



Pediatric Stroke Warriors Family Tool Kit



A MESSAGE TO PARENTS

We know that when you dreamt of becoming a parent, you never thought that your child could be impacted by a stroke. Oftentimes, our first experience with pediatric stroke is when our own child has received this diagnosis. When you are faced with the unimaginable, your initial reactions and feelings can become entirely overwhelming. *Guilt, anger, sadness, fear, loneliness* are all the most common feelings parents have shared. These feelings will demand to be felt at one time or another. **Be gentle with yourself. Acceptance is not an easy process. Fear of your child's unknown future can be very overwhelming.**

Creating an army of advocates not only for your child's care but also for your family, is vital in this process. We simply cannot stress the importance of support enough. Support can come from sources you may not have expected. Your child's doctors and therapists can often become an extension of your family. While you adjust to the ongoing medical appointments and therapies your child will need, keep in mind these medical professionals care about your child and their success. As you become familiar with them, continue to build those relationships and conversations over your child's care. **You are not just a bystander in this. You will learn how to advocate for your child and their needs.**

We encourage you to gain as much knowledge about the resources and support available to your family. **The Pediatric Stroke Warriors Family Toolkit** is intended to give families guidance on how to navigate this journey after their child has suffered a stroke. Our leadership team of dedicated parents and professionals have worked together to bring a comprehensive resource about pediatric stroke into the hands of those that need it most- families. It is our hope to empower you and share with you knowledge that will help you ask some of those important questions, advocate for your child's best care and fill your family with strength. We want you to know that **you are not alone.**

You may not be ready to read these pages or desire to learn more just yet, and that's ok! Take the time that *you* need to process. When you are ready, ask questions and seek support.

Sincerely,

Kaysee Hyatt
Founder and President of Pediatric Stroke Warriors

THE MISSION WITH PEDIATRIC STROKE WARRIORS

Pediatric Stroke Warriors is committed to serving the needs of children impacted by stroke, their families and the caregivers involved in their care. We are dedicated in a mission of building community awareness for Pediatric Stroke and hope for impacted children and families.

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PARENT TO PARENT – TAKING CARE OF YOU

In order to care for our children, we must make it a priority to take care of ourselves as well. (This is often easier said than done). From the voice of parents who have been there, make it a point to put these shared words of advice into practice:

“It’s ok to ask for help.” Acknowledging you need help balancing it all, can be just as difficult as accepting it. Your family and friends often want to help you and giving that help lets them feel like they are supporting you during this stressful time. Make a list of things that need to be done to keep your life running, and be realistic about what you have the time and energy to accomplish. Keep the list handy, and next time a friend or family member asks, let them know what they could do to help.

“Recharge your batteries once in a while.” Taking a break helps you be a better parent, partner and person. You do not need to have all the answers or be “on” every second. We know it is scary to leave your child’s side, but you do really need to get away - even for a little while. Make plans for a friend or family member to spend time with your child while you spend time away. Read a book, go shopping, have a meal at a restaurant, nap - just be sure to relax!

“Build a village of support.” Being the caregiver of a child with medical needs can be an isolating experience. Whether friends and family, parent to parent support groups or your child’s medical team - it is important that you reach out and connect with others who can help you feel less alone in this journey.

“Distraction, Distraction, Distraction.” Keeping up with favorite hobbies or developing a new one is a good way to take a mental vacation. Gardening, golfing, reading, drawing, blogging are all easy ways to busy your hands and quiet your mind.

“Take care of your own health.” When you are caring for your child, your health becomes secondary. However, if you aren’t healthy, meeting your child’s needs will be more difficult. Find time to exercise, even if you are just taking a walk. Pay attention to your emotional state and contact your doctor if you are concerned about anxiety or depression. Do not be ashamed to admit when you may need support.

“Knowledge is power.” Learn about your child’s diagnosis, medication and treatment plan. (Be sure to ask your doctor for reputable websites ONLY). Keep a notebook nearby and write down questions as you think of them to address later with your child's care team.

“Educate others.” Knowledge is power to family and friends as well. Ask them to take the initiative in learning more about your child’s diagnosis. This becomes especially important if your child has risk measures to avoid or has seizures. All family and friends who care for your child must understand these risks and how to respond.

“Take back your family.” Don’t let your child’s diagnosis define them or your family. Of course recovery takes precedence, but it’s important to recognize that your child’s recovery places all members of the family under stress and makes it more difficult for you to support each other. This is especially true for siblings in the family who may have thoughts or fears that they aren’t sharing. Make it a point to spend time together as a family in ways your family can all enjoy.



DISCLAIMER

Please note that the Pediatric Stroke Warriors Family Toolkit is for educational purposes only. The content is not intended to be a substitute for professional medical advice, diagnosis, or treatment or for legal advice or representation, nor is it intended to be interpreted as such. Please seek out a medical or legal professional for those types of services/advice.

Pediatric Stroke Warriors provides general information about Pediatric Stroke as a service to communities. The following information provided in this toolkit is not a referral or endorsement of any resource, therapeutic method, medical service provider and does not replace the advice of any medical professional.

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QUICK GLANCE AT THE FACTS

- The causes of stroke in children are many and often not well understood. Recognition of stroke is often delayed or even missed in children.
- Stroke is as common as brain tumors in the pediatric population.⁵
- Stroke is one of the top ten causes of death for children.¹
- Of children surviving stroke, roughly 60% will have permanent neurological deficits, most commonly hemiparesis or hemiplegia. Hemiplegia is the most common form of cerebral palsy in children born at term, and stroke is its leading cause.²
- Other long-term disabilities caused by a stroke in childhood can include cognitive and sensory impairments, epilepsy, speech or communication disorder, visual disturbances, poor attention, and behavioral problems.²



WHAT IS STROKE?

Stroke happens when blood that carries oxygen and nutrients stops flowing to part of the brain. Without a steady supply of blood, brain cells in the area begin to die within seconds. This can lead to stroke symptoms and sometimes to lasting neurologic deficits or sadly, death.⁴

While most have heard of stroke in adults, a stroke can and does happen at any age. Stroke can happen in newborns, children, teens - and even around the time of birth. Stroke in children is often different from adult stroke, with different causes and sometimes different symptoms and treatments. In babies and children, epilepsy, tumors, migraine headache and many other conditions can mimic stroke. Careful, expert diagnosis is essential to tell pediatric stroke from other health problems so your child gets the right treatment.

A stroke is a medical emergency. If you think a child is having a stroke, call 911. A rapid response, quick diagnosis and treatment for a child may help limit damage to the brain.

CATEGORIES FOR PEDIATRIC STROKE

There are two age categories when referring to pediatric stroke:

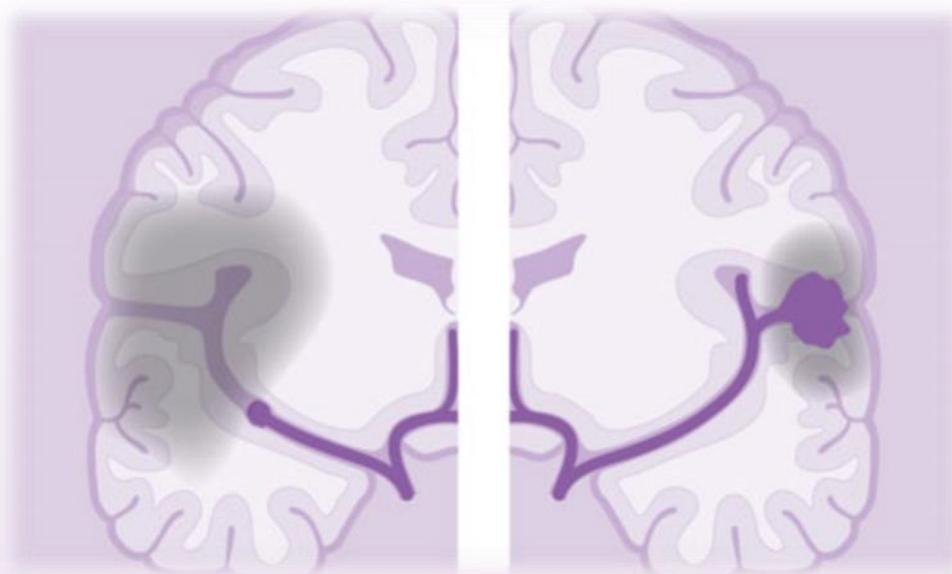
- **Perinatal**, which refers to the last 18 weeks of gestation through the first 30 days after birth. Other terms for this include **fetal**, **prenatal**, **in utero** for the period before birth. **Neonatal** and **newborn** for birth through one month of age.⁵
- **Childhood**, which refers to ages 1 month to 18 years.⁵



TYPES OF STROKE

THERE ARE TWO MAIN TYPES OF STROKE:

- A blood vessel in the brain is blocked. This is ischemic stroke (**pronounced iss-KEE-mik**). Blood cannot get through the vessel to deliver oxygen and nutrients to the cells that need it.⁴
- A blood vessel in the brain is bleeding. This is hemorrhagic stroke (**pronounced hem-or-ADJ-ik**). Blood is leaking from the vessel before it can get to the cells that need oxygen and nutrients.⁴



ISCHEMIC STROKE

In ischemic stroke, the blood vessel may be blocked by a blood clot that formed in the blood vessel (thrombus) or a clot that formed somewhere else in the body, such as the heart, and then traveled to the brain through the bloodstream (embolism).⁴

Doctors group pediatric ischemic strokes by the age of the child.

- Perinatal ischemic stroke (PIS): Stroke before birth or in a newborn (age 28 days or younger).
- Childhood arterial ischemic stroke (childhood AIS or CAIS): Stroke at age 29 days or older.⁴

HEMORRHAGIC STROKE

In hemorrhagic stroke, the lack of oxygen-rich, nutrient-rich blood to brain cells is only one problem. Another problem is that blood builds up where it does not belong - in the brain but outside a blood vessel. This blood can put pressure on the brain, form clots or cause nearby blood vessels to close up (vasospasm), which can also damage the brain.⁴

Causes of hemorrhagic stroke include:

- Weak blood vessel bursting
- Trauma, such as a head injury, that tears the wall of a blood vessel
- Blood that does not clot as well as it should

PERINATAL STROKE KEY POINTS

- The majority of Pediatric Strokes occur in the perinatal period affecting roughly 1 in 2000 live births.¹
- The most common type of stroke in the perinatal period is ischemic stroke.⁵
- Less than 1% of children who have had perinatal stroke will go on to have more strokes.¹
- A stroke before birth may be called fetal, prenatal or in-utero.⁴
- A stroke just before birth may be called neonatal or newborn.⁴
- In most cases of perinatal stroke a cause cannot be determined.
- Perinatal strokes are often missed because the signs and symptoms are subtle. Many infants do not show any signs of stroke until they are 4 to 6 months old.
- Infants with early hand preference before 12 months should see their pediatrician and request a referral to a pediatric neurologist to rule out anything neurological.¹



PERINATAL STROKE SYMPTOMS

Symptoms of stroke tend to be different in newborns (age 28 days or younger) than in older children. Seizures are a common symptom of perinatal stroke. They usually start 12 to 48 hours after birth and repeat.⁴

Some babies have no clear symptoms for weeks or months after their stroke. Often parents, caregivers and doctors do not notice any signs of perinatal stroke until age 4 to 6 months, when the baby starts to appear weaker or partly paralyzed on one side of the body (hemiplegia or hemiparesis).⁴

Symptoms may include:

- Baby not moving one side of their body as well as the other
- Baby keeping fingers and toes on one side of the body clenched in a fist
- Child clearly using 1 hand more than the other (not common before age 1 in healthy babies)⁴

PERINATAL STROKE RISK FACTORS

- Disorders of the placenta
- Congenital heart disease
- Sickle cell disease or other blood conditions that cause abnormal clotting (thrombosis) or bleeding
- Infections, such as meningitis⁴

It is very important for mothers to understand that there is often nothing they did or did not do during their pregnancy that lead to their child's stroke.

CHILDHOOD STROKE KEY POINTS

- Childhood strokes may be missed because there is a lack of awareness that children can indeed have a stroke. However, the risk of stroke from birth through age 19 is nearly 5 per 100,000 children per year.²
- Many children with stroke symptoms are misdiagnosed with the more common conditions that stroke can mimic such as migraines, epilepsy or viral illnesses.⁴
- In older children, the signs and symptoms of stroke are very similar to those in adults and depend upon the area of brain involved.
- It is very important that families take immediate action and call 911 if they see sudden signs of stroke or sudden changes in their child's health status.
- To date, the use of tPA (a clot busting treatment) is not currently FDA approved for children in the US.¹
- Early recognition and treatment during the first hours and days after a stroke is highly critical in long-term functional outcomes and minimizing recurrence risk.



CHILDHOOD STROKE SYMPTOMS

Children who have a stroke tend to have one or more of these symptoms that come on *suddenly*:

- Sudden weakness, paralysis or numbness in the face, arm or leg, most often on one side of the body
- Sudden confusion, trouble speaking or understanding language
- Sudden changes in vision, such as decreased vision or double vision
- Sudden dizziness, loss of balance or loss of ability to stand or walk
- Sudden, severe headache with or without vomiting and sleepiness
- Seizures in a child who has not had seizures before (usually on one side of the body)⁴

CHILDHOOD STROKE RISK FACTORS

In many cases of childhood stroke, a cause is not found. However, roughly half of the children presenting with a stroke have a previously identified risk factor.¹

- Congenital heart disease
- Abnormal blood vessels in the brain, such as moyamoya, vasculitis arteriovenous malformation⁴
- Infections such as chickenpox or meningitis⁴
- Head injury or trauma
- Arterial Dissection
- Sickle cell disease or other blood conditions that cause abnormal clotting (thrombosis) or bleeding⁴
- Autoimmune Disorders

STROKE DIAGNOSIS

To diagnose stroke, the doctor will examine your child and ask about your child's symptoms and health history. It is important to make sure these tests are explained to not only you, but also to your child in words they will understand. Describe the equipment, the sounds and environment they will experience. Make sure they know they will not be alone.

To see pictures of your child's brain and look for blockage, bleeding or problems with the blood vessels, the doctor may ask for your child to have one or more of these imaging studies:

- CT (computed tomography) scan
- MRI (magnetic resonance imaging) scan
- MRA (magnetic resonance angiography)
- Ultrasound
- Cerebral angiogram

Your child may also have one or more of these tests performed:

- Blood tests to check for clotting or bleeding problems, infection or diseases that might increase stroke risk
- Echocardiogram to check for heart problems
- Electrocardiogram to check for problems with heart rate or rhythm
- Electroencephalogram to look for possible of seizures

HOSPITAL TREATMENTS

Treatment for perinatal stroke and childhood stroke depends on:

- The type of stroke
- The short-term and long-term effects of the stroke
- Any underlying condition that caused the blockage or bleeding in your child's brain

Children who have had an acute stroke will be admitted to the hospital for further tests to determine the causes and impact of the stroke and to provide treatment.

- If a blood clot is blocking blood flow in your child's brain (ischemic stroke), doctors may use blood thinners (antithrombotics, either antiplatelets or anticoagulants) to keep clots from getting larger and to prevent new clots. In general, (tPA), a medicine that dissolves clots, is used in children only as part of a clinical trial. This drug is widely used in adults in the hours right after an ischemic stroke. However, doctors are still studying how it affects children and which children can benefit.⁴
- If an artery in your child's brain is bleeding (hemorrhagic stroke), a neurosurgeon may have to surgically repair the artery.⁴
- If your child has an underlying condition that might have caused the stroke - and might put your child at risk for future strokes or other health problems - doctors will recommend treatment for this condition.
- Medicine to prevent a second stroke, such as blood thinners, may be recommended by your child's doctor. This will depend on the cause of your child's stroke.
- Rehabilitation including physical, occupational and speech therapy is key to improve outcomes over the long-term.

HOSPITAL RECOVERY AND REHABILITATION FOR YOUR CHILD

A child's brain is still growing, developing and constantly learning. Rehabilitation is key following stroke, and can lead to significant improvements in the long-term outcome for your child. The length and type of rehabilitation needed will be different for all children.

Your child's rehabilitation team will collaborate and determine the types of therapy best suited to incorporate for your child's recovery. Parents and caregivers are an important part of this team and should be encouraged to ask questions and receive training on how to best to support their child throughout recovery.

Important things to know during rehabilitation:

- Your child's rehabilitation plan will continue to change as progress is made. The medical team should work with your family to prepare for your child's return home. You may need to consider making modifications to your home to make it safe and accessible for your child.
- When you leave the hospital, rehabilitation should continue and may occur in different settings depending on your child's age and need. Programs can include an outpatient clinic, early intervention services, pediatric specialty clinics and/or community programs in your area.
- Your child will continue to have appointments with their rehabilitation specialist to assess and follow up on their recovery. Every child's recovery from stroke is unique, and the medical team is there to make sure your child has the services they need in order to have the best recovery possible from their stroke.





ALISA – MOTHER TO JACKSON, PERINATAL STROKE WARRIOR

“Never be afraid of a diagnosis. It will only open your child up to more services and don't be afraid to push back on any therapist or medical provider when you feel you are not getting the clear information you need. Always work as a team when it comes to your child. “

YOUR CHILD'S CARE TEAM

There will be a variety of different types of medical professionals involved in the care of your child while in hospital and when rehabilitation begins. They should all work together as a team. Family members and patients are very important members of this team and should be active participants in care planning and decision-making for their child.

Each of these medical professionals, at one time or another, may be involved in your child's care. Based on your child's specific needs their medical team may include:

- Pediatric Neurologists who specialize in stroke
- Neonatologists
- Cardiologists
- Hematologist
- Genetic Counselors
- Physiatrists– doctors who specialize in rehabilitation
- Pediatric Ophthalmologists
- Developmental Pediatricians
- Developmental Psychologists
- Speech Language Pathologists
- Physical Therapists
- Occupational Therapists
- Social Workers
- Case Managers

It is important to keep communication open and to continue asking your child's medical team questions throughout your child's care. Important questions can include:

- What type of stroke did my child have, and will my child need ongoing medications?
- Is my child at risk for seizures and what signs should we be aware of?
- What should I look for once my child is discharged from the hospital that may warn me that something may be wrong?
- What effects might the stroke have on my child's development, and what rehabilitation programs are available in my community?
- Does the hospital have a pediatric stroke support group or know of resources available within the community to help support our family?
- What types of financial and/or educational support is available for my child and our family?
- Who should I contact if I have a concern or if I have further questions?



CREATING A CARE NOTEBOOK

Creating a care notebook is one tool that can help you organize important information about your child. Even with the electronic medical records that are utilized among hospitals, parents and caregivers still receive countless printouts and paperwork at each appointment. Having a portable medical summary for your child to take to appointments and keep all documents in one place will serve a vital purpose in the ongoing advocacy for your child's overall care. It will also prove helpful while working with your insurance provider and ensuring the coverage to expect with the different therapies and services being provided.

Creating a care notebook can help you:

- Keep track of medications, therapy and treatment plans, tests and evaluation results
- Organize contact information for health providers, social workers, therapists and organizations
- Keep track of communication from meeting sessions about your child (IFSP and IEP records).
- Help you to prepare for appointments and address questions and concerns
- Keep track of all statements and communications between your insurance company

How to get started:

- Build a notebook using a 3-ring binder, expandable folder or box and add dividers that are important to you. Examples can include: Portable Medical Summary, Quick Contact, Discharge Reports, Records, Logs, Therapy Calendar.
- Gather all existing information such as discharge reports, clinic visit summaries, immunization records, school plan, test results and scheduled care plans.
- Clear page protectors make it easy to remove and update pages as needed. Some families have found it works best to have different notebooks for school and health records - find what works best for your family.
- *Frequently used forms can be found and printed from our website at under the Family Support section.*



STRONGER AFTER STROKE: RECOVERY & THERAPY

THE FAMILY'S ROLE IN RECOVERY

Parents and families have a primary role in their child's development. Your child's therapy team should collaborate with your family to promote development and to implement an individualized intervention program for your child based on age and areas of focus.

Families should be supported through coordination of services, advocacy and assistance to enhance the development of their child. Families should also address the questions on how to coordinate therapy in day to day living for their child.

Frequently asked questions can include:

- How can I modify or adapt toys, feeding utensils, items for selfcare - used in my child's daily routine?
- What mobility options with equipment are needed and available?
- How do I best facilitate safety within the home, school and community?
- What information can be provided to other members of the family, daycare and/or my child's school district on how to best support my child's needs?

UNDERSTAND YOUR INSURANCE

Private and public health insurance programs may cover payment for certain therapy, medications and/or mobility equipment, but the services and reimbursement may vary greatly. Families should become familiar with the benefits provided by their policy or program in advance and keep track of all communications and statements of explanation.



THE PATH TO THERAPY

EARLY INTERVENTION THERAPY – BIRTH TO THREE

Early intervention programs provide specialized health, educational and therapeutic services during the first three years of life for children who have developmental delays or disabilities.

Children who are considered “at risk” of developing a delay may also receive services. The most common intervention services for children after stroke are physical therapy, speech therapy, and occupational therapy. These services are mandated by a federal law called the Individuals with **Disabilities Education Act (IDEA)**. The law requires that all states provide early intervention services for any child who qualifies, with the goal of enhancing the development of infants and toddlers.⁶

Intervention is vital during this very early time after stroke because a child learns and develops at the fastest rate during these first few years of life. It’s important not to miss out on this crucial part of your child’s development.

The goal is always to help your child achieve the highest function and interaction at home and within the community. Early intervention can also be a huge support and guidance to your family. There is a lot to know about early intervention, so we have covered the basics to help as you get started. Your child’s neurologist can put you in touch with early intervention programs in your community, or many states have online information and further explanations for parents detailing the early intervention services in each state.

WHAT TO EXPECT FROM AN EVALUATION

Your child needs to be evaluated to determine if he or she is eligible for early intervention services. This evaluation is of no cost to your family because it is funded by the state and federal government.

You will be asked to sign a consent form prior to the evaluation and share information about your child’s development, health and their medical history. You will be asked to provide information about your family’s resources, priorities and concerns. This detailed information is necessary to help the early intervention team develop a plan that meets the needs specific to your child and family.

One step at a time.

In the beginning, it can feel like simply breathing becomes hard work.

As you begin going through the motions of doctor appointments, evaluations, therapy and all the encompassing medical moments in your child's early life, you will reach a place of courage and determination that you may have never known as a parent.

As parents, we believe we are our child's teacher, but often it is our child that teaches us the greatest life lessons.

EARLY INTERVENTION THERAPY – BIRTH TO THREE

A team of professionals will work with you to evaluate your child's development in five areas:

- **Physical:** reaching for and grasping toys, crawling, walking, jumping
- **Cognitive:** catching activities, following simple directions, problem-solving
- **Social-Emotional:** making needs known, initiating games, starting to take turns
- **Communication:** vocalizing, babbling, using two- to three-word phrases
- **Adaptive:** holding a bottle, eating with fingers, getting dressed

Once your child has been tested and determined to be eligible for early intervention services, you will meet with your early intervention team to develop a plan of services, called the **Individualized Family Service Plan**. The (IFSP) contains goals, or outcomes, that you and other members of the team will identify based on your family's concerns, priorities and resources. Services will be identified to help your child and family meet the IFSP outcomes and will continually be updated as growth and goals are met.

Examples of early intervention services:

If your child has a disability or a developmental delay in one or more of the above developmental areas, then they will likely be eligible for early intervention services. These services will be specifically tailored to your child's individual needs and may include:

- Assistive technology (devices a child might need)
- Audiology or hearing services
- Speech and language services
- Counseling and training for the family
- Medical services
- Nursing services
- Nutrition services
- Occupational therapy
- Physical therapy
- Psychological services

Every effort is made to provide services to all infants and toddlers who qualify for services, regardless of family income. Services cannot be denied to a child just because his or her family is not able to pay for them. Under IDEA, the following services must be provided at no cost to families: evaluations and assessments, the initial development and ongoing review of the IFSP and service coordination.⁶



TRANSITION FROM BIRTH TO THREE

EARLY DEVELOPMENTAL PRESCHOOL AND THE IEP PROCESS

The transition to Developmental Preschool can bring about big emotions not only for parents, but can become challenging for your child as well.

Families who choose to enroll their child in these services can help the transition process and preschool experience be more meaningful and productive. By visiting the school and building relationships with the teachers and therapists, you and your child can feel more comfortable in what to expect from a developmental preschool program.

Greater success can be reached when both the school and family are working together toward the same goals.

Early intervention services will come to an end on your child's third birthday. A transition meeting with your family care coordinator, your child's current therapy team and a school district representative will be scheduled 6 months prior to your child's third birthday, allowing time for a transition plan to be put into place.

Services for preschool children (ages 3 through 5) will be discussed and are provided free of charge through your public school system, if your child qualifies. These services are made available through the **Individuals with Disabilities Education Act (IDEA)** - the same law that applied to Early Intervention Services.

This transition meeting is a time of review, planning and new goal setting for your family and child. You will talk next steps and learn about the programs or services that may be available for your child and for their continued development. Special education services can include individualized, specially-designed instruction in academic, self help, communication, motor, vocational and social skill areas.

Individual Education Programs (IEPs) are developed for your child's specific needs based on the results of formal and informal testing and observations. The question as to whether or not your child will qualify for early childhood special education services and/or whether or not that is the route you believe would be best for your family are often heavily weighted.

Personal emotions, intertwined with the responsibility of making the right choices for your child's future, can often result in a time of uncertainty. This can be exacerbated by a new education process that may seem overwhelming at first. You may feel as if you are starting over in building a new plan of therapy for your child. In retrospect, you are. However, it is so important to stop and appreciate just how far your child has already come!

At the preschool age, families may decide to pursue private clinic therapy, and seek school based services at a later age. Some families may even choose both school based services and private therapy to be used in conjunction. The reality is, family dynamics of your child's therapy may vary. The best choice is always the one that fits your own family and your child's ongoing needs the most.

STRONGER AFTER STROKE: PHYSICAL THERAPY

Pediatric physical therapy (PT) in all ages, promotes independence, increases participation, facilitates motor function and development, improves strength and endurance, enhances learning opportunities, and eases challenges with daily caregiving.

Physical therapists will use their expertise in movement and apply clinical reasoning through the process of examination, evaluation, diagnosis, and intervention. Physical Therapy will address the child's general strength and their abilities in the areas of gross motor skills and mobility.

Pediatric physical therapy may include any of the following services as part of your child's plan of care:

- Developmental activities
- Movement and mobility
- Strengthening
- Motor learning
- Balance and coordination
- Recreation, play and leisure
- Adaptation of daily care activities
- Tone management
- E-Stim (a form of therapy that can help improve muscle function)
- Use of assistive technology
- Posture, positioning and lifting
- Orthotics, AFO'S, SMO'S

STRONGER AFTER STROKE: OCCUPATIONAL THERAPY

Occupation refers to all of the "jobs" that make up our daily life, whether you are child or a young adult. **Occupational Therapy (OT)** will evaluate your child's ability to perform self care, play, and school skills at an age-appropriate level. The goal of OT is for the child to participate as actively and fully as possible in all areas - self care, play and school skills.

Through a comprehensive evaluation the therapist can begin to identify issues that interfere with a child's performance. This may include problems with strength, abnormal muscle tone, eye-hand coordination, visual perceptual skills and/or sensory processing skills.

Pediatric OT may include a variety of approaches in assessing and treating children, including neuro-developmental treatment (NDT), sensory processing, motor learning approaches, constraint therapy, kinesiotaping, sensory integrative (SI) therapy, vision related therapies and feeding related therapy. Therapy is child directed and based on activities that are meaningful and purposeful to that specific child.

Your child's therapist may incorporate various tools and adaptive equipment to increase independence. Examples can include specialized feeding utensils, adaptive scissors, writing utensils and hand splints. They may recommend and show a parent and child how to use adaptations to clothing such as zipper pulls, button hooks and Velcro in order to allow a child to learn further independence in self care.



STRONGER AFTER STROKE: SPEECH THERAPY

Speech-Language Pathologists (SLP) evaluate communication skills and treat speech and language disorders. This can include both receptive and expressive language, auditory processing, memory, articulation, fluency, oral-motor development, and feeding skills. The speech pathologist may also screen a child's hearing and make a referral for further evaluation if needed.

Speech disorders include:

- **Articulation disorders:** difficulties producing sounds in syllables and/or saying words incorrectly to the point that listeners can't understand what's being said.
- **Fluency disorders:** such as stuttering, in which the flow of speech is interrupted by abnormal stoppages, repetitions (st-st-stuttering), or prolonging sounds and syllables (sssstuttering).⁸
- **Resonance or voice disorders:** problems with the pitch, volume, or quality of the voice that distract listeners from what's being said. These types of disorders may also cause pain or discomfort for a child when speaking.
- **Dysphagia/oral feeding disorders:** difficulties with drooling, eating, and swallowing.

Language disorders can be either receptive or expressive:

- **Receptive disorders:** difficulties understanding or processing language.
- **Expressive disorders:** difficulty putting words together, a limit in vocabulary, or inability to use language in a socially appropriate way.

Strategies:

- **Language intervention activities:** The SLP will interact with a child by playing and talking, using pictures, books, objects, or ongoing events to stimulate language development. The therapist may also use repetition exercises to build speech and language skills.
- **Articulation therapy:** The SLP will model correct sounds and syllables for a child, often during play. The SLP will physically show the child how to make certain sounds, such as the "r" sound, and may demonstrate how to move the tongue correctly to produce specific sounds.
- **Oral-motor/feeding and swallowing therapy:** The SLP will use a variety of oral exercises - including facial massage and various tongue, lip, and jaw exercises - to strengthen the muscles of the mouth. The SLP also may work with different food textures and temperatures to increase a child's oral awareness during eating and swallowing.

BEST SPEECH APPS TO TRY

- Articulation Station Pro by Little Bee Speech
- Brainbean
- BubbleABC
- Fun & Functional by Smarty Ears
- Language Adventure
- Peekaboo Barn by Night & Day Studios, Inc
- Sounds At Home
- Speech4Good
- ToyBrush 3D by Croco Studio

Please Note: The use of apps in no way replaces receiving certified help from a therapist. These speech apps are suggestions to assist your child at home and to help reinforce skills already being practiced at therapy sessions.

ONGOING CARE: BENEFITS OF HIPPO THERAPY

“The term Hippotherapy is a form of physical, occupational and/or speech therapy in which a trained therapist uses the characteristic movements of a horse to provide motor and sensory input.”⁹

Therapeutic horseback riding has been around for years. Riding not only builds on self-confidence, but the physical benefits of riding for children with disabilities is huge.

Riding can assist by improving a child’s balance, strengthening the muscles and improving a child’s overall coordination. It can also promote sensory and motor input and improve sensory processing and neurological function.



CONSTRAINT INDUCED MOVEMENT THERAPY (CIMT)

Constraint Induced Movement Therapy (CIMT) has been applied to adult stroke patients with some beneficial results. This therapy is thought to increase the neural connections in the area of the brain that controls the affected side. Because of the success in adults with strokes, this therapy is now being applied to children.⁴

Pediatric CIMT is a motor therapy program for children with limited function in one of their arms. It is geared for children who are able to cooperate with others during one-on-one and group therapy with children in the same age range.

CIMT is often given in an intensive series of lessons over a 2 to 3 week period and will take place in a fun environment that motivates the child to use the affected side. The non-affected arm is put in a long arm cast. During this time, your child will do intensive training of the arm that has limited motor function. Therapists will help your child use the affected arm often, repeating the same motion over and over again, shaping the desired movement.

Research continues to show that this form of therapy can increase the awareness and quality of movement required for two-handed activities.

Talk to your therapist about the appropriate age for your child in order to participate in this form of therapy and if there is a program in your community. Based on insurance and diagnosis, coverage varies for this type of therapy so we encourage you to confirm with your insurance before you attempt scheduling.

FINDING THE PERFECT “FIT”

The struggle is most often real in finding the perfect shoe for your child to wear over their orthotic. Some may only need to wear an orthotic on one foot, thus making a difference in shoe sizes and an increased challenge in purchasing shoes.

Check out these recommended brands by parents:

- Nordstrom (will sell separate sizes in same shoe)
- Keeping Pace
- EasyUp Shoes
- Hatchbacks
- New Balance
- Stride Rite – Wide
- Plae – with XL Tabs
- Nike Flyease
- BILLY Footwear



INTRODUCTION TO BRACING & ORTHOTICS

When a child first receives a diagnosis and treatment plan it will most often include a recommendation for bracing or orthotic intervention. This usually proves to be a learning process for both the parents and the child.

It's natural for parents to question the need for bracing and the benefits it will serve. As you learn more about orthotics and their potential role in the life of your child, you will come to know that orthotics can be a valuable resource for improving overall physical health and emotional well-being.

The Benefits of an Orthotic

Ankle Foot Orthotics (AFO'S) are commonly prescribed in children with neurological disorders such as stroke and Cerebral Palsy. Simply put, an AFO (sometimes called a brace or splint) provides support to help a child maintain a foot/ankle position, encourage mobility and overall improve stability and success.¹¹

Helping your child adjust emotionally

Even when an orthotic is properly fitted, in a fun design - your child may still experience frustration in wearing one. Most treatment plans require the orthotic to be worn continually, day and/or night. Be understanding that they may be somewhat apprehensive. Children don't want to stand out from their peers, so it can be difficult to wear an orthotic because it is noticeable to others.

To help a child adjust:

- Be positive and explain how much the orthotic helps. Encourage your child to think of it as a something that makes them *stronger, faster and safer*.
- Talk with and prepare your child with answers for when others may ask about their orthotic.
- Share pictures and stories of other children or adults, that also wear orthotics.





ORGANIZATIONS & FAMILY SUPPORT RESOURCES

PEDIATRIC STROKE SUPPORT GROUPS

Hospital based Pediatric Stroke Support groups are an area of need that are growing. Pediatric stroke support groups provide a re-occurring meeting place for parents to discuss topics, share stories and help ease the isolation that is common after a child's stroke. Check with your child's medical team and ask if the hospital has this type of program for your family to take part in.

Many parents have expressed the desire for an ongoing family support group, but that there is simply no time to fit one into their schedule. This is especially true as you begin balancing medical appointments, care, career, family and all of the many details of everyday life. If time restrictions make it hard to prioritize support, there are a number of online and social media support pages that exist.

Virtual family to family support groups allow you to connect and ask questions on your schedule - without leaving the comfort of home. Having those connections with other families who have "been there" is a proven source of ongoing support that we encourage you to consider joining. We have included a number of these virtual support groups in this toolkit, find one that works best for you.

ONLINE PEDIATRIC STROKE NETWORK

American Heart and American Stroke Association Support Network for Pediatric Stroke: This Support Network offers a dedicated Pediatric Stroke discussion board where you can connect with other families and caregivers, share your stroke experiences, and give and get emotional support and encouragement.

Set up a profile at Supportnetwork.heart.org

PEDIATRIC STROKE SUPPORT GROUPS ON FACEBOOK

CHASA Hemiplegia Parent Support - National
www.facebook.com/groups/1419182238299142/

KISS Pediatric Stroke Support Group - National
www.facebook.com/groups/829527060489244/

Little Stroke Warriors Support Group - (Australia and New Zealand)
www.facebook.com/groups/1214183908703615/

(MISS) Moms of Infant Stroke Survivors - National
www.facebook.com/groups/122984791109944/

Pediatric Stroke Warriors of the Inland Northwest - (Idaho & Spokane)
www.facebook.com/groups/736904209754503/

Pediatric Stroke Warriors Family to Family - (Greater Pacific Northwest Region)
www.facebook.com/groups/411005725758581/

Pediatric Stroke Support Group of Colorado - (Rocky Mountain Region)
www.facebook.com/Colopedsstroke/

PEDIATRIC STROKE RELATED ORGANIZATIONS

Pediatric Stroke Warriors believes in the importance of being inclusive and sharing with families all of the organizations, programs and/or resources that currently exist to make a difference in supporting children and their families impacted by pediatric stroke.

American Heart/American Stroke Association: www.strokeassociation.org

Bellaflies Foundation: www.Bellaflies.org

Canadian Pediatric Stroke Support Association: www.cpssa.org

CHASA: www.chasa.org

Childrens Stroke Foundation of the Midwest: www.kidscanhavestrokesto.com

Fight The Stroke: www.fightthestroke.org

HemiHelp (UK Based): www.hemihelp.org.uk

International Alliance of Pediatric Stroke: www.iapediatricstroke.org

Strokidz (Australia): www.strokidz.com

World Pediatric Stroke Association: www.worldpediatricstrokeassociation.org



GENERALIZED SPECIAL NEEDS RESOURCES

Center for Parents Information & Resources (CPIR) serves as a central resource of information for families (www.parentcenterhub.org).

Child Neurology Foundation connects partners from all areas of the child neurology community so those navigating the journey of diagnosis and management of care have the ongoing support of those dedicated to treatments and cures (www.childneurologyfoundation.org).

Family Voices is a national nonprofit, promoting quality health care for all children and youth, particularly those with special health care needs (www.familyvoices.org).

Parent to Parent USA provides emotional & informational support for families of children who have special needs (www.p2pusa.org).

Sibling Support Project is a national program dedicated to the life-long and ever-changing concerns of millions of brothers and sisters of people with medical needs. Find a local SibShop program within your community (www.siblingsupport.org).

The Arc provides assistance to individuals with disabilities and their families in locating resources and community services (www.thearc.org).

Understood provides resources to help parents work constructively with schools and professionals (www.understood.org).

SPECIAL NOTE

For the purpose of this guide, we have included frequently used resources specific to Pediatric Stroke.

Our comprehensive website lists further resources that families have found helpful in day to day living and co-occurring conditions.

We recommend looking at our website under the Family Support Section for more information and links.

BOOKS & PUBLICATIONS

The Brain That Changes Itself by Norman Doidge

Healing the Broken Brain by Dr. Mike Dow

The Boy Who Could Run But Not Walk by Karen Pape, MD

Raising A Sensory Smart Child by Lindsey Biel

The Cerebral Palsy Tool Kit: From Diagnosis to Understanding by CPNOW

I See You Little Naomi by Stefanie Boggs -Johnson

The Little Dark Spot: How I came to terms with my Baby's Stroke

The Luckiest Girl in the World: My Story of Struggle & Hope in Overcoming Pediatric Stroke by Jamie Lee Coyle

RESOURCES SUPPORTING MEDICAL FINANCIAL ASSISTANCE

Alyssa V. Phillips Foundation, assists children with cerebral palsy to help with therapies or other medical treatments that insurance doesn't cover. The Foundation may provide financial support to those impacted by CP so that they can receive ongoing and necessary therapy treatments or medical equipment to increase independence where such benefits are not covered by medical insurance. www.alyssavphillipsfoundation.com

Air Charity Network, has been coordinating free air transportation for children and adults with medical needs for over 25 years. Air Charity Network is comprised of network member organizations serving all 50 states. For general guidelines, restrictions and a full directory, refer to www.aircharitynetwork.org/about-us/

CHASA (Children's Hemiplegia and Stroke Association), exists to improve the quality of life for children and their families affected by hemiparesis or hemiplegic cerebral palsy due to pediatric stroke or a variety of other conditions. CHASA helps with financial needs through their orthotic grant program, educational, retreat and athletic scholarships. www.chasa.org

Firsthand Foundation, is a public charity that provides funding for individual children with health needs when insurance and other financial resources have been exhausted. www.firsthandfoundation.org

Medicaid, is a federal government managed program by the Centers for Medicare & Medicaid Services. Learn more at www.medicaid.gov

MY GYM Challenged America, (MGCA) accepts applications for children with physical, cognitive and/or developmental disabilities and those coping with chronic illness. Requests, may include but are not limited to: rehabilitative therapy, assistive devices, medical equipment and sensory items. www.challengedamerica.com

Ronald McDonald House, is a network of Chapters have been making children happier and healthier by keeping families close - giving them a place to rest and refresh. These programs, tailored to meet the urgent needs of each community, can be found in more than 64 countries and regions across the globe. (Find your local RMHC) www.rmhc.org/about-us

The Lindsay Foundation, is a 501(c)3 non-profit organization whose primary goal is to assist families with the resources necessary to provide medical treatment, therapies, and rehabilitative equipment grants in order to improve the quality of life for their special-needs children. www.lindsayfoundation.org

The Stroke Fund at Seattle Children's Hospital, was established in 2016 by Pediatric Stroke Warriors in an ongoing effort to provide emergency financial aid to stroke impacted children and their families treated at Seattle Children's Hospital. Connect at Support@pediatricstrokewarriors.org

United Healthcare Children's Foundation, provides financial help/assistance for families with children that have medical needs not covered or not fully covered by their commercial health insurance plan. They aim to fill the gap between what medical services/items a child needs and what their commercial health benefit plan will pay for. www.uhccf.org

Wheel to Walk Foundation, is a non-profit organization that helps children with disabilities, 20 years of age and younger, obtain medical equipment or services that is not provided by insurance. This organization strongly believes that no child or young adult with special needs should go without items that could improve the quality of his or her daily life. www.wheeltowalk.com

These organizations, resources and programs can change in what is available to support the medical financial assistance to families. It is important to refer to each organizations individual website for all details and guidelines.



WORDS FROM THE HEART

“THE MOMENT WE FOUND HOPE AGAIN AFTER MY CHILD’S STROKE.” - FEATURED ON THE MIGHTY BLOG

There is no memory as vivid to any parent as the day they meet their child for the first time. It’s the day the anticipation comes full circle and they hear their child’s first cry into the world pierce the silence. The complications towards the end of my pregnancy made her cry even more monumental for me and even more reassuring that our beautiful girl was here. I finally got to hold her, see those beautiful red curls and soak in those 10 tiny toes and fingers - my little sunshine mixed with a hurricane was here.

Those first weeks home were as beautiful as they were difficult. While most newborns sleep, our daughter had difficulty, sleeping no more than a two-hour stretch at a time. While most newborns build an appetite and yearn to eat, our infant would eat for minutes at a time and then cry with frustration and discomfort. We were at a loss and had many questions, but we were assured at each of her appointments that she was healthy and this phase was all a part of being an infant.

As weeks turned into months and sleep and eating continued to prove difficult for her, we had many appointments. There were many discussions on colic, acid reflux and allergies. We sought support from lactation specialists, therapists trained in reflux and made countless morning calls to her pediatrician to be seen that day after a horribly hard night. All attempts proved futile with the constant reassurance that she was healthy.

As my daughter began taking notice of toys and figuring out her world, I started to notice that she never unclenched her left fist. I had to try with all my might to get her little thumb out of her fist to introduce toys to her left hand or to clip her tiny nails. It was strange to me, but I didn’t have any knowledge to be overly concerned. At first, we believed she was born to be a righty. When she continued to disregard her left hand in play, I became scared that her arm or a nerve may have gotten hurt during my delivery.

It was at her six-month checkup that her pediatrician took notice with my concern. But, he added to my concern by sharing the possibility of a stroke - words that, no matter how hard anyone tried to explain away the rarity of it, I couldn’t get out of my mind. A child having a stroke - *how is that even possible?*



TRAPPER – FATHER TO ADDISON,
PERINATAL STROKE WARRIOR

"Regardless of what the MRI entailed or that stroke diagnosis, they are words and they are pictures. It all serves an undeniable purpose, but it has been my own daughter, and it will be your own child, that will define themselves."

We had a month of waiting to be seen by a specialist who performed a sedated MRI. In that time I had poured over Google to scour for every possibility and every relatable story. I was filled with anxiety, questioning myself, my pregnancy and any new behavior my daughter showed. I was lost, overwhelmed and scared. Friends and family tried to reassure me, to help calm my feelings by saying everything would be all right and that there must be an easy explanation.

When the call finally came and the doctor shared the results from the MRI, there was nothing easy about the explanation. Her words came across in slow motion, indicating the results reflected a stroke. The relief I had hoped to feel, that I had longed for after months of knowing there was something wrong, wasn't there - only new questions and emotions to struggle through.

That following week, we sat together huddled over a computer screen with the neurologist, scared and unsure of what all this meant for our little girl's future. Would she ever walk? Would she ever talk? Would she have another stroke? The doctor began to show each scan from her MRI, different angles and "slices" of images taken of my daughter's brain. The room filled with medical terms and more uncertainty until she paused on one image - an image from my daughter's chin up to the top of her head. It wasn't the dark void in the image on my daughter's right side of her brain that I focused on anymore. Now I could see the outline of her little face, the way her chubby cheeks left an outline even in an X-ray, and there she was. In that moment among the fear and uncertainty, I sat grounded, brought back to my senses that no matter what we could come to learn about this diagnosis, it did not define my daughter. She was still right there. My little sunshine mixed with a hurricane.

It's been nearly five years, and not only have we learned so much about stroke, but we also learned that we truly have to take it one day at a time. To say that it has always been easy, would be a lie. There have still been moments of feeling lost in emotion and worry. It's human and it's part of being a parent.

Families often want to know if this ever gets any easier. That answer is yes, but the timing is different for all of us. Hold fast that no matter the diagnosis, an image from a MRI - it is all a tiny part of the picture. Your child will make their way in overcoming and becoming so much more than you could ever imagine. Take Heart.

Kaysee Hyatt - Mother to Addison, Perinatal Stroke Warrior



WORDS FROM THE HEART

“WHEN I WAS TOLD I MAY NEVER DANCE AGAIN AFTER A STROKE AT AGE 10.” - FEATURED ON THE MIGHTY BLOG

When I was 6 years old, I was diagnosed with cavernous hemangiomas, a hereditary disease that causes weak veins in the brain. The veins can leak and cause a seizure or stroke. My doctors advised my parents that it was dangerous for me to play contact sports, so I took dance classes. I became a competitive dancer and trained 10 hours a week in dance and tumbling. I went along with my life not worrying about the time bomb in my head.

When I was 10, I was at the beach surfing when I had a hemorrhage in my brain stem, which caused a severe stroke. The bleed in my brain stem did not stop, and I had to have emergency brain surgery to save my life. Later, I found out the doctors did not know if I would survive, and asked my parents if they would sign papers to donate my organs. When I woke up, I was completely paralyzed. I could not eat, speak or walk. I felt like I was trapped inside myself. I saw the worry on everyone's faces and wanted to scream, “I'm here!”

I was transferred to a rehab hospital and received intense therapy. When I was told I may never dance again, I used my training as a dancer to help me focus, even when I was so tired I could barely hang on. It took two months of hard work and determination, but I was able to walk out of the hospital.

I used dance and music as a large part of my recovery. I could do things to music that I couldn't do at the therapy center. I was fortunate enough to have a very supportive dance studio, teachers and peers who understood how important dancing was to me. When I could not stand, my dance teachers would hold me up. I was back on a competition team a few months after I got out of the hospital. I continue to compete to this day, and have received many awards and honors for my unique style of dance and the way I share my story through dance. I am still partially paralyzed, and have not let that stop me.

Three years ago, I co-founded a class called the “Rising Stars” at my dance studio. This class is a chance for kids with physical and cognitive challenges to experience the same healing and joy that dance has given me.



GRACIE DORAN – PEDIATRIC STROKE WARRIOR

“It is a miracle that I lived through everything, and I believe I’m alive for a reason. I’m here to show the world that you can’t control what happens to you, but that you can control what you do because of what happened.

Your disability, no matter what it is, does not have to define you.”

GET CONNECTED

WEB: www.graciedoran.com

TWITTER : @daysofgrace99

EMAIL: daysofgrace99@gmail.com

Dance helped me recover and find my purpose after I got sick, and there is nothing that makes me happier than to see the kids smiling when they start to dance.

It is a miracle that I lived through everything, and I believe I’m alive for a reason. I’m here to show the world that you can’t control what happens to you, but you can control what you do because of what happened. You control your future, so when someone tells you that you can’t do something, show them you can. Your disability, no matter what it is, does not have to define you.

I have been fortunate to share my story at schools and to community members. I speak about resilience and showing people that you can do anything you can set your mind to. I have a favorite quote from Audrey Hepburn, “Nothing is impossible — the word itself says I’m possible.” I share the message that our differences don’t define us as people. What is “normal,” and who wants to be normal anyway? Our differences make us unique as individuals and beautiful in our own way. We may be very different on the outside, but we all share hopes and dreams. We all want to grow up and be successful and have a fulfilling life of our own.

My hope is to continue to be an advocate for people like me who may not have a voice. I want to continue to make an impact and be proud of what I’ve done. Someday, I want to be able to share the stories of my life with my children and grandchildren, and make them proud.

This is my disABLEd life.

Gracie Doran - Warrior



GLOSSARY OF MEDICAL TERMS

COMMON MEDICAL PROFESSIONALS

Cardiologists study the heart and its functions.

Developmental pediatricians are specially trained pediatricians who are primarily concerned with the evaluation of a child's development.

Developmental psychologists study the physiological, cognitive, and social development that takes place throughout life. Some specialize in behavior during infancy, childhood, and adolescence.

Genetic counselors are specialists who assess whether the stroke may be due to an inheritable condition.

Hematologists diagnose and treat diseases of the blood. A child who has had a stroke may see a hematologist for blood tests to determine if there is a clotting disorder.

Occupational Therapists (OT) help children improve their ability to perform tasks in their daily living. They help children succeed in their "occupation" of learning, playing and growing. They may help children with tasks such as improving hand function, strengthening hand, shoulder and torso, and eating skills.

Orthotists are responsible for the provision of orthoses (supportive devices such as braces) to children with muscular and skeletal disabilities.

Pediatric Neurologists diagnose and treat diseases that involve the nervous system in children. Children may see a neurologist to discover the cause of their condition, recommendations for treatment, diagnosis and treatment of a stroke, seizure disorder (epilepsy) and for other information concerning their condition.

Pediatric ophthalmologists can evaluate how well the eyes work together, exam vision and health of eyes, prescribe glasses, diagnose eye disease and perform corrective eye surgery.

Pediatric orthopedic surgeons are concerned with deformities, injuries, and diseases of the bones, joints, ligaments, tendons, and muscles. Treatment provided by an orthopedist may include manipulation, the fitting of braces or other appliances, exercising, and surgery.

Physiatrists (also called Physical Medicine and Rehabilitation Specialists) are familiar with rehabilitation from injuries including stroke.

Physical Therapist (PT) provide services that help restore function, improve mobility, relieve pain, and prevent or limit permanent physical disabilities of patients suffering from injuries or disease.

Neonatologists are specially trained pediatricians who study the development and disorders of sick newborn children.

Neuropsychologists study the relation between the brain and behavior.

Speech-Language Pathologist (SLP) assess, diagnose, and treat speech, language, cognitive, communication, voice, swallowing, fluency, and other related disorders; audiologists identify, assess, and manage auditory, balance, and all other neural systems.

GLOSSARY OF MEDICAL TERMS

COMMONLY USED MEDICAL TERMS

Apnea: Cessation of breathing. It is common for premature newborn infants to stop breathing for a few seconds. They almost always restart on their own, but occasionally they need stimulation to maintain regular breathing.

Ankle Foot Orthotic (AFO) (DAFO): A brace that is worn on the lower leg and foot to support the ankle and hold the foot in the correct position.

Arterial Ischemic Stroke (AIS): Brain injury caused by blockage of blood flow in an artery caused by a blood clot and/or narrowing of the artery.

Arteriovenous Malformation (AVM): An abnormal connection of arteries and veins in the brain.

Botulinum toxin type A: Most commonly called Botox. Botox is a therapeutic muscle-relaxing medicine. It is often used to reduce stiffness of muscles and to help with muscle spasms.

Cerebral Angiogram: A procedure that uses a special dye (contrast material) and x-rays to see how blood flows through the brain.

Cerebral Palsy (CP): Difficulty with physical movements that result from an abnormality or injury to the brain at birth. Medical professionals may describe a perinatal stroke survivor using the term 'Cerebral Palsy'.

Cerebral Sinovenous Thrombosis (CSVT): Impaired brain function or brain injury caused by blocked drainage of blood from the brain by clotting in the brain's venous system. CSVT may or may not cause brain injury or dysfunction

Constraint-Induced Movement Therapy (CIMT): Therapy that promotes hand and arm function by using gentle restraint. Most often a cast or splint is used on the stronger side to help promote better function and use of the affected side.

Congenital heart problems: Birth defects of the heart present at or before birth. Some heart malformations may not be apparent for several days to weeks after birth.

CT scan: Computerized tomography scan. This is a specialized procedure that takes multiple x-rays at various angles and then integrates all of them into pictures of high resolution.

Electrocardiogram (EKG): Non-Invasive test that records the electrical activity of the heart and can show if there is a heart condition present.

Electroencephalogram (EEG): A study used to measure the electrical activity of the brain.

Epilepsy: Sometimes called a seizure disorder, is a chronic medical condition produced by the temporary changes in the electrical function of the brain, causing seizures which affect awareness, movement, or sensation.

Hemorrhagic stroke: Hemorrhagic stroke occurs when a blood vessel that is damaged or dead from lack of blood supply, located within an area of infarcted brain tissue, ruptures and transforms an *ischemic* stroke into a *hemorrhagic* stroke.

Hypertonia: Increased muscle tone, with too much resistance to passive movement. Also referred to as spasticity.

GLOSSARY OF MEDICAL TERMS

Hypotonia: Decreased muscle tone - the infant may feel limp or “floppy” when held.

Hydrocephalus: Abnormal accumulation of cerebrospinal fluid within the ventricles of the brain. This can lead to increased pressure and enlargement of the ventricles, known as obstructive hydrocephalus. Abnormal re-absorption of the cerebrospinal fluid can also lead to fluid accumulation, known as communicating hydrocephalus. The accumulation of fluid puts pressure on the brain, forcing it against the skull and enlarging the ventricles.

Individualized Education Program: An IEP is the legal document that defines a child's special education program. It includes the classification under which the child qualifies for Special Education Services, services in which the team has determined the school will provide, yearly goals and objectives and any accommodations that must be made to assist in learning.

Intracranial hemorrhage: Bleeding in the brain that leads to brain injury. Arteries and other small blood vessels create pathways throughout the brain that bring blood from the heart. If these arteries or blood vessels weaken and burst, they can cause a hemorrhagic stroke.

Magnetic Resonance Arteriography (MRA): Non-invasive test that is used to visualize arteries and their blood flow.

Magnetic Resonance Imaging (MRI): A process that creates high-quality picture of the inside of the body. An MRI uses a large magnet to create these pictures⁴

Magnetic Resonance Venography: Non-invasive test that is used to visualize veins and their blood flow.⁴

Moyamoya: (pronounced MOY-a-MOY-a) : Happens when the major blood vessels to the brain (internal carotid arteries) become narrowed (stenosis). This narrowing decreases the space inside the vessels, making it harder for oxygen-rich blood to get through.⁴

Neurologic deficits: Problems with how your body works or what you can do, caused by decreased function of the brain, spinal cord or nerves. Examples can include numbness, weakness, trouble walking or speaking, loss of balance, vision changes and problems with memory or thinking.⁴

Plasticity: Sometimes called neuroplasticity, refers to the brain’s ability to reorganize connections and pathways.

Seizures: Involve a sudden change in a child's consciousness, motor activity or physical sensation. Abnormal electrical activity in the brain causes seizures, which can vary in intensity. They are called chronic if they continue over time. A seizure can involve many muscle groups or can seem to be as simple as staring into space.⁴

Supra Malleolar Orthosis (SMO): A Brace that supports the leg just above the ankle. It is the shortest of braces and helps to keep the heel in the correct position.

Transient Ischemic Attack (TIA): A temporary block of flow that can cause stroke like symptoms. It does not cause permanent damage and may be called a “mini-stroke.”

Ultrasound: An ultrasound uses sound waves to show pictures of the brain and blood vessels.

Vasculitis: A condition that involves inflammation in the blood vessels.

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- ³ **American Heart Association.** Heart and Stroke Encyclopedia. http://www.heart.org/HEARTORG/Conditions/The-Heart-and-Stroke-Encyclopedia_UCM_445688_SubHomePage.jsp
- ⁴ **Seattle Children's Hospital.** Pediatric Vascular Neurology and Stroke Program (Online) - <http://www.seattlechildrens.org/medical-conditions/brain-nervous-system-mental-conditions/stroke/>
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- ⁸ **KidsHealth.** Speech Therapy in Children (March 2015) Online at <http://kidshealth.org/en/parents/speech-therapy>
- ⁹ **American Hippotherapy Association.** (2016) http://www.americanhippotherapyassociation.org/wp-content/uploads/2015/02/AHA-Intro-PPT-for-Families_9_28_2016_final-ver.pdf
- ¹⁰ **Seattle Children's Hospital.** CIT Program (Online) <http://www.seattlechildrens.org/about/stories/innovations-in-occupational-therapy/>
- ¹¹ **Cascade DAFO.** Education Library- (online) <https://cascadedrafo.com/cascade-dafo-institute>

IMPORTANT NOTES

IMPORTANT NOTES

GET CONNECTED

EMAIL - SUPPORT@PEDIATRICSTROKEWARRIORS.ORG

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