

Color Me Different



Color Me The Same

A publication of
The Sturge-Weber
Foundation



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Hey, it looks like someone
our age is moving in. I
wonder if they can
play soccer.

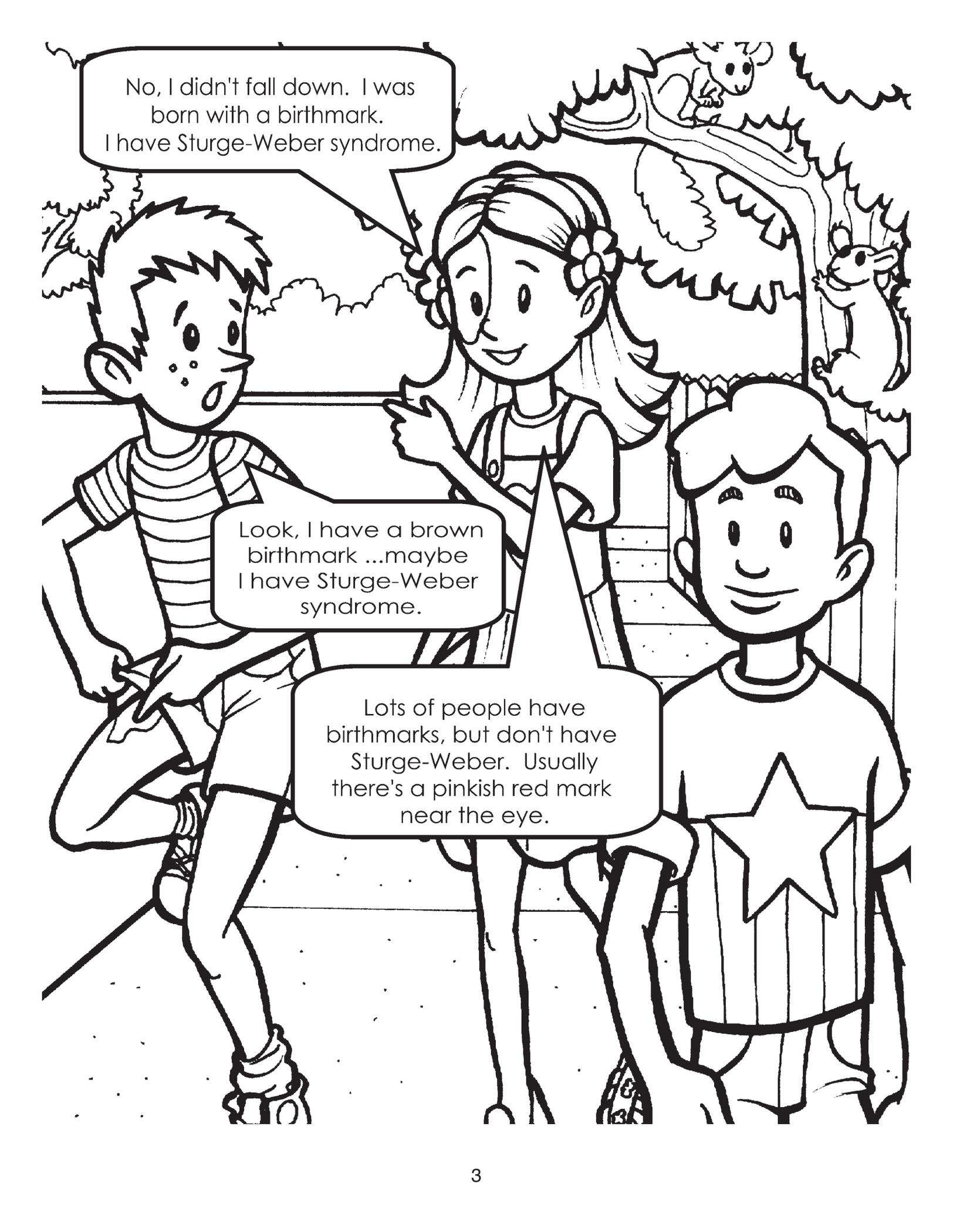




Hi, my name is Katy, what's yours?

Hi, my name is David and this is Michael and Allison.

Hey, I was wondering... what happened to your face? Did you fall off of your bike?



No, I didn't fall down. I was born with a birthmark. I have Sturge-Weber syndrome.

Look, I have a brown birthmark ...maybe I have Sturge-Weber syndrome.

Lots of people have birthmarks, but don't have Sturge-Weber. Usually there's a pinkish red mark near the eye.



Some people with Sturge-Weber also have glaucoma, that's a problem with their eyes. Another thing you might have with Sturge-Weber is seizures.

What's a seizure?

That's something that happens in a person's brain.

If I'm having a seizure, I might stare straight ahead and not answer you if you talk to me, or sometimes my legs and arms shake.

Wow, that sounds scary... what should we do if that happens?

If I have a seizure, you should go get a grown-up right away.



I caught the chicken pox from my best friend once, can I catch Sturge-Weber syndrome from you?

No, you can't catch it. It's something you're born with.



Please tell me about your birthmark on your face, does that hurt?

Wow, cool...like laser beams in the movies?

No, but sometimes I have laser treatments for it.

It's not really the same. I go to the hospital and have a laser treatment. After the treatment, that part of my face turns dark purple and gets dotted. Then the purple goes away. It helps lighten the color of my birthmark and one day removes it.



Hey, there's Brian and Amy. Let's introduce Katy!

Boy, look at that sunburn...I guess you stayed in the sun too long!

OUR TREE HOUSE

AMY

ALLISON MIKE

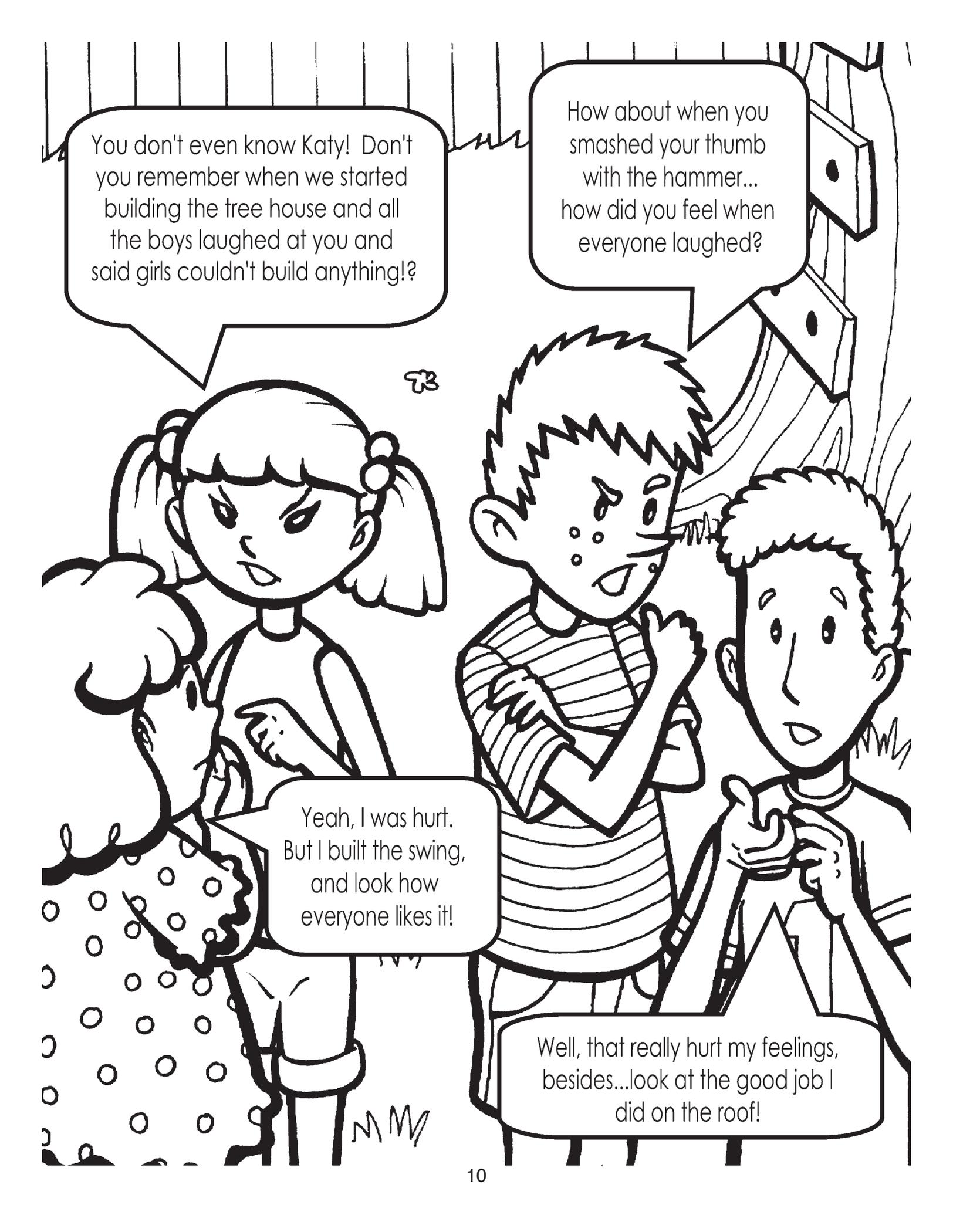
DAVID BRIAN
SAM

You'd better say you're sorry!!

That's okay...
people always
stare and say
mean things.
I try not to let
it bother me.

That wasn't very nice!
You shouldn't say mean
things or make fun of
people like that!





You don't even know Katy! Don't you remember when we started building the tree house and all the boys laughed at you and said girls couldn't build anything!?

How about when you smashed your thumb with the hammer... how did you feel when everyone laughed?

Yeah, I was hurt. But I built the swing, and look how everyone likes it!

Well, that really hurt my feelings, besides...look at the good job I did on the roof!



Want to come help build our tree house?

OUR TREE HOUSE

Do you like soccer?

KATY

ALLISON MIKE

DAVID BRIAN

Come on, let's play soccer now!

Hey, Katy, the boy who used to live in your house was our goalie. Did you ever play goalie? We could really use you on our team!



Dear Friends,

This story is an example of just one situation that may be faced by a child with Sturge-Weber syndrome. Children with Sturge-Weber need to have a broad-based circle of support that includes more than just their immediate family and teachers. This means we need to consider friends but also other relationships, such as mentors, other adults, fellow enthusiasts for particular hobbies or activities, acquaintances, colleagues. In considering this broader view, we not only reflect more accurately human needs but it also gives a number of options to work on if there are real problems in establishing friendships at a particular moment in time.

Only through education and understanding can we hope to enlighten those around us to the individuality and beauty in each of us. It is our hope that this publication will be used as a tool to educate siblings, classmates and friends about Sturge-Weber syndrome.

The hallmark feature of Sturge-Weber syndrome is a facial Port Wine Stain birthmark, pink to purple, usually located in the eye region. Other manifestations include glaucoma and seizures.

Until just a few years ago, little was known about these conditions and what caused the vascular malformation to develop. The Sturge-Weber Foundation (SWF) is the worldwide preeminent organization in dedicated to supporting families coping with these conditions and fostering research into vascular birthmarks. We welcome your participation in the Sturge-Weber Foundation's Month of Awareness. If you would like more information, please contact:



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