## DR. LINDA'S VASCULAR BIRTHMARK FACT SHEET <br> 10 FACTS ABOUT HEMANGIOMAS

## Hemangiomas (also known as Infantile Hemangiomas):

- 1. Are rarely present at birth
- 2. Grow for up to a year (or a little more) and then begin to regress
- 3. Are lesions of infancy (do not occur in adults)
- 4. Occur more frequently in females than males
- 5. Have a high association with placental issues during pregnancy
- 6. Respond positively to propranolol (Hemangeol) and other beta blockers
- 7. Also respond to early treatment with a pulse dye laser
- 8. If more than 3, require an ultrasound to rule out internal involvement
- 9. No gene has been identified for an Infantile Hemangioma, though many tend to run in families
- 10. Can grow quite large, ulcerate and need immediate treatment

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## DR. LINDA'S VASCULAR BIRTHMARK FACT SHEET <br> 10 FACTS ABOUT ARTERIO-VENOUS MALFORMATIONS (AVM)

- 1. Arterio-venous malformations are irregular connections between veins and arteries. The capillaries normally serve as the intermediary between veins and arteries, but for some reason, they are missing in AVMs, causing a cluster (a back-up of sorts).
- 2. Most AVMs occur in the brain and in the spine, but they can occur anywhere.
- 3. If symptoms of an AVM have not appeared by age 50, they likely will not appear.
- 4. Women sometimes have issues with an AVM during pregnancy.
- 5. One of the biggest concerns with AVMs is uncontrolled bleeding (or hemorrhage) that can occur.
- 6. Although considered "present at birth", no symptoms or obvious appearance may be found until after birth or later in life.
- 7. AVMs tend to grow with the person and can become apparent after an accident or during puberty.
- 8. AVMs are classified, or organized, according to a scale called the Schobinger Staging System.
- 9. No one knows why AVMs form. Some believe they are genetic.
- 10. Patients diagnosed with an AVM should seek the medical opinion of someone with experience diagnosing and treating these often complex and problematic lesions.


# DR. LINDA'S VASCULAR BIRTHMARK FACT SHEET <br> <br> 10 FACTS ABOUT <br> <br> 10 FACTS ABOUT CUTIS MARMORATA CUTIS MARMORATA TELANGIECTATICA TELANGIECTATICA CONGENITA (CMTC) 

 CONGENITA (CMTC)}


- 1. CMTC is also known as Van Lohuizen Syndrome. It is a rare skin condition where the skin appears as marbled.
- 2. Most CMTC cases involve the legs, but can also occur on the arms and trunk. The face is rarely involved.
- 3. CMTC usually occurs in a specific area of the body, but a few cases have been reported where it covers the entire body.
- 4. This condition can occur alone or with other defects or syndromes, particularly involving undergrowth or overgrowth of the area affected.
- 5. CMTC is generally present at birth and some newborns may have the marbled stain in addition to ulcers and limb size discrepancy.
- 6. No one knows what causes CMTC, but it has been reported to be from a combination of factors that may include diet, viral infection and genetics. In a very few rare cases, it may run in families.
- 7. Most CMTC cases are diagnosed by clinical examination.
- 8. There is no specific treatment for CMTC and some patients have the marbling actually fade out by age 2 and even disappear by adolescence. Treatment is usually based on symptoms.
- 9. CMTC can often be confused with KTS (Klippel Trenaunay Syndrome).
- 10. Because this is a rare type of vascular anomaly, an expert team with experience in diagnosis and treating CMTC should be consulted.


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# DR. LINDA'S VASCULAR BIRTHMARK FACT SHEET 10 FACTS ABOUT KLIPPEL-TRENAUNAY SYNDROME (KTS) 

- 1. KTS is a syndrome typically involving a port wine stain (or vascular birthmark stain), as well as bone and tissue overgrowth of a leg, arm, torso or combination.
- 2. KTS has a broad range of symptoms from relatively inactive to severe.
- 3. Primary symptoms include bleeding, infection, and/or pain, and sometimes blood clots.
- 4. Treatment consists of managing the concerns of the patient because there is no known cure.
- 5. Swimming 3 times per week is highly recommended by VBF experts. Swimming promotes a gentle stimulation of blood to circulate properly throughout the body.
- 6. For varicosities involving the leg, keep the leg elevated at regular intervals ( 15 minutes every 2-3 hours, or every hour, if possible) so that the affected leg is higher than the heart. This allows the blood to flow away from the leg.
- 7. Wear a compression stocking on the affected limb throughout the day. This can keep blood from pooling in the extremity and protect from subtle trauma.
- 8. Pay close attention to your skin and seek medical care at the slightest sign of cellulitis (skin infection).
- 9. A cool bath in a tub with a small portable bath spa or water circulator will have a similar effect to swimming in that it will promote good circulation.
- 10. As with most complex vascular birthmark syndromes, seek the opinion of an expert with experience in treating KTS. This condition requires multidisciplinary expertise including experienced physicians from different fields of medicine



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## DR. LINDA'S VASCULAR BIRTHMARK FACT SHEET 10 FACTS ABOUT LYMPHATIC MALFORMATIONS

- 1. Lymphatic Malformations (LMs) are also referred to as Lymphangiomas and Cystic Hyrgromas.
- 2. LMs are usually present at birth; some may not be evident until later in life.
- 3. LMs can be either Micro or Macro-Cystic, or a combination, and can involve bone overgrowth.
- 4. LMs may cause asymmetry, distortion and bony hypertrophy (overgrowth) in the areas where they occur.
- 5. A LM of the arms or legs is frequently associated with lymphedema (swelling of the limb).
- 6. When an LM is superficial, it may appear with small blister type lesions (on the tongue, they look like frog eggs).
- 7. LMs never shrink or go away on their own.
- 8. Sclerotherapy is the main form of treatment, although Sirolimus is gaining popularity for treatment of these lesions.
- 9. Surgery remains the primary way to remove LMs completely.
- 10 Sudden swelling of a LM may be associated with virus, infection, or bleeding.

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# DR. LINDA'S VASCULAR BIRTHMARK FACT SHEET 10 FACTS ABOUT PHACE SYNDROME 

- 1. PHACE is an acronym for a specific vascular birthmark syndrome. $P=$ Posterior Fossa, $\mathrm{H}=$ Hemangioma, $\mathrm{A}=$ Arterial defect, $\mathrm{C}=$ Cardiac problems and $\mathrm{E}=$ Eye problems.
- 2. Infants with a hemangioma in the "beard area" or facial area are suspicious for PHACE Syndrome and should be checked.
- 3. You only need the H (Hemangioma) and one other issue to qualify as PHACE Syndrome.
- 4. Affected infants rarely suffer from all of the associated conditions.
- 5. PHACE Syndrome is often confused with SWS (port wine stain and associated issues). However, PHACE Syndrome involves an Infantile Hemangioma, and SWS involves a PWS. Sometimes they are hard to differentiate at birth. Differentiation becomes easier in the first and second month of life.
- 6. Structural vascular anomalies of the brain are the most common associated condition, along with the hemangioma. They are also the most worrisome.
- 7. In addition to brain involvement, aortic anomalies have also been detected with some PHACE Syndrome cases.
- 8. Nearly $90 \%$ of all diagnosed PHACE Syndrome cases are girls.
- 9. There has been no clinical evidence that these run in a family.
- 10. PHACE Syndrome requires a thorough examination and knowledge from a medical team that understands the complexity of this syndrome. Because the hemangioma itself is rarely present at birth (usually appears a week or two later) data on newborns with PHACE Syndrome is virtually non existent.



# DR. LINDA'S <br> VASCULAR BIRTHMARK FACT SHEET <br> 10 FACTS ABOUT PORT WINE STAINS 

Port Wine Stains (also known as Capillary Malformations)

- 1. Are always present at birth
- 2. Very, very rarely fade out naturally
- 3. Respond best to pulse dye laser treatment
- 4. Occur equally in males to females
- 5. A GNAQ gene mutual has been identified in PWS
- 6. PWS can be associated with Sturge Weber Syndrome
- 7. Most commonly occur in the head and neck
- 8. Are progressive lesions
- 9. Can thicken and cause cobbling with some PWS as they age
- 10. Can result in maximum clearance if treated early and frequently (Done by One)


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# DR. LINDA'S VASCULAR BIRTHMARK FACT SHEET <br> 10 FACTS ABOUT STURGE-WEBER SYNDROME 

- 1. Glaucoma is the most common serious eye problem of SWS, with a reported incidence of $30-70 \%$. It is defined as an increase in intraocular pressure that causes pathological changes in the optic disk and typical defects in the field of vision.
- 2. A condition where the involved eye can have a darker colored iris (Heterochromia) may occur in those with SWS.
- 3. Various experts report that nearly $50 \%$ of all infants diagnosed with a port wine stain on the eyelid will be at risk for glaucoma. Involvement of the upper eyelid has the highest association with SWS.
- 4. Recent studies have pointed to SWS as the result of a genetic mutation associated with the nucleotide transition in gene GNAQ on chromosome 9q21.
- 5. Glaucoma associated with SWS usually affects only one eye, but in rare cases can affect both eyes.
- 6. Individuals with upper and/or lower eyelid involvement, but no glaucoma, are still at risk for late-onset glaucoma. It can occur in late childhood or adulthood.
- 7. With SWS, $60 \%$ of the glaucoma is diagnosed in early infancy (when the eye is susceptible to stretching effects of increased intraocular pressure-glaucoma). These infants can have enlarged corneal diameters and myopia (actual eye enlargement called Buphthalmos). For the other $40 \%$, glaucoma begins later in childhood or early adulthood. When it is late onset, there is usually no eye enlargement.
- 8. Most doctors agree that the management of glaucoma associated with SWS is difficult. Lifelong anti-glaucoma drugs with a potential for systemic side effects are frequently needed and, often, multiple surgical procedures are needed.
- 9. Treatment of SWS should always involve an ophthalmologic physician who is a glaucoma expert and is familiar with this syndrome.
- 10. Eye exams for those with SWS should be conducted under anesthesia and performed at least every six months.


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## DR. LINDA'S VASCULAR BIRTHMARK FACT SHEET 10 FACTS ABOUT VENOUS MALFORMATIONS Venous Malformations:

- 1. Can occur at any time in life - from the cradle to the grave.
- 2. Are a type of vascular malformation that results from veins that have developed abnormally, which stretch or enlarge over time (hypertrophy).
- 3. Can be extremely painful, sensitive and problematic.
- 4. In appearance, usually looks like a bluish discoloration.
- 5. Can be a single lesion or multiple lesions. They can be confined to one area (local) or spread out (diffused).
- 6. Can be superficial (on the top of the skin), or deep (going beneath the skin).
- 7. Tend to get bigger if you cry, push, or otherwise increase pressure on your venous system.
- 8. If you pressed, they usually have a "dent or depression" like appearance.
- 9. If no chief complaints, the VM can be managed with compression garments and low dose aspirin.
- 10. If complex, VM treatment consists of sclerotherapy; endovenous laser therapy, venous embolization and/or surgical excision.


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