FOR PARENTS BY PARENTS

a guide to epilepsy

Compiled by Elizabeth Grand
Designed by Jillian Daidone

epilepsy SERVICES NEW JERSEY

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About this book

Dear Parent,

My name is Elizabeth, and I created this book during the summer of 2011 after my first year of medical school at Robert Wood Johnson Medical School. This guide began as an idea I had to write children's books about different illnesses that are common in children. After getting accepted into the Student Experiences And Rotations in Community Health/Community Oriented Primary Care (SEARCH/COPC) summer program, I met with members of the Epilepsy Services of NJ and together, we came up with the idea of a "For Kids By Kids" guide to epilepsy. We realized that there were lots of resources for adults and teenagers with epilepsy, but only a few for younger children who have epilepsy. We figured that the best way for kids to learn about epilepsy was from other kids who are living with it as well. So, I interviewed children with epilepsy and asked them about their own unique descriptions, emotions, and opinions.

Since the children were always accompanied by a parent, we thought it would be useful to develop a "For Parents By Parents" guide as well. I interviewed many parents of children with epilepsy and learned about their inspirational struggles and journeys. They shared their experiences and offered guidance to other parents who have children with epilepsy.

"For Kids By Kids" and "For Parents By Parents" are resources for children with epilepsy and their parents to learn that they are not alone. They are compilations of stories, feelings, perspectives, and advice from real children with epilepsy and their parents. I hope that this book helps you learn more about epilepsy, alleviate some concerns you may have, and take comfort in the fact that there are thousands of people out there just like you!

Sincerely,
Elizabeth Grand

Janet

Looking back, what do you wish you would have known when your child was first diagnosed with epilepsy?

I guess just being more aware of all the different types of seizures there are. You know, just being more aware about epilepsy itself 'cause I knew nothing about it. They don't talk about it in school, it's a big stigma so I had never met anybody with it, never talked about it, never heard about it in school. Nothing.

> *And the most important thing for parents is to remember that they are not alone. There are many children suffering with epilepsy, but because of the stigma, you dont hear about it.*

What advice would you give to a parent whose child was just diagnosed with epilepsy?

I think to get the most information that you can get about it. Whether it's through the epilepsy you know, depending on what doctor you're seeing. I just think it's really making yourself aware of all the different types of seizures and medications that are available.

What makes you most proud of your child?

How well he deals with the seizures. For him, he's gonna be 15 in July but mentally he's a lot younger. You know it's hard for them to deal. I think it's a lot, he doesn't understand all of it, but he deals with it very well and he rebounds. As frustrated as he gets, he rebounds very well from it and I'm proud of him for that.

Was there anything you wanted to add or you wanted to say that we didn't cover? Or anything you would want to say to a parent?

No that's really it. You know, it's just not an easy illness to deal with but you just do it one day at a time and I'm lucky I have a child that has a good personality and is easy-going so that makes it a lot easier.

MARY BETH

Looking back, what do you wish you would have known when your child was first diagnosed with epilepsy?

I wish I would have known all of the other things that it affects. Like, the side effects of the medication, that in time, sometimes kids get toxic from certain medication; the educational part of the challenges, like that part becomes like a disability in school, how hard it was going to be to get him accommodations at school.

What advice would you give to a parent whose child was just diagnosed with epilepsy?

To communicate, to be open and honest with your child right from the beginning. To communicate and get a plan to make them feel safe because they're gonna have the seizures and you don't really know where they're gonna have them and to keep that normalcy. Say, we live by the shore, we go in the ocean so, you know, those things are... you know, like in the pool we have a plan. We have different signals that we know at different places. He knows to do certain things at school. You know, put your hand up. Float on your back right away if you're in the pool... I mean , my eye is on you but, you know. Or like in school so he doesn't feel uncomfortable, put your head down. Every kid puts their head down when they don't feel good, but that's the signal: head down, hand up. You got a plan and so that's why I think it keeps that normalcy in their lives where they don't feel different. They kind of know they're different but if there's a plan in place, and to tell the appropriate people, that eliminates the stress when it does come.

MARY BETH

What makes you most proud of your child, Mark?

'Cause he's really a kind kid. He's 8 years old but he's mature enough to understand everything that comes along; with all his extra school work that needs to be done at home and in class, that he puts the time in and he sees the progress. Because kids with epilepsy or if there's a learning challenge, he's always gonna have it, he just has to make accommodations. So we're really proud of him because he doesn't see that he's different. Like, there's no barriers. Things happen to people all the time, it's just how he's handling it which is what inspires us.

He's handling it really well?

Yeah. As adults, if children can handle things then, you know, it just makes the people around him handle it the right way. So that's what makes us proud.

Was there anything you wanted to add or anything else you wanted to say?

No, I just think this is a wonderful thing 'cause it makes kids lot of times, you know, when they know they have certain things they don't want to talk about it. You know, they're not gonna openly talk about it unless something happens. So it'll be a good thing because then maybe, like you said "Do you and your friend talk about it?" They don't, but they say goofy little things, like funny little things.

Just like, that whole thing, like the anticipation of what we're going to be faced in 10 years isn't really important right now. Just handling, you know, day by day, and making sure our biggest thing, that no matter what, the only thing that really matters is that (my son) Mark develops the confidence to know how to handle it as he grows into a teenager and a young adult. And that's the important thing when they're diagnosed young like this.

...he puts the time in and he sees the progress.

ELLEN

Kelly's Mom

Looking back, what do you wish you would have known when your child was first diagnosed with epilepsy?

The hardest part for me was, having had three children before, I had no idea the symptoms I was seeing so I didn't have the understanding of what I was seeing. I wish I'd known what I was seeing. I was attributing Kelly's problems to other things. Stomach problems, because rolandic epilepsy really affects the mouth, throat, and stomach area, so I was thinking it was other things. I think just being a traditional mom or normal mom I was ready to take on the guilt of "Why didn't I know what I saw?" But why would I have known? It wasn't anything clear cut. But looking back, the threads all tie together and it all makes sense. I was sorry she had to suffer for that extra time, and I don't think we would have escaped the grand mal seizures anyway.

What was your experience like going to different physicians and hospitals?

That's a maze. First of all, physicians are not ready to accept that your child's had a grand mal because they have not seen it- you saw it. And when you see a grand mal seizure, it doesn't matter whether you've ever seen one before, you're like, "That's a really big seizure," and then you learn the name for it later. So there was no doubt in my mind that Kelly had a seizure. But it's interesting... the police officer and EMT that arrived five minutes afterwards, and Kelly's big seizure lasted several minutes, they came in at the tail end. Later on the police officer came back, and he's become a good friend of Kelly's, and he stood on my doorstep looking down at his shoe and I so admired him for his, he said, "What did I see there?" He didn't even know for sure. And I said, "You saw a grand mal seizure." So initially the medical profession wasn't ready to accept it, that's fine, but they were giving me very odd suggestions, such as, "Maybe she was brushing her teeth, breathed in, and choked on her toothpaste." I said, "You know, I think I know the difference between choking and something... this was very significant, her behavior."

And then going through the first EEG- that's rough because I'd never seen one happen. It's tough on the child, it's tough on the parent having to see the poor thing go through all of that stuff. They hyperventilated her, that's tough. And watching the technician's face, I could just read right away we had a problem. And then there was a little bit of guesswork that was being thrown at us, that's always tough. So eventually my decision, and I do believe we have wonderful physicians in this area, but I needed someone who was dealing specifically with pediatric neurology so we took Kelly to Children's Hospital. And after the right testing, the pediatric neurologist knew within ten minutes of talking to us. it was almost as if, and he wasn't smiling at the fact that she had it, but he smiled because he said, "I know what's wrong with your child." Knowing what was wrong with her was 3/4 of the battle, because then we had a road. We could make a plan. The unknown was the hard part.

ELLEN

What advice would you give to a parent whose child was just diagnosed with epilepsy?

I would want to learn about their specific type of epilepsy and I would read only about that, if they were sure. For example, Kelly has very specific rolandic epilepsy, so I went to work, I learned everything I could but I didn't learn beyond that because it can be frightening and overwhelming, and you're already frightened and overwhelmed. So you want to become really, really well-versed and prepared in what your child is facing and not take any extra in.

What makes you most proud of Kelly?

The fact that Kelly took such a negative... I'm sorry that's wrong, took something that could have been a negative and turned it around and has owned it. Her favorite line is "If you say I can't do it, I can do it." She hasn't been afraid, she's persevered, she's decided every time she sees something that's a challenge she doesn't go in it with a downside- she goes in and says, "Okay, do I walk around it, over it, or through it?" Well good for her! But I do give my family, her sisters, her father, they get the credit too because they've created an environment where Kelly has a condition that has to be accepted and dealt with but it's not the whole Kelly- it's just a part of her. And we've learned to just figure out what that part was and then we were on and going. But Kelly had to do the big work because she's the one doing the experiencing.

> "I had hoped that five years ago looking down the road... I had hoped that I felt the way I do today."

ERIN

What advice would you give to a parent whose child was just diagnosed with epilepsy?

I think, again, just to... I keep saying it but remain calm and realize that their life can be as normal as you make it. If you make it... we've kind of... like, Emily is the youngest of 4 children and we have some other children with... a son who's visually impaired and we've kind of lived our lives just always like: you are you, you are not the disease or whatever you want to call it. You are a human being first, and a great human being, and you can do whatever the heck you want. You just have to... you might have some limitations but so far she hasn't had any so I've been thrilled with that. And that just continue to be a person that you are going to be; with or without epilepsy, she's the same person.

Looking back, what do you wish you would have known when your child was first diagnosed with epilepsy? If anything?

I guess just... you know, I didn't realize how common it was really, that there's that many people affected by it. And that, really once it's under control with the medication... it's frightening when you first hear those words and you don't really know what her life is going to be like, but since she's been able to be controlled with medication... and I guess thinking back to it then I wish I could have been a little... I guess I got upset probably in the beginning, I can't remember now... and a lot of tests. But I think we remained fairly calm about it and just sort of, researched it, did a little research on what it was and what her life, you know, that it wouldn't be any different than anybody else's.

ERIN

> *"You are a human being first,*
> *and a great human being, you can*
> *do whatever the heck you want."*

What makes you most proud of your child, Emily?

I guess the very fact that she doesn't use this as anything, as a crutch or... she does whatever she would normally do. She loves cross country and even though that's when she's had some difficulty, where her seizures came out unfortunately running in the heat and dehydration, you know all the things that can bring it on did, but she... she was strong and knew what she wanted to do. So she knows to take her meds and take them on time, and do what she has to do so that she can continue to run cross country, go places with her friends, do what she needs to do. And I think her strength is probably what I'm most proud of.

Was there anything else you wanted to say or anything you wanted to tell a parent?

No I guess just, like I said before communication with your child is the best thing you can do. Keep talking to him or her and make them realize that... you know, there's been times where the medication- she gets annoyed that she has to take it, or when she was little and she didn't understand and it tasted bad in the liquid form, but we just kind of kept talking about it and kept saying if that's all you have to do so that you can continue to do what you want to do... if it's just taking a few pills or doing this then that's easy. And just, I think communication and just talking and understanding that there's going to be moments where there's ups and downs and always try to focus on the positives and the ups.

TRACY

Looking back, what do you wish you would have known when your child was first diagnosed with epilepsy?

Well over time the education that I learned... I wished when she was first diagnosed I had that available. But over the years I looked for education, I looked for support. I just wished I would have known earlier.

What advice would you give to a parent whose child was just diagnosed with epilepsy?

Contact doctors. Use the internet. Join support groups. Especially talk to your doctor, talk to your school. Communicate your child's needs so it makes it much easier.

" Communicate your child's needs so it makes it much easier. "

What makes you most proud of your child, Rachel?

Basically how far she's come, how mature she got. She's been dealing with this most of her life and she's just... there are good days, there are bad days, but she makes the good days better and the bad days we deal with and we get through them.

Anything you would want to tell a parent who was just starting out with this?

Well, what Rachel said, how she always felt different; but I always didn't allow her to feel different. I made her feel like everyone else, she could do everything else... but I always had my eyes open. We dealt with something that came across but she was always... I never limited her to do other things and just self esteem, confidence builder.

When Rachel was younger she was very frustrated with the diagnosis of epilepsy. She hated going to the doctors... She had a lot of anger in her. She had a lot of anger, why her... And the medications, the side effects of medications, and she always had her brothers helping, and why did it happen to her, and her friends don't have epilepsy... but my advice to everyone:. there are people out there with epilepsy. Unfortunately people are embarrassed and they don't want to see they have epilepsy but there's nothing to be embarrassed about. You're like every other child and this is what you're dealt with and you just have to deal with that and, like I always told her, it could be worse. And it makes her a better person and she matured from it, and she dealt with having an illness early on in life but it'll make her stronger when she gets older.

> ...but I went on and I wanted to educate other children and other adults that there's nothing wrong with a child with epilepsy.

TRACY

...Other adults saw ambulances outside our house, knew her diagnosis, and associated her "sick"; that my child (Rachel) shouldn't become involved with because she's "sick". So as soon as I heard that I was very upset, but I went on and I wanted to educate other children and other adults that there's nothing wrong with a child with epilepsy.

Jean

"Jean's daughter, Morgan (20) and her service dog named Tomba."

Looking back, what do you wish you would have known when your child was first diagnosed with epilepsy?

What I wish I'd known was everything there was to know about it. It's hard to start with all the literature at that point but you don't know that you're going to need it obviously. But there's so much to learn about it, just even technically so that you can become an advocate and it's just a lot of material. There's so many diverse aspects of epilepsy; one profile is not the same as another.

What advice would you give to a parent whose child was just diagnosed with epilepsy?

Gain as much knowledge as possible and to work on developing your own skills as a class advocate in medical, educational, community spheres. I would encourage people to always speak up. Just know as much as you can and share as much as you can... I actually did read that before, so that's the number one. Number two, equally really number one, is to get the best possible care for your child. The way to do that is a little daunting at times but I think that it's absolutely critical to your child's future. So I tried to think about how you do that... I think you really do have to connect to other families, that's one. But secondly you have to connect to your physicians and really ask them the pointed questions.

You have to ask your physicians, "If my daughter, my Morgan, were your child, where would you go and who would you talk to?" And you ask them that at every single stage. One thing we learned early on is that epilepsy is where the art and science of medicine connect. Unfortunately, there's no magic treatment and intervention in most cases. Nowadays there's more protocols perhaps but it's still a crapshoot with the meds, and if you have a more severe situation and you fail some meds statistically there's such risk for failing more meds... you really have to seek second opinions. We're big believers in seeking second opinions and being involved with physicians who support seeking second opinions. Some of the community doctors are not as open about that. So I would say, advice to other parents: learn as much as you can, get to the possible care, and follow your heart. If there's a physician who you don't feel is supportive of your efforts in any way to get the best possible care then follow your heart, follow your best thought on that.

We ended up changing some doctors and it was with angst too because you develop a relationship, especially with a child with high level medical needs but you get to the point sometimes where you just feel like, we want to learn more, we want to seek the best possible future for her, we're not willing to just sit back and to take "you just have to accept it for what it is" kind of thing. The goal in epilepsy is seizure-free. Accept nothing less. In many cases it's achievable, certainly more achievable if the intervention early on is aggressive and complete and thorough. I feel too many people don't get to adequate care still, it's just unfortunate. It's hard, it's not always in your backyard. It takes some doing. And my third thing, I guess it's equal but enjoy your child. Our daughter is a trip and a half, she's so much fun. She was very critically ill and we really learned to appreciate everything that she did so we may have had an advantage that way.

Make as much fun in your lives as possible. It sounds trite but it's really... our two girls used to play seizure with their dolls. Morgan loves to go to the hospital, she thinks every hospital is an amusement park. She loves the people she's met there, she gets upset if she can't go to the hospital, if she's going for a check up she gets upset that she cant stay overnight. She just has a great attitude toward her care and you have to look at it as a journey and you have to keep having fun. Concentrate on the quality of life. I do see some people what I consider, and professionals, over-protecting children with seizures and it's an individual decision, families have to make their own decision on it. We decided and we don't regret it for a second, to try to make fun a priority. So Morgan swims... yeah, we take some precautions: clear water, whatever needs to be done to make her as safe as possible but she swims, she rides horses, she bikes, she walks downtown by herself. We just placed quality of life at a premium.

My husband and I actually sat down and said if she dies today, we will have felt like she had a great go. So it's more important for her to keep great-going than to put a bubble around her and say you can't do this, you can't do that. It's just something we revisit sometimes because it does get scary. She's had a seizure in the water, she's had falls, she's gotten run over by a car, everything has happened. But we don't regret, we always rely on that decision and use that as our guide post when you want to say no, you just say yes instead. Your heart may go up in your throat a little bit but you go "You go girl!"

you go GIRL

Ellen

Claire's Mom

Looking back, what do you wish you would have known when your child was first diagnosed with epilepsy?

I wish someone, like another family or another mom, would have given me some information because I was going through a situation where I didn't know the right answer, how to deal with talking to the doctor, what medication, what we should be trying. They give a lot of options and suggestions, but no one knows the bottom line. I was just not very educated. I wish somebody could have called me and told me "We went through it. It's gonna be okay," because I was very crazy, very nervous because I had no information about this disease. I had heard about other diseases that children had gotten but not this particular one. So I was in the dark. I had no information and just relied on the doctor telling me. I think practical matters is a little different from what the doctor can help you with. They don't really give you practical matters, like day-to-day, because they don't have epilepsy and most likely their kids don't have epilepsy. I think the information is much more valuable coming from a parent as far as dealing with the stress.

How did you go about getting the practical information?

I went online. Epilepsy Services of NJ had a little blog conversation between parents asking other parents advice and that helps. Sometimes it makes you more nervous but overall I think it helped as far as dealing with day-to-day routine. Especially since she was in school, I wasn't sure if they were going to call me, waiting on the phone, are they going to call me and tell me to go pick her up? It was very crazy, not knowing the disease and not knowing what's going to come and what's going to happen. I think this book will give parents some comfort to let them know that it's not that bad. Eventually everything will be okay. It's just that initial, first diagnosed period that's a little crazy. If you have some parents telling you, like a support group or something, I think it would be very helpful.

I think the information is more valuable coming from a parent, as far as dealing with stress.

What advice would you give to a parent who just found out their child had epilepsy?

Obviously they will be worried but they should get a good doctor and get a very good diagnosis as far as what type of epilepsy because there are so many different kinds. From that point on if they have to have medications... it's a very long process to try different medications but hopefully one of the medications will work. And it will. It's just patience. You have to find the right medication and make it work. Eventually they're going to have to get used to it. It's a process that you have to get used to. You just have to be calm and be patient and listen to the doctor for advice and go about day-to-day routine, not let it be an obstacle and stop everything. For a while I just stopped all... I went crazy, I couldn't go back to a routine. That's important. It's hard but you have to cope with it somehow, just as if you were diagnosed with anything.

What makes you most proud of Claire?

She is a very brave girl. She dealt with it much better than I did. She didn't let it become an obstacle in school. She's still doing very well in school and she's trying very hard and I'm very proud.

Just get some support, I think that's the most important. Obviously get a good doctor, but I think if they can't cope by themselves then they really need to reach out for help and that's why I reached out to Andrea (from ESNJ). She gave me some parents' names and I was able to communicate with them for a little bit and I looked online. Time will heal- I think that's the bottom line as you go along with this whole process. Eventually you'll get used to it and eventually you kind of figure out what triggers it, what type of seizure it might be... The children usually do better than parents for some reason. Parents worry too much. She (her daughter, Claire) knows something's wrong but I don't think on a daily basis she thinks something's wrong with her. I think the parents are more worried by the kids and it's natural, you overprotect your children. But after a while you realize: let them do what they have to do, don't cut out any activities because the situation has changed. We did cut out some, some are not suitable for her, but we still keep some of the activities for her to do. As long as it's safe it should be okay. I think everything will be okay, will all work out eventually.

The medication makes them very tired, so eating food on a routine, small meals on a regular basis, I think it helps. It's a practical matter. Unless you're going through it you don't really know. But each child is different.

Debbie

Olivia's Mom

Looking back, what do you wish you would have known when your child was first diagnosed with epilepsy?

I wish I would have had access to a group of parents who had kind of walked the walk already because so much information is thrown at you and your head is spinning and you're trying to wrap your mind around a diagnosis that's life-altering. And to have a source to go to aside from a neurologist who, like you said, uses big words and sometimes it's nice to be able to talk with somebody who has lived through it and is living through it and experiencing it from the same perspective.

How did you go about finding that sort of resource?

It took me a while. You're almost in mourning initially because it's a life-altering diagnosis for sure. I started going to the website and reading some of the other parent posts. I started engaging that way, that was my comfort level. But in terms of people who are local, who also have children with epilepsy, there were not... a lot of people try not to be too vocal and they try to sweep things under the carpet and I am not one of those people. I was much more comfortable being able to be in touch with people who are already owning it and experiencing it and I could learn and pull from them.

What advice would you give to a parent whose child was just diagnosed with epilepsy?

Fasten your seatbelt- it's an unpredictable and emotional ride. But ultimately, like everything else, it's what you do with it and I think we've had a lot of good come out of it. I have two older children, and I think Olivia's brothers have benefitted from it. I think the boys are more tolerant, and you have to appreciate that your lens is going to be forever changed. The way you view everything and your perspective is forever altered.

What makes you most proud of your child, Olivia?

I could talk for hours about that! She's resilient. I think kids are more resilient than parents a lot of the time. She's a fighter, she always was. You go to get your blood work done, you don't cooperate so well, but she's definitely making strides with starting to own the fact that she has epilepsy and it's something that she has and something that she's always going to have and I'm very proud of that. I'm proud of the progress Olivia has made in terms of coming to peace with who she is and that this is part of who she is.

fasten your seatbelt.

Any recommendations for talking to your child about it?

There are a couple of really good books out there. "Dotty the Dalmatian with Epilepsy," "Lee, The Rabbit". But I think the best way... it's hard because it's a very abstract thing when a child has a seizure. There was a period of time where Olivia was not cooperating so well with her medicine and she had a seizure and I wanted so desperately to remember. I wanted her to remember something, whether it be not feeling well before, or the paramedics coming in and putting oxygen on her, or the ride in the ambulance, I wanted her to remember so that she could put two and two together that this is what happens when you don't take your medicine. But it's a very abstract thing, between the Diastat and the effect of the Diastat, and the effect of the seizure, she doesn't recall anything.

It's hard to find a way to break it down to make it palatable for a child, where they can process it in a way where they are able to. A lot of kids with epilepsy have other developmental problems so I think it's that much more complex (to Olivia). But what's the way that we've talked about it... what is a seizure? It's a what in your brain? A thunderstorm in your brain, right? She's been hearing that for a long time. We read that in one of the books, and that's one way that you can try. Get them some visuals, show them the brain. There are some that have little stars coming off of them to show how it's supposed to look and how it looks during a seizure. But again, epilepsy is as abstract as can be so that's a hard concept for a child.

You're not going to sleep so well. You need to find ways to find some peace. It's not easy because you're constantly waiting for the next shoe to fall, you're waiting for that phone call when they're not with you. It's a life-altering diagnosis and it can be a challenging existence. And you have to work very hard to keep you and your spouse on the same page because it can be very stressful having a child with any kind of special need, including a medical condition. It's a challenge. It's work . It's a whole other job. It definitely changes the way you view the world.

Try to include and involve any other siblings as much as possible, even in doctors appointments. We have our boys come to the hospital when we're there for EEGs and spend time with her . It's important for them to feel somewhat involved and not to feel excluded from the situation because it's part of their reality as well.

You think that you have it all figured out as much as possible and then... the one thing our neurologist taught us from the very beginning is the one thing that's predictable about epilepsy is that it's unpredictable. That can be a difficult way to exist. It's hard not to let it rule you. You cant let it rule you. It's always there, of course, but you have to enjoy every day the way that you would regardless of what kind of medical condition you're dealing with.

sarah

Looking back, what do you wish you would have known when your child was first diagnosed with epilepsy?

That it's not an exact science and you'll be dealing with the unknown and one medication can be wonderful for one individual and not so great for another. It's unpredictable. And also I think I felt very alone at first and that there weren't a lot of other people who would understand but that is just so not true. There's a lot of us that do understand, and I wish I reached out to ESNJ sooner to get that support because it would have made our journey much easier.

What advice would you give to a parent whose child was just diagnosed with epilepsy?

Patience, a lot of patience. Try to do your best to understand what they're going through. They're scared, they're most likely adjusted to medications and side effects of medications. It takes a lot of patience and time to help support them through that. You have to support them physically through their seizures but there's also an emotional component of it and helping them handle that piece of it as well and making sure they're as comfortable as possible. Jack felt very different at first when he received his diagnosis so we tried to do our best to help him feel comfortable with what he was facing.

What about talking to your child about it?

My father had grand mal or tonic-clonic seizures so I had that background information of knowing how it can affect you emotionally and the stigma attached because I grew up with that watching my dad go through it. So I knew from the get-go I needed to be very open with Jack and talk to him about his feelings. He finally told me one day he felt so guilty that he was making us sad because he had a rough road going through numerous medications to become controlled and that's a lot for a child to carry emotionally... We wanted to make sure Jack was as comfortable as possible with his diagnosis and when he wasn't he got him the support he needed to accept that. I think he finally started to accept everything when he had the courage to tell his friends and tell other people and talk about it; that was a big weight off his shoulders.

I explained to Jack about making sure the people he's around understand what he has so that if he has a seizure they know what to do and then they wouldn't be so fearful or scared or think he's strange or different, or if he's having an absence seizure and he's not responding to them- now his friends in his class know if Jack does that they know what it is and they know to wait until he makes eye contact again and they keep on about their business. Jack used to walk around pretending that he heard everything and it was very stressful for him to do that so once he was able to kind of get that out he felt more comfortable and didn't have to pretend.

"Patience...a lot of patience"

What makes you most proud of your child, Jack?

His courage. It wasn't easy in the beginning and he cried quite a bit and he went misdiagnosed for a while from what we think, and he was in the hospital 5 times in a year and a half and 4 medications and he kept plugging away. He had his moments where he was in tears, but he would get that strength back together and keep moving forward. As a result I'm very proud of him because I think he's much stronger now because he's taught himself to work through it and reach out to others. I think he's found a lot of strength in reaching out and helping others. He did a fundraising walk at school, he spoke in front of hundreds of people at a fundraiser in the city, he participates in the walks, he went to Kids Speak Up down in D.C., he volunteered at the camp this past summer. His experience, instead of sitting down and being upset about it and negative, he's now turning it into something positive in reaching out and helping others and that's not easy to do. He could easily just sit there and say "I'm good. I don't want to reach out to anyone," but he's not, he's helping others and talking about it. He never used to talk about it but now he will, and that takes courage to say, "Hey, I have something."

I think the biggest thing, I just spoke to a brand new parent the other day and she said "I'm overwhelmed and no one understands me," and I get that because I've been there myself. So the first thing I said to her was "Well, let's take that off her list because you're not alone. I know you're overwhelmed but you're not alone and there's so many of us that understand." And that she'll meet, I've met some of the most amazing people because of this journey that I never would have met if we didn't have this diagnosis. So there are some silver linings. My first and foremost would definitely be that you're not alone and to reach out, get on the internet, reach out to your Epilepsy Services of NJ wherever you are. That's why you guys are all there to help support us and it's a huge piece when you're going through some of the rough times to have that support. Some of my other epilepsy moms- I don't know what I would do without them because they're just so supportive and they understand.

Everyone has different seizure types and there's variation in their stories but the theme of epilepsy is it's unpredictability, side effects of medications, and the stigma attached is all the same. I think if we all can muster up the courage that our children do to talk about it to others and help educate we can reduce that stigma even further.

> "I think he's found a lot of strength in reaching out and helping others."

Raina's Mom

"I WISH PEOPLE TALKED ABOUT IT MORE"

Looking back, what do you wish you would have known when your child was first diagnosed with epilepsy?

Nobody really talks about epilepsy or seizures like they do other diseases that kids have like cancer or juvenile diabetes or head conditions and stuff. It's almost like, nobody really talks about it.... I don't know if it's because of the stigma. I just feel like I wasn't educated enough. It really came out to left field for us, which I think happens to other families as well. When it happens it just kind of hits them. Not really being on our radar. I wish people talked about it more like they do cancer or leukemia or something. I feel like there's more people talking about those types of illnesses rather than epilepsy or any kind of neurological thing. I wish it was out there more. Now that my daughter has it I'm more aware of what's out there. The resources are there but just not as much. You just don't know who to go to or who to turn to unless you have a nonprofit like Epilepsy Services of New Jersey.

How did you go about finding different resources?

Initially it was just our pediatrician and our neurologist that was giving us the resources just to tell us this is what we need to do, and this is the medication she needs to be on, you come in for your blood work, you come in for your periodic EEGs and that type of thing. I actually found out about the Foundation (ESNJ) through Sarah who lives in our town. You know we're friends... we were kind of casual friends but once we realized that we had something a little more in common we became really close and through her involvement in the ESNJ she told us about the walk (Glow Walk Run) so we all went down to Washington D.C. for the walk which I think was really good for Raina as well as the rest of us to see that we weren't really doing this all by ourselves and there were others out there who are going through the exact same thing. If anything it's just a source of comfort to know that there were others out there. It's a support group. When Raina had her episode a few weeks ago I called up Sarah and she had walked in my shoes. It's not like calling my neighbor who has no idea what it's like. There's a kind of support where unless you've walked in our shoes you really don't know. In that respect I met some people like Sarah who had gone through the exact same thing which it's just a source of comfort and something to bounce things off of. That's been tremendous.

What advice would you give to a parent whose child was just diagnosed with epilepsy?

Don't lose hope. There are resources and the medical technology for finding the answers and for finding some resolution as to getting your child healthy- it's out there. Just don't lose hope. Some days you might feel like there's really nothing that you can do but there is a light at the end of the tunnel.

What makes you most proud of Raina?

How strong she is. Even though she's nine years old she's wise beyond her years and really has been handling this really, really well. My husband and I had said we don't want this to hinder her or define her. We don't want it to define her as a person to stop her from doing the things that she wants to do. Granted there are some limitations to the things she can do but we don't want her to feel that she can't do it at some point... maybe she'll be able to do some of the things she wants. She wants to do swim team but she cant do it right now. It's kind of a scary thing to be swimming and have something happen, but eventually she'll get in a place where she'll be able to do it. So that's what we've instilled in her in the past year. I think it's made her a stronger person and we're stronger too watching her be strong about it. There have been times where she hasn't been able to do certain things because of the over-exertion and whatnot. She gets a little upset but then she's like, "I know I'll eventually do it," like going and playing laser-tag and watching 3D movies. There's certain things she wants to do but she knows she can't because she doesn't want to have an episode. At some point hopefully we'll get to a place where she can.

Don't lose hope and keep the faith... Search out those

resources through ESNJ. There are

so many things that you can look to in order to

get some resolution, get some peace, get some answers.

Joanne

Looking back what do you wish you would have known when your child was first diagnosed with epilepsy?

I didn't really know much. I had to research. I never realized all of the different types. I had to do a lot of reading just to find out what I was up against. But it gave us hope that he'll grow up and grow out of it. As I found out more it gave me more hope.

What advice would you give to a parent whose child was just diagnosed with epilepsy?

Read as much as possible. Write down questions for your doctor. Remove yourself from the situation and focus on your child. It becomes so emotional, and it's easier to deal with if you take yourself out. Remove yourself and take care of your child.

What make you most proud of your son?

His accomplishments. The little things. His language is improving and now he knows how to read. He is more social; he goes up to other children and introduces himself. He's a hard worker.

DON'T GIVE UP HOPE.

There are a lot of people out there who can help.

Find a support group.

KATHY

What was your initial reaction to her first seizure?

It's been about 2 months (since Cortney was diagnosed with epilepsy). I didn't know what was happening but I knew it wasn't normal for her because she's usually very alert and always listening and always paying attention and then when she was getting out of the car one day just froze and looking blank in her eyes and looking up and just not moving and talking, and I was like "Come on Cortney, get out of the car," and she just stood here, I was like, "What is going on?" So I started telling my husband to watch her more and more to see if he saw what I saw and then he thought he saw the same thing so then I started looking it up on the computer and every symptom that she was doing, all the same stuff she was doing was partial seizures. So that's when I called the pediatrician and they told me to call a neurologist.

When you first got the diagnosis from the doctor, what was your initial reaction?

I guess I kind of just felt, kind of relieved because I knew I wasn't going crazy- that there was something wrong with her. And she's so little that I thought... online a lot of the time, stuff that I was reading people were saying that usually it's not diagnosed this young so I was like, "Am I really seeing what I'm seeing?" Because they're telling me that usually they're not diagnosed until they get to their grade school and she's four. So when the doctor said "Yeah there is something abnormal," I felt... I mean I was upset because I didn't want her to have a problem, but I was kind of relieved knowing that I knew what it was and the doctor was telling me that it could be treated with medication.

Do you remember any of the initial questions you had when you first found out? is there anything you're still wondering now?

Just the whole medication thing, because she's never really been on any medication. I have to give her... first it was twice a day, then three times a day, then twice again, now three times again. So that's kind of nerve-wracking, wondering "Is this medicine going to work? And how much do I have to give her? And when do I have to give it to her?" That's just always my worry, about the medications. And more testing. We gotta do more testing.

What makes you most proud of Cortney going through all of this at such a young age?

Just that she's really good. She doesn't give me a hard time about taking her medicine. And she knows what's going on. I mean she doesn't really remember it but she kind of understands that something's happening and I think she's handling it pretty good for a 4-year old.

What advice would you give to a parent whose child was just diagnosed?

I guess just go with your gut and if you think something's wrong with your kid see the doctor. Even if you read online that it's not usually common for them to have a problem at that age, if you see something then I think the mom's gut is probably the best thing to go by. Because if I didn't go with my gut then she wouldn't have gotten diagnosed and be on medication so quickly, and everybody tells me that it's really awesome that I saw it so early and that she got on medication so early, so hopefully she'll outgrow it early.

RITA

Looking back, what do you wish you would have known when your child was first diagnosed with epilepsy?

Not to panic and that it does get easier and that it's not really life-threatening. And that, in my daughter's case, it's been easily controlled.

What advice would you give to a parent whose child was just diagnosed?

Not to panic. You can live with it. Just take the medication, take her to the doctor. It's not really life-altering, it really didn't alter Rosa's life at all. She's learned to adapt to it and she lives with it.

> She learned to adapt
> & she lives with it.

What makes you most proud of your child, Rosie?

That she manages the epilepsy, manages the seizures, takes her medicine all the time. She's very aware of it and she's shared it with some of her friends, she talks about it. She makes me proud doing all of that.

It's frightening when it first happens; the first seizure is very frightening. But after a while, after you've been through it, you time it, you watch the movements, and it becomes almost mechanical.

Cathy

Looking back, what do you wish you would have known when your child was first diagnosed with epilepsy?

I wish I had, when she was first diagnosed, I wish I had more explanations. I wish the doctor hadn't just said, "She has epilepsy". I wish he would have gone into more detail to explain exactly what that meant. And as far as what to expect, how things may change in my life and what ... I wish there was a support system set in place so that when the diagnosis first came there was another person to sit there to say "Are you ok? Do you understand what this means?" And that's basically it. There was no... there wasn't anything like that at the time.

What advice would you give to a parent whose child was just diagnosed with epilepsy?

Ask questions. Until you feel that you've gotten an answer that satisfies every question that you may have. Regardless of what the doctor is saying, ask about the types of seizures and what to expect; the types of medications, what could you expect from possible side effects; what kind of an impact will this have on my family? Ask as many questions and if you feel that the doctor is not answering your questions don't be afraid to just keep asking. There's some doctors out there who have a tendency to just say "This is the way it is," and what they say the parents should take it at face value. However, the parent really needs to understand that they are a vital part of their child's care and they are part of that child's healthcare team.

What makes you most proud of your child?

Her ability to look past other people's... (what makes me proud of her?) That's a hard question to answer. I'm just proud of what she does every day. I'm proud of her accomplishments. I'm proud of her trying. I'm proud of her impact that she has on everyday people.

Was there anything you wanted to add or you wanted to say that we didn't cover? Or anything you would want to say to a parent?

I think I would be going on too long! I'm ten years into this so, there's a lot of information out there. There's probably... there's so much information out there that you're not capable of giving a two-line answer to any of this because it's so, so complicated. And it's very complex.

ASK QUESTIONS

"And the more information you have the less scary it becomes. And there's also a lot of other people who have epilepsy and it just makes you feel a little better."

Debbie

Looking back, what do you wish you would have known when your child was first diagnosed with epilepsy?

Hmm, that's a good question. Umm.. wish I would have known? I wish I... I didn't know anything about epilepsy or seizure disorder. I'd never even seen a seizure so I was kind of ignorant...

When she first had her first seizure I didn't even know what was happening. Like, I thought she was choking on something. I didn't even recognize it as a seizure. So we called first aid and then we realized. Then a week later she had another one so, you have to have two seizures for it to be called epilepsy. So I wish I would have known a little more about epilepsy and seizure disorder just to have identified what was happening the first time she had one.

What advice would you give to a parent whose child was just diagnosed with epilepsy?

I think go find the best doctor you feel comfortable with and don't give up. Keeping trying, you know, everything you can do to control the seizures because there's a good chance that if you find the right medicine and you can keep your child seizure-free for 2 years, they may never have seizures again so the main thing is to find the right thing to calm their brain.

What makes you most proud of your child, Katie?

Everything. But she's... she's just a trooper and she's pretty fearless and she doesn't give up and she's very compassionate and... like I have... there's too many things to say in a short amount of time but I'm really proud of the way she handles this because its hard for her and she keeps a positive attitude.

There's a lot of other families dealing with it and it gives you strength cause you're not the only one and that other people do it. And there's a lot of resources out there.

MICHELLE

He's very nice, friendly to EVERYBODY

Looking back, what do you wish you would have known when your child was first diagnosed with epilepsy?

A little more information from the doctor. They just said he has.. at first they didn't know what it was and they were just waiting and they just said "Oh he has seizures". They didn't give me nothing. They just said "Seizures, here, take this medicine" and that was it.

What advice would you give to a parent whose child was just diagnosed with epilepsy?

To ask a lot of like, questions and get a lot more information from the doctors or look it up, you know how you can look up everything online like they have more information but to see if they have any reading material. They didn't give me nothing, so like, I didn't know anything.

What makes you most proud of your child?

He is.. he is.. a very good person. Very warm, he's very nice, friendly to everybody.

CAROLINE

Looking back, what do you wish you would have known when your child was first diagnosed with epilepsy?

That if you're not understanding what the doctor is saying or it doesn't seem right, seek out someone else. We went through several neurologists before we got an epileptologist up in Hackensack Medical Center who is wonderful and that's really when we were able to get her epilepsy under control.

In your experience going to all these different doctors, are there specific things that you look for?

Look for a doctor who listens to you. She was first misdiagnosed with benign rolandic epilepsy, and I know doctors hate when you look online and read up everything, but what was happening with her was not meeting the profile at all and it just did not jive. I knew that, and I would go to the doctor and say "Look, this doesn't..." and they'd go, "Meh, you know we said it's this," and I'm going, "It's just not jiving." Finally I found a doctor who listened to me and he looked at the old EEGs and he said "You're right. They're wrong. This was a red herring... I see the frontal lobe spikes and they missed them because they were too busy looking at that..." It was only then that he brought her back in for a week-long EEG in Hackensack Medical Center and from there he was able to better diagnose it and switch her medicine to Keppra and, knock on wood, she's been pretty much seizure free ever since.

What advice would you give to a parent whose child was just diagnosed with epilepsy?

To reach out to the Epilepsy Services of NJ. Andrea and all the folks there have made such an amazing difference in the quality of her life. We would not have found the doctors we found had it not been for them, we would not have been able to interface with the schooles as well had it not been for them. Definitely reach out to Epilepsy Services of NJ.

What makes you most proud of your daughter, Sam?

A lot of things! She's a great student and she's funny, but also that she just does not let it stop her at all. She means what she said, to her it's just a non-event. She's not afraid to speak up.

I would say, when dealing with schools, know your rights. Don't feel shy; if they're being infringed upon, say so. Be very careful what's in writing. Don't assume if someone is smiling and saying "It'll be okay," that it will be okay. Take it very seriously and don't feel apologetic if you need to ask for things from the school. We're kind of going through that a little bit now where we thought things were handled and they weren't, and you think it's done but it kind of never ends. You need to know your rights.

don't be shy

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- Elizabeth Grand

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