Do You Know A Childhood Stroke Surviver?

by Gwenda Conner

On Sunday, September 24 at 8:00 a.m., the American Heart Association will launch its four-hour Heart Walk at the College of DuPage to raise money for cardiac research and education. Joining them this year will be friends and members of "Childhood Stroke and Hemiplegia Connections of Illinois," a local support group for pediatric stroke survivors and their families.

Never heard of pediatric strokes? Neither had Forest Park resident Michelle Dirks until she learned that her daughter, Katie, had likely suffered a stroke in utero. She was not prepared for that news. The standard twenty-week ultrasound had revealed something atypical but apparently harmless in Michelle's pregnancy. The umbilical cord had only one artery, not two, a condition that can prevent pairs from being formed in fetuses and result in babies with only one eye, ear, kidney and the like. From then until delivery, Michelle and Katie were monitored closely by ultrasound, which revealed no irregularities.

Barely had Michelle breathed a sigh of relief at having a seemingly healthy baby but she detected something unusual about her daughter's movements. They were asymmetric. Katie reached primarily with her right hand at four months, while her left hand stayed clamped shut. Knowing Katie was too young to demonstrate a dominant side, Michelle called the pediatrician, who referred her to Loyola for testing. The CT scan of Katie's brain showed that she had suffered an ischemic infarction, or stroke, most likely before birth.

A stroke occurs when part of the brain is deprived of oxygen. In adults, the cause is generally easy to isolate. Hypertension, hardened arteries, diabetes, and smoking are all known contributors to strokes. But in prenatal infants, the cause is rarely understood, despite the fact that 1 in 5000 children are known to suffer strokes pre- or perinatally. Post-partum, roughly 10 in 100,000 children suffer strokes, generally by age 8 but sometimes as late as 18.

Strokes are almost twice as prevalent in children as brain tumors. Indeed, they afflict about as many children as elderly. 12% of childhood stroke sufferers do not survive, making strokes among the top ten causes of death in children in the United States. And yet there are no national children's stroke programs here as there are elsewhere in the world, including Canada. As a result, little is understood about their causes and less about their prevention.

Studies have suggested that prenatal stroke sufferers are more often born to mothers who have had C-sections, amniocentesis, ruptured or infected uterine membranes, cord abnormalities, infertility problems, preeclampsia, or prolonged second stage labor. And yet there is no known causal correlation between any of these risk factors and prenatal stroke.

The Taira Family (clockwise from top): MaryJo, Nick, Kelly, Ella, and Lauren. photo courtesy of MaryJo Taira.

The causes of strokes experienced by kids after birth are sometimes easier to identify. Kids with congenital heart deformities and sickle cell anemia are at higher risk for stroke. Occasionally, whiplash can result in stroke if neck arteries are damaged, impeding the flow of oxygen to the brain. Sometimes bacterial meningitis and even the common chicken pox are triggers. Still, there is no underlying medical condition found in roughly one-third of the childhood stroke cases recorded.

Regardless of the cause, the treatment needs to be immediate. As the AHA says, "Time is brain." The long-term effects of a stroke can be severe. 60% of the survivors suffer some permanent disability, such as hemiplegia, or muscle weakness on one side (sometimes categorized as cerebral palsy). Many later suffer from seizures, epilepsy, and problems with language delay.

The plasticity of kids' brains helps them compensate and adapt after a stroke better than adults do, if diagnosed and treated quickly. Unfortunately, strokes in kids often go undiagnosed too long, partly because physicians are inadequately trained to recognize the signs and symptoms in children, and partly because these signs and symptoms mimic many other more common afflictions. Strokes in children, as adults, can produce severe headaches, vomiting, loss of motor control, speech, and vision. A child's limited ability to communicate these problems makes diagnosis all the more difficult. The only way to definitively diagnose a stroke is through the advanced brain imaging only recently available in CT scans and MRIs.

Aggressive therapy is prescribed upon diagnosis. Katie is one of the lucky ones, relatively speaking. Her stroke is known to have been more minor than some. At five years of age, she has exceptionally high verbal abilities, but still she struggles to strengthen the left side of her body, weakened by the stroke. Katie has done weekly physical and occupational therapy since she was an infant. She participates in a speech and language study at the University of Chicago, and until she was three, she also underwent developmental evaluations twice a year. Indeed, trying to squeeze in "normal" daily life activities can be a challenge in time management, says Katie's mom Michelle. The family takes off from therapy the whole month of July, which helps. But more importantly, Michelle emphasizes play as therapy, so Katie has fun doing the activities she enjoys as a typical five-year old

while still honing fine and gross motor skills. Katie takes dance lessons, swims, bicycles, and has recently discovered the joy of rock wall climbing. Other kids have discovered the benefits of horseback riding.

yet to manage his seizures effectively. So, until they find the drug that fits, Nick is subjected to a barrage of epilepsy treatments—all "dirty meds" with known side-effects that only compound his other problems. "That's

12% of childhood stroke sufferers do not survive, making strokes among the top ten causes of death in children in the United States.

She dreams of becoming a doctor and a dancer and may well do both. She hopes to tie her own shoes and wear flip-flops someday, too, and likely will. "She's all girl," Michelle says with a smile. "She wants to be able to wear fancy shoes, and I want her to also."

Sometimes known therapies are inadequate in addressing the complex needs of childhood stroke survivors. This is especially true when it comes to the behavioral issues that are widely reported but poorly understood. River Forest mom MaryJo Taira is all too familiar with such behavioral concerns. Her son, Nick, suffered a prenatal stroke—a major one. He is now 9 years old and doctors are pleased by the impressive recovery he has made over the years through the usual routine of physical and occupational therapy. But the stroke has impacted every aspect of his life, even his personality, says MaryJo.

She and her husband thought Nick had been spared any emotional or cognitive impairments until he reached second grade and they began to manifest. He struggles with an anxiety disorder and periodic breakdowns. Plus, Nick is a perfectionist. The combination of wanting to perfectly execute something he is unable to make his body do results in frustration for him, as it does for so many of these kids.

He now works with his pediatrician, neurologist, psychiatrist and psychologist to address the emotional repercussions from the stroke. And he continues to commute to DuPage Easter Seals in Villa Park for weekly PT and OT sessions. But Nick tires more easily than does an average kid his age, his body being less efficient. Even getting through a school day drains him. And getting the therapy he needs further fatigues him, exacerbating the existing issues. He, like Katie, engages in recreational therapy, riding his bike, playing baseball, soccer, and even one-handed piano under the instruction of Steckman Studios in Oak Park. And all these help. But still he can be, his mom says candidly, "a difficult kid."

To complicate matters, Nick has developed epilepsy, as forty percent of childhood stroke survivors do. The doctors have

Katie Dirks Photo courtesy of Michelle Dirks.

what's hardest," says MaryJo. "Not being able to fix things for him right away…He's got the toughest job there is. He's got to live through all this first-hand."

But it can be hard for parents of stroke survivors, too, incessantly advocating for the best from doctors, therapists, insurance companies, and schools. How do they do it all? "You just have to. He's your child," explains MaryJo. And at some point you stop asking why it happened and just move forward. Both MaryJo and Michelle found a great resource to help them do just that when they found the support group called Childhood Stroke and Hemiplegia Connections of Illinois (formerly Parent Association for Children with Hemiplegia and/or Stroke). Begun in April 2002 with one meeting organized by one woman, Mary Kay Ballasiotes (whose own daughter, now 8, suffered a prenatal stroke), the organization has evolved and expanded to include fifty families and offer a variety of services to "just help the families dealing with this situation," says Mary Kay.

CSHC hosts annual social events for stroke survivors and their families. Once a year, the organization offers a day devoted to resource sharing, during which they dish on doctors, hospitals, activities and treatments that work and don't work. They locate and help enroll kids in local research studies in the hopes of contributing to a better understanding of the disease. They recruit doctors and other medical professionals to donate their time for free conferences, in which members learn about studies and developments in the field, and are allowed the opportunity to ask questions. Often as not, though, the doctors leave having learned something, too, from these families who have learned so much from their own personal journeys.

Educating the public about pediatric strokes is another main component of CSHC's mission. To bring awareness to the condition, its prevalence and seriousness, CSHC hopes to have 100 representatives at the American Heart Association Heart Walk on September 24, all wearing t-shirts that say, "I know a childhood stroke survivor." Though the money they raise will not go specifically to childhood stroke research, Mary Kay hopes that with enough awareness one day it will. One day, she hopes CSHC will fund its own pilot study for the pediatric research so urgently needed in the U.S. Until then, Mary Kay, Michelle, MaryJo and their kids will be there to remind you that, yes, kids can have strokes. But with proper treatment and intervention, they can also have the most remarkable lives, too. As Michelle says, the insurance company and medical records department may see Katie as a composite of physical aberrations. "But that's not Katie to me or anyone who knows this little dynamo. She is my daughter. She is my hero."

To participate in the walk or show your support for those who do, visit the CSHC home page at www.cshconnections.org and follow the link for HEART WALK. More general information about CSHC and the support services offered may be found there as well.

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Babies & Children Can't Have Strokes....Can They?

By Janice Youngwith
Wednesday, February 1, 2006

When Judy Bergman of Grayslake gave birth to her second child, Noelle, on Feb. 13, 2003, she had no inkling that stroke was something that could occur in newborns or young children.

Neither did Lori Malawski of Aurora, whose twin children, Alex and Amanda, were born 11 weeks prematurely Sept. 5, 2001. Another mom, Diane Ellig, Naperville, whose six-year-old son, Jack, suffered a grade three intracranial brain bleed, says she, too, was shocked.

Noelle Bergman and her family of Grayslake

Bergman, Malawski and Ellig are not alone as experts say it is only recently that efforts are underway to detect strokes and bleeding faster in these young patients and to begin treating them faster to help rescue their brains.

What Is Infantile & Pediatric Stroke?

Pediatric stroke occurs in approximately one in 5,000 births each year, according to Mary Kay Ballasiotes, president and founder of the Childhood Stroke & Hemiplegia Connections of Illinois family support group.

"Strokes can happen before or around the time of birth, or even in the childhood years," she says. "It's a common misconception that children can't have strokes. While still considered rare, thousands of children do have strokes each year and some experts fear the rate is on the rise."

National Institute of Neurological Disorders and Stroke statistics point to as many as one in 5,000 infants a year suffering a stroke during the newborn period or before birth and another six of every 100,000 children under the age of 18 having strokes each year. With 12 percent of pediatric stroke victims dying each year, stroke has become one of the top 10 causes of childhood death.

Stroke, the third leading cause of death in adults, is barely on the radar when it comes to young children.

"There are lots of misconceptions and knowledge gaps when it comes to childhood stroke," explains Ballasiotes, who started the suburban family support and information group almost four years ago to share her own family's resources and eight-year-old daughter's stroke experience. "Yet, most agree that age difference is important as newborn strokes seem different from those in babies and older children."

Scientists tend to agree, saying if good news exists it lies in the resiliency of young brains and their ability to carve new neurological pathways and rebuild after a major assault. Others say sobering new research suggests more than half these children will have permanent motor or cognitive disabilities.

High blood pressure and atherosclerosis often are cited as leading causes of adult stroke. For children, causes vary and in many cases, are unknown.

Researchers say strokes appear to occur at a higher rate in babies born to mothers who delivered by Caesarean section, had an amniocentesis, ruptured membranes, prolonged second-stage labor, cord abnormalities, preclampsia or histories of infertility.

New research, according to Ballasiotes, shows strokes are as common in newborns as in the elderly, and they can happen in otherwise healthy babies.

Two main types of stroke, both relatively rare in children, include hemorrhagic bleeding in the brain and ischemic stroke caused by a blockage in blood vessels.

Common perinatal stroke survivor disabilities include cerebral palsy, a diagnosis that describes children with problems ranging from clumsy movement to severe weakness; epilepsy; language delay and behavioral problems including attention deficit hyperactivity disorder.

With the cause of stroke in babies still not known, experts say infants with unexplained weakness on one side of the body or seizures should be evaluated by a neurologist.

Eight-Year-Old Michelle's Success Story

Michelle Ballasiotes, an eight-year-old second grader at Kingsley Elementary School in Naperville, loves to read, draw, jump rope and run after her 14-year-old brother and 11-year-old sister.

Michelle Ballasiotes

"We knew before birth of a possible brain anomaly," recalls her mom, Mary Kay Ballasiotes. "The diagnosis was hydrocephalus (an abnormal build up of fluid on the brain). Doctors at Advocate Lutheran General Hospital, Park Ridge, walked us through the last few weeks of pregnancy before Michelle's birth in November 1997.

According to Ballasiotes, the neurosurgeon who treated Michelle's hydrocephalus shortly after birth detected signs of an old hemorrhage. That's when she and her husband, Mike, learned their tiny newborn had suffered a stroke between 20 and 29 weeks gestation.

"It just didn't seem possible that this little baby, who looked so perfect to us, could have experienced such trauma," she recalls. "By three months of age, Michelle was given a diagnosis of right hemiparesis, a weakness on the right side of her body. We found that hemiparesis is very common in children who have a unilateral brain injury such as stroke."

Ballasiotes says the family is fortunate and grateful to have received the early diagnosis, enabling tiny Michelle to begin intensive physical and occupational therapy at six months of age.

"Because her disability is mild, most people don't have a clue of Michelle's challenges unless they see her leg brace," her mom reports. "Because her right side is weaker, Michelle wears an ankle-foot orthotic device on that leg. She's left-handed and works daily to strengthen her right side thanks in part to the challenges of a new birthday guitar.

"We truly believe that if Michelle had not been diagnosed so very early in life and had not received early intervention therapy during those first formative years, she would not be where she is today," Ballasiotes reports. "Not all children who suffer a stroke at or before birth are so lucky."

Three-Year-Old Noelle Inspires Grayslake Family

Princesses and baby dolls top little Noelle Bergman's day-to-day playtime preferences and birthday wishes. Soon to celebrate her third birthday on Feb. 13, Noelle's infancy and toddler years have been marked by challenges.

"It was a normal pregnancy and full-term delivery when Noelle made her debut at Lake Forest Hospital," mom Judy, 36, recalls. "Her one-year-old brother, Connor, was thrilled and even though she cried lots, we didn't think too much of it."

By her fourth month, Noelle exhibited a distinct preference for using her left hand to reach for objects. "We thought she would be a lefty," Bergman says. "But by her six-month check-up Noelle still wasn't using her right side. We were referred to a pediatric neurologist and astounded to be told she could have suffered a stroke."

A later MRI exam at Children's Memorial Hospital confirmed Noelle's stroke, indicating a left-sided stroke had occurred in the perinatal period between the 28th week of gestation and the first 28 days of life.

With the stroke located near the brain's speech center, Bergman says she is amazed her daughter's speech has not been affected and that she is on track for language development. She also credits early intervention physical and occupational therapy for helping her daughter make big strides.

Noelle began walking by 21 months and currently wears an ankle-foot orthotic on her right leg. Botox injections have helped relax tightened hand muscles and temporarily provide Noelle additional sensory input and time to improve strength and motor control.

This past August, Bergman began training for the American Stroke Association's rigorous Train To End Stroke fundraising marathon and last month successfully completed a half-marathon in Phoenix. Bergman trained for more than six months with a local Train To End Stroke team and raised thousands of dollars to fund American Stroke Association research.

"My husband, Rich, and I aren't the only parents who didn't know children could have strokes," she admits. "Even many physicians don't know much about pediatric stroke, dismissing parents' concerns and inadvertently delaying diagnosis. Noelle is among the lucky ones diagnosed early and able to take advantage of early intervention therapies. Getting involved in the Train To End Stroke program seemed a good way to help spread the word, and get in better shape at the same time."

Double Challenges For Sugar Grove Twins Alex & Amanda

Lori Malawski, a 36-year-old mother of five-year-old Sugar Grove twins, has her hands full.

The twins, Alex and Amanda, arrived 11 weeks earlier than anticipated after only 29 weeks gestation. The dynamic duo, who weighed in at three pounds-five ounces and three pounds-three ounces respectively, immediately faced a number of challenges. For their first 38 days of life, they called the neonatal intensive care unit at Good Samaritan Hospital, Downer's Grove, home.

Alex and Amanda Malawski of Sugar Grove

Due to their prematurity, both required assistance breathing, had to be intubated and required supplemental oxygen.

"Alex' situation was at times more severe," recalls his mom, a former insurance adjustor. "He suffered severe bleeding and doctors feared hydrocephalus. At nine months, he was evaluated for a special shunt on the right side of his brain."

According to his mom, Alex has left-sided hemiparesis. Early intervention occupational, physical and developmental therapy helped the little boy achieve many motor goals. His parents credit therapists at the nearby Association for Individual Development (AID) in Aurora, with much of their son's progress, along with the early intervention program.

Alex currently tips the scales at 47 pounds, possesses a natural curiosity, an incredible sense of humor and is very social, enjoying Veggie Tales, Thomas the Train and Shrek videos as well as swimming lessons. Special daytime and nighttime ankle-foot orthotics help maintain proper positioning of Alex's right leg.

Alex' sister, Amanda, also suffered severe bleeding on her brain, which resulted in right-sided hemiparesis. Early intervention services included developmental, physical and occupational therapies. Ongoing efforts include therapy as well as right-sided ankle-foot orthotic devices for daytime and nighttime wear as well as medications to relax tightened muscles each evening.

The 34-pound little girl, who loves Disney princesses and mom's make-up, is athletic and shares her mother's passion for scrapbooking. Both Alex and Amanda attend preschool together.

"My husband, Matt, and I knew we were expecting twins and had all kinds of special books on raising twins," Lori recalls. "None mentioned even the possibility of babies having strokes. It was a landslide first year for us. In-home daycare meant I was able to work, but therapy consumed our evenings. In August 2004, I became a full-time at-home mom so I could devote my time to the kids and their therapy needs."

According to Malawski, Botox treatments every three to four months help decrease the children's muscle tightness and allow therapists time to help retrain the brain and extremities. Casting of the legs also helps reposition and retrain muscles.

"Our children are walking miracles," Malawski states. "They're not in wheelchairs, are very articulate and prime examples of how early diagnosis and therapy can help."

The twins' mom says speaking with parents who have faced similar challenges, not being afraid of the unknown, keeping an open mind to explore all resources and the family's faith are the keys to her family's stroke success.

Family Of Six-Year-Old Naperville Boy Credits Early Diagnosis & Interventional Therapy In Overcoming Health Challenges

Jack Ellig, a six-year-old kindergartner at Fry Elementary in Naperville has faced some major challenges in his short life.

Jack, Bryan and Marissa Ellig of Naperville relax on a recent Florida vacation.

He and his identical twin brother, Bryan, shared a placenta while in the womb. When crossing of some major vessels occurred, Jack became the recipient of some of his brother's blood supply in an event known as twin-twin transfusion syndrome.

According to his mother, Diane Ellig, a pediatric nurse at nearby Edward Hospital, Jack's journey is miraculous.

"Doctors tell us he suffered a severe intracranial bleed around 18 weeks gestation," his mom reports. "Current diagnoses include left-sided hemiparesis, some developmental delays, cerebral palsy and seizures. As an infant, he received physical and occupational therapy early intervention services at home and currently attends DuPage Easter Seal in Naperville for weekly for occupational, physical and speech therapies."

A happy and content child, Jack's loves include trains and fire trucks. Therapists are working to help Jack to achieve a variety of daily living skills including zippers, snaps, buttons and shoes. Speech is limited to three-word simple sentences and physical therapists focus on stretching and gross motor skills to help Jack learn to climb stairs at home and get to his bedroom.

"Learning to make friends and play with others are the biggest social challenges," his mom worries. "He simply can't keep up with his classmates and peers. The Easter Seals therapists are terrific and have helped Jack a lot. It's amazing how children with the same bleeds can have dramatically different outcomes."

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About Childhood Stroke & Hemiplegia Connections of Illinois

By Janice Youngwith
Wednesday, February 1, 2006

Formerly known as the Parents' Association for Children with Hemiplegia and/or Stroke (PACHS), the Chicago-area based Childhood Stroke and Hemiplegia Connections group has been providing families with support and local resource information for almost four years. More than 40 area families currently share infantile and pediatric stroke and hemiplegia experiences and information, attend parent meetings with guest speakers, enjoy social outings and network to find answers and resources to aid their children.

Group meetings are offered on a regular basis at Good Samaritan Hospital, Downers Grove. Physicians, researchers, therapists and childhood rehabilitation experts donate their time and expertise providing presentation on a variety of childhood hemiplegia and stroke-related topics.

Many group members participate in one of two childhood and young adult stroke research studies currently being conducted by Dr. Steven Small and Dr. Susan Levine at the University of Chicago Hospital. Both studies---one targeting children ages eight months to 58 months and the other for anyone age seven to 30 who suffered a stroke or other unilateral brain injury, focus on language development.

For information on the Childhood Stroke and Hemplegia Connections group, write to P.O. Box 356, Bolingbrook, IL 60440, visit their website at www.cshconnections.org or contact Mary Kay Ballasiotes, founder and president, at 630-854-4058 or via e-mail at info@cshconnections.org.

Effects Of Stroke In Children

Recovery from stroke is different with each child. Prompt medical treatment and rehabilitation therapy

Infant & Childhood Stroke Facts
A stroke occurs when the blood supply to any part of the brain is interrupted, resulting in tissue death and loss of brain function. There are two main types of stroke: ischemic and hemorrhagic.

How often does childhood stroke occur?
• A number of strokes occur prior to birth; but it is unclear how often this happens.
• One in 4,000 live births.
• Six out of 100,000 children.
• 12 percent of children die due to stroke.
• More frequent in children less than one year old.
• 25 percent happen in infancy, often around childbirth.

What are the symptoms?
Symptoms vary according to age of the child
• Infants: seizures, apnea, poor feeding and/or hand preferences before six months of age.
• Children: delays in gross motor development, tightness or restricted movement in arms and legs and/or language delays.
• Older children: acute hemiplegia.

Why is diagnosis delayed?
• Infants may not present with symptoms for several months.
• Non-use of affected limb attributed to normal hand preference.
• Delays in crawling or walking attributed to normal lateness.
• Normal cognitive functioning doesn't raise suspicion.

What are the outcomes?
• More than 85 percent of newborns who have a stroke survive to adulthood.
• More than 50 percent of infants and children will have serious, long-term neurological disabilities including hemiplegia, seizures, speech, vision, behavioral and learning difficulties.
• Requires acute and long-term rehabilitation

can maximize recovery. In general, most younger people will recover more abilities than older people. Children often recover the use of their arms and legs and their ability to speak after a stroke.

Effects of stroke in a child are generally the same as in an adult. Common effects include:

- Hemiparesis, a weakness on one side of the body;
- Hemiplegia, paralysis on one side of the body;
- One-sided neglect (unilateral), which causes the stroke survivor to ignore or forget their weaker side;
- Aphasia, difficulty with speech and language or dysphagia, difficulty swallowing;
- Decreased field of vision and trouble with visual perception;
- Loss of emotional control and changes in mood;
- Cognitive changes or problems with memory, judgment and problem-solving; and
- Behavior changes or personality changes, improper languages or actions.

Source: American Stroke Association debar:

• Over 100 risk factors for stroke in newborns and children have been reported, however, in one-third of all cases, no cause is found. The more frequently reported risk factors include:
• Cardiac disorders
• Hematological disorders
• Metabolic disorders
• Vascular disorders
• Infection, including chicken pox.

Where can families find support?
www.cshconnections.org
www.pediatricstrokenetwork.com
www.pediatricstroke.org

Source: Children's Hemiplegia and Stroke Association, a non-profit family support organization found online at www.chasa.org.

canada.com
WHERE PERSPECTIVES CONNECT

Strokes: Children can have them, too

Neil Friedman
National Post

Friday, August 11, 2006

Only a baby. Three months old. But there was something strange about him. His mother noticed it. Little Aiden Von Gunten didn't reach out like other children. Only his right hand. He didn't kick like other children. Only his right foot.

"His left arm and leg just lay there," recalls his mother, Shannon. "As if he didn't realize his left side existed." Aiden had a stroke -- a blood vessel was blocked or broken in his brain. A baby having a stroke? It can happen. To anyone. At any age.

We hear of children with brain tumours. But twice as many have strokes. Stroke can strike babies even before they're born. Or very soon after. This is what happened to Aiden. Childhood and infant strokes can have many causes. Coagulation problems in mother and child (infants and newborns). A blow to the head. Congenital heart disease. Viral infections (chicken pox), sickle cell disease. Various blood vessel disorders.

But a third of childhood strokes have no known cause.

The tragedy is that so many childhood strokes go undiagnosed until it is too late. This should not be. We know the signs of stroke in adults. They're the same for children: seizure; paralysis of one side; severe headache; slurred speech; vomiting; vision problems; and difficulty walking. However, there is also something called silent stroke. No signs. But it still causes damage. Children with sickle cell disease are at particular risk.

Like adults, children need rapid treatment. Within three hours of onset is ideal. But it rarely happens. Too often, the symptoms are not taken seriously, or they are misdiagnosed.

Yevgania Baron was 18. She had the worst headache of her life and went to her local emergency room. They sent her home with a pain killer. But Ms. Baron came back. She knew something was very wrong. Doctors did an MRI (the best way of diagnosing a stroke). It showed a damaged blood vessel in her brain. They treated her as well as they could so long after the event.

"Make doctors understand that you know your body well enough to know when something is not right," Ms. Baron advises. Now a college student with only occasional verbal impairment, she says, "I feel lucky."

She is. Considering what could have happened. If there is good news about children with strokes it is this: They do better than adults. Their brains are more flexible. More adaptable. Healthy parts of the brain take over the functions of damaged parts. Children also don't have associated conditions. Like degenerative vascular disease. These complicate adult recovery.

But nobody gets off easy. A majority of pediatric stroke survivors will have some neurological or cognitive impairment.

They can lose muscle function on one side of the body. The muscles weaken. Become spastic. Physical therapy helps. Aquatic therapy can also be very useful. My colleague Barbara Weschler, MD, specializes in children's rehabilitation. "When we can't restore function, we teach the patient how to compensate," she says. "We help them gain independence. We work

on fine- and visual-mother activities. And playing, too. That's the children's occupation -- they go to school and they play." Speech and language therapists can help retrieve language skills. They can also help with cognitive deficits.

Aiden Von Gunten, who had a stroke as a newborn, is now two. Physical therapy has taken up most of his young life. He has weekly sessions. Wears a brace on his left foot. But he is fortunate. "His self-help and motor skills are a few months off what is normal for his age," says his mother. "Other than that, he is a very happy, typical kid who is above his age level in everything."

- Neil Friedman, M.B., Ch.B., is a pediatric neurologist at Cleveland Clinic. Cleveland Clinic is ranked as one of the three leading hospitals in the United States and operates Cleveland Clinic Canada - Toronto Health and Wellness Centre (clevelandcliniccanada.com). Cleveland Clinic Canada offers executive physicals, prevention and wellness counselling, and personal health care management. Send comments, questions or inquiries to nationalpost@ccf.org.

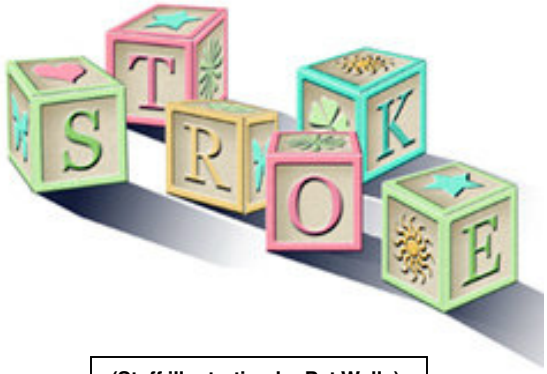
CAPE COD TIMES

Stroke knows no age limit

By ANNE BRADLEY

Saturday, 4-year-old Carolyn, a bubbly and tenacious preschooler from East Sandwich, will be participating with other children just like her in Childhood Stroke Awareness Day events at Worcester's EcoTarium.

Carolyn is a stroke survivor.



(Staff illustration by Pat Wells)

Carolyn is also my daughter.

In Worcester, she will join other children who have had strokes to play and laugh, while their parents garner support from each other. All will be there to raise money and bring awareness to this often under-diagnosed issue of childhood development.

"We don't think of babies as having a high risk of stroke, but strokes do occur in babies and cause significant lifelong disabilities," wrote Dr. Donna Ferriero, professor of neurology and pediatrics at the University of California, San Francisco, in an article in HealthDay, a national health awareness publication.

In a recent study, examining records of almost 200,000 children born in northern California over a five-year period, Ferriero and other researchers found that approximately 1 out of 4,000 infants had strokes near or at birth - a rate equal to that of the elderly population.

Furthermore, almost 80 percent of the infant strokes caused lifelong neurological problems including cerebral palsy, epilepsy, language problems, hyperactivity and hemiparesis (one-sided weakness).

Unless a child experiences a severe stroke, the diagnosis is often overlooked until the child demonstrates significant delays. Since recovery is highly contingent on the timeliness of the diagnosis, quick treatment and rehabilitation is critical.

According to Tara Souve, a pediatric physical therapist at the Rehabilitation Hospital of the Cape and Islands Eileen M. Ward children's rehabilitation center in Sandwich, "The sooner the treatment is after the stroke, the quicker the recovery. The longer you wait, the slower the progress."

Souve reports that all of the children currently being treated for stroke rehabilitation at RHCI received their diagnoses long after their stroke actually happened. Souve says she believes an inpatient pediatric rehabilitation facility is sorely needed on the Cape. The closest facilities are at Franciscan Hospital and Spaulding Rehabilitation Hospital in Boston.

"It's just too far," she said.

Children have strokes, too

- Six out of 100,000 children will have a stroke during childhood.
- One-third of them will have strokes as newborns.
- 20-35 percent of infant stroke survivors go on to have another stroke.

Sources: Pediatric Stroke Network, www.pediatricstrokenetwork.com; www.pediatricstroke.org and Children's Hemiplegia and Stroke Association, www.chasa.org.

Diagnosis is often delayed because infants may not show obvious signs for many months after the stroke. Delays in childhood development, particularly in gross motor skills, like crawling or walking, are often attributed to normal "lateness."

Carolyn, like many other child stroke survivors, suffered an ischemic stroke in the left hemisphere of the brain, in an area known as the basal ganglia. The basal ganglia region is primarily responsible for motor control and movement. Her stroke resulted in hemiparesis on the right side of her body.

Her stroke went undiagnosed for over a year, largely due to the fact that she was also born with cleft lip and cleft palate. She underwent three surgeries within her first year of life to correct the facial defects.

The first indication there might be something amiss took place in her pediatrician's office at her three-month checkup. Her doctor noticed that the folds in her chubby legs did not match up together. Hip dysplasia was initially thought to be the possible cause, but an ultrasound ruled it out.

During her first year, Carolyn demonstrated a left hand preference and dominance, which is not typical of most infants. Most infants use both hands with equal facility. Although she crawled, stood and walked within the typical range of development, there continued to be signs of motor delays.

When Carolyn started to walk at 16 months, it became quite obvious that there might be neurological involvement. She dragged her right leg, her foot turned down and away from her body, and her right hand remained close to her body as she walked.

Since the initial suspicion was cerebral palsy, Carolyn met with a neurologist from Franciscan Hospital. He spent 10 minutes with her, watching her walk four steps, and immediately said that she looked like a stroke survivor.

An MRI confirmed the diagnosis. It is believed that Carolyn suffered a stroke either in utero or right at birth.

The cause is unknown.

Other than her right leg brace, it's hard to tell that Carolyn has had a stroke. She is incredibly adventurous and has never let anything get in the way of her fun. She takes ballet, loves playgrounds and is planning on playing T-ball in the spring. She loves her dolls, playing house and all things pink.

Carolyn receives weekly therapy from school. and from a local chiropractor. Carolyn is also an active advocate for stroke survivors. She is currently the Stroke Hero for the Southeastern MA/Cape Cod Train to End Stroke marathon training program, a division of the American Stroke Association. She has had the opportunity to pair up with New England Patriot and stroke survivor Tedy Bruschi to help motivate program participants.

While Carolyn and Brian were in the backseat of the car, an argument broke out over who was the biggest sport fan. Brian yelled out, "Raise your hand if you like the Red Sox."

They both raised their hands.

Brian yelled out once more, "Raise your hand if you like the Patriots." They both raised their hands.

Then Carolyn yelled out, "Raise your hand if you had a stroke." Waving her hand vigorously in the air, Carolyn yelled out, "I did, I did, yeah!"

It's all in how you look at it.

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