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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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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.

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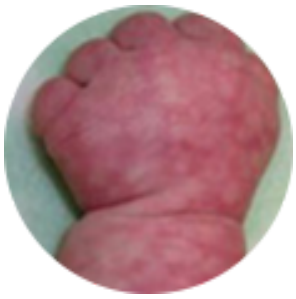

10 FACTS ABOUT CUTIS MARMORATA TELANGIECTATICA CONGENITA (CMTC)

- 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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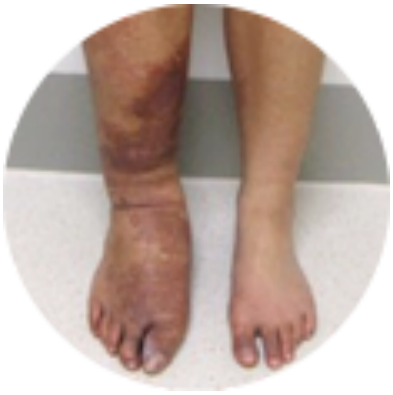
10 FACTS ABOUT KLIPPEL-TRENAUNAY SYNDROME (KTS)



- 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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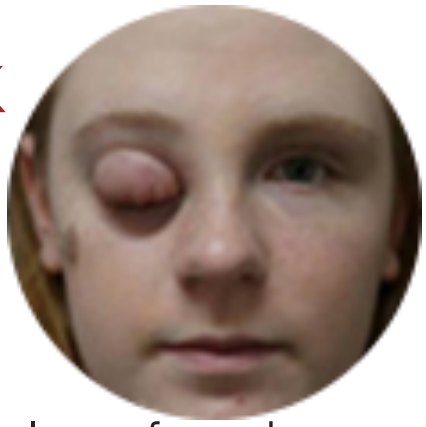

10 FACTS ABOUT LYMPHATIC MALFORMATIONS

- 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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10 FACTS ABOUT PHACE SYNDROME

- 1. PHACE is an acronym for a specific vascular birthmark syndrome. P = Posterior Fossa, H = Hemangioma, A = Arterial defect, C = Cardiac problems and 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.

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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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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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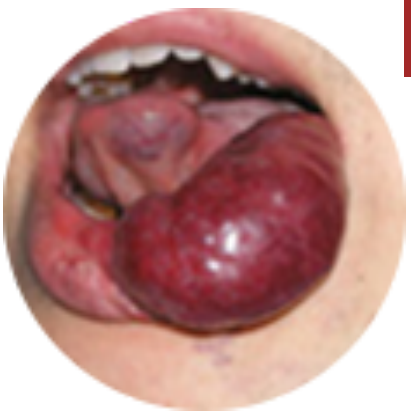
10 FACTS ABOUT VENOUS MALFORMATIONS



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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