The adventures of Tito

Tito was born brave

Written by
Inês Cabral da Fonseca

Translated by
David Gonçalves

Illustrated by
Mafalda Mota

APNF
Associação Portuguesa
de **Neurofibromatose**

The adventures of Tito

Tito was born brave

Written by
Inês Cabral da Fonseca

Illustrated by
Mafalda Mota

Index

Introduction

Inês Cabral da Fonseca and Ana R. Santos, November 2020
Psychologists

Receiving a rare disease diagnosis such as a neurofibromatosis type 1 (NF1) is hard for children and their relatives. The family's routine is bound to be put under stress with the succession of events, emotions and problems that inevitably comes from such news. Besides all emotional, familiar, social, logistic and financial challenges, there's some chance that NF1 related health issues occur such as attention deficit, behaviour problems and social interaction struggles. This will have an even greater impact on the family's quality of life. It is quite difficult for the child and relatives to manage all appointments that will follow after the diagnosis. Here, we address all those challenges and offer tips on how to deal with them. Tito represents all children facing such challenges. He's a gentle, resilient and brave six year-old willing to share his adventures with the readers.

The goal of this book is to inspire, sensitize and encourage both children and adults. This story provides the reader with guidelines on how to talk to children about various topics. Mirroring can be used to make children realize others are also facing challenges and experiencing some ailments. Bridging can also be useful to link Tito's feelings to their own emotions. Adults can lead the child to ask new questions so they can be followed by concrete answers. They can also promote resilience to problems and teach children to celebrate each surmounted hurdle. Grown-ups can also show that different strategies can be used to solve the same problem (e.g. similar fears).

Tito invites us all, in our NF1 journey, to be more complete and aware by deeply know what's inside of us (and others).

Excalibur to the worthy

Risoleta C. Pinto Pedro, September 2020
Writer

Life's an adventure, a great adventure with no known beginning or end. Like any other adventure, exciting moments are followed by more restful ones. Rechargeable breaks. This book can be read during one such break or, who knows, during turmoil: by kids, by parents, by parents to kids or, who knows, by kids to parents; eventually, by technicians.

Ad venture, the Latin word for adventure, means "what lies ahead". Adventures begin somewhere though. In the case of children whose story is told here, what lies ahead is as exciting as the beginning because that's where a complete understanding is to be found and, surely, the cure of the disease. Scientists won't give up finding it.

In an adventure, it is important to always be prepared since you never know what's coming your way. Hence this story, a simple way of lovingly following kids and their families in their grand adventure overcoming obstacles to small bodies and their great souls.

We're talking about a radical adventure for kids, something often inaccessible to them. Well, these kids are either born heroes or self-made ones. The doctor's role is to keep all risks under control. This book is part of that control program: at the medical level, providing helpful clarifications; and at the psychological level, for the soothing serenity it may offer.

Courage is always an intrinsic part of every adventure, as is fear. In the adventurous lives of these children and their families, fear and courage go side by side. Courage is promoted by fear and fear is controlled by courage. Ironically, these are two inseparable companions that may open new quarters inside people, as well as new paths leading to a deeper knowledge about themselves… and others. Definitely, they are agents of change, always for the better, I would dare saying.

Going to the hospital may put the adventure's protagonist into a scary situation while discovering new disease-related problems; or can mitigate or even solve them. Fear can be anywhere, there are no safe havens besides the one that will never let the hero down: his own heart surrounded by the affections of loved ones

from family, friends, school and hospital. It's not a physical place but it is absolutely safe. Some sort of a magic circle which, once found, recognized and activated, is totally impermeable to evil – it won't be able to break in.

Next to these children's life games, virtual games are naïf, innocuous and tasteless. They're a far cry from the hero's odyssey lived by children with NF1 who don't really need heroes because they're heroes themselves. They deserve a medal though as well as a sacred sword like the one once held by King Arthur because their greater worth is to pull it from stone, everyday.

Our Titos

João Passos, October 2020
Neurologist – *Instituto Português de Oncologia de Lisboa*

Tito knows he's different and, although he can't precise the exact moment he realized it, that realization is crystalline and overwhelming. He's different… and the emotion filling him afterwards is sadness, thick as a foggy morning. Although he lives in a bubble that cultivates difference and tolerance, his intuition tells him something negative resides on what makes him so special, as if he's endangered or somehow broken. Otherwise, why would there be any need to be constantly monitored and under treatment.

We deal ambiguously with the chronic problems experienced by our beloved. Our wish to mitigate such struggles commingles with our wish to accept them fully, which is basically the same as stopping to see them as actual problems. Latent to such ambivalence is the fear of other's views, which is perceived as being rooted in unfounded prejudice. This internal dialogue over NF, a condition with so many possible manifestations, is inextricably linked to the kind of experience it provides. This explains why people may react so differently to it, and why their attitude about it is continuously reformulated throughout life.

Let's go back to Tito. The ravishing reasoning of a child finds no solace on the euphemisms coming from adults or on their murmured half words. So, the outspoken clear and easy-to-understand truth is usually the best approach. It certainly is in

Tito's case. Since I carry with me all my patients' stories, I can't tell Tito not to be afraid or that his sadness is unfounded. The MRI room can indeed be scary if you're only 6 years old and, except for Lisch nodules, other NF manifestations may cause distress and reduce the quality of life.

Tito is still in the consultation office and is becoming increasingly uncomfortable. That's when it's worthy to call his attention to other important facts which will counterbalance adversity: his caregivers love him unconditionally; we have a plan to prevent and control problems; we have a clear objective which is to allow Tito to grow up in a fulfilled manner.

By dilating time, during this profound and paused breathing-reading exercise, we become fully aware of the challenging long road ahead of us, which is somewhat bumpy but travelled by many other pilgrims who are willing to give a helpful hand.

Courage to every child and family

Marta Amorim, October 2020
Medical Geneticist – *CHLC – Hospital Dona Estefânia*

Life's greatest gift is what we do for each other.

As a medical geneticist, my biggest challenge is coping with the distress felt by families of patients with a rare disease. For every rare patient, there's a rare family too, snowed under multiple medical appointments and information, quite shaken for fear of the prognostic and the lack of a cure – as well as a lack of understanding and references. Follow-up of these patients is not accomplished in the 15, 30 or even 60 minutes of the consultation. It implies understanding and approaching all aspects of the disease. Truth is, however, the national healthcare system provides not enough tools for that to happen.

My professional path led me to studying neurofibromatoses (NF) and brought to my attention some lost but brave families who invested in the revitalization of a patient's organization for the behalf of patients and relatives. Working with APNF

and supporting their projects and ambitions provided me a bridge to access these families something that was lacking in my clinical practice. I congratulate them for all their hard work.

To NF families, I hope this book brings you answers and strength in your journey.

Mum: – You know what? Son: – I love you...

Ana Elisabete Pires, October 2020
Elected President of APNF

It is very hard to find the hero, the brave, the special... the truth is that it's difficult to escape from this fate... We need to face thousands of medical appointments and treatments. We need to face the anxiety and the doubts. We try to handle all these as a family and sometimes we need to ask for help.

This book was written having in mind all the children and their families who are intimately linked to this disease. It attempts to give some light and support about the cause and symptoms of NF by describing the daily experiences of a fictitious boy named Tito. It accomplishes that goal with some humour, charm and poetry. The book is beautifully illustrated! In it, we witness some events of Tito's life to better understand the real dimension of the disease and its impact at the personal and family level.

Someday, a cure will free all the children from neurofibromatosis type 1. And when that day comes, I'll be applauding science, celebrating health, embracing solidarity and breathing such a newly found freedom.

Until then, as a mother, I'll do my best to offer relief, safety and trust.

The adventures of Tito

Tito was born brave

Adventure 1

Tito at the hospital

Tito goes often to the hospital since he was a little boy. A few days after he was born, his family noticed some spots on his back, arms, legs and belly as well as freckles on his armpits. And that's how they found out Tito had neurofibromatosis type 1. Dr. Martha diagnosed it and explained how important it was to watch for the disease's progress. From that moment on, Tito started to visit the doctor several times each year. She also told him that, nonetheless, he could still have a normal life. Now that he's six years old, Tito's no longer afraid of the hospital and sees it as a second home. It may sound strange at first... but he now knows every inch of that building and is friendly with everyone who works there.

Each time Tito goes to the hospital, he carries a backpack with his favourite colour books and other fun stuff that help spending time. He also never forgets his favourite teddy bear. Tito is followed by many doctors, especially Dr. Albert who informed him that his spots are known as *café-au-lait* spots, due to their brownish shade, and that they differ from kid to kid. They're not painful although their size and number can increase with time. There's no way of predicting if that will be the case though.

Tito pays little attention to his spots and he even forgets he has them. He thinks they make him different, somewhat special, and because he doesn't like coffee, Tito prefers imagining them as chocolate spots all over his skin. He loves chocolate! That helps him dealing with the condition. Besides Dr. Albert, Tito is also followed by other doctors, such as Dr. Alexandra, a dermatologist. She's the one taking a closer look at Tito's skin and, in their last appointment, she measured all the spots with a ruler under a bright light.

Dr. John is a neurologist, a doctor who looks inside Tito's head and brain. He asks him to do some balance exercises, such as walking down a line on the floor or

stand up holding his hands over the head. In their last encounter, Tito's head was even measured from one side to the other with a measuring tape.

Another expert following Tito is Dr. Miguel, an ophthalmologist who looks after his eyes. Dr. Miguel uses eye drops during the examination which burn a little. And Tito is bothered by the bright light he uses. He's a bit scared of it, actually, but his dad is with him at all times and they hold hands for support. Tito focuses on the skin on his dad's hand and thinks how good it is to have his company during the examination. Then, he takes a deep breath and counts to ten. Before he knows it, the examination is over.

From time to time, Dr. Albert asks him to do some blood tests. He doesn't like it very much but his mum and teddy bear are always with him. Holding hands with her and with his teddy bear sitting on his lap, Tito feels brave and lets the nurse draw blood from his vein. In

the meanwhile, Tito recalls a secret shared with his best friend on the previous day.

Another unusual thing Tito had to do was a magnetic resonance imaging, also known as MRI. It's a tunnel-like chamber that allows taking pictures to the inside of your head and really looks like a spacecraft! It was not his first time on the "spacecraft" but he doesn't remember it since he was too little. Besides, Dr. Albert gave him something to help him sleeping during the procedure so that he wasn't frightened by the MRI's loud noise. This time, he stayed awake and the technicians gave him some special headphones and glasses so that he could watch a movie or listen to music or a story. He felt like a real astronaut while the giant machine took thousands of pictures of his head and brain. These would help Dr. Albert to better understand Tito's condition.

Doctors need to study, to talk to each other, and sometimes to examine their patients to know what's going on with them.

Tito has always been very brave but gets tired sometimes with all the testing, medical exams and conversations... so many different things to experience! In such days, he feels a bit down although he still tries to

be patient and do everything he is asked to do. Doctors always congratulate him for being so cooperative.

The last doctor he met was Dr. Rita. She's an oncologist and sees if there are small bulks in Tito's body. After being examined, Tito's always thrilled to go play with the other kids and toys in the waiting room.

After doing the medical exams, the waiting for the results seems endless. Tito's parents are usually on their toes even though he seems to take it lightly. Parents want to see their kids happy so they do their best to keep them entertained.

Finally, Tito and his parents go back to the hospital to have an appointment with Dr. Albert. Fortunately, Tito is in good health although they've found a small spongy bulk on the upper region of his leg. Sometimes, this kind of bulk grows in kids with neurofibromatosis type 1. When Tito heard of it, he got worried but the doctor reassured him.

— I understand you're a bit concerned with what I told you and your parents. However, let me tell you that doctors and researchers have recently developed a drug that we hope is going to stop your bulk from growing and causing you pain. The drug has a long name that is quite difficult to pronounce. Do you want to learn it?

— I do — replied Tito, feeling a bit calmer.

— It's named Se-lu-me-ti-nib. And you know what? We've been using it with great success on other kids being followed here at the hospital and who also have neurofibromatosis type 1.

Tito remained thoughtful while the doctor was giving his parents some instructions about the drug. When they got home, he asked them:

— Dr. Albert used a word that I didn't understand - "neuro" something. What is it that I have, after all?

They thought hard about the words they should use but, truth is, they were also trying to figure it out themselves.

— Tito, neurofibromatosis type 1 is the name of your condition. It is a big word so we can shorten it to NF1. Other kids have it as well, you're not the only one, but don't you worry. You'll still keep going to school, playing with your friends, spending time with your family and watching the cartoons you love. Like all other children, you'll need to go to the doctor but, in your case, you may

have to go more often. Together, we'll be watchful and make sure that you're healthy and happy.

— Do I have NF1 because I behaved badly? — inquired Tito.

— No, that is not the reason. No one is to blame. We may struggle a bit when parts of our body are unhealthy, and that's the case for some of your body cells (the body is composed of cells and each one has a specific function). However, that is not a punishment for something you did or did not do. We'll do everything we can to make sure you always feel ok.

And then, they added:

— You know what? There will always be plenty of people to help you out, like both of us, the rest of your family and friends, doctors and nurses. You'll never be alone and you can rely on us to give you the support you need so that you are as brave as you can be.

All this roaming to the hospital
Is now my new normal.
Doctors take care of our pains
as millers do to their grains.
They sting,
while perspiring,
investigate,
evaluate.
Often, attenuate!
Them I salute
for being so acute!

Adventure 2

Tito and Neurofibromatosis Type 1

The day after celebrating his seventh birthday, Tito went to the hospital for yet another medical appointment with Dr. Albert. He met a 6 year-old girl in the waiting room named Lu and they talked and played together for a while.

— Do you also have spots on your skin? — asked Tito while pointing to his own neck.

— Yes, I have neurofo... neurofibra... neurofibroma-tosis! It's a bit hard to pronounce! — replied Lu.

— Me too! — Tito was astonished since he had never met someone who also had the condition.

— I come from far away to be seen by the doctor — Lu told him.

— Why? — asked Tito.

— My parents told me the best doctor is here at this hospital. Besides the spots, I also have poor eyesight... I have a broken eye and some lumps on my skin – confided Lu while pointing to her forearm.

— I only had spots until recently but now I have a lump here — Tito said and pointed to his upper legs region.

While the children were talking, their families were

also sharing their own experiences with one another about life with kids who have NF1. At times, it is important to remind ourselves that we're not the only ones living with NF, that we're not that rare or odd and that other people are dealing with similar challenges. When Tito got alone with his parents in the waiting room, he became thoughtful and asked them:

— If Lu and I have the same condition and she has an injured eye, does that mean I'll have one too?

— That is a good question, Tito. We've also considered that... Truth is it may or may not happen. Only time will tell but it may well be that nothing serious will

come out of it. We are not able to guess how your body will be in a month, in a year or in ten years. However, that is the case for any other person, no one knows. That is why everyone goes to the doctor from time to time, so that they can check if they're healthy or not. Most often, all is under control and doctors find nothing serious.

And Tito's mum added:

— NF1 is not the same in every child, giving way to different symptoms. And despite both of you carrying the same condition, it may present itself in distinct ways which will also vary as you grow old. We really need to keep watchful... A very tight watch, just like this... — and they hugged each other closely.

Tito started thinking about Lu and her injured eye. Seeing her son so lost in his thoughts, mum continued:

— That's why we must go to our hospital appointments. We need to stay strong and brave and, of course, keep doing the medical exams we're asked to do. Even when they're boring and take so much time. They're important to check how the condition is evolving as you put some years under your belt. With all our vigilance, you'll feel properly escorted and protected.

Meanwhile, they were summoned to see the doctor.

Before entering his office, dad told Tito:

— Tito, we trust all these people because they want to help you to make sure everything is alright, just like your mother and me.

When Dr. Albert saw Tito coming in through the door, he winked and asked:

— Tito, I know you've started going to school already! How grown up you are! Do you fancy it?

Tito replied:

— I do! I'm able to write and read many, many things now.

— Wonderful! Look, please make a drawing of what you want to be when you grow up.

While the doctor was speaking to his parents, Tito scribbled a small boy with a hat and a magnifying glass.

— What is this kid doing? — asked Dr. Albert.

— He's an NF1 researcher and a really, really nice guy.

— That's so cool! Tito, is that what you want to be?

— Yes, but with this condition that I have... I'm not sure that's even possible.

Dr. Albert smiled:

— I don't see why not! You should choose something that makes you happy and you have all the abilities to be a researcher. Besides, no one works alone and everyone needs help sometimes to learn new things.

Tito smiled, feeling more confident, and embraced the doctor tightly. Before leaving, Dr. Albert informed Tito and his parents of a patients association devoted to NF which can help clarify doubts regarding neurofibromatosis conditions, including NF1. He told them it also provides support to patients, their families and even research groups dedicated to NF. That way, children and their families do not feel so lost. Dr. Albert encouraged them to contact the association.

Tito interrupted them to ask:

— Do they have researchers?

And the doctor replied:

— Not on their team, I think. However, they know researchers in every corner of the world who are working hard to find a cure for NF1.

When, in a few years,
a boy full-grown,
blossomed, reborn,
through a magnifier
(not knowing this scryer
jumped farther and higher)
yells Eureka!, It's done,
then everyone will know
his skin was as spotted
as ladybirds are dotted.
But he'll find out today,
realize and reveal,
magic new medicines
unknown to all denizens
that will for sure heal...
many pains. Pacify,
and thus slowly gratify
with a wellness that's nigh.

Adventure 3

Tito's family

Sometimes, Tito's parents are left with their heads spinning with all the medical appointments they have to attend. Once, while they were both exchanging ideas, his mum blurted out:

— What are we going to do? Our son has Neuro... fi...bromatosis... I can't even say it right!

— We need to do our best to figure out this disease. Nobody knows our son better than we do. How he's like, what he likes, what scares him, what he needs... — his dad said.

One thing they knew for sure. Tito would be loved and cared by his family and closer friends. That would always be the case despite all concerns, doubts and emotions, regardless of whether it was rainy or sunny, warm or cold, night or day, and no matter where they were, at home, at school or at the hospital.

Lucas, his older brother could not avoid being worried about Tito. He soon learned that his younger brother required a bit more attention from their parents. The two brothers enjoy playing together, but sometimes Lucas does not let Tito do things by himself because he fears he might get hurt. He worries Tito may be too fragile and that something may happen to him.

Some time ago, they were hiking and they got to a small stream. Tito wanted to cross it with the aid of stepping stones. Lucas offered some help but Tito was feeling quite brave that day:

— Thank you bro, but I think I can do this by myself! — and he jumped onto the first stone without falling or getting hurt.

When Tito went to the beach with his family on a lovely sunny day, he asked:

— Dad, how come Lucas has no spots like mine?

— Well, sometimes this condition shows up without any apparent cause. That's what happened to you, Tito. No one else has NF1 in our family, you were the first. Some other times, a parent has it already and passes it on to the children.

— Do you have it, dad? — Tito was curious to know.

— As I told you, I don't have it. No one in our family has it but it's not always like this. Do you remember Lu?

— Of course I do! — replied Tito.

— Lu's father has the same condition you both have. Someone who has it can pass it on... or not. Lu's sister doesn't have NF1 but you know what? Doctors can help avoid passing the disease from parent to children. So, if you decide to have kids one day, it can be done without putting them at risk of getting the disease. Tito became thoughtful and dad noticed:

— You look sad...

— No, I'm just wondering why I have this condition if no one else in the family has it.

— Anyone can have NF1. Half the kids who have NF1 are just like you, the only ones in their families to have it. The other half are kids like Lu, one of their parents has it. Tito insisted:

— But how did it show up?

— NF1 is caused by a change in the code we have inside us. That code is passed along from the parents to the child and defines features such as the colour of the eyes, hair and skin. One half of the code is taken from the father and the other half is taken from the mother. It just so happens you're a fine mix of the two, my dear boy!

The two laughed out loud. Then, dad continued:

— However, a small change in the code is enough to create new features like, in your case, a disease. Imagine a word, if you change one of the letters, it no longer has meaning. Let me give you an example: If you insert a small error to "a fat cat climbed a giant tree" you could get "a cat cat climbed a giant three". That would change the sentence a lot, right?

— Right, the cat is no longer fat, it became a... cat cat?

— Now, would Garfield stories be so funny if it stopped being fat?

Tito felt a bit confused with so much information. He took a deep breath and said:

— Thanks, dad! I think I understand it better now. When I become an NF1 researcher, I'll find answers to all questions kids like me might have.

— I'm sure you will, son. We can all help doctors and scientists on their jobs. Who knows, maybe someday a cure will be found.

— I'll do it, dad!

When a boy with smarts so great
holds a dream dear to his heart.
it turns into written fate,
as sound-&-colour recorded art.
All one needs is to grow up,
Learn up, and keep in mind
what wishes stars unbind:
Tito's great care and success
are bound to his skin with finesse.

Adventure 4

Tito at school

Tito attends school just like every other kid. He sometimes misses a class or two to go see the doctor and then comes back the next day with plenty to tell his best friend Becas. At first, it was super difficult to explain his school mates what neurofibromatosis type 1 is. He was ashamed to show them his spots, although he kind of like them. Everyone was quite baffled by the rather long and overly complicated name of the disease. That is not the case for teacher Andrea though who actually knows what NF1 is and is expertly skilled at making Tito feel like right at home in her classroom.

Once at recess, some older kids made fun of Tito's spots. They called him a giraffe and mocked him cruelly. Tito was by now used to this kind of displays but, for some reason, this one really got to him – it made him very sad and nervous. He was struggling to snap out of it. Luckily, one of his friends saw the whole thing and told Tito's teacher what had happened. She then called Tito aside:

— Tito, is someone mocking or harming you during recess? — She asked.

— No, teacher — he replied, assertively.

— You can tell me. It's very important that I am aware of what is going on with all kids at school. Don't worry, I'm really good at keeping secrets, you can trust me. Reluctantly, Tito confided.

— There's this group of older kids who, almost every day, enjoy making fun of me and calling me bad names. They called me a giraffe today and... I don't know what to do about that.

— You know, sometimes kids make fun of others because they want to see them sad or mad. Other times, they're mocking without even imagining how badly that makes others feel. They think no harm comes from it. Also, sometimes they're just ignorant. They have no idea what causes those spots and why you have them while they don't. I believe they mock you because they're now

more aware of your condition. They probably just see the differences between you and them and are unable to see everything else they share with you, for instance stuff you all like to do. They were not nice to you.

Teacher Andrea added:

— It's absolutely normal to be sad when we're being mocked. If you find yourself in that situation, you can try to ignore them or tell them to stop because you don't like what they're saying. My advice is for you to look for an adult you trust, explain what's happening, and ask for help. This is very important and you can always come to me for help.

The teacher's advices didn't convince him. Tito was angry and he wanted to go home. Nonetheless, he tried to put them in practice in the following days. It wasn't easy but he kept on trying. He tried to ignore some wicked comments, he went playing to a different part of the playground and he shared with Becas how annoyed those mean boys made him feel. After some time, they lost interest in him and started leaving him alone. After all, the teacher's advices worked out.

In the following week, the children's families attended a party held at school. The kids participated in a talent show, either by playing an instrument, singing, drawing, juggling or showcasing all kinds of skills. At the end of the show, Tito was the big winner! He is a really wonderful singer and everyone was very well impressed. His teacher, his relatives, his friends... everyone was amazed! Tito was so happy to be applauded by the audience. He was even congratulated by one of the kids who used to bully him. That cheered him up. Who would have guessed that, maybe, they could actually become friends.

At school, Tito is sometimes unable to complete his tasks at first, although he always tries to be swift about it. That is so frustrating, because he's puzzled by the fact of being so good at some things and not so much at others. Of course, when he's feeling a bit angry, it becomes much more difficult to think and to answer questions correctly. What Tito is about to learn though, is that he's not the only one feeling this way. Many kids are not as fast or as deft as others. They can take more time to complete their tasks but that doesn't make them worse in any way. It is important though to clearly identify which tasks they can complete more easily as well as those that may be a bit more challenging.

Tito's best friend Becas is always mindful of his progress at school. She's a very observant and sympathetic girl who likes reading and telling stories. No one knows Tito better at school and they love playing on the swing together.

Becas noticed that Tito was making some orthographic mistakes and misspelling some words. Being such a prolific reader, she's quite good at reading and interpreting texts and therefore decided to help him. Although a bit embarrassed, Tito accepted his friend's help because he trusted Becas and really wanted to get better results at school.

Becas' positive influence led him to spend more time reading. He saw how happy she was after finishing a story and was fascinated by the tales she shared with him. The two of them were spending a lot of time together reading during recess. Some schoolmates made fun of them for that but bullying no longer bothered Tito.

He now felt well supported and safe by knowing he was never alone.

After a while, Tito was able to overcome many of the struggles he felt while writing and Becas was glad to know she had helped him with that. Tito learned that people's talents could really help others to improve and that, just because he has difficulties in some things, that doesn't mean he can't be good at other things.

If you're really good at math,
one plus one can outreach two.
If you give Tito a hand,
a reward you'll get, though unplanned,
farther greater than you knew,
further than your original path.
More is learned at school
if you're willing to help out,
more is gained then, as a rule,
than by keeping in time-out.
Talents were given to all,
finding them is everyone's call:
I dance when you're singing,
you charm me when I'm reading,
we cry and laugh... that's living:
marvellous at times, other times stinging.

Adventure 5

Tito's emotions

When the bell rang at the end of the day, all children cheerfully stepped out of class. Only Tito was feeling a bit sad. He didn't feel well and was sobbing. When Becas saw him that way, she asked him what was wrong.

— Sometimes, I get sad because of my condition. I get so tired and fed up of always being the weakling kid.

— I see... Well, it's normal to be sad sometimes but you should know that's not how I perceive you. You're so much more than your condition and you're good at many things. You draw and sing wonderfully! And you're the best friend I could have — said Becas, smiling.

Tito thought about that for a moment, unconvinced. Then, Becas said:

— You know, when I'm sad, the best way to turn things around is to do pleasant things and try to change my mood. For example, I sometimes ask my mother to fill the tub so I can take a warm bubble bath. I also enjoy listening to my favourite music while I play. Some other times, I read or spend time with my family or friends. That usually improves my disposition. And if that doesn't work, I can always embrace my teddy bear! That's what I like the most. He's so cute!

Tito listened to her and started smiling. The first thing he did when he got home was embracing his own teddy bear very tightly. He immediately felt better.

Although he may feel sad at times, Tito is usually in a cheerful mood. He always gets extremely happy when his parents and Becas' parents plan a play date at the park. There's plenty to be happy about there and he loves playing with the swing along with his best friend. They feel like they're flying! He can't stop laughing and jumping around.

Tito is certainly more patient when he feels happier. He doesn't get mad so often and is nicer to others. He's also more able to help his friends when they're sad or angry. He knows very well how it is to be sad so he does his best to make them feel better. Helping others makes him feel well in turn.

Tito is sometimes afraid of the dark. He's frightened of scary shadows and strange noises at night. Dad and Mum are aware of this so they've placed a night lamp in his room. Right before he falls asleep, he amuses himself by repeatedly pushing the button to change the lamp's

colour. Lucas also has one and Tito feels reassured to known that everyone, even his brave older brother, can be afraid. That tiny light makes him feel much safer at night. Other times, Tito is furious! He once returned home very angry and red-faced. He just wanted to throw things at the walls. Calmly, his dad asked him:

— You look annoyed. Do you want to tell me what's going on? Did something happen at school?

Tito remained silent, on edge, and with his arms crossed. Dad suggested:

— Do you want to draw what you're feeling? Here is a paper sheet and some colour pencils...

— This is an evil, evil rock. I tripped on it this morning — Tito told dad, quite aggravated.

— I see... did you hurt yourself?

Tito then drew a boy next to the rock and said:

— This is Henry, a very silly boy. He laughed at me when I tripped and fell – Tito placed the pencil on the table and re-crossed his arms.

— Henry should not have laughed, especially because you could have been hurt. What if we go back to the place where it all happened and we remove the rock from the path? It won't make any other kid fall down and get hurt — Dad suggested.

— That's actually a good idea – Tito smiled.

— Thank you for telling me what happened – Dad said while holding him close.

By drawing and sharing his feelings with his dad, Tito felt better even though he was quite enraged by what had happened. When dad suggested a solution that would help other kids avoiding tripping the rock, he was glad for not feeling completely powerless over his life.

Emotions are a part of life and it is important to go through all of them, accepting and learning how to cope with them. With the help of his family, Tito is finding ways of expressing himself and growing in touch with his feelings, without having to repress them.

When emotions flood me,
whether joy or rage,
I sometimes lend them a stage,
they rule me, you see?
I'm fair when happy,
nasty when snappy
just like my neighbour
after a hard day's labour.
One strains not to fail,
to not succumb to ire,
grievance or to wail,
escaping an end too dire.
All need a friendly shoulder
to purge out their feelings
maybe when I'm older
I'll excel at such healings.
Rage will be eclipsed
as worn clothes are dismissed,
no one should choose anger
over joy as a commander.

The end

A letter to you, from Tito

Probably, Tito will need to enter the spaceship once again. He'll count to ten while holding his parents' hands as is blood is drawn. He'll devise new strategies to help him keep calm while doctors examine him, sometimes with cold hands. And maybe they'll find other reasons for concern besides skin spots and small lumps. However, Tito holds one precious thing in his heart: courage.

Courage does not make fear and difficult days to go away. Courage is an extra power that helps us face and overcome those difficult days as best as possible.

Tito's courage can be witnessed in several circumstances: when he cries for help, when he apologizes for being enraged, when he plays with friends, when his blood is drawn, when he does what doctors tell him, when he wakes up after a nightmare and when he helps other kids. Tito wants to have a good life, not letting his condition ruin it. He's always committed to be a good person and help children who have the same spots. He also wants to give you a message:

"*I may still have a lot of doctors' appointments to attend to but I'm always curious to see what they'll do. Will my height be measured? I grow every day. Maybe my head will be measured as well. I know I'll have my share of measurements and auscultations and I can almost guess what they'll do to me next. Maybe I'll have to put that strange bracelet on, the one that tightens my arm and makes numbers show up in a screen. Does that happen to you too? My mum usually holds my hand and I squeeze it hard, but she can take it. She told me I was going into the big spaceship again, the one that makes loud noises while it's taking pictures of the inside of my head and body. Those pictures are seen by the doctor to assess how I'm growing and if neurofibromatosis is giving me further trouble.*

My dad also told me the doctor will sometimes make me questions I won't know the answer. But that's ok because my parents will be there to help. Since I want to be a researcher myself when I grow up, I make a lot of questions too about things I don't understand all that well. The doctor or my parents tell me all I need to know. Facing so many uncertainties and questions, one thing is for sure: I was definitely born brave! What about you?"

Did you know that all kids with Neurofibromatosis Type 1 are different?

Neurofibromatosis type 1 can be expressed in different ways. Some kids have more skin spots than others, some others wear glasses and others still have their backs a bit bent. However, we are all different from each other. Not even twins are completely alike! We all have something special that differentiates us from others. In this story, we saw that Tito and Lu were not alike as well although both have NF1. Some other children with NF1 that Tito has met also presented a different condition from his:

Bia lives in a small town nearby Braga. She has an older sister and wants to be a cook when she grows up. Sometimes, she struggles to understand the world and stuff people tell her. And she can have some trouble pronouncing some words. That is why her older sister tries to help her, taking her time to explain things with simple words.

John is five years old and lives with his parents and a baby dog. Even having to go to the hospital and take some medication that make him feel tired, him and his family enjoy going to the park or visiting other relatives during the weekend. John is a very popular kid and what he likes the most is hugging and kissing. He is very affectionate.

Teresa also has NF1 and loves reading. She owns a vast library. Her books are pretty special because they're written in Braille. Teresa has poor eyesight so she had to learn how to read and write using this adapted writing system. All her books use it and they are so special. Teresa secretly started writing her own stories. Someday, I bet you'll read one of her tales.

> ***At times, it is important to remind ourselves that we're not the only ones living with NF, that we're not that rare or odd and that other people are dealing with similar challenges***

What have we learned from Tito?

• People feel happy and relaxed when they're doing something they love, something "special";

It's alright to be different. We are special and important because we are who we are. There's always something about each one of us that makes us special;

• A disease can't stop you from having wishes and dreams, let alone making them come true;

• We are not alone;

• There are many children with Neurofibromatosis type 1;

• Doctors keep an eye on your condition and your parents, family and friends love you;

• It's normal to feel sad, angry, happy or even afraid, sometimes;

• We are entitled to be sad, that is our right. We can cry, sometimes it helps. If the sadness persists, you can:

- Talk to someone to unburden yourself, like our parents or friends;

- Do something pleasant (playing with a toy or a game we fancy);

- Cuddle with our parents.

• Happiness is an awesome feeling! It makes us love and feel good about ourselves. No one is happy every day. So, we need

to enjoy those moments, be grateful and say thank you for such a cheerful day;

• It's also normal to be afraid sometimes. When we're afraid, we can:

- Share our thoughts and feelings with an adult;

- Play with a toy, teddy bear or a game we like to feel calmer;

- Draw our fears;

- Imagine how we could stop being afraid, for example inventing a super-hero.

• We can feel enraged at times. In those moments, we can:

- Talk to an adult and explain why we're feeling that way;

- Play with a toy, teddy bear or a game we like to feel calmer;

- Breathe deeply, count to 10, strike a pillow, roar like a lion, clap hands, dancing or jumping 10 times.

Tips for parents

If children with NF1 are well surveilled, their quality of life may not be noticeably impaired. Being regularly followed by doctors with several medical specialties is essential. Signs and symptoms vary according to age and from patient to patient. NF1 does not define a person. Patients are entitled to their wishes, ambitions and dreams. They must try to live life normally. It is a rare disease but plenty of children have it. Estimations point to about 4000 persons having NF1 in Portugal.

It's important that...

- the child's parents remain involved;
- the child remains informed and involved accordingly to his/her age and necessities;
- the school be informed of the NF1 diagnosis so the child may be suitably followed;
- the child feels properly attended;
- the child knows for sure the disease is not his/her fault. It's nobody's fault!

Tips for hospital trips:

- keep a logbook about the disease and hospital appointments;
- encourage the child/youngster to prepare a backpack with toys and snacks;
- if possible, during the MRI, read the child a story, chat with him, or allow him to listen to music. Time will go faster.
- praise the child (e.g.: "You did that so well" or "I'm so happy you were able to...")
- establish a reward/surprise system with your child for when he overcomes challenges (e.g.: playing football, inviting a friend for a stay over, or eating his/her favourite meal);
- have rewards for yourself for being such a good parent (e.g.: meeting friends for a coffee, taking a stroll, having a relaxing bath, etc);

Respecting everyone's differences

We all have our struggles, whether at math, English or even both. However, we can excel at other skills and activities like theatre, sports, cooking or drawing. Pay attention to your child's vocations and congratulate him for doing them well.

It is important parents share their own personal struggles with the child. For instance, something looking like a disadvantage at first could be turned into an opportunity to find a new vocation.

Let's play a game to learn how to value your child's skills

Together, make a list of all things the child doesn't fancy about himself/herself. It can be anything: body parts, abilities or even objects. Then, from that list, join forces into finding three ways of positively potentiating those features.

Pass on to your child constructive and soothing ideas

- It is important to be aware of our own individuality. Appearance, health and personality differ from one person to another and each one of us is unique.

- We mustn't cuss anyone for being different. Everyone has something special.

- It's ok to notice differences; they do exist. These can be openly talked about. Our head is used to compare and evaluate (it's good, bad, pretty, etc.) but it is much more constructive to merely observe. That's when we discover new and unique things everyday and there's no need to make someone feel sad over what we find out.

About dealing with emotions

Sharing his/her feelings with someone, a friend or a relative, can make the child feel better. It is normal to feel different emotions and to feel sad, miserable or angry. We all do it, including parents, and when they do, that may be a good chance to let the child know how they're feeling.

About fear

- Fear is as valid and important as any other emotion.

- Avoid ignoring and toying with the child's fears. What seems funny to an adult may be sensed quite differently by children.

- When scared, the child will look for an adult. It is crucial you remain calm, confident and available.

- Adults must always pay attention and be respectful when the child is sharing his/her feelings. It is essential to propose an activity or a challenge to face fear so that the child is not led to believe that the only way of dealing with it is by running away from it.

- Encourage the child to talk about his/her fears. Expressing them into words makes them less scary and easier to deal with.

- It is important to listen your child carefully and openly make questions about what's troubling him/her.

- Help the child identifying the source of that fear and to express it.

- Together with the child, think about possible solutions to deal with his/her fear so that he/she can feel safer and have more control of the situation (in Tito's case, that was achieved by using a night light).

- Here are some activities that may help the child expressing and solving his/her fear:

· Encourage the child to use his/her imagination and knowledge about the world to overcome fear;

· For example, if the child is afraid of a monster or an evil man showing up, he/she can imagine being helped by a knight, an angel or a super-hero. Children's imagination, when well directed, can be a powerful tool to overcome fear.

· Put the child's fear onto a paper. For example, draw a monster with a scary or angry look. On paper, the child will be able to deal more easily with it.

· Children's stories are essential in any overcoming process because kids often identify themselves with the character and, that way, feel they're not the only ones having a particular fear: "Someone's feeling the same!" The child may be curious about how the tale's character solved that fear or how that could have been done differently. Preferably, in this kind of approach, use other than the child's specific fear.

- It is critical to show the child that all problems have solutions!

· Hugs help calming down and reducing children's concerns. They're especially soothing and emotionally beneficial in children who are afraid of something.

· In frightful situations, protection or feel-good objects transmit calm, safety and comfort (e.g.: a teddy bear; a toy; a blanket).

· Positive reinforcement can be applied whenever the child overcomes a fear by receiving a sticker or a collection item. A special treat at breakfast, toys or other sorts of prizes can also be used to reward the child and reinforce his/her self-confidence. Additionally, empowerment can be achieved verbally: “Wow, you’re so brave!”; “I’m proud to see you reacting so strong and brave!”

About Rage

- Rage, sense of being treated unfairly and angriness should be taken seriously. Acknowledge your child’s feelings: “How angry you are”; “You must have good reason to be so upset”; “It’s so unfair”.

- Encourage the child to tell you why he/she is so unsatisfied.

- Ask the child to write a few words about the reasons for being angry or to draw the motives of his/her dissatisfaction.

- Distraction can have a positive effect on children who have trouble letting go some feelings or actions. It allows them to find out that it’s possible to feel and do other things, so that they may deal with it benefiting from a fresher perspective later on.

- Suggest a fun activity to distract the child (e.g. a game, a promenade or watching a movie together);

- Encouraging the child to focus on his/her own body movements can be soothing. For example, breathing in and breathing out, or repeatedly opening and closing both hands;

- Give the child some time;

- If the event leading to the child’s rage occurred at home, leave her alone for a while, so that he/she can process, calm down and have another perception of the situation.

- Some part of the house can be designated as the family’s cool down area. The adult may suggest using it but should never force it to the child;

- After the child cools down, you can both have a talk to identify what made the child so nervous. Best strategies to deal with that can be discussed among yourselves. It may help preventing new fits of rage or, at least, make them go away quicker.

About APNF

APNF was created in 1999 by patients and their relatives, healthcare professionals and friends (the NF community) who, one way or another, have some kind of association to neurofibromatoses (NFs). It has almost 400 members and its mission is ruled by four axes: it is a centre for the dissemination of NFs clinical and scientific information; it gives support to patients, their families and their caregivers; it works towards the finding of a cure for NFs; and it aims to create a multidisciplinary centre for the treatment of NFs.

Every day, we aim to keep reducing the impact of such diseases on the lives of patients, families and caregivers. Neurofibromatoses are, so far, incurable rare genetic diseases predisposing patients to develop tumours on the nervous system. They affect approximately four thousand people in Portugal, 250 thousand people in Europe and 2.5 million people worldwide.

APNF holds annual meetings involving the NF community to promote and share information on:

- new advances in the knowledge of the diseases;
- clinical follow-up progress;
- social/job-related and legal aspects relevant to patients;
- NFs patients' access to higher education;
- public awareness campaigns such as Shine a Light;
- the association's activities strategic planning;
- collaborations with other patients organizations;
- life experiences from patients, relatives and friends;

The APNF's activity is continuously increasing. To better fulfil our mission, we work every day to raise NF awareness. Digital, technological and in-person resources are used to reduce the impact of the diseases on the NF community. APNF is part of the European network of NF associations, the NeuroFibromatosis Patients United (NFPU).

Neurofibromatosis in school aged children

School aged children with neurofibromatosis can eventually face several learning disabilities caused by attention deficit hyperactivity disorder, motor coordination (including fine motor skills), language difficulties and problems in social and emotional development. It is impossible to anticipate how each child with NF will end up being affected by these difficulties. Additionally, many of the NF-related signs (e.g.: neurofibromas, *café-au-lait* spots) are quite visible and have an impact on aesthetics. This complicates integration and socialisation at school because the child may be seen as different. In those cases, psychological and educational support must be provided to children with NF.

Because they're rare, neurofibromatoses are not well-known. School age children are usually more affected by NF1. When the impact is small, it tends to be underrated and children are not directed to a specialised doctor or to an expert in special-needs education. The disease is not introduced to future teachers, not even those aiming to become special-needs educators, during their training. Most do not know the implications of having NF1.

NF1 limitations are shared by other conditions and constitute barriers to learning. Given the myriad of disruptive manifestations caused by the disease (physical, sensory, cognitive and socio-emotional), the child's school success can be seriously jeopardised. A good support system at school is critical to delineate strategies promoting learning and inclusion according to the needs of each particular child. To that effect, it is important to raise the awareness of teachers, multidisciplinary teams, school management structures, parents and education sponsors who may not be informed about the learning challenges experienced by children with NF.

Acknowledgments

Inês Cabral da Fonseca, October 2020
Psychologist

I'm grateful to:

All the children with NF1 I followed and am following. They inspired me to write this story which is theirs (and mine).

Ana Santos for her constant guiding, care and tips.

APNF which supported this dream of mine, especially to Ana Elisabete Pires, Marta Amorim, David Gonçalves and Theo Fernandes.

The *Associação das Famílias dos Diplomatas Portugueses* which funded this book's illustration, edition and donation of 60 copies to children and institutions.

Mafalda Mota. Without her, this book would not be as delightful as it is. I fell in love with her project since day one. A giant thanks for her contributions.

Last but not least, to my friends, co-workers and relatives who have been alongside me during this endeavour.

Inês Cabral da Fonseca
Born in Lisbon, she concluded her Master degree in clinical psychology at the Faculty of Psychology of the University of Lisbon in July of 2019, being involved in several projects of the Student's Association. She worked on educational and ludic activities for children and youngsters since 2013.

She soon realised her main interest was the development and behaviour of children and youngsters as well as challenges stemming from those.

In October of 2019, she committed herself to implement the APNF psychology project with the objective of providing expert support in clinical psychology to children, youngsters and their caregivers.

Contributions

In the past, APNF received multiple support from: the Municipality of Lisbon which offered the space for the current head office; the Instituto do Emprego e Formação Profissional which granted the internship of the clinical psychologist, specialized in neurofibromatosis, who authored this book; several donations from benefactors who made possible the establishment of the head office; the Associação das Famílias dos Diplomatas Portugueses e Associação do Bazar do Corpo Diplomático which funded the illustration and edition of this book; the Direção Geral da Educação which granted APNF with a teacher to provide specific pedagogical support to children and youngsters with NF1.

APNF
Associação Portuguesa
de **Neurofibromatose**

www.apnf.pt
(+351) 960 173 375
info@apnf.pt
facebook.com/APNFpt
youtube.com/channel/UCCkT5j0abQaYHtRe3InGAiQ/

About HsC

A *Heróis sem Capa* (Heroes without Cape, in English) started as an investigation project for the Masters Degree in Editing and Publishing at the Pompeu Fabra University - Barcelona School of Management. The original plan for the project was nothing like what it ended up becoming: a book collection for the younger ones that offers a repertoire of stories inspired by real-life people who, in one way or another, live or lived the life of a hero. Although different, all stories share a purpose: to teach about the importance of self-love and overcoming.

The project, under its original title Héroes sin Capa, won the second extraordinary prize of the Masters Degree in Editing and Publishing, given by the Spanish authorial rights entity CEDRO and Pompeu Fabra University - Barcelona School of Management, in 2018.

Today, HsC is a project that celebrates real-life heroes through children's illustration and literarure, using both as tools to inspire and show children that our value comes from within, that a hero can be found anywhere and that having a cape does not elevate our status as one. It celebrates real heroes, with real life stores of all colours, shapes and sizes through art.

HERÓIS
sem capa

www.heroissemcapa.com
info@heroissemcapa.com
instagram.com/herois.sem.capa

The adventures of Tito - Tito was born brave

Project by APNF and *Heróis sem Capa*

Original version - Portuguese

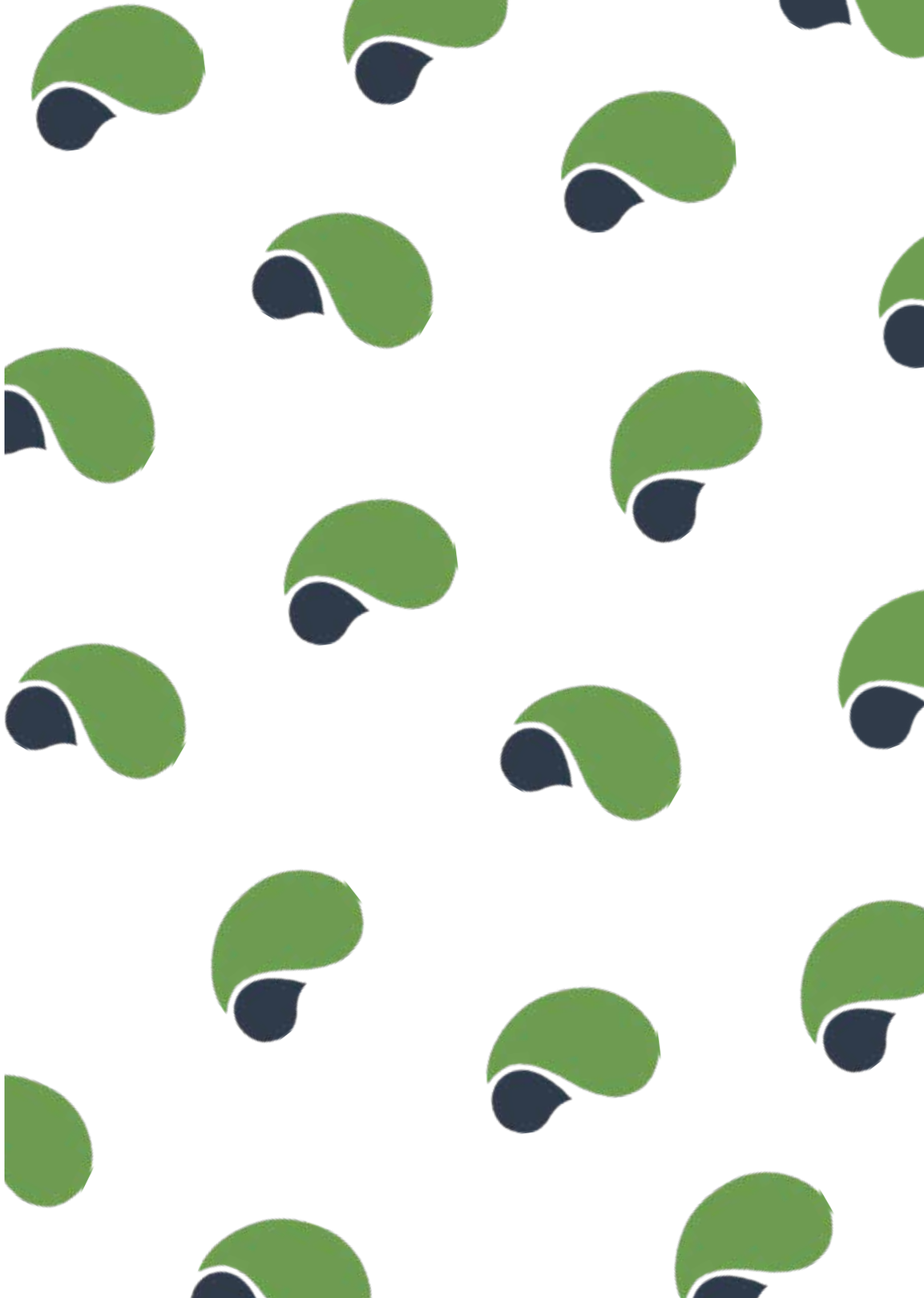
Revision: Risoleta Conceição Pinto Pedro
Design and cover: Mafalda Mota (HsC)

ISBN: 978-989-33-1504-0

Printing: Gráfica Manuel Barbosa & Filhos, Lda.

English version:

Design adaptation: Mafalda Mota (HsC)



The adventures of Tito – Tito was born brave

This book reveals 5 stories – Tito's Adventures – about the experience and adaptation of a child with **neurofibromatosis type 1** to different contexts (hospital, school and family).

This publication was the end-result of a professional internship of clinical psychologist Inês Cabral da Fonseca at the Portuguese Neurofibromatosis Association. It was illustrated by Mafalda Mota from the Heroes Without a Cape project which is focused on the celebration of real-life heroes of all kinds. The translation of the Portuguese version was carried out by medical writer David Gonçalves.

Tito's Adventures were written especially for kids, their relatives and friends as well as for health professionals who deal with neurofibromatosis and/or other rare diseases.

APNF
Associação Portuguesa de Neurofibromatose

www.apnf.pt
info@apnf.pt

Associação das Famílias dos Diplomatas Portugueses

ABCD
Associação do Bazar do Corpo Diplomático

www.afdp.blog
adcdp@mail.telepac.pt

HERÓIS sem capa

www.heroissemcapa.com
info@heroissemcapa.com