FOR TEENS by Teens

A Guide to Epilepsy

Compiled by Jane Lee, Seo Young Lee, and Savannah Ray

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about US

Epilepsy Services of New Jersey

Epilepsy Services of New Jersey (ESNJ), an affiliate of the Family Resource Network, is a statewide non-profit charitable agency dedicated to helping improve the quality of life for people living with epilepsy and their loved ones. ESNJ celebrates 50 years of services in 2020. ESNJ ensures that people with epilepsy are able to participate in all life experiences and prevents, controls and cures epilepsy through services, education, advocacy, and research. We provide comprehensive support, personalized services, and advocacy for individuals and their families in order to maximize their participation in society.

For more information:

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Savannah

Jane

Seo Young

about this BOOK

Dear Reader,

We are Savannah, Jane, and Seo Young and we created this book during the summer of 2015 while we were in Physician Assistant and Pharmacy programs at Rutgers University. This project began after we were accepted into the Community Oriented Primary Care (COPC) program through the Robert Wood Johnson Medical School. Within this extraordinary opportunity, we worked with the Epilepsy Services of NJ on the book called *"For Teens By Teens: A Guide to Epilepsy."* We came across the epilepsy guidebooks called *"For Kids By Kids"* and *"For Parents By Parents"* which were created a few years ago by a medical student. These books have been a great resource for parents and kids newly diagnosed with epilepsy. We saw a need to make one specific to teens, so we started interviewing teens with epilepsy who are in high school and college about their personal experiences and advice for other teens.

"For Teens By Teens: A Guide to Epilepsy" is a resource for teens newly diagnosed with epilepsy to learn that they are not alone. It's a compilation of stories, struggles, achievements, and advice from real teens with epilepsy. We hope that you enjoy reading this book, learn more about epilepsy, and take comfort in the fact that there are many people out there just like you!

Makenzie

age: 18

Makenzie is an upcoming first year student at Rutgers University. She was diagnosed with juvenile myoclonic epilepsy when she was in 8th grade.

Diagnosis & Initial Reaction

I had previously thrown brushes and shampoo bottles in the shower involuntarily and my muscles jerked uncontrollably. I started to realize there was something wrong when my knees buckled and I fell against the sink in front of my brother. One day I was in the shower and I passed out. So we had EEG testing done and saw a doctor at a satellite office of Children's Hospital of Philadelphia (CHOP). When she told us that I have epilepsy, my mom started crying. At first, I was shocked. We just weren't ready. I was in 8th grade so I didn't understand completely. I understood the fact that I would have to take medication everyday, but I didn't really understand anything else.

Your Initial Questions

My mom asks a lot of questions to doctors and she writes down all the answers. So, most questions I had, I know now. One question I am still wondering is whether I will grow out of my epilepsy. I can't tell the future but I want to know if I'm going to grow out of it. I want to know if I have to be on medication for the rest of my life. We're not going to know that until I'm older.

Biggest Challenge You Faced

In high school, it was really frustrating for me when I saw people that I used to excel in comparison to, take several AP classes during junior year and I was only able to take one because my brain can only handle so much information. So it was tough to see people getting into the Ivy League schools. I got into some really good private schools but I would have liked to go above and beyond. I'm really active in school and I love learning, so I wish I could have learned more.

Running track and cross country is huge in my life, and I was a captain my senior year. Junior year, there were many instances where I felt sick during races and I had to hold back what I could do to not stop because I'd rather make it through the race than have to stop. I saw my teammates excelling and it was difficult to not be able to contribute to my team, so that was really tough since running track and cross country was a huge part of my life.

My brother was diagnosed with the same epilepsy this past year, so it was tough to see my parents and my brother struggle more than myself at the time.

> *"I'm not ashamed of it at all."*

Useful Resources

My mom has done so much. She takes all my appointment notes and knows every question to ask to my doctor. She went to a support group for parents that she knew through ESNJ and she told me all the eye-opening stories when she came home.

Friends' Initial Reaction

It was difficult to tell my friends at first and my town is really small so once one person knows, everyone does. I told a few very close friends and their parents when I would sleep over at their houses. My mom would make sure she talked to my friends' moms to make sure that they know I feel comfortable at their house. That's how it first started, and then over the years it was my decision to tell my close friends, teammates, and coaches.

There were some situations where friends at a party would ask me why I don't drink and I told them I can't and why. But I never tell anybody that I don't think needs to know. I'm not ashamed of it at all. I don't suffer socially. People wouldn't know unless I say something to them. But sometimes it would be touchy subject. I wouldn't be in this interview if I wasn't comfortable telling people. It's more comfortable to share now.

Getting a Driver's License

I had to wait two months after my birthday to get my permit because I had just changed my medication and I couldn't drive for a while. I didn't have any problem after that. I still get a headache when I am driving at night sometimes and when people's highbeams are on.

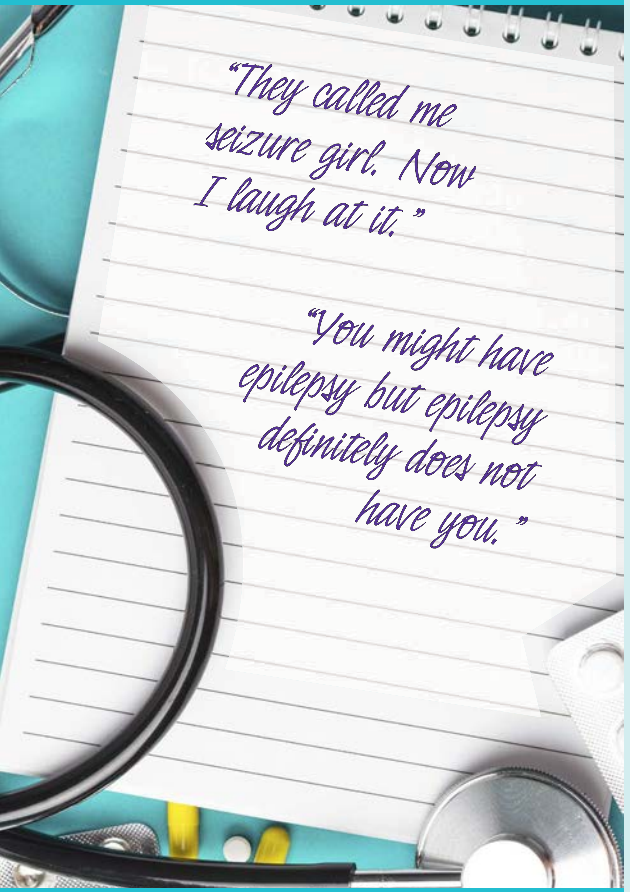
Your Life in High School

My epilepsy is well controlled by my medication. I had previously taken a medication that makes your mind foggy, so I wasn't able to do well in school and my grades during sophomore and junior year suffered. So I couldn't take all the classes I wanted to take. My doctor finally changed my medication midway junior year and things started to pick up. So I just went for what I could do my senior year and I performed very well academically. I ended up taking 4 AP classes that I wanted to take during my junior year and it was rewarding. I was so involved with track and school, and I previously didn't have time for work, but I recently got a job.

Tips for Taking Medication

Take your medication on time within an hour or two. For the first few years, I went to the bathroom to take my medication because I didn't want people to see. But now it comes to a point where I'm just like 'Hey guys, gotta take pills.' No one questions it anymore because a lot of people are also on medication. No one will ask why and if they do, I just make a sarcastic joke.

Brittany is 18 years old. She graduated from high school and will begin studying Nursing at Southern Illinois University this fall. She recently hit the mark of being seizure free for four years!



> "They called me seizure girl. Now I laugh at it."

> "You might have epilepsy but epilepsy definitely does not have you."

Brittany

age: 18

Diagnosis & Initial Reaction

I was 5 or 6 when I had my first seizure and I was 6 when I was diagnosed. So I just remember my parents being scared. Luckily my mom is a nurse, so she knew what it was and she knew how to handle it.

I thought it was normal, to be honest. I thought everyone had it. I was just a little kid.

Your Initial Questions

When I was growing up, as I learned about what I have, I started wondering if other people have it and why it happened to me. The cause of mine is unknown so they don't know why I have it. I was really just wondering why this was happening to me.

Biggest Challenge You Faced

Probably the hardest thing is growing up and trying to fit in at school. I remember that I had a seizure in school and got made fun of. I was bullied in middle school. They called me seizure girl. Now I laugh at it.

As time went on, people matured. Back then people didn't know what epilepsy was, what a seizure was, and didn't understand why it was happening to me. Now, people understand like "Oh, she has something that she can't prevent." They are more supportive of it now.

Most Proud Moment

A couple of months ago, I spoke at a concert for epilepsy hosted by Eric Miller. Definitely check out all of those concerts. He does an amazing job and has an amazing story. That was my first time speaking publicly about my epilepsy. Once I said that I've been seizure free for four years, I got a huge round of applause and it just hit me. I was like "Wow, this many people care and support me and think that my story is inspiring." That meant a lot. I was truly proud of myself at that moment. It made me very happy.

Friends' Initial Reaction

When I tell my friends, some people are shocked at first. The response I get the most is "Wow, you don't even look like an epileptic." I don't really know how to respond to that because I don't know what we're supposed to look like. Some of my friends already knew what it was but some didn't so I usually explain it so that they can understand better.

Some people definitely have changed their behavior towards me. They treated me differently. No matter what the situation is, some people from that point on will treat you differently. Sometimes in a good way and sometimes in a bad way. People are more cautious around you too.

Getting a Driver's License

When I was younger, they told me that I would never be able to drive. That used to upset me a lot because when you turn 17, that's a big deal. I had stopped having seizures in 8th grade so during 11th grade, I was cleared by my neurologist to get my license. When I first got it, I was afraid that I would have a seizure behind the wheel, but I've been seizure-free for so long that I feel a little bit more safe now.

Your Life in High School

Epilepsy can affect playing sports but I don't actually play any sports. I'm more of a theater person. I like to sing. I was in the drama club, and I was the lead in a musical. I was president of my choir too. Having epilepsy hasn't really affected any of that.

In terms of my social activities, a lot of people in high school unfortunately go to parties where drinking or smoking is involved. That is one thing I have to stay away from because of my epilepsy.

Your Life in College

I'm aware of drinking and the activities that happen during college. I have a roommate right now that doesn't do any of that. I have a group of friends that already attend my college and we all plan on hanging out a lot. I've already told them my situation, and I've already made friends through orientation too.

Tips for Avoiding Triggers

If someone's trigger is flashing lights, stay away from those. If you're at a theme park, ask the ride attendant if strobe lights are involved with the ride because unfortunately some places don't have signs.

If stress is a trigger and you feel like you're getting stressed out, take a deep breath and take a break from what you're doing. I've asked a teacher for an extra day for assignments. I hate to use my epilepsy as an excuse but there are moments where I can't do something because I feel like I'm going to get stressed out. I try not to put too much on my plate. If I'm asked to do multiple things, I try to stay away from letting things pile up.

Tips for Taking Medication

I would definitely tell people to remember to take their medication everyday, even if they're feeling lazy and don't want to do it. There can be serious consequences. If you're having side effects from the medication and you don't want to take it anymore, talk to your doctor instead of just refusing to take it.

When I was getting off my medication, I was afraid that it would be too much of a change for my body. I was afraid because I was doing so well and I didn't want to lower the medication and lose that. But eventually I had a friend who helped me a lot with the situation. He called me and told me that it would be fine. I had people that supported me if anything did happen.

Your Support Group

A lot of my friends are accepting it now. They really support me. I always attend the epilepsy walk and I usually have my own team, and support from my friend group.

I'm part of different Facebook pages. I'm part of Epilepsy Services of NJ. I'm attending all of the walks and events that they have. I've attended candlelight concerts for epilepsy and I spoke at a couple of those events. I'm definitely a part of a group, and I have met a lot of people with epilepsy from different states and a few different countries.

Advice for Other Teens

I would definitely tell anyone who is recently diagnosed to reach out to the epilepsy community. There are a lot of Facebook pages where people just ask questions. Definitely Epilepsy Services of NJ. Attend the walk. It's a great way to meet people. It's helpful to reach out to other people who are struggling with the same disorder. It will really help you.

Growing up and being with epilepsy at the same time is hard. Just trying to fit in is hard and then having epilepsy makes it even harder. But I like to say don't let it get you down. Epilepsy may be there but try to ignore it. You might have epilepsy but epilepsy definitely does not have you. You can get through it. It is possible. I used to have like six seizures a day and I went to having none. It is possible for people to get through this. Try not to let it affect you. You can live a normal life. Having a seizure may get in the way of you doing certain things but try not to let it get you down.

Last Thoughts

Unfortunately a lot of people don't know what to do when somebody has a seizure. It is upsetting that people know what epilepsy is but they don't really know what to do if somebody were to have a seizure in front of them, which is sad because I wish more people had awareness.

Ashley

age: 18

Ashley was diagnosed with juvenile epilepsy when she was 13 years old. She will be attending Rowan University in the fall.

Diagnosis & Initial Reaction

I was diagnosed during the summer before I started high school. My initial reaction was definitely fearing the unknown. My parents and I feared not knowing what was going to happen and what things I had to stop doing to control my epilepsy. I feared being limited from certain things in life that an average teenager wouldn't be limited to. I feared an epileptic attack and dying. We just didn't know what to do.

Your Initial Questions

I'm not really wondering much anymore, but when I was diagnosed, I definitely had many questions such as 'Will I be able to drive? Will I be able to have kids and will they also get diagnosed with epilepsy? Am I going to be taken out of school?'

My first doctor from the Children's Hospital was a very black-and-white person and he told me "You're going to have epilepsy for the rest of your life, and medication will not always stop your seizures." Coming from a faith-based home where we believe that God is the healing God, and hearing that from my doctor when I was a 13-year old teenager, I felt like my doctor set this limitation on my life. We saw him for a year and my seizures weren't stopping and medication wasn't helping, so I fell into a deep depression. Finally we switched doctors and my new doctor told me that there's a 25% chance that I grow out of epilepsy, which was nice that he gave us some hope that I can manage the disease and not let the disease manage me. Ever since then, I've had a great relationship with my doctor and he's helped us a lot to stop my seizures.

Biggest Challenge You Faced

During the summer before my junior year, the medication I was on caused side effects of depression, anxiety and weight loss. I just fell into a deep depression. I felt like my fears had overcome me and they defined who I was, and epilepsy defined who I was. I just didn't know anymore who Ashley was and I feared everything that's inside. I feared the unknown, feared being different, feared that I might die, feared being limited, and feared people looking at me in a certain way. I had seizure after seizure, having at least 2 to 3 seizures in a month during a 6 month span, so it was really hard for me. I actually ended up in the hospital because of my depression. So at that time I grew to a point where I had to fall to my knees and cry out to God. My mom always used to tell me "God did not give you the spirit of fear but of love, power and sound mind." And that's the exact verse that I heard in that moment and I thought "Wow, God, you didn't give me the spirit of fear that I am feeling right now, but gave me those three great qualities. Help me to use those." It took me being at my hardest point in life to realize that I can use my triumph over the fear and depression to help others, and that's when I actually came up with the Fearless Movement through the verse that God said: "You need to be fearless. You need to trust me."

About the Fearless Movement

I'm the founder and it is a non-profit organization for epilepsy awareness and research. We promote those who live fearlessly because fears hold you back from amazing things whether that is from epilepsy or any disease or any battle you fight in life. We raised over $1,400 for epilepsy research and awareness in our first 6 months. Our slogan is actually "Drop Fear. Gain Courage." I heard stories that I would have never imagined and there are people that live a harder life than I do, so I became grateful for the life I have and to only be diagnosed with epilepsy that I have. All of our proceeds go to Clayton's Hope Organization for epilepsy research and awareness. By raising research funds, I believe that we can make epilepsy a disease of the past, not of the present. I just want the Fearless Movement to become worldwide where everyone in the world knows how to become fearless.

Friends' Initial Reaction

Most of my friends already knew that I had epilepsy because of the seizures I had in school. Nothing but support came from Glassboro High School and my classmates helped me spread as much awareness as they could. Over 70 students plus faculty played in Volleyball for the Cure, so it was very heartwarming to see my classmates coming together to raise awareness and research funds for the disease that I am battling.

Getting a Driver's License

I currently do not have a license. When I was supposed to get my permit, that's when I had continuous seizures and you have to be 6 month seizure-free to get a license in NJ. I was just 10 month seizure-free and then in May, I had 2 seizures in one month. So I am only about a month seizure-free now and we are figuring out whether I should switch my medication and how much medicine I should be on. This is something I've been dealing with more recently and I'm frustrated that I can't drive, but it's okay because I believe that I will be seizure free and I will be able to get my license!

Your Life in High School

I had seizures in school and I had to go home those days and stay home for the next day because seizures took a lot of physical strength out of my body. I just didn't have the strength to get up the next morning and be alert to everything. I got a concussion from a seizure I had in school and I had to stay out of school for a week which held me back a lot academically. My junior year was not very successful academically because I was absent for a couple weeks from my seizures and I had to retake history during my senior year. I also retook physics just because I didn't like the grade I got because of my absences, and I knew I could do better. So, I retook those two classes and got better grades for my GPA. My teachers were very supportive and helped me with catching up with my work, but it was very stressful.

Advice to Other Teens

You're going to have fears throughout this battle that you're facing with epilepsy. You're going to feel like your parents are overprotective, but just know that your parents are being protective because they care. Fear is the only thing that will set limitation on your life, not epilepsy. Do not let epilepsy define you. Fear holds you back from amazing things and that is why the Fearless Movement promotes to drop your fear and gain courage. Be courageous throughout this. Live fearlessly.

"Drop fear.
Gain courage."

RYAN

age: 19

Ryan is a rising second year student at Wesleyan University in Connecticut. He was diagnosed with epilepsy when he was 11 years old.

Diagnosis & Initial Reaction

I was brushing my teeth in the bathroom with my dad when I started to feel an aura and collapsed into his arms. I had a tonic-clonic seizure and was taken to the hospital. My first reaction was shock because I didn't know what epilepsy really was. As an 11-year old little kid, I had all the big questions in my head like 'Am I going to die? What is this going to do to me? Am I sick?'

Biggest Challenge You Faced

The most difficult time was when I was 16 to 17 years old. People around my age got their driver's licenses and started to experiment with alcohol and other recreational drugs. I was unable to do that because of the risk of seizure behind the wheel and the medicine I was on. Sometimes I still feel like I'm stuck at 15 years old. I watch my friends being able to drive and drink. I'm not going to know what that is like.

When I got to college, I told my friends that I can't drink with them but I am more than happy to go out with them and look out for them. My friends have been always great about understanding me and they made it a whole lot easier for me. It's still just an annoying thing to have to explain to people why you're acting the way you're acting.

Useful Resources

Epilepsy.com has a good walkthrough about different types of seizures, different medications, and strategies for lowering the number of seizures, and it also has forums. There are also different epilepsy groups on Facebook and other websites where you can submit questions to a neurologist.

Getting a Driver's License

I never had a license. There are times where I will be stuck at home with a car in the driveway and I just can't drive. That can get really frustrating for me. But my parents have been great and are always willing to drive me and pick me up from somewhere. They understand that it is frustrating for me. My friends are also great about going out of their way to give me rides.

Tips for Avoiding Common Triggers

If I don't get an adequate amount of sleep for continuous days in a row, it will raise the risk of having a seizure for me. So I'm always good about understanding what time I went to bed and I always shoot for eight hours of sleep.

I've had anxiety since I was a little kid, so I watch out for bouts of anxiety and stress as a warning sign for having a seizure. To avoid some stress, I try to plan out my week and I meditate. It has helped me work with more focus and work quicker. It helped out with the anxiety as well.

Your Life in College

I play baseball for my college and this season we made it to the NCAA Division tournament. With that came a lot of travelling and not getting enough sleep, and I ended up having two seizures in a week.

It was tough for me since obviously playing a sport, especially in college when it gets more serious, is stressful to the body and epilepsy gets worse when you put stress on your brain and body. During both of my seizures, I hurt myself. I really hurt my back so I wasn't able to play for the last couple of games.

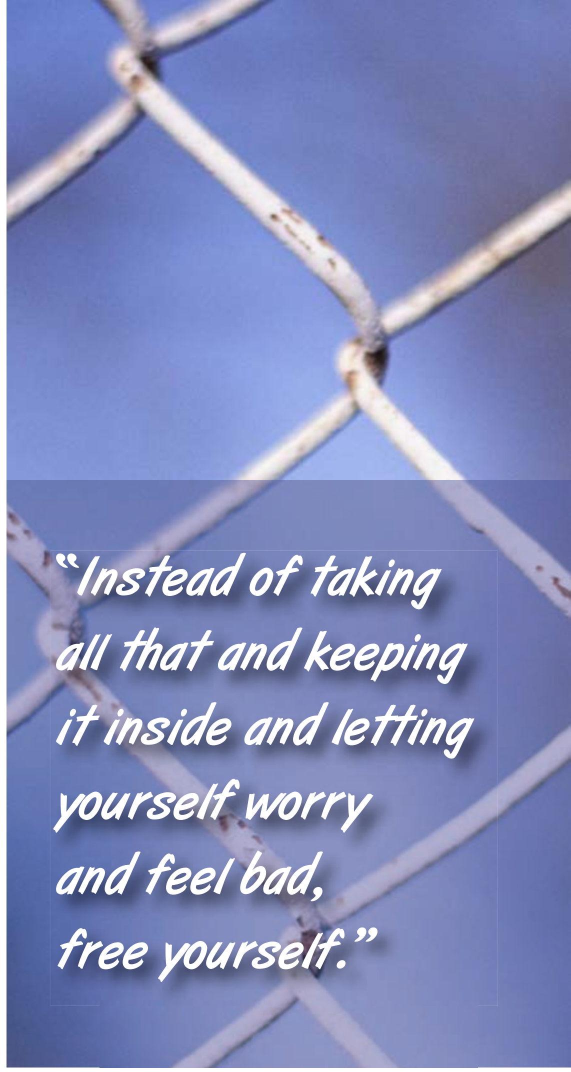
Tips for Taking Medication

One thing I'll do is to set reminders on my phone. I take my medication in the morning, so I put it right on the desk next to my bed so that I don't forget to take it. My biggest advice would be to put the pill bottle in a spot where you're going to see it, so even if you forget, there is still a chance for you to look at it and automatically remember to take it. I also find a pill organizer helpful because sometimes you forget if you took your medication or not and you can always look in and see if there are still pills left in there.

Advice to Other Teens

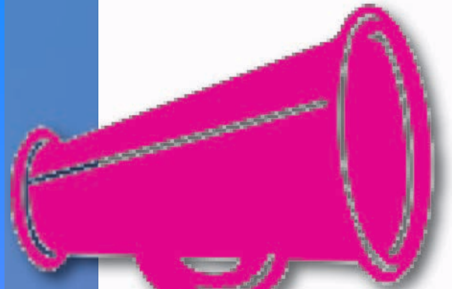
Your life is going to be so much better if you reach out to organizations like ESNJ. Learning to live with your epilepsy is a big hurdle. Watching your friends grow when you can't drink or drive, that's another big hurdle. Instead of taking all that and keeping it inside and letting yourself worry and feel bad, free yourself. I think it's better to go out and talk to someone who understands your disability and understands how you have to live your life because you have epilepsy. Reach out to someone and they can offer you information about side effects of medicine, different medical tests, and different questions you have and you will find out that there is a big support community.

You shouldn't be embarrassed about epilepsy either. I think some people may feel embarrassed by it. They think it's their weakness. I think it's who you are. It's part of you, and if someone can't deal with the fact that sometimes you fall down and shake, then they shouldn't be able to be your friend and they shouldn't be someone that you care about.



> *"Instead of taking all that and keeping it inside and letting yourself worry and feel bad, free yourself."*

CHEER



Morgan

age: 19

Morgan is a rising second year student at Alderson Broaddus University in West Virginia. She was diagnosed with generalized tonic-clonic seizures when she was a freshman in high school.

Diagnosis & Initial Reaction

I was pretty shocked because I've been a gymnast all my life and landed on my head multiple times during my practice and never had a reaction like I had with my seizures. So when my doctor told me that I have epilepsy, I got out my phone first and looked it up, and I thought this can't be possible.

Biggest Challenge You Faced

I was a cheerleader and a gymnast. So when I became a cheerleader in high school and had my first seizure within the first two months of my freshman year, I just didn't know how to announce that I have epilepsy. It was just really hard because I have ADHD as well. Overcoming epilepsy and ADHD, staying focused in high school, and making sure that I get into the right college was all really stressful.

Your Greatest Accomplishment

Graduating high school having ADHD and epilepsy and doing four years of cheerleading was my biggest accomplishment. Then, getting a scholarship to go to college for what I like to do as well was a really good accomplishment, but nothing beats graduating despite all the stress I had.

About Your Support Group

I am a part of the South Jersey Epilepsy Services. So I meet with SJES members at their meetings and I always see their Facebook posts related to epilepsy research and awareness. Especially coming home for the summer, there's always something for me to do and somewhere to help.

Friends' Initial Reactions

When my mom first dropped me off at school, she told my friends, "If Morgan ever has a seizure, make sure you guys lay her on her side and don't touch her." So my coach, my whole cheerleading team, and my suitemates knew what to do just in case something happened.

Getting a Driver's License

When I had my first seizure, it was during my freshman year and I have been seizure-free for the past four years. So getting a license wasn't a problem for me, and I'm just crossing my fingers that nothing happens. But I do still take a precaution of not driving at night because I don't like the lights flashing at me. It's just scary and makes me feel like something's going to happen, so I just avoid driving at night at all costs.

Your Life in High School

Having epilepsy has affected my cheerleading life because when I had my first seizure, I wasn't allowed to cheer for a few months. It was frustrating but my doctor told me that it was for the best. My cheerleading team was really supportive about everything.

Your Life in College

I haven't had any difficulties but a lot of people go out drinking, and you just really have to watch what you're doing and be aware of where you are 24/7. Make sure you're with someone who knows what to do in case something were to happen.

"Do as much research as you can."

Tips for Avoiding Common Triggers

Staying away from the lights is key no matter if you're at concerts or not. You can just close your eyes or try not to stare at them. Just look at something else in the distance. Don't look ahead at them. If you have epilepsy, that can trigger a major seizure.

Tips for Taking Medication

I'm on a medication that I take twice daily. I never had to change my medication but when I first started taking it, I had mood swings and tiredness. Once I continued taking it, I got used to its side effects. So I take my medicine right when I wake up and I have an alarm set at 9:30 to take it at night as well.

Before I went to college, my doctor at Children's Hospital of Philadelphia (CHOP) actually wanted to get me off my medication, but I didn't feel comfortable because if something were to happen, my parents would have to drive seven hours to come see me. So I stayed on the medicine and so far I'm not stressed about it.

Advices to Other Teens

Do as much research as you can because you will always find something new that no one has discovered yet. For me, my mom is literally my side kick. My mom is very involved with ESNJ and she is always talking to Andrea and other people at ESNJ about their meetings and walks. She's so helpful and we have awesome teamwork together.

Nadia

age: 19

Nadia is currently attending Pace University in NYC. She was diagnosed with temporal lobe epilepsy when she was 10 years old.

Diagnosis & Initial Reaction

I was only 10 years old at the time so I didn't think much of it. The adjustment to medication and refraining from certain activities was probably the hardest part, especially all while I was going through puberty.

Your Initial Questions

My seizures began as absence seizures, so in the very beginning, it was difficult to understand why I would "space out" all the time and why it was such a big deal. Of course the concept of losing control of your body to a fourth grader is scary so most of my questions were just about trying to understand my illness and why certain things happened to me. After growing up with epilepsy, I've researched a lot and don't really question anything anymore. It's just interesting how people are all affected differently by the same disease.

Biggest Challenge You Faced

Definitely high school. Although my seizures were completely under control by then, the stress of driving, tests and SATs, and applying to college affected me very negatively. On top of that, I was getting weaned off my medication and in the past whenever I would slowly lower my dosage, I would either have breakthrough seizure activity or go through severe mood swings and depression.

Your Greatest Accomplishment

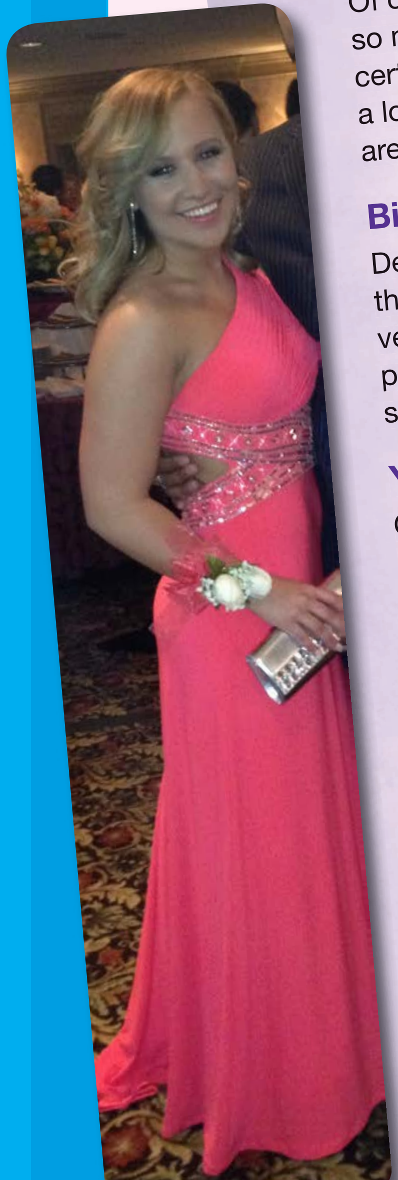
Getting into my dream school and letting the obstacles of my illness to motivate me to apply for scholarships and pursue a college degree.

Useful Resources

Dr. Rina Goldberg has been my neurologist since my diagnosis. So, growing up with the same doctor who diagnosed me was very helpful in my transition. I also learned a lot through my mother who is a nurse. She tried her best to help me understand and adjust.

Friends' Initial Reaction

In all honesty, most of my friends do not know about my diagnosis. I guess in my head because my diagnosis is not as severe as it could be, I never felt it necessary to share. I also was very embarrassed and in denial about it so I'd rarely open up. Even to this day having been diagnosed nearly 10 years ago, I've only told a handful of people. But the few friends that are aware are very supportive.



Getting a Driver's License

For a while, the discussion of getting my license was very stressful. Although I had been seizure-free for about five years by the time I turned 17, the pressure of my doctor and my parents constantly stressing the severity of the situation made things very difficult. My mother would stress about the legal liability having my license would be if anything happened, especially since the doctor was attempting to wean me once again off my medication.

Your Life in High School

When I was first diagnosed, it definitely affected my sports. My mother was a lot more conscious about the activities I participated in. I never took much care to it, but sometimes she'd say something that'd scare me. Despite it all, I stayed extremely active my entire life. I competitively swam (against my mom's will because she thought I'd have a seizure and drown). I cheered, both on varsity and competitively, even though I suffered multiple concussions. I played softball, and I continue to surf and participate in other activities. My social life was never really affected because as I said, I never really told people. I also obtained my lifeguard certification when I turned 15 and began working part time.

Your Life in College

As a New York City college student, I figured it'd be best to get a medical bracelet since I have a tendency of not telling people about my condition and just in case if anything ever happen while on a subway or walking around in a huge city. So the bracelet has definitely been a conversation starter and I've become a lot more confident in speaking about it. Other than that, it doesn't affect me any more than it did in high school.

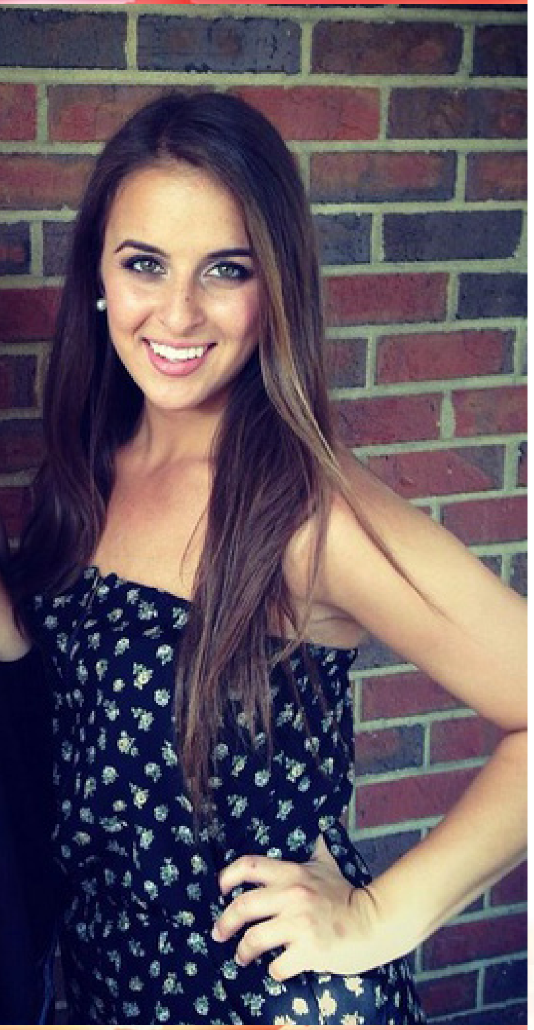
Tips for Taking Medications

I was lucky enough to have been placed on a medication that controlled my seizures right away and I never experienced bad side effects. However, with my experience of constantly adjusting my medication dose, I would say be patient. I know it can be frustrating when you feel controlled by your medication or that you can't be yourself. The best advice is to tell your parents or doctor when something doesn't feel right. If you aren't happy on your medication, there are plenty of other options out there. You'll find one that suits you perfectly.

Advices to Other Teens

Don't hold yourself back. Epilepsy can be scary, but you can't let the fear of the possibility of having a seizure keep you from enjoying your life. Be open about it. As a child or a teenager, it can be confusing, especially with all the other changes going on with your body and your life. Don't be afraid to ask questions. The more you understand, the easier it is to adjust and move on.

> *"Don't hold yourself back. Be open about it. Don't be afraid to ask questions."*



Lauren

age: 20

Lauren is currently attending Georgia Institute of Technology and is studying abroad in France. She was diagnosed with focal temporal lobe epilepsy.

Diagnosis & Initial Reaction

At first, I denied it was true. I said I brought the seizures on myself through lack of sleep and lack of proper nutrition in my diet. But according to the definition of epilepsy, it is not possible to have multiple seizures without having epilepsy. I was upset initially because I thought it would hold me back from a lot of things in life and most of all, I was sad to give up my license. Thankfully, I was proven wrong on being held back from activities. I have to be more careful than my peers in taking care of myself, but live a normal life otherwise.

Your Initial Questions

My main concern was when I would be able to get my license back. After getting past that, I wondered what exactly was happening in my brain that triggered the seizures.

Biggest Challenge You Faced

I lost my license when I was diagnosed with epilepsy, so that was the most difficult time for me. I also had to change my lifestyle to accommodate my needs. Thankfully, I remained seizure-free since being put on medication and was able to get my license back and drive again.

Most Proud Moment

My most proud moment was remaining seizure-free for a year. I learned how to live a lifestyle that prevents seizures and remembered to take my medication every day.

Useful Resources

My doctor provided me with all the information I needed. He was super helpful and willing to answer any questions I had.

Tips for Telling Friends about Epilepsy

More people than you think do not know what epilepsy is. I explained to my friends that it's a condition in which I could potentially have seizures but it is thankfully controlled with my medication and a healthy lifestyle. I usually go on to tell them exactly what it would be like if I were to have a seizure. I always turn to my left when I'm about to have a seizure because the incorrect firing of neurons begins on the right side of my brain. I also foam at the mouth and convulse. My first day of college, I had to tell my roommate that I had never met before that I had epilepsy. I began with "So there's something I have to tell you," which scared her way more than I had intended. Once I explained, everything was fine.

Getting a Driver's License

I had my driver's license before being diagnosed with epilepsy. Unfortunately, I had to wait a certain amount of time after being diagnosed until I could get my license back.

Your Life in School

For the most part, epilepsy didn't really affect my high school and college career. When it came to sports, I had to be more careful not to hit my head too hard or get knocked around too much.

Tips for Avoiding Common Triggers

I have noticed certain things over others trigger my seizures, so I think triggers depend on the person and the type. I have been to concerts with flashing lights and did not have a seizure or an aura (I get an aura before a seizure so I know when I'm going to have one). Lack of sleep, lack of nutrition, stress, and dehydration are the main triggers of my seizures, so I work hard to accommodate my needs to avoid those.

Tips for Taking Medication

I would suggest taking it everyday at the same time, so you can get in a routine of doing it. I set a reminder on my phone just to be sure I do not forget taking it. Taking it every morning when you brush your teeth would probably be the easiest!

Advice to Other Teens

Keep your head up and realize it doesn't have to change a big portion of your life. I've been seizure-free for three years now after adapting a more healthy lifestyle. It is now such a small part of my life.

> *"Keep your head up. It is now such a small part of my life."*

MATT

age: 21

Diagnosis & Initial Reaction

I stuttered some words and I told my parents that had been happening. So we decided to go see a doctor. When I first heard the diagnosis, I wasn't completely surprised even though it surprised me a little.

Your Initial Questions

I was concerned with medication and if they had any side effects.

Biggest Challenge You Faced

In high school, some of the teachers were not as accommodating as they could have been and that kind of made it hard academically. Fortunately, professors in college now are a lot more understanding and willing to accommodate my needs. They go out of their way to help you out.

Your Greatest Accomplishment

My senior year in high school was my best year. Most seniors slow down at the end because of 'senioritis', but since I was on waitlist for a lot of schools, I really wanted to get my grades up. I worked on my GPA a lot and I was able to get into the school that I wanted. I'm very proud of that.

Useful Resources

My mother joined a couple of groups online including Facebook groups and learned a lot about epilepsy and communicated with people who have epilepsy. We asked our doctor a bunch of questions. I joined ESNJ and played in a golf tournament to raise funds.

Friends' initial reaction

I just told my friends straight up, so all my friends know. They didn't tease me or do anything to bother me. They understood it , which is exactly what I would've expected.

Getting a Driver's License

I didn't have any problem because I haven't had a seizure for a long time and my seizures aren't triggered by lights.

Your Life in High School

In gym, if I felt really hot and started to breath heavy, I was able to sit down because that is a trigger for me. I played golf in school but that doesn't trigger anything.

Tips for Avoiding Common Triggers

I make sure I'm hydrated. When I feel dizzy, I stop and sit down. Stress is also bad. Just try to avoid stressful situations. Sleep is extremely important for me and for most people with epilepsy. I try to get an ample amount of sleep and try to stay on a consistent sleep pattern.

Advice to Other Teens

I want to emphasize the importance of watching your sleep, heavy breathing and hydration. Make sure you are properly hydrated. A couple of things that may be really bad are caffeine and stimulants such as ginseng and plant sage. Also watch out for strong depressants like alcohol.

Matt is 21 years old and is currently attending the University of Pittsburgh. He was diagnosed with absence seizure epilepsy when he was a junior in high school

> *"I worked on my GPA a lot (during my senior year) and I was able to get into the school that I wanted. I'm very proud of that."*

acknowledgements

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- Jane Lee, Seo Young Lee, Savannah Ray

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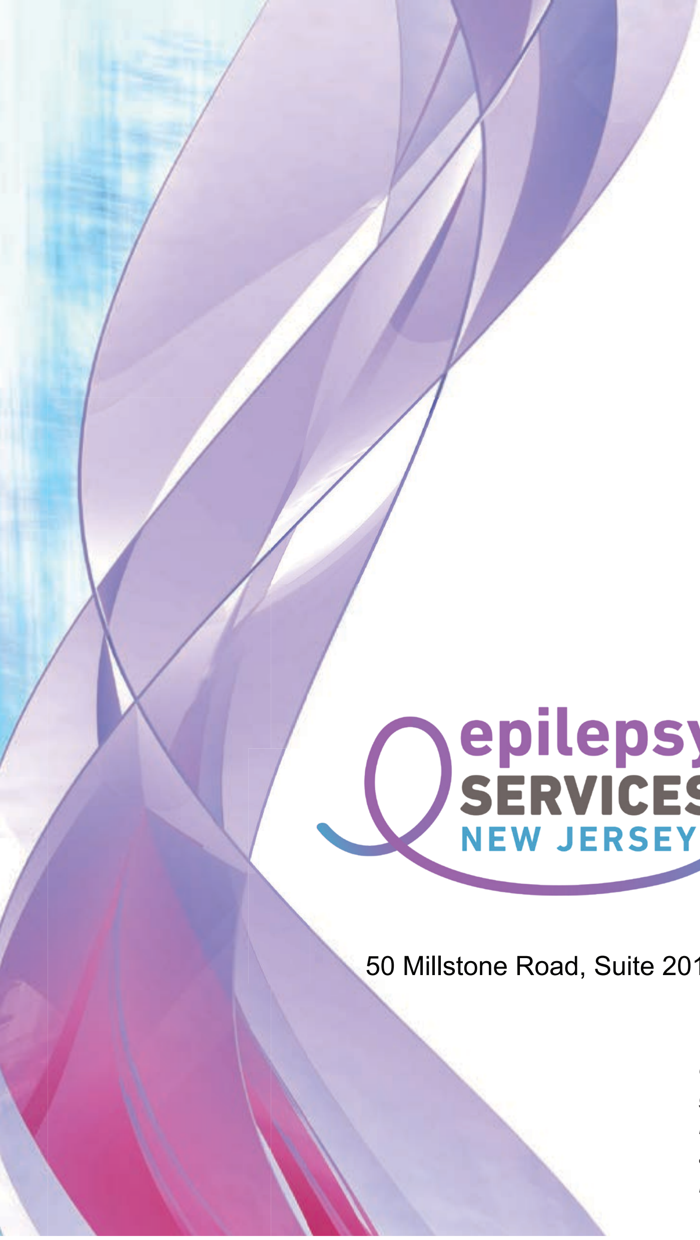

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