



NF

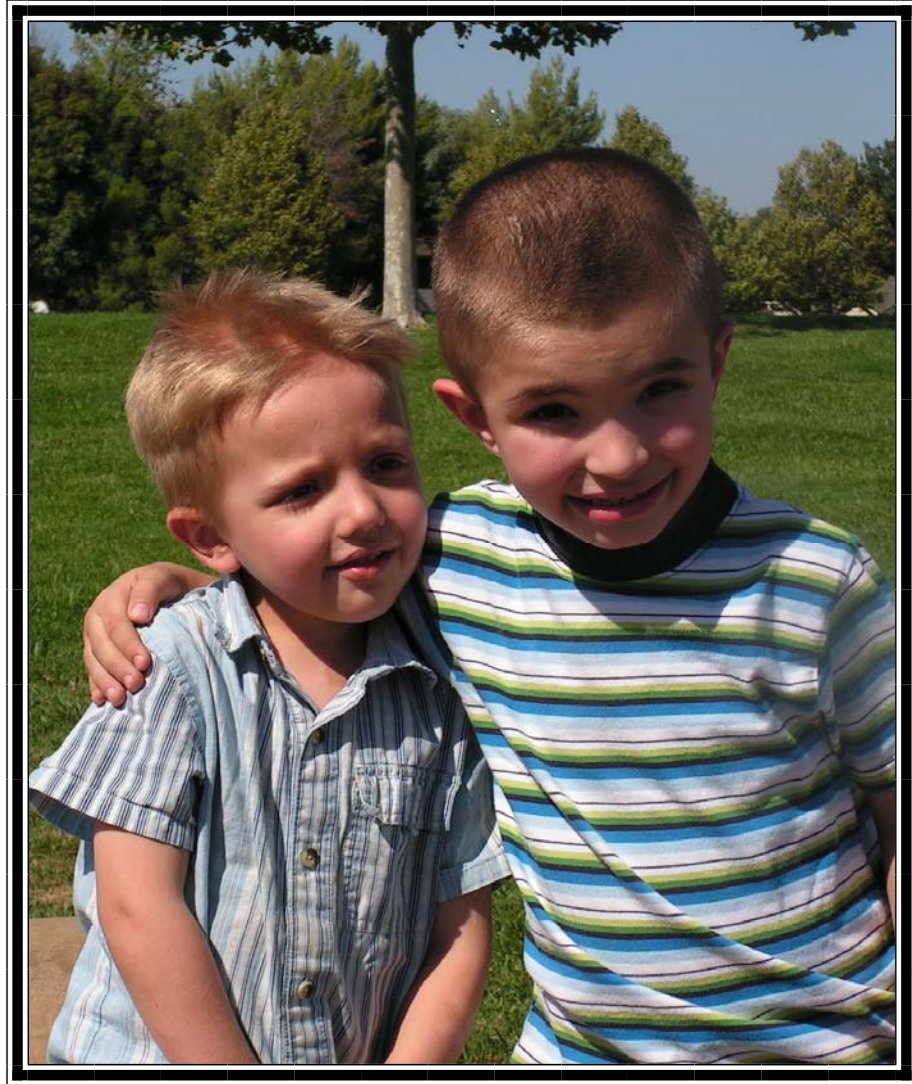
BUDDIES

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

Thank you to all of  
the professionals who truly  
care for our children.

Thank you Dr. Teena Rosser and  
Dr. Randolph Thomas for your  
support in creating this book.

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

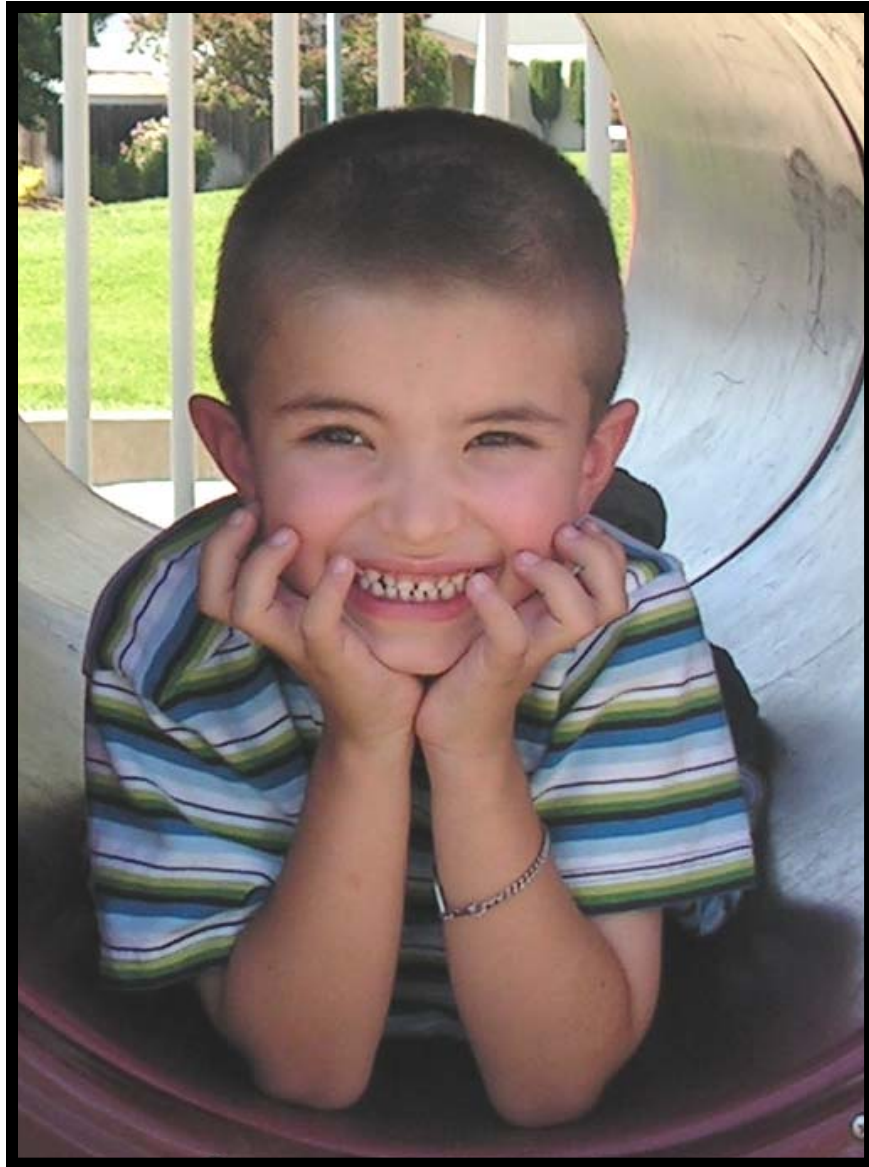


**NF**  
**BUDDIES**



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.

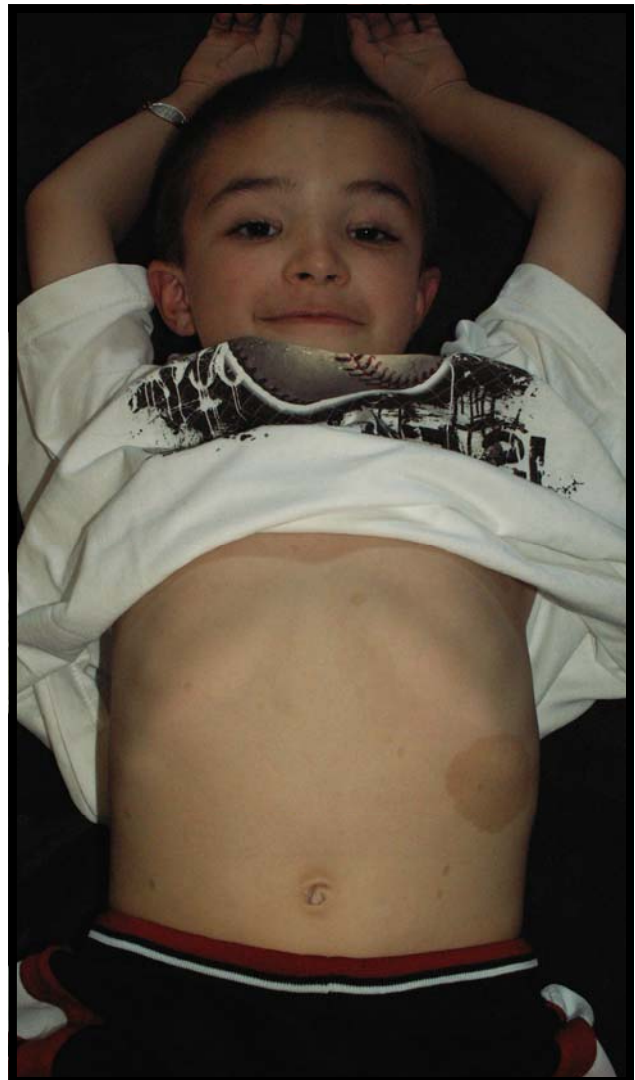
They are called café au lait spots.



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!*

**gilliananderson.ws**  
THE OFFICIAL GILLIAN ANDERSON WEBSITE

*Funds raised through Gillian's auctions  
and website brought this book to life.  
Gillian, your hope, your service, and  
your optimism inspire us to focus on  
the things that matter most!*

Needing more support and information?

Check out [www.nfinc.org](http://www.nfinc.org)



Click on the State/Local groups link to find U.S.  
NF organizations and also international support groups.

"NF Buddies" shows a child's perspective of Neurofibromatosis. It lets children with NF know a little of what they might expect and will provide a natural way for them to introduce their family, friends, and teachers to this condition.



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