NF BUDDIES

A child’s perspective of Neurofibromatosis
A huge thank you to those who made this book possible!

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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.
So do our other NF buddies.

Carter and I love to smile.

One thing you will notice in these pictures is that we are happy.
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!
If you have NF, we hope that you can make new buddies, find great doctors, and go to fun activities too.

We have met many new friends because of Neurofibromatosis.
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
“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.

Information contained in this publication is intended for educational purposes only and does not constitute medical advice. Please consult a physician for specific medical management and treatment recommendations.

If you would like to order copies of “NF Buddies” please contact the NF Network at admin@nfnetwork.org or 630-510-1115.