

# C5'S BUZZ

National Support Group for Families with Cri du Chat Syndrome



## Our Fearless Leader

NICK WALLACE



Looking ahead:

**C5'S BUZZ—  
ADULT SERVICES**

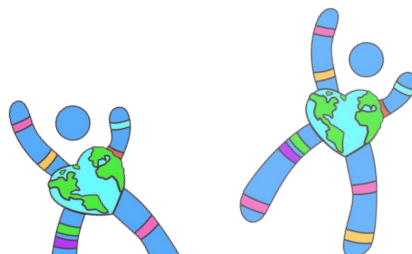
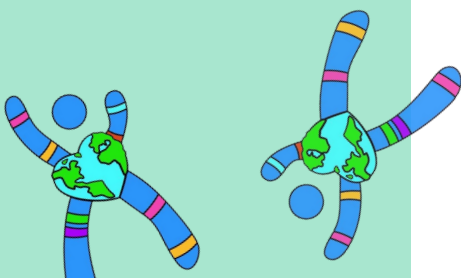
**IN-PERSON  
CONFERENCE  
CHARLOTTE, NC  
—JULY 2022**

Welcome To Summer Everyone!

I hope you all understand how wonderful the families within the 5p- Society are! The support we give one another during the celebrations, during the difficult times, and during our times of sorrow often has me in awe.

I know that one of the places where some of this bonding happens is at our annual conference. It was quite a difficult decision to postpone this event once again, but for the safety of our families, it was really the only option. We are planning to sponsor more regional gatherings this year, so keep an eye out on our Facebook page, as info is already starting to come out regarding some of these events. We will also be having another virtual conference in September, but more info will come out about that soon.

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**...and how they  
felt like  
part of our  
5p- family now.**

### Our Fearless Leader continued from previous page

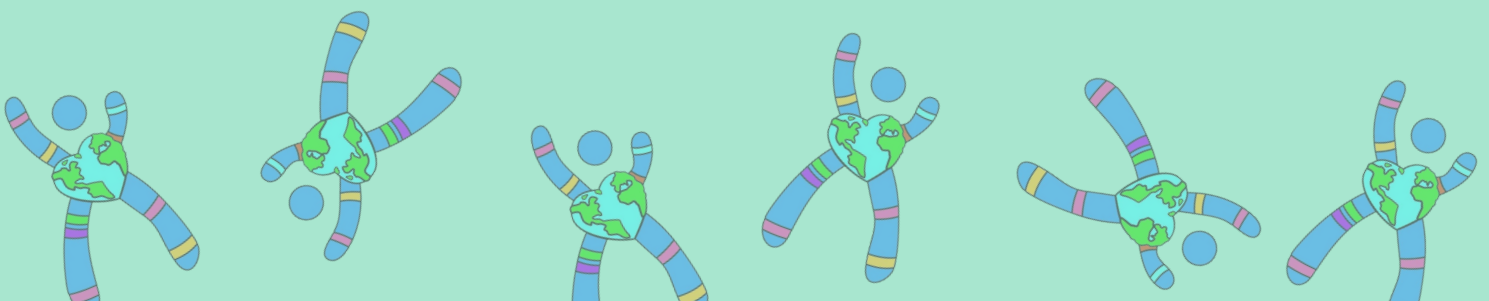
Although we have had to forgo in person events, we have been fortunate to have our Zoom accounts to help us continue to connect families virtually. Again, I know this is not the same as meeting someone in person, but it has helped us to connect families. This technology has also helped us continue our mission of supporting families with the Zoom talks we have been having recently. We have been trying to pick topics like puberty, group home transitions, communication, and feeding tubes, that are relevant to our families, give a platform to discuss some of these issues, and help support each other with ideas and suggestions of what may have worked for other families.

Ok, Nick ... how does this cause you to be in awe of how supportive our families are? Well, I had the privilege to moderate one of the Zoom talk sessions. During this session, it started out as most of them start. People introduced themselves and talked a little bit about their families, their life situations, and why they decided to join the talk.

This is where things changed a bit. We had one family on the call that had their camera turned off and really didn't say too much. Eventually this family, who happened to be a new family to our group, asked a question of the members on the call, and per the usual, the families started assisting with the question. As the talk progressed, the new family stated that they were sorry to hijack the talk. This is where the awe comes in for me. I witnessed our families do what they do best. They noticed that this family needed some support, and they embraced that family with all the love and support that they could give.

Some of you may be wondering why I inserted the comment about the camera being turned off during the meeting, and here is why. By the end of the call, the family turned on their camera, and we were able to see this beautiful family and see the relief that our support had given them. The family commented that this was not how they expected the call to go, how appreciative they were for our support, and how they felt like part of our 5p- family now.

So, I just wanted to say thank you for being such an awesome group of people. A group I am so happy to call my family. Hopefully, I will be able to connect with some of you at one of our regional gatherings or next year at our conference in Charlotte.



# Scoliosis and 5p- Syndrome: A Practical Approach

CEDRIC L. WONG, MD

Scoliosis is a condition of the spine where there is formation of a curve or curves in the spine as viewed from the back. This can appear like the shape of a “C” or “S” and can affect many aspects of life, such as sitting posture, balance for walking, or even breathing issues when severe. Monitoring this condition is critical to ensure proper interventions can be made at the proper time.

Due to the lower muscle tone in kids with 5p- Syndrome, the typical type of scoliosis is called Neuromuscular Scoliosis. Curves like this have a higher tendency to progress than Idiopathic Scoliosis, which is typically seen in young adolescence. However, there is also Congenital Scoliosis, where the abnormal curvature is caused by malformed bones in the spine.

The things to look for as a parent of a child with 5p- are many. The first thing is how the spine looks to you. This may be noticeable when changing your child’s clothing or giving them a bath. You may notice that one shoulder sits higher than the other, or the ribs look more prominent on one side. It may not look too bad at first, but over time, you may notice a change in posture, especially if your child sits in a wheelchair. Perhaps the child appears more slouched than in the past. Maybe the child is having more difficulty sitting up and has to lean on an arm or hand more. Or you might notice the child is getting pressure sores on one side where they sit.

If they are not already, your child should be getting annual checks with a pediatrician. This is a service that is typically covered by most insurance companies, but you should verify first to make sure. As your child’s advocate, you should point out your observations so that the pediatrician can perform a more focused exam on this area. Most pediatricians have NOT had a patient with 5p- Syndrome, due to its rarity, and sometimes you may know more about the health conditions than they do, so do this POLITELY AND RESPECTFULLY.

The pediatrician may notice findings that warrant an x-ray of the spine. This is usually done from the front to back as well as a side view. This is the best way to differentiate between Congenital and Neuromuscular Scoliosis, noting the possibility that there may be components of both. If there are concerning signs of soft tissue issues, especially of nerve roots or the spinal cord, then sometimes an MRI will be recommended. Do not be surprised if this has to be done under sedation to minimize risk of motion artifact, as it can be difficult to get a child to lay still long enough to do the scan properly.

If there are abnormalities on the x-ray and/or MRI, then the next step will depend on severity. If mild, then the pediatrician will often recommend x-rays to be repeated every so often to watch for progression. The frequency will depend on the concerns at the time. If the abnormalities are more severe, or showing signs of progression on serial studies, then the pediatrician may recommend referral to a pediatric or spine orthopedic surgeon or neurosurgeon. This is the type of provider who can discuss treatment options, both non-operative and operative, and perform surgery when necessary. This may be as basic as adjustments to an existing wheelchair, bracing, or physical therapy. Surgical interventions will depend on many factors, such as patient age, type of scoliosis, rate of progression, or levels of the spine involved.

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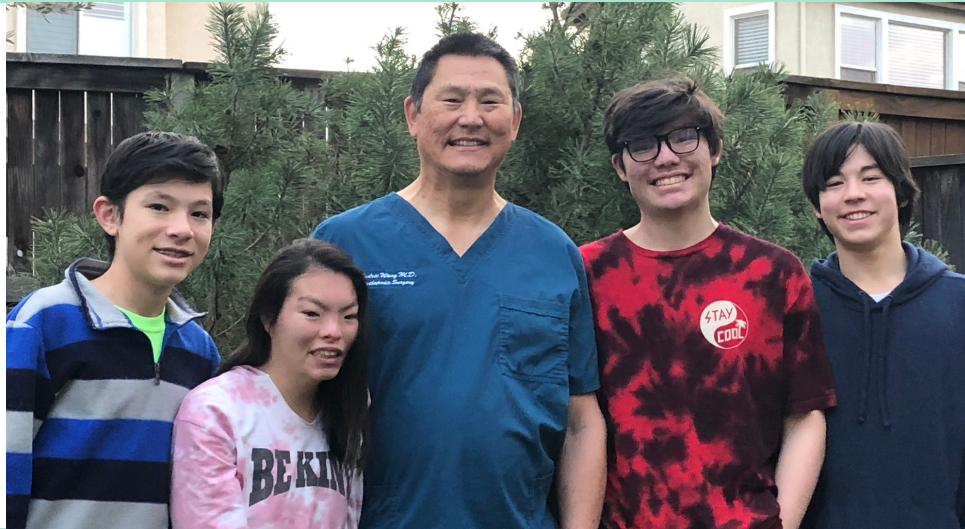


## Scoliosis and 5p- Syndrome: A Practical Approach continued from previous page

The most challenging cases are those where the scoliosis is so severe that it affects other areas, such as lung function or skin in the form of pressure sores. When the cases are more severe, having access to what's called "multidisciplinary care" can pay dividends. Team members work in different specialties but work together to coordinate care for the benefit of the child. This includes physical therapy, occupational therapy, prosthetics lab, and various physicians, such as pediatrics, orthopedic surgery, neurology, pulmonology, dermatology, general surgery, and others, depending on the child's general health as well as any prior or progressing conditions. This is typically present at the major medical centers, such as Shriners or Stanford University. If your child has scoliosis, it may benefit you to research the medical capabilities in your area. Should they need more intensive services, knowing what is available will make planning easier later.

In summary, scoliosis is an abnormal curvature of the spine. It can be identified by a parent being observant or a pediatrician who sees your child on a regular basis. It may need referral to a local specialist, or in extreme cases, to a facility with a multidisciplinary approach to care. Options for treatment can be nonsurgical, or in the worst cases, surgical. Remain that strong advocate for your child. (It was my intention in this article to specifically avoid the more medical-specific discussions of scoliosis. There are plenty of very good sources out there for scoliosis, such as the American Academy of Orthopedic Surgeons and the Scoliosis Research Society).

Cedric L Wong, MD is a general orthopedic surgeon from Folsom, CA. He trained with the US Air Force and served in various locations until 2003. He has been in private practice since then. His wife, Jennifer Wong, is an active proponent for special needs kids and is a past president and current board member of the 5p-Society. Their daughter, Emma, who has 5p- Syndrome, is 19 years old.



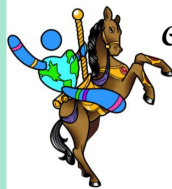
SAVE THE DATE

### 5p- Society

Virtual Conference 2021

September 18 & 19, 2021

DETAILS TO BE  
RELEASED SOON



*C5's Carousel  
of Possible  
Dreams*

5p- Society  
www.fivepminus.org



The 5p- Society is happy to announce our 2021 Regional Gatherings. Here are the locations and the dates: Please check our website and/or Facebook for more information.

**June 26**—Moses Lake, WA—Kristen Turner, kdt43967@gmail.com

**July 17**—Austin, TX— Zeena Querbach, Zeena.Osmany@gmail.com

**July 24**—Dayton, OH—Jolene Towers, gnjtowers@aol.com

**July 31**—Milwaukee, WI—Hutch Renk, hutchjpr@gmail.com

**October 2** - Mclean, VA, Gina Song, mrsginasong@gmail.com

**October 9**—Greenbush, NY—Amy Severson, amysever73@gmail.com

**October 23**—Auburn, AL—Shari Campbell, djcshc@charter.net

Dates/times coming soon for: Southern California, Utah and Virginia.





# Hannah's Scoliosis Journey

SANDY COOLEY

Hannah started out her scoliosis journey with no clue from me that she even had a curvature. Hannah was a very active young girl and was always in to something. I knew that she was very left dominant and much stronger on her left side. I didn't know that this would lead to scoliosis and later surgery.

When she was about 10 years old, she was going to Children's Rehabilitation Clinic for a check up in the orthopedic clinic for difficulty walking and to see if she required new SMO's. The doctor at that point suggested we get an x-ray of her back to see what her spine was looking like. This was the first step in the diagnosis of her scoliosis. After the x-ray was looked at, he suggested that we take a wait and see approach with periodic x-rays every six months to a year to watch for progression of the curve.

With each approaching visit, I was anxious and prayed that her curve would not get worse. As the doctor stated, if her curve became greater than 45 degrees, he would consider rod placement in her back. As the years moved on, she had a very slow progression of her curve, and the hope was that the curve may stabilize. Instead, she developed 2 curves, essentially making her spine in an S shape.

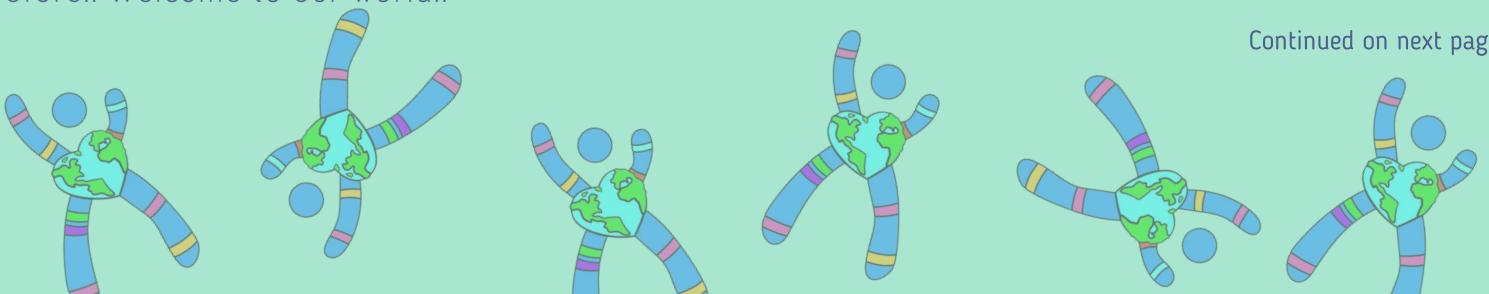
She began to complain of pain in her back periodically around 15 years old. The pain was easily remediated with Tylenol and rest. However, as she grew, her curve was progressing. At 17, her curve was at 54 degrees, and I was told it was time to consider surgery. Needless to say, I was devastated and scared, as she had not had any major surgeries up to this point.

I was concerned about her being intubated for surgery due to her recessed mandible and small tracheal opening. In addition, she was diagnosed with osteoporosis due to the birth control shots that she had been receiving since she began menstruating. Also, I was worried about her neurologically coming out of the anesthesia.

The surgeon and I decided that her surgery could wait until the end of May, when I would be out for the summer to help her recuperate from the surgery. By then she was 18 years old. Her surgery was scheduled, and the doctor stated that it would take at least 8 hours to perform the surgery. I prepared Hannah as best as I could for her upcoming surgery. I explained to her that they would have to put a metal rod in her back to keep it straight, and it would help her. I was able to be with her up until they wheeled her toward the surgical suite. Hannah was scared but seemed to understand that she was going to have surgery for her back and would see me after the surgery. I was then sent to the waiting area, where several supportive friends waited the day out with me.

The surgery took 8 hours to perform, and I was a nervous wreck as I waited. The surgeon came out and said that although everything went well, it was a challenge to operate on Hannah, as she had to be given a lot of anesthetic to get her to go out. Once he was inside her back, he stated that she had a lot of physical anomalies that had to be taken into consideration with her muscles on bones. She also has an extra set of ribs that he discovered. The surgeon placed rods in her back from T2-T11, which is almost all of her thoracic spine. Your thoracic spine runs from T1-T12. He had to graft cadaver bones in to stabilize the rods. It seems like only minutes later that a nurse came rushing out of the recovery area looking for me. Hannah was awake and attempting to climb out of the bed to find me. So, they let me back in recovery to calm her down and keep her in the bed. They stated that they had never had a child come straight out of having their rod placement and attempt to climb out of the bed like that before!! Welcome to our world!!

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## Hannah's Scoliosis Journey continued from previous page

When we were placed in a room, Hannah was given a pain pump, and I was told to let her operate it herself when she was in pain. Well, let's just say that didn't go over too well!!! Hannah was too weak and didn't understand to press the button when she was in pain. So, I pressed it when she looked like she was in pain and got fussed at by the nurses. I did it anyway!! I wasn't going to let her be in pain.

Two days later, they stated that she could go home. What?!?!?! Her back was held together with staples and steri-strips, and she was in a tremendous amount of pain. Her neck was also in an extended position toward her back. She did not want to bend her neck forward, as she stated it hurt. She was not allowed to bend or twist her back, which was a constant battle to keep her from doing this. She also reverted to being non verbal and just using her limited sign language and grunts for responses. This frightened me. However, she does this now and again when she is feeling sick.

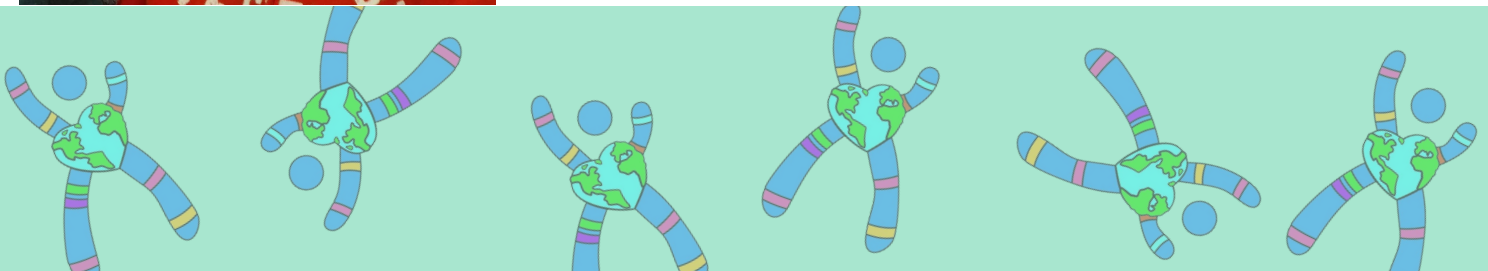
Well, I drove 2 hours back home from the hospital (her surgery was in Atlanta, GA, and we live in Phenix City, AL). She did well on the ride home, propped up with pillows for comfort. When she got home, I made her comfortable on the sofa and let her watch TV with me sitting guard. She did well with that. At one point, she wanted to go to her room. I set a dining room chair in her room for her to sit on and put her TV on. I left her in there for 5 minutes max and came back, and she was on the floor!!! I was scared out of my mind that she fell or hurt her back. I asked her how she got down there, and she pantomimed that she got off of the chair by sliding down. Mind you, the precautions were not to bend or twist her back. After this, I had a friend buy me a baby monitor to keep in her room. This way I knew what she was up to.

Hannah healed well from the surgery, even with picking the steri-strips off the first inch of her incision and opening it up some. It was probably a month before she was out of pain, that I can remember! It was a constant battle to watch her to make sure that she wasn't twisting or bending the wrong way and destroying what the surgeon had done. She had to follow these restrictions at school as well as at home, and they were very accommodating at school. She has follow ups with the surgeon now every year, and he states that she is doing fine.

Looking at Hannah today, you couldn't tell that she had the surgery, unless you see the long scar on her back. She is as mobile as she was before the surgery.



Hannah and her mom, Sandy, live in Phenix City, Alabama with a busy house including Jerry (Sandy's boyfriend) and his son, Joel, who has Down syndrome. Sandy has been an occupational therapist for 36 years and retired in May. She had been doing teletherapy for the local school district since March of 2020. Hannah loves having her mom at home all of the time and doesn't miss going to her day program since it has shut down. Hannah spends her days playing with her dogs and cats, walking when it is nice outside, helping cook, and playing on her Kindle.

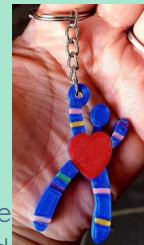


# Awareness Week 2021 & Virtual 5k for 5p- Party Like It's 1985p-

Laura Castillo



Our Fearless Leader, Nick Wallace, summed it up in his article. YOU GUYS ROCK!! Parents, siblings, grandparents, aunts, uncles, friends, teachers, co-workers: the success of awareness week was all YOU!! The creativity that you shared with us and the world was outstanding. From the t-shirt designs by Nancy Martinez, to the C5 keychains by Stephanie Brett, to the family awareness videos several of our parents shared, to the Eykyn family's successful Dream Like Drew Event that Jim Kelly (former NFL player) even contributed to, and everything in between there are just too many to list! Many thanks to Nick & Nate Wallace for hosting two '80s themed virtual dances. It was a pleasure to meet some new families during the Welcome to the Community Zoom Talk and others during the wrap up meeting on the last day of awareness week.



You outdid yourselves. We had over 700 participants register for the Virtual 5k for 5p- (compared to 400 in 2020); not only that, but we also had several Race Sponsors. Thank you to all the Race Sponsors:

**Footloose Sponsorships:** The Losen Family, The McBride Family, and Sabrina Sadler of One Bead at a Time.

**Retro Runner Sponsorships:** The Talarico & Rogers Family.

**Boom Box Sponsorships:** The Wilson & Manning Family of Alchemy The Salon, The Barnes Company, The Bodle Family, The Pineda Family of Jean Nikol Designs, Jennifer Nicole Lee of JNL VIP Health & Fitness Celebrity and Coach, Chester Dental Care, The Weber Family, The Stamer Family, The O'Leary Family, The Corkery Family, The Connery Family, The Johnson Family, The Thornton Family, and The Wright Family.

There were also many donations made through the Virtual 5k platform and through the Fundraising Ambassador Program. We are extremely grateful to all of you who donated through both platforms.



The Losen Family



On a personal note, this year's success could not have happened without a dedicated volunteer who assisted with the theme, design, marketing, ideas, time, and her talents. Thank you so very much to Melissa Sabin, new mom to Logan, who approached me early in the year and asked me some questions about awareness week. The conversation ended with her agreeing to assist, and with her background in communications and marketing, Melissa is just who we needed to move the events to new levels.

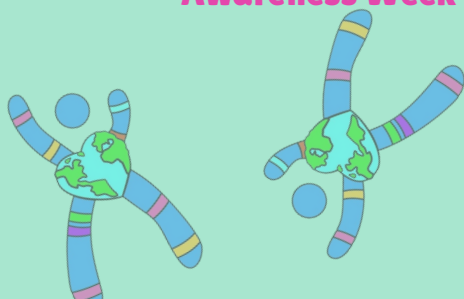
Melissa is responsible for the new international logo, the Virtual 5k for 5p- theme and design, and for spearheading and working closely with the videographer to create a new awareness video. Melissa also has a lot of social media experience and assisted us in creating posts and promoting the Virtual 5k and awareness events. You can watch the new awareness video here: <https://youtu.be/i7aDbh05q8w>



**Looking forward to next year.**

**Awareness Week dates: May 1 - May 14, 2022 (let's extend it this year)**

**Theme: 5P Mighty**





# Our Journey With Scoliosis

ANGIE WALLACE

I'm not a doctor or any kind of medical expert, but I am a mom, and sometimes I feel like I've learned enough to pass some courses in Med School! When I had Allie, back 17 years ago, I heard a quote that has stayed with me through the years, "I have learned more about things that I wish I had never heard of." Allie has been diagnosed with a variety of conditions through the years, but when she was diagnosed with scoliosis, I had to learn a lot about something I wish I never had!

Allie, like many of our children with Cri du Chat, has scoliosis. Scoliosis is a condition that is characterized by a sideways curvature of the spine. Allie was initially diagnosed with scoliosis when she was about 5 years old. Her pediatrician had noticed that she appeared to have a small hump on the upper part of her back. He sent us for x-rays and then referred us to an orthopedic doctor at Nationwide Children's in Columbus, OH. Thus, began our 7-year journey in the management and treatment of scoliosis.

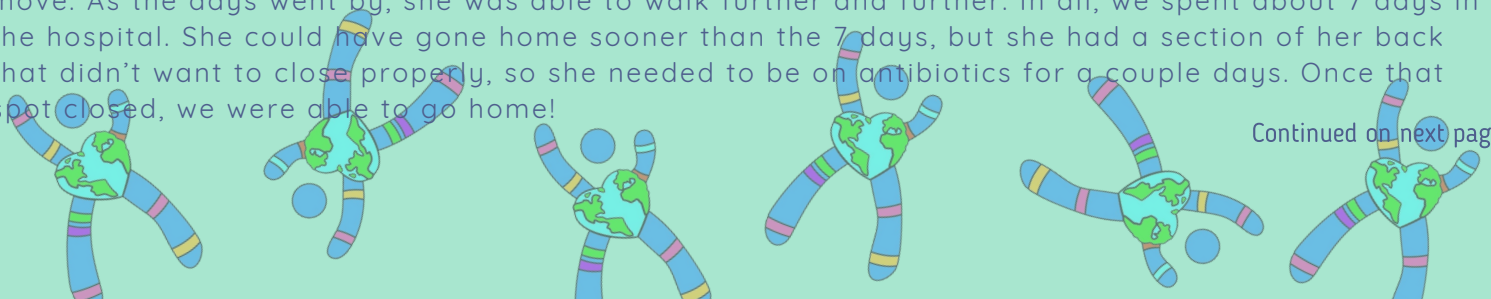
In the beginning, the doctor would do x-rays just to monitor the curve's progression, and there was no action taken to correct the curve during that time. Then, a few years later, we began bracing. Allie would wear a brace around her torso around 20 hours per day to try to stop the progression of the curve. I can honestly say that the brace was difficult for all of us to manage. She hated wearing it, and we hated putting it on her. There were tears when we would initially put it on, but then she would get used to it and move about her day. It did impact her mobility in that she took longer to get off the floor. She spent a lot of her time on the floor playing, so this was a nuisance to her.

By the time Allie was 11, the bracing was not slowing the progression of the curve any longer. The doctor in Columbus had still wanted to brace, but as parents, we could see that the brace was not really working, and Allie still hated it. So, we decided to get a second opinion. This is when we went to Dayton Children's and received a second opinion from an orthopedic surgeon who had been working with scoliosis for over 30 years. He had performed many surgeries over the years. He had a great team of experienced doctors working with him and used the latest technologies during his surgeries. We had our first meeting with him, and after looking at Allie's x-rays, he concluded that bracing was indeed not working and that surgery was our best option. He laid out the details for us, the good and the bad. He was extremely honest with us about the benefits and the risks that we could face. After speaking with him, we decided to move forward with spinal fusion surgery, for at that time there was a 75-degree curve on her upper spine.

Allie had her surgery in January 2016. The surgery itself was possibly one of the most terrifying experiences I had ever had as a mother. The surgery lasted around 7 hours. During that time, we sat in a waiting room with our family members and prayed that it would go smoothly. And it did. She received a blood transfusion and had rods and screws implanted in her spine from the base of her neck to her lower back. Now, started the healing process.

She was moved to the ICU after her surgery. She did have a breathing tube and far more IV's than I would have liked to have seen. She took a while being able to breath on her own, but eventually she was able to breathe on her own and come off the tube. She was in the ICU for a couple of days and then moved to a regular room. After a couple days, the nurses started getting her up to move around. This was a challenge for her. Like many of us after surgery, she was sore and afraid to move. As the days went by, she was able to walk further and further. In all, we spent about 7 days in the hospital. She could have gone home sooner than the 7 days, but she had a section of her back that didn't want to close properly, so she needed to be on antibiotics for a couple days. Once that spot closed, we were able to go home!

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## Our Journey with Scoliosis continued from previous page

Amazingly, she was only out of school for 3 weeks! She didn't need a day of physical therapy after the surgery. She was able to get off the floor easily and move about her day just like any other preteen! After her initial follow-up with the doctor about a month later, we were told that she would only have a yearly appointment. This was a shock to us, because we had been so used to many appointments throughout the year. About a year after her surgery, we went for her follow-up, and the doctor did more x-rays. The curve was still corrected! So, in what was truly a crazy thing for us, the doctor said we didn't have to come back for any follow-ups. He said that if she ever had any issues to let him know, but we were essentially dismissed! This was back in January 2017, and we have not had an appointment since for her scoliosis. I suppose she technically will always have the diagnosis of scoliosis, but we are fortunate that it has been corrected and that she has no lasting effects other than a pink-line scar down her back.

It's been fascinating through the years to hear the stories regarding our children and their scoliosis diagnosis. Some have had success with bracing, some with watch and wait, and some with surgery. What I can say for sure is that it can be difficult and scary, but having the support of others has made this journey easier for our family. If your child is living with scoliosis and you have the same questions/concerns that we did, please feel free to reach out to us. I may not have the medical knowledge, but I have some "mom" knowledge on this topic, and I know that together we can support each other through our individual, crazy journeys!

Angie Wallace is a proud (and a little exhausted) mom of 3 kids, maybe counting 4 if you count Nick! Angie is married to our Society president Nick Wallace. Allie is their oldest, followed by Nate and Laney. She lives in Bellefontaine, OH. She works as a Child Care Licensing Specialist for the State of Ohio.



### 5P- SOCIETY ZOOM TALKS

## LET'S TALK ADULT MALES WITH 5P-

JOIN US FOR A CONVERSATION AS WE DISCUSS  
ISSUES WE FACE WITH ADULT MALES WITH 5P-  
SYNDROME. EVERYONE WELCOME

SUNDAY, JUNE 13, 2021

1:00 PM PST, 2:00 PM MST, 3:00 PM CST, 4:00 PM EST

REGISTER AT:

[HTTPS://US02WEB.ZOOM.US/MEETING/REGISTER/TZWR-FYRQZSJE9HYUWDHXUIYD86VS2UAK2YM](https://us02web.zoom.us/meeting/register/tzwr-fyRQZSJE9HYUWDHXUIYD86VS2UAK2YM)

### 5P- SOCIETY ZOOM TALKS

## Let's talk Adult Females with 5p-

JOIN US FOR AN OPEN CONVERSATION AS WE DISCUSS  
ISSUES WE FACE HAVING AN ADULT FEMALE WITH 5P-  
SYNDROME. EVERYONE WELCOME

Saturday, June 12, 2021

10:00 AM PST, 11:00 AM MST, 12:00 PM CST, 1:00 PM EST

Register here:

<https://us02web.zoom.us/meeting/register/tzCscOurpzkoHtxMFQidC70VmHy3TmV7yM6Q>



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Email: [director@fivepminus.org](mailto:director@fivepminus.org)

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International 5p- Syndrome  
Awareness Week is  
May 1-14, 2022

We're on the Web

[www.fivepminus.org](http://www.fivepminus.org)

Share Pictures with Us

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Tweet with Us

[www.twitter.com/5pminus](https://www.twitter.com/5pminus)

Find Us on FaceBook

[www.facebook.com/CriDuChatSociety](https://www.facebook.com/CriDuChatSociety)

## Help the 5p- Society with all your Shopping



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[C5 socks, headbands, and masks are available.](#)

