



Newsletter

NATIONAL SUPPORT GROUP FOR FAMILIES WITH CRI DU CHAT SYNDROME

Volume 35

Issue 1

Happy New Year Everyone!! Welcome to 2020! _____ Nick Wallace

impact

transitive verb

1 : to have a direct effect or impact on

As I have been reflecting on the past decade, the word “impact” has been coming to mind the most for me. I have been thinking about how a person’s actions can have an impact on another person’s minute, hour, day, month, year or even their life. It occurred to me that we may never know that we even had an impact on a person’s life. Our impact on a person could be positive or negative and could cause a ripple effect that we are completely unaware of.

Just think about this scenario ... an individual is running late to work because their kid spilled milk on their clothes while getting ready for school. Then, on the way to work, someone cuts them off in traffic causing them to miss their exit. When they finally reach work, someone pulls into the parking spot they were planning to park in. Then, on the way into the office, they have their arms full and are rushing into the office and trip and spill the contents of their bag. In the meantime you have just gotten out of your car and are heading into the office and are running late yourself. Instead of stopping to help this individual, you rush past them to try to make it to your desk on time. This one action could have been the proverbial point of no return for this person. They are now convinced that this whole day will be a bad day and will probably take their frustrations out on several other people and those individuals may then take it out on several other people. Little did you know that by passing the person by you started a chain reaction impacting so many other people. Had you stopped and helped the person pick up their stuff, they might still have had a bad day, but it was an opportunity for you to make an impact on that person. In doing so, your actions could have had an impact on so many other people.

By helping this one person they could go on to help several other people.

The above is a generalization of how actions can impact a person and then cause ripples into the lives of other people in a negative way, but what about positive impacts? Occasionally I like to pay for the car behind me when I am in the drive thru. I don’t know what impact that might have on a person’s day, but I know that I have had someone do that for me before during a time that I wasn’t in the best mind set, and it completely changed my mood and my outlook for that day.

So what does this have to do with Cri du Chat or the 5p- Society? During my reflections on the past decade, I started thinking about the impact having a child with Cri du Chat has had on my life. Just as I have had an impact on Allie’s

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Happy New Year Everyone!! Welcome to 2020! ---

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life, Allie has also had a major impact on my life. Sometimes that impact is positive and other times it is negative, but in reflecting on the impact she has had on me, the majority of the time it has been a positive one. She has pushed me to do so many things that I would never have imagined that I would do, and in turn, the things I have done have had an impact on others that I may not even know about. I would have never thought that I would have co-hosted a national conference or become the president of the board of directors for a national society. I never would have met some of the amazing people that I have met through the 5p- Society and would have missed out on meeting some truly amazing friends who understand what life is like raising a child with special needs.

My challenge to you is to take a look at the impact that your child has had on you and even the community that you live in. Then take a look at how that impact has pushed you to do things that you never thought you would do and the impact that your child has on the people around them. Now we are calling for your help with a project. In the project we are looking at the impact that our kids/adults with Cri du Chat have had on the world outside their family unit. So start thinking of people your child has impacted within your community. This could be anyone ... teachers, therapists, community leaders, your next door neighbor. See page six for further details and check out our Facebook group for additional information on this project.

2020 Regional Family Get-Togethers

Thank you to all the families who responded to our call for host families. The board of directors has identified the six sponsored locations for the 2020 Regional Family Get-Togethers:

California—Southern

Washington State—Puyallup/Tacoma area

Ohio—Dayton/Columbus area

New York—Upstate

Alabama—Auburn

Canada—Western



We will be announcing dates and exact locations soon. Watch Facebook for the events to be posted. Invites will be sent out to the surrounding areas. If you are interested in hosting a future regional gathering, please contact Jolene Towers on Facebook or by email gnjtowers@aol.com and she can add you to the list.

International Meeting—Planet 5p ---

The 5p- Society will host the first International meeting of families, researchers and leaders of the worldwide support organizations. The meeting will be held Wednesday, July 22, 2020 the day before the 5p- Society Chicago Conference. More information and a dedicated registration form will be announced in the Conference Brochure. If you are not from the US or Canada and are planning to come to the conference, please contact Laura directly at director@fivepminus.org.



Make Plans Now!! Conference Info

Dates: July 23-26, 2020

Location: Eaglewood Resort & Spa, 1401 Nordic Road, Itasca, IL 60143

Hotel Room Rate: \$149.00

Please visit our dedicated website page at: https://fivepminus.org/event/2020-5p-society-conference-chicago-illinois/?event_date=2020-07-23

Hotel reservations can be made either online or by calling the hotel directly at (630) 773-1400.

Hotel Reservation link: <https://reservations.travelclick.com/15450?groupID=2279963&hotelID=15450#/guestsandrooms>

Please note that there is a one-time \$20.00 fee if you request adjoining rooms.

Conference Registration and Hotel Reservations are two separate items

Early-bird Conference Registration will open on March 1, 2020. (There will be a \$50.00 increase to each registration below after July 1, 2020) Here are the registration options:

Member – Individual registration (no add ons) \$100.00 - <https://5psociety.regfox.com/2020-5p-annual-conference-member-individual-registration>

Member – Family registration (up to 4 individuals same family) \$200.00 (each additional individual – same family - \$50.00) - <https://5psociety.regfox.com/2020-5p-annual-conference-member-individual-registration>

Non-Member – Individual registration (no add ons) \$150.00 - <https://5psociety.regfox.com/2020-5p-annual-conference---individual-non-member-registration>

Non-Member – Family registration (up to 4 individuals same family) \$250.00 (each additional individual – same family \$50.00) <https://5psociety.regfox.com/2020-5p-annual-conference-non-member-family-registration>

Scholarships: We will offer five scholarships. The scholarships will pay for hotel room for three nights and registration fee for 4 individuals in the same family. Link for scholarship Guidelines and Application can be found at: <https://forms.gle/89A3ScbWvzxoyLgd9>

2019 5p- Society Donors

The 5p- Society is very thankful to the many supporters we have who continue to assist us in reaching our mission and vision. All efforts were made to make sure we list everyone who has donated \$100 or over. If you feel this is in error, please contact Laura at the 5p- Society office or send an email to Laura – director@fivepminus.org. Conference registrations are not included in this list.

Platinum Donors

Over \$2,000

William & Rita Bourne
Matt & Heather Grasso
Life to the Max Foundation
Jason & Michelle Myatt
Matthew & Ashley Summers
Pam & Bonnie Wald

Gold Donors

\$1,000 to 1,999

Eileen Abbruzzese
Jason & Gina Burke
Christine & Daniel Blake
Dale Huffman
Key Banc
Mountaingate Financial
Ripple Coworking, Inc.
Yvette & Steve Ruano
Silicon Valley Community Foundation
Trenton & Arlie Sisson
Trans Service Insurance Agency
Wade's 5k for 5p
Jay Zises

Silver Donors

\$500 to \$999

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Adolfo & Summer Castells
Cedar Sinai Park
Darlene David
Lisa Juliar
Danielle & Brian Karcz
Joseph Lombardi
Michael Miller
Millies Home Made Ice Cream
Monticello High School
Ryan & Jill Murphy
Lucille Nykiel
Philip & Judy Rogers
Kimon & Christine Rumanes
Terrence Schallich
Tim & Dawn Turner
Zallo Trucking, Inc.

Bronze Donors

\$100 to \$499

Derita & Mike Adams
David & Gloria Adler
Jorica & Joe Veres
Ann & Tony Lopez
Henry & Caroline Ansell
Farid Ashdji

Bronze donors, continued

Thomas Ballogg
Norene & Jim Bauman
Roger & Angela Borek
Robin & Lee Bowdish
Nancy Boyette
Tami & Samuel Brentano
C&M Sporting Goods
Nancy Campbell
Fara Captain
GE & JW Cort
Henry Cousineau
James & Nicole Craig
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Charles Falkowski
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Hilda Godges
Michele Godges
John & Bonnie Goess
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Bart & Chris Harms
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Peter Healy
Damien & Frances Hillseth
Jill Holsen
Charlene & Steve Hood
Darrcie & Kevin Inman
Gary & JoAnn Inman
Josh & Katie Johnson
Ronald Johnson
Kimberly Ketterman
Haslam Khalid
Mary Jane King
Katherine & Kevin Klinger
Stephanie Koppes
Mr./Ms. Lane
Lauren & Chad Townsend
Joseph & Minako Le
Lee Lenker

Bronze donors, continued

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Charles & Jennifer Marvin
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Bruce & Cynthia Rambacher
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Diane Raquet
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Russ & Wanda Rattunde
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Jo Redmon
Brenda & Hutch Renk
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Jose & Rebekah Rocha
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Ruth Betts Community School
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Sylvia Shattuck
St. Matthew's Elementary
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Pat Strong
Marsha & Arnold Swiller
Kelly & Marco Szabo
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Frank & Rita Torre
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Michael Vicencia
Gary Vicencia
Warrensburg-Latham High School
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John & Barbara Yauch

How to Get Your Governor to Declare May 5 as Cri du Chat Awareness Day



Before we know it, May will be here and that means CRI DU CHAT SYNDROME AWARENESS DAY!

For those of you who live in the United States, here is how to request a proclamation from your governor requesting that they declare May 5 as Cri du Chat Awareness Day.

First, just because a governor declared May 5 as Cri du Chat Awareness Day in 2019 – you still will have to ask in 2020 **and all future years!**

Start Early – the best thing to do is make your request before March 1 as most states say it takes up to six weeks to determine whether or not the request will be granted and to issue the proclamation.

Do a google search “Governor OF STATE?” (for **your** state) This will take you to the governor’s website.

On the governor’s website, on the home page search for “Request a Proclamation” – usually there will be an online form to request the proclamation.

You are the “requestor” – the requesting organization is “The 5p- Society” Sample language is below – ALL STATES WILL ASK YOU TO PROVIDE LANGUAGE.

Some states do not have online forms – so when you search for “Request a Proclamation” you will be directed to an office – call there and ask how to send an email request for a proclamation.

Keep a copy of the request and write down the date you submitted it. This will be helpful when you call or email to follow up the request. I suggest that you do this about 2 weeks after you submit the request. Be prepared to call back several times!

You may have to call a general phone number from the web page and ask to speak with the person who handles requests for proclamations.

And remember, governors get hundreds of requests every month for them to declare given days so if the request is turned down, do not take it personally!

If you run into issues feel free to email me at jaggerwatt@hotmail.com

Whereas, the 5p- Society of North America, along with support organizations from over 30 countries around the world are proud to announce that May 1 through May 10, 2020 will be designated as International Cri du Chat Syndrome Awareness Week.

Whereas, May 5 has been designated internationally as Cri du Chat Syndrome Day.

Whereas, Individuals with Cri du Chat deserve to be recognized for what they can do versus what they cannot do and our hope is that we can raise awareness of Cri du Chat Syndrome by spreading our message to each and every person we meet.

Whereas, each year in the United States alone, approximately 50 to 60 children are born with **5p- Syndrome** (five p minus), also known as **Cat Cry Syndrome** or **Cri du Chat Syndrome**. Some common characteristics of Cri du Chat Syndrome at birth are a high pitched cry, low birth weight, poor muscle tone, microcephaly, and potential medical complications. “5p-” is a term used by geneticists to describe a portion of chromosome number five that is missing in these individuals.

Whereas, one of the goals of Cri du Chat Awareness Week is to end the outdated misinformation given to families when their child is diagnosed with Cri du Chat.

Whereas, children born with this rare genetic defect will most likely require ongoing support from a team of parents, therapists, and medical and educational professionals to help the child achieve his or her maximum potential.

Whereas, there are many families with family members with Cri du Chat living in (FILL IN YOUR STATE) with the syndrome that are members of the 5p- Society and over 1,000 families in the Country.

Resolved, I Governor (FILL IN YOUR GOVERNOR’S NAME) declare May 5, 2020 as Cri du Chat Awareness Day in (FILL IN YOUR STATE.)



The Impact of Cri du Chat Syndrome on the Community


Video Project

As you may have read in President Nick Wallace's newsletter article, we have a big awareness week project coming up. This year we are looking to have short videos submitted of people outside of your family unit (examples: teachers, aides, nurses, doctors, community leaders, community members, etc.). These videos should not exceed 30 seconds and will be of the individual discussing how your child/adult with Cri du Chat Syndrome/5p- Syndrome has impacted their life. The 5p- Society will upload these videos to our social media outlets the week leading up to awareness week, during awareness week, and beyond. We may not be able to upload all of the videos, but we will try our best to get every video that is submitted uploaded. So, what do you need to know to participate in this project?

1. Download the [video release form here](#). Or you can find it on our website at: <https://fivepminus.org/event/awareness-week-events/>
2. Select an individual and record a 30 second or less video of that person discussing the impact your child/adult has had on them. (If you are recording your video with your phone, please record the video with your phone being horizontal versus vertical.)
3. With this being International Awareness Week, if you submit a video in your native language, please submit an English translation with your video.
4. The parent(s)/legal guardian(s) as well as the individual being filmed will need to fill out and sign the video release form. No video will be shown unless a release form accompanies the video.
5. Submit the video and the release by March 15, 2020 using the following link: <https://www.dropbox.com/request/7OUxtQvPSH6PYNfxIEKC>

We will start accepting videos and releases on February 1st, and the final day to submit videos is March 15th. We are looking forward to seeing the impact your child/adult has had on the people around them.

Ways to Help the 5p- Society

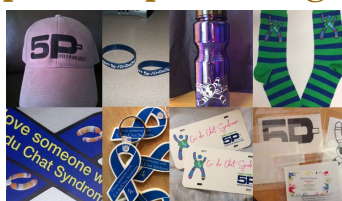
When SEARCHING the internet, don't forget to use GOODSEARCH  – sign up and put in 5p- Society as your Cause. The 5p- Society gets a penny for every search. www.goodsearch.com.



When purchasing items on Amazon, make sure you go to AmazonSmile at <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

<https://fivepminus.org/shop/>



[Shop on CafePress](#)

[Shop on SquareUp](#)

[Shop on InkSoft](#)

**5p- Families
Have Talent...
So Show Us
What You've
Got!!!**

We know you're out there because you write wonderful books and great blogs, you even produce script for videos!! You can't hide anymore, we need your help to make the newsletter enjoyable reading. Please submit articles and ideas to Shari Campbell at: djchsc@charter.net.



Let's all assist C5 walking around the globe and spreading awareness of Cri du Chat Syndrome.

What is a Virtual 5k?

It is just like any other 5k (or 3.1 miles), except there is no official race location (and no early start times)! The virtual part of this means no traveling or fighting crowds. It also means you get to choose where, with whom, and even how you want to go about that 3.1 miles! (Walk, run, bike ride, bowl, jump, couch surf – anything you want to do).

The Virtual 5k for 5p- can be done at any time and on any day during Awareness Week. It can even be done in increments throughout the course of the week! Do you walk to school in the morning, around town during the day, or around the office? Great! Keep track of your distance until you hit the 3.1 miles.

This event is open to individuals of all ages and abilities. Once you register, either as an individual or as part of a team, you are set! Team Captains will be in charge of hosting their local events (if they choose to gather as a group).

Hosting an event? Please make sure you share the information with us on one of our pages on Facebook (www.facebook.com/CriDuChatSociety or www.facebook.com/Virtual5kfor5pminus). We will make sure to encourage others to participate with you and will boost posts. If you plan to have an event at a particular site, i.e. school, park, etc., check and make sure if there is a need for any type of contract and insurance. The 5p- Society can help with that, too.

Registration opens February 1, 2020.

Individuals with 5p- can participate for FREE! Apply for a coupon code to use during the registration process at <https://forms.gle/xHEapyYKDJ53jQy9>. The coupon code will be good for registration/t-shirt/medal for participants in the USA and Internationally. Only one coupon code per individual with 5p- Syndrome and must be used for that individual.

Registration can be located here: <https://5psociety.redpodium.com/virtual-5k-for-5p-2020>

Cost to participate:

Registration only: \$5.00 USD

Registration/t-shirt/medal (USA participant): \$20.00

Registration/t-shirt/medal/socks (USA participant): \$35.00

Registration/t-shirt/medal (International participant): \$35.00

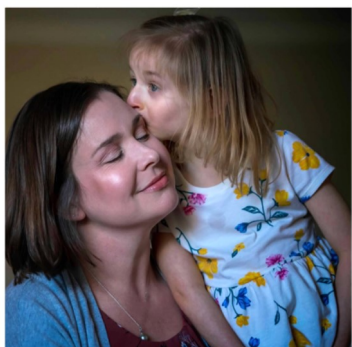
Registration/t-shirt/medal/socks (International participant): \$50.00

Since this is not a sanctioned event, there is no penalty if you are unable to complete any or all of the 5k. However, during Awareness Week, we will be asking participants to post pictures of you on your 5k route. This is completely optional – but since our goal is to bring awareness to 5p- Syndrome, we want to do just that! And by using the special #5pminus5k hashtag on your photos, we will be able to keep up with the fun!

Be a Fundraising Ambassador for the 5p- Society!

During the registration process, you may also select the Fundraising option and become a Fundraising Ambassador!

The fundraising page is something you can send to your friends and family not participating in the race so they may have a way to pledge donations in support of your team, your participation, and to help spread awareness about Cri du Chat Syndrome. (This is not required to participate, but is a great way for your virtual cheering section to show you some love and help the 5p- Society at the same time!)



For me, the hours, days, weeks, and months following Claire's birth were filled with a flurry of emotions with an emphasis on survival. When the doctor entered Claire's intensive care room in the hospital and handed us her diagnosis of Cri du Chat, every single part of me changed.

The feeling of falling from the world's greatest building and never landing took over my existence.

Because of Claire's heart condition requiring a high level of medical care, I quickly assumed the role of her advocate. For me, this was natural. The greatest part of my nursing career is being a patient advocate. It would only make sense that I would accept this challenge fiercely.

As time passed, I became painfully aware of the deficits that existed in raising a child like Claire in our home state of Tennessee. When I realized there were many kids like her, unable to access the resources they need to survive and thrive, I became a leader.

The truth is, I never thought I would be a health care expert meeting with legislators in our state Capitol, but now I am. Because I have to be.

Too often, our policies on health care are made by people who do not understand what it's like to care for a child who has had more doctor's appointments than play dates. That is why I started speaking up and fighting to change our state law.

How could I not look at everything Claire has overcome and fight for her? Today, Claire is a happy, healthy five-year-old child. She loves to tease her sibling and to go to school and see her friends. Her favorite things are music, water, and playing dress up.

In many ways, she's just a kid living her best life; but unlike most kids, she has spent more than her fair share of time in hospitals, racking up millions of dollars of medical bills in the first two weeks of her life.

We were very fortunate to be covered by my employer's commercial insurance plan to pay for her medical care. In addition, due to Claire's extended hospitalization, we also qualified for our state's Medicaid plan, called TennCare, as a secondary policy. This was necessary because as great as our insurance was, it did not cover everything Claire needed, like her therapies,

medical equipment, and surgeries.

Then, one day, just prior to Claire's 4th birthday, we lost her Medicaid because we no longer qualified. Just like that. I appealed not once, but twice and lost. How could a disabled child be denied access to life-saving medical care in America?

I sat in the grocery store parking lot crying one day, and I knew I had to do something.

I have to confess that a year ago, I had no idea who my State Representative was. We all start somewhere. I began a letter writing campaign and asked everyone I knew to join me.

For me, the greatest asset was connecting with organizations like Tennessee Disability Coalition, Family Voices of Tennessee, and the Little Lobbyists. These family-led organizations advocate for people with disabilities in all aspects of life. By connecting with these organizations, I felt encouraged and a sense of community. I made calls to my State Senator. I attended health care forums. I took notes as candidates campaigned for the mid-term elections. After tucking my kids in bed, I spent my late nights reading and learning about our state government. I learned about the Katie Beckett program, a Medicaid waiver program that allows medically complex children to live at home with their parents instead of an institution, by waiving the parent's income. I learned that Tennessee was the only state in the country without this program.

I told Claire's story in several newspaper and television interviews. Claire's face became the front-page center piece article of our local newspaper, talking about why we need the Katie Beckett program. I joined four other families with children like mine, and we took off to our state Capitol. That day, my husband and I took our daughters to meet various lawmakers who agreed to sponsor a bill that we hoped would become a Katie Beckett program in Tennessee.

I remember we sat in a legislator's office, next to Claire as she rocked in his rocking chair. When you show up with your kid at the state Capitol, legislators are forced to see them with their own eyes. Claire is not a number or statistic; she's a real child.

At the end of the last legislative session, the House and Senate unanimously passed a Katie Beckett bill for Tennessee. On July 11th, Governor Lee signed the bill into law. This bill will ensure Claire can access the medical care she and so many other kids need and for us, that means we give them every fighting chance to reach their highest potential.

This is why we have conversations with our lawmakers. They need to understand how policies affect our lives. We are the ex-

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Emma's Story: The Success of Inclusion

Jen Wong

Inclusion ...isn't it something we all want? Whether it's a sports team, theater group, school club, or just a group of friends. However, at some point in our children's academic career, some administrator decides that being a part of the general education community is not in our child's best interest. While for some that may be true, for most it's not; it's just easier and cheaper for school districts to collect all the students with disabilities into a classroom "with similar peers". Each of our children's stories are as unique as they are. That, in combination with dealing with different school districts and staff, makes all our journeys uniquely our own. Here is Emma's.....

Emma started her academic career in a special education preschool classroom for children with communication delays. At this time, I was unaware of her full academic options, as they were not presented to me. This was the only option given. In my mind, I thought it must be the best option; they would not have presented just one if it wasn't, right? I've learned A LOT since then, but we all have to start somewhere, and this is where Emma started. We met some friends that we are both still in contact with today, and I am grateful for them. She went into a co-teacher inclusive class through the county program. It was a great experience with teachers that worked hard and cared about their students' success. When it was time for kindergarten, we decided it was time for her to join her peers at our home school in a general education class. Luckily, I had the support and experience of the county teachers that supported this decision.

Despite a rocky start and after finally finding the right paraprofessional, Emma thrived despite having very little verbal language skills. She had peers that wanted to learn ASL so they could communicate with her better; they loved to read to her and help her at lunch and in the classroom. She taught a newer, very skeptical teacher that her inclusion was a good thing, for him and her peers. I consider kindergarten a big success, for nothing else but this. Emma just broke down the wall so that this teacher was open to teaching in an inclusive classroom. In elementary school, Emma was blessed to have welcoming teachers (minus one) and two VERY incredible paras, that were the main reason her inclusion was so successful. Em-



ma remained in a full inclusion setting until moving onto middle school.

Middle school, ugh, the home of the 12 hour IEPs, the constant "we need to call a meeting" to discuss the latest disaster. Once again, it was Emma's para that made the disaster of middle school successful. Her para was a hard worker, didn't let Emma get away with being lazy, and kept me informed of the day to day

happenings, which was key to me being able to intervene when her IEP was violated.....frequently. However, because we fought to keep her in the general education setting for part of her day (homeroom, lunch, 2 elective classes, PE, and assemblies) with the remainder of her day in a special education class, she continued to make friends and thrive. Middle school was hard for many reasons. It was the time we had to face the reality that it was no longer beneficial to keep Emma in full inclusion. The curriculum was too far advanced and the teachers/admin were neither qualified nor willing to make the accommodations/modifications she needed....and frankly this is when my battle strength weakened. I reconciled my disappointment in myself for "giving up/in" by watching how happy Emma was. She LOVED school. She was excelling socially and continued to thrive, despite not having the full support she was legally required to receive. She picked up on all the latest fashion trends and lingo. This redefined my goals for Emma. My main priority was that it didn't matter what class she was in, it was about what made her happy. Don't get me wrong, we still pushed her academic goals to challenge her, it just happened in a different location.... And that was okay.

High school, ahhh the sound of angels singing enter my head. Her high school experience is the complete opposite of her middle school experience. Her high school is on the block schedule, which means she has 4 classes a day, instead of 6/7. She attends 2 classes in general education electives and 2 classes in special education to work on her academics. Her special education teacher is a quiet force. She is sweet and caring, but has zero tolerance for anyone not supporting her students in their least restrictive environment (LRE.) She created a team of paras that are amazing. This was my first experience that Emma's "1:1" was not just one person. Initially I was not happy, but was quickly aware that there wasn't a bad one in the bunch. She has her primary 1:1 that stays with her the most, but she also rotates in/out with others. Each

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perts on our children. We are the experts on policies that affect our children.

If you do nothing, nothing changes. Your advocacy has an impact. Together we are a part of something bigger.

We are the Fox Family from Johnson City, TN. My husband, Sean, and I are the parents of three amazing children. Our son, Carter, is 10 years old and in the 5th grade. He is an awesome big brother. Our daughter, Claire, is 5 years old and is in her final year of Pre-K. She has thrived in a fully inclusive educational program. Claire loves being the middle child. Our daughter, Charli, is 3 years old. She was the greatest surprise and completion to our family. Sean and I both were born in Tennessee and feel that our region is a great place to raise a family. I am a Registered Nurse and working full time in the 17th year of my career. Sean is a professor at East Tennessee State University. He teaches Microbiology and Human Genetics to young aspiring health care professionals. He loves to lecture about Cri du Chat and shares Claire's story each semester. His students gain invaluable personal insight and will never forget his lectures.

Emma's Story: The Success of Inclusion

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has given their best to Emma and she is better for it. Her general education teachers have not only been welcoming but said that they would love to have her in their class again, as she adds a level of educational experience that they could not provide to their students without her. A science teacher/football coach, who didn't know how to initially take this very social and sometimes very loud young lady who insisted on greeting him by name, everyday and telling him football was boringeveryday :), changed so that the daily "boring football" conversation became their "thing" to laugh about as he tried to convince her it was not (he won her over at cheerleaders and music). Emma is definitely the Queen on campus, and this year, her senior year, it was made official. When her para told me she was nominated for the Senior Homecoming Court, I was stunned. How did this happen??? I found out it's a 100% student voted nomination. Her para said to me, "I don't think you realize how popular Emma is here. There is a social media campaign going on to vote for her." I knew Emma was social and knew a lot of people, but I never equated that to her "being popular". That night at the football game, when they announced her name, was probably one of my greatest moments, for so many reasons. Emma, my daughter, my special needs daughter, had an entire football stadium cheering for her. It was deafening, in the greatest way possible. This moment defined Emma's success of inclusion. She exploded with joy like a nuclear bomb. Just look at the picture; it says it all, pure joy, not just Emma, but everyone around her.

While her journey wasn't perfect, these last four years proved that all the hours of frustration, anger, and tears were worth it. She was included!! She is a part of her high school community, just the same as any sports star, cheerleader, or academic scholar.

In fact, out of all of those, she has probably made the biggest impact on their community. Her peers will go on to be doctors, nurses, lawyers, engineers, teachers, and more. When they enter the workforce, they will have the experience with Emma to hopefully guide them to be better and more understanding of disabilities while practicing in their fields. They will have the knowledge that ALL members of a community have value and bring their own unique lessons to the world. They will not be scared/unsure of the disabled adults they encounter because they've never had the opportunity to interact with them and see their beauty. Our community, the disabled community, is the last group to still experience "acceptable discrimination/segregation". Our children, with our support, are the ambassadors to erase that barrier and show the world that they are important and valued members of our society.



We are the Wong family from Folsom, CA. Cedric and Jen have four wonderful children: Emma (17) runs the whole show, Christopher (16) is our gamer and volleyball pro, William (14) is our soccer star and politician, and Daniel (12) is our avid book reader and has inherited the most sarcasm from his parents. Cedric is an orthopedic surgeon in private practice in Folsom, a Lt. Col in the Air Guard, and works part-time at the VA. He is on the 5p- Society's Professional Advisory Board. In his "spare time", he enjoys fishing. Jen, an RN/SAHM, is on the 5p- Society's Board of Directors and former President. I enjoy helping other parents learn about the IEP process so they can be a better advocate for their child.