



**Sturge-Weber Syndrome Community
Presents**

Glen Has Laser Surgery

**Sturge-Weber Syndrome
Community**

P.O. Box 24890

Lexington, KY 40524-4890

859-272-3857

<http://swscommunity.org>

Email: swsc@swscommunity.org



**The Sturge-Weber Syndrome Community
is a Branch of The Vascular Birthmarks Foundation
www.birthmark.org**



Treatment for Port Wine Stain A Guide for Parents and Children

By Glen and Glenda Ethington
Edited By Randi T. Ethington

Copyright © 2007 Vascular Birthmarks Foundation and
Sturge-Weber Syndrome Community

Forward

NOTES



Approximately two-thirds of all port wine stain (PWS) birthmarks occur on the face and neck and many lesions also involve the upper and lower eyelids. The pulsed dye laser (PDL) is the treatment of choice for pediatric patients with PWS.

Although the development of cooling technologies has decreased the discomfort associated with PWS laser treatment, the procedure can by no means be considered painless. Therefore, many institutions including the Beckman Laser Institute treat pediatric patients with PWS using general anesthesia. In addition to rendering the procedure itself painless, general anesthesia also ensures that the eyes are properly protected during the laser surgery. Moreover, adequate pain medication can be administered intraoperatively so that when the child does wake up, they do so comfortably.

Children are naturally fearful of general anesthesia and laser surgery. Very often, parents have more anxiety regarding the proposed laser surgery than their children. This guide for parents and children provides an excellent description of what happens to pediatric patients undergoing PWS laser surgery. It should provide reassurance as well as educate patients, their families, and medical professionals that it is reasonable and, most importantly, safe to treat pediatric PWS by laser using general anesthesia.

J. Stuart Nelson, M.D., Ph.D.

Beckman Laser Institute website: <http://www.bli.uci.edu>

Dr. J. Stuart Nelson is Medical Director of the Beckman Laser Institute and Medical Clinic, Professor of Surgery, Dermatology and Biomedical Engineering, University of California-Irvine, and serves as Medical Director for the VBF.

LOOK FOR OTHER VBF/SWSC PUBLICATIONS

- Facts About Vascular Birthmarks and Tumors
- About Sturge-Weber Syndrome
- Glen Has An MRI
- Glen Goes to the Dentist
- Glen Goes to the Neurologist
- Glen Goes to the Ophthalmologist

These publications are free, courtesy of VBF and SWSC.

Contents

Chapter 1 - Glen Checks In

Follow along with Glen as he checks in for laser surgery.
Page 1-2

Chapter 2 - Getting Ready for Surgery

Preparation for surgery with General Anesthetic.
Page 3-5

Chapter 3 - Having Surgery

See what a laser machine looks like and how it is used.
Page 6-7

Chapter 4 - The Recovery Room

Glen wakes up in the recovery room after surgery.
Page 8-9

Chapter 5 - Resting at Home

Tips for taking care of the treated area.
Page 10

Chapter 6 - Follow-up Doctor's Visit

Follow-up visit to the doctor's office.
Page 11

Contact Information

Page 12

Glen's Gang – Pen Pal Newsletter Group

Page 13

Acknowledgments

Page 14

Chapter 1 - Glen Checks In

My name is Glen and I have a facial port wine stain. I'm having laser surgery to lighten my birthmark, and to help prevent bumps (sometimes called nodules or blebs) from forming on it.



Going to the hospital and having laser surgery can be a little scary sometimes. I hope my story helps you understand what laser surgery is all about, so that when you have a treatment you won't be afraid.

Come along with me, and you will see what happens.

Acknowledgements

SWSC would like to thank Dr. Henry C. Vasconez and his staff for their assistance. Dr. Vasconez is Professor of Surgery and Chief, Division of Plastic and Reconstructive Surgery, University of Kentucky Chandler Medical Center.

Thanks to Dr. J. Stuart Nelson for his continued support and dedication to patients with port wine stain and other vascular birthmarks.

A special thanks to Linda Rozell-Shannon, President and Founder of the VBF.

Photographs on pages 6 and 7 by Dr. Henry C. Vasconez and staff. All others by Glenda Ethington.

Glen's Gang

Kids, join "**Glen's Gang**" a pen pal group and monthly newsletter for kids with birthmarks. Share your ideas, experiences, and hobbies with other kids who understand.

Glen's Gang is free. Each member receives a "VBF Kids Who Care" bracelet compliments of the SWSC.

Be sure to get your parent's permission to join.

Visit the SWSC or VBF website for more information or call or write to:

Glen's Gang
C/O SWSC
P.O. Box 24890
Lexington, KY 40524-4890
859-272-3857

~Glen's Gang is a VBF Kids Who Care program~

Here I am with my Mom. I'm checking into the surgery clinic at the hospital.



At the registration desk I get an armband. It lets the hospital staff know who I am and what I'm there for.



Chapter 2 - Getting Ready for Surgery



The nurse places a blood pressure cuff on my arm.



As the cuff inflates, it feels like it's squeezing my arm, but it doesn't hurt. They check my blood pressure and temperature to help make sure that I'm healthy enough to have a general anesthetic – that's what the doctor uses to make me sleep during the laser surgery.

For more information on port wine stains and laser treatments, contact the following:

Sturge-Weber Syndrome Community

P.O. Box 24890

Lexington, KY 40524-4890

859-272-3857

<http://swscommunity.org>

Email: swsc@swscommunity.org

Vascular Birthmarks Foundation

P.O. Box 106

Latham, NY 12110

877-823-4646

<http://birthmark.org>

Email: HVBF@aol.com

VBF/Sturge-Weber Syndrome Community Canada

143 St. Henri

Gatineau, QC.

J8X – 4J6

<http://swscommunitycanada.org>

Email: info-swsc@swscommunitycanada.org

Chapter 6 - Follow-up Doctor's Visit

The doctor will make an appointment for a follow-up visit. He will check to see how your port wine stain looks, and to check how well the laser treatment worked.



These are my favorite visits, as the doctor just needs to look at the port wine stain.

Depending on the thickness of your port wine stain, you might see a lot of

fading. Remember, each port wine stain is different and it is hard for the doctor to predict how many laser treatments will be needed to get the best results for you.

Your doctor will probably talk with you and your parents about setting up a regular schedule for laser treatments.

I hope my story helps you when you go for laser treatments. I would like to hear your story, so please write to me at: swsc@swscommunity.org.

Happy fading! Glen

That way I don't feel anything. My doctor lets me sleep during surgery because my birthmark covers most of the left side of my face and it can take a long time to treat it with the laser. Some people use numbing cream so the laser won't hurt as much. The numbing cream is applied to the surface of the skin where the birthmark is. Some people with birthmarks don't use numbing cream or a general anesthetic when having laser treatments. They say the laser feels like getting snapped with a rubber band.



I have to change into surgery pajamas. I don't mind, because they are really comfortable.

Chapter 5 - Resting At Home



Next, I need to have an IV put in my arm. The nurse does this with a very tiny needle that pricks the vein. The needle is removed and a very small plastic tube is inserted in the vein. This is done so that I can get fluids and medicine through the tube. That way I shouldn't have to have any shots. The medicine goes right into the tube, and I don't even feel it.

Having an IV put in hurts a little, but the nurse put numbing medicine on my arm before she started. I didn't cry and barely felt a tiny needle stick.

If you are really afraid of needles, sometimes the nurse will put the IV in after you go to sleep, making sure you won't feel any pain.

You and your parents can talk to the doctor, nurses and anesthesiologist (the doctor that helps you sleep) about the best way for you to prepare for laser surgery. Everyone at the hospital wants you to feel safe and comfortable, so let them know if you are afraid or having pain. The doctors and nurses will explain everything to you and your parents before they do anything.



Once you get home, you should take it easy – especially the first couple of days after laser treatment. Your doctor might let you go back to school (or back to work if you are an adult) but you need to be careful. You should keep your face clean and well protected with pure petroleum jelly or an antibacterial ointment. Your doctor will tell you which ointment is best for your skin type. You will probably be able to do most of the things you would normally do, but you should avoid being in the sunlight as much as possible. The sun's ultraviolet rays darken your skin (or give you a suntan), and lighter skin responds better to the laser treatment.

If you have any pain, the doctor will prescribe pain medication. If blisters, scabs or bleeding occur, then your parents should contact your doctor immediately for advice. If you follow the doctor's instructions and keep the area clean and protected with ointment, you probably won't have any problems.

Usually, the dots start to fade within a week, and any swelling should be gone.

Once the effects of the sleeping medicine wear off, and I'm able to stay awake, the nurse in the Recovery Room will have me drink clear liquids. If I can drink without feeling sick or vomiting, they will start to prepare me to go home.

While still in the Recovery Room, the nurse will remove the patches, the oxygen clip, and the IV. The nurse will go over any instructions with you and your parents, and explain what you need to do to care for the area treated by laser when you get home.



Chapter 3 - Having Surgery

The nurse puts some medicine in my IV tube to help me relax. When that takes effect, I will be taken to the surgery room.

In the surgery room the anesthesiologist puts a mask on my face. I am given some gas to make me sleep. After I'm fully asleep, the doctor places a tube in my mouth to help keep my throat clear during the surgery, and this helps me to breathe. Some people just have the facemask with gas to keep them asleep. Before your surgery, the doctor and anesthesiologist will talk with you and your parents to decide which is the best way for you.

This is what a laser machine looks like. Your doctor might use a different type of laser, but it will probably work and look much the same way.



The doctors and nurses wear special goggles over their eyes for protection from the light of the laser beam, and the doctor also puts a special type of contact lens over my eye to protect it. The laser uses beams of light to make small dots on my face. These dots help shrink the capillaries in my face (tiny blood vessels that become full of excess blood, causing my port wine stain to look pink or purple). Later, these dots will turn a dark purple-black color.



This is how I look right after the laser treatment is finished.



Chapter 4 - The Recovery Room

Here I am waking up in the recovery room. You can see that the dots are already turning a dark color.



The tube has been removed from my mouth, and there are round patches with wires attached on my chest. These patches are attached to a machine that records my heart rate. This helps the doctors and nurses know that I'm doing just fine after surgery. I also have a small clip with a red light attached to one of my fingers. This also has a wire attached to a machine that checks the oxygen level in my blood. This lets the doctors and nurses know that I have enough oxygen to breathe without a mask.