Sturge-Weber Syndrome

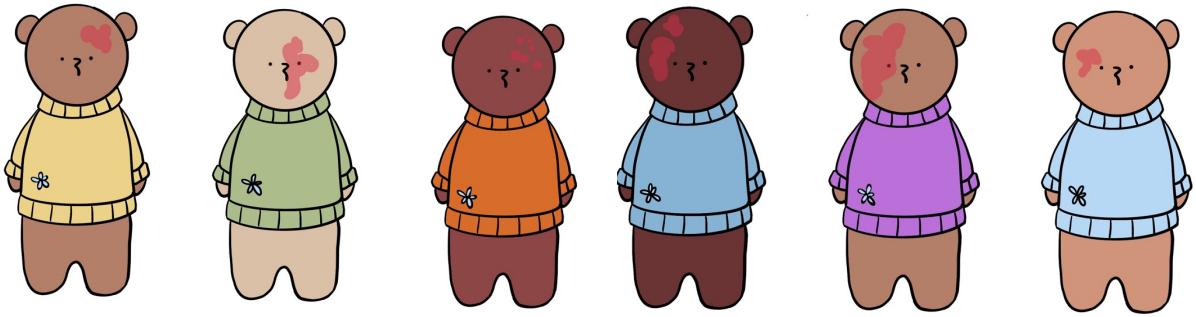
Maria Augusta Montenegro, MD, PhD
Anna L. Pinto, MD, PhD

Sturge-Weber Syndrome
First edition, 2024
Illustrations Copyright by Maria Carolina Montenegro

Text Copyright by:
Maria A. Montenegro
Department of Neurosciences
Division of Pediatric Neurology
Rady Children's Hospital / UC San Diego

Anna L. Pinto
Department of Neurology
Division of Epilepsy and Clinical Neurophysiology
Boston Children's Hospital/ Harvard Medical School

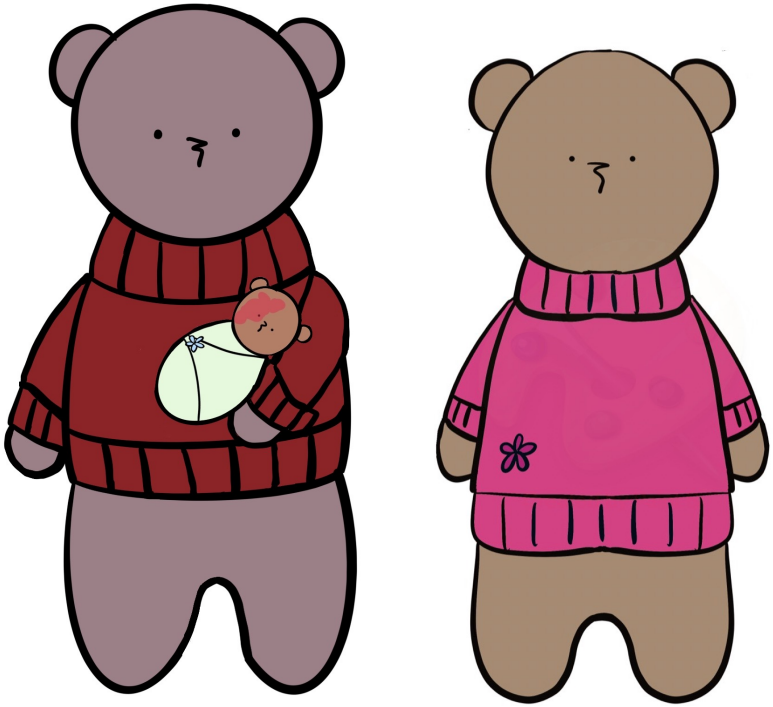
This is a work of fiction. Names, characters, places and incidents are either products of the author's imagination or, if real, are used fictitiously.
All rights reserved.
No part of this book may be used or reproduced in any means, electronic or mechanical, including any information storage and retrieval system, without written permission.



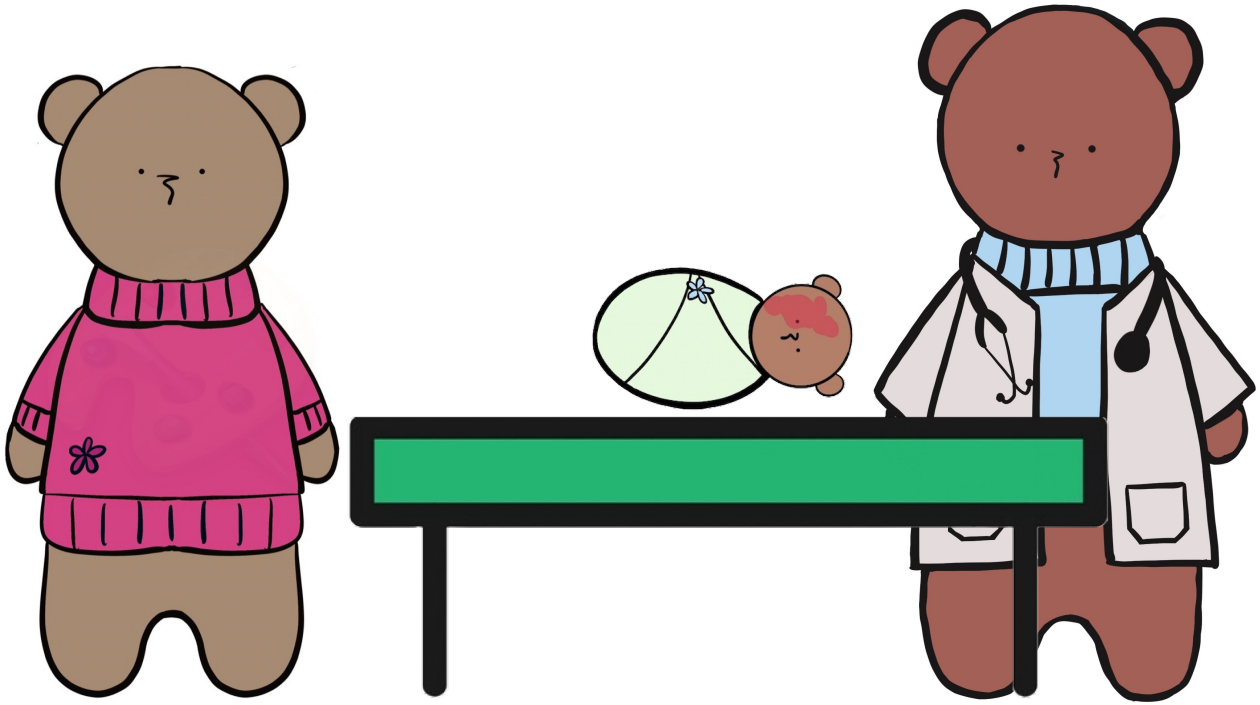
I was born with a birthmark and I want to tell you my story.

"Hello"

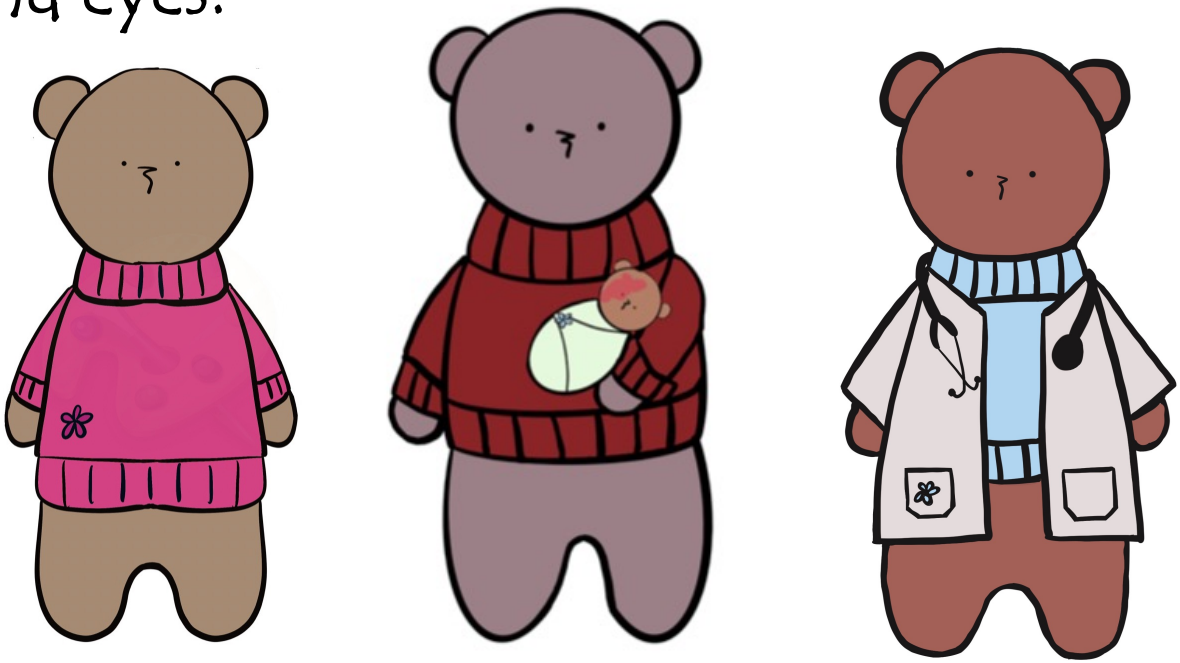
When I was born the doctors noticed that I had a birthmark in my face. My parents tought it was really cute, but the doctors said that I needed to see a birth mark specialist.



My parents took me to a very nice doctor and after a few tests the doctor explained that I have Sturge-Weber Syndrome.



Sturge-Weber Syndrome is a genetic condition that causes increase proliferation of tiny blood vessels forming capillary malformations. It may affect the brain, face, and eyes.



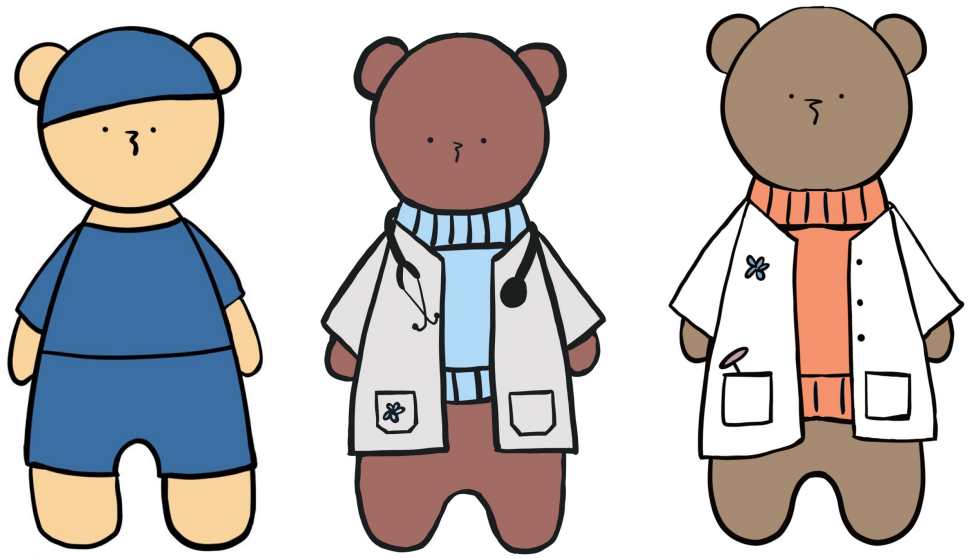
The facial birthmark is made of these tiny blood vessels, this is why it is red.

There are 3 types of Sturge-Weber Syndrome:

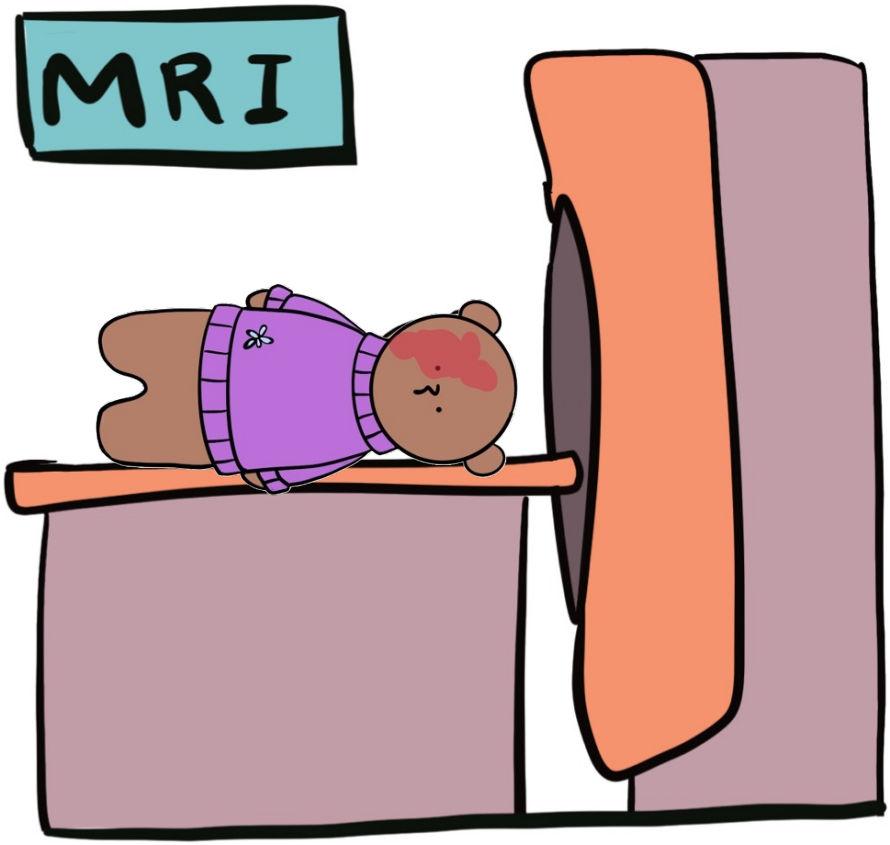
- Type 1: This is the most common type. Patients have both facial and leptomeningeal (brain) capillary malformations.
- Type 2: Patients have facial capillary malformations and the possibility of glaucoma (increased pressure in the eye). There is no brain disease.
- Type 3: Patients have only leptomeningeal (brain) capillary malformations. There is no facial birthmarks and usually no development of glaucoma.

In the beginning my parents were scared. But the nice doctors explained that there is a lot they can do to help patients with Sturge-Weber syndrome.

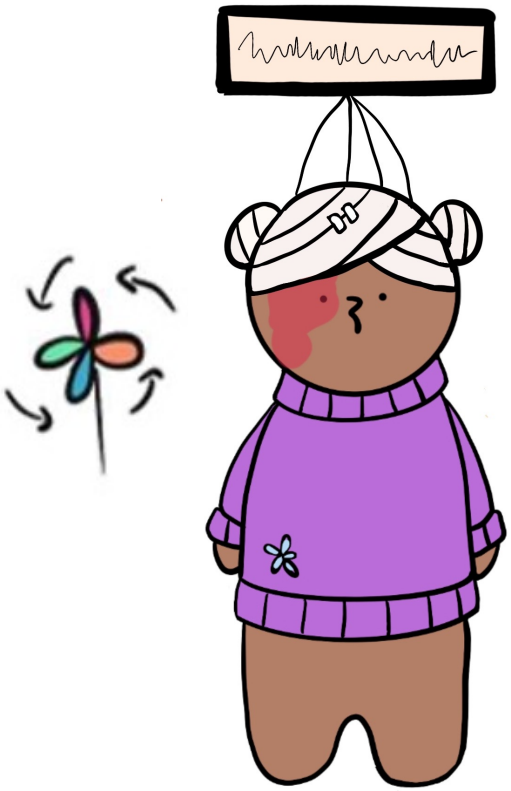
Brain doctors (Neurologists), eye doctors (Ophthalmologists) and skin doctors (Dermatologists) will help control the Sturge-Weber symptoms and make me feel better.



Sometimes I get a picture of my brain called MRI. It doesn't hurt, I just need to be very quiet and try not to move.

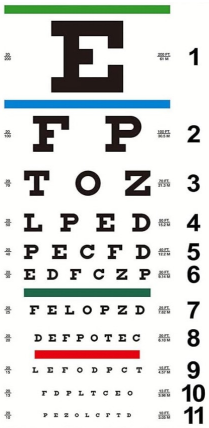


I also need to get an electroencephalogram (EEG) to help check if I am at risk for seizures. Some patients with Sturge-Weber syndrome have epilepsy and need medication to help control it.



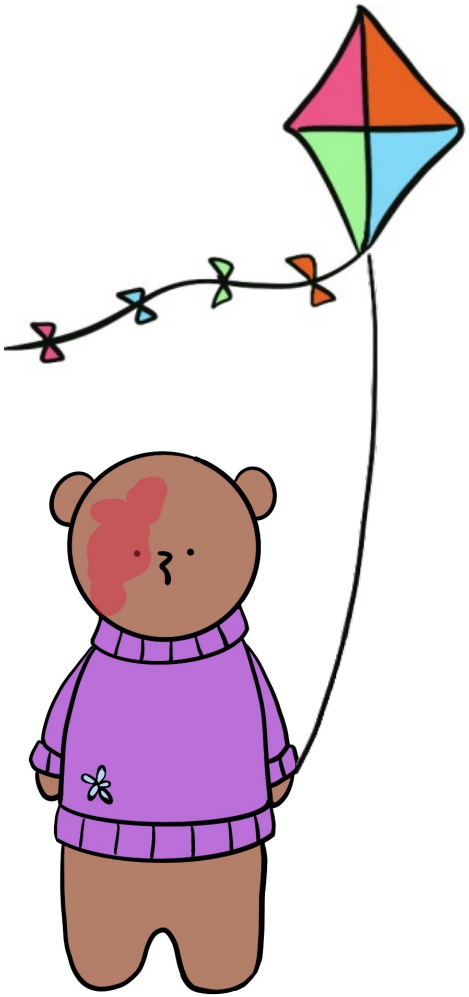
Getting an EEG is funny because they put several wires in my head. I have blow on a pinwheel and lay down quietly. Just like the MRI, It doesn't hurt.

I regularly go to the ophthalmologist (eye doctor) to check the pressure in my eyes. If the pressure gets high it is called glaucoma, and I will need to use eye drops to help lower the pressure.



In the beginning, I thought I was the only person with Sturge-Weber syndrome, but now I know that although rare, many people also have it.

Everyone is a little different and although I have a birthmark, I am a regular kid, just like you.



The End