



Port Wine Stain/Port Wine Birthmark (Capillary Malformation): Frequently Asked Questions

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Q: Are Port Wine Stains (PWS)/Port Wine Birthmarks (PWB) present at birth?

A: Yes, all PWS/PWB are present at birth, but the color may vary depending on the baby's skin tone.



Q: Does a PWS/PWB ever go away naturally?

A: It is extremely rare for a PWS/PWB to resolve spontaneously without treatment. They are persistent lesions.





Q: Other than laser therapy, are there any additional treatment options?

A: Laser treatment (therapy) is the current standard for treating a PWS/PWB. There are other “light or energy sources” which may also be helpful in treating these lesions.

Q: Do PWS/PWB occur equally in men and women?

A: Yes. It occurs equally across sexes.





Q: Has the PWS/PWB been associated with (the) GNAQ gene mutation?

A: Yes. There is an association.

Q: Do most PWS/PWB occur in the head and neck area?

A: Yes. Approximately 67% occur in the head and neck area.



Q: Are PWS/PWB progressive lesions?

A: Yes. It is reported that around 75% of all PWS/PWB will get darker and thicker over time.



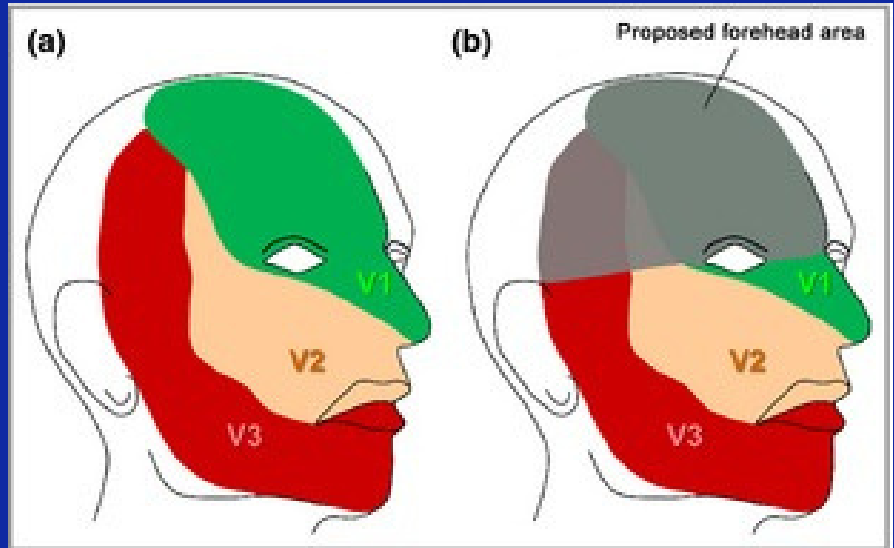


Q: Can a PWS/PWB be associated with other syndromes such as SWS, KTS, etc.?

A: Yes. A PWS/PWB can be a clinical indicator of an underlying syndrome.

Q: Are there common sites of predilection for PWS/PWB of the head and neck area?

A: Yes. There are common sites of predilection in the head and neck area.





Q: Is it important to treat a PWS/PWB early?

A: Yes. A PWS/PWB treated in infancy can result in maximum clearance if treated with frequent sessions. Regardless, treatment is still highly effective at any age and similar clearance can occur at any age.

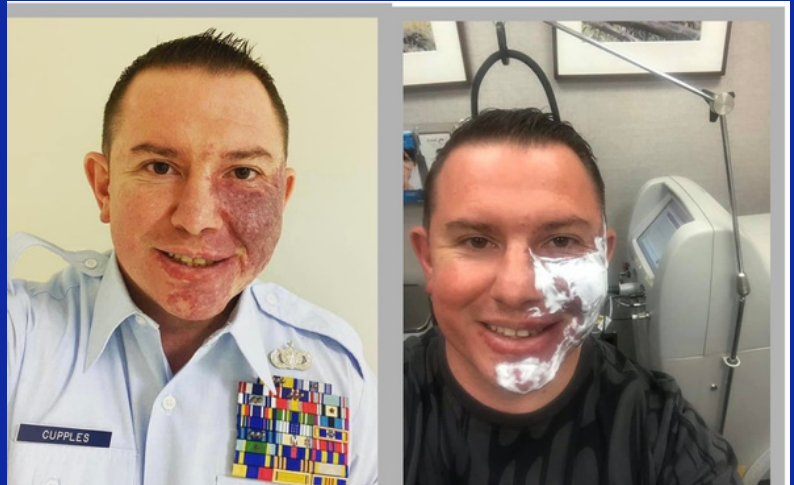
Q: What is a PWS/PWB and what is the purpose of treating it with a laser?

A: A PWS/PWB consists of malformed capillary blood vessels, which is why the medical term is “capillary vascular malformation.” The purpose of treating a PWS/PWB is to reduce the excess blood in the malformed vessels. “Treatment” does not mean “removal.”



Q: What is the best treatment for a PWS/PWB?

A: Laser therapy is the gold standard for treating a PWS/PWB. Along with reducing malformed vessels, it also preserves the integrity of the skin by preventing tissue thickening or cobbling.



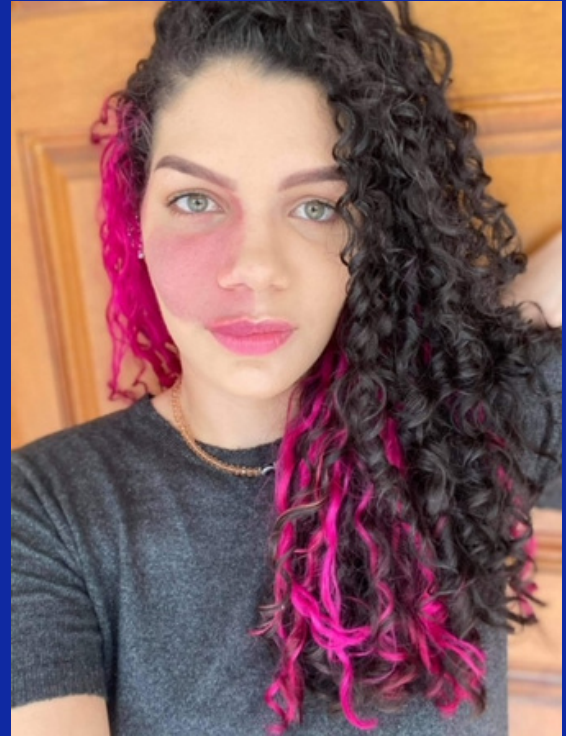


Q: Will all PWS/PWB get thicker or develop cobbling?

A: The majority of untreated PWS/PWB will thicken and produce cobbling over time. For this reason, it is not cosmetic to treat a PWS/PWB. Laser treatment focuses on preventing thickening, spontaneous bleeding, and cobbling.

Q: Is a PWS/PWB a cosmetic condition?

A: A PWS/PWB is not a cosmetic condition. The entire affected area is abnormal; both the visible portion of the PWS/PWB, and the area beneath the birthmark.





Q: How does laser therapy lighten a PWS/PWB?

A: Light from the laser goes into the skin and is absorbed by blood in the abnormal vessels. During this process, heat is generated, which coagulates the abnormal blood vessels.

Q: Will treating the PWS/PWB remove the condition?

A: Treating a PWS/PWB with a laser will not "remove" the condition, however, some PWS/PWB can achieve 100% clearance so that the stain is not visible to the naked eye.



Q: Can a laser clear all PWS/PWB vessels, or just the ones it can reach?

A: The laser can only destroy the excess blood in the vessels that it can reach. Currently, there is no laser that can reach all capillary vessels. Additionally, some vessels have a very fast blood flow that the laser cannot reach. The current lasers only penetrate 1-2 mm. Capillaries (which make up a PWS/PWB) vary in depth and size. You cannot target something that you cannot reach in depth, or catch in speed. However, in some cases, complete clinical clearance can occur.





Q: Are PWS/PWB the most common vascular birthmark?

A: No. They are the second most common vascular birthmark, after the Infantile Hemangioma.

Q: What are the different names for a PWS/PWB?

A: Port Wine Stains/Port Wine Birthmarks are also known as a capillary malformation, nevus flammeus, or a firemark.





Q: Does skin tone have anything to do with a PWS/PWB?

A: Skin tone does not matter as far as the pathology of the PWS/PWB. However, it will “appear” different based on skin tone. A PWS/PWB will appear more prominent on a lighter-skinned individual as compared to a darker-skinned individual.

Q: What is the prevalence of babies born with a PWS/PWB?

A: 1 in 300 babies are born with a PWS/PWB.



Q: What do you call the spots/dots that appear following a laser treatment?

A: The spots that appear following a laser treatment are called “purpura.”





Q: Can a PWS/PWB get lighter or darker based on the temperature?

A: A PWS/PWB can appear darker or lighter based on temperature.

Q: Is it important to use an ocular shield when treating a PWS/PWB close to the eye?

A: Yes. Any birthmark that is lasered near or around the eye should be fitted with an ocular shield prior to treatment to prevent eye damage.





Q: If one of my children has a PWS/PWB, will my other children have one?

A: There is no evidence that subsequent children will have a similar vascular birthmark, anomaly, and/or related syndrome.

Q: Do PWS/PWB follow any patterns when they are on the face?

A: There is some suggestion that PWS/PWB follow the dermatomes of the 5th cranial nerve of the face, favoring V1, V2, and/or V3.



Q: Is there any area of the body that a PWS/PWB does not occur?

A: Every area covered by skin is subject to having a PWS/PWB, but this has not been formally documented.



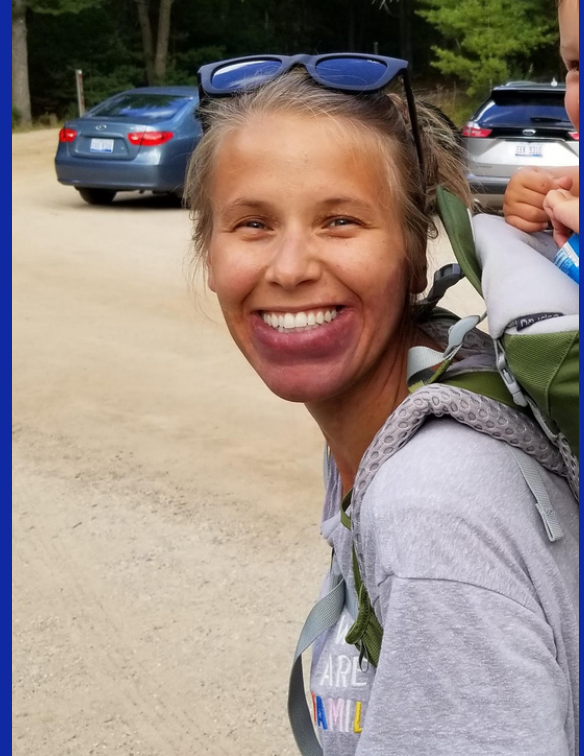


Q: If I have a PWS/PWB near my eye, could it affect my vision?

A: There is a higher chance of developing glaucoma if a PWS/PWB is in or near the eye. Anyone with a PWS/PWB in that area should have an annual retinal examination for glaucoma.

Q: If I have a PWS/PWB and am pregnant, can it affect me or the baby during pregnancy?

A: Changes in hormonal status during pregnancy can make a PWS/PWB darker, but there is no known association with pregnancy and a PWS/PWB affecting the baby.





Q: Do people who have a PWS/PWB have a shorter life span?

A: No, people with a PWS/PWB have a normal life expectancy.

Q: Why are PWS/PWB mostly red?

A: PWS/PWB are reddish in color because they are made up of excess blood. This expands the capillaries, causing them to be closer to the surface of the skin and therefore, be more visible.



Q: Are there any new developments regarding the treatment of a PWS/PWB?

A: Dr. Nelson and Dr. Mihm are the first doctors to propose the use of anti-angiogenic drug therapies in combination with laser treatment to enhance PWS/PWB clearance and inhibit vessel recurrence. Another new development is to initiate treatment in infancy.





Q: Does having a PWS/PWB increase my risk for skin cancer?

A: There is no evidence that having a PWS/PWB can increase the risk of skin cancer.

Q: Can a PWS/PWB be tattooed over?

A: The results of tattooing over a PWS/PWB are not ideal. We recommend patients do not get cosmetic tattoos on their birthmarks.





Q: I have a facial PWS/PWB with dark red stains on my gums. Is that related to my birthmark, and can it affect my teeth?

A: It is likely due to the PWS/PWB and it can affect gums and teeth. The excess blood in the capillaries can cause swollen gums, which cause the teeth to splay. Many report that teeth on the side of the birthmark grow in earlier than teeth on the non-birthmark side.

Q: If a PWS/PWB is the result of a gene mutation, why does only one of my identical twins have one?

A: The GNAQ gene has been described as a somatic mutation. It is unlikely that fraternal twins would have one in the same place. Identical twins may both have a PWS/PWB, but not in the exact same location.



Q: Can a PWS/PWB on the scalp or eyebrow area be treated, and will it affect the hair?

A: Yes, it can be treated. About 20% of all hair-bearing PWS/PWB will have hair loss if treated with a laser. Some hair regrowth will occur. In rare cases, the laser can cause permanent hair loss in the treated area.





Q: What about a PWS/PWB on the face in the beard area, or on the legs? Will shaving with a razor on these areas affect my birthmark?

A: Some PWS/PWB can thicken and develop small blebs. These blebs can be sensitive to being shaved, and can result in bleeding. Caution should be used when shaving over a PWS/PWB.

Q: Should I take aspirin or any vitamins for my PWS/PWB?

A: There is no evidence that either will have a positive affect on a PWS/PWB.





Q: If I have a PWS/PWB on the face, will I get Sturge-Weber Syndrome (SWS)?

A: If you have a PWS/PWB in the orbit or temple region, you run the risk for SWS. There is also a lifelong risk for glaucoma. For meningeal involvement, it can be ruled out with proper imaging after age 1.

Q: Are the stains on extremities with Klippel-Trenaunay Syndrome (KTS) considered a PWS/PWB?

A: The stains associated with KTS are often called PWS/PWB, but some believe they are a different etiology. These KTS stains do not respond as well to laser as the face area does.



Q: Is CMTC the same as a PWS/PWB and can it be treated with laser?

A: Cutis Marmorata Telangiectatica Congenita (CMTC) is a type of PWS/PWB in that it is comprised of dilated capillaries, but it is not entirely the same. The CMTC stain is bluish to deep purple in color, and becomes more apparent in cold temperatures and when crying. It can respond very well to laser treatment. In some cases, CMTC can also resolve without intervention.





Q: Do hormones affect PWS/PWB, especially during puberty, pregnancy, and menopause?

A: Yes. PWS/PWB have been known to darken, thicken, and/or bleed during times of hormone changes or in times of growth spurts.

Q: Can a PWS/PWB around/inside the ear affect hearing?

A: Yes, if the PWS/PWB travels down the ear canal. Many individuals with a PWS/PWB that involves the inner ear canal report a loss of hearing or chronic ear infections.





Q: Do PWS/PWB grow in the mouth and airway? If yes, how is it treated?

A: Yes. A PWS/PWB in the beard distribution can also be present in the mouth/palate. It can be treated with laser.

Q: Do all PWS/PWB thicken and develop blebs?

A: Various reports indicate that around 70% of all PWS/PWB with thicken and at least 50% will develop blebs.



Q: Is having a PWS/PWB a disability?

A: In general, a PWS/PWB is not a disability. However, if it is associated with SWS or KTS, it can involve other functions that can render the individual disabled.





Q: Why do some people with a PWS/PWB have tissue overgrowth and others do not?

A: PWS/PWB around the eye, mouth, and jaw seem to have the most overgrowth. Some believe the “intensity” or confluence of the stain color from birth may be an early warning that the tissue may thicken if left untreated.

Q: Did my mother or father do anything to cause my PWS/PWB?

A: No one can “make” a PWS/PWB happen. It is the result of a mutation.





Q: Will laser therapy clear the entire PWS/PWB?

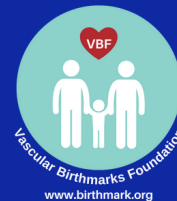
A: If some PWS/PWB are very deep in the skin, they may be unaffected by the laser treatment.

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