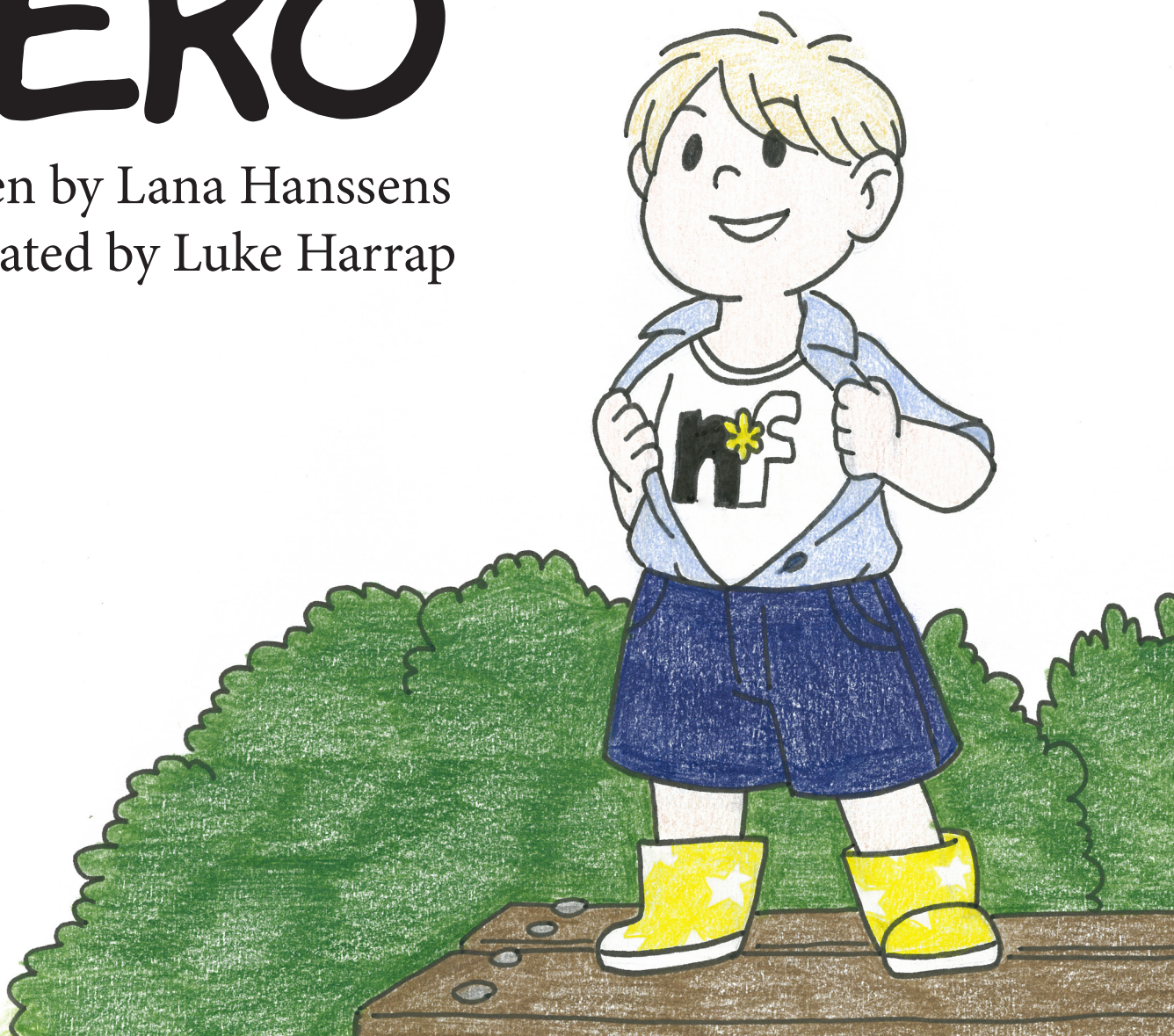
# THE NF HERO

Written by Lana Hanssens
Illustrated by Luke Harrap



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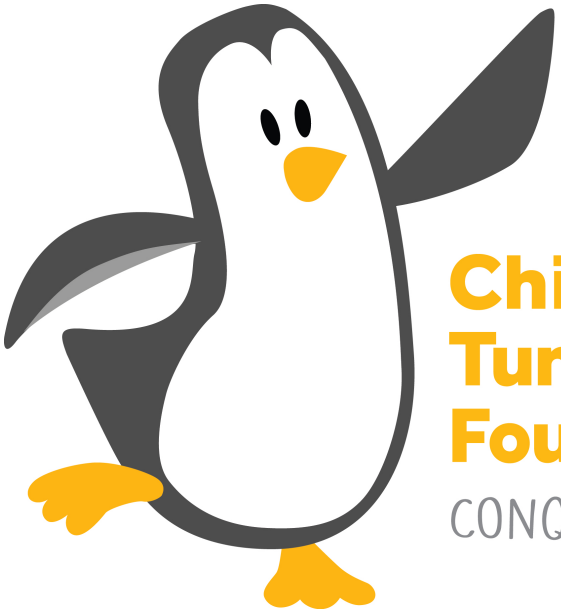

Children's Tumour Foundation
CONQUERING NF


Written by Lana Hanssens
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*To Fraser, our very own NF Hero – never lose your super hero smile little buddy. You make us so proud.*
*Love Mummy, Daddy & Sissy.*

*Dedicated to all the NF heroes, near and far.*
*May you always have your super powers to face your challenges.*

“I’m Alex the GREAT, I’m Alex the BRAVE, I’m Alex the SUPER HERO!!”.

“You are not a super hero” says Jack.
“Am too”
“Are not”
“AM TOO!!”
“Well, if you really are a super hero then why don’t you prove it.”

“Well I’m BRAVER than Batman...”

“I’m STRONGER than Spiderman...”

“And I’m more SUPER than Superman!!”

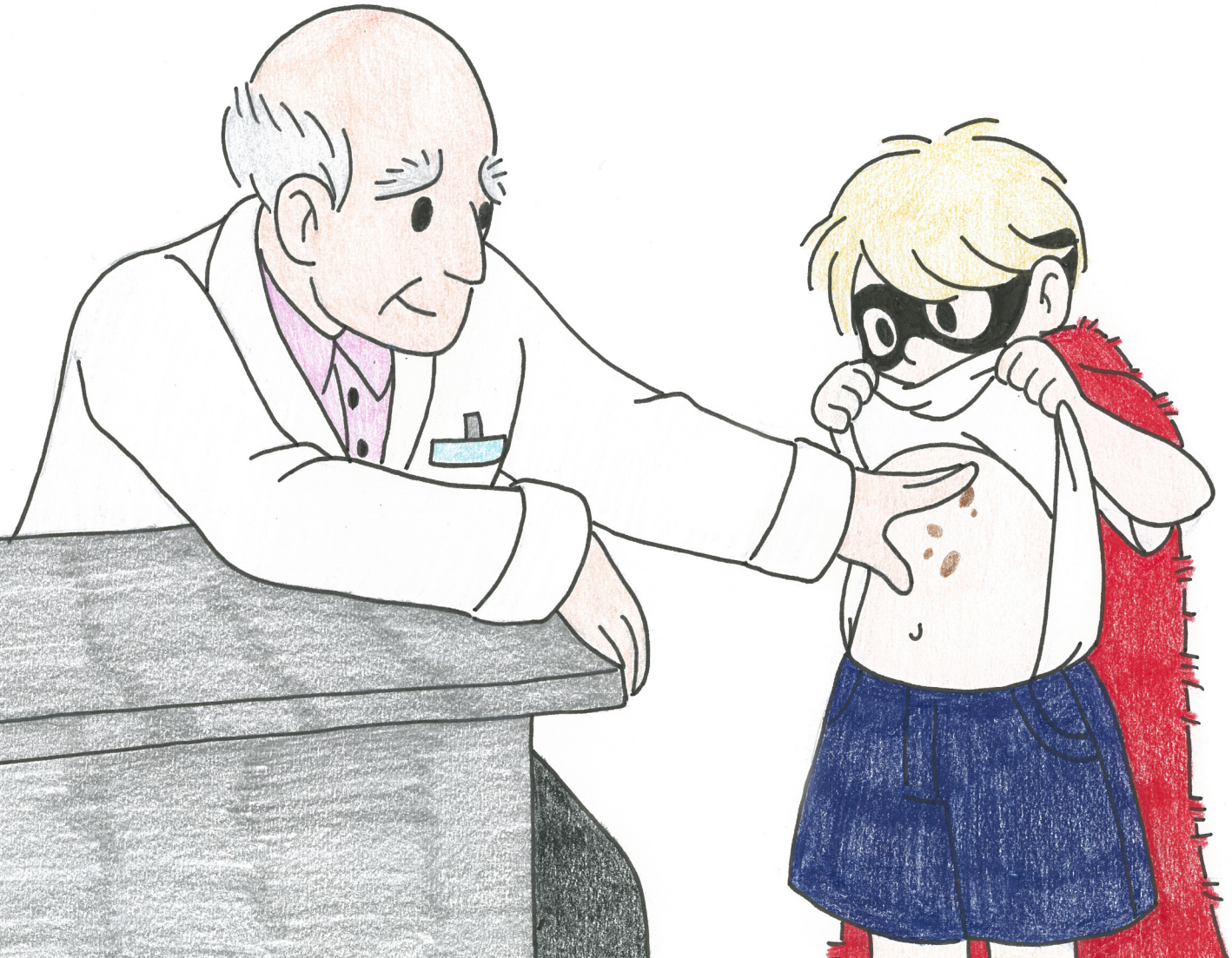
“Oh yeah. Well if you REALLY are the BEST Superhero of all time, what is your superhero name smarty pants?” says Jack.
“Well that’s easy. I’m the NF hero”.

Jack is not convinced. “The NF hero? What is an NF hero? Let me guess, it stands for Not Funny?” he says jokingly.
“No Jack, everyone knows you’re the one that’s not funny. NF stands for Neurofibromatosis”.

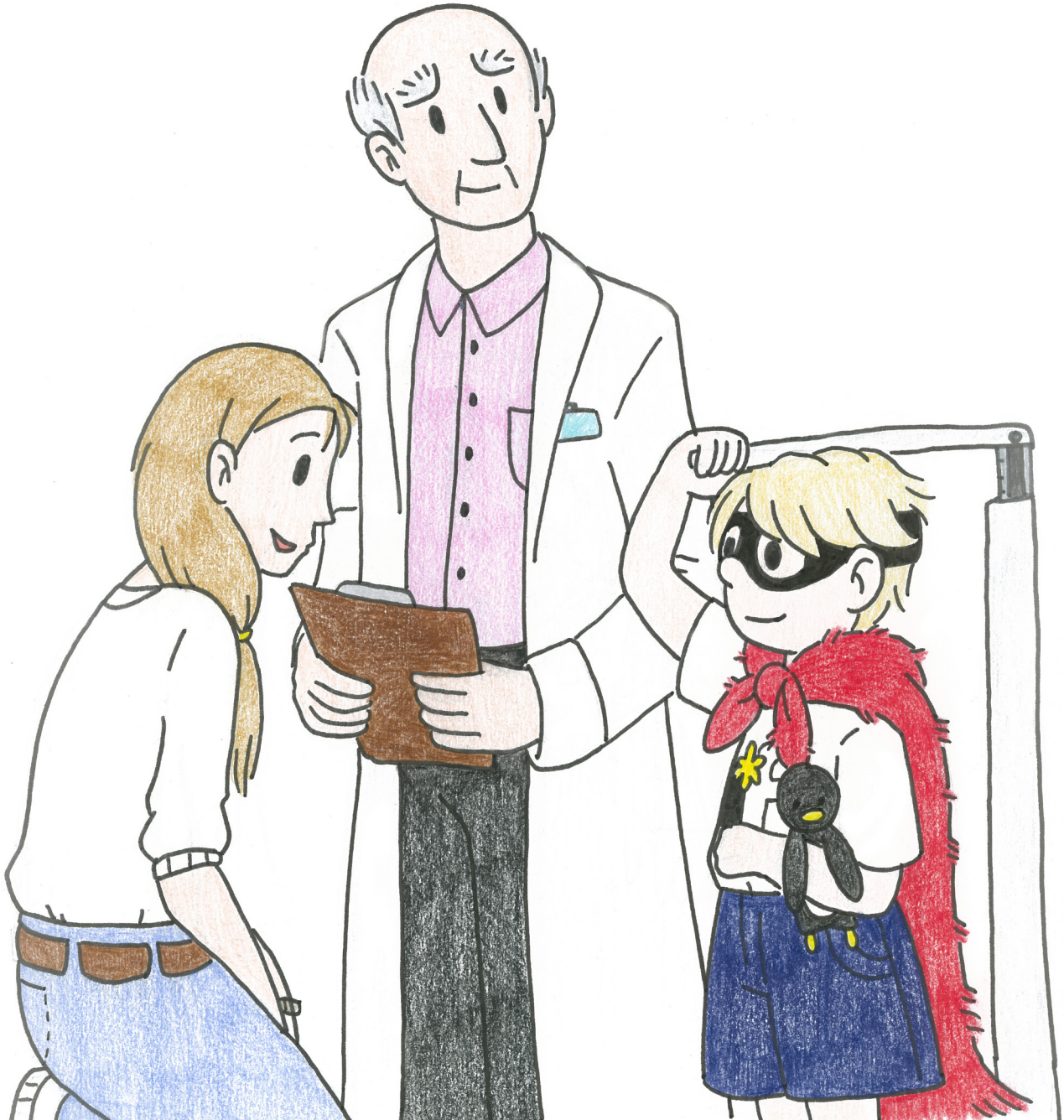
“Nemo what?” says Jack.
“Not Nemo silly, Neuro-fibroma-tosis but you can call me the NF hero for short.” Alex responds.

“Well what’s so special about an NF hero anyway?” Jack questions.

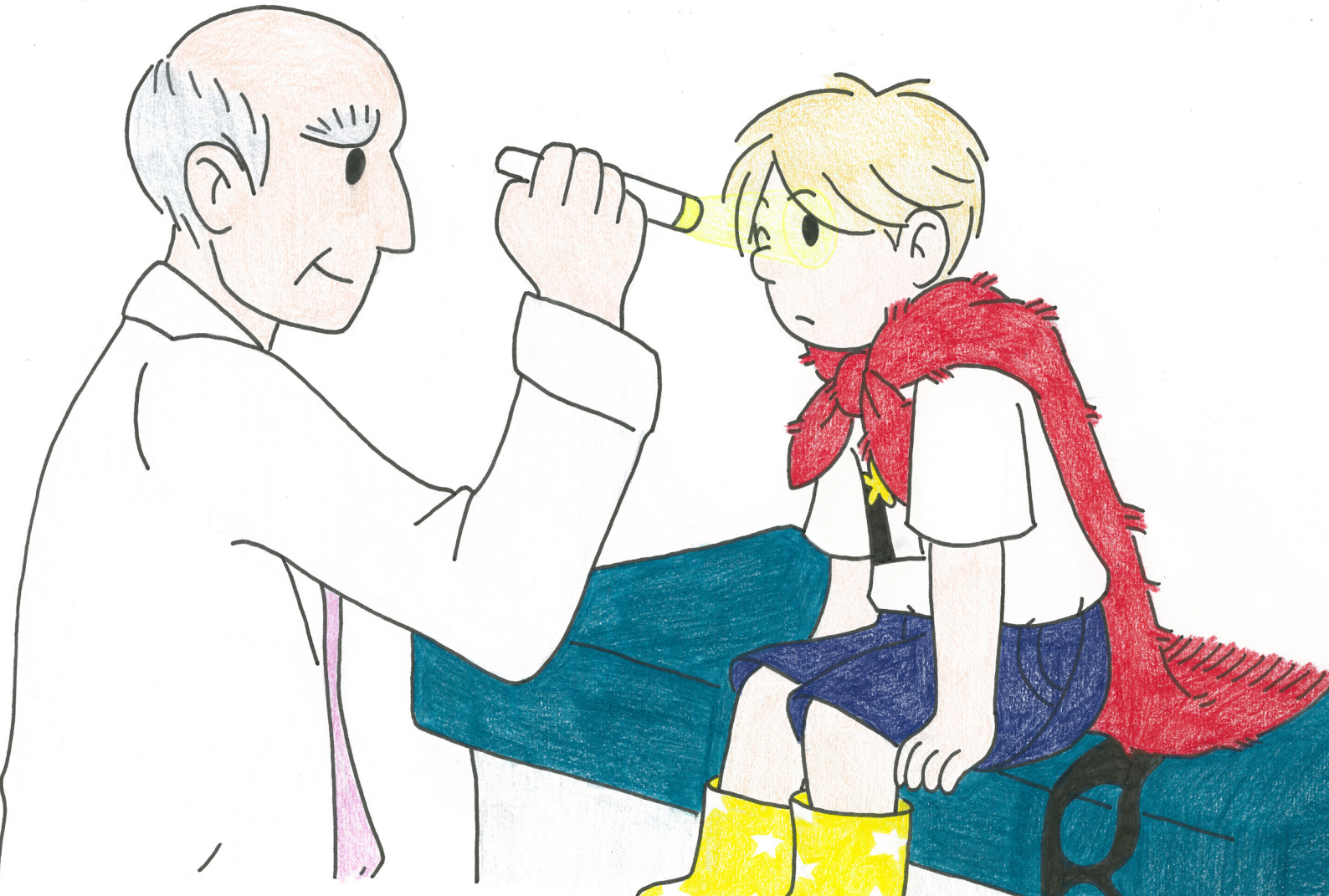
"Well I'm so special that sometimes the doctors check out my super hero spots..."



“They see how tall I’m growing and how big my brains are...”



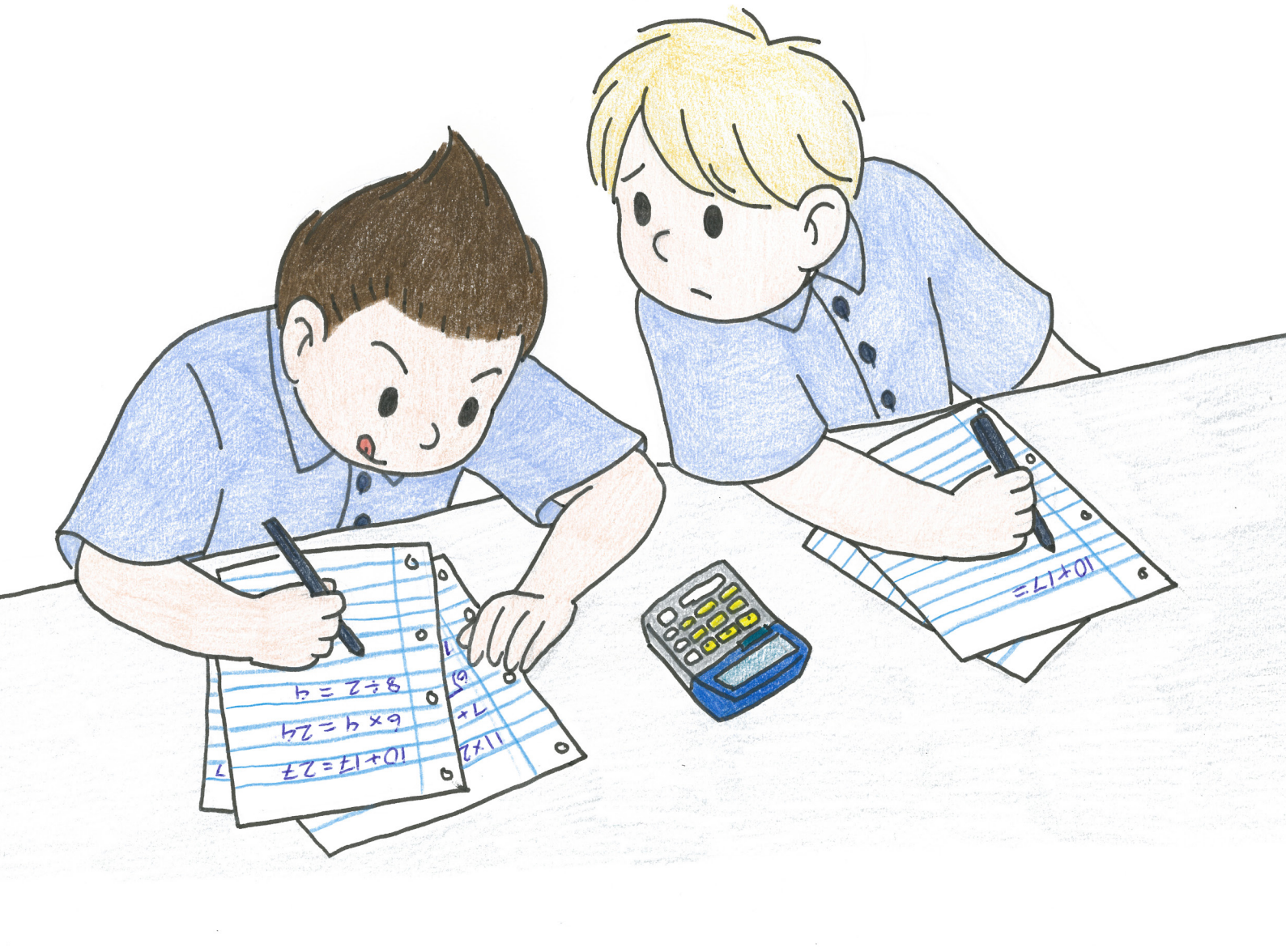
“They check my eyes for super hero vision....”



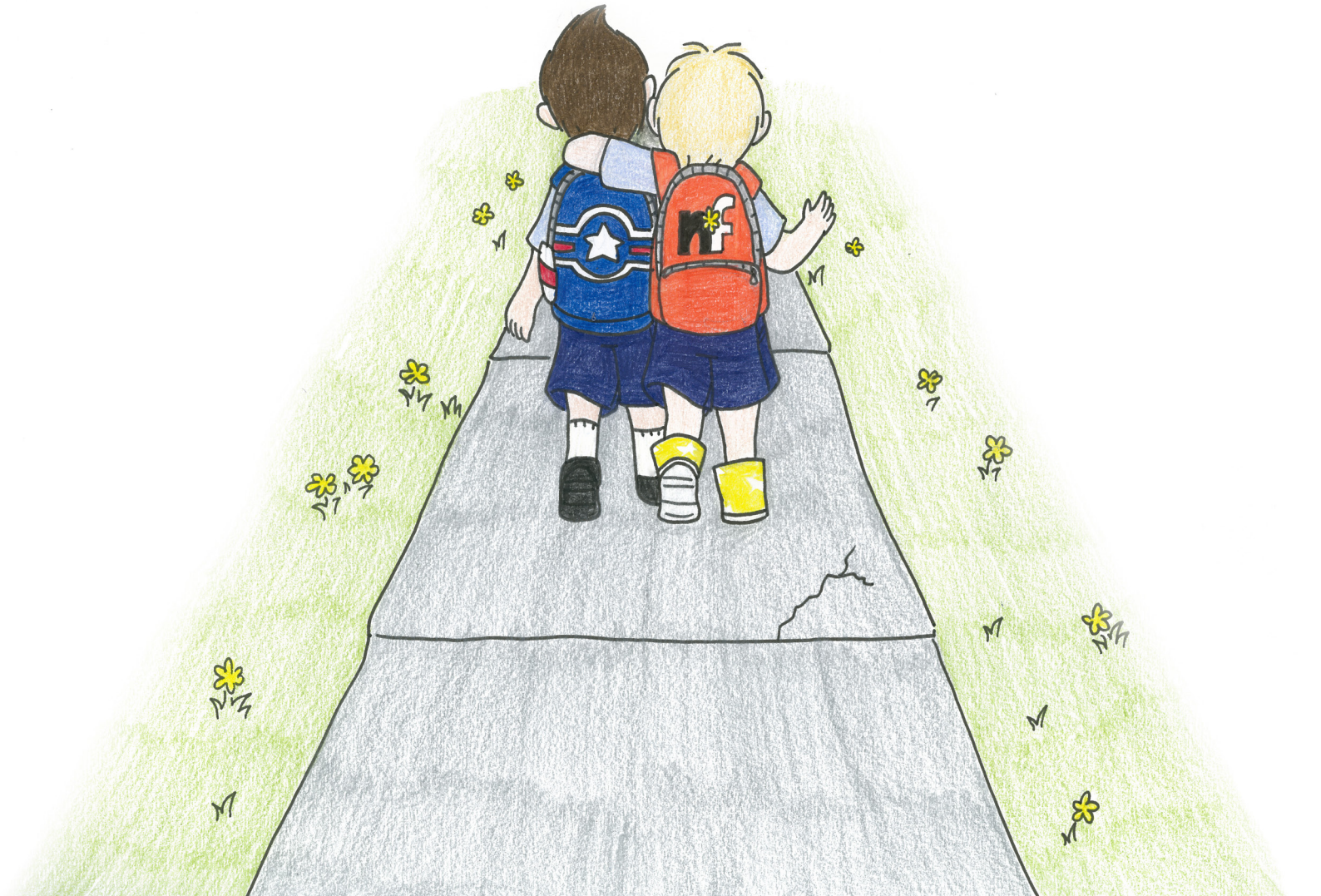
"And sometimes they even put me in a big tube to check my super hero insides!"

“Well if being an NF hero makes you so special, how come I can still beat you at basketball?” asks Jack.

“And I’m even better than you at maths!”



“Because not even a super hero can be good at EVERYTHING Jack.”



# What is Neurofibromatosis Type 1: Information for Parents

Neurofibromatosis type 1 (NF1) is a genetic condition affecting approximately one in 2,500 children. This means it is as common as Cystic Fibrosis, Huntington's Disease and Muscular Dystrophy. NF1 can affect anyone, regardless of race, gender, or ethnic background.

Approximately half of children affected by NF1 have inherited the condition from one of their parents, while the other half are the first in their family to have NF1.

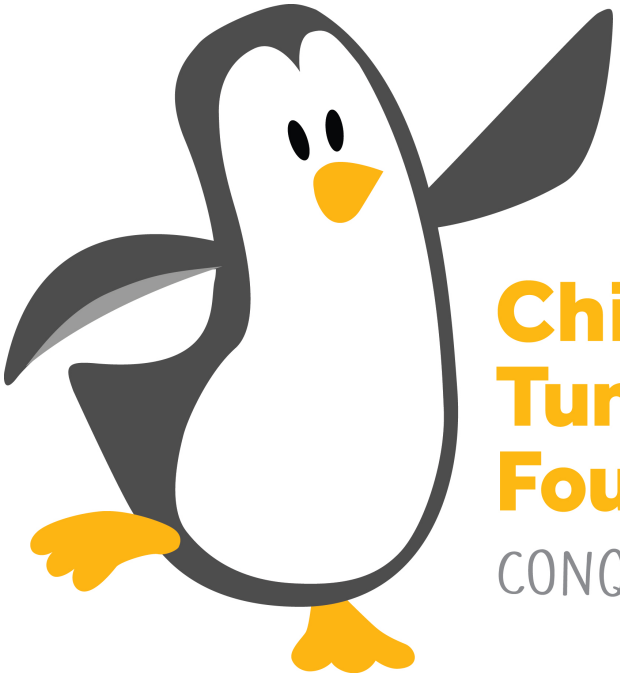
NF1 is usually diagnosed in the first few years of life often with the development of a number of café-au- lait spots (coffee-coloured birthmarks) as the first indication. Many will also develop freckling in skinfold areas and pigment changes in the eye.

The hallmark feature of this condition, the growth of benign tumours on the skin, called neurofibromas, usually do not develop until later on in childhood or adolescence. Neurofibromas can also grow anywhere in the body where there are nerve cells. This includes nerves just under the surface of the skin, as well as nerves deeper within the body, spinal cord, and brain. Tumours which form on the nerve to the eye, called an optic pathway glioma, can develop in some children. In a small number of cases these tumours may progress and cause problems with vision.

NF1 can also impact upon many other systems within the body, but there is no way to know how each child will be impacted by NF1 during their lifetime. It is an extremely variable condition. Most people with NF1 will be affected mildly to moderately, and lead normal, healthy lives, yet there is a small proportion of those impacted who will have or develop life-limiting or life-threatening complications of this common rare condition.

It is this uncertainty that makes a diagnosis of NF1 so challenging.

For more information visit our website: www.ctf.org.au



# Children's Tumour Foundation

CONQUERING NF

Neurofibromatosis type 1 (NF1) is a genetic condition affecting approximately one in 2,500 children. NF1 can affect anyone, regardless of race, gender, or ethnic background.

This is the story of Alex...
The NF Hero