Remember, there are many kids dealing with
Sturge-Weber syndrome.
You met just a few in this book.
If you'd like to meet more, or share your own
tips, thoughts, or experiences,
write to us at the address below.

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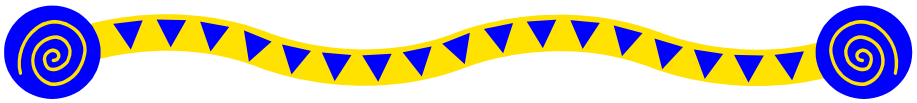
A Kids Guide to Sturge-Weber Syndrome

If you are reading this booklet, it probably means that you are a young person who has Sturge-Weber syndrome (SWS). You may have symptoms that started only a short time ago, or you may not be able to remember a time when you didn't have SWS. The first thing you should know is there are kids all over the world who have SWS – there may even be others in your state or province. You don't have to feel like you are the only person on the planet who has SWS.

This booklet was created for young people with SWS between the ages of 8 and 12. We hope this booklet will help you understand this disorder and give you information to help you live successfully with SWS. You may choose to read this book privately or share what you read with your family as a way to start a conversation about how SWS affects you.

Children with SWS are just as smart as other people their age. SWS may make you look differently than others, but it does not affect your ability to be liked or make friends. SWS is what you have, not what you are. Young people with SWS succeed at school, make friends, get dates, graduate from college, get good jobs, get married, have families, and accomplish great things!

Although living with SWS can be confusing at times, it is nothing to be embarrassed about. If you need help understanding what is happening to you, talk to your parents. Together you can find the right words to describe what SWS is to you.



blasts] of electricity in the brain.

electroencephalogram (i-lek-tro-en-sef-ah-lo-gram) [EEG] a test that helps doctors study seizures.

glaucoma (glaw-ko-mah) a problem with pressure in the eye.

laser (la-zer) a piece of equipment that can "shoot" light to kill extra blood vessels.

MRI [Magnetic Resonance Imaging] a test that uses magnetic energy to show the growth of the brain.

neurologist (noor-ol-ahjist) a doctor who deals with the nervous system [and the brain].

ophthalmologist (of-thal-mol-ahjist) an eye doctor.

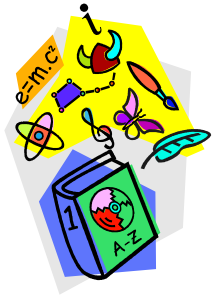
PET SCAN [Positron Emission Tomography] a test to look at how the brain works.

plastic surgeon (plas-tik-serjun) a doctor who does surgery to change how the body looks

port-wine stain (port-win-stan) a purplish-red color on the skin that is caused by blood vessels.

seizure (se-zhur) a sudden attack when there is too much energy in the brain.

symptoms (simp-toms) a part of a disease. When lots of symptoms occur together, it is a syndrome.



Glossary

anesthesia (an-es-the-ze-ah) medicine to dull pain [make it hurt less].

anticonvulsant (an-ti-kon-vul-sint) any medicine that helps to control seizures.

blood vessels (blud-vesls) tubes that carry blood around the body.

calcification (kal-si-fi-ka-shin) hard parts on the brain of many people with Sturge-Weber Syndrome.

CAT SCAN [Computerized Axial Tomography] a test that uses X-ray to show sections of the brain. This is the test that shows calcification.

chemical charges (kem-i-k-l-charjs) charges [like blasts] of chemicals in the brain.

contagious (ken-tajes) a disease that spreads from person to person.

cosmetologist (kaz-me-tol-ahjist) a person who makes the skin look better.

dermatologist (derm-ah-tol-ahjist) a skin doctor.

EEG a short name for an electroencephalogram (e-lek-tro-en-sef-a-lo gram). A test for studying seizures.

electrical charges (e-lek-trik-al-charjs) charges [like

Chapter 1: What is Sturge-Weber Syndrome?

Sturge-Weber Syndrome has an unusual name. It is named after two English doctors. One man's name was William Sturge. The other man was Frederick Parkes Weber. These doctors discovered Sturge-Weber Syndrome. Together, their last names make the name Sturge-Weber.

Sturge-Weber Syndrome, also called SWS, is a condition you are born with. It may or may not show up in other members of your family. No one knows why people are born with SWS and no one knows what causes it. We do know SWS is not contagious. You cannot catch SWS from another person.

If you have Sturge-Weber Syndrome, you probably have a birthmark on your face or body. You may have eye problems and other problems inside of your body. You may also have trouble learning. This booklet will tell you more about port wine stains, eye problems, and brain findings in people with SWS.

Even though people with SWS have some of the same symptoms, there is no set rule for everyone with SWS. Not everyone has seizures, glaucoma and a birthmark. Each patient is an individual.

What is A Port Wine Stain?

Most people with Sturge-Weber Syndrome have what doctors call a port-wine stain on the face. Port-wine is a color. It is a dark, purplish-red color. If you have a port-wine stain, part of your skin may be a purplish red color. (Sometimes, the skin is lighter pink and some people with SWS have no stain on their skin.) The port-wine stain is caused by blood vessels. If you have a port-wine stain, you have more blood vessels in the area of the port-wine stain than in the rest of your skin.

If you have a port-wine stain, you were born with it. You may feel comfortable with the stain. This means that you don't mind the stain. Or you may want to try to take the reddish color out of your skin. It you don't want to have the stain, you have two choices. The first choice for a doctor to treat the stained skin with laser treatments. A dermatologist or a plastic surgeon can do laser treatments. (The next page will tell you more about the laser and what it can do.)

The other choice is to cover up the stain with make-up. A cosmetologist has makeup that is the color of skin. The makeup is thick so it can cover up the red color of your stain. With the makeup on it is hard to tell that you have a stain on your face or body.

Laser Treatments

Some people feel better if they can have their port-wine stains lightened or removed. This can be done using a laser. The laser is a piece of equipment with a trigger. When the doctor pulls the trigger, a beam of light comes out of the

Questions & Answers

How does the doctor know I have SWS? If you were born with a birthmark on your face, your parents were probably told that you might have SWS (although not all children have a birthmark). If you began having eye problems or seizures, the doctors probably did a test on your brain and saw you had SWS.

Will the SWS go away? SWS is something you will have for the rest of your life. But the things that come from having SWS like glaucoma and seizures can be helped by medication.

Can other people catch SWS from me? No they can't.

What is going to happen to me in the future? There is no way to predict anyone's future. If you have seizures or glaucoma, you may need to continue taking medicine. Many children with SWS grow up to be grandparents, teachers, firemen,...anything they want to be.

Nothing you say, the way you look, or what you believe in gives anyone else the right to make fun of you, hurt you or say mean things.

What to Do About Bullying

• Tell your parents, and talk with them about ways that they can help you to be safe.

• Tell a teacher, counselor, or your school's principal. They can take action to stop the bullying.

- Help Yourself

  Try to walk away from the bullies.

  Sit near the bus driver on the school bus.

  Take different routes to and from school.

  See if you can get a friend or two to walk with you.

  Try to stay in areas where other students are.

laser. This beam of light is sometimes called a "shot" of light. The beam of light is about the size of a pencil eraser. The light destroys the extra blood vessels under the skin.

It takes time to remove the extra blood vessels. The exact amount of time depends on the size and darkness of the stain. If your stain is little, then it will need fewer laser "shots." If your stain is bigger, it will need more "shots" of light.

The laser "shot" feels like snapping yourself with a rubber band. It doesn't hurt too much the first time. But it stings after a few snaps. Some doctors will give you medicine (called anesthesia) before the laser treatment. Other doctors may use a type of cream that goes on the face before surgery to dull the pain of the laser treatment.

After a laser treatment, the treated skin will look gray or purple. It will look like a bruise. Over the next 4 to 10 weeks, the skin looks lighter. After laser treatment, be sure to use sunscreen. Suntans are bad for anyone's skin, but they are especially bad after laser treatments.

If you are thinking about having laser treatment, don't be afraid to ask any questions. Parents and Doctors like to know how you feel. If you are scared, or don't understand about the laser, just ask.

Eye Problems

Patients with Sturge-Weber Syndrome often have an eye problem called glaucoma. However, even people who don't have SWS sometimes have glaucoma. Glaucoma is a problem with fluid pressure that is pushing on the eye. When there is too much fluid pressure, your eye can't see very well. For people with SWS, glaucoma is usually found on the same side of the face as a port-wine stain. An ophthalmologist (an eye doctor) can tell you if you have glaucoma.

To check for glaucoma, the doctor will put drops in your eyes so you can't feel anything. He may use something that looks like a pen to press against your eye or shine a very bright light in your eye. He will also check to see how far away you can see things.

There are three main ways to treat glaucoma. The first way is with eye drops. The second way is with oral medicine. This is the kind of medicine you swallow. The third way is with surgery. There are many different kinds of surgery. An ophthalmologist will choose the best way to help each person.

Brain Findings

Your brain is a very important part of the body. It helps you learn and grow. It controls many of the functions of your body. The brain is usually soft and bumpy on the outside.

Sometimes people with Sturge-Weber Syndrome have hard parts on the outside of the brain. These hard parts are called calcifications. Doctors aren't sure why calcifications

and read it when your confidence needs a boost. Remember to keep adding to it and include nice things that other people have said About you.

- Shout positive statements out loud—you can try this in your bedroom or in the shower or on top of a hill. Say things like "glad to be me!" or "This is me and I'm proud of it!" or "I can do it!"
- Think of somewhere you've been where you felt good. Maybe a special vacation place or the SWF Conference. How did that place make you feel? Relaxed? Full of energy? Happy? Hang on to that image in your head for some feel-good vibes when you need them.

Teasing & Bullies

Bullying is when one person hurts or threatens someone else physically, verbally, or in writing. The bullying might happen once or over and over again. Bullying can include pushing, shoving, kicking, hitting, teasing, or writing mean or threatening notes.

Bullying can make you:

- feel angry, sad, lonely, or depressed.
- Feel like you have no friends.
- Find that you are always getting into fights.
- Feel helpless to stop the bullying.
- Be afraid to go to school, or feel worried all the time.
- Feel badly about yourself.

Self Esteem

If you have a port wine stain, you probably know how hard it can be to look different from everyone else. You might be reminded of the difference every time you look in the mirror or see someone staring in your direction. Although it's perfectly normal to have negative thoughts and feelings towards your appearance, finding ways to feel proud of the person you are, both inside and out is important.

You may have a birthmark or seizures, but it's not who you are. Think about something that makes you special. What are you good at? You should recognize or appreciate your individual character, qualities, skills, and accomplishments. Believing in yourself gives you the:

- courage to try new things
- power to believe in yourself
- confidence to make healthy choices for your mind and body now and throughout your life

Here's some ways to feel more confident:

- Make a list of everything you are good at—playing the drums, dancing, sports, art. Put it in a private place

grow on the brain. They just happen to occur in people with SWS. A brain doctor (a neurologist) can test for calcifications using many special tests.

If you have been visiting your neurologist for a while, he or she will be more interested in how your body is doing and if your SWS symptoms have changed since the last time he or she saw you.

The second big thing the neurologist will want to do is to take a look at you. He or she will probably ask you to do things like grip his hand, or ask you to walk a straight line. Sometimes the doctor will have to do things that are uncomfortable such as take blood. All these things are necessary so the doctor can understand what's going on in your body and help you be as healthy as possible.

The doctor may need to look inside your head at your brain. The machines used for these tests may be scary because they are loud, or you need to hold very still for the test, but they do not hurt you. If you are scared, you can ask the person doing the test to turn on music or talk to you during the test. Many times, your parent will be allowed in the room with you.

Here are some ways to test the brain:

CAT SCAN
This is a special X-ray that takes pictures of different layers of your brain. Then a computer shows the layers on the screen. Most doctors use this test to find calcifications.

MRI
This test uses magnetic energy. It can show how your brain grows as you grow up.

PET SCAN
This test looks at what your brain is doing. It measures how well your brain is working.

Each brain test shows something different. A neurologist will decide which test is best to use on each person. None of the tests hurt.

Seizures

Most people with Sturge-Weber have seizures. A seizure involves your brain. Your brain is filled with billions of tiny cells that "talk" by sending electrical messages to each other. The cells tell us to move, think and do other things. During a seizure, some of the cells don't work right and they send mixed messages. The mixed messages can change a person's movements, or what they feel, hear, see, taste or smell for a few moments. That's a seizure. Seizures can often be controlled with medication. Most young people with SWS who have seizures take medicines by mouth. You have to take them every day, or even many times a day. This medicine is called an anti-convulsant.

No matter how discouraged you get and no matter how many medications or surgeries you have, it's worth living your life…we can make a world of difference.

It's not easy…having a syndrome like SWS is very, very hard…you have to be very self-confident in yourself.

Don't let anyone tell you what you can't accomplish, it can always turn out for the best, not matter how bad it looks. Just be yourself, who you are.

Try to tell people like your teachers and classmates about seizures, so they are aware if you have one.

Just do your best in life.

Stay on your medication.

You have to stand up for yourself, don't let people try to take you down. I was teased a lot. I finally learned to stand up for myself.

Chapter 7: Feelings & Dealings

Living with SWS

Young people with SWS are normal kids. You may have challenges that other children do not, but you will succeed in doing everything that children without SWS do! You may have to do things a little differently, but you will find creative ways to achieve whatever you want.

Having SWS is not always easy, and there will be times when you feel sad, angry and depressed, but if these feelings stay with you for more than a few days, tell your parents. Remember, you don't have to do it all on your own.

Here is some advice kids with SWS have for other kids like them:

There's different kinds of seizures. I learned about glaucoma and seizures and kids won't be as afraid if they know about them and what to do.

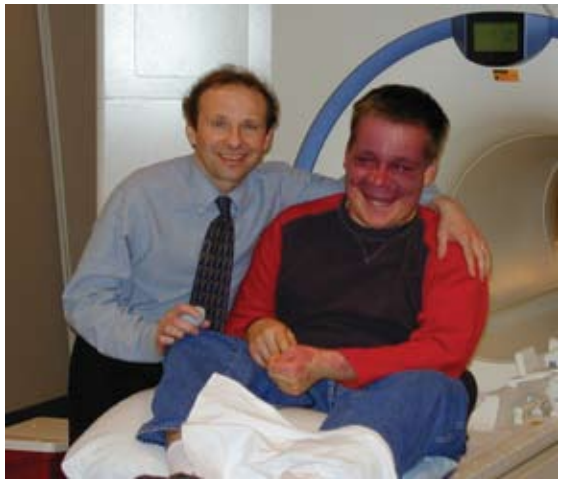
Don't be afraid to be open to questions, because people just don't know.

I tell them it's just a birth mark – you can't catch it.

Convulse is another word for shake. Anti means "against." This medicine is against shaking. It can help stop the shaking and the seizures.

It is very important you take your medicines exactly the way the doctor tells you to. Imagine the medicine is putting the seizures to sleep inside your brain, but they don't go away. If you forget to take your medicine, the seizures might wake up. Even if you don't have any seizures for a long time, you may still have to take the medicine. There is not one medicine that works for everyone. So, you may try a medicine and find that it doesn't help or it makes you sleepy or forgetful or cranky. You may have to try more than one medicine before you find one that helps you the best.

If you have a seizure, doctors will test you to learn more about the seizure. The test they use is called an electroencephalogram. An easier name for the electroencephalogram is EEG. For an EEG, the doctor will stick little sticky circles onto your head. These circles will have wires attached to them. The wires will give information to a machine. The machine will show what the brain is doing. This test does not hurt. It will take one or two hours.



Chapter 2: Explaining SWS to Other People

Talking About SWS

If you have SWS, it is good for you to find out all about the condition. Talk to your doctors and your parents. Ask them any questions you have. Asking questions helps you learn. If you ask lots of questions, you can become an "expert" on Sturge-Weber Syndrome.

Once you are an expert, then you can teach others about your disorder. Other people need to have their questions answered, too. When they ask, you can explain to your friends that you were born with SWS and that they will not catch it from you. You may have a syndrome, but in most ways you are just like every other person.

If you want to learn more about Sturge-Weber Syndrome, you can ask a doctor, parent or friend. Or it might be easier for you to talk to someone else with Sturge-Weber Syndrome. The Sturge-Weber Foundation can help you meet other people with SWS. The Sturge-Weber Foundation can also answer questions you may have about the syndrome.

It is helpful to have a way to explain SWS to other people. People who care about you will want to know what SWS does to you. Other people may be curious about why you have a birthmark, don't participate in some activities, or other things. Sometimes it is helpful to let other people know about SWS. Sometimes you may not want to talk

member, they want to be liked as much as you!

Making friends doesn't happen automatically—some of it is about what we say and what we do. Here are some ideas to get you started:

Making friends doesn't happen automatically—some of it is about what we say and what we do. Here are some ideas to get you started:

- Smile and say "hi" to people. You know you're friendly and others will too.
- Make eye contact. You'll feel more confident and you'll look confident to other people too.
- Make the first move—other people will be happy to see that you are taking the first step, especially if they are shy.
- Ask lots of questions—most people love talking about themselves! Try questions that can't be answered with a yes or no and people will know you're interested in what they have to say.
- Be a good listener—we all like to be listened to.
- Have a quick explanation of your SWS ready if you notice someone is a bit shy. This will get any curiosity out of the way and you can tell them more later.

It's also worth thinking about the kinds of people that you want to be friends with. Most of the time it will be people who the same interests and feelings about things. Not everyone likes the same things or has the same interests.

Here are examples of what the school can do for you:

- More time to complete assignments, including tests and quizzes
- Typing assignments on a computer instead of writing long hand
- One set of textbooks for school and one set for home so you don't have to lug them around
- Excuse from phys ed class

Making sure you have a buddy in class with you to help you out if you need it.

You should not feel embarrassed that you do things a little differently than your classmates, or to remind the teacher if he or she forgets. If you have a substitute teacher, you should feel comfortable telling him or her what you need such as "I can't write the test answers, but I can take the test and tell you the answers."

Chapter 6 Friends

Everyone has a different story to tell about making friends. One thing we all have in common though is meeting new people can be scary whether or not you have a port wine stain or SWS.

If you have a port wine stain or SWS, chances are that new friends will be curious the first time they meet you but there are a few things to make them more comfortable, and re-

about SWS, and that's okay, because it's up to you! When it comes to explaining SWS to other people, you have choices about:

WHO TO TELL?

Chances are, you know a lot of people. There are your family, friends, neighbors, teachers, kids at school, people at church, coaches, teammates, and so on. You get to choose who to tell about your SWS. For example, you may want your close friends to know you have SWS. You may want the annoying kid on the school bus to know nothing about you at all. Having SWS is a personal thing, and it is ok to be picky when you talk about yourself.

HOW TO TELL?

Once you decide who you want to tell, you may wish to think about how to tell them. For example, think about the students in your classes at school. Do you want to talk to them one at a time, or would you like to give a presentation to the class that lets everyone know how SWS affects you? Do you want your parents to help you speak to your teachers?

WHAT TO TELL?

You can also decide exactly what each person needs to know. Close friends may like to know having SWS means you can't run quickly or you may have trouble remembering things. Teachers will need to know if there are things they can do to help you succeed in school such as having you sit closer to the front of the room, or having more time to take tests (we'll talk more about this in the "School" chapter).

WHY TELL?

An important thing to think about is the reason for telling someone about SWS. For example, teachers at school need to know at least a little about SWS so they can help you get the best education.

You may find strangers come up to you and ask weird questions. Sometimes these people mean well, and sometimes they are just being nosy. Trust your feelings about whether it seems like a person is trying to be friendly or just being rude. Remember it is your choice to tell them as much or as little as you want. A common question people get is, "What's wrong with you?" or "What happened to your face?"

As you go along it will become easier to see who needs to know the truth and who doesn't. While we all need to help educate people about SWS, this does not give anyone the right to ask you about your symptoms in a rude way.

There are several ways to handle this:

- You can put on a big smile and say "There's nothing wrong with me. Why?"
- You might just say, "I have a birthmark and seizures."
- Another way to answer nosy questions is by saying "I'm sorry, but I don't discuss these things with people I don't know."

SWS or do not have the courage to get to know you.

Once people understand why you may not run quickly, or why your birthmark looks the way it does, they are less likely to act funny around you. It is up to you and your parents to decide who at school should know about your SWS, but it probably makes sense to at least educate the teachers and students in your classes.

Tools to Help You Succeed In School

SWS can make it difficult to study, remember, or concentrate. Some of the medicines used to treat SWS can make it difficult to focus on things. All of this can make it hard to succeed in school. The good news is the school will recognize kids with SWS often need to do things differently than other students.

Now, unfortunately, you cannot go to your teacher and say, "Hey guess what? I have SWS so you should just give me all A's on my tests because that's what I would get on them anyway." It doesn't quite work that way. You and your parents need to meet with your teachers and people at school and figure out what will help you succeed. Every student with SWS is different.

Siblings

Depending on the age of your sibling, you may have different issues. If he is very young, he may be confused by what's going on. Older brothers and sisters may seem like they are acting more like parents sometimes and tell you what to do (which may be because your parents have asked them to look out for you). Your siblings may get angry because they feel like you are getting more attention than them or they might not know how to tell you their feelings. It's important to discuss your feelings with your siblings and parents.

Chapter 5: School

Many children with SWS are just as smart, if not smarter, than others their age. SWS may make you look or move differently than other people, but it doesn't affect your ability to be liked or make friends. Remember no one at school can "catch" SWS from you.

Many kids with SWS have found that one of the best ways to avoid being stared at or whispered about at school is to find a way to explain SWS to the other kids. You may want to go back to the other section of this booklet called " Explaining SWS to other People." There is no excuse for anyone to be rude to you or make comments about your symptoms, but people may act weird around you simply because they do not understand

Chapter 3: Taking Care of Yourself

Visiting the Doctor

If you are reading this book, you have probably visited many doctors. You probably have a "regular" doctor who you visit when you get an ear infection or sore throat. You may also visit a Neurologist, Dermatologist, or Ophthalmologist, depending on your medical issues.

As you have probably learned by now, for most medical visits, there will be more than one person for you to see. Doctors usually work with teams of people to treat their patients. So even though you are going to see "the doctor" which makes it sound like you will only see one person, the truth is you will probably have more than one person asking you questions and examining you during your visit.

Before you visit your doctor, you and your parents should write a checklist of how things have been going lately. Remember things like having headaches, your eyes hurting, having problems remembering things, not being as strong as usual, or having problems walking. Little things like this will help your doctor to decide the next step in your treatment. You should also write down questions you have for the doctor. Writing a list (and remembering to bring it with you to the appointment) will help you remember everything.

Talking with Your Doctor

One of the funniest questions you may be asked at the doctor's office is, "How are you?" It is a funny question because usually the person who answers the question just says, "I'm fine, thank you." But if you are there because you haven't been feeling well, you're really not "fine". So one way to answer your doctor if he or she asks, "How are you?" is to smile and say, "Well, I'm here because I have some things to talk to you about." The doctor will then probably ask you what you'd like to talk about. At that time, you and your parents can tell him about the things you wrote on your list and what is happening with your SWS.

Even though you can probably think of other things you'd rather be doing than visiting the doctor, it's very important. Hopefully you can find a doctor who you trust and don't mind visiting.

Chapter 4: Family

Even though you are the only one in your family who has SWS, the fact that you have it will affect the other people in your family – especially your parents, siblings, and family members you live with. SWS will affect them mostly because they see how it affects you and they want the best for you.

Parents

Your parents are responsible for raising you and protecting you. There may be times where you feel like your parents are too protective, worry too much, and do not give you the freedom to do things on your own. You may feel like there are times when your parents push you too hard or nag you about things that don't feel important. All kids feel this way, and all parents act this way, whether their child has SWS or not! It is good to talk these feelings over with your parents, because just like you, they are still learning.

Tell your parents about any changes (seizures, vision, etc.). Even if it's something small, you may think it's no big deal, but your parents and doctors need to know.