

# C5'S BUZZ

National Support Group for Families with Cri du Chat Syndrome



## Our Fearless Leader

NICK WALLACE, BOARD PRESIDENT AND PARENT



Looking ahead:

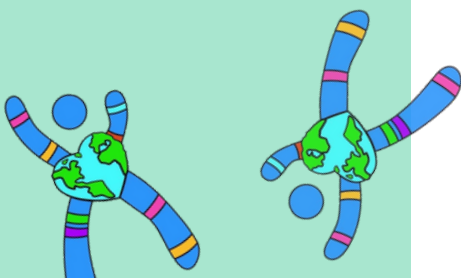
C5'S BUZZ—  
ADULT SERVICES

IN-PERSON  
CONFERENCE  
CHARLOTTE, NC  
—JULY 2022

Hello everyone! I am not sure about your kids/adults with Cri du Chat, but there are moments when Allie can just crack me up. People don't realize how funny she can be, be it intentional or not. So I asked a few parents/siblings to give me some funny stories, and I am dedicating this article to some moments where our kids/adults have cracked us up. I really think right now we can all use a little laughter to help get us through these crazy times.

I will start with an Allie story. Recently, we took a trip to Niagara Falls, New York, and during one of our lunch stops, Allie decided she was going to have breakfast for lunch. We always allow Allie to order her food, and this time was no different. So Allie orders her breakfast for lunch, and the server asked how Allie would like her eggs cooked. We

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**...we can all use a little laughter...**

### Our Fearless Leader continued from previous page

assumed she would say scrambled, the way she always gets them, but instead responds with, “medium rare”! Obviously, this had us all cracking up, even the server. I am not sure that medium rare scrambled eggs will make it on their menu any time soon.

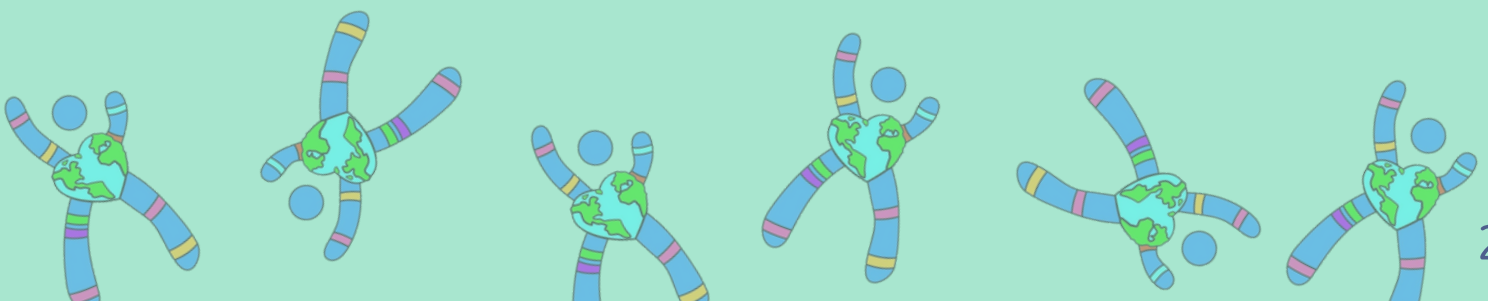
Delaney LOVES wet wipe wrappers. Every time I change her, she asks if she can have it. My response is always, “When its empty you can have it.” One day a few weeks ago, she asked for it, and I gave my standard response and followed with, “There aren’t many left. I bet you can have it next time.” She grabbed the few wipes left, threw them, and said, “uh-oh,” and then grabbed the wrapper in celebration. I guess it was empty now!

Emma is quite the rule follower, at least outside the home. We were at a red light, and the lady in the car next to us was texting (she was the driver). Emma yelled over, “Put your phone away!” She used to tell that to kids in class as well.

Taylor got asked to prom by a cute boy that has Down syndrome. The first year he asked her, she said, “Oh yuck! Gross!” He asked her again the next year, and she said, “I’m busy.” Of course, her teachers didn’t tell me in time to make her go with him. The poor kid!

Well, it’s official. I finally embarrassed Amy! I had to take her to school one morning not too long ago. She woke up on her own that morning at the same time I did, so I did not get a chance to actually get ready. So I just threw on an (old) T-shirt, sweatpants, and threw my hair up into a quick bun. We were about to leave, and she looked me dead in the face and said, “No, brush your hair.” She then looked me up and down at what I was wearing, and said, “NO, NO, NO.” She took my hand and lead me to my room, put some pants on my bed, undergarments, along with a different shirt, and gave me a brush. She gave me her final approval before we could leave the house.

I hope you have enjoyed hearing these stories, and I would like us to continue the funny stories on our Facebook group. So after you read this newsletter, I would like you to go onto our group and share your funny story. We may even publish it in our next newsletter!



# The Mystery of Menstrual Management—or—My Daughter is Growing Up, What Do I Do?

GEOFFREY D. TOWERS, MD, FACOG PROFESSIONAL ADVISORY BOARD, AND PARENT

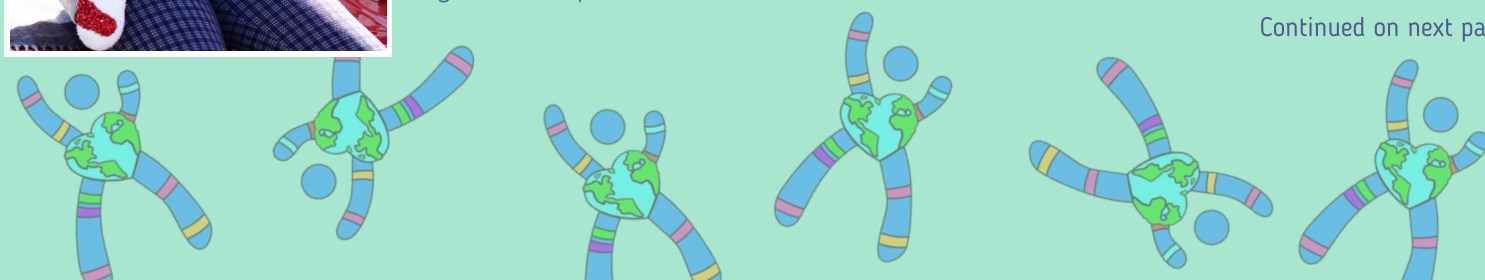
Among the myriad worries, concerns, or fears that plague parents and families of children with physical or developmental challenges, wondering how best to manage the inevitable onset of adolescence looms large. At least, it loomed large for my wife and me as we contemplated approaching puberty for our daughter Taylor. We had many questions, such as, “How will she handle this change?” “How can she (or we) keep herself clean during her menstrual cycle?” “How will her behavior change?” And most of all, “What can we do to help both her and us through this process?” Though daunting looking forward, now that we can look back, we can see that much of our concern, though understandable at the time, was unwarranted. Despite this, we remember how grateful we were for any guidance we could receive. This brief article will focus primarily on menstrual management for our adolescents.

We know that as our children mature, they, like their typical peers, will undergo the natural changes in their bodies and emotions that come with nascent adulthood. Though their communication (and our reception) is challenged, they will inevitably grow up. For our girls, this means starting their menstrual cycle. When it might happen varies greatly from child to child, but usually there are some indications that the body is preparing. For example, most children need to establish a certain height and weight (the amount is individual), and most will demonstrate some growth spurt, breast budding and pubic/axillary hair development prior to the onset of the cycle. Complicating the picture for our children is the fact that many have other medical conditions, and they may be on medication or have other metabolic disorders that disrupt the typical hormonal axis. These cases are, of course, individual and in many cases unique to each child. Parents and families, however, can universally start to prepare each child for the onset of the menstrual cycle by educating the child through whichever communication means works best. We may be surprised how much our children will retain, for as we know, they understand a lot more than they can say!



When seeking gynecologic health care for our daughters, it is important to realize that “optimal care ... is comprehensive; maintains confidentiality; is an act of dignity and respect toward the patient; maximizes the patient’s autonomy; avoids harm; and assesses and addresses the patient’s knowledge of puberty, menstruation, sexuality, safety and consent.” (1) If possible, seek out a provider with interest in caring for individuals with developmental challenges and advocate for comprehensive evaluation, including evaluation for sexually transmitted infections for appropriate situations. Examinations may be performed in the office for select patients, but in many cases, anesthesia in a hospital setting may be required. Again, each situation is individual, and in certain cases, with an adolescent who we can confirm to be in a setting where she is not sexually active or at risk, a pelvic examination may not be necessary in the setting of regular monthly menstrual cycles without significant pain.

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## The Mystery of Menstrual Management—or—My Daughter is Growing Up, What Do I Do? continued from previous page

When considering medical management of the menstrual cycle, which may be indicated for behavioral, hygienic, social, pain or other reasons, there are many viable options and some to avoid. When considering treatment, however, remember that it may be difficult to completely shut down menstruation with any method short of hysterectomy, and that each method has potential benefits and risks. In 2016 (reaffirmed in 2020), the American College of Obstetricians and Gynecologists (ACOG) released guidance regarding menstrual management that applies to our population (1), much of which is summarized below. The optimal goal overall is reduction in amount and days of flow, not necessarily complete cessation. Here are several available options, though this list is not comprehensive:

1. Anti-prostaglandin medications (i.e., tranexamic acid (TXA), mefenamic acid, etc.). These may be appropriate both for pain control and reduction in menstrual bleeding (by up to 30-40%). (2) Dose and choice of medication should be based on weight and chosen in conjunction with a licensed provider.
2. Combined oral contraceptives (COC, “the pill”). This is an outstanding choice for many of our children, if they can take an oral medication and don’t have any other medical condition that would preclude use (such as high blood pressure, a history of blood clots in deep vessels or lungs (DVT/PE), history of stroke, and others). Of course, COC’s need to be given daily, and preferably around the same time. They contain both an estrogen (typically ethinyl estradiol) and a progestin (many different types) and can be used continuously for an extended period if needed. Like any treatment, COC’s have risks such as possible elevated risk of DVT/PE, especially if mobility is limited (3), and the choice should be made carefully along with your licensed provider. For any hormonal method (including 3-5 below), the prescribing provider should refer to the U.S. Medical Eligibility Criteria for Contraceptive Use (<https://www.cdc.gov/reproductivehealth/contraception/mmwr/mec/summary.html>) which provides appropriate guidance and evidence.
3. High-dose oral progestins. This class includes progestin-only birth control pills (i.e., “the mini-pill”). These medications are readily available and inexpensive, but the success in achieving optimal suppression is dependent on dose and timing. One advantage is that these medications can be used in some medical conditions that would preclude use of a COC.
4. Depot medroxyprogesterone acetate (DMPA, “Depo Provera”). This medication is given as an intramuscular injection every 90 days and has the advantage of high rates of menstrual suppression (90% per 90-day cycle); but it may take several doses to reach optimal results and, in some cases, may stimulate appetite, resulting in weight gain. (4)
5. The progestin-containing intrauterine device (IUD, usually with levonorgestrel). This is a very effective means of suppression, but irregular bleeding is common initially, and it requires an examination and procedure for placement. It can be used in most medical conditions but checking placement and discovering complications may be difficult.
6. Hysterectomy. Removal of the uterus is effective, but it requires a surgical procedure, carries surgical and anesthesia risks, and should only be considered after non-surgical options have been tried or considered and have failed or been deemed inappropriate. Because it results in permanent infertility, court involvement may be required in some states. (5)

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## The Mystery of Menstrual Management—or—My Daughter is Growing Up, What Do I Do? continued from previous page

The following are NOT recommended procedures or practices for routine menstrual suppression:

1. Menstrual suppression before the onset of menses. The onset of the menstrual cycle serves several important purposes, including confirming the presence of a patent genital tract and normal hormonal axis. Early intervention may also affect growth.
2. Endometrial ablation. This requires a surgical procedure, does not reliably result in long-term suppression of menstruation, and may result in scarring and pain.
3. Subdermal progestin implants (i.e., Nexplanon). While convenient and very effective for contraception, this implant does not result in reliable menstrual suppression in most cases. Rather, the amount of bleeding per cycle tends to remain relatively the same, while the timing becomes irregular.

Geoffrey D. Towers (MD, FACOG) is an obstetrician-gynecologist in Dayton, OH, and an Associate Professor and Residency Program Director at Wright State University Boonshoft School of Medicine. He is board-certified in obstetrics and gynecology and in female pelvic medicine and reconstructive surgery. He is married to Jolene Towers and is father of four children, the oldest of whom, Taylor, has Cri du Chat syndrome.



As mentioned above, my family and I now have the luxury of looking back on this process rather than worrying, wondering, and waiting. As we know, however, our children are individuals; each is unique. Each of them may respond differently, and each has her own set of co-existing medical issues that will need to be considered. Hopefully, this initial guidance above will enable families to have informed discussions with their providers and eventually make the appropriate choice for their individual family member. As for Taylor? We chose combined oral contraceptives and use them continually. Yes, she has an occasional breakthrough but has learned about “her period,” her cramping is minimal, and she manages episodes with relative ease. Will we change someday? Maybe, but for now it’s working well.

### References:

1. Menstrual Manipulation for Adolescents with Physical and Developmental Disabilities. Practice Bulletin No. 688. American College of Obstetricians and Gynecologists. Obstet Gynecol 2016;128(2):418-419.
2. Bonnar J, Sheppard BL. Treatment of menorrhagia during menstruation: randomised controlled trial of ethamsylate, mefenamic acid, and tranexamic acid. BMJ 1996;313:579-582.
3. Girolami A, Spiezia L, Rossi F, Zanon E. Oral contraceptives and venous thromboembolism: which are the safest preparations available? Clin Appl Thromb Hemost 2002;8:157-162.
4. Bonny AE, Ziegler J, Harvey R, Debanne SM, Secic M, Cromer BA. Weight gain in obese and nonobese adolescent girls initiating depot medroxyprogesterone, oral contraceptive pills, or no hormonal contraceptive method. Arch Pediatr Adolesc Med 2006;160:40-45.
5. Sterilization of women, including those with mental disabilities. ACOG Committee Opinion No. 371. American College of Obstetricians and Gynecologists. Obstet Gynecol 2007;110:217-220.



# Puberty! Say It's Not So!!

KRISTA KELLS, BOARD MEMBER AND PARENT

Puberty.

I know.

No parent wants to think about it.

Especially when your child has extra needs.

But, it's going to come eventually.

And it's not just girls...BOYS go through it to!

So, let's talk about that.

For me personally, it was a pretty scary thought.

When Dalton was about 5, I remember a normal afternoon, changing his diaper when it hit me.

"One day, I'm going to be changing him and he'll have pubic hair! NOOOO!!!"

Well, that day DID come.

But pubic hair was not our only problem.

We dealt with mood swings, frustration, heightened behaviour issues, body exploration, and body hair.

The mood swings, frustration, and worsening behaviour issues pretty much all went hand in hand. Big

changes in hormones send every teen boy into a fury of emotion. Couple that with a child that cannot

understand or communicate what is happening, and it presented itself in big behaviour changes. Head

banging, pinching, and hitting that were always present became almost unbearable. We did use

medication at this time to calm him somewhat. In our case, about 12-18 years of age were the worst.

After 18, the behaviours gradually eased and now at 28, we see almost no negative behaviours.

Body exploration is probably the most taboo.

But it's a natural part of growing up!!

The problem is, many of our kids don't understand that it maybe should be a private thing.

I never thought I'd have to tell my 28 year old that while I'm sure it feels really nice to explore

yourself on the deck in the sunshine....your bedroom would probably be a better place.

To be honest, he gets mad (embarrassed I think) but he goes to his room.

Body hair.

So. Much. Hair.

I struggled with this for a long time.

Especially with Dalton being incontinent.

The mess can get pretty bad in a diaper. Add a bunch of hair, and you've got yourself quite the

tangled mess!

But, I seriously questioned myself in regards to grooming/trimming in that area.

Is it weird?

Is it proper?

You can't ask your friends with typical teenage boys. They'll definitely give you that 'deer in the headlights' look. (You know the one. Where they couldn't possibly imagine ever having to think about some of the things that we do.)

In the end I had to decide, by myself, for sake of cleanliness and my own sanity, the best approach was to trim.

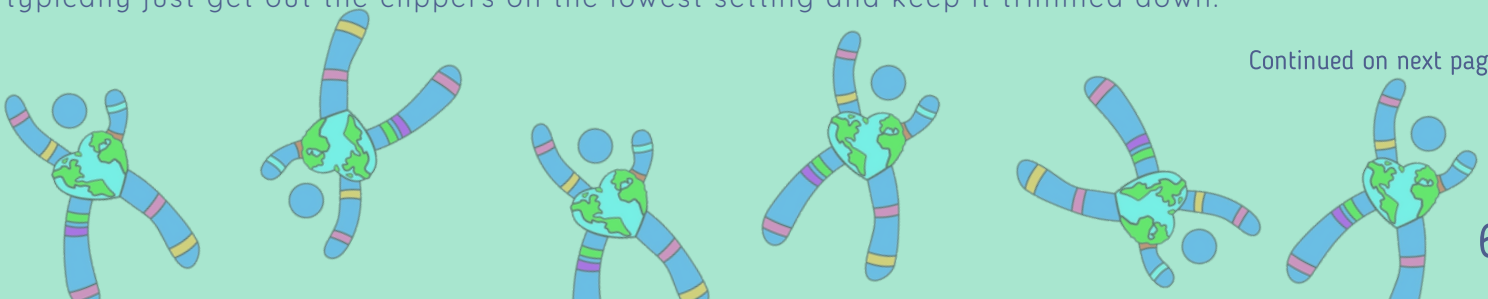
Next up....the beard.

Let's be real. I have a hard enough time trying to shave my legs without cutting them.

How am I expected to shave somebody else's whole face?!?

I typically just get out the clippers on the lowest setting and keep it trimmed down.

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## Puberty! Say It's Not So!! Continued from previous page

But sometimes, when I'm just tired of being completely responsible for another grown human, I will convince him that he looks "Sooooo rugged and handsome, just like daddy" with a beard. Because, let's face it....we all get tired of dealing with all the things that we do from time to time. And it's ok to feel that way.

Our kids, unfortunately, didn't come with an instruction manual.

So, puberty... like everything else that comes our way...we deal with the best that we can.

We reach out to our Cri du Chat family that are going through the same things.

We learn from those that have gone through them before us when we can.

Know that you are not alone.

No matter how scary it is, you will get through,

With a little bit of help, a whole lot of love,

And maybe....every once in a while....a small glass of wine (or two).

Krista Kells is mom to Dalton, 28 (aka; Big D).  
They live in Ontario Canada with Dad Bill.  
Brothers Taylor 26 and Gavin 22.  
Sister Grace 15.  
Sister in laws Nicole and Kenzie.  
Niece and nephew Callie and Christopher.  
As well as many dogs, goats, and chickens  
on our funny farm!



## With Love From a Sibling

FROM CHRIS CHALMERS, YOUNGER BROTHER OF JAMES CHALMERS

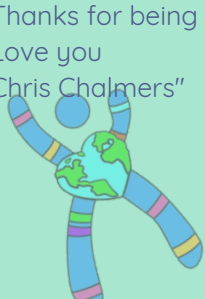
This is what my big brother Chris said about me:

"Growing up with a brother with Cri du Chat has helped me realize what is most important in life. Without you and your gift of Cri du Chat, I would too often get caught up in the appearances society holds to be so important of looking good and impressing others superficially. You continue to teach me each and every day the importance of pure emotion and honest love. You love so many unconditionally. Unconditional love is a challenge in a world that keeps such a close tally on bottom lines and net returns.

At times I have to admit that you can be challenging, but the challenges usually say much more about me and my insecurities than anything about you. Life can be difficult with or without Cri du Chat, but I am so glad you have shared your many gifts with me and so many others. When it gets right down to it though, I don't think Cri du Chat has made you. I think you have made you. Cri du Chat is not you anymore than the color of your eyes is you or your scruffy beard. Thanks for being my brother and friend to all.

Love you

Chris Chalmers"





# Male Puberty—A Forbidden Topic

DAN HOOVER, BOARD MEMBER AND PARENT

First of all, I want to begin by saying there are no right or wrong answers. I am by no means an expert in any of this but have only learned from my own experiences when it comes to male puberty in individuals with Cri du Chat. I was asked to write a brief article on this topic, and to be brief would be very hard, but I will do my best.

My son, Austin, is 20 years old; he is nonverbal; he is not potty trained, which is very frustrating in itself. I know he is intelligent enough to know what to do and how to do it, but time will tell on that issue. By and large, he is just very delayed in his motor skills. To be honest, we didn't recognize major differences in him other than a few key things. There is the obvious; the irritability and short temper of a teenager and that can be typical kids or our kids, so I believe that was to be expected; the body or pubic hair and how to maintain that so it doesn't make more of a mess since he is not potty trained (a cordless adjustable beard trimmer is a life saver); having to utilize deodorant and so on. Parents getting ready to go through puberty with a male with Cri du Chat need to also understand they are human. Just like most boys that age, they will start to get erections and, yes, just like most boys their age, they are going to want to have their hands on it at some point, as almost to check to see what it is and if it's still there. **DON'T WORRY. IT'S NORMAL AND NOT UNUSUAL!!!** Just like all of us, they need to figure out their own bodies. One of the hardest things to do is learning how to shave the face of a moving target, but even that has become better with time. We shave after bath time, and it is now just part of the routine.

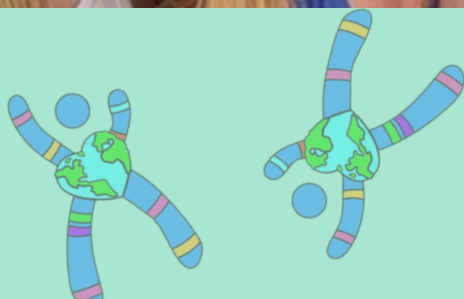
The more technical part of him going through puberty was the medicine adjustment. As many of our kids do, Austin takes several medications for a variety of different reasons. As his body and hormones changed, we learned that some medicine no longer gave the desired effect, or the dosage needed to be changed. That part can be very frustrating, because it was a fine line of trying to find the right balance to keep things moving in the right direction. Having a very patient and understanding doctor that you can keep an open dialogue with about what you are experiencing and seeing is so important.



**...there are no  
right or wrong  
answers...**

Pictured: Dan, Jessica, Austin, Siarra and Lauren Montgomery (top right—Siarra's roommate at college) taken at the Ohio regional gathering this summer.

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## Male Puberty–A Forbidden Topic continued from previous page

Also, as Austin got older, we have realized with this hormonal change that his anxiety level has been higher. Now, that may not have anything to do with puberty, but that was about the time we noticed that change. He doesn't want to be in large unfamiliar crowds or anywhere that might be loud or boisterous. By and large, those are the major issues we dealt with during this time, and I am not so sure I did a much better job going through this period in my own life. HAHAAH!

All of our kiddos are different, and just as they are different, so are we as parents. Again, there are no right or wrong answers, and what we experienced may not be like what you will experience. That is why having the network of families that belong to the 5p- Society is so important to be able to share experiences and ideas for the betterment of our kids.

Dan, Jessica, Austin, and Siarra Hoover live on their family farm in central Ohio. Dan is a Court Administrator for the Licking County Common Pleas Court. Jessica coaches track and cross country for our local high school and also works for Dan's brother's company as his office manager. They have been married for 21 years. Austin graduated high school when Covid struck and now is attending a day program a few days a week. Siarra is getting ready to start her sophomore year of college at Ohio Wesleyan University, where she is studying special education and also competes on the swim and track teams for the college.



## C5'S BUZZ HAS GONE

digital

Starting with this edition of the 5p- newsletter, newly named C5's Buzz, we will no longer be mailing printed copies of our newsletter to those members who have requested them. We will be focusing solely on our online version. Doing this will allow us to add more content, including videos to enhance the viewer experience. This will also help the society reduce costs by eliminating printing and postage expenses associated with mailing the newsletter. These savings can be put to good use in other areas of need, such as our annual conference scholarships or even our regional gatherings. We are excited about the new changes, and we hope that everyone enjoys our new online only newsletter! Please make sure that you get in on all the *BUZZ* by sending your updated email address to Laura Castillo at [lc5pminussociety@aol.com](mailto:lc5pminussociety@aol.com).





# Regional Get Together Highlights

On July 17th, the Querbach family had the privilege of hosting the **Texas 5p- Regional Gathering** at Little Land Play Gym in Buda, Texas. Families that attended were able to learn lots of great new information from each other as well as our special guest speaker from Any Baby Can (the local ECI and family services program). We enjoyed pizza, snacks, and desserts as well as playing with all of the cool sensory things in the gym. All of our kiddos with CDC and their siblings went home with fun gifts, too! It was such a great experience for everyone, and we all really got the chance to bond and make life-long friendships. We can't wait to see everyone again! —Submitted by Zeena Querbach



The **Midwest Regional Gathering** was held in Yellow Springs, Ohio, on July 24th. We had families join us from Ohio, Michigan, Kentucky, Indiana, and Nevada! We met at a Jersey Dairy, where we had lunch and enjoyed talking with each other. The Dairy has a petting zoo, miniature golf, batting cages, golf range, tractor playground, huge slide, and, of course, amazing ice cream. It was a fun filled afternoon. —Submitted by Jolene Towers



## Upcoming Regional Gatherings:

Please check the events page on the Cri du Chat / 5p- Society Facebook page for more information:

- August 28—Moses Lake, Washington (rescheduled from June)
- September 25—Kenosha, Wisconsin
- October 2—McLean, Virginia
- October 9—East Greenbush, New York
- October 23—Opelika, Alabama





# C5 Says Three Cheers!!

MELISSA AND JEREMIAH RIVERA, PARENTS



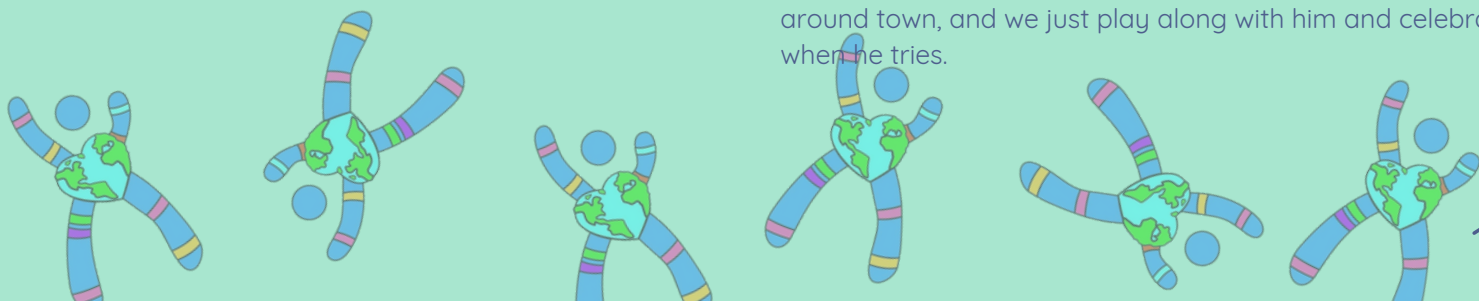
Ethan has been in various schools since he was 3 years old and has been moved around almost every year because the school has not felt like they could meet his needs. He was in 7 different schools by third grade, and we were getting frustrated. He was coming into adolescent years, and we were feeling more desperate in need of constancy and better support and instruction for him.

Two years ago, we decided to move to a different state and city that we felt would have a better school district to meet his needs. Ethan started third grade at Village Elementary in Coronado, CA, and is now finishing the fourth grade. You never really know what a school is going to be like until your child is in it. Village Elementary has a unified philosophy from the principal to the teacher to therapists and his aide that has been instrumental in Ethan's growth. I really loved that Ethan was with his peers in a typical classroom and had an aide assigned to him, something we have struggled to get in the past.

I didn't really expect Ethan to learn to read. Like most of us parents, I just wanted Ethan to meet his potential and keep growing to meet his own ability. I've always loved reading bedtime stories to Ethan and his brothers since he was a baby and taken him to library storytimes. Bedtime is really the only time I could get Ethan to sit still to look at a book.

So much with our children is building in them a routine. These past two years, we have seen huge educational growth with Mr. Connor, his special education teacher, along with his aide, Leon. Leon has a background in behavioral therapy, which has been so valuable to Ethan.

The fruit of all this reading work has only recently become visible. When Ethan read his Phil Wickham sentence strips, we were as surprised as anyone. They have worked using a reading development program where Ethan reads part and then the adult reads part of a book or workbook. They use sight word flash cards a lot. Leon makes Ethan work hard on these cards for short periods of time and rewards him with his favorable choice like Youtube time or fan time. His reading has really blossomed, and he is getting the hang of sounding out words. To be honest, as Ethan has learned to read his sight words, he has gained some confidence and is having fun with it. He usually initiates trying to read signs around town, and we just play along with him and celebrate when he tries.



## "Ethan himself has been the driving force..."

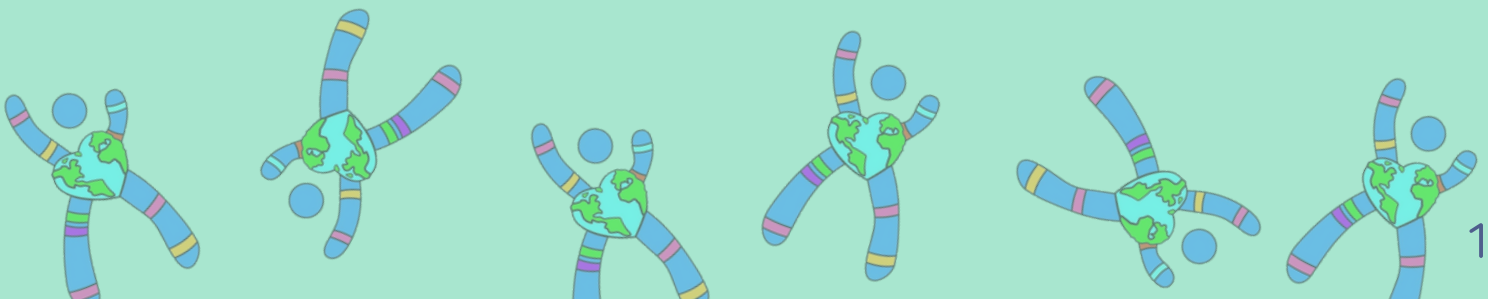
We are the Rivera family. Melissa (Mom), Jeremiah (Dad) and our 4 boys: Grant (10), Landon (4), Luke (6), and Ethan (11). We currently live in Coronado, CA, and have also lived in South Carolina many years. We ran out of schooling options in South Carolina, so we moved to Coronado, in the San Diego area, for Ethan to have a better school. We have been here for the past 2 years. My husband was Navy, which brought him here before kids, but is now a pastor and a hotdog/sausage caterer with Golden State Dogs. Funny combination, but it's working. I am a stay at home mom. Ethan loves riding in his dutch bucket bike that looks like a big wheelbarrow around the island. That is the only time I can relax, and I don't have to chase him. He is a runner, and it's hard taking him outside because he runs off. I do meet a lot of people through Ethan because he is so social and loving. His other love is playing drums, and he usually has drumsticks in his hands. Ethan is going into 5th grade and is finally finding a school that works for him. Entering adolescence and having 4 boys is keeping us busy and tired. We love going to the conferences and can't wait for the next time we can all get together. We are so grateful for the 5p-family!



When I asked Mr. Michael Connor how he taught Ethan to read, he said, "Ethan himself has been the driving force throughout his successful reading instruction. He has shared his interests and hobbies, which provides our staff with a ton of ideas to create learning opportunities. We have used his interests to deliver sight word and phonics instruction through a variety of activities, including songs/rhymes/chants, videos, stories, games, and flash cards. Progressive time delay has been a specially effective instructional method."

This year with Covid, Ethan has not been in his general education class very much because wearing a mask is very difficult for him. He was able to be a part of the 4th grade end of the year biography project. Ethan picked Phil Wickham, a San Diego musician, as Ethan loves to watch his videos. His aide, Leon, and teacher, Mr. Connor, worked on researching Phil Wickham's life and condensed Ethan's biography to 4 sentence strips that Ethan practiced reading for a few weeks. His voice is high, and his articulation is not clear, but he was able to learn to read the sentences and say them to the class. I love that he has had the opportunity to stand in front of his peers and fight all his distractions (fans, projectors, lights, and air conditioners, which are BIG distractions) and present to his classmates. He had so much fun dressing up like Phil Wickham, and I feel like opportunities like this bond him to his peers and give him so much confidence!

Much love to our 5p- family,  
Melissa and Jeremiah Rivera



# Hey Y'all... Announcing



We are proud to announce that the 2022 5P- Society's annual conference will be held in Charlotte, NC, at the Sonesta Charlotte Executive Park hotel July 14-17, 2022. The Sonesta Charlotte is a beautiful, newly appointed hotel that is located just minutes away from uptown Charlotte and Southend, one of the city's trendiest areas.

Charlotte is known as "The Queen City," named after Queen Charlotte, as it was founded in 1768 by European colonists under King George III. To honor this, the conference theme will be "A Royal Celebration." Charlotte is a wonderful, family-friendly city with something for people of all ages and interests. You will find beautiful parks, greenways, and modern cityscapes, along with a variety of culturally eclectic areas, lively neighborhoods, and suburbs, all with a touch of southern heritage. There is no lack of sportsmanship in the area as Charlotte boasts five (soon to be six) professional sports teams, along with several college and university teams. While in Charlotte, you can expect to experience the urban lifestyle, along with good ol' southern hospitality. Charlotte's truly got a lot! When visiting Charlotte, there are several highlights to consider exploring:

- [Carowinds](#)
- Uptown Charlotte
- [Mint Museum](#)
- [Discovery Place Science](#)
- [Whitewater Center](#)
- [Bank of America Stadium](#) and [Spectrum Center Arena](#)
- [NASCAR Hall of Fame](#)

There are so many great places to visit, and we can't wait to share our city with y'all! We hope to see you in Charlotte! For information on how to reserve your room at the hotel, please visit our dedicated website for [2022 Charlotte Conference](#).

#### **Your Host Families are:**

Russ and Amanda Bennett  
Brandon and Christina Brown  
Zach and Maria Maxell  
Jack and Alexis Magill  
Chris and Danielle Sudler  
Barbara Mena

The Charlotte Conference Committee





# 5P-

Sept. 18-19  
2021

## VIRTUAL CONFERENCE



### When & Where?

Saturday, Sept. 18 & Sunday, Sept. 19  
9:00AM-4:00PM Pacific Time Zone  
Zoom details provided to registrants

### What is the cost to attend?

Note that registered attendees will have access to presentations that are recorded and available for three months after the event in case you cannot attend live. You can register at any time now until December 15, 2021.

- \$25.00 per email—5p- Society Members
- \$50.00 per email—Non-Members (Opportunity to register as a Member for \$25.00)
- \$50.00 each—Professionals

Complete schedule can be viewed by visiting the [Virtual 5P- Conference page on our website](#).

### What's on the schedule?

- Cortical Visual Impairment & Neurological Vision Issues
- Genetics & 5p- Research
- Physical Therapy & 5p- Syndrome
- Special Needs Trust vs. ABLE Accounts
- Transition through Adulthood
- Positive Behavior Therapy
- Welcome to My World (an Inclusive program)
- 5p- Syndrome and Infections: Research Update
- Moms' Support Group
- Dads' Support Group
- Grandparents' Support Group
- Medically Fragile—Translocation Parent Panel
- Virtual Dance

### How can I sponsor?

We are actively looking for Virtual Conference Sponsors to assist us with the technological costs. If you know of any businesses who may be interested or if you have any questions or concerns, please contact Michelle Myatt at [mmyatt5pminusociety@gmail.com](mailto:mmyatt5pminusociety@gmail.com) or direct them to our dedicated sponsor page.

### Thank you to our Sponsors!!

**Protector:** The Batdorff Family, North Carolina

**Champion:** The Arango Family, Florida

[Download the 5p- Society Virtual Conference 2021 mini brochure.](#)



# Zoom Talks—Positive Feedback

LAURA CASTILLO, FIVE P MINUS SOCIETY EXECUTIVE DIRECTOR AND PARENT

As we evaluate the future of the Zoom Talks, this arrived in our mailbox. "S" is a 36 year old female, and the following was submitted by her mother. If anyone has positive feedback to the Zoom Talks and would like to share them, we would be very grateful.

"So far, we have simply been using CBD gummies bought over the counter. My family normally reacts strongly to medicine, and "S" has had the choice of a half or a quarter of the CBD gummy rings at a time.

Within the last three weeks, we have been to a wedding and reception (4 hour drive each way), amusement park with friends, and outdoor get together around a fire with singing and games with friends.

She had ZERO instances of nausea and/or throwing up. This is huge for her. I don't expect 100% success ongoing, but this has been a blessing.

For the wedding, she had half of a CBD gummy the night before, half at 10 in the morning, and a quarter during the loud dinner.

The CBD gummy instructions said you could take one whole gummy in the morning and one at night.

She has been somewhat more independent and interactive as well while taking the CBD. Her being braver means she may not stick as close to me, which can be a bit more challenging. I haven't identified any negative side effects at this time.

I am only giving it in anticipation of and during events which I know are likely to trigger her nausea and/or offering it if she seems anxious or on her request. I let her choose which amount (among 1/2 and 1/4 ring) and now carry a ring in a plastic pill bag in my purse just in case.

The doctor was glad it seemed to be helpful for her. I am expecting to follow up with a prescriber as well but may just stick with over the counter ongoing.

The ones we have taste a little bitter. It seemed she didn't appreciate the flavor and wasn't sure about the effect on first try. But then she recognized it was helpful and wanted to take it at a later time. I clearly refer to it as medicine and keep it stored with other meds.

I thought you would like to know. The story shared in the Zoom call was the key to us finding this success. Hopefully we will have similar success during the conference."



**5P-** FIVE P MINUS SOCIETY  
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FALL 2021

*C5's Buzz*



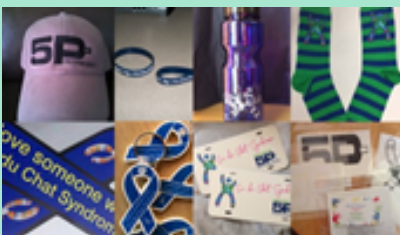
## Help the 5p- Society with all your Shopping



When purchasing items on Amazon, make sure you go to [AmazonSmile at https://smile.amazon.com/](https://smile.amazon.com/) and choose to support 5p- Society (Lakewood). The 5p- Society gets a small % of what you purchase. Every little bit counts, and we are grateful to you for your participation.

**Shop for your 5p- items below at**

**<http://fivepminus.org/shop/>**



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[Shop for new items on the website!!](#)

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



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

**THE BUZZ  
NEEDS  
HELP!**

We'd love to hear your comments! Do you have an interesting article you'd like to share? Or, do you have an idea for future newsletter content? Please let me, Shari Campbell, know at [djcschc@charter.net](mailto:djcshc@charter.net).

Many thanks to Lora Piepergerdes and Laura Castillo.