

President's Message

Nick Wallace



Well, autumn is upon us, and the leaves are already starting to change. In autumn I tend to reflect on the changes

that have happened in my life over the past year, and this year has brought some major changes.

My past articles have focused on the coronavirus pandemic, but just like the season, I think it is time for a change in focus. In this article I am going to write about one of the ways being a parent of a child with special needs has changed me.

When Allie was diagnosed, we were given a litany of things that she would never do. She would never walk, she would never talk ... in short, she really wouldn't be able to do anything. This didn't stop us. We believed that Allie would be Allie, and instead we started focusing on the small things in life. What so many parents take for granted were now our major success stories. Allie's first steps were like winning a Tony Award.

This focus on the small things didn't stop with just Allie. It caused us to start looking at life with a different pair of

glasses. I recently had the opportunity to share the duty of being the DJ for the virtual dance at the first ever 5p- Society Virtual Conference with my son Nate, and during this event my heart swelled. Being at the controls of the Zoom program was amazing, because I was able to see all the different families near and far enjoying life without a care in the world. During this hour they were free of the concerns that life brings. Then when I started spotlighting different families and individuals, the looks on their faces were priceless. Their faces were often that of pure joy. When they were in the spotlight, they danced with even more fervor than they had before.

This event was one of those small moments that too often people would glance over as just another dance, but because Allie's diagnosis caused me to slow down and to start looking for the small things in life, I was able to see how this was so much more than a dance. This dance was a moment of respite in a time that is filled with so much uncertainty and change.

So, remember that when changes seem to be too much for you to handle, try looking for the small victories, because they may be the moment that will bring you joy when you need it.

"We can complain because rose bushes have thorns or rejoice because thorns have roses." — Alphonse Karr

Contest Time—C5 is Hiding!

Where's C5? C5 has been hidden throughout this issue. Count all of the different size C5's and submit your guess to the link below for a chance to win one of 8 bags and a C5 mask from the Virtual Conference. Contest ends 10/31/2020. Winners announced November 1, 2020. Submit your guess here: <https://forms.gle/vRtLapdCKVbowNAN8>



DJ's Nick and Nate

J O I N U S !

Wear your Costumes!!

5 P - SOCIETY HALLOWEEN

VIRTUAL DANCE

OCTOBER 24, 2020

7 PM EASTERN
6 PM CENTRAL
5 PM MOUNTAIN
4 PM PACIFIC

5 P - SOCIETY
MEMBERS
ONLY



If you are interested in joining us please contact Laura at lc5pminus-society@aol.com to confirm your membership to the 5p- Society and receive an invitation to register for the Halloween Dance!! We are looking forward to seeing everyone in their costumes!!



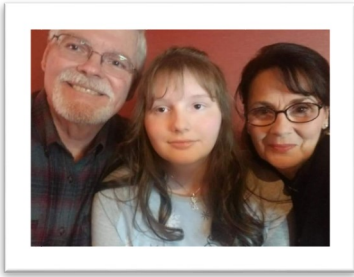
Get your 5p- official masks on the SquareUp link below.
Another great way to not only support the Five p Minus
Society but also to help raise awareness!

[Shop on SquareUp](#)

First Time Conference Attendees



McClure and DeLine Families



I want to thank everyone that worked to put together the recent live streaming 5p- Syndrome conference and all that were able to participate.

Ivory Rose White is our 17 year old granddaughter with Cri du Chat Syndrome who we raise. She was our tiny little 6 lb 6 oz grandbaby. She was nearly 4 weeks early. She was very sick and was in the NICU for 11 days. She was our first grandchild. We had never heard of 5p- Syndrome or Cri du Chat Syndrome. We soon learned that Ivory's mother and her twin also both had Cri du Chat Syndrome. Ivory's aunt has two children younger than Ivory, and one of them also has Cri du Chat Syndrome.

Ivory is such a loving girl and has definitely taught Don and me about true love. She was easily taught to read and reads anything and everything. She even has captioning on her television. She loves music and sings much of the time. She has lately been learning to make her bed and help out around the house. She loves baking, too.

I very much enjoyed the online conference. I loved meeting some families and making new friends. It is so comforting to meet other families and compare notes on our family members with Cri du Chat Syndrome. I learned so much from listening to the speakers and also from what other parents had to add. I was very grateful for the information each speaker had to offer. It is so important to learn more about the health and well being of our children as they go through different stages of life. I thought the conference was a wonderful event and a great success.

Hi! We are the DeLine family. I am Pam, and along with my husband Shawn, we have 3 boys. Our Superstar with 5p- is B (Bradley). He is our oldest at 21. His Brothers Jacob (15) and Colin (13) are his best friends.

We live in Sarnia, Ontario, and while B was diagnosed at birth, we only met our first families affected by Cri du Chat last year at a local meet. The 2020 Virtual Conference is our first conference.

I found the 5p- Society a little bit late in B's life, so although he is 21, Chicago was going to be our first ever conference. We were so excited! Excited to meet the other families and excited to learn more.

Then Covid. As we all know, that threw a wrench in everything. The conference was postponed until next year, and I was suddenly home full time with B. When they decided to do the virtual conference, I knew right away I wanted to be part of it.

True, I still wouldn't be able to meet new families yet. But the information was still going to be made available to us through presentations.

I wasn't sure what to expect from the virtual conference for a few reasons. First, how much would I be able to participate and still keep up with B and his never ending energy? And second, how would the information be presented?

I have done research of course, as we all have. However, as I am sure many of you have also found, reading on the internet only tells us so much. So now we had excitement and nerves.

My expectations of a virtual conference were far exceeded. The presentations were well done and held my attention through ear buds and my cell even while chasing B around the house. It really couldn't have been any more convenient! The few that I was unable to make it on for I was able to access afterwards so there was nothing missed.

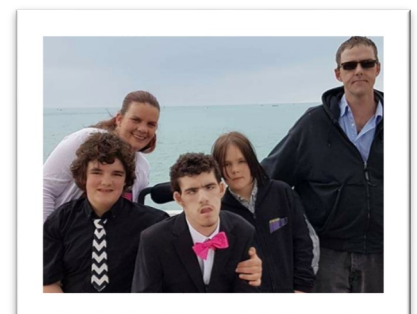
As for my personal reaction to the conference itself, one word came to mind over and over and over. Justification. And then someone mentioned "affirmation" during one of the Q&A periods and it was just an "Aha! Yesssss!" moment for me.

We have sort of blindly raised B up until we found the Facebook Group and through it the 5p- Society. We had great doctors and therapy offerings. His schools have done everything they can to learn from him so they can help him learn. But with that comes questions. Did I do everything wrong? Is he different than other kids with Cri du Chat or only other kids with special needs? Am I the only mom that doesn't have it "all figured out"? Is he the only one that seems to use what I call "The path of most destruction" for example? The conference taught me that is called "Creating Chaos aimlessly."

So, yes, I've always known I am a good mom. I am doing my best. He is healthy and still learns new things. But that little voice, that nagger, the one that sits in the back of your head, wasn't as easy to convince. We tend to present our best selves on social media, which can make that voice become more persistent.

So the conference discussions were truly like a weight lifted off my shoulders as things I understood so well were being discussed and other parents were nodding or showing looks of total understanding. Subjects I had tried to convince people I KNEW but couldn't say how I knew were being validated, affirmed, and okayed.

I highly suggest any family hesitant about attending a conference do so. I am even more excited about the possibility of Chicago next year, but even if the conference is again virtual, I will absolutely be joining again. If only to be reminded that we are not alone.





Virtual 5p- Syndrome Conference

Three weeks before the Virtual Conference I got a panicky stress knot in my stomach. The deadline for families to register was coming up, and we were close to the Zoom license cap of attendees . . . We could have increased the amount of attendees, and would have if we saw a large increase in registrations in the days to follow, but we didn't, so we didn't. We did however reach our cap. It is the first time that we instituted a registration deadline. As most of you know, we accept registrations to our in-person conferences during the conference. It wasn't easy to turn the handful of you away who reached out to register after the deadline, but since it was our first virtual event, I felt it necessary to stick to my guns.

As expected there were a few technological issues, but we handled them as best we could. Passcode issues and cutting off presentations a tad bit early during transition from one speaker to another were a few of those technological snafus.

I would like to say a big THANK YOU to Michelle Myatt and Nick Wallace for holding my hand and reassuring me that everything would be great, Dennis Campbell and AmySue Reilly's testing out the presentations with me, along with my dad testing out the technology with me. Without them all I think I would have been an absolute mess.

I've been leading the 5p- Society as your Executive Director for 23 years and have lead 22 in-person conferences. I have a rhythm and ride, I know how it's all going to work out, and I am cool under pressure. You can ask my husband — I was a nervous wreck about this virtual event!!

The Virtual Conference was absolutely WONDERFUL!! The speakers were spot on. Thank you to the following for providing us with really great information:

- Dr. András Spaan, researcher at Rockefeller University, who updated us about his research on lung infections and 5p-. With COVID front and center in all of our lives, he also kept us up-to-date with what we know about 5p- and COVID (not much). He also let us know how individuals can participate in his study (contact him at aspaan@rockefeller.edu).
- Stephen Furnari, Attorney at Law and parent, talked about guardianship and special needs families and how to best protect your child when they turn 18. Steve has created an organization called the Guardian Project, US. You can visit their Facebook page called @guardianproject.us. Here you can get information, resources, and connect with volunteers to help you with the guardianship process. Designed for families who live in Florida, there are many points that he presented that can be used in other states as well.
- Dr. Laurel Daniels Abbruzzese, Assistant Professor of Physical Therapy at Columbia University and parent. Laurel provided a really good and overdue presentation on physical therapy and movement overview of the research that she has done over the past several years on 5p- Syndrome. Laurel is also a member of our Professional Advisory Board.
- Dr. AmySue Reilly, retired Associate Professor of Special Education at Auburn University, gave us not only one effective positive behavior modification presentation but a second presentation on day two to continue her presentation and answer behavior questions from the attendees. We are eternally grateful to AmySue for her dedication to the 5p- Society and sharing her knowledge with us – and yes, every individual with 5p- Syndrome has behavior problems. AmySue is also a member of our Professional Advisory Board.
- Dr. Geoff Towers, Obstetrician and Gynecologist and parent, gave a presentation on puberty and girls with 5p- Syndrome. As a parent of a 24-year-old daughter with 5p- Syndrome, he was able to give first-hand experience and provide candid answers to the many questions that were asked. Questions about how to handle menses, to birth control methods, to PAP smears were all on the plate for Geoff. Geoff is also a member of our Professional Advisory Board.
- Dr. Dennis Campbell, retired Associate Professor of Special Education at University of South Alabama and parent, gave an updated presentation on Cri du Chat 101. Even though his presentation is designed for new parents, with the new and updated info that he has from the recent articles that he and a few of his colleagues have written regarding

Continued on page 5

Virtual 5p- Syndrome Conference *Continued from page 4*

5p- Syndrome, it seemed like learning about the syndrome all over again. Dennis is the Chairperson of the Professional Advisory Board.

Michelle Myatt, Ed.D., Licensed Social Worker and parent, provided us with some helpful tools to get through these trying times of COVID and our special needs child. I will need to relook at her presentation as she gave us some really great tools. Michelle is the Vice President of the 5p- Society and the Virtual Conference coordinator.

Michelle Myatt, our Virtual Conference coordinator, did a FANTASTIC job with the schedule and making sure to work in socialization time along with learning. Many thanks to the members of the Board of Directors for facilitating the Parent Panels, Grandparent Panel, Dad's Panel, and Virtual AmySue's Place. Virtual Coffee breaks were available for chatting, connecting, and getting to know each other better.

Many many thanks to our conference sponsors who helped us fund the Virtual Conference: Chicken Express and the Sparks Family, Life to the Max and the Owens Family, the Sandbulte Family, Grandparent Donna Grasso, the Bowdish Family, and the Furnari Family. Special thanks to my friend Peter Martinez of MTZ Graphics for donating the conference bags that held all the 5p- swag.

We had 37 families attend a conference for the first time. I really hope that they enjoyed it and were able to walk away with new information and new friends. We had families from all over the world, from Taiwan, Germany, Spain, Colombia, Saudi Arabia and Peru. Several of our members from Canada attended with us, too. Eighty swag bags were sent out that had a 5p-mask and other 5p- swag. 5p- masks are still available at <https://5p-society.square.site/product/c5-masks/62?cs=true>.

The families who attended are currently filling out the conference survey for us to see where we can improve. Pictures will begin to post on October 1st of the different families who participated (only of the families who submitted pictures).

Virtual events for the future?? We would like to plan on hosting future virtual events including presentations, socializing events, parent panels, and maybe even a time for the individuals with the syndrome to meet for an informal get to know you type of event. We will post these events on our social media and website, so make sure you are always checking.

I enjoyed meeting many of you, even virtually. I look forward to many more conversations.

A Note About IEP Process Dennis Campbell

Jen Wong always asks me to review her IEP articles for accuracy. Again, this one is accurate. However, I felt a short addendum might be helpful for some of you, including a little background on me for those who don't know my background. Besides being Amy's dad and navigating through her schooling in 3 different districts and 2 different states, I also worked almost 20 years as a teacher educator. In that role I worked with hundreds of special education teachers and also provided support for many families.

The reason I wanted to comment is that Jen's statements are based on her experience in California. Although the process is similar in all states, each state and actually districts have different processes. Special education teachers for the most part have your child's best interest at heart. The bottom line is to show you appreciate their effort on your child's behalf.

How you play your part as an IEP team member is a choice you need to make. Be a team member that works from your strengths. Being informed and letting everyone know you are informed goes a long way in making the process go smoothly. So do your homework and make a list of what your priorities are. You can do as Jen describes, being very thorough and dotting all the i's and crossing the t's, or be less assertive. But what is critical is that you play your role and make sure that you get what is best for your son or daughter.

This is how I explain it to both school personnel and parents. The parents' job is to get the best they can for their child. The school personnel must meet the requirement of the law, their district's policies, and stay within their budgetary constraints. It makes the process an inherent conflict. The bottom line is that special education has not been fully funded since it's inception. So, go into the process eyes open and take advantage of the resources in your state, i.e., parent resource centers and national resources like Wrightslaw. Hopefully you won't need an attorney.

Individual Education Plan Part Two: The Meeting——Jen Wong



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

In Part 1 of my series on IEP's, I discussed what you should do to prepare ahead of time for the actual IEP meeting. You have requested and received all assessments about one week before the meeting. You reviewed them and emailed any questions to the individual therapists. You wrote your report on your child, including Parental Concerns, likes/dislikes, "what works," and especially what does not. You've asked a trusted friend to take notes for you so you can be fully engaged in the discussion. You've brought a treat, cookies, muffins, coffee, water, just a little gesture to show you appreciate their attendance.

The meeting should begin with everyone introducing themselves and their role on the IEP. An agenda should be provided along with your child's procedural safeguards. If able, the case manager should be utilizing a projection board (e.g. smart board) so that everyone can follow along during the meeting. If anyone is absent, by law, they needed to ask your permission in writing/email prior to the meeting. Obviously, unexpected issues come up. I usually excuse them with-

out issue. There is a page on the IEP you need to sign to show you have okayed the absent parties. The attendance sheet will also be passed around. I always sign and write "attendance only" next to my name. The case manager should go over the basic information on the beginning of the document (name, phone numbers, etc) to ensure accuracy. When looking at the primary language, if your child uses ASL along with spoken language, ask that this is reflected in the primary language line. For Emma, we had primary language as English/ASL. All educational instruction needs to be provided in the student's primary language. This ensures ASL is not dropped as a communication method used by your child. The district will need to provide ASL support. If this is your child's first IEP or a triannual IEP, eligibility is determined. A student must qualify for IEP services under one or more of the 13 disability categories per IDEA: Specific Learning Disability, Other Health Impairment, Autism Spectrum Disorder, Emotional Disturbance, Speech or Language Impairment, Visual Impairment/Blindness, Deafness, Hearing Impairment, Deaf-blindness, Orthopedic Impairment, Intellectual Disability, Traumatic Brain Injury, Multiple Disabilities. A child may be eligible under more than one category. My daughter's eligibility was primary—Multiple Disabilities/secondary—Orthopedic Impairment.

Next, you will be asked about your "Parental Concerns." This should be part of your Parent report. EVERY CONCERN you have should be listed in this section. By law, every Parental Concern needs to be "addressed" in the IEP. This can simply mean a discussion but no action, but this is an important part of the IEP. You should not be told you have too many concerns or to pick a few. If the IEP document cannot contain all your concerns, you will submit your report and make sure that it is documented in the Parental Concerns section as "See Parent report for full list of Parental Concerns." This is to ensure an attached document is not "lost." Any document you have added to the IEP must have its presence acknowledged somewhere in the IEP document. Your child's Present Level of Performance (PLOPs) will be documented. This is their general baseline of development. The therapists and teacher will take turns reporting their assessment results and observations. Some districts have everyone read just their reports first and then do goals and recommendation of services. Keep notes of any questions you have and ask them after each team member finishes reporting out. Do not move on until your questions are answered and you fully understand the therapist's report. Assessment validity is one of the most difficult aspects to understand in the IEP process. Standardized tests have very strict restrictions. Assessors need to be qualified and understand the standards of each test. Assessors can have the best interest for your child to do well, but they cannot falsely alter the standards of the assessment or else the entire assessment will be invalid. With some assessments, if subtests are out of range by a certain factor, the test is invalid. This doesn't mean you cannot get good information regarding your child from the test. It simply means that standardized scores cannot be given. There are many resources to help you understand assessment results. I have used material from Wrightslaw.com. The key thing to remember about an assessment is that it is a snapshot of your child in time. Things to consider about assessments are: when were they taken, was it perhaps not at the best time of day for your child, were multiple assessments taken in the same day/week? I usually request assessments to be started at least a month in advance of the IEP meeting to help alleviate the stack up of assessments all in one week. For Emma, she would know an answer if you asked it in a specific way, but if that changed, even slightly, she wouldn't know the answer. This is why I request assessments in advance so I can read them, and if it causes any emotions, I can have them outside the meeting. Reading/seeing an assessment on paper on how your child is doing, even if you are aware of their ability level, can be difficult, especially that first time. In your own report on your child, you can detail what you observe of his/her abilities at home.

Moving on in the meeting, you will go over goals that your child will work on in the next year. Key things to remember about goals: 1) There is no such thing as too many goals if all areas of need have not been addressed. 2) If you feel a goal is not aggressive enough, ask to up the skill level. A goal does not necessarily need to be met in a year. It's the team's "best guess" as to how much your child can accomplish on that specific task in a year. A goal can always be revised if needed. As we all know, our kiddos surprise us all the time. Some years a child will have academic gains and others not as much but may have physical gains. They will teeter totter between developing a skill and mastering it, so you could see an uphill gain and then a plateau. That doesn't mean that's all they can do, it's simply they are putting that skill into their "mastery skill bag." 3) Goals need to be SMART. SMART stands for Specific, Measurable, Attainable, Results oriented, and Timely (different sources change the names of a few sections).

Specific—The goal needs to have a clear description of the knowledge/skill taught and how it will be measured. To say, "Mary will increase her focus in class," is not specific. Instead, the goal should read, "Mary will increase her focus during reading a 3rd grade level pas-

Continued on page 7

Individual Education Plan Part Two: The Meeting *Continued from page 6*

sage by 5 minutes from base-line in a quiet setting with no verbal/tactile cueing.” In the benchmarks, you can start with supports in place, such as verbal cueing to stay on task or lower minutes of focus. I try not to have multiple supports being adjusted in between benchmarks, depending on the difficulty of the task.

Measurable—Means simply you can count or observe it. Every goal should have a baseline so that you know where your starting point is. You cannot measure progress unless you know where you’re starting. I see many goals with “80% in 4/5 trials.” 80% is the typical level that is considered “mastered.” In the example, your child could get 80% 4 times and then 3% in the 5th, and the goal is met. In certain goals, such as safety goals, this level of “mastery” is not acceptable. Watch and closely read the goal language and how they’re measured. If a goal is for safety, you want that to be accomplished “100% of the time in x trials per week over 1 month.” This means over a month’s time, your child will be assessed x times each week, and to meet this goal, every assessment will be 100% accomplished. If a goal is academic, where mistakes are understandably to be made in the beginning, a % mastery increase can be used throughout benchmarks.

Attainable/Action words—The goal must be a realistic progress for the student. There are three components that must be stated in measurable terms: 1) the direction of the goal (increase, decrease), 2) area of need (behavior, communication, activities of daily living (ADLs), safety, academic), and 3) level of attainment (grade level, developmental age, %, with levels of assistance).

Realistic and relevant—The goal should be unique to your child’s needs and within their assessed level of accomplishment within the IEP timeline. This puts the “I” in IEP. Many districts utilize goal banks to pull their goals. This is fine as long as the goal is tweaked to support your child’s individual needs/abilities.

Timely—Starting from the student’s baseline, present level of academic performance and functional achievement (PLOPs), a goal will be developed with the anticipation, based on assessments, that it will be accomplished in a one year timeframe, broken down into timed segments (usually around general education report cards or a set schedule determined by the district). Benchmark assessments are critical to the IEP process as they are used to monitor goal progress at regular intervals. If it’s determined to be unrealistic, either being too easy or difficult, a goal can be adjusted at a benchmark rather than waiting and wasting a full year. Parents should receive a benchmark report on all goals at each stated time break.

Once assessments and goals are complete, therapists will give their recommendation of services. This includes how many sessions per week, minutes per session, and how the therapy is provided (1:1 vs group, push-in or pulled-out from the classroom). Remember, goals drive the service time! This is why I say to make sure the IEP addresses all areas of assessed needs. A 1:1 paraprofessional (para) is also a part of the services discussion. Some districts have formal assessments to determine a need, others discuss and determine as a team if a para is needed. If your child is mainstreaming, a para needs to be available to take your child to their general education classes each day. If they don’t have a para, issues can arise that can prevent them from attending. If a classroom para is sick and a sub is not obtained, this could prevent your child from mainstreaming due to class ratios. A special education teacher cannot/should not be the only adult in a self-contained special education classroom (special day class—SDC). Also, if they try and utilize a 2:1 ratio, what happens if the other student needs to leave the classroom? How will your child be supervised? Staffing issues should never prevent your child’s IEP from being implemented each day.

You will also have the determination of placement. By law, the team needs to start this discussion with the least restrictive environment (LRE) with all needed supports and services in place. A general education classroom at your child’s homeschool is the first option. If this is not the placement that will meet your child’s needs, options such as mainstreaming (pulling out from a SDC) into the general education setting, all day in an SDC setting, private school, or home/hospital will be discussed to find the appropriate setting.

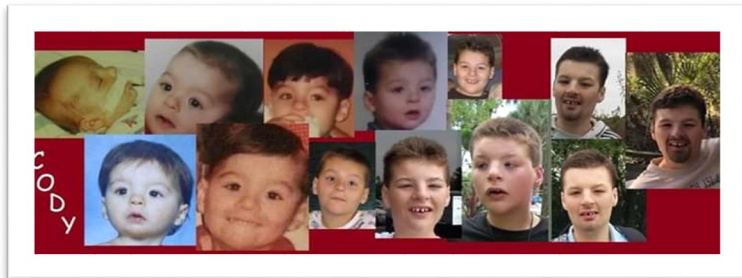
One of the final steps of an IEP meeting is the district’s offer of FAPE (Free and Appropriate Public Education). This will be a list of the classroom placement and all services/therapies being offered. At the end of the meeting, you may be asked to sign the IEP, accepting it to be implemented. I always recommend you ask for a complete copy of the IEP to take home and go over. An IEP meeting can be emotional, which can cause you to miss elements. At home, you can go over each section of the IEP to ensure it’s what you understood in the meeting. My daughter’s lawyer recommends writing out a Parental Consent letter. In this letter you may have two sections: “I consent to the following” and “I do not consent to the following.” Each therapy/support service and its goals get their own “paragraph” to describe what you are consenting to. This is to ensure there is no confusion/misunderstanding. An example of this is: “I consent to the Speech Service of 3x60 minutes per week and all Speech goals. I understand this to be provided by a Licensed and Credentialed Speech and Language Pathologist 1:1 in a quiet private setting.”

This shows exactly how I understood this service to be provided and by whom. I’ve had instances where services were altered from the discussions in the IEP. This consent gives me the ability to document the discussion, and if the service is altered, to address it with documentation. Note: If a new service provider takes over the therapy, the License/Credentials cannot be lower than those of the therapist providing initial therapy without an IEP meeting/addendum. It’s polite to try and return the document to your child’s case manager within a week. If this is your child’s first IEP, they cannot start services until the IEP is signed. Remember this is a legal contract between you and the district.

This article is just a brief rundown of the IEP meeting/process. My hope is that this will give you some good tips and a starting point for you to start your own IEP educational training, whether that’s on-line, books, meetings provided by school districts, or local special education or disability groups. IEP documents and laws can differ slightly from state to state, so make sure you are looking at your state’s Department of Education, Special Education Code for any variations of timelines/requirements.

Cody's Adult Transition

Holly Gattone



Cody transitioned from his school years to a day program in June of 2017, and we started preparing for that transition a year ahead. I am thankful that we had a wonderful supportive team, both at school and with his Supports coordinator, who made recommendations for what they felt would be a good fit for Cody. I was not prepared, however, on what an emotional time it would be in trying to find “the right fit” for Cody’s needs, knowing that we as parents want what is the

absolute best for our young adults as they transition into the next chapter of their lives.

Cody is covered under the Consolidated Waiver here in Pennsylvania. I know there are different services in every state. We are very fortunate to have this in place for Cody, as it opens the doors to a lot of resources for him.

Hope Springs Farm was the first place that we visited for Cody while he was still in school. It was only a 30-minute drive, which wasn’t too horrible of a commute, as these programs can be quite a distance when you live rurally. It seemed to have everything that would be a good fit for him, and he started attending one day a week with his personal aide for his last year of school. Unfortunately, only two months in, his behaviors got out of hand, and he was no longer able to attend. I was devastated to say the least, because he loves to be outdoors and to be around animals. I was so sure that this was “it.”

So, it was back to square one in our search. We then toured four more places over the course of the next few months. Cody was always along for the tours. He is nonverbal and can’t tell us his feelings. I thought it was important to see his reaction when we toured, if he was open to the possibility of attending, and how he interacted with those at the program. You can tell a lot by body language and their reaction to certain environments or situations.

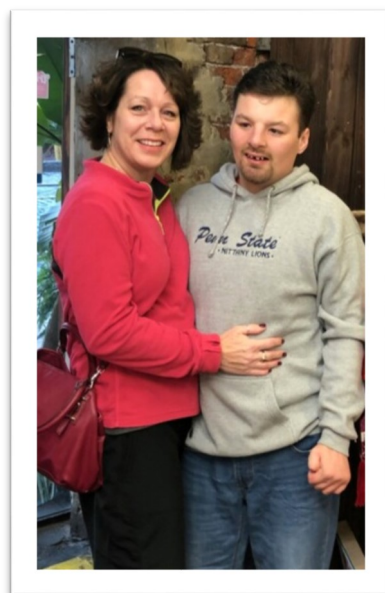
I was asked to consider a “workshop environment,” where Cody would be able to work for a pay check; however, after much discussion we decided that he would need an extreme amount of one on one to make that happen. And at the end of the day, you want your young adult to be able to function in the least restrictive environment.

As a Mom, I was stressing over everything from toileting and how far they would have to take him to get to the bathroom, lunch and would he be monitored closely enough, and how he would deal with his peers who now are no longer school age but adults and older adults. I was feeling overwhelmed at times. But I kept in close communication and shared my thoughts with our team. They were wonderful in talking things through and listening to my concerns.

We finally decided that Prospectus Berco was the best fit for Cody. He had a few rough days to start, but I think that is to be expected. Once he got to know the staff and his classmates, he has flourished! He is in a deaf/hard of hearing classroom, so they continue to sign with him. He continues to receive all the therapies he had in school and is still in a learning environment; however, it is without the demands of the school setting. He loves the Life Skills class and is always willing to help. It warms my heart to know that he is happy in his program and living his best life!



Holly and Cody Gattone live in Harrisburg, PA. Cody will turn 24 this December. He enjoys spending time with his family and friends, swimming, and being outdoors. He also enjoys watching ice hockey (Go Flyers!) and game shows, as well as anything that involves clapping.



Turner's Adult Transition

Kelley Morgan



Our son Turner is 22 years old. Turner has a sister Kacie who is 26 and a brother Tucker who will be 20 at the end of this year. My husband Terry and I have been married for 30 years. We have lived in Sonoma County (Northern California) for 30 years. Turner has been in various school districts around the county; always in a special day class. Most of his classes/teachers were great and a couple not so much. Turner is non verbal, incontinent, can walk but prefers to scoot, and very social. He just loved being in school with his friends. He also loves to ride the bus. In February of 2019 I got a list of adult programs from our regional center. I started calling each program knowing that in 18 months Turner would age out of the school district class. I called every program even if I knew he wouldn't qualify. I found it very helpful to talk to all of the directors and get opinions on different programs that they would recommend. I started to make appointments to visit some programs on my own without Turner. I didn't want to bring him to visit if I found it wasn't a good fit for him. I really liked the first program that I went to visit, but by the time I got back to my car, I was in tears. It's one thing to talk about the transition at 22, but when you go into a program and the clients are 22 to 65 plus years old I found it

very overwhelming. Our child that has been with his peers for 17 years is now going into a whole different type of experience. Transitions were always a little bit difficult in the school district, but this is just a different level. I also discovered that unless my young adult can "work," is emotionally disturbed, or medically fragile there are not a lot of options for him. Turner does not fall into any of those categories, so finding a program for him is more challenging. After being declined by 3 programs, I was losing hope. I also found that I really had to keep in touch with them during this process, because it takes a long time for them to get back to you. The one option that I knew I could choose was just a 1:1 for Turner that would take him out each day, but I knew, and his high school teacher even agreed that Turner would not be happy because he is so social and just thrives being with friends. Due to COVID we Zoomed the end of his school year and said goodbye which was so sad for me. Turner doesn't have the understanding of COVID or why he is not in school with his friends. We look at pictures everyday of his old classmates. On the bright side, in July we did receive an email from a program that decided they would give Turner a try!!!! We have been Zooming with them 5 days a week. Turner is not too sure about his new friends and just asks for his old friends. I do have hope that once he can go to his in person day program things will fall into place. I'm kind of hoping that all this Zooming now will help with his transitioning. His high school teacher did say to give it a good 3 months and expect several steps backwards, but eventually things will fall into place. My advice to you is to start this transition process early, and don't wait until they are almost done with school. It's a lot of work and waiting, but it's a good feeling when you finally get that "yes we accept your young adult." It's been a long 6 months!



Now's YOUR time to jump on Board!! That's right, you could be the next 5p-Society Board Member!

We are currently seeking one position on the Board. Please contact our nominations chair, Jolene Towers at (937)241-3226 or email gentowers@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

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



PO Box 268
Lakewood, CA 90714-0268
Toll: (888)970-0777
Phone: (562)804-4506
Fax: (562)920-5240
Email: director@fivepminus.org

RETURN MAIL REQUESTED
RETURN SERVICE REQUESTED



Meet C5

The Mascot of the International
Cri du Chat Awareness Week

WE'RE ON THE WEB
WWW.FIVEPMINUS.ORG

TWEET WITH US
[@5PMINUS](https://twitter.com/5PMINUS)

FIND US ON FACEBOOK AT [HTTP://WWW.FACEBOOK.COM/CRIDUCHATSOCIETY](http://WWW.FACEBOOK.COM/CRIDUCHATSOCIETY)

Help the 5p- Society with all your Holiday Shopping

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.

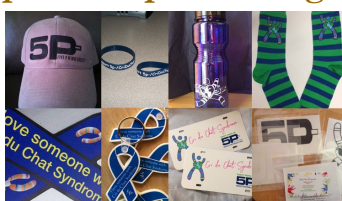
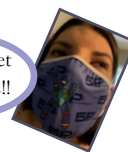


When purchasing items on Amazon, make sure you go to AmazonSmile at <https://smile.amazon.com/> and choose to support 5p- Society (Lakewood). The 5p- Society gets a small % of what you purchase. Every little bit counts and we are grateful to you for your participation.

Shop for your 5p- items below at

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

Don't forget
your masks!!



Shop on CafePress

Shop on SquareUp

Shop on InkSoft

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: djchc@charter.net.