



Maria Dellapina
Mother of child with Moyamoya

Life can change in an instance or through an email.....



You have a new message:

Via: <http://www.specs4us.com/>

Message Details:

Name XX XXXX (removed) 33

Subject: Fantastic!

Message: We lost our dear, sweet Tracy three years ago this next Friday, on her twenty-eighth birthday. She was born with Down syndrome, but, fortunately, her eyesight was fine and she never needed eyeglasses. Many of her friends, though, suffered from ill-fitting glasses which, as you noticed, had very little "real estate" at the bridge of the nose, causing them to be constantly falling down and changing the refraction. You are, truly, an angel sent from Heaven for these special people. Thank you.

Email ed_watts@verizon.net

Sent on: 1 March, 2016

Thank you!

Hello Ed,

Thank you so much for the lovely note, it has made my day and probably my whole month!

I am sadden to her of your daughters passing, Erin (now 17) is the sunshine of my day as I am sure your daughter was to you. I tell myself daily as I get up in the morning, I have the best job in the world!

And note like yours just confirms it. Thank you for that.

Hope you have a great day too

Best Wishes

Maria Dellapina

I would counsel you to have Erin checked yearly for "Moyamoya", which is a Japanese term for "puff of smoke", a cerebral vascular abnormality common to Down syndrome folks. It shows up in the third decade of life and will, ultimately, cause a massive cerebral hemorrhage; but it is treatable and entirely curable through surgery...IF it is discovered in time.

Give Erin a hug for Tracy and me.

Ed



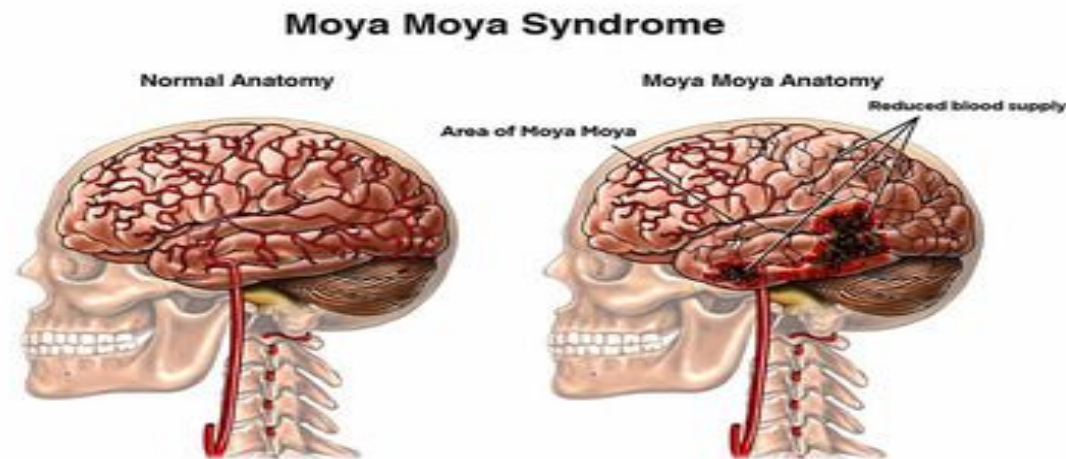
(The Angels often use other people to warn you of possible dangers; whether they are friends and family, or strangers, these messages have a meaning that makes you stop and listen.)

Read more at <https://www.beliefnet.com/inspiration/angels/5-warning-signs-from-the-angels.aspx?p=6#cya1xYqszv7WB45E.99>

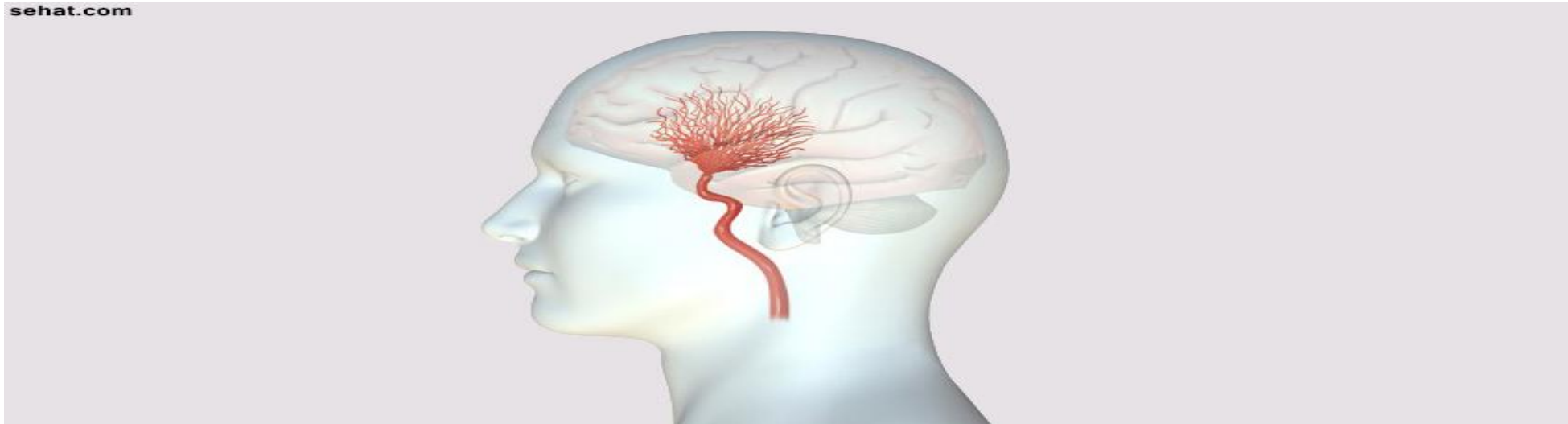


What is Moyamoya ?

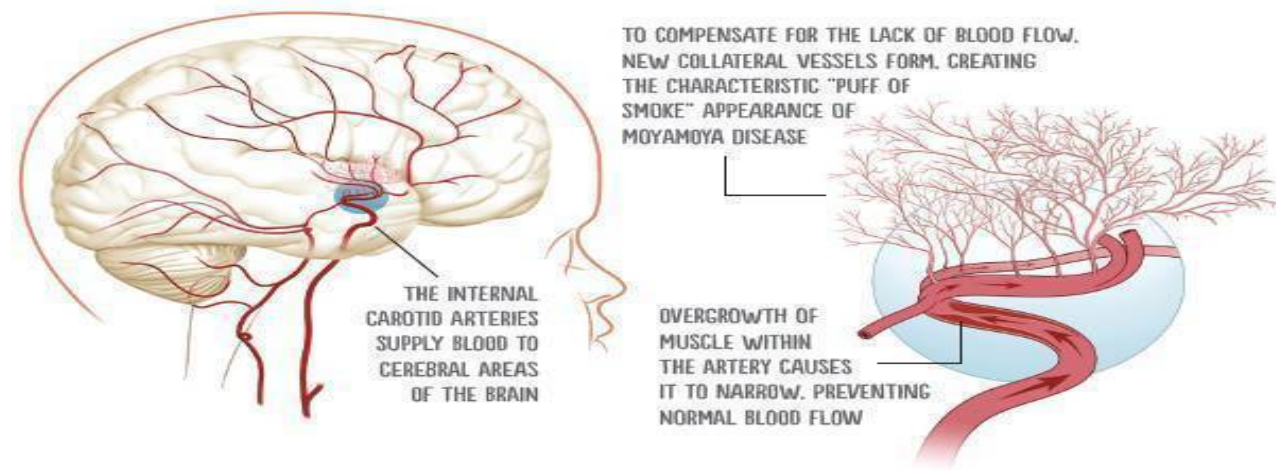
Moyamoya disease, which is also known as Moyamoya syndrome, is considered a rare but very serious condition in which the walls of the internal carotid arteries—the vessels that supply blood to important areas of the brain—become thickened and narrowed. This causes the flow of oxygen-rich blood to the child's brain to gradually slows down, and makes it more likely that a blood clot will form.



“Moyamoya” means “puff of smoke” in Japanese. The disease gets its name from the wispy, tangled appearance of the new blood vessels that emerge in the brain (as the body attempts to compensate for the inadequate blood supply).



Occurring in approximately 1 out of every 100,000 people, Moyamoya disease can be fatal if left undiagnosed and untreated. It is estimated that people with Down syndrome are 26 times more likely to develop the disease, compared with the typical population. It is important for parents of children with Down syndrome to know the warning signs and next steps if their child is diagnosed.



- Moyamoya disease is a progressive condition, meaning that symptoms worsen over time and the child's chances of suffering a stroke increases.
- The only proven treatment for this is surgery to create a healthy, adequate new supply of blood for the impacted areas of the brain.

What are the Symptoms of Moyamoya ?

Moyamoya may cause headaches. But often, children have no symptoms until they have a transient ischemic attack (TIA) or stroke.

Symptoms of a TIA or a stroke from blocked blood flow (ischemic stroke) include:

- Trouble speaking, such as slurring words
- Weakness or numbness on one side of the body
- Sudden vision problems, such as blurred vision
- Trouble walking or balancing
- Seizures

Rarely, children with Moyamoya have a stroke from a burst blood vessel (hemorrhagic stroke). This type of stroke may cause:

- Sudden, severe headache
- Trouble walking or balancing
- Trouble staying awake or alert
- Nausea or vomiting

Sometimes, breathing too fast or too deeply (hyperventilating) triggers a TIA or stroke in a child with Moyamoya. Crying hard or running may cause quick breathing.

Accompanying signs and symptoms of MoyaMoya disease related to reduced blood flow to the brain include:

- Headache
- Seizures
- Weakness, numbness or paralysis in your face, arm or leg, typically on one side of your body
- Visual disturbances
- Difficulties with speaking or understanding others (aphasia)
- Developmental delays
- Involuntary movements
- Cognitive decline
- These symptoms can be triggered by exercise, crying, coughing, straining or fever

Diagnosing Moyamoya

Sometimes Moyamoya is found when a child has a brain scan for another reason. More often, a child has symptoms of stroke or TIA and sees a doctor who specializes in blood flow to the brain. If your child might have Moyamoya, usually the doctor does a complete neurological evaluation to check:

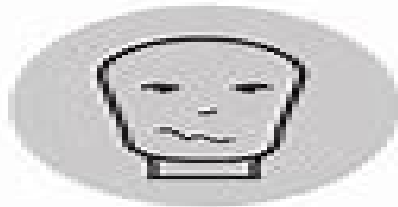
- Balance
- Reflexes
- Motor skills
- Sense of touch
- Memory and thinking



Stroke signs



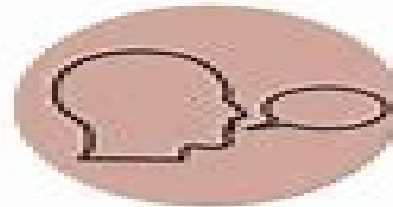
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Think "FAST" and do the following:

Face. Ask the person to smile. Does one side of the face droop?

Arms. Ask the person to raise both arms. Does one arm drift downward? Or is one arm unable to raise up?

Speech. Ask the person to repeat a simple phrase. Is his or her speech slurred or strange?

Time. If you observe any of these signs, call 911 immediately.

*Did you know that the tongue is an easy possible stroke indicator?

Seizures come in many forms

Be alert!

Simple seizures :

- Short attention span or “Black outs” looking like a day dream
- Rapid blinking
- Memory or emotional disturbance

Generalized seizures:

- Stiff muscles
- Fall backwards/or forwards
- Muscles relaxed /floppy or jerking
- Brief loss of consciousness

Recognizing the Signs of a Seizure

There are as many as forty different types of seizures known.

Symptoms of seizures vary depending on the type of seizure you experience. A generalized seizure is the most common, and it tends to show these symptoms:



Loss of Mobility



Trembling and Shaking



Numb & Prickling Sensation



Unconsciousness



Muscle Contractions & Cramps



Change in Emotions & Behavior



Confusion & Uncertainty



Loss or Alteration of Basic Senses
(smell, sound, look, taste, or touch)



Incontinence

Great resources for MoyaMoya

The two best resources in the world for Moyamoya are :

Edward R. Smith M.D.
Director, Pediatric Cerebrovascular Surgery
Department of Neurosurgery / Vascular Biology
Program
Children's Hospital Boston / Harvard Medical
School
Email: Edward.Smith@childrens.harvard.edu

Dr. Gary Steinberg
300 Pasteur Drive 2nd Floor, Room R-281,
Stanford, CA 94305
Phone: (650) 723 - 5575
Stanford Moyamoya Center
steinberg@stanford.edu

**I believe both give free image consults

<http://www.childrenshospital.org/conditions-and-treatments/conditions/m/moyamoya-disease>

<http://www.childrenshospital.org/conditions-and-treatments/conditions/m/moyamoya-disease/frequently-asked-questions>

Everyone says in HINDSIGHT or if I had known then what I do know..... Well now you know !

What Families
Should Know About
***Moyamoya
Disease***



<https://www.globaldownsyndrome.org/moyamoya-disease/>

Feel free to contact me with any further questions you may have on Moyamoya. I am by no means an expert but can help you find the answers. You can reach me at mdellapina@specs4us.com or 800-586-1885