education.**

	Strongly Disagree		Disagree		Neutral		Agree		Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	--	----------------

Comments:

- 2. The website emphasizes the journey-like nature of epilepsy surgery and will help parents visualize what to expect for the entire journey.**

	Strongly Disagree		Disagree		Neutral		Agree		Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	--	----------------

Comments:

3. The color-coded journey is an effective parent education graphic.

	Strongly Disagree		Disagree		Neutral		Agree		Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	--	----------------

Comments:

4. The photographs aid in understanding the text.

	Strongly Disagree		Disagree		Neutral		Agree		Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	--	----------------

Comments:

5. The brain illustrations are clear and at an appropriate level for parent education.

	Strongly Disagree		Disagree		Neutral		Agree		Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	--	----------------

Comments:

6. The success story video is a valuable addition to the website.

	Strongly Disagree		Disagree		Neutral		Agree		Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	--	----------------

Comments:

7. The frequently asked questions, glossary, and helpful links are trusted resources that I would recommend to patient families.

	Strongly Disagree		Disagree		Neutral		Agree		Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	--	----------------

Comments:

8. The printable PDFs are effective alternatives for families without computer or internet access.

	Strongly Disagree		Disagree		Neutral		Agree		Strongly Agree
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Comments:

9. The website navigation is clear and easy to use.

	Strongly Disagree		Disagree		Neutral		Agree		Strongly Agree
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Comments:

10. The aesthetics of the website are pleasing and appropriate given the seriousness of the content.

	Strongly Disagree		Disagree		Neutral		Agree		Strongly Agree
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Comments:

11. The overall level of information is appropriate for patient families.

	Strongly Disagree		Disagree		Neutral		Agree		Strongly Agree
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Comments:

12. The website will aid in communication between epilepsy health professionals and patient families when discussing the surgery process.

	Strongly Disagree		Disagree		Neutral		Agree		Strongly Agree
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Comments:

13. The website will be a useful parent education resource.

	Strongly Disagree		Disagree		Neutral		Agree		Strongly Agree
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Comments:

14. Please write any additional comments below:

APPENDIX G
Completed Evaluations

RESPONSE 1	163
RESPONSE 2	167
RESPONSE 3	171
RESPONSE 4	175
RESPONSE 5	179
RESPONSE 6	183

Post-Project Evaluation

A Parent's Guide to Pediatric Epilepsy Surgery

Your professional title Neurology Resident MB

Instructions: Place a check in the box to the left of the statement that corresponds to your level of agreement. You may also make comments after each statement.

1. The information in the section, *Understanding Epilepsy*, is a good foundation for the information on surgery and is at an appropriate level for parent education.

<input type="checkbox"/>	Strongly Disagree	<input type="checkbox"/>	Disagree	<input type="checkbox"/>	Neutral	<input type="checkbox"/>	Agree	<input checked="" type="checkbox"/>	Strongly Agree
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Comments:

2. The website emphasizes the journey-like nature of epilepsy surgery and will help parents visualize what to expect for the entire journey.

<input type="checkbox"/>	Strongly Disagree	<input type="checkbox"/>	Disagree	<input type="checkbox"/>	Neutral	<input type="checkbox"/>	Agree	<input checked="" type="checkbox"/>	Strongly Agree
--------------------------	-------------------	--------------------------	----------	--------------------------	---------	--------------------------	-------	-------------------------------------	----------------

Comments:

3. The color-coded journey is an effective parent education graphic.

<input type="checkbox"/>	Strongly Disagree	<input type="checkbox"/>	Disagree	<input type="checkbox"/>	Neutral	<input checked="" type="checkbox"/>	Agree	<input type="checkbox"/>	Strongly Agree
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Comments:

4. The photographs aid in understanding the text.

	Strongly Disagree		Disagree		Neutral		Agree	✓	Strongly Agree
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Comments:

5. The brain illustrations are clear and at an appropriate level for parent education.

	Strongly Disagree		Disagree		Neutral		Agree	✓	Strongly Agree
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Comments:

6. The success story video is a valuable addition to the website.

	Strongly Disagree		Disagree		Neutral		Agree	✓	Strongly Agree
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Comments:

7. The frequently asked questions, glossary, and helpful links are trusted resources that I would recommend to patient families.

	Strongly Disagree		Disagree		Neutral		Agree	✓	Strongly Agree
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Comments:

8. The printable PDFs are effective alternatives for families without computer or internet access.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

9. The website navigation is clear and easy to use.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

10. The aesthetics of the website are pleasing and appropriate given the seriousness of the content.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

11. The overall level of information is appropriate for patient families.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

12. The website will aid in communication between epilepsy health professionals and patient families when discussing the surgery process.

	Strongly Disagree		Disagree		Neutral		Agree		Strongly Agree
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Comments:

13. The website will be a useful parent education resource.

	Strongly Disagree		Disagree		Neutral		Agree		Strongly Agree
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Comments:

14. Please write any additional comments below:

Very Nice and well done project.

Having an audio supplementation will be helpful for some people that like to listen rather than read..

Post-Project Evaluation

A Parent's Guide to Pediatric Epilepsy Surgery

Your professional title Associate Professor of Pediatrics
+ Neurology

Instructions: Place a check in the box to the left of the statement that corresponds to your level of agreement. You may also make comments after each statement.

1. The information in the section, *Understanding Epilepsy*, is a good foundation for the information on surgery and is at an appropriate level for parent education.

<input type="checkbox"/>	Strongly Disagree	<input type="checkbox"/>	Disagree	<input type="checkbox"/>	Neutral	<input type="checkbox"/>	Agree	<input checked="" type="checkbox"/>	Strongly Agree
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Comments:

2. The website emphasizes the journey-like nature of epilepsy surgery and will help parents visualize what to expect for the entire journey.

<input type="checkbox"/>	Strongly Disagree	<input type="checkbox"/>	Disagree	<input type="checkbox"/>	Neutral	<input type="checkbox"/>	Agree	<input checked="" type="checkbox"/>	Strongly Agree
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Comments: Presenting this as a journey is an inventive idea that will really help families feel part of the process.

3. The color-coded journey is an effective parent education graphic.

<input type="checkbox"/>	Strongly Disagree	<input type="checkbox"/>	Disagree	<input type="checkbox"/>	Neutral	<input type="checkbox"/>	Agree	<input checked="" type="checkbox"/>	Strongly Agree
--------------------------	-------------------	--------------------------	----------	--------------------------	---------	--------------------------	-------	-------------------------------------	----------------

Comments:

4. The photographs aid in understanding the text.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
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Comments: Kristen worked very hard to connect with families + get photos of all steps of the surgical process.

5. The brain illustrations are clear and at an appropriate level for parent education.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
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Comments:

6. The success story video is a valuable addition to the website.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
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Comments: This humanizes the process. In real life situations giving a family a chance to meet a child who has gone through surgery is invaluable. This is the next best thing.

7. The frequently asked questions, glossary, and helpful links are trusted resources that I would recommend to patient families.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

8. The printable PDFs are effective alternatives for families without computer or internet access.

	Strongly Disagree		Disagree		Neutral		Agree		<input checked="" type="checkbox"/> Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	--	--

Comments: This will be a huge advantage for us in patient education in clinic.

9. The website navigation is clear and easy to use.

	Strongly Disagree		Disagree		Neutral		Agree		<input checked="" type="checkbox"/> Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	--	--

Comments:

10. The aesthetics of the website are pleasing and appropriate given the seriousness of the content.

	Strongly Disagree		Disagree		Neutral		Agree		<input checked="" type="checkbox"/> Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	--	--

Comments:

11. The overall level of information is appropriate for patient families.

	Strongly Disagree		Disagree		Neutral		Agree		<input checked="" type="checkbox"/> Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	--	--

Comments:

12. The website will aid in communication between epilepsy health professionals and patient families when discussing the surgery process.

<input type="checkbox"/>	Strongly Disagree	<input type="checkbox"/>	Disagree	<input type="checkbox"/>	Neutral	<input type="checkbox"/>	Agree	<input checked="" type="checkbox"/>	Strongly Agree
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Comments: Many families are overwhelmed by the information + do not fully understand the process. They agree to surgery without comprehending fully what it means + without knowing how to ask questions.

13. The website will be a useful parent education resource.

<input type="checkbox"/>	Strongly Disagree	<input type="checkbox"/>	Disagree	<input type="checkbox"/>	Neutral	<input type="checkbox"/>	Agree	<input checked="" type="checkbox"/>	Strongly Agree
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Comments:

14. Please write any additional comments below:

Kristen's hard work + persistence (especially when dealing with busy physicians) has really paid off. The tool she has developed surpasses anything I have ever seen clinically available. I anticipate it will be widely used not just by our patients + families but by centers nationally as a teaching resource.

Post-Project Evaluation
A Parent's Guide to Pediatric Epilepsy Surgery

Your professional title ADRIAN LACY, MD - PEDIATRIC/ADOLESCENT NEUROLOGIST

Instructions: Place a check in the box to the left of the statement that corresponds to your level of agreement. You may also make comments after each statement.

1. The information in the section, *Understanding Epilepsy*, is a good foundation for the information on surgery and is at an appropriate level for parent education.

<input type="checkbox"/>	Strongly Disagree	<input type="checkbox"/>	Disagree	<input type="checkbox"/>	Neutral	<input type="checkbox"/>	Agree	<input checked="" type="checkbox"/>	Strongly Agree
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Comments:

2. The website emphasizes the journey-like nature of epilepsy surgery and will help parents visualize what to expect for the entire journey.

<input type="checkbox"/>	Strongly Disagree	<input type="checkbox"/>	Disagree	<input type="checkbox"/>	Neutral	<input type="checkbox"/>	Agree	<input checked="" type="checkbox"/>	Strongly Agree
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Comments:

3. The color-coded journey is an effective parent education graphic.

<input type="checkbox"/>	Strongly Disagree	<input type="checkbox"/>	Disagree	<input type="checkbox"/>	Neutral	<input type="checkbox"/>	Agree	<input checked="" type="checkbox"/>	Strongly Agree
--------------------------	-------------------	--------------------------	----------	--------------------------	---------	--------------------------	-------	-------------------------------------	----------------

Comments:

4. The photographs aid in understanding the text.

	Strongly Disagree		Disagree		Neutral		Agree		Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	--	----------------

Comments:

5. The brain illustrations are clear and at an appropriate level for parent education.

	Strongly Disagree		Disagree		Neutral		Agree		Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	--	----------------

Comments:

6. The success story video is a valuable addition to the website.

	Strongly Disagree		Disagree		Neutral		Agree		Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	--	----------------

Comments:

7. The frequently asked questions, glossary, and helpful links are trusted resources that I would recommend to patient families.

	Strongly Disagree		Disagree		Neutral		Agree		Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	--	----------------

Comments:

8. The printable PDFs are effective alternatives for families without computer or internet access.

	Strongly Disagree		Disagree		Neutral		Agree		Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	--	----------------

Comments:

9. The website navigation is clear and easy to use.

	Strongly Disagree		Disagree		Neutral		Agree		Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	--	----------------

Comments:

10. The aesthetics of the website are pleasing and appropriate given the seriousness of the content.

	Strongly Disagree		Disagree		Neutral		Agree		Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	--	----------------

Comments: WOULD MAKE COLOR BLOCK A MORE NEUTRAL PASTEL (LIGHT YELLOW/PALES BLUE)

11. The overall level of information is appropriate for patient families.

	Strongly Disagree		Disagree		Neutral		Agree		Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	--	----------------

Comments:

12. The website will aid in communication between epilepsy health professionals and patient families when discussing the surgery process.

	Strongly Disagree		Disagree		Neutral		Agree		Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	--	----------------

Comments:

13. The website will be a useful parent education resource.

	Strongly Disagree		Disagree		Neutral		Agree		Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	--	----------------

Comments:

14. Please write any additional comments below:

IN THE FUTURE, ADDING A NARRATED AUDIO TRACK FOR EACH PAGE AND AUTO-ADVANCE FEATURE WILL IMPROVE THE PROGRAM

Post-Project Evaluation

A Parent's Guide to Pediatric Epilepsy Surgery

Your professional title LEAD Tech - Neurophysiology Tech

Instructions: Place a check in the box to the left of the statement that corresponds to your level of agreement. You may also make comments after each statement.

1. The information in the section, *Understanding Epilepsy*, is a good foundation for the information on surgery and is at an appropriate level for parent education.

<input type="checkbox"/>	Strongly Disagree	<input type="checkbox"/>	Disagree	<input type="checkbox"/>	Neutral	<input type="checkbox"/>	Agree	<input checked="" type="checkbox"/>	Strongly Agree
--------------------------	-------------------	--------------------------	----------	--------------------------	---------	--------------------------	-------	-------------------------------------	----------------

Comments:

2. The website emphasizes the journey-like nature of epilepsy surgery and will help parents visualize what to expect for the entire journey.

<input type="checkbox"/>	Strongly Disagree	<input type="checkbox"/>	Disagree	<input type="checkbox"/>	Neutral	<input type="checkbox"/>	Agree	<input checked="" type="checkbox"/>	Strongly Agree
--------------------------	-------------------	--------------------------	----------	--------------------------	---------	--------------------------	-------	-------------------------------------	----------------

Comments:

3. The color-coded journey is an effective parent education graphic.

<input type="checkbox"/>	Strongly Disagree	<input type="checkbox"/>	Disagree	<input type="checkbox"/>	Neutral	<input type="checkbox"/>	Agree	<input checked="" type="checkbox"/>	Strongly Agree
--------------------------	-------------------	--------------------------	----------	--------------------------	---------	--------------------------	-------	-------------------------------------	----------------

Comments:

4. The photographs aid in understanding the text.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

5. The brain illustrations are clear and at an appropriate level for parent education.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

6. The success story video is a valuable addition to the website.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

7. The frequently asked questions, glossary, and helpful links are trusted resources that I would recommend to patient families.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

8. The printable PDFs are effective alternatives for families without computer or internet access.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

9. The website navigation is clear and easy to use.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

10. The aesthetics of the website are pleasing and appropriate given the seriousness of the content.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

11. The overall level of information is appropriate for patient families.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

12. The website will aid in communication between epilepsy health professionals and patient families when discussing the surgery process.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

13. The website will be a useful parent education resource.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

14. Please write any additional comments below: *This was a great presentation & I feel that help the patients have a clear understanding of the process.*

Post-Project Evaluation

A Parent's Guide to Pediatric Epilepsy Surgery

Your professional title RESBT

Instructions: Place a check in the box to the left of the statement that corresponds to your level of agreement. You may also make comments after each statement.

1. The information in the section, *Understanding Epilepsy*, is a good foundation for the information on surgery and is at an appropriate level for parent education.

<input checked="" type="checkbox"/>	Strongly Disagree	<input type="checkbox"/>	Disagree	<input type="checkbox"/>	Neutral	<input type="checkbox"/>	Agree	<input checked="" type="checkbox"/>	Strongly Agree
-------------------------------------	-------------------	--------------------------	----------	--------------------------	---------	--------------------------	-------	-------------------------------------	----------------

Comments:

2. The website emphasizes the journey-like nature of epilepsy surgery and will help parents visualize what to expect for the entire journey.

<input type="checkbox"/>	Strongly Disagree	<input type="checkbox"/>	Disagree	<input type="checkbox"/>	Neutral	<input type="checkbox"/>	Agree	<input checked="" type="checkbox"/>	Strongly Agree
--------------------------	-------------------	--------------------------	----------	--------------------------	---------	--------------------------	-------	-------------------------------------	----------------

Comments:

3. The color-coded journey is an effective parent education graphic.

<input type="checkbox"/>	Strongly Disagree	<input type="checkbox"/>	Disagree	<input type="checkbox"/>	Neutral	<input type="checkbox"/>	Agree	<input checked="" type="checkbox"/>	Strongly Agree
--------------------------	-------------------	--------------------------	----------	--------------------------	---------	--------------------------	-------	-------------------------------------	----------------

Comments:

4. The photographs aid in understanding the text.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

5. The brain illustrations are clear and at an appropriate level for parent education.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments: As well as for children.

6. The success story video is a valuable addition to the website.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

7. The frequently asked questions, glossary, and helpful links are trusted resources that I would recommend to patient families.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

8. The printable PDFs are effective alternatives for families without computer or internet access.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

9. The website navigation is clear and easy to use.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

10. The aesthetics of the website are pleasing and appropriate given the seriousness of the content.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

11. The overall level of information is appropriate for patient families.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

12. The website will aid in communication between epilepsy health professionals and patient families when discussing the surgery process.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

13. The website will be a useful parent education resource.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

14. Please write any additional comments below:

This can also help
Bridge gaps between
techs & parents.

Post-Project Evaluation

A Parent's Guide to Pediatric Epilepsy Surgery

Your professional title Patient Care Tech

Instructions: Place a check in the box to the left of the statement that corresponds to your level of agreement. You may also make comments after each statement.

1. The information in the section, *Understanding Epilepsy*, is a good foundation for the information on surgery and is at an appropriate level for parent education.

<input type="checkbox"/>	Strongly Disagree	<input type="checkbox"/>	Disagree	<input type="checkbox"/>	Neutral	<input type="checkbox"/>	Agree	<input checked="" type="checkbox"/>	Strongly Agree
--------------------------	-------------------	--------------------------	----------	--------------------------	---------	--------------------------	-------	-------------------------------------	----------------

Comments:

2. The website emphasizes the journey-like nature of epilepsy surgery and will help parents visualize what to expect for the entire journey.

<input type="checkbox"/>	Strongly Disagree	<input type="checkbox"/>	Disagree	<input type="checkbox"/>	Neutral	<input type="checkbox"/>	Agree	<input checked="" type="checkbox"/>	Strongly Agree
--------------------------	-------------------	--------------------------	----------	--------------------------	---------	--------------------------	-------	-------------------------------------	----------------

Comments:

3. The color-coded journey is an effective parent education graphic.

<input type="checkbox"/>	Strongly Disagree	<input type="checkbox"/>	Disagree	<input type="checkbox"/>	Neutral	<input type="checkbox"/>	Agree	<input checked="" type="checkbox"/>	Strongly Agree
--------------------------	-------------------	--------------------------	----------	--------------------------	---------	--------------------------	-------	-------------------------------------	----------------

Comments:

4. The photographs aid in understanding the text.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

5. The brain illustrations are clear and at an appropriate level for parent education.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

6. The success story video is a valuable addition to the website.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

7. The frequently asked questions, glossary, and helpful links are trusted resources that I would recommend to patient families.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

8. The printable PDFs are effective alternatives for families without computer or internet access.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

9. The website navigation is clear and easy to use.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments: *Very clean and clean webpage*

10. The aesthetics of the website are pleasing and appropriate given the seriousness of the content.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments: *Nice font layout and font*

11. The overall level of information is appropriate for patient families.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

12. The website will aid in communication between epilepsy health professionals and patient families when discussing the surgery process.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

13. The website will be a useful parent education resource.

	Strongly Disagree		Disagree		Neutral		Agree	<input checked="" type="checkbox"/>	Strongly Agree
--	-------------------	--	----------	--	---------	--	-------	-------------------------------------	----------------

Comments:

14. Please write any additional comments below:

A well done website that will be a valuable resource for both patients, families and even healthcare professionals.

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