

# NF BUDDIES



A child's perspective of Neurofibromatosis

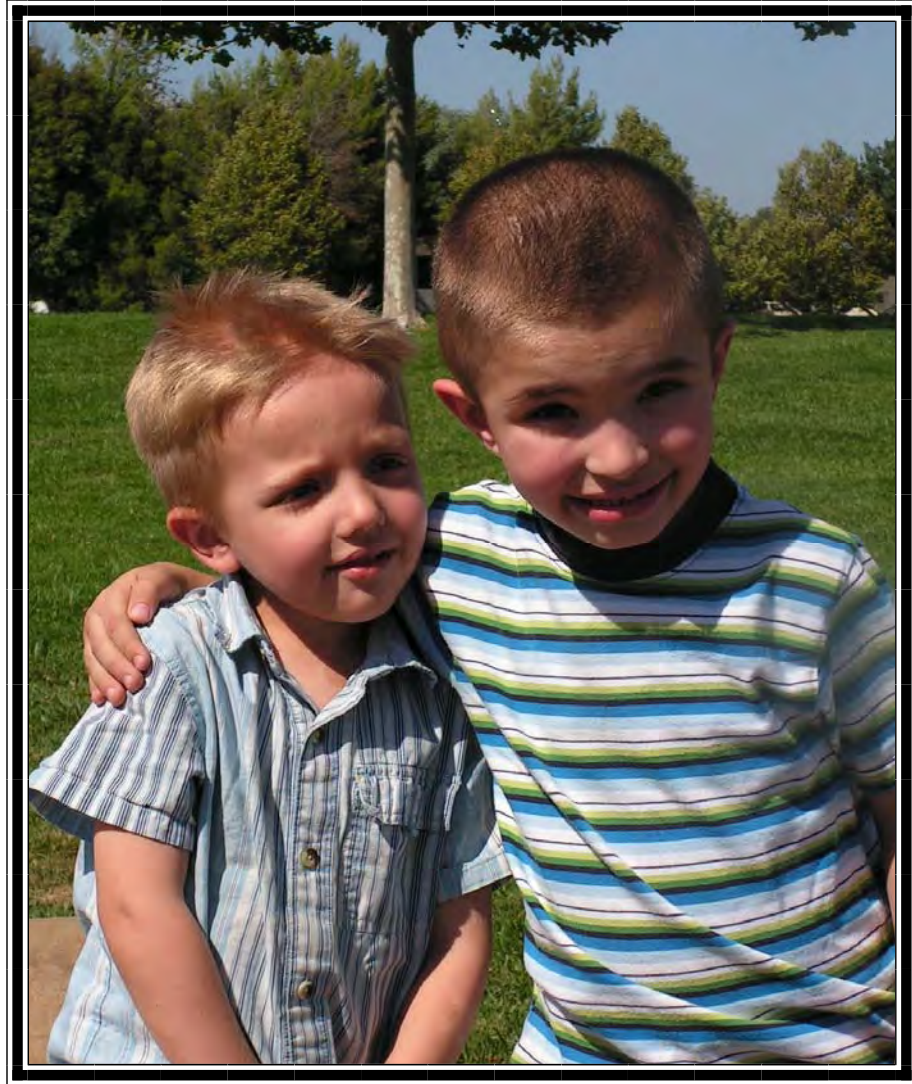
A huge thank you to those who made  
this book possible!



Thank you to our NF California colleagues,  
Debbie Bell and Maria Powell, for conceiving  
and creating this book.

Thanks also to Dr. Tena Rosser and  
Dr. Randolph Thomas for providing  
project support.

A special thanks to Alexxis, Carter, Daria,  
Gillian, Jaxon, Nicky, Sofia, and Zachary.  
We dedicate this book to you and to all of  
our NF buddies.



**NF  
BUDDIES**





Hi!

My name is Jaxon.



And this  
is my buddy Carter.



We are both four years old.  
We love to play.



We both love to laugh, jump,  
play ball, and blow bubbles.



We have  
something  
else the same  
too. We both  
have spots.

They are  
called café  
au lait spots.

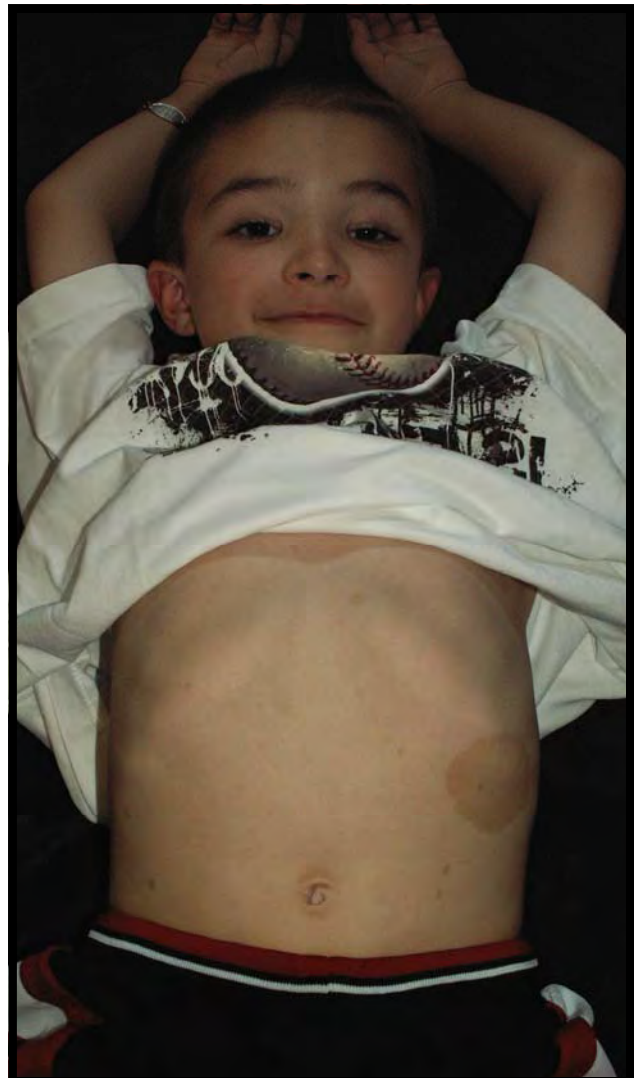


These spots  
aren't like  
chicken pox.

They don't  
itch, and you  
can't catch  
them by  
hugging us.



We have café  
au lait spots  
because we have  
Neurofibromatosis  
Type One. Most  
people call it  
"NF1" because  
that is easier  
to say.





There is another kind of  
Neurofibromatosis.  
It is called "NF2".



Our friend Alexxis has this kind  
of Neurofibromatosis.



Kids with NF go to the doctor a lot - even when we are not sick. Our doctors like to see us often to make sure that we stay healthy.



Most people  
with NF1 are  
like our buddies  
Zachary  
and Daria.



Their  
NF1 hasn't  
given them any  
problems—just  
spots.



For some NF1 kids, learning new things is kind of tricky. When Carter was little, he started going to therapy. Therapy is a place where a special teacher shows you fun ways to practice doing tough things (like hopping on one foot and coloring between the lines).



NF1 has given our friend Sofia many challenges, but she does not give up. Learning to walk was really hard for her, but she kept trying. Now, Sofia can walk, play basketball, hula hoop, and even tap dance!



Learning to talk was tough for me at first. I even went to a special speech teacher and preschool class.



Now, I am really good at talking, and it is one of my favorite things to do.





I really like to talk to the doctors  
and nurses at the hospital.

During some hospital visits, I even get to go in the MRI tunnel so the doctors can get a picture of my brain.

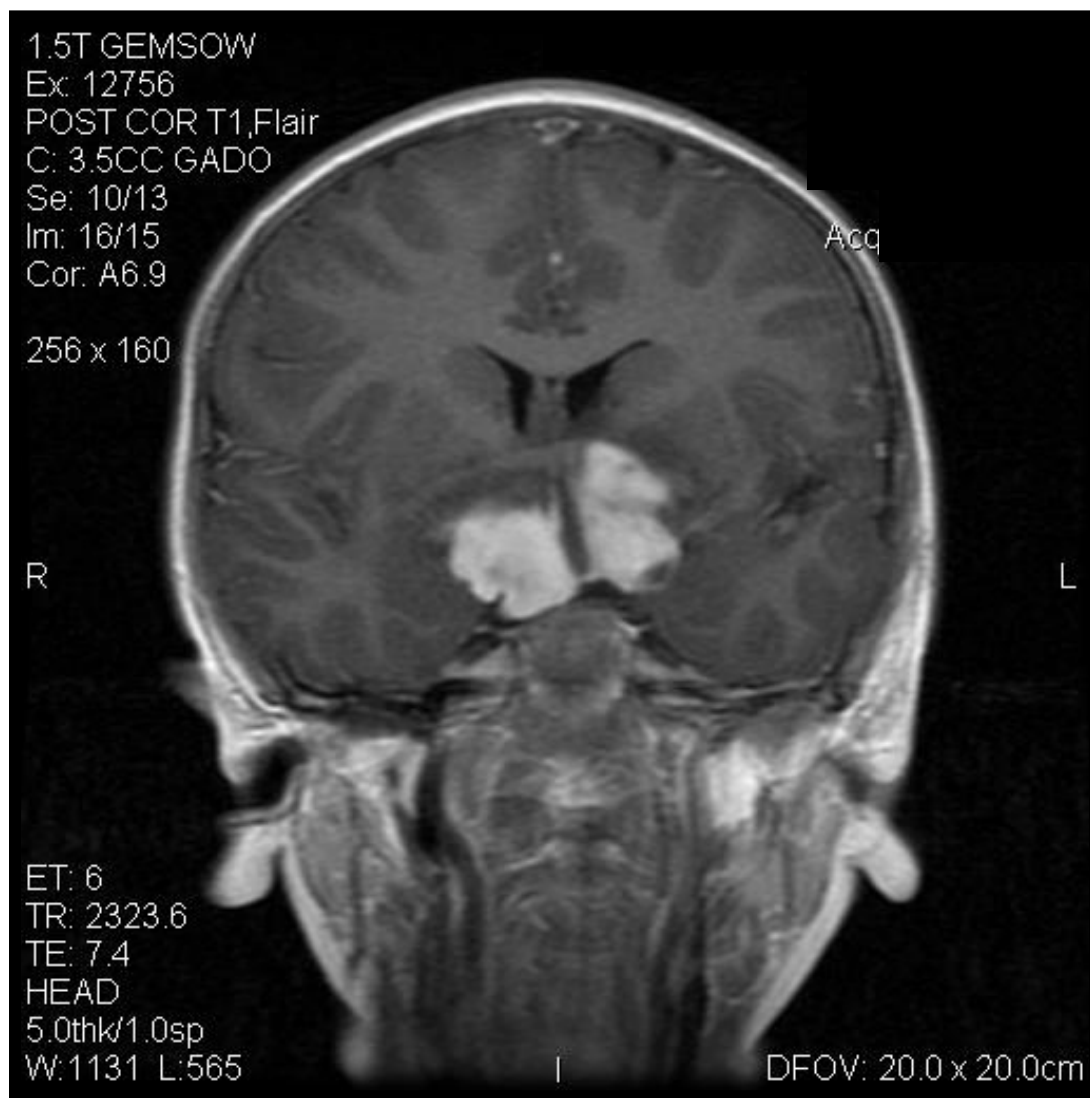


I like to pretend that I am a train when I go through the tunnel.





To have an MRI, you have to hold really still. I wiggle too much, so the nurses give me medicine that helps me sleep. They put it in my arm through an IV.



When the doctors looked at my MRI pictures, they found out that I have a tumor. Many people with NF get tumors, and there are many different kinds of tumors. Carter has tumors too.



And, when Carter was a baby, he had hydrocephalus. That means he had extra spinal fluid around his brain.





This  
is our new  
friend  
Nicky.  
If you  
look really  
closely,  
you can see  
that his  
left leg is  
curved.  
Because  
of NF1,  
he was  
born with a  
bowed tibia.



Sometimes NF is so mild that people don't even know they have it.

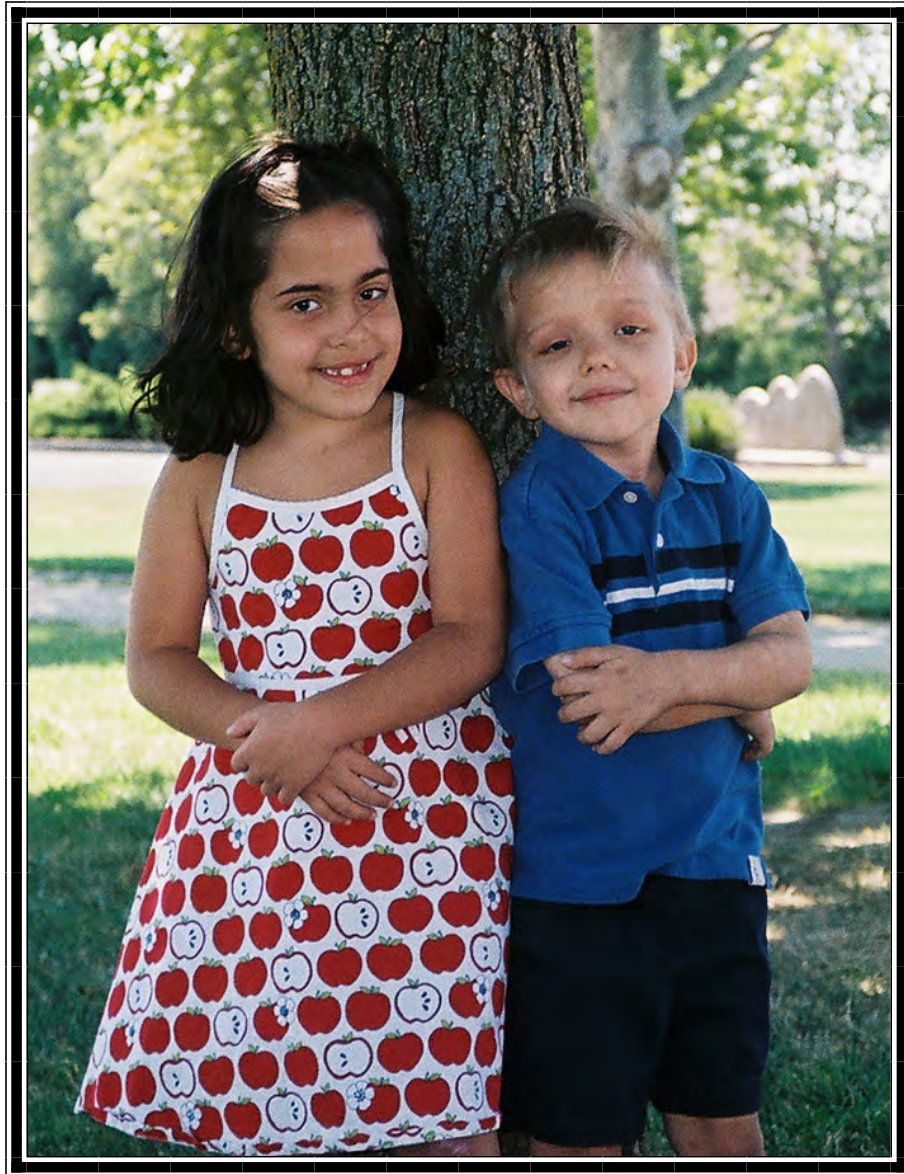


Our friend Gillian's dad didn't even know he had NF1 until he found out that Gillian had it.



Alexxis' NF2 hasn't given her many cafe au lait spots or learning delays, but she has needed surgery because of her tumors. As soon as the doctor said it was okay, she was back to her favorite activity - swimming! (She is very careful and always swims with a grown up to help her stay safe.)





Having Neurofibromatosis has taught us a lot. We have learned about how our bodies work, and also how to be brave and strong. Through meeting us, many others learn these important lessons too.



One thing you  
will notice in  
these pictures  
is that we are  
happy.

Carter  
and I  
love to  
smile.



So do our other NF buddies.



Having NF  
isn't always  
fun, but  
lots of the  
things we  
do because  
of NF are  
fun.



We really like the NF walks and  
support group activities!



We have met many new friends  
because of Neurofibromatosis.



If you have NF, we hope that you  
can make new buddies, find great  
doctors, and go to fun activities too.

*Thank you Gillian Anderson!*

Funds raised through Gillian's auctions and website brought this book to life.

You can learn more about Gillian on her official website

<http://gilliananderson.ws>



Need more information?

Visit us at:

[www.nfnetwork.org](http://www.nfnetwork.org)

"NF Buddies" introduces children to other youngsters who live with NF. It provides a simple way for them to explain their condition to family and friends, teachers and classmates.



213 S. Wheaton Avenue, Wheaton, IL 60187  
630-510-1115  
admin@nfnetwork.org

**[www.nfnetwork.org](http://www.nfnetwork.org)**

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