

**HIGGY
BEARS
SCOLIOSIS
SUPPORT
GUIDE**

Dear Scoliosis Family,

My name is Lauren, and I am the founder of Higgy Bears. As a scoliosis patient myself, I know how hard this condition can be. Not only for kids, but for the entire family.

I have been making Higgy Bears for 10 years now and have come across some great resources that I wanted to share with you! In this guide, I focus on support groups that will help you and your child, and things that will help make bracing and your child's surgery recovery a little easier. I also include information on what to bring to the hospital when having surgery, recommended scoliosis books, and even grants to help cover the cost of the brace. This guide doesn't include specific medical information as that is not where I specialize, but I have found some wonderful guides you can download that will help you learn more about scoliosis.

Thank you to all of the parents, kids, organizations and scoliosis professionals that helped make this guide possible.

I hope you find the information helpful. If you ever have any questions, please feel free to reach out to me at lauren@higgybears.com. If I don't know the answer, I can usually point you in the right direction.

A handwritten signature in black ink that reads "Lauren Higginson". The signature is fluid and cursive, with the first name "Lauren" written in a larger, more prominent script than the last name "Higginson".

Lauren Higginson
Higgy Bears Founder
& Scoliosis Warrior
(269) 364-0655
lauren@higgybears.com
www.higgybears.com

SUPPORT GROUPS FOR KIDS & TEENS

Higgy Bears ScoliZooms:

I am using the power of Zoom to connect kids & teens with one another. We meet every other week in one of four groups- ScoliKids, ScoliTweens, ScoliTeens and ScoliBruhs. In each of the groups, we talk about scoliosis at an age-appropriate level. In the kids group, kids will share what pattern they have on their brace and what their Higgy Bears names are. We spend most of the time playing fun games together like ScoliBingo and ScoliTrivia.

In teens group, the teens will share their scoliosis stories and support one another. This group is a bit more serious than the other groups. The tweens group is a mixture of the kids and teens group. We talk for a bit at first and then we play games! The ScoliBruhs group is specifically for boys and young men with scoliosis. (18 and under.) I know that there isn't much support for boys, and I am trying to do everything i can to change that.

Please visit higgybears.com and click on ScoliZooms for the latest schedule! I would love for your child or teen to join!

Scolios-us Mentor Program:

www.bracingforscoliosus.org

Scolios-us is a wonderful organization that I will talk more about but wanted to share with you their mentor program first.

The Scolios-us Mentor Program offers scoli warriors the opportunity to connect with a mentor who can help cheer them on as they navigate scoliosis. As a mentee, you are connected with one mentor who will help you through your good and bad days. However, another big benefit of the program is connecting with fellow Mentor Program participants through group chats (on the app Slack) and video calls. You are not going through this alone - you are part of a whole community that is rooting for you!

Whether you are beginning Schroth therapy or bracing or heading into surgery, you can connect with a mentor who knows exactly what you're going through. Especially when you first find out about your scoliosis, talking with a fellow scoli warrior can be incredibly powerful and helpful as you adjust to a new normal.

Curvy Girls

www.curvygirlsscoliosis.com

A wonderful support group for girls with scoliosis. They have in person groups run by teenage girls that meet throughout the world. Meeting other girls with scoliosis was the single most helpful thing for me. I highly recommend getting your daughter involved.

Teens With Scoliosis- Facebook Group

A group for any teen/young adult (12-22) who has scoliosis. The page is to share your journey through scoliosis and receive support from others who have had similar journeys. You can ask questions, give advice, and share updated about scoliosis.

FACEBOOK GROUPS FOR PARENTS

Scoliosis isn't just hard on kids and teens, but on parents, too. There are tens of thousands of parents out there all going through the same thing that you are. I've found that other parents often have the very best tips, as they have learned from their experiences. The scoliosis community is incredibly supportive. No matter where your child is at in their scoliosis journey, having other parents to lean on for tips and support can make all the difference. I have met such amazing and caring parents this way.

In groups, you can search previous posts to gather information and research ways to help your child or teen. There are a lot of wonderful posts on clothing tips. Either brand name or generic brace shirts to wear under the brace, and tips on finding shirts to wear over the brace. Parents also talk about what type of pants work well with the brace. I see a lot of posts discussing how to address any concerns at school,

such as bathroom tips with the brace, taking on and off the brace for PE, and accommodations for kids in school.

Scoliosis Support Group for Teens, Tweens and Parents of These

This group is specifically for the issues and challenges teens and tweens face with a scoliosis diagnosis. The admins of this group are so wonderful, incredibly helpful and extremely knowledgeable. I highly recommend to join this group It is one of the best groups out there.

Mothers of Children with Scoliosis

This is a group for mothers of girls, tweens and teens who are battling scoliosis. Another excellent group with wonderful admins and very supportive parents.

Parents of Kids with Juvenile Scoliosis

This is a group for parents (family and friends are also welcome) of kids who have scoliosis. Parents share experiences, tips, and tricks-of-the-trade! A wonderful group!

ScoliBoys Support Group- For Boys with Scoliosis & Their Parents

This is a group that I created so boys with scoliosis and their families could have a place to come together and support one another. I know that scoliosis is just as hard on boys as it is girls. There isn't much support out there right now for boys, and I am doing everything I can to change that.

If you are a boy with scoliosis or a family member, please join this group so we can all support one another.

Embraced- Scoliosis Support Group for Parents

This Facebook group was created to support families currently using bracing to treat scoliosis and to provide them with a forum for sharing bracing experiences.

Dr. Derek Lee's Ultimate Guide to Navigating Scoliosis Treatment/Research

This group is one of a kind. Dr. Derek Lee has created this group to bridge the gap between scoliosis providers and scoliosis families. Top scoliosis experts from all over the world have joined this group to help answer parent's questions about their child's specific case. This is an amazing opportunity to get answers on your child's condition from the experts. There are also parent experts that are extremely knowledgeable and helpful. The latest research will be posted here, too. I cannot say enough great things about this group. Definitely one to join!

Scoliosis Support Group Girls Aged 8-12

A group that focuses specifically on helping girls with scoliosis aged 8-12. You will find a lot of great information in this group.

Early Onset Juvenile Scoliosis Support Group

A great group for parents of younger kids with scoliosis.

Scoliosis Support Group

There are two separate Facebook groups with this name. One with around 30,000 (the second largest Facebook Group for scoliosis) and the other with about 8,000. Both are great. There is a mixture of parents of kids with scoliosis and adults with scoliosis in these groups.

Infantile Scoliosis

This is a group specifically for parents of infants and very young children with scoliosis.

Early Onset Scoliosis & Mehta Casting

A great group that has several thousand parents of casted kiddos and younger kiddos with scoliosis. The admins here are very helpful. The families will be able to help guide you through your child's scoliosis journey.

Scoliosis Tethering (VBT & ASC) Support

A group specifically for parents and patients interested in learning more about VBT & ASC surgery.

ONLINE BRACING AND SURGERY INFORMATION/RESOURCES

Scolios-Us

www.bracingforscoliosus.org

Scolios-us is a web-based platform intended to empower patients with the tools and resources they need to be successful along their scoliosis journey. My friend, Megan, has put together all of the information you may need throughout your family's scoliosis journey. There is information on bracing, physical therapy and exercise, surgery, understanding X-rays, and more! Megan also has great articles about questions to ask your orthotist, what to bring to the hospital, and tips for what to wear both under and over the brace. I highly recommend visiting www.bracingforscolioius.org and browsing the site. There is a ton of very helpful information here. While you're there, check out the Scolios-us Mentor Program previously mentioned in this guide.

Setting Scoliosis Straight Patient Handbook:

<https://www.settingscoliosisstraight.org/patient-handbook/>

Setting Scoliosis Straight is a wonderful organization. They have created two very detailed patient handbooks. The first about scoliosis as a whole, and the second is a surgery guide. You can download each

of these handbooks for free on their website. I highly recommend downloading if you are interested in learning more about scoliosis.

Setting Scoliosis Straight also has a great collection of patient stories:

<https://www.settingscoliosisstraight.org/patient-stories/>

Scoliosis Research Society- Patients & Families Section

<https://www.srs.org/patients-and-families>

A great collection of information about scoliosis and treatments available. There are wonderful recorded webinars and educational videos you can watch, patient stories, and ask the doc section and more.

Michael G Vitale MD MPH- Columbia Orthopedics-

Educational Resources

<https://pediatricscoliosissurgery.com/educational-resources/>

Dr. Vitale is a world-renowned surgeon at Columbia Orthopedics in New York City. He has a lot of wonderful books and resources on his website for patients and families. I highly recommend these books:

Scoliosis- A Guide for Children and Their Families

What to Expect- Your Child's Spine Surgery

Setting Scoliosis Straight YouTube Informational Videos:

<https://www.youtube.com/@SettingScoliosisStraight>

Many informational videos for both kids and parents.

Scoliosis & Spine Online Learning (SSOL)

<https://www.scoliosisandspineonlinelearning.com>

A wonderful website with information and webinars from top scoliosis professionals across the world. A great way to learn more about scoliosis!

APPS TO TRACK BRACE WEAR

BraceTrack

A great app for your phone that allows you to track the hours you have worn your brace. I highly recommend it.

PHYSICAL THERAPY INFORMATION

Scolios-Us Physical Therapy & Exercise Information: (An overview)

<https://www.bracingforscoliosis.org/physical-therapy-and-exercise-information/>

Great overview of all of the different physical therapy options for physical therapy. Includes information about Schroth Physical Therapy, and Physiotherapeutic Scoliosis-Specific Exercise (PSSE).Schroth Method Exercises for Scoliosis

Schroth Method Exercises for Scoliosis

Visit the Schroth Method website to learn more about Schroth. The scoliosis exercises are designed to reverse all of the abnormal curvatures with a variety of means, based upon the therapist's analysis of a patient's muscle imbalances.

<https://www.schrothmethod.com>

Worldwide Schroth Therapist Directory:

<https://www.schrothmethod.com/contact>

(Directory links show on the left side of the page)

Schroth-Barcelone Institute

Schroth Barcelona mission is to provide a central organization based in USA which facilitates the training and certification of physical therapists and to develop standard of education and practice standards in the Schorth Method.

<https://www.schroth-barcelonainstitute.com>

FINANCIAL RESOURCES

HealthWell Foundation:

When health insurance is not enough, they will fill the gap by assisting with copays, premiums, deductibles and out-of-pocket expenses.

<https://www.healthwellfoundation.org>

The Children's Scoliosis Foundation

The Children's Scoliosis Foundation offers financial aid grants of up to \$500 per trip (\$750 for international travel) are available to help support children and their families who are traveling long distances for bracing or surgical treatment for scoliosis.

<https://www.childrensscoliosisfoundation.org>

United HealthCare Children's Foundation:

UHCCF grants help with medical expenses not covered, or not fully covered, by their commercial health insurance.

The amount awarded to an individual within a 12-month period is limited to \$5,000. Awards to any one individual are limited to a lifetime maximum of \$10,000.

<https://www.uhccf.org>

Mercy Medical Angels

Mercy Medical Angels is the largest charitable medical transportation system in the world. Mercy Medical Angels removes the barrier to medical care with transportation on the ground with gas cards, bus and train tickets and in the air with flights flown by volunteer pilots and the commercial airlines.

<https://www.mercymedical.org>

FASHION GUIDES

Scolios-Us- Dressing with Your Scoliosis Brace

<https://www.bracingforscoliosis.org/what-to-wear-what-not-to-wear/>

National Scoliosis Center Fashion Blog:

<https://nationalscoliosiscenter.com/topics/fashion/>

Scoliosis 3DC Blog:

<https://scoliosis3dc.com/2018/07/09/what-to-wear-with-scoliosis/>

<https://scoliosis3dc.com/2018/04/06/best-shirt-to-wear-under-a-scoliosis-brace/>

WHAT TO LOOK FOR IN A BRACE SHIRT

You want an extra layer of protection between your skin and your brace, so always wear a tight-fitting shirt underneath your scoliosis brace. Wrinkles are the enemy! They can create excessive pressure in certain areas and cause skin irritation.

- Fit should be snug with no wrinkles (stretchy and tight fitting)
- Seamless shirts are preferred. When seamless shirts aren't possible, flip the shirt inside out so the smooth side faces the body
- Blend of cotton or bamboo (more breathable) and spandex which allows some stretch. (Shirts that are 100% cotton tend not to work as well.)
- Terms to use when searching: seamless, anti-bacterial, moisture-wicking and anti-microbial.
- Thick enough to provide skin protection and not get ruined by the brace, but thin enough to not be too hot.
- High enough under the armpits to provide protection there.

Find more tips at scoliosis3dc.com (blog) & scoliosisliving.blogspot.com

BRACING SHIRT RECOMMENDATIONS FROM PARENTS

- Embraced in Comfort
- Brace Buddies
- Hope's Closet at Align Clinic
- The Boston T
- Sugarlips Seamless T-Shirts
- SO Seamless Tanks (Kohls)
- Boys Under Armour Heat Gear Shirts (Amazon)
- Sanaa's ScoKhloeTees for WCR Braces- Email Sanaa at scokhloetees@gmail.com to order. She sews t-shirts that offer a little padding to decrease chaffing of the plastic against the skin in the armpit area. She makes the tees custom to your child/teen's brace.

HELPFUL YOUTUBE ACCOUNTS

There are a lot of awesome girls out there that want to help others and have created YouTube channels. Search, "back brace fashion," "back brace tips," "scoliosis surgery tips." Izzy & Malia jade have great accounts that I recommend you check out.

Surgery Tips from Izzy:

<https://www.youtube.com/@izzyann6798>

Malia Jade Brace Fashion Tips:

<https://www.youtube.com/watch?v=CWUxL43Wygw>

<https://www.youtube.com/watch?v=eXjwlzA1xyI>

My Back Brace YouTube Channel:

<https://www.youtube.com/@MyBackBrace>

HIGGY BEARS SURGERY GUIDE

Helpful Items for Hospital Stay:

Electronic/Helpful Accessories

- Long charger for laptop/tablet and headphones for kids
- Parents- don't forget your phone charger!
- Mini personal fan (very helpful!) The best purchase you can make. The medicine makes them so hot and nauseous
- Pen & paper to take notes
- Adult coloring book or mindless activity books for parents to keep you occupied during the surgery.
- Pillow for yourself
- Surgery Higgly Bear to help with recovery
- High calorie snacks for your child while they are recovering. They aren't able to eat much. Be sure to bring snacks and a water bottle for yourself, too.

Clothes

- PJ (tops) that button up or button up shirt
- Grippy socks for walking in the hallways
- Underwear
- Elastic shorts or pajama pants
- Rolling suitcase or bag

Toiletries

- Toothbrush, toothpaste, comb and brush
- Chapstick- lips get very dry after surgery
- Pads or period underwear- the stress of the surgery will cause many girls to start their period.

Car Ride Home

- Several pillows for the car. It is incredibly hard to get comfortable in the car on the way home. The more pillows, the better.
- Stool to get in and out of the car, if needed.
- Slip on tennis shoes.

Recovery At Home:

Medical & Helpful Items

- Large ice packs (2 of these) and large heating pad. ColPac on Amazon are great ice packs and they do have a large size
- Miralax
- Grabber to be able to reach/pick up things. Very helpful!
- Walker- usually supplied by hospital
- Water bottle with non-leaking squirt top or water bottle with bendy straw to take medicine while lying down in bed.

Bedroom & Living Room

- About 5-7 pillows for the bed
- Wedge pillows or body pillows can be comfortable
- Lift Recliner- you can rent these from medical supply companies in your area. I found this really helpful, because I couldn't get comfortable in any other chair. They stand you up automatically and sit you down, also. They are usually \$150 to rent for the week.
- Zero Gravity Chairs can be helpful for some. Some kids don't find them comfortable. They can be tricky to get in and out of.
- Some have found that a wheelchair with lots of pillows can be comfortable for home as you can bring it anywhere
- Bed support arm to help sit up in bed
- An adjustable bed is great if you have that option
- Foam mattress toppers can be helpful to keep kids comfortable

Bathroom

- Shower chair and/or shower stool
- Toilet riser with handles
- Non-slip mat for shower
- Handheld shower head for help with cleaning
- Hairdresser cape for washing hair (can sit in chair and wash their hair- hairdresser cape for privacy/and or to keep clothes dry.)

- Loofah on a stick for the shower- they will not be able to bend in the shower
- Long reach toilet aid- can be very hard to wipe after surgery without twisting
- Urinal for boys
- Baby wipes
- Dry shampoo

Clothing

- Athletic shorts, loose pants or PJ pants
- More button up loose shirts

- Front closure sports bra for girls

Helpful Tips:

- Make a schedule with your child in order to squeeze in all of their PT, meds, water, spirometer, walks, chair time, etc.
- Braid long hair before surgery.
- Join Facebook Support Groups and post any issues you are having.
- Stay on top of pain medicine schedule, even in the middle of the night. Incredibly important.
- Walking is very important after surgery. It's hard, but it helps! Start slow and work up to longer distances. I started walking from one door in my house to the other door, then to the mailbox the next day, stop sign, around the block, etc. Use a walker, if needed.
- Ask if the hospital has a program for service animals to come and visit.
- Don't forget your own phone charger to use in the waiting room.

Please don't feel like you have to get all of the items on this list. Certain items are helpful for some, and not needed for others. Parents, don't forget to take care of yourselves during this time, too. This recovery is hard for your child- and it will be hard for you, too. The first couple of days are similar to taking care of a newborn at home. You will need to do everything for your child. Sleep when they sleep. Eat nutritious meals to keep your energy up. Be sure to reach out to parents in Facebook groups for support. We are all here for you!

Back to School

- Pillow for chair
- Rolling backpack or friend to carry their things
- No bus- drive them
- Ask teachers to dismiss them a few minutes early from each class so not to be rushed in the hallway
- Ask if they can still "be on the team" for their sports activities even if they aren't playing this season.

RECOMMENDED SCOLIOSIS BOOKS:

Scoliosis Books for Children:

- **The Silver Horned Girl by Lisa Owens- I highly recommend for both children and teens! Amazing book to help with self-confidence with wearing a back brace or having surgery.**
- The Scoliosaurus by Lauren Amy Davis
- Being Grace: A Story for Children About Scoliosis by June Hyjek
- Beamer Learns About Scoliosis by Cindy Chambers
- Cole & The Crooked Flower by Russell Leggett

- Beautiful Crooked Letter I by Shae Smith

Scoliosis Books for Pre-Teens & Teens:

- Scolios-us Brace Journal by BracingforScoliosis.org
- Tangled in the Curves: Real Life with Idiopathic Scoliosis by Caroline Bell
- Braced by Alyson Gerber
- Straight Talk with the Curvy Girls by Theresa E Mulvaney & Robin Stoltz
- Straight Talk Scoliosis- The Journey Continues by Theresa E Mulvaney & Robin Stoltz
- Fighting the Curve: My Battle with Scoliosis by Haley Guidry
- Harry Scores a Hat Trick With Pawns, Pucks, and Scoliosis by Mary Mahony
- Abby's Twin by Ann M. Martin
- Heaven Sent by S.J. Morgan
- Deenie by Judy Blume

- When Life Throws You a Curve by Elizabeth Golden
- There's an S on My Back by Mary Mahony
- Plastic Back by Anna Rakes

Scoliosis Books for Parents:

- Tangled in the Curves: Real Life with Idiopathic Scoliosis by Caroline Bell
- The Emotional Journey of Scoliosis by Reshmi Pal
- Help, My Daughter Has Scoliosis by Hilary Lowne
- What Can I Give You by Mary Mahoney
- No One Else Like Me by Karla Auerbach
- I Have Scoliosis, Now What by Ein Myers
- Scoliosis- A Guide for Children & Their Families by Michael G. Vitale MD MPH and Amber Mizerik PA-C
- Setting Scoliosis Straight Digital Handbooks Previously Mentioned

SHARING YOUR SCOLIOSIS DIAGNOSIS WITH CLASSMATES

The wonderful ladies at Scolios-us put together a power point presentation kids can present to their class about scoliosis. I've found that teaching the class about scoliosis, and why your child needs to wear a scoliosis brace or have surgery is especially helpful for elementary students. Here is the link:

<https://www.bracingforscoliosis.org/presentations-for-warriors-heading-back-to-school/>

504 PLANS FOR SCHOOL

504 plans are designed to ensure your child receives needed accommodations at school. Definitely look into this if the school is not being helpful with what your child needs.

Examples of Accommodations in 504 Plans Include:

- Preferential seating
- Extended time on tests and assignments
- Reduced homework or classwork
- Verbal, visual or technology aids
- Modified textbook or audio-video materials
- Behavior management support
- Adjusted class schedules or grading
- Verbal testing
- Excused lateness, absence, or missed classwork
- Pre-approved nurse's office visits and accompaniment to visit
- Occupational or physical therapy

Examples from Parents- How 504 Plans Can Help Scoliosis Patients

“We asked for a top locker, made sure she had a chair with a back, the ability to stand anytime as needed, extra books for home or to leave in the classroom, ability to leave class early if needed to get stuff from locker and instrument if needed, ability to go to the nurse anytime. This was stuff right after her surgery but we kept it and still have it 4 years later.” – Melissa

“We requested one with a doctor's note in hand. Our doctor put in some recommendations in the note (air conditioning, brace breaks, using restroom in nurses offices, options for chairs, set of materials for home, etc). Once the school had the note, the school psychologist observed Paige in class. We had the 504 meeting and she was found eligible. Paige goes to the nurse to take her brace off for PE and recess. The nurse holds the brace in her office when she is not wearing it.”

– Tennille

- "Stretch breaks!! My daughter is in middle school now, but even in elementary, the schools have been very good at allowing her to just stand up next to her desk and stretch for a minute.” – Lauren

“I'm a school psychologist with scoliosis and a parent of 3. 504 plans have different criteria in different states/county. In Florida, and in my district, a parent needs to present a letter from a doctor with a diagnosis to the school. The parent can request a 504 meeting and this meeting will consist of a team of professionals.” -Katie

HIGGY BEARS & SCOLIOS-US TIPS FOR SCHOOL

What to Wear:

“If you feel like you want to hide your brace, you can wear your pants/shorts over your brace, then wear spandex or bike shorts under the brace. This way if your shirt comes up you see regular pants.

Just make sure you keep an eye on your pants, you can't feel them if they fall down.” -Claire

“Leggings, leggings, leggings!! If you don't wear a uniform” – Holly

“Everything oversized (tees, hoodies) and leggings or sweatpants are lifesavers” -Illiana

“Wear a tee one size down from your regular size under your school blouse/shirt. You could also seek permission from your school to wear your blouse as a tunic instead of tucked in for your comfort.” – Ann

Seating:

“The hard plastic chairs stink and can be super uncomfortable. Ask your teachers for a different chair. In past years, they've given me the soft office chairs which are sooo helpful!”

“You can make a little pad to make the chairs more comfortable (it helped me more when I didn't have my brace but it could be helpful with a brace.)” – Karen

“Make sure to talk to your teachers to get some extra time to stretch during class if you need because wearing a brace and sitting all day can make your back really stiff and sore.” - Lily

“Offer to run papers for the teacher so you can get up and walk around!” – Madelynn

“For surgery patients: bring a pillow (whatever softness or firmness is best for you!) to help support your back, most of chairs are horrible after surgery.” - Teagan

Backpacks

“I like a backpack with thicker, more padded straps so they don't pinch my skin (between your brace and backpack.)” – Claire

“My daughter used a rolling backpack when she wore a brace. We made sure to put it in her 504 plan, because some schools don't allow rolling backpacks.” – Vickie

“I always make sure the straps are opposite the curve. My left shoulder is higher than my right, so I pull the left strap higher than the right to even myself out a bit.” – Madelynn

“When I was bracing I used a smaller tote bag that I could just carry by hand instead of putting all the weight on my shoulders.” – Ky

“A Higgy Bear Brace Bag is a great way to store your brace and keep it covered if you have to take it off for gym or sports.”- Alex

BackTPack has helped any school child who has used it as a replacement for their standard backpack. Those with scoliosis especially benefit!” – Marilyn- backpack.com

Telling Friends and Classmates:

“My daughter (7) starts school on Monday. Got the brace 2 weeks ago. We are planning to have a Q&A session with her class. Met with the school nurse today to coordinate her accommodations. My hope is that the other kiddos will be curious and open to em”bracing” this change.” – Callista

“Just try to be as open as possible. Let the questions come, as curiosity is powerful. People will stare less if they have knowledge. For me personally, my teacher let me go in front of the class, talk about it, and then take questions.”

“Never assume that when a person comments on your brace, that it’s always something negative or that they’re being rude to you. Most of the time, people are just curious and have never seen a brace before! Use this as an opportunity to maybe educate them a little! I’ve had a ton of girls coming up to me and asking about my brace, and a few of them (once I explained everything) even discovered they had scoliosis too!” – Kat

Lockers/Carrying Around Books

“If you need help carrying books, ask a friend who you trust!” -Hailey

“Ask for an extra set of books to keep at home.” – Kymberly

“At my daughter’s middle school, they had top lockers and bottom lockers. We always made sure she got a top locker, so she got a top locker, so she wouldn’t need to squat. And she used a rolling backpack. She also got a second copy of all of her textbooks, so she wouldn’t have to carry them in her backpack.” -Vickie

PE & Activities

“I played sports when I had two curves over 50 degrees. Something

that helped me was taking my medicine right before practice/games. Definitely helped with pain. Extra stretching helped me so much, too! Yoga can help as well!” - Juliette

“Doctor’s note!!! Neither my middle school or high school accepted parent notes, so just make sure you have a doctor’s note that specifically says things you can’t do or says you can decide what you feel comfortable with.”

“Communication with teacher, PE teacher, and nurse about getting a few minutes before and after PE to take off and put back on brace. I will encourage our school nurse to remind my daughter to tighten it up!” - Alyssa

Bathroom Breaks

“Talk to your school nurse! I used to always feel nervous going to the bathroom in my brace at school and she gladly let me use hers anytime! Best decision I’ve made so far!” -Canyon

Communication With Teachers:

“Let the teacher know that your allowed to visit the nurse whenever it is needed ahead of time (if that is the case)” – Maddie

“I would highly recommend either the person in the brace or a parent talking to a teacher/teachers about any difficulties with the brace. I had to get mine in September last year so I told mine about my situation and saying I would need seats in the back of the class so I could stand when needed when my back got sore and needed more time in the bathroom (it took me about 10 minutes for the first month I had it) so communication is key!!” – Lucy

“Let your teachers know ahead of time in case you need to take a break from your brace so they won’t start asking questions in front of people who you may not want to know about your

“Communicating with my teachers helped me through high school! It’s important to understand that not everyone can see or understand what you are going through. The extra hand or understanding from teachers made such a difference.” - Michele

Transportation:

“Bus seats are hard on kids! See how long their route is. Sometimes transportation can have your student on a shorter route if they need it. Transportation, the buses, are always happy to try to help! Just call and ask! Also, if they have had a surgery recently, see if the transportation will allow your child to ride the small bus. They can pick up at the house and shorter ride. Seating pad for longer rides if that is needed.” – Annie

For even more school tips, search in the Facebook Support Groups or ask the question yourself. There are thousands of parents out there that have been through the same thing you are and would be happy to help you and would be happy to help you and your child.

INSTAGRAM:

I recommend if your teen is on Instagram to follow several of the teens that have scoliosis accounts. There are so many wonderful girls out there that are giving back and helping others that have scoliosis. There are several that I recommend. I know these girls personally and they would love to help your child or teen any way possible through their scoliosis journey. Their DMs are always open. Izzy (@scoliosis_warrior_2019), Alia (@scoliosis_brace_sister) Olivia (@olivia.scoliosis) Brooke (@scoliosis.brooke) Chloe (@_chloe_strong_) Hailey (@haileyscoliosis), Sarah (@scoli_sarah), Ashlyn (@klaus_the_higgy_koala), Several Girls (@higgybearsandbraces), Haley (@haley_scoliosis12), Hayden (@hayden.scoliosis), Lucy (@lucysscoliosis), Charlee (@scoliosiswarrior_charlee28.) Don't forget to follow Higgy Bears! (@higgybears)

There aren't any boys that have support accounts on Instagram that I know of (which is unfortunate), but there is a huge need! If your scoliosis teen is interested in starting an account for scoliosis boys, please let me know! I would be happy to share and promote it!

There are several celebrities and influencers with scoliosis that are great role models for other patients. Martha Hunt (@marthahunt), Meredith Martin (@bionic_ballerina), Gigi Crouch (@scolerina9247), Kyra Condie (@kyra_condie), Paige Fraser (@lovingthispaige), Julia Carlile (@juliacarlile_xo), Princess Eugenie (@princesseugenie) and Alyson Gerber (@alysongerber)

HIGGY BEARS AMBASSADOR PROGRAM

Join dozens of kids all over the world that have started Higgy Bear Fundraisers! Kids can fundraise any way they would like, and when their fundraiser is complete, they get to pick out all of the animals they would like. I send the Higgies directly to your child and they can personally take them into their hospital or clinic to donate. This is a great volunteer opportunity for your child. Kids and teens really enjoy giving back and helping other kids. Please visit higgybears.com and click on how to help for more information or send me an email!