



The 5P- Buzz

National support group for individuals with 5P- and their families

October 2022, Vol. 38, issue 1

5P- Society President's Message: Strength

Well, here we are ... summer is fading, and fall is here. We just finished a wonderful conference in Charlotte, and it felt so good to be back in person again. Now we are starting to focus on our conference in Chicago. I know the Chicago families are ready to host this conference after three years of waiting!

The theme of this newsletter is strength, and when I sat down and thought about what strength was, I started thinking about muscles, athletes, the gym, superheroes, the button that holds my shorts together (sometimes we put a lot of faith in that one button!). Everything that I initially thought of had to do with some sort of physical strength or some type of power. I am sure if I asked most of you the same question, you would probably have some of the same thoughts that I had. The thing is that while strength does mean power, there is also strength in weakness.

Let's look at a newborn, when they are born, they are weak and fragile, but as time goes on, they start developing.

Continued on next page.

2022 North Carolina Conference Wrap-up

We did it! We survived our first in-person conference since COVID hit. After having to postpone the in-person conference for two years we finally were able to meet. Our crowd was very small, but we had 5p- Society families from all over the US and even a family from Bogota, Colombia.

Many thanks must go out to Brandon & Christina Brown, Russ & Amanda Bennett and Zach & Maria Maxell for their amazing hospitality, planning, preparing, and executing the outstanding event. On top of that it was the Brandon's and the Maxell's first 5p- Society conference.

Many thanks also need to go out to the Board of Directors who stepped in and

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Visit our website at <http://fivepminus.org/>

President's message (cont.)

Think about how much strength that takes. Now, let's think about our kids, with 5p-, and how weak we, along with others, thought they were. If you thought a typically developing child was strong because of the various trials, they have gone through, our kids with 5p- are superheroes!

As we know, 5p- is a spectrum. We have some individuals who may run a 5k someday while others struggle to move at all. We have individuals who can make presentations to crowds and others who are unable to speak. Neither of these individuals is stronger than the other. The individual who is unable to move physically has the power to move someone emotionally. They can inspire. The individual who cannot speak, can provide comfort to another person, or change that person's mood by giving just one hug or high five. Sometimes no words are needed to provide comfort. This is just another form of strength.

Finally, being a parent of a child with special needs can make you feel weak at times. I know that I have had my moments of weakness. Knowing that there are families, who understand what I am going through, families that I can reach out to during my moments of weakness, provides so much comfort. Parents who have a child with special needs are strong although we sometimes have our moments of weakness and again it is through that weakness that we can become stronger. So, thank you to those who have been a strong for me so that I can become stronger during my times of weakness.

Nick Wallace

President, 5P- Society

"You say 'show me the path out of weakness', I say, 'weakness is the path, walk on it daringly and it'll turn into strength'."

- Abhijit Naskar, Martyr Meets World: To Solve The Hard Problem of Inhumanity

Core Strength & Toning

by Sarah Berry, Physical Therapist, Children's Mercy KS



How to help your child or adult strengthen their core

No matter your age or what diagnosis you may or may not have, the core is a key factor in progression of development and function. Impairments in your core strength can affect developmental and age-appropriate skills. Whether a child is presenting with hypotonia (low muscle tone) or hypertonia (high muscle tone), a consistent stretching routine for a child's arms, legs, and trunk mobility are key to allowing a child to reach their full potential. A child can become tight or have limited range of motion with either high or low muscle tone. Adequate range of motion allows a child's muscles to then have the ability to strengthen in that range and progress their skills. I am going to break down some of my favorite core exercises based on the developmental skill that you may be working on with your child.

Tone can often play a role in a child's ability to roll. If a baby has increased tone, rolling back to belly may be easier because

Adequate range of motion allows a child's muscles to then have the ability to strengthen in that range and progress their skills.

they may arch to roll over instead of bringing their arm across their body to assist with the roll. Alternatively, rolling tummy to back may be more difficult because arching does not work that direction. In order to help minimize the effects of increased tone with rolling back to belly, you can help roll your baby's hips forward to prevent them from arching and allow the top arm to reach across their body to complete the roll. This technique also works for babies with decreased tone as it helps position them to activate their core to complete a roll.

Sitting practice can begin as early as 6 weeks old. In fact, babies in the NICU often begin working on sitting with therapist support earlier to begin working on head control. In order to obtain independent sitting, a child must be able to activate their core to hold them in an upright position first. To begin activating the core, a simple activity to work on is pulling the child up to sitting by holding their hands to encourage a chin tuck, think of this as a baby crunch. This activity can also be modified easily, as children will often demonstrate a head lag when pulled up to sitting. Some ways to modify this activity include holding the child closer to their shoulders to complete a pull to sit or completing this activity from an elevated surface instead. As the child gets stronger and more consistent with tucking their chin, the activity can be completed from a more horizontal starting position. You can progress this activity by pulling the child up to sit, hold the child in sitting for a few seconds, and then slowly lower them back down to their back. Often, babies with increased tone will prefer to "fling" themselves backwards while in sitting.

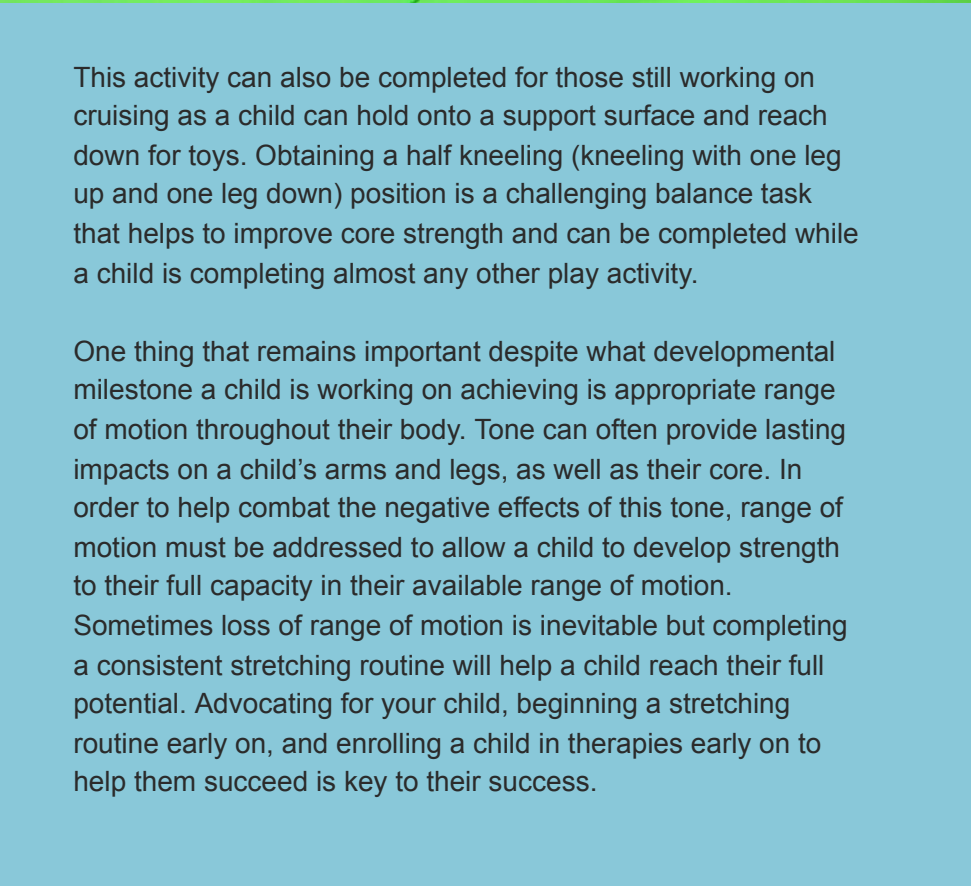
One way to counter this is by working on sitting at the edge of a couch or other surface in which the child's feet cannot hit the ground. In this position, the child cannot use their feet to help fling their body backwards. This helps encourage core activation to maintain sitting.

Side sitting is a great activity as a pre-requisite to playing on knees, getting in and out of sitting, and crawling. This activity also often helps those babies that like to "fling" backwards. Using an inclined toy to get a baby's hands off the ground while achieving a side sitting position with a child's legs brings focus to core strengthening and helps to limit the effects of tone taking over.

Using a wedge or inclined couch cushion to promote a hands and knees position helps a child to activate the core in a functional manner to progress skills.

Encouraging weight bearing through the ankles by rocking a child side to side while sitting on a bolster is a great early weight bearing activity that also engages the core. Your leg works as a great substitute for a bolster. Another activity to encourage the use of the core while working on standing is helping a child transfer from a sitting position up to standing. Start by having your child sit on the edge of your leg or a bench in front of a coffee table or couch. Encourage a child to reach for toys of interest at higher level surface and transfer up to standing. Facilitating a child's "nose over toes" while transferring up to standing will help to minimize the effects of increased tone to use their large back muscles to arch into standing. This technique also helps those with lower tone to activate their core muscles to transfer up to standing.


Walking is a complicated task and can be further complicated by effects of tone or core weakness. Often, ankle bracing helps to minimize effects of increased tone such as locking out knees, as well as effects of decreased tone such as poor stability and positioning of feet in standing. In a child that is walking independently, there are still great activities to help improve core strength and improve tone. Encouraging a child to squat down to the floor to pick up toys encourages full body strengthening and balance that begins in the core.

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Considering the protective power of rage

Originally written by Liz Morris for the Courageous Parents Network

There's no easy entry point for the topic that's been rattling around my mind for weeks now – so bear with me as I dive right in. I want to write about rage. But I'm scared to write about rage, because in doing so, I may cloud in my reader's mind two truths that are center to my soul: 1) My son Colson was a miracle in my life, and I love him eternally. 2) Being Colson's mom was the most fulfilling thing I've ever done, and I miss mothering him every day. Please bear this in mind as I expound on a third truth: 3) I experienced primal rage as Colson's mom that felt otherworldly, and it breaks my heart that he was proximate to that rage. But I'm beginning to rethink that rage as something more than a failing on my part. I'm starting to see it now as a source of strength – of primordial rallying in the face of encroaching death.

I can count on one hand my moments of rage in Colson's four short years living with mitochondrial disease. The time that I punched my cot over and over while he slept in the crib beside me, because I was so wired from parenting a medically fragile newborn that I ironically couldn't sleep – though I was desperate for it. The time, several months later, when I had to leave him crying in that crib to go hurl a toy at the hallway wall because his anti-seizure medication was making him inconsolable. I once kicked a dresser with Colson bare in my arms, while shouting expletives at the God of my youth for making it seemingly impossible for my child to keep food down. (I believe my words to the heavens were, "you can f*** right off.") And then there was a time when Colson was a toddler that I, with one hand, patted his back to clear his airway after he choked on his own saliva in the middle of the night, while throwing a pack of wipes at

continued on next page.

Resources for grief, stress & anger

Exercise. This may seem like a no-brainer but so many of us don't take time out for mental health or just "me" time. Exercise for caregivers can be a stress reliever and exercise for children/adults with 5P can be a way to get out extra energy that can sometimes lead to episodes of acting out. Exercise as a family or group is also a great way to bond. Hikes, walking around a park, playing in the sprinkler are all great ideas!

Therapy. This one gets talked about a lot but can be expensive and not all of us have time or resources to get out and see a therapist. Trying online resources such as Betterhelp, Talkspace, or Regain.us may be good alternatives and are certainly cheaper.

Aromatherapy or other relaxing activities. You'd be surprised how much a short bath, a face mask, or shutting yourself in a room and listening to your favorite music can calm the nerves. We all have bad days and moments of stress or anger - it's about finding the little things that help you unwind.

I'd forgotten about the best type of mother: a protective mother.

at the headboard with my other hand and howling with wrath.

The source of shame for me, in all of these instances, is the physicality of this rage. This throwing of things; this shouting; this volcanic explosiveness that runs so contrary to my relentless pursuit of calm, quiet, gentle and cozy for Colson. I've also been hounded by Colson's proximity in these instances – it feels important to say that my ferocity was never, ever, remotely directed at Colson – in word or action. **But what kind of mother lets loose her fury with her child close by? A tired mother, yes. A scared mother, absolutely. A lonely mother, likely. But until recently, I'd forgotten about the best type of mother: a protective mother.**

The best way to protect any child, and especially a medically complex child, is to have protective measures in place. Make sure to have all meds filled at all times. Stay on top of scheduling doctor's appointments and therapy visits. Keep your personal commitments light to maintain energy for caregiving. The best defense is a good offense, etc. This hypervigilance is critical, and often the thing that leads to caregiver burnout.

Rage is different from burnout. Rage is a defensive stance in the face of an immediate threat. Mothers of all kinds will instinctively rage like hell to defend their children.

It's helpful to understand what is happening in our own bodies when the threat of our children's disease overwhelms us.

Mama bears, lionesses, elephants. Cats, dogs, ducks. Predators are the primary threat in the animal kingdom. **A rare disease is its own kind of perverse predator. It shadows our children relentlessly, yet the only shape it takes is our children's suffering.** We, as caregivers, can turn ourselves inside out to protect our children, but the defenses don't always hold.

It's helpful to understand what is happening in our own bodies when the threat of our children's disease overwhelms us. This framing is from *The Body Keeps the Score: Brain, Mind and Body in the Healing of Trauma* by Bessel Van Der Kolk, M.D.

*"The autonomic nervous system regulates three fundamental physiological states. The level of safety determines which one of these is activated at any particular time. Whenever we feel threatened, we instinctively turn to the first level, **social engagement**. We call out for help, support and comfort from the people around us. But if no one comes to our aid, or we're in immediate danger, the organism resorts to a more primitive way to survive: **fight or flight**. We fight off our attacker, or we run to a safe place. However, if this fails – we can't get away, we're held down or trapped – the organism tries to preserve itself by shutting down and expending as little energy as possible. We are then in a state of freeze or collapse," (p. 82).*

Upon reading these words recently, I realized that my moments of rage as Colson's mom were actually my body's attempt to activate *fight or flight* mode. In each of the instances, I was alone with Colson, without another person nearby to help me work through the immediate challenge. I was battling my own exhaustion with the need to keep

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5P- Buzz Call for content

Calling all Society members and friends! Do you have an interesting article you'd like to share or future newsletter content? Or did you see interesting content online that may benefit others in the 5P community? If so, please contact Mel Sabin at mel5p@outlook.com.

functioning at an intense frequency to keep him safe. **Shutting down is not an option when your caregiving is the only thing keeping your child's decline or death at bay.** Van Der Kolk indeed notes that, *"...for many people, panic and rage are preferable to the opposite: shutting down and becoming dead to the world. Activating fight/flight at least makes them feel energized,"* (p. 85).

I so desperately wish that I had understood my rare rage as energizing and protective when Colson was alive, as I may have forgiven myself for it sooner. I'm also oddly grateful, here in my mourning, for my emerging understanding of my own body's response to the intensity of caring for him.

Two months before Colson died, I wrote in my journal: *"I feel increasingly frustrated, tired, isolated, unmotivated, more like a nurse than a mom and, in my worst moments, resentful of that role. Not resentful to Coley (never, ever, ever,) – just – tired of the whole situation."* This feeling was so present for me when we decided to cease medical intervention for Colson and let him pass in the midst of an acute medical crisis. I realize now that I myself was moving towards a state of *freeze or collapse* in his final months. I have no idea if or how my other built-in responses for *social engagement* or *fight or flight* might have come into play to mitigate this had Colson lived. But as I've learned, rare-disease parents tap into some of the most visceral, instinctive, and protective mechanisms of any creature on this earth. In our world, even rage can look a lot like love.



**Join us for the 36th annual 5p-
Society conference and get a
“Taste of Chicago.”**

Conference 2023 will be held at the beautiful Eaglewood Resort and Spa, where the host families will bring the best of Chicago to you.

Chicago-style hot dogs, Italian beef, deep dish pizza, Garrett's Popcorn and cool off with a delicious Italian ice.

Book your room now: [reservation link](#).





Iryna's Ballet

by Inga Dubinina, 5P- Parent

Iryna (or “Ira” as she is called in the family) was born with the cri du chat syndrome. The fact that “something is wrong” was not noticed until the 38th week. At that moment doctors noticed an extremely small size/weight of a child and started to insist on C-section. Completely intuitively I refused. This was the first lucky turn in Iryna’s (then-future) life.

Iryna was born under 2kg (probably around 4lb). She was cute and ... silent. Only later I understood that her lungs are too small and her diaphragm is too stiff for a normal baby cry. Iryna was my third child, which was another lucky situation — I was breast-feeding her and trying to cope with the “disaster” that happened to me and to our family. My family was around, supportive but scared. We did not know what this was and what to do.

To make a long story short — within the first year I learned that such a serious diagnosis (3 deletion points in the 5th chromosome plus a duplicate “shoulder” of the 7th chromosome) means that Iryna “will not walk”, “will not talk” and “will hardly recognize her parents”. This was another lucky turn — the prognosis was so bad that I refused to accept it.

What followed was 10 years of hyper-intensive work. The whole family worked around the clock stimulating not know this, as we do not know the future of our other children. And this is the main beauty of our life — diverse options instead of a grim certainty.

Iryna’s physical and mental abilities (whatever weak they were). Plus an extremely strict diet (intolerance to milk, sugar, and gluten). She made her first steps at



the age of 3, started to read in Russian at 5 and in English at 6. Said her first words at 7, but before that she could use an iPad for writing. At the age of 10 we moved to Denmark. It took Iryna 2 years to learn to read, write and speak Danish.

Iryna can swim and ski. She has always been fond of dancing and we found a small ballet studio that accepted her as a student. She works individually and also dances with older, more experienced girls. When I let my daughter’s hand go and she walked to the stage together with other ballet girls — my heart stopped beating. 13 years ago, when I refused to believe her grim perspectives — I secretly hoped for a moment like that.

We often joke in the family about Iryna’s future and who she can become. A first 5p- ballet dancer? A CdC fashion model? Beloved daughter and sister? We do not know this, as we do not know the future of our other children. And this is the main beauty of our life — diverse options instead of a grim certainty.



2022 Hall of Fame Winners

Every year the 5P- Society selects Hall of Fame winners for individuals and families who have gone above and beyond. This year's winners are:

Superhero of the Year



Justin Valenti

Parents of the Year



Leah Moore



Mark & Eileen Sherman

Grandparents of the Year



Mike & Ginny McBride

Sibling of the Year



Kaylee Pineda

A Struggle & a Blessing

by Don Monteirh, 5P- Parent

Andy entered this world in a dramatic way, with a very fast delivery. The nurse whisked him away to check him, having picked up on the unusual sound of his cry. But we, along with the nurses and doctor, did not attach any special significance to this as he checked out as a healthy baby. It wasn't until much later, when his development was noticeably delayed, that we started investigating.

The diagnosis was crushing, particularly for his loving mother. I remember well her tears. What would his future hold? What would our future hold? The doctors painted a grim picture. After his diagnosis, we went through a grieving process. We grieved the future that would not be, the life experiences Andy would not have, and that we would not have – sports, graduations, marriage, grandchildren. Time validated some of the doctors' early predictions, but not all of them. Andy has proven them wrong in many ways.

Yet ongoing life experiences with CDC taught us that there would be limitations on what Andy would be able to do. He will always be dependent. He has behaviors that can be frustrating and exasperating at times. And whenever we are in public, or whenever we have people at our house, Andy has quite a presence. He loves talking with people, and he has no concept of personal space, nor of social graces like not interrupting conversations. If it comes to his mind, it comes out his mouth, and not very quietly. As a side note, there are no secrets, either. Everything that happens in our house will inevitably be mentioned to other people. Andy is 34 years old now. Despite the challenges, there have been a lot of blessings that would not have come without our experience with CDC.

I think we could all learn from his attitude about life. He has friends everywhere we go, friends who have been changed by their experiences with Andy.

Andy is for the most part a very happy man. Everyone is his friend. Life is very simple, and he has no worries. I think we could all learn from his attitude about life. He has friends everywhere we go, friends who have been changed by their experiences with Andy. He has a very vivid imagination, and he envisions himself as Indiana Jones, or a US Marine, or Darth Vader, or Luke Skywalker, and when those movies are playing he will point himself out and say, "That's me." He has a pet tiger named Shirkan that lives in his room, and he feeds Shirkan pork chops and lets him outside to chase chickens in the back yard. There is never a lack of stories to tell.

Andy was our second child. After his diagnosis, the question was, should we have more children? This is a highly personal decision; we decided we would. We had three more children, all of whom have been great blessings to us. They have all grown up, graduated, gotten married, and some have had our grandchildren. We are so, so glad we decided to have more children. Andy's four siblings have grown up learning from CDC as well. They are different people as a result – more compassionate, more understanding. They are better people than they would otherwise have been.

So yes, there are reasons to grieve the unfulfilled dreams, the challenges that have been and will be faced. They can be daunting at times, or for some of us all of the time. But there are also reasons for gratitude, even if those reasons are not yet apparent. As is often the case in this life, significant challenges – and grief – pay more than one visit, in various forms. Eleven years ago Andy's mother, the wife of my youth, my reason for living, died. It took me a long time to accept the fact that I had not also died, that I could actually survive her death. Although I have not completely healed from that experience, and probably never will, I can see that there are still blessings in this life, there are still reasons for gratitude. And I, and we as a family, have been blessed immeasurably. I have learned a lot through these experiences.

These were and are very hard lessons, and I was not grateful for many of them while I was in the depth of them. But with the passage of time I can see the good. I have married again. I stumbled upon her by "chance," someone I knew when we were teenagers, and discovered that she had also been widowed. It had been much longer for her, and she was able to help me process the grief, and figure life out again. She understood my experiences since she had already been walking a similar path.

I think that is an immense blessing to people in the 5P-group – you can interact with people who have experienced and are experiencing similar challenges, and truly understand. The new marriage has brought blessings as well as new challenges. It is no surprise that Andy has played a role. He and my now wife have developed a very good relationship. Andy's influence has extended to four step-siblings, who have also learned from experiences with Andy. It has been fun to watch Andy develop relationships with our grandchildren on both sides of the family (currently 15). They love Andy. They like to play with him. And while this can be too much at times, and everyone needs breathing room, I can't help but think that the next generation is being changed in a positive way because of their experience with CDC.

I have come to view this experience with CDC as described in the story, "Welcome To Holland," by Emily Perl Kingsley. You planned a vacation to Italy, and had bought guide books and made lists of all the things you wanted to see and do. When you get off the plane, you are dismayed to find that you are not in Italy – you had landed in Holland instead. You are not happy. You would not be able to do what you had so anticipated. You need to buy new guide books and make new plans. In time you discover that Holland is not a terrible place; it is, in fact, a nice place, just different, with its own beauty and uniqueness.

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"We have never
lived anywhere
except in heaven."

While you may always mourn the loss of not going to Italy, you do actually enjoy a different experience in Holland.

A quote from C.S. Lewis has become very meaningful to me, and relates to the CDC experience, and other life-altering experiences we all face. I believe it speaks truth:

"Ye cannot in your present state understand eternity....But ye can get some likeness of it if ye can say that both good and evil, when they are full grown, become retrospective....All [this] earthly past will have been Heaven to those who are saved....That is what mortals misunderstand. They say of some temporal suffering, "No future bliss can make up for it," not knowing that Heaven, once attained, will work backwards and turn even that agony into a glory....The good man's past begins to change so that his forgiven sins and remembered sorrows take on the quality of Heaven....And that is why, at the end of all things, when the sun rises here...the Blessed will say "We have never lived anywhere except in heaven."...Ah, the Saved...what happens to them is best described as the opposite of a mirage. What seemed, when they entered it, to be the vale of misery turns out, when they look back, to have been a well; and where present experience saw only salt deserts, memory truthfully records that the pools were full of water."

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The Remarkable Aaron Watt

by Ruthie Liberman, 5P- Parent

After our first son, Aaron, was born in 1993 and diagnosed with Cri Du Chat syndrome at 5 months, my husband Danny and I had the opportunity to meet with an extraordinary developmental Pediatrician, Dr. Alan Crocker. Dr. Crocker urged us not to compare Aaron to any other child, but to know that Aaron would "the best Aaron Neil Watt" there ever was. He reminded us that while Aaron's chromosomes contained one small glitch, all the others were just fine and contained so much more than his deficits ever would. We took those wise words to heart. We experienced many days that were harder than we could ever imagine, but Aaron never failed to be the best Aaron Neil Watt, ever.

Aaron lived at home with his two younger brothers until he was 19 years old. Danny and I worked outside the home. We aimed to live as much of a "normal" family life as possible. For many years, we hosted live-in au pairs (see [AuPair In America](#)) to provide childcare for all three boys. With 40 hours per week of flexible, affordable childcare, we were able to spend quality time with each of our kids and resolve the huge challenge of finding after school and vacation care for Aaron. Through the years, Aaron learned many words in German and Portuguese and developed a love for different cultures, languages and flags from these au pairs who provided him with so much love. We were stunned that he could transfer his trust to a new caregiver every year when the old au pair departed and the new one arrived.

Aaron attended Hebrew school, first at our synagogue and then through a special needs Jewish education program called [Gateways Jewish Special Education](#) and celebrated his bar mitzvah (a Jewish coming of age celebration) when he was 13. We took him to synagogue and community events throughout his life and tailored our family vacations on the coast of Maine to meet both his and his brothers' different needs. Bringing the au pair on vacation with us helped make this possible.

Continued on the next page.



At 19, Aaron moved to a residential school in our area. He lived in a group home with other students and we saw him regularly. He moved out just about the time that his younger brother (a junior in high school) was starting to visit colleges. Aaron was really fascinated with his brother's college search process. We told Aaron that since he was the oldest, it made sense for him to move out first. He was excited about the prospect and helped pick out posters and bedding for his new room. On the moving day, we walked into his new room in the group home. He was hyped up and excited. And then, the reality hit him. He looked around and saw stuffed animals and items from home and burst out into tears. "No new room! No new home! I want to go home."

I'm not going to kid you. It was hard for about a year. He was happy in his residential placement but as soon as he saw us, he wanted to move back home. We started having his younger brother drive him back to the group home because he didn't cry when Jonah dropped him off. It got much easier as time went on.

He's been out of the house for nine years now. Aaron is truly remarkable. We cannot believe how much he has grown and what he can now do such as shower himself, put his shoes on, safely put food in a hot oven, serve food, find anything he needs in the house, carry groceries, and lift weights (see video). Some other highlights include "lecturing" about 5Pminus at Harvard University with Taylor Towers and her mom and dad and participating in Dr. Andres Spaan research at Rockefeller University in New York City.

Aaron volunteers regularly at a local food pantry with his dad and has learned to break down boxes for recycling, sort food, and keep everyone smiling and entertained while they are working! He also rides a tandem bike with his Dad going for 20+ miles together regularly!

Danny often needs to rest after the ride because Aaron yaks non-stop. "DAD, DAD, Dad what time are the Red Sox playing??" They ride together every year in the Best Buddies Challenge and recently added a second charity bike ride raising funds for local food pantries.

Aaron's moving out was also a life changer for rest of the family. We were much more available to focus on Jonah during his senior year of high school and his little brother, Noam, enjoyed a more typical high school experience without the stress of Aaron being at home. I started taking much better care of myself and re-learned the joy and luxury of sleeping through the night.

We see Aaron weekly and he participates in all the family events that work well for him. Over time we realized that his behavior challenges were a sign that something was not working right for him. We try to engage him in family events and activities that are catered to his need (not too late, a place where he can move around and be gleeful) and we no longer include him in everything, at this expense of his and our well-being. It was hard to leave him behind when we travelled out of the country or went to see a show, but we knew he was happier and so were we.

We are grateful to have our amazing 5P minus family to share in this remarkable journey. As the "Welcome to Holland" story expresses so well, it's not what we dreamed about or expected, but it's an equally thrilling and beautiful adventure.

The 5P- Buzz

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To submit content, please reach out to Mel Sabin at mel5p@gmail.com

Recap of 2022 North Carolina conference, continued

needed to take over some areas, especially Taimie Hoffman and her daughter Kaila for quickly learning the childcare check in system and President Nick Wallace for needed to quickly take over for me on the last day of the conference after having tested positive for COVID. Some of the highlights:

- Speakers & Topics – so very grateful for the speakers who donated their time to come out and speak to our members.
- Family Fun Event – the members went to The Discovery Center for fun and adventures
- Sibling Event – the siblings went to an indoor water park and then headed over to a local painting place.
- Family Dance – so much fun watching everyone dance.

Our speakers were a mix of parents of a child with 5p- Syndrome, local friends of the host families and one of our individuals living with 5p-.

Parents:

- Stephen Furnari, Esq. presented on Guardianship and 5p- Syndrome.
- Dr. Dennis Campbell gave us two presentations, 5p- 101 and Transition Planning, and
- Nakita Nelson, attending her first conference, spoke to us about Caregiver Burnout.
- Our longtime volunteer and friend, Dr. AmySue Reilly presented on Effective Behavior Modification.

Local speakers:

- Gwen Bartley presented on Navigating and Thriving the Journey of having a child with a disability.
- Ryan Platt, spoke about Planning for Two Lifetimes, and
- Lynne Keene, Dana Salerno, and Judy Mott presented on Accommodations in the Classroom.

Justin Valenti gave us a presentation on his life and living with 5p- Syndrome.

In honor of their over 20 years volunteer service to the 5p- Society, Dennis & Shari Campbell were awarded with a life-time award.

Looking forward to 2023 in Chicago. Hope you can join us. You can find some information on our website. Registration materials will be available in March of 2023.



REGIONAL FAMILY GET-TOGETHER

NOVEMBER 5, 2022, 11AM-5PM
EDWARDSVILLE TOWNSHIP PARK, AIRPLANE PARK
6368 CENTER GROVE RD, EDWARDSVILLE, IL 62025



Food Fun Fellowship

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