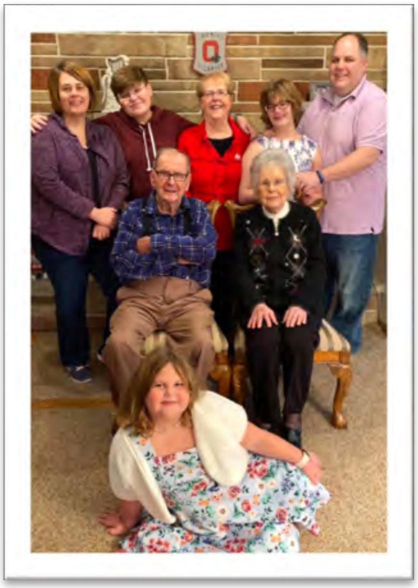
5P- FIVE P MINUS SOCIETY Newsletter

NATIONAL SUPPORT GROUP FOR FAMILIES WITH CRI DU CHAT SYNDROME

Volume 35 Issue 3

President's Message

Nick Wallace



Nick, Angie, Allie, Nate, and Laney; Nick's Mom, Cathy and great grandparents Fred and Ruth Meredith

What a strange and weary time we are living in right now. I don't know about the rest of you, but I am worn down. This crazy virus has upended so many things and has caused so much uncertainty. Angie was recently released from a 14-day self-quarantine due to encountering a person who had been in direct contact with 3 individuals with Covid-19. Let's just say it did cross my mind that she did it just to get 14 days away from the chaos that is known as the Wallace family! Actually, she almost went stir crazy during the 14 days.

As I said, I am worn out. Trying to figure out what info is correct, what style of learning should your child participate in this year, and we cannot forget those that are in an endless comment war about what side of the argument is the right one … obviously it is my side though … right?

The whole pandemic has been draining on all of us, but if your child is like my child, Allie is going stir crazy. She is such a social person and having her social distance from people has been quite a task. We have gone on several rides and have visited a few places, like the grocery store and pet store, but for the most part we have been doing our best to try to keep her away from this crazy virus. These drives and short visits give a little reprieve for her, but she is still very unsettled. One blessing for us is that Allie has adjusted to wearing a mask when she goes out into public. For me, Allie being unsettled along with the other stressors that this virus has brought along with it, has mentally exhausted me.

Lately, when all of this has been getting me down, a song from one of Angie and my favorite artists has come to mind. It is the song "Bottom of The Barrel" by Amos Lee. The lyrics are below:

"I keep on livin', to keep from cryin'. I keep on dreamin', to keep from dyin'. I keep on trying, I ain't gonna stop. Get right down to the bottom of the barrel and float back on top.

We all know someone, who's always hurtin', The sun is shinin', they draw the curtain. One thing for certain, the pain ain't gonna stop. You get right down to the bottom of the barrel and float back on top.

Cuz I know the grass, is always greener in someone else's yard. And the world is so much meaner, when your heart is hard.

I go out walkin', in any season. It could be rainin', it could be freezin'. I don't need no reason, it's just so pleasin' and I can't stop. You get right down to the bottom of the barrel and float back on top."

Although I have been mentally exhausted by this pandemic, I try to realize that eventually this will end. When we do come out of this time in our lives, it will not be back to what we consider normal, but it will come back to a new normal. We will eventually float back on top and hopefully we will come out of this stronger then when we were at the beginning of this. I know that your 5p- Society Board of Directors has been hard at work trying to innovate and figure out ways to keep following our mission statement during this unprecedented time in our lives. We are doing what we can to help keep our families connected and informed on topics that will help to maximize the quality of life for individuals with 5p- and their families.

As you all know by now, we have moved our 2020 annual conference to 2021, but we are working hard to create a new experience. We are planning a virtual conference that

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President's Message

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will take place September 12 and 13, 2020. We just couldn't go a year without our main event. While it will be different, this virtual conference will still feature some of our normal staples. Later in this newsletter you will learn more about our plans for the upcoming virtual conference.

Just as we have taken Allie on rides and to a few stores in order to give her a change of scenery, we hope that this virtual conference will give you something to look forward to and will hopefully help hold you over until we can all meet in Chicago in 2021.

Hang in there friends. I know this has been a difficult time, but know that we are all going through this and that we are all here for each other during the times of joy and during the times that may not be so wonderful.

Stay safe everyone!

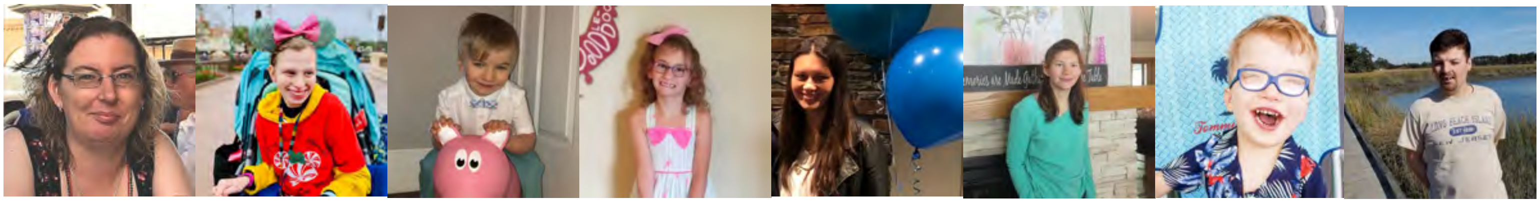
5p- Conference – *Going Virtual!*

September 12-13, 2020

We are excited to announce that we will be having a conference this year utilizing an online platform. This abbreviated program will offer something fun and exciting for everyone. We will include breakout sessions, parent panels, games, a virtual AmySue's Place, coffee breaks, and more. This year we will also be having a session aimed specifically at those in the medical field. Pass the word on to those who work with your child and encourage them to sign up. The conference will be open to members and non-members as we hope to bring comfort and fun to all of our families during this difficult time where so many feel isolated. Sign up information is included in this newsletter, the society webpage, and on social media outlets. Registration opens August 1.

Now's YOUR time to jump on Board!!

That's right, you could be the next 5p-Society Board Member! We are currently seeking two positions on the Board. Please contact our nominations chair, Jolene Towers at (937)241-3226 or email gnjtowers@aol.com for more information.



Books to read

A Book to my son Nathan: http://www.mixbook.com/photo-books/interests/blank-canvas-8309369?vk=ymWDidOAWC.

Raised by my Child by Sally D. Yantis-Grube, 2011—Mom to Heidi, 18-year-old with Cri du Chat Syndrome.

Her Name is Montel, by Casey Evans, 2005—Dad to Montel, 20-year-old with Cri du Chat Syndrome.

Beauty in Broken Dreams: A Hopeful Handbook for the Early Years as a Special Needs Parent, by Kathy McClelland, 2017, Mom to Nathan, 4-year-old with Cri du Chat syndrome. https://www.amazon.com/Beauty-Broken-Dreams-Hopeful-Handbook-ebook/dp/B06W575N8Q/ref=sr_1_1?ie=UTF8&qid=1509381275&sr=8-1&keywords=beauty+in+broken+dreams.

Confessions of a Special Needs Dad by Mark Wallace Maguire, a book of hope, healing, and honesty that dads are not alone.

Stripes for Eliana by Ana Camelo Jackson

Coming Soon…

Love You Big by Leah Witman Moore

From a Cat-Like Cry at Birth to Essential Tremors Now: An Educational Health Memoir by Debbie Small

5P- SOCIETY PRESENTS

VIRTUAL 5P- SYNDROME CONFERENCE

Registration required
Registration opens August 1, 2020

★★★★

SEPTEMBER 12-13, 2020

SCIENTIFIC SPEAKERS
PARENT PANELS
VIRTUAL AMYSUE'S PLACE TO HANG OUT

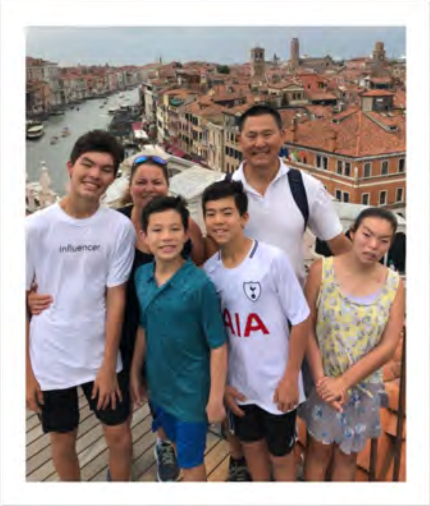
Registration fee: $25.00 (5p- Society members)
$50.00 (Non-members)
$50.00 (Professionals)

Registration link:
https://5psociety.regfox.com/5p-2020-virtual-conference

You will receive a unique conference code to join the meeting

Individual Education Plans (IEP): In the beginning

Jen Wong



Jen, Cedric, Emma (18), Christopher (16), William (14), and Daniel (12)

For many of us, our children starting school at age 3 is the first time they will be leaving us for an extended period of time, and that is really scary! In order to ensure a smooth transition to school, it is imperative to start educating ourselves on all the academic placement options, Special Education Law (both state and IDEA) and IEP process. Many disability groups and some school districts offer free IEP training. If not, there are many books that give step by step directions. My favorite is "The Complete IEP Guide: How to Advocate for your Special Ed Child." Wrightslaw.com is a great on-line source for information, books, and other on-line resources. Your best resources will be those families that have gone before you. They will be able to tell you what to avoid and what to fight for. Our Facebook group is a great resource for CDC specific questions, but you should also find parents in your area that have experience working with your district. In this article, I hope to give a few pointers to make this transition less stressful for you and your child.

Somewhere around 2.5 to 3 years old, the school district will reach out to you to request an Initial Evaluation to qualify for special education services. A key element in this step is to request a list of all tests an evaluator will perform and the evaluator's name and credentials. You need to ensure that all tests being performed are age/developmentally appropriate and current, and the evaluator is qualified to perform the test. These are key to ensure results can be accurate when comparing them to the test standards. Most assessment consent forms are very generic. You will probably need to request the above information be provided to you via email or in writing. When you sign consent, I would suggest doing so on a separate document. On the original, you can sign and write, "See Parent Consent Letter for clarification." This way it's documented that there is another document they need to read. If not, it may be overlooked.

Wrightslaw does have a book that helps demystify assessments, their tests, and results. For most, assessment results are the hardest part to understand, unless you're a researcher or statistician. Understanding the standards in which tests should be given are important. If an evaluator differs from the standards, while the test can provide some important information, it cannot be given a standardized result. It's a personal option, but many (me being one) choose not to IQ test. Most IQ tests require the ability to understand and use language. Since this area is one of the biggest issues for people with Cri du Chat, the language based IQ test may not accurately reflect the child's intelligence. Many standards of a test also restrict the evaluator to fully test. There was a study conducted with our group that showed many participants had splintered skills above where the evaluator has to stop testing due to the standard of the test.

Make sure to try and schedule tests during the best time of day for your child, as well as spread out so as to not overwhelm them and you. Make sure you request all test results/reports to be provided to you at least 7 days prior to the IEP meeting, so that you can be an "active and informed participant" during the meeting. There is no way you can be fully attentive at a meeting when you are just presented a report. You need time to read, digest, and prepare for the meeting. For many of us, seeing the results for the first time, even if we already know what our child's strengths and weaknesses are, can be very emotional and overwhelming. It's better that you can "have your moment" privately so that your emotions don't distract you from participating in the meeting. We were all nervous at our first meetings. Slowly go through the reports, take notes, and you can email the teacher/therapist with any questions/clarifications before the meeting. This will help expedite the meeting as well as decrease your nerves.

Along with the above preparations, developing an IEP binder is key. There are many examples of how to organize it. You need to figure out which template works best for you. One basic example is to section out: 1- IEP team contact information, 2- Complete copy of the IEP, 3- Separate sections for each therapy, including sections for academics and school RN. I put a current picture of my daughter on the front of the binder to remind everyone why they are at the meeting. Many suggest not combining your child's medical binder and IEP binder. You never want to give anyone access to your child's medical

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Individual Education Plans (IEP): In the beginning

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information without your consent (a school needs to have a documented consent signed to access medical information and providers). I would be very careful about signing a blanket access. Many parents only allow medical questions from schools to come to them, then they provide it to the MD, who then returns information back to the parent. The parents can edit out any information they do not wish to share with the school. It is also suggested that you write a letter to your medical providers stating you do not give consent for them to speak or provide any information to any school or person outside of those named on your document. This is redundant with HIPAA, but I don't think it's a bad thing to have a backup to maintain your child's medical privacy.

Now that you have the paperwork started, the school district should be arranging for you to tour EVERY academic placement option, starting with your homeschool/general education class through the spectrum to a self-contained classroom. Observe each classroom, ask about staff/child ratio, class make up (any behavior issues, age/grade levels, number of students), and any questions that would be specific to your child (does the school have an RN available everyday/all day, how they address toileting, behaviors, medical needs such as trach, feeding tubes, etc.) Some schools provide 1:1 nurses for certain medical needs. Also, ask about 1:1 paraprofessionals (aka aides) and what qualifies a child for that support service (hint: going into a general education class either full time or part time helps.) Have your questions written out and take notes on each placement. If you have the ability, you can also look into homeschool/charter/private schools. I've had friends that placed their child in a private preschool and kindergarten (at the parent's expense) but the school provided therapy services.

If looking into Homeschool/Charter, make sure they will be providing you with a General Education and Special Education teacher. Ask who they contract through for therapy services.

Keep in mind, even schools within a district can vary greatly with what they provide. Staff is the key to a successful program. Don't be afraid to ask for what you think is the perfect plan for your child; you may not get everything; but you may be pleasantly surprised with what they offer. My daughter's school did not have many programs (e.g. Handwriting w/o tears) until I requested them and gave evidence to back up why the program was needed. It helps if a therapist can make the recommendation, but many school therapists are limited to only recommend general therapies (e.g. "Tactile cueing" vs "PROMPT").

Despite what you may think, in an IEP meeting, you are in charge. The district may have a person running the meeting/agenda but nothing can happen without your consent. Make sure you understand your individual state laws on timelines for parent consent. Some states are allowed to go forward with an IEP if a parent doesn't sign in a designated time period.

You are the expert on your child. Therefore, you need to write and present a report on your child, just like every other IEP team member. You should include your child's interests/likes/dislikes, what makes them happy, what makes them sad/mad, what helps them when they're "in that mood" (e.g., sensory diet), what personality your child responds to best, and the ones they do not. Write your goals for them for the year; short-term and long-term.

These are not set in stone and will probably change, but you cannot develop a plan, if you don't have a goal in mind. And yes, vocational (aka job skill) goals are started right now (focus, task completion, sorting….). Discuss any medical/dietary/ADL (Activities of Daily Living) needs. Include a little about your family. Mention any special concerns, if siblings will be attending the same school. Create a separate document labeled "Parental Concerns." This is a part of the IEP document. ANYTHING that concerns you, write it down. By law, every parental concern has to be addressed during the IEP meeting. This doesn't mean there will be an action regarding every concern, but they are at least documented if one becomes an issue during the school year, to come back and address.

One of the last few things to get ready for the meeting is to see if you have a friend that can come and take notes. It's helpful if they are familiar with special education but not necessary. It's nice if you are able to give your full attention to the discussion instead of trying to divide your attention between listening and taking notes. I always recommend bringing a little snack (muffins, cookies, ...) and maybe coffee or small waters to the meeting. It helps break the ice as well as many teachers and therapists are in the meeting through their break and sometimes even lunch.

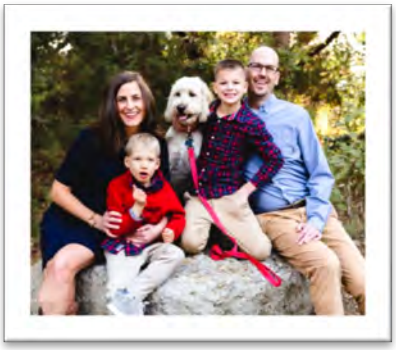
Many IEP team members will be a part of the team throughout your child's elementary level. It's good to develop a positive relationship from the start. Okay, this was A LOT, and we haven't even attended the meeting yet!! This article is not an expert opinion, just things I have learned along the way. I hope it gives you some beginning steps and sparks ideas for you to prepare.

I've given some ideas of where to find resources, but when in doubt, ask or google it. Next newsletter, I will get into tips to use during the IEP meeting.

The Treatment Burden Placed on Parents of Kids with Medical Needs

By Kathy McClelland, Published in Medium.com, All About Health

(https://medium.com/all-about-health/the-treatment-burden-placed-on-parents-of-kids-with-medical-needs-6b64f1964dc)



Kathy, Greg, Matthew (10), and Nathan (7)

Parents of children with special needs have burdens of extra responsibility. This is not something we talk about much because we love our children and of course will care for them in the best way possible. But it is still incredibly burdensome.

Treatment burden is anything extra you're made responsible for on behalf of your child.

Things like tube feedings, stretching exercises, behavioral interventions, medication administration, post-op recovery procedures, the lists goes on and on. These are often good things. Necessary things for our children.

There is the treatment burden placed on us by the nature of our child's needs. But what about the treatment burden placed on us by health care providers and therapists? It's real y'all.

Let me clarify: our children are not burdens, but their needs often are.

The thing with the treatment burden is that it is often thought of as a sacrifice that I can do for the sake of my child. Of course, I will tube feed my child if he can't eat by mouth. But over time it becomes hard to manage and wearisome to each and every day—it becomes too much to carry.

And if you think your child doesn't feel it, you're wrong. Children are intuitive little creatures who feel the weight of all of the extra things required from your family.

Here are some tips to help alleviate the treatment burden you, and your family, feel on a daily basis:

First off, you need to model calm leadership. Nothing will set your spirit and the tone of your family into a tailspin more than some added drama to an already dramatic situation. In fact, you need to diffuse all drama surrounding regular treatments in the day-to-day life of your child. Let the daily treatments become a gentle habit. Make them routine and regular without the extra flare you could add to the situation.

Second, minimize the friction involved in caring for your child. In other words, make the daily tasks easy to do. With Nathan's tube feedings, we have a tray that we prepare all of his formula on and then we bring it to him. He knows he needs to pop a squat near us on the floor and wait for us to administer the food through his tube. It takes 3 minutes at the most, and then he can carry on with his play.

Repeat the task in the same way over and over again. The repetition will become routine to your child and they will expect nothing less. Ever notice there are some things your kids don't fight you on because they've just always been that way? For us, it's wearing seatbelts and reading a book before bed. It's also tube feedings and catheterization.

Finally, when you go to a doctor's appointment or a therapy session, model good behavior to your child. Don't roll your eyes or complain about how hard something is. There is a place for that but it's best not to do in front of your kid. Ask good questions. Challenge suggestions in a respectful way. Afterward, talk positively about upcoming treatment and therapy changes to your kid.

So yes, it's hard.

The first time I heard the concept of a treatment burden it felt incredibly validating. That was what I was feeling! I was able to name what was causing the bulk of the pressure and stress in my life.

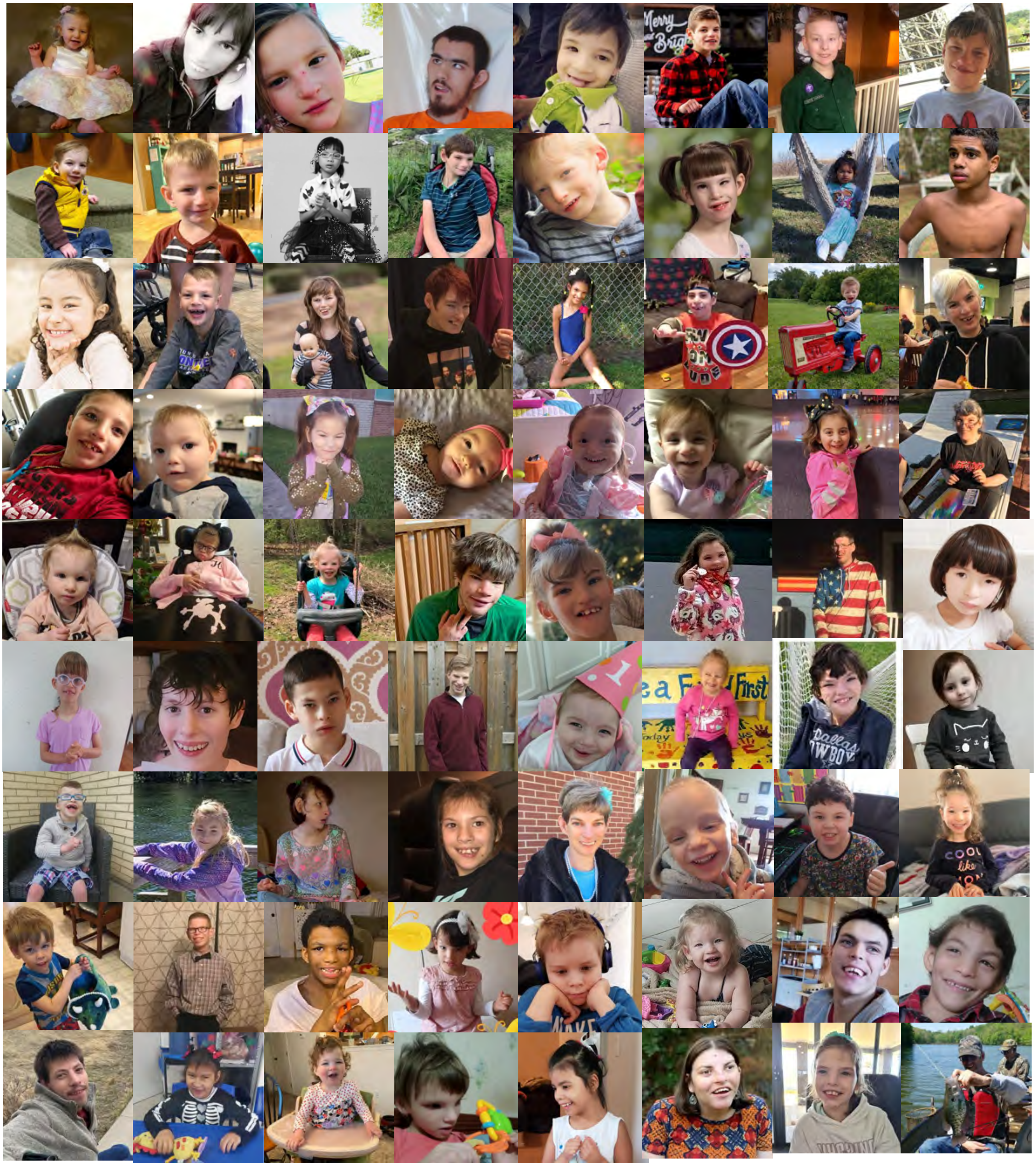
I am even able to use the term "treatment burden" with doctors and therapists and they know exactly what I'm talking about. The good ones realize all they are asking you to do on top of everything else going on in your life. When you have a true team partnering for the best outcomes for your child, you can talk these things through and come to a mutually agreeable plan.

Pace yourself and remind yourself that you are doing the best you can with the load you are carrying.

About the Author: Kathy McClelland is dedicated to sharing hope and encouragement with fellow parents of special needs children. This became her passion when her youngest son was born with Cri du Chat syndrome. The author of *Beauty in Broken Dreams: A Hopeful Handbook for the Early Years as a Special Needs Parent* she writes her story of faith along with practical parenting information she's learned along the way. She is a contributor to PreemieBabies101.com and KeyMinistry.org and has published on TODAY.com, TheMighty.com, HerViewFromHome.com, EllenStumbo.com, and Medium.com. Go to her blog, kathymcclelland.com, and grab a free copy of *All Things Beautiful: Finding Beauty and Hope in a Special Needs Diagnosis*.

The Faces of 5p– 2020

Thank you to all the families who participated in the 2020 Faces of 5p– campaign. We had over 80 individuals to showcase on our social media pages.



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Meet C5

The Mascot of the International
Cri du Chat Awareness Week

WE'RE ON THE WEB
WWW.FIVEPMINUS.ORG

TWEET WITH US
@5PMINUS

FIND US ON FACEBOOK AT HTTP://WWW.FACEBOOK.COM/CRIDUCHATSOCIETY

Have you moved?

Do you have a new phone number?

Do you have a new email address?

Are you a current member?

Please contact Laura Castillo, Executive Director at lc5pminussociety@aol.com to update your records and check on your membership status!

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

We are actively looking for sponsors to help offset some of the technology cost of the Virtual Conference. If you know of a company or individual willing to help please contact Michelle Myatt at mmyatt5pminussociety@gmail.com. For information on the Sponsorship packages below, please visit our website at www.fivepminus.org and click on News & Events—Virtual Conference.

Guardian	$5,000
Hero	$2,500
Defender	$1,000
Champion	$500
Protector	$100

Newsletter Submissions Request

We are asking all members to submit ideas, photos, or best yet, articles to be published in future editions. We need to know what interests you and your family. Please submit articles, photos, and ideas to Shari Campbell at: djcshc@charter.net.

The 5p– Society is a 501(c)3 organization. It's Federal EIN is 48-1022202. Donations in any amount are greatly appreciated.