

## **Hannah Storm reveals truth about vascular birthmarks**

**By John Morgan, Spotlight Health**

**With medical adviser Stephen A. Shoop, M.D.**

CBS *Early Show* host Hannah Storm has covered too many stories to count during her 20 years as a journalist. But perhaps the biggest story Storm has reported involved a cover-up spanning several decades.

Storm revealed on camera during her morning show that she has a port wine stain under her left eye.

"I took my makeup off on air, because I wanted people to see what a port wine stain is," says Storm, who hosted four Olympics for NBC. "My birthmark essentially looks like I have a black eye. It isn't that bad so you can imagine if it has been this big a part of my life - think of what it must be like for children with more serious birthmarks that cover half their face."

Port wine stains, sometimes called vascular birthmarks, are an accumulation of larger than normal blood vessels. The blood flowing through these vessels gives the appearance of a stain, ranging in color from pale pink to dark purple in color.

"My mom always told me it was my beauty mark instead of a birthmark," Storm, 41, says. "When I was little at least one friend would ask, 'Can I have one too?'"

Many kids, unfortunately, get that very wish.

An estimated 1 million Americans are living with port wine stains. According to the Vascular Birthmarks Foundation, approximately three in every 1000 people is born with a port wine stain. Annually about 40,000 children born with a port wine stain will require the care of a specialist.

Storm probably would have continued living quietly with her birthmark had the Sturge-Weber Foundation not contacted Storm after she revealed in an interview she had a birthmark.

"They asked me to help increase awareness about the health concerns for people with port wine stains," Storm explains. "I said, 'What health concerns?' I had no idea."

That is how Storm learned port wine stains are not just a cosmetic issue but a medical issue.

"It is very important people understand that these birthmarks seriously affect a person's health," stresses Storm, who told her story on the *Early Show*.

"A port wine stain that involves the upper eyelid, forehead, and scalp -- alone or in conjunction with the cheek -- may put the child at risk for Sturge-Weber Syndrome," says Roy Geronemus, a dermatologist and director of the Laser and Skin Surgery Center of New York.

**Marked difficulties**

Sturge-Weber syndrome involves three different organs - the skin, the eye and the brain-that are all affected by the port wine stain. The skin involves the port wine stain itself. The eye can involve glaucoma, and the brain can involve seizure disorders.

"When I see a newborn with a port wine stain over the forehead, eye and/or scalp, I will make sure that child sees an ophthalmologist immediately who can treat any possible glaucoma and prevent them from losing their eyesight," states Geronemus, who is also a clinical professor of dermatology at New York University Medical Center.

Port wine stains also thicken and get bumpier as patients get older. This can be not only a cosmetic problem but also a functional problem because the bumps have a tendency to bleed - or ulcerate - spontaneously.

Storm admits that she didn't even know positive outcomes in treating port wine stains were possible. "I hadn't ever explored anything because of my past negative experiences," she says.

Storm's first procedures began in third grade - procedures which are now considered antiquated and even barbaric. Instead of improving her condition, these treatments actually left Storm with quite a bit of scar tissue.

"I had a serial excision - basically they tried to cut the birthmark off of my face," Storm explains. "So they cut the skin out under the left eye where the birthmark is and then stitch it up. I had that done twice. Each time the doctor said it would be gone, but each time it regenerated as they do."

Dermabrasion followed the surgeries.

"I also had the area tattooed which required general anesthesia like the surgery," Storm recalls. "They tattooed this sort of milky-white color that wasn't anything close to skin tone on top of my birthmark. Now I have some red and some white below my eye, so it gives it that bruised sort of look."

In college Storm received a couple of laser surgeries which doctors promised her would finally rid her of the birthmark. But the lasers were not advanced like they are now, and Storm was left with third degree burns under her eye.

"I had to undergo burn recovery twice," Storm states. "The skin is quite heavily scarred. It was very disappointing, because every time each procedure didn't make it get better. So I gave up and really did nothing about it for twenty-some years."

## **New hope**

But now treatments are producing far more positive results.

Laser, specifically the pulsed dye laser, is the treatment of choice for port wine stains afflicting children. The pulsed dye laser is designed to treat blood vessels only. It targets the blood vessel by penetrating the skin without producing any injury and shrinks the dilated vessels.

Geronemus and Storm both want parents to know that early treatment is critical in achieving the best possible results.

"Treating the skin component is much more effective when the child is younger," Geronemus notes. "The skin is a bit thinner and the blood vessels are more accessible to the laser."

But even adults like Storm can still be helped.

"Hannah will benefit from some very simple, straight forward treatment," Geronemus says. "It will not be anything like what she has been through before. Her treatment would take a few seconds, and she would probably need to be treated a few times."

While Storm is considering having new laser surgeries, for many children and their families it's not an option - it's too expensive.

This is because many insurance companies will not cover procedures to treat port wine stains. Despite expert medical opinion, insurers still claim the laser treatments are a cosmetic procedure. Only Minnesota has mandated by state law that insurers cover port wine stain procedures.

Non-coverage is often a painful injustice for families and the children. One that only gets more painful as the child approaches school age.

"Of course, you're self conscious," Storm says. "As I got older, I became so self conscious about my birthmark that I was very hesitant about going to a pool party, because I didn't want my makeup to rub off."

Geronemus believes this kind of insecurity as well as the endurance of teasing and strange stares is unnecessary. "If we can treat infants early, then they may not ever have to deal with the school issues. These treatments offer children the opportunity to feel very differently about themselves."

Storm also wants to make sure parents understand that port wine stains require specialized care.

"If your child is born with a port wine stain, they should be seen immediately by a pediatric dermatologist," Storm urges. "Your pediatrician does not understand these birthmarks as well as a specialist. Get the correct diagnosis because with early intervention so much can be done. You can save your child from possibly losing their eyesight or having seizures - not to mention save them from a lot of heartache."