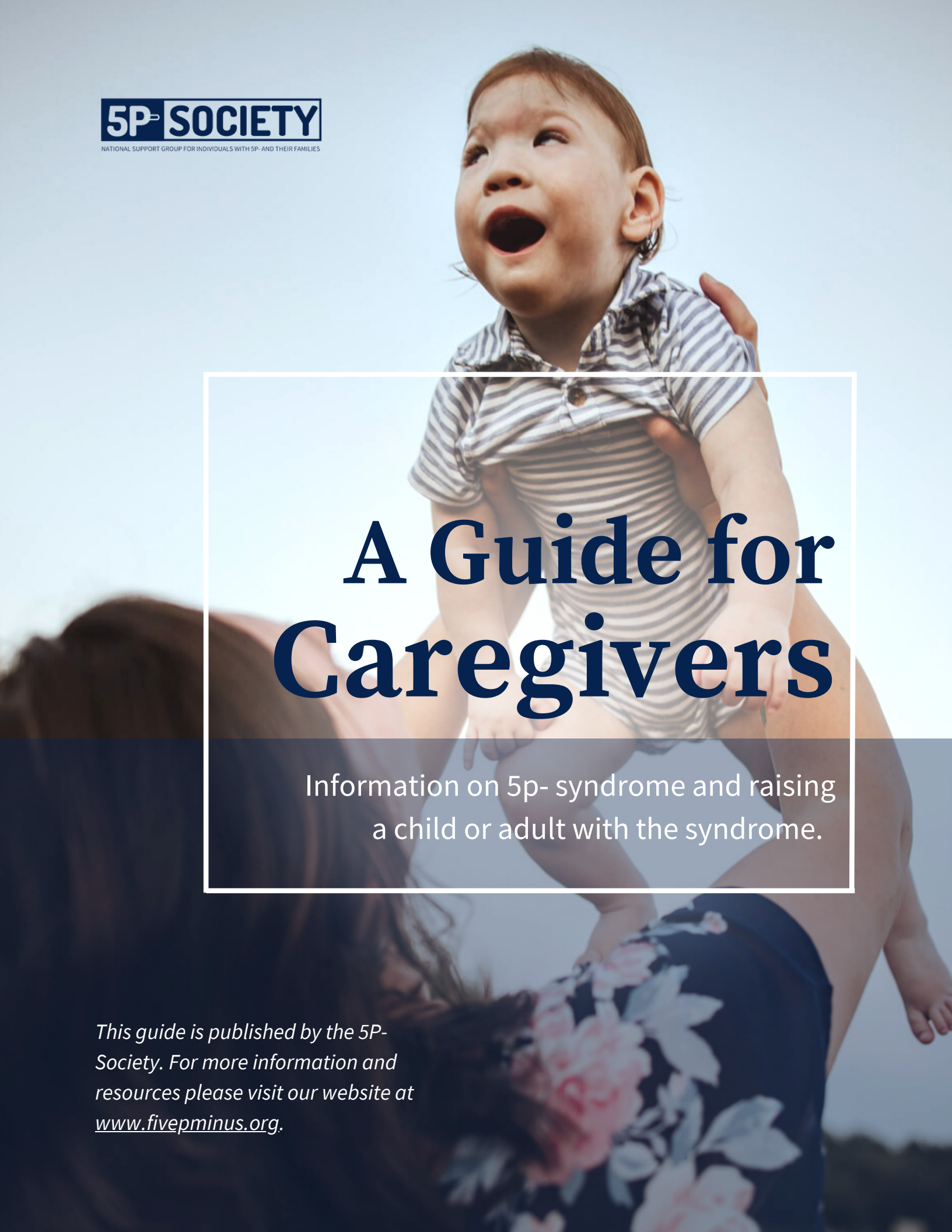

5P- SOCIETY

NATIONAL SUPPORT GROUP FOR INDIVIDUALS WITH 5P- AND THEIR FAMILIES

A Guide for Caregivers

Information on 5p- syndrome and raising a child or adult with the syndrome.

This guide is published by the 5P-Society. For more information and resources please visit our website at www.fivepminus.org.

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Introduction

You just received your child's diagnosis. Maybe you just became a caregiver to a child or adult with 5p- syndrome. Or you are a friend trying to better understand how this is affecting someone you love. This stage can be difficult—learning the medical complexities of the syndrome, overcoming challenges, helping your child to reach their maximum potential. That's why we put together this guide—to help alleviate some of that burden and assist you on this journey.

Message from the Executive Director

Caregiving for a child with intellectual and physical disabilities is not an easy task. Caregiving for a child with a genetic disorder that you've never heard of, and is so rare that your doctor has never seen a child with it, can leave you overwhelmed and seeking out answers to questions that are hard to find. That is why resources like this are so important to our community and membership.

This guide is dedicated to Kent Nicholls and the original founders of the 5P- Society. I also wish to thank the over 100 families who participated in the many questionnaires that provided the basis of each of the chapters in this guide.

Finally, I need to thank my daughter Katie, who provided me with the true meaning of unconditional love. Without her I would not have met, counseled, or assisted hundreds of families around the world. This guide is a living document. As the world around us changes, so does caring for an individual with 5p-, with new therapies, educational opportunities, research and medical advances.

Warm regards,

Laura Castillo

Laura Castillo
Executive Director
5P- Society

What is 5p- syndrome?

As you read through this guide, keep in mind that no two children born with 5p– Syndrome are exactly alike. We asked 100 families to complete questionnaires and conducted interviews to compile the findings in this guide. What we observed is that many of the children shared similar challenges and characteristics.

The Syndrome

Simply put, 5p– syndrome is a genetic condition that is caused by a deletion of the short arm of chromosome five (5). The syndrome was discovered in 1963 by Dr. Jerome Lejeune, a French doctor who also identified Down syndrome among other genetic conditions. Dr. Lejeune observed a high-pitched cry in three infants and coined the original name of the syndrome, Cri du Chat, a French phrase meaning “cry of the cat.”

Each of us is born with two sets of chromosomes, one from our mother and the other from our father, and they are what make us individually unique. Individuals with the syndrome have a deletion on the “p” arm of the fifth chromosome, on which there are several hundred genes providing the instructions for making proteins in our bodies.

Research revealed that the area on chromosome 5 responsible for the high-pitched vocal characteristic is found at the

Continued on next page.

Facts

- Discovered in 1963
- Affects one in 50-60,000 live births
- 90% of cases are "de novo" or spontaneous—not passed down

The syndrome

- Caused by a deletion on the "p" arm of the 5th chromosome
- Often initially diagnosed because of infant's high-pitched cry
- Spectrum disorder
- Many children have intellectual disability delays
- Affects muscle tone in almost all children

5p15.3 band. 5p- syndrome is diagnosed when the child has a deletion that includes the 5p15.2 band. This band also includes the CNNTD gene know to be responsible for intellectual delays.

Note: A child can have a 5p– deletion and not have 5p- syndrome if the deletion does not include the 5p15.2 band (i.e. 5p15.31). Most 5p– deletions are terminal, which means that the deletion starts somewhere within the 5p region to the terminal end. The end point of the 5p chromosome is 5p15.33.

In 90% of the cases, there is no known reason for this to happen and is called a "de novo" or spontaneous occurrence. There is no evidence to suggest that these spontaneous deletions are caused by any specific reason or lifestyle—they are just that...spontaneous.

In some rare instances, the syndrome is passed down from parents to children. In approximately 10% of the total cases, one of the parents has a balanced translocation. This means that the parent had the 5p– deletion, but the deleted material was attached to another chromosome.

Upon conception, the 5p- portion of that parent's chromosome and the deleted material did not continue together and therefore the child was born with an unbalanced translocation. In most cases, parents with a balanced translocation are unaware that they have it until they have a child born with 5p– syndrome and undergo testing. If a parent has a balanced translocation, they have a one in four chance of having another child with the syndrome.

Other types of deletions, which are more rare, include the following:

- **Mosaicism**—is when the deletion occurs later in the cell division process and therefore not all cells in the body are affected by the deletion.
- **Ring Deletion**—is when both arms of the deleted chromosome reunite.
- **Interstitial Deletion**—is a 5p– deletion but occurs within the 5p region and does not include the terminal end of the chromosome.

Getting a Diagnosis

5p– syndrome can only be diagnosed by either a blood test or saliva swab. It is not discovered prenatally through routine testing such as a CVS or ultrasound. It can be diagnosed prenatally by an amniocentesis or through new specific testing done by blood tests. Of those individuals who participated in the questionnaires, only 2% of the parents knew about the diagnosis prior to giving birth.

There are several tests that can be ordered by your doctor to correctly diagnose the syndrome.

- **Karyotype**—A simple blood test not often used today. It was used extensively from the 1960s to early 2000s to diagnose genetic disorders.
- **FISH test**—Looks at chromosomes through a high-powered microscope and specific dyes. Both the karyotype and the FISH provide a diagnosis to a specific band on the "p" arm.

Currently, all testing is done by what is called a microarray. The microarray is able to not only detect the deleted band chromosome but can detect the deletion down to a specific location on a band.

Of the 100 families we surveyed for this guide, the average age for their child's diagnosis was three months old. Diagnosing was as early as right after birth to 10 years of age. Within the society's membership, we have families who received diagnoses prenatally as well as when their child was in their 40s or 50s.

The syndrome is relatively new, and there may be quite a few individuals who have never received a diagnosis; therefore, it is important that families get genetic counseling after giving birth to a child with 5p- syndrome to identify any translocations within the parents' own genome. Additionally, parents can then make informed decisions about future family plans.

Is There a Cure for 5P-?

Currently there is no known cure for 5p- syndrome. Because of the dynamics of the "p" arm of the chromosome and the different genetic make up of each individual, it would be almost impossible to re-create the missing piece.

Research is continually being done to see if amino acids or other nutrients can be provided to a child with the syndrome to assist with improving the prognosis and cognitive development.

Characteristics of the Syndrome

90% of the questionnaire respondents reported that their child had the high-pitched cry, small head circumference, low muscle tone, low birth-weight (average 5lbs 10oz) and feeding difficulties; 70% of the children had low set ears; 25% of the children had skin tags; and 10% were reported to have seizures.

Others included:

- Microcephaly
- Micrognathia
- Hypotonia
- Wide-set eyes
- Epicanthal folds
- Flat nasal bridge
- Skin tags
- Low set ears
- Cleft palate
- Laryngeal cleft
- VSD or ASD
- Low birth weight
- Dislocated hip
- GERD or reflux issues
- Constipation issues

Rarer characteristics:

- Simian crease on the palm of the hand
- Club foot
- Knuckle displacement on hands
- Stridor when breathing

Note: This is not an extensive list of characteristics of the syndrome. We compiled common traits for educational purposes.

Medical Considerations

Individuals with 5p- syndrome are medically complex and typically experience intellectual and developmental delays. 60% of our survey participants reported that their children required surgeries to address medical needs before the age of three.

In this section we have addressed possible medical conditions and challenges that you may face as a caregiver to someone with 5p- syndrome. We cannot address every possible issue; however, we hope this assists and helps to alleviate some of the burden of advocating for your loved one.

Height & Weight

A common issue among children and adults with 5p- syndrome is that they do not conform to the World Health Organization's (WHO) standard growth charts. A child with 5p- syndrome may be at 5% or less on the WHO growth chart.

A growth chart specifically for 5p- syndrome has been developed for the community. Providing this to the child's medical team is extremely important so that they are aware of the specifics of this syndrome and do not pressure the family into making decisions not appropriate for the child.

To access the chart, click here.

Overview

- Those with 5p- syndrome can be medically complex
- Your child or adult's primary care doctor and medical team should collaborate to ensure best care

Takeaways

- Many children have issues with weight gain
- Children will experience low muscle tone, which affects many different areas of the body
- Younger children may get sick more often but improve as they get older
- Other medical conditions are specific to child

Head, mouth, neck & throat

Head

Microcephaly, or smaller than normal head circumference, is a common characteristic of the syndrome. The child's pediatrician or medical team should continue to monitor this to ensure it is growing commensurate with the rest of the body's growth. Typically they will monitor and show this to parents on a "growth curve."

Eyes

Strabismus, low vision, visual corrective devices (glasses) for both nearsighted and farsighted, blindness

Children with 5p– syndrome have low muscle tone. This may include the muscles of the eyes. Some doctors will patch one eye if it is found to be weaker than the other eye. Many children with 5p– syndrome do wear glasses, with some starting as young as 1 year of age.

Some parents reported that the flexible frames and wrap around the ear arms work the best for young children. Very few children with the syndrome have been diagnosed with blindness.

Ears, Nose, Throat (ENT)

Ear infections, eustachian tubes, congestion, sinusitis, laryngomalacia (stridor), laryngeal cleft, adenoidectomy, tracheostomy, paralyzed vocal chords, swallowing issues, constantly sick

All children get sick; many families report that their child with 5P- Syndrome gets sick more often than a neurotypical child.

Due to the smaller size of the head, excess fluid may tend to build up and be a cause of ear infections. Oftentimes, ear tubes are placed to help fluid drain properly and reduce infections. As the child grows, the tubes are replaced (for larger tubes) until such time that the child no longer needs the assistance of the tubes. Associated complications of ear infections are sinus infections and congestion. To assist with these issues:

- Use a dehumidifier
- Ask medical team about over-the-counter (OTC) decongestants
- Ask about percussion drums to help break up mucus, especially for younger children who cannot clear airways on their own

Laryngomalacia is also common in those with the syndrome. Laryngomalacia is a congenital softening of the tissues of the larynx (voice box) above the vocal cords. The laryngeal structure is malformed and floppy, causing the tissues to fall over the airway opening and partially block it. Laryngeal cleft can also occur and can be repaired. This is the most common reason for noisy breathing, otherwise known as stridor. Low muscle tone in this area can cause other issues, such as:

- Obstructive apnea (OSA)
- Swallowing and feeding issues
- Paralyzed vocal chords
- Removal of tonsils and adenoids
- Issues with breathing

Breathing issues

In some instances, a tracheotomy may be required for affected individuals who have trouble breathing.

This can be a very scary and overwhelming experience, often requiring long hospital stays and recovery. However, many families share that their child shows great progression once they are getting optimal oxygen needs. We have a community of families who have gone through this experience and are more than happy to speak to families who are making this major decision.

Many hospitals also offer special support to families that have a child or adult with a tracheotomy. Many of those with a "trach" qualify for Medicaid and may receive 24/7 nursing care to help alleviate the pressure on the family for round-the-clock care.

Mouth

Cleft lip or cleft palate, small jaw, crowding of teeth, teeth misalignment, overbite, grinding of teeth, brushing issues, dental cleanings, dental surgeries, braces

Many of the children with 5P- Syndrome are born with micrognathia, or an undersized chin and/or jaw. As with issues associated with microcephaly, this can have effects on breathing, obstruction in the airways, feeding, etc. Often, the child's chin will grow as they get older, alleviating some of the issues. In other instances, the ENT team may discuss a procedure called "jaw distraction," which will surgically enhance the jaw. Not all individuals with 5p- syndrome will be good candidates for this procedure.

Those with 5p- syndrome may be born with a "high palate" in the mouth. This high arch may present issues with suckling and other functions in the mouth; however, they are not typically addressed until the child is older, if at all.

More common is overcrowding of the teeth in adults with 5p- syndrome due to the shape and size of the mouth. Braces or other orthodontics may be used to fix these issues.

Different versions of clefts often present in individuals with 5p- syndrome—not all are visible or need to be treated. If your child is born with a more serious cleft palate (such as cleft palate or laryngeal cleft), your medical team will discuss options with you.

Dental hygiene

Due to developmental delays, many children with 5p- syndrome may have issues seeing a dentist, as they do not understand the procedures. For regular check-ups and cleaning, a standard children's dentist may be suitable. For cavities, tooth extraction, or other more involved procedures, the child may need to be referred to a pediatric dentist, as pediatric dentists often have practices associated with hospitals. The individual may need to be sedated for major dental procedures.

There are methods to acclimate your child or adult to dental procedures and make them more comfortable seeing the dentist, such as oral stimulation, and other sensory inputs.

Other considerations

Many families report that their child likes to place their hands or items into their mouth. Excessive drooling may also be an issue. For extreme cases, surgical corrections are available.

Heart & lungs

Heart

VSD, ASD, PDA, heart murmur, tetralogy of fallot

The above listed conditions (VSD, ASD and PDA) might be found in a newborn with 5p– syndrome. Very few of the children required surgery. In most cases the condition healed itself with time. Pediatricians or cardiovascular specialists will make sure that they are constantly monitoring the heart.

Lungs

Primary Ciliary Dyskinesia (PCD); chronic pneumonia, bronchitis, asthma

In 2014, a discovery was made that some individuals with 5p– syndrome were co-diagnosed with PCD. PCD is found on the same band that Cri du Chat syndrome is located: 5p15.2 (DNAH5). Chronic lung infections and sinus infections contributed to the diagnosis.

The only way to truly diagnosis this is to have a sampling of the ciliary in the lungs. PCD will not go away and is a lifelong and chronic disorder. It is also very disabling and can cause a shortening of life expectancy. If your child has constant lung infections, including pneumonia and sinusitis, it would be the recommendation of the 5p– Society to question your doctor about a possible link with PCD. Likewise, many children with 5p– Syndrome also have severe asthma and require daily inhaler treatment or nebulizer treatments, especially when sick with a lung infection.

Gastroenterology

Stomach, Digestion, etc.

Reflux, gagging, vomiting, constipation, hernia, colic, j-tube, g-tube, ng-tube

Just about every child with 5p– syndrome has some sort of gastrointestinal problem. Many of these issues can be attributed to neurological issues, as well as those associated with hypotonia or dystonia (remember the esophagus, stomach and intestines all have muscles within them).

Most common, and occurring in approximately 75% of the children, is constipation, both in children and adults with the syndrome. Parents have tried just about every over-the-counter medication, holistic cure, therapy treatment (for example massage therapy) or prescription medication to assist with the movement of the bowels. It is very common, although not desirable, for an individual with the syndrome to have a bowel movement every three days. You will eventually learn the habits of your child. Of course, we don't want your child to be in pain or for the constipation to cause other medical issues, so it is always wise to tell your pediatrician about the issue. Motility studies can be done to observe the emptying of the stomach and intestines and will tell your medical team what the next step is.

Another major issue is reflux or GERD. For most families this means vomiting and/or gagging. Note that sometimes gagging is a sensory response and may not be associated with GERD. Reflux is common with children who have the syndrome and can be dangerous.

Swallow studies should be done early on to see if the child is aspirating fluids (breast milk, formula, etc.). A child may be “silently” aspirating, meaning they are not showing signs of fluid getting into their lungs. This can lead to pneumonia and be very dangerous. Aspiration can be tied to physical obstructions making it difficult to swallow, as well as developmental issues that may resolve over time.

In the event that feedings are not tolerated, your medical team may suggest a type of feeding tube. This can include a G-Tube, NG-tube, J-tube, or G/J-Tube (these are the most common, but there are other types of tubes as well). We have a large community of members whose children have had to have a feeding tube placed. They can be daunting at first,but rest assured, many of our families see them as beneficial once they get into a routine. Many Facebook groups exist specifically for tube fed children and adults.

Muscle tone

Hypotonia, Hypertonia, Dystonia

Most of the children have low muscle tone; however, they can experience a mix of high (hypertonia) and low (hypotonia). Low muscle tone includes both the large voluntary muscles in the legs, buttocks, abdomen, neck and arms, but also includes the involuntary muscles of the tongue, esophagus, vocal cords, stomach, intestines, lungs and heart.

Don't be discouraged! Physical therapy and exercise can help with building tone and improving overall function!

Hands & feet

Hands

Small, simian crease, knuckle misalignment, weak, cold, blue

Children with the syndrome tend to have poor circulation in the hands and feet, and you will notice your child’s hands colder then usual and maybe turning blue at times. You will also notice that they have a difficult time picking up items with their pincher grasp and will instead sweep the item with their hand to pick it up. Make sure when you talk with the occupational therapist that they work with you on improving their grasp. Many children with the syndrome also have a difficult time with writing skills. They may not like to color or hold a crayon or pencil. Repetition, encouragement and trying different sized items can assist with this. Do not become too discouraged by the lack of ability to use their hands correctly; this is very common, and your child will figure out what will be his or her best way to do things. A lot of children do learn to fasten a button and a snap, zip up a zipper and tie their shoes.

Feet

Small, pronation, flat feet, club feet, weak, cold, blue

Children with the syndrome will also have quite a few issues with their feet. Pronation tends to be one of the main issues. Many of our children will need to wear some form of orthotics to assist with keeping the ankles strong and maintaining good posture for standing and walking. Few children with the syndrome are born with club feet and/or flat feet.

Therapeutic Considerations

Early intervention of therapies is critical for children with 5p- syndrome. The good news is that many states offer early intervention programs. Note that each state has different programs, services, and processes to access the services. Your family will need to do research or seek guidance on what is available in each state.

Some families do choose to pay out-of-pocket for therapies, depending on the availability and quality of state-run programs. Therapy should also be done at home, with guidance from experts and online resources. Much of the therapies can be incorporated into playtime and sensory activities.

Many of the children and adults with 5p- syndrome begin with individual therapy over group therapy, as they typically need a regime more suited to their needs. Therapies that many of our families receive include:

Physical Therapy (PT)
Physical therapists work on gross motor skills and strengthening of muscles. This sometimes is the first type of therapy a child with 5p- Ssdrome will receive. This type of therapy does overlap with occupational therapy (see next section). Both land-based and aqua therapy are beneficial to those with the syndrome.

Therapies

- Physical therapy
- Occupational therapy
- Speech therapy
- Feeding therapy
- Vision therapy
- Behavioral therapy
- Music therapy
- Aqua therapy
- And so much more!

Thoughts

- The earlier the better when it comes to starting therapies for children with the syndrome
- One size does not fit all!

Many of our families report that their PT works on core strengthening exercises, weight bearing through the legs for hip and leg bone development, and integration of primitive motor reflexes.

Occupational Therapy (OT)

This type of therapy focuses on fine motor skills and developmental skills. An OT may work on feeding, holding items, coordination, and sensory issues. An OT may also provide speech therapy, although sometimes these are done by separate therapists. OT and PT overlap, and it is useful for these therapists to communicate with one another (especially if they are at different facilities or clinics).

Speech Therapy

As the name suggests, speech therapists work on communication skills, mouth movement, breath control, sign language, etc. They also sometimes provide feeding therapy (instead of OT). Communication skills may not be important during infancy but become more important around the age of one (1). Not all children with 5P- Syndrome will become verbal. They may be “non-verbal," but this does not mean they cannot express themselves. They may use different tools to communicate, such as sign language, communication pads or binders, or other expressive language.

Vision Therapy

Many of the children with the syndrome display similar visual impairments to Cortical Visual Impairment (CVI). In a nutshell, this means that the brain is taking longer to process what the eyes are seeing. Your child may display a delayed reaction or not show interest in toys. Many children with CVI prefer the color red and may use their peripheral vision to process new things. Vision therapy can help with coordination of eyesight and processing, and there are many techniques to keep children and adults with 5p- syndrome motivated and interested in toys and/or aids. Symptoms of CVI can only get better with time and can be incorporated into all other therapies.

Behavioral Therapy

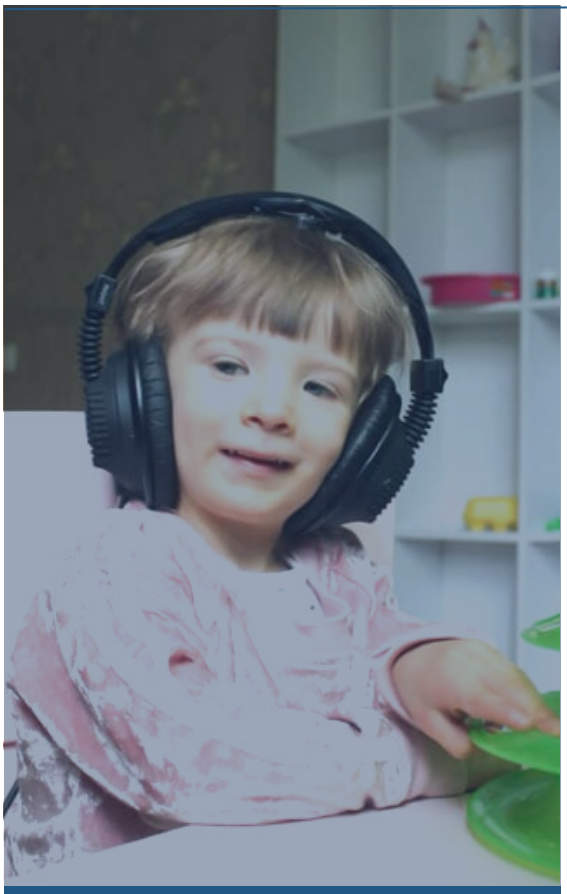
As the child with the syndrome gets older, you may seek behavioral therapy to address:

- **Sleep**: difficulty staying asleep for long periods of time
- **Arching back**: could be caused by gastrointestinal discomfort
- **Sensory input**: sounds and touch tend to upset them
- **Vestibular movement seeking**: head banging, twirling string
- **Communication**: child may bite, kick, hit, pull hair to get attention

Other therapies you may want to consider include:

- ABA Therapy
- ·Anat Baniel Method Therapy
- Aqua Therapy
- Behavior Modification Therapy
- CBD Therapy
- Cranial Sacral Therapy
- Hippotherapy
- Music Therapy

Note that not all therapies work for each individual child. Some may be by trial and error. This will take working with your medical team and practitioners to discuss and monitor if therapies are helping your child reach goals and milestones.



> *Every child is a different kind of flower that altogether make this world a beautiful garden*

Autism & 5p- Syndrome

Research shows that one of the genes found on the “p” arm of the 5th chromosome also causes autism. According to a study done in the United Kingdom, 31% of individuals with the syndrome exhibited autistic-like characteristics. According to the study, the rate of autism among those with the syndrome is similar to that reported for autism in the wider intellectual disability population (up to 40%).

It is very important to remember that the characteristics of autism spectrum disorder (ASD) can sometimes look very similar to those identified in individuals with severe and profound levels of intellectual disability. This means that it is essential to take the person’s level of intellectual disability into consideration when thinking about a diagnosis of ASD.

If you feel that you child has autism, bring up the concern to your pediatrician for testing and confirmation of the dual diagnosis. If your child is diagnosed with both autism and 5p-syndrome, make sure that you have it documented and presented to the school/facility. This way, your child can get all the services available to him or her with the autism diagnosis.

Prescribed Medications

Below we have provided a list of medications that our families have reported were prescribed to them. This is for reference only and medications should only be prescribed by your child's doctors.

Allergies
- Cetirizine
- Zyrtec
- Over-the-counter meds

Anxiety
- Amitriptyline
- Buspar
- Buspirone
- Klonopin
- Paroxetine (including OCD)
- Sertraline (social anxiety, OCD)

Asthma
- Albuterol
- Atrovent
- Dulera
- Levalbuterol
- Qvar
- Salbutamol (bronchial inhaler)
- Singulair
- Tobramycin neb treatments
- Xopenex

Attention Deficit Disorder (ADD)
- Adderall

Attention Deficit Hyperactivity Disorder
- Clonidine (and hypertension)
- Dexedrine Spansules
- Dextroamphetamine
- Methylphenidate
- Quillivant XR (chewable)
- Ritalin
- Strattera
- Tenex
- Vyvanse

Behavior (Other)
- CBD Oil
- Chlorpromazine
- Fluoxetine (OCD)
- Kepakote (bipolar)
- Luvox (OCD)
- Paxil
- Prozac

Risperadol
- Seroquel
- Valium
- Venlafaxine
- Zoloft (including OCD)
- Zyprexa

Bladder
- Bethanechol
- Lasix (diuretic)
- Vesicare (bladder relaxant)

Constipation
- Aloe Vera Capsules
- Ex-Lax
- Lactulose
- Miralax
- Movicol
- Probiotics
- Restoralax

Depression
- Abilify
- Celexa
- Citalopram
- Lexapro
- Remeron
- Trazodone
- Wellbutrin

Eyes
- Atropine Sulfate Ophthalmic
- Eye drops

Infection
- Amoxicillin
- Bactrim
- Doxycycline
- Erythromycin
- Penicillin

Gut Motility
- Cyproheptadine
- Erythromycin
- Periactin

Reflux/GERD
- Axid
- Carafate GI Distress (including ulcers)
- Cimetidine
- Losec
- Mexium
- Nexium
- Omeprazole
- Prilosec
- Prevacid
- Protonix
- Ranitidin
- Ranitidine with Gaviscon
- Zantac

Respiratory
- Hypertonic Saline

Seizures
- Ativan
- Depakote
- Divalproex
- Ethosuximide
- Gabapentin
- Keppra
- Phenobarbital
- Trileptal

Sleep
- Hydrazine
- Valerian Root

Stomach & Digestion
- Gaviscon
- Glycopyrrolate (peptic ulcers)
- Budesonide (colitis)
- Pulmicort (colitis, ulcers)
- Reglan

Vitamins & Supplements
- Calcium
- DHA
- Ferrum (iron)
- Methyl Folate
- Poly-Vi-Sol (iron)
- Vitamin B12
- Vitamin B6
- Vitamin D

Miscellaneous
- Codeine (pain/cough)
- Cogentin (anti-tremor)
- Cortoderm (itching & inflammation)
- Cyproheptad (antihistamine)
- Digoxin (heart meds)
- Gabapentin (muscle tone issues)
- Heparin (blood thinner)
- Levothyroxine (hypothyroidism)
- Mucomyst (cough)
- Propranolol (high blood pressure)

Educational Considerations

Will my child learn? What should our expectations be from our child and their instructors? How do we set goals? What is an IEP? You will have many questions over this journey, as may your friends and family. Often advocacy—or speaking up for your child's and the family's wants and needs—becomes second nature. Sometimes it feels like an uphill battle—even an internal battle. Here are some insights into education and those with 5P- Syndrome. We are going to address them in age groups:

Birth to Three

After the diagnosis of your child, you will want to start your child with the different types of therapies available. We listed those above on pages 12-13.

From ages birth to about 2, you will have home therapies as well as those at outside facilities. The goals that you and the therapists come up with will be mostly strengthening and fine and gross motor skills. There will also be goals to improve cognitive and speech and language skills. When you talk with the therapists about the goals you'd like to see your child reach, keep in mind that they should be broken down into small steps. A goal can be as simple as tracking an object with the eyes.

Takeaways

- Ages 1-3 will primarily be therapies and maybe a social class
- Elementary school will be beginning of IEPs; children can also be homeschooled
- Middle school can be frustrating as therapies decrease, and children are going through many transitions
- High school focuses on life skills and transition to adulthood
- Other takeaways
  - Don't be afraid to advocate for your child and their needs
  - You will be asked many questions and have to make a lot of decisions

Repeat, Repeat, Repeat. Then Repeat again! Goals should be worked on in a formal setting but also at home on a continual basis. What we have learned about our children is that they have great memories. The more repetitions that you have your child perform will hopefully help him or her be able to attain the skill you are working on.

From age 2-3, you may consider a classroom or group type of class where a parent or caretaker attends a social group with their child. Interaction is key, and we've observed that children with 5p- syndrome respond well to "peer models." These are children who are more developmentally progressed or are neurotypical and act as a peer to your child. Siblings are also great peer models.

Sometimes, during this age group, it may feel that your child is not learning. They may seem like the most delayed child in the classroom or setting. However, the attitude you take towards your child's development will assist in the overall understanding and acceptance of who your child becomes. Attitude and patience make all the difference. Be assured that your child is observing, is understanding, and through repetition and time they will begin to respond.

Those who are severely affected by the syndrome may always have difficulty with speech, fine motor skills, feeding, etc. Outside stimuli is critical to continue to learn. The more exposure, the better. You will find individuals with 5p- syndrome have big personalities and will surpass your expectations and continue to surprise you, if you let them.

Review and revise your child's goals to continuously create a positive experience for your child. If the goals are too hard to attain at the present time, your child may become defiant and discouraged, causing undesirable behaviors to emerge. If your child attains a goal quickly, then add to it. Don't be too discouraged yourself if your child is having difficulty attaining a goal.

A final note during this stage—most likely your family is still adjusting to taking care of a special needs child, and it can be overwhelming and isolating. Your friends and, perhaps, your family can't understand the effort it takes to support a child 24/7 as well as the other commitments in your life. During this stage it is extremely important to rely on a community of parents and others who can empathize and support you, mentally or in other ways, when needed. This is a main pillar of the 5P- Society, and we encourage you to remain active in the community and use it as a safe space to communicate your own worries, frustrations, and—MOST IMPORTANTLY—your successes!

Birth to three goals:

- Track objects with eyes
- Respond to own name
- Make choices—choose a toy preference
- Choose drink over food, for example
- Learn to sit unaided
- Improve upper body strength
- Lift head while on tummy
- Sign for communication needs
- Drink from a bottle
- Learn to crawl
- Produce sounds
- Roll over

Elementary School

As your child reaches the age of three, they may go into the public school system or early childhood center. In most cases the public school system will offer therapies to your child, depending on their needs, but in a group setting rather than an individual setting. Some learning and therapies will be offered on an individual basis. These can include PT, OT, Speech and Language, Adaptive PE, Social Skills, and Self-help skills.

First, you will need to register your child with the home school district by calling the district and telling them you need your child to be evaluated for special needs. You will have to produce documentation. You will get assigned a representative at the school district to help you navigate the system. If you are not assigned a representative up front, you may need to request that one be provided to you. Your child will have to be tested in various areas to help give the school district a better understanding of what your child's specific needs are.

After your child is tested, you will be called into a meeting called an IEP (Individualized Education Plan). At this time the representative will go over the testing result and discuss a road map for you to navigate for your child and his or her future goals for the next year. This is a great time for you to have your ideas on paper of what you'd like for your child to attain. The goals discussed are annual goals. There is need to think too far into the future—just immediate goals you'd like your child to work on. You will also discuss at this time what environment will work best for your child: an integrated environment, a segregated environment, a combination of the two, or perhaps a program where the majority of the individuals have little-to-no mobility but are cognitively higher functioning. Ask about all the different types of programs that are available.

DO NOT SIGN THE IEP YET. Schedule a follow up IEP so that you can visit all the different programs of interest. Bring your questions to ask the instructor(s) that are of concern to you. Keep an open mind while visiting these programs. You will quickly weed out the ones that will not work for your child, as you know your child best. Before reconvening with the group, discuss with the district representative who you'd like at the meeting, including the teacher of the classroom you have decided to enroll your child in. Be prepared, as there will most likely be anywhere from 5-10 individuals at the meeting.

After introductions at the follow up IEP meeting, take the time to tell the group who your child is: the diagnosis, what you know about the diagnosis, your child's strengths and weaknesses, what makes him/her happy and what can cause your child distress.

Also, talk about what you do in case of behavior meltdowns. Perhaps talk about a future behavior management plan if one is needed (most likely one will be needed). You should discuss what your immediate goals are and how they can align with the goals that will be presented in the meeting. If you don't agree with a goal or think a different goal would be better, discuss it. You can also add into the IEP that you'd like to meet in six months to discuss how things are going and if things need to be changed.

Only sign the IEP if you are in complete agreement with it. If there is anything you don't agree with, don't sign it. Don't forget to discuss transportation. Also, don't forget to discuss the ability to visit the classroom and how you can help in the classroom. Teachers do like it when parents show an interest in the classroom. After your initial IEP you will have an annual IEP with your child's teacher and usually one or more additional district personnel. You can bring anyone you want to the IEP, but you will need to let the teacher know ahead of time. Every three years (3 years old, 6 years old, 9 years old, 12 years old, 15 years old, 18 years old and 21 years old) the IEP is called a Tri-Annual IEP. These IEPs are longer than the annual IEPs because your child will be re-evaluated to check his or her overall progress.

PLEASE NOTE THAT YOU CAN CALL AN IEP MEETING AT ANYTIME YOU FEEL THAT THE NEEDS OF YOUR CHILD ARE NOT BEING ADDRESSED AS PER THE IEP OR IF YOU FEEL A CHANGE NEEDS TO BE MADE TO THE CURRENT IEP.

Elementary school goals:

- **Cognitive**: Recognize name, colors, letters and numbers; use electronic device, such as iPad; focus and attention; perform a one-step command; squeeze and pull apart/push together toys; fingertip grasp; scribble; increase stabilization/manipulation skills; imitate basic pretend play behavior; explore cause/effect toys; stack blocks; match objects; learn over, under, around, front and back.
- **Gross Motor**: Floor mobility (crawl, roll over, supine to sit); sit unaided, balance, sit to stand, pull to stand, stand with assistance, stand unaided; walk with assistance, walk unaided, use of walker if needed; ride a bike; jump; catch a ball; roll a ball.
- **Fine Motor**: Rake hands/fingers to move an object; pincher grasp; pick up food; grasp a marker; self-feed; use loop scissors; use tongs; hold a pencil/pen correctly; attempt to write horizontal, vertical and circular lines; use a zipper; manipulate a button; thread a hole; pull on pants; put on a shirt; put on socks; unscrew/screw on a cap; place pegs in a hole; stack blocks; move items from one container to another.
- **Social Skills**: Engage in appropriate parallel play; make eye contact; ability to communicate his or her needs through gestures and signs; vocalize appropriately to interact appropriately with his or her peers; spatial awareness; meaningfully point to choose between two pictures; understand the concept of sharing; sit appropriately

in class, church or a restaurant; learn to take turns; learn to keep hands to his or herself; play games.
- **Speech and Language**: Sign language; Picture Exchange Communication System (PECS); use of iPad; switches; produce or imitate developing consonants and/or vowel sounds; say one word consistently; say two words; say a short sentence; work with feeding; take small bites of food; chew food.

Some of the activities and tools parents use during this stage to help their child's development include:

- Devices such as iPads, light boxes
- Sensory bins or activities (shaving cream, paints, taste-safe textures, beans, sand, water play, beads, cold and hot items, etc.)
- Books, flashcards, magnet letters, photos to help prompt memory
- Command buttons (for more, all done, yes/no)
- Enrollment in music, sports, aqua therapy, animal programs
- Tabletop play, kneeling play, reaching
- Educational shows or movies
- Coloring books, tracing books

Middle School

Middle school years can be very trying. There is a split between children who are in full inclusion programs, partial inclusion programs, special day programs with pull-outs for therapy, and segregated programs. Many of the children do not change schools or programs from elementary to middle school. Some children have full time aides, whereas others share an aide with two to three other children. Most schools have resource specialists that assist the instructors, especially in the full inclusion classrooms. During this time, outside therapies seem to come to an end or are reduced tremendously.

Middle school goals:

- **Cognitive**: Read (safety signs); academic standards; regular school goals; identify coins; use addition, subtraction, multiplication and division; use a calculator to compute answers; retell stories; art.
- **Gross Motor**: Dance/Movement therapy; swim; independence on stairs and curbs; sit; pull out and push in chairs; catch a ball, kick a ball, throw a ball; walk a short distance; run a short distance; use walker or wheelchair to get from classroom to classroom independently; motor planning, trunk & extremities strengthening, jump.
- **Fine Motor**: Sit at a desk independently and use pen, pencil, crayons or markers to create shapes, numbers and letters; work on puzzles; use utensils correctly; drink from a cup; learn sign language; learn how to use a computer correctly; tell time on a digital clock.
- **Speech and Language**: Increase vocabulary and form sentences; understand opposites; improve sign language; learn to use communication devices appropriately; follow a two or three step direction; make eye contact with peers and say "hello"; ask/answer "wh" questions.

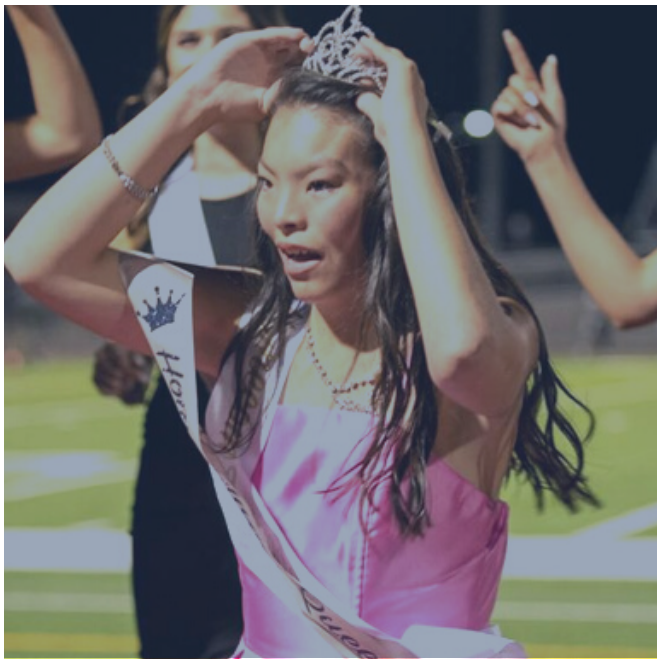
- **Self Help/Care**: Safety skills; learn to cross the street; use of streetlights; stranger safety; equipment safety; learn manners and appropriate behaviors in a public setting; learn how to control behaviors; create behavior plan; trips into the community to practice safety skills; dress oneself; housekeeping skills, such as vacuuming and sweeping; basic hygiene and self-care; create and maintain friendships.

High School

As you can imagine, as your child ages and goes into high school, goals and expectations change. By this time, most kids have gotten to a relatively consistent cognitive level, although they are still learning and understanding.

At this stage in a child's life, while it is important to continue to work on practical daily living and social skills, it is also important to create a successful environment to improve your child's self-worth. Most children at this age will be in a self-contained classroom. They may have the opportunity to have a job on campus. If so, you may want their job to enable them to interact with all the students and staff (e.g., deliver the mail, pick up recyclables). If your high school has a Best Buddies program, consider having your child participate. This is a great way for your child to engage with his or her peers and some might become life-long friends.

In high school your child will most likely go out into the community weekly to learn and improve his or her safety skills, communication skills, directional skills, money handling skills and job skills. He or she should also learn how to manage time and be responsible for executing a daily schedule at school. Although he or she may not be receiving therapies, all goals should include a communication and functional aspect to the goal.



High school goals:

- **Cognitive**: Increase use of computer to assist with math and language production; construct sentences to communicate effectively; improve independent skills; improve routine skills, such as enter classroom, hang up coat and backpack, place lunch in refrigerator, etc.; correctly identify coins and paper money and assign their value; learn calendar skills—dates, days of the week, month, etc.; learn telephone skills and etiquette; learn laundry sorting skills.

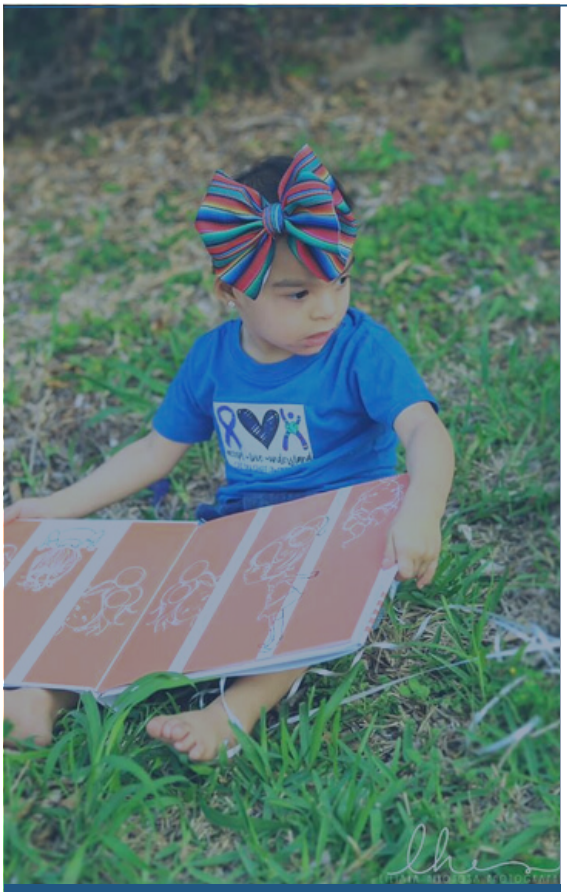
- **Gross and Fine Motor**: Learn to use large and small tools necessary to clean up both outside and inside; maintain balance while bouncing on a therapy ball; improve upper body strength; continue to work on writing skills; continue to work on dressing skills, such as buttoning, tying shoes, zipping up pants/jackets.
- **Social Skills**: Improve self help skills; learn appropriate job related skills; improve daily living skills; engage in social activities and games with peers; follow instructions; use calendar to keep track of activities; learn to cook or prepare own snacks and also to clean up work station and table; go shopping and learn how to use money (dollar over).
- **Speech and Language**: Accurately identify new words; work on increasing speech by lengthening of sentences; use pictures and signs to improve communication with others; continue to work on speaking more clearly and appropriately; improve sentence structure with the use of a communication device; ask appropriate questions and answer questions correctly; work on oral motor activities to improve tone and coordination; use social stories to decrease inappropriate behaviors; initiate conversations; use appropriate eye contact and say “hello” to both familiar and non-familiar individuals; work on appropriate lip closure during mealtime; work on appropriate posture while eating.
- **Extracurricular Activities**: Special Olympics; school dances or dance groups; music groups; church groups; hippotherapy; teen afterschool programs.

Transition

In the United States and many other countries around the world, a young adult can stay in school until he or she turns 22. In most cases, when a young adult turns 19 or 20, he or she is encouraged to leave high school and go into transition.

This 2-4 year program is designed to get them ready for adulthood and adult programs and is still the responsibility of the public school system. Most goals are strictly daily living skills based and communication based.

The young adult will be given (or should be given) a wide range of possibilities to see what he or she thrives at. Some young adults will have volunteer jobs in markets, clothing stores, animal shelters or daycares. Some will learn social and self help skills. Others will learn how to do jobs around campus. There are reported cases of young adults not going through a true transition program. They continue into high school until they age out at 22.



RESOURCES

- Different by Design Learning
- SPED Homeschool
- Homeschool Legal Defense Association
- Every Star is Different
- Facebook groups
- Members in the 5p- society that have homeschooled
- Articles
  - https://okbookshack.org/teaching-the-special-needs-child/
  - https://goodschooling.net/blog/homeschool-unique-needs
  - https://educationpost.org/i-broke-up-school-district-homeschool-child-special-needs/

Home-schooling

There has been an increase in parents deciding to keep their child at home and schooling them. Some of the reasons listed include the following:

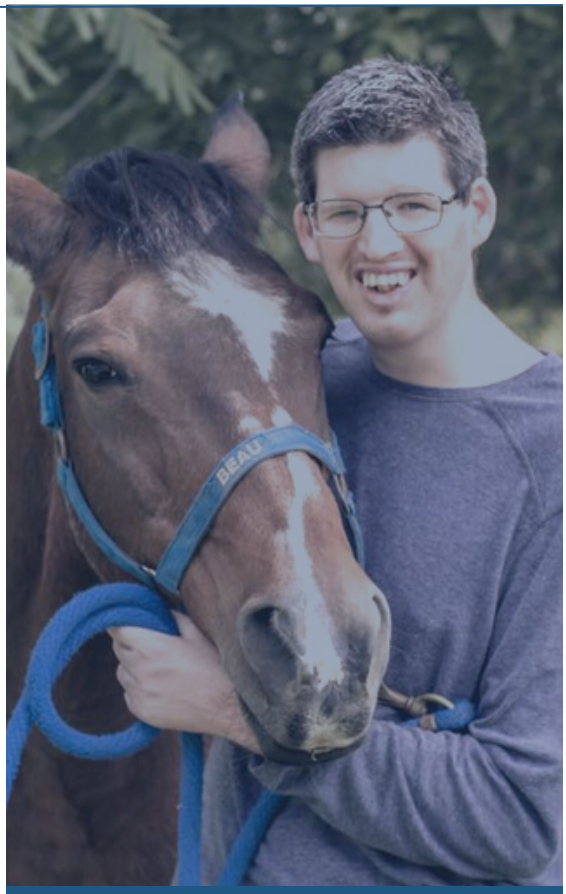
- Safety of child in an environment where they cannot communicate
- Child is fragile and is medically compromised
- Parents want to make sure that child is getting an education and not just being babysat
- Child/Adult not being properly supervised in the public school

The 5p- society can connect parents who want to homeschool with others in the society who have experience. Some places to look into information and curriculum for homeschooling are through your church, parent groups, and homeschooling support groups on the internet.

Parents report the advantages to homeschooling a child include the following:

- Teaching the child at his or her own pace
- Having the ability to continue therapy sessions during school hours
- Following age appropriate curriculum and teaching the child the way he or she can learn (auditory, visual, tactile, sensory) with great response.
- Using real life to teach the child practical skills

Raising an Adult with 5p-



Approximately one-fourth of the database is now an adult at 21 years or older. Our participants in the survey were extremely generous and honest in their answers, and we have compiled the topics that generated the most interest among our membership.

- **Overall Health**: The majority of the parents surveyed stated that their child was in good overall health with very few colds.
- **Weight**: Responses by parents regarding their adult child's weight varied. Several parents reported that after their child turned 30, there seemed to be a thyroid issue with symptoms, including gaining weight, becoming irritable and being tired. Many were then put on thyroid medication. This seemed to assist the weight and behavior issues. Other parents reported weight loss. Issues that contributed to weight loss included choking, swallowing, not tolerating foods, inability to chew properly, loss of teeth, Barrett's Esophagus, GERD and other underlying issues. These individuals were given higher caloric foods and/or supplemental drinks. More females then males had the thyroid issue, and more males than females were underweight.

> *We must be willing to let go of the life we have planned so as to have the life that is waiting for us!*

- **Seizures**: Many parents reported that their adult child started to have seizures as they got older. Seizure medications were used to assist in controlling them.
- **Tremors**: A handful of parents reported that their child had hand tremors when attending to a task that required a lot of concentration. One parent talked with a doctor about the tremors and felt that it had a lot to do with low muscle tone and the need to strengthen the back muscles.
- **Diabetes**: A few parents reported that their adult child had elevated levels of A1C for pre-diabetic considerations, but none of the parents reported that their adult child had diabetes.
- **Arthritis**: A few parents reported that their adult child had arthritis type symptoms in the knee and hip joints.
- **Walking**: Several parents reported that as their adult child became older, the harder it was for him or her to walk unassisted. Some were afraid of falling due to a loss of depth perception (off a curb, etc.). Some adult children did not pay attention to their surroundings and would fall or stumble over cracks in the ground and uneven sidewalks or have poor motor planning and could not maneuver properly around obstacles.
- **Vision**: Those individuals who already had vision loss tended to get worse as they aged.
- **Hearing**: Some parents reported that their child had increased hearing loss as they aged.
- **Constipation**: Unfortunately, the constipation issues that our younger children have continue into adulthood. Parents reported that they continue to give over-the-counter medications to assist with the constipation.
- **Hormonal Changes**: Very few parents talked about the hormonal fluctuations in their adult child. One parent did report that her child had a hysterectomy due to an increase in behavioral issues and hormonal changes.

Daily Routines

A majority of our families have reported that their adult children attend either an adult day program or sheltered workshops. Some others may live in group homes, but we will get to that a bit later.

Adult day programs and workshops help individuals with 5p- syndrome work on their social and daily living skills including, but not limited to:

- Communicating with others
- Cooperation and following directions

- Improving social interactions
- Improving vocabulary
- Safety skills
- Specific skills such as cooking, using money, gardening, artwork, theatre, typing, carpentry, etc.

Volunteer opportunities are also great ways for adults to get involved in daily activities. These may include Meals on Wheels, homeless shelters, animal shelters, churches, camps, day care centers, sports programs (like Special Olympics), etc. Many local businesses now hire individuals with special needs, so it is worth doing research to see if any coffee shops or other businesses have special hiring programs. Local farms may also offer programs where the volunteers learn to care for animals. Many of these programs require transportation by the family. Some of them may be state-funded.

Another large group of adults with the syndrome stay at home during the day with their parent or guardian. The adults will engage in daily living skills including daily chores, assisting with meal prep, going to the store, going to the library, running errands, engaging in therapy, and playing with their favorite things. Ways to keep adults active and engaged can include:

- Exercise (gym memberships, daily walks, classes, etc.)
- Group outings or social meetups
- Technology time (iPad or television time)

A handful of adults work. Most work with a job coach; however, a few are able to work independently. Because of Social Security laws and income requirements, those who work make less than their neurotypical colleagues. Each state has its own rules on how much a disabled individual can work; please make sure you check or know the income rules before your adult becomes employed. The Able Act, however, is one tool that families can use to save money for their child without worrying about social security and income limitation.

Challenges

Some parents report that their adult child may have medical issues, be severely affected by the syndrome or have difficulty with behaviors when in a day program.

Routine can be very important to those with 5P- Syndrome. This is difficult to keep, especially if parents have commitments to other children, work, etc. Changes to routine may prompt unwanted behaviors. Some adults will also be sensory seeking if they do not get enough interactions and may begin to self-harm, withdraw or engage in unwanted behaviors.

Living Options for Adults with 5p- Syndrome

There are several living arrangement options for adults with 5P- Syndrome. These may include:

- Living at family home under parental or other family supervision
- Living at family home in a semi-independent space
- Living with another family member or caretaker
- Living in a group home with 4 or fewer individuals of the same sex
- Living in a group home with 8 or fewer individuals of the same sex
- Living in a group home facility or community with over 10 individuals, mixed sex

- Living on own or in a group home owned by parents, where adults pay rent and parents hire support staff
- Living on own with support staff to assist with meal planning, budgeting, cleaning
- Completely independent (for higher functioning individuals)

Your decision on keeping your adult child with you or having him or her move to his or her own home is one that is not easy to

make. Some adults are ready to take the leap and assert their independence. Some are quite content with their current living situation. You have to do what is right for you and your family. The biggest concern is what happens when you are no longer around to care for your adult, and he or she only knows how to live with you. Even having them go to a week-long overnight camp will provide them with a few days where they can learn some independence away from parents/guardians.

Guardianship or Conservatorship

When a child with the syndrome (or any genetic disability) turns 18, he or she is considered an adult, and your rights as a parent are severed, according to the US government. What does this really mean? As the parent/guardian of your now adult, you will need to apply for either guardianship or conservatorship of your child's estate. This way you can be in control of his or her monies, medical decisions, living decisions, and relationships.

Each state has different rules when it comes to applying to be your child's guardian/conservator. Some states require that you hire an attorney; other states will walk you through the process. In most cases, there will be a court hearing where a judge will grant you guardianship or conservatorship over your child. You will receive a legal document that you can then use as needed for your adult child.

Special Needs Trusts

These are designed to have a plan set for your adult child when you are gone. A special needs trust can be part of your own family trust. Consult with an attorney who can assist you in designing the trust. Make sure you talk with family members before adding them into the trust to make sure everyone is okay with the future plans.

A letter of intent can be added to the trust, which outlines the family's wishes for their child in the event that they are not there to see them carried out. One parent surveyed explained that "everything is spelled out in her trust from what she eats, likes to do, medications/vitamins, things she cannot do and needs help with, etc."

Many parents reported that they periodically updated the trusts to keep the information current. Note: Trusts typically have a cost associated with setting them up; however, they do provide peace of mind to the family in the event they do not outlive their child with the syndrome.

Social Security

At the age of 18, your adult will also be able to apply for Social Security benefits that not only include a monthly living allowance but also medical care through Medicaid/Medicare. 5P- Syndrome is now listed as one of the covered conditions. Make sure you reference: "SSI Compassionate Allowance Conditions – DI 23022.375 Cri du Chat Syndrome."

Contact the Social Security Administration at least 2 months before your child turns 18 to schedule an appointment. Bring all documents that support your child has a syndrome to the appointment along with your child. Social Security will send you a notification of what you need to bring. Even though your child is sitting with you at the appointment, don't assume that they will grant the Social Security benefits immediately, due to necessary protocols. They will schedule an appointment for you to meet with a psychologist to confirm that your child is unfit to handle his or her own affairs, even if the step seems unnecessary.

Keep in mind when you visit the Social Security office that your child cannot have any more than $2,000.00 in his or her name. This includes savings accounts, savings bonds, and more. Also note that the parents' income does not count toward the child's eligibility.

Parents report that the amount of the social security monies that their adult child receives a month is minimal but that there are annual cost of living increases. There are several factors that will assist SSA in determining the exact amount. You will need to make sure you do not let your child's income exceed the $2,000.00 limit or the Social Security Administration will take it away from you and make you pay back the overage.

For most families the adult will contribute to the family budget. You, as the beneficiary of your adult child's account, can withdraw the money and utilize it for rent, food, utilities, personal items, gifts, clothing, medical, dental, vision co-pays or other items that insurance does not cover. Keep receipts and records as you may be asked to present them. You may be asked to prepare an annual statement to let SSA know how the monies are being spent A rep may call you annually to ask if anything has changed (living arrangements, etc).

Every couple of years a rep from Social Security will contact you and ask you a series of questions to confirm that your child is still disabled. While this seems unnecessary, please be prepared and ready for them to ask these questions.

Learning and Growing

Don't let anyone tell you that your adult with the syndrome will stop learning. Keeping in mind that many of our adults are over 30 years of age and technology was just beginning, many of our adults know how to use computers, iPads, communication devices, and smart phones. Many adults learn how to complete chores, including laundry sorting, washing dishes,

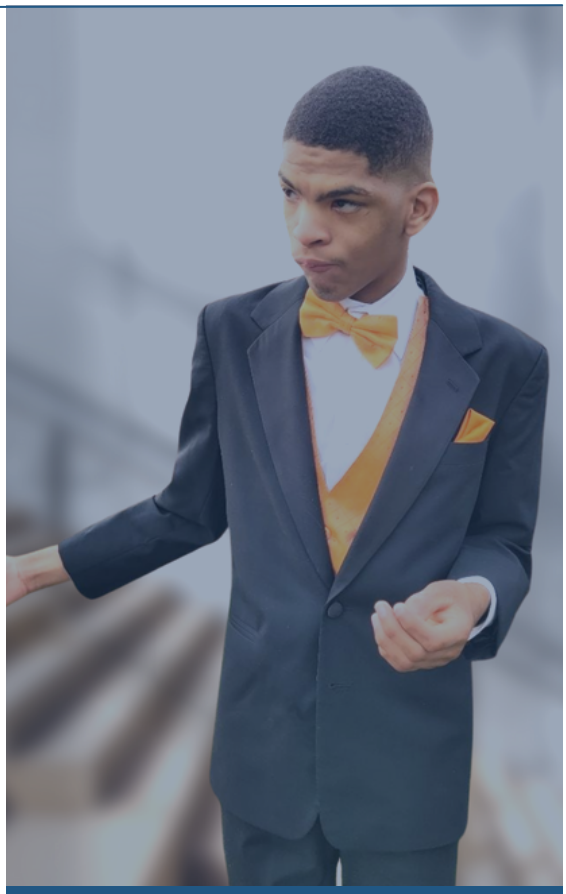
making beds, managing their items, taking care of their animals (feeding them and walking them), bathing independently and controlling their behaviors. Some are able to complete more difficult tasks, such as cooking with assistance, managing a budget, working independently, putting on make-up and operating a pod-like coffee maker. Even parents who have adults who are severely affect by the syndrome report that they continue to learn, recognize, and understand the world around them.

Safety Concerns

A common concern among the parents of adults with the syndrome is in regard to safety. For the most part, our children and adults are very outgoing, friendly, happy and curious. They like to go up to strangers and say hello, touch little babies and kids, and give hugs “just because” to anyone.

We, as parents, continually have to teach our kids about boundaries; what is appropriate and not appropriate. Fist pumps, high fives, and waves are constantly being encouraged at home, at programs, and in the community. Safety with strangers is only one of the safety concerns. Another is safety out in the community. Learning how to cross the street correctly, being mindful of their surroundings, and walking without walking into something or somebody are a few of the safety concerns.

Most parents report that they make sure that their adult is being monitored at all times—providing just enough space so that they feel some sort of independence.



OVERVIEW

- There are many programs available for adults to keep active lifestyles and get involved in the community
- There are many living options available depending on the child’s and family’s wants and needs

RESOURCES

- Guardianship/Conservatorship
- Supplemental Security Income (SSI)
- Special needs trust
- State programs
- 5p- Society facebook groups and members
- Facebook groups

Before You Go...

You've just taken in a lot of information about 5p- syndrome and your child's or loved one's prognosis. You might be overwhelmed, confused, angry, scared...maybe all the above! So, let us give you some good news.

It gets easier. Children and adults with 5p- syndrome are wonderfully unique, sociable, and lovable. Almost everyone who crosses paths in the society shares how their loved one or child has enriched their life for the better. Here's what some of our parents have to say:

> You will realize very quickly, your child is MUCH more than their diagnosis. The happy moments and the successes will mean that much more!

> Your child will surprise you but don't spend too much energy stressing over what the future holds. Enjoy them as a baby and celebrate the milestones as they come.

> They are the most amazing little humans ever!! They love like no other.

> It will change your life but in the best way. They are the happiest, sweetest and most innocent people.

> One day, probably not that far into your journey, you will look back and realize that your child made you into a stronger, better, more patient and loving person.

> We felt grief and loss for a few months and that was gradually replaced by joy!

References & Resources

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- Social Security Administration, www.ssa.gov

More resources:

- CPN | Courageous Parents Network
- Feeding Tube Awareness

NATIONAL SUPPORT GROUP FOR INDIVIDUALS WITH 5P- SYNDROME AND THEIR FAMILIES.

Acknowledgements

We are grateful to all the families who participated in the Caregiver's Guide questionnaires for their honesty and practical information for current and future families. A special thank you to Lora Piepergerdes for her thorough review of this publication. Thank you also to Julien and Maryline Ducry and the members of Switzerland's support organization for their generous donation in funding this project.

5P- SOCIETY

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