

Patches

*and The Very
Special Diagnosis*

Written for Childhood Tumour Trust
by Sophie Marsh



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Project title: (LEARNT - Lets drEAm ouR common future)

Pupils from 7 schools / 6 countries write a collaborative story, based on Sophie Marsh's Patches tale.

Every pupil writes his/her name & country and then by adds 2-3 phrases continuing the story

Meet Patches the giraffe

Patches lives at home with their mum and dad in the grasslands in Africa. Patches loves playing with the other animals, going to school and finding the very best leaves to eat. Patches is quite a normal little giraffe, who likes doing all the normal giraffe things. One day, the family got some big news and things didn't feel quite so normal for a while. Patches and their family had gone to the hospital to see the doctor. They didn't mind going, all animals had to go sometimes, and the doctors and nurses were always friendly and kind. Even better, there were lovely drawings on the walls that Patches loved to look at.

While Mum and Dad were busy talking to the doctor, Patches wasn't really listening, the little giraffe was too busy looking at the colorful artwork on the walls. But then the doctor said something that sounded important and Patches' ears twitched, eager to listen in. The grown-up animals were all talking about something called a 'diagnosis'.

"What a funny word," Patches thought. "I have never heard of that before." It sounded complicated. What did it mean?

The doctor turned to look at Patches and said, "your diagnosis is something called Neurofibromatosis Type 1."

Huh? What was that? It didn't explain anything at all. Now there were just two very funny words that didn't make much sense. Patches couldn't even SAY Neurofibromatosis.

"We call it NF1 for short because it is a very tricky word to say," said the Doctor.

Well that STILL didn't explain anything either. Poor Patches felt confused. What was a diagnosis? What was NF1? What did it all mean?

Patches had lots of questions, but the words wouldn't come out. "It feels like they are stuck in my throat," thought Patches. "There are butterflies in my tummy and my long legs feel wobbly too." This did NOT feel like a normal day.

Luckily, the clever doctor seemed to know that even though Patches hadn't said anything, there were still lots of questions and so they started to explain some more.

"NF1 is a condition that makes you a little bit different to some of the other animals. It can cause brown marks just like the ones you have on your skin," they said.

Hmm. Patches couldn't decide if being different was a good thing or a bad thing. It was kind of nice feeling different and special, but it wasn't so nice to feel a little bit alone and worried...

Patches asked if anyone else in the family had NF1, but it turned out that Patches was the first one in their family. The doctor explained that in some other families a mum or dad could have NF1 and pass it onto their children when they were born. The doctor explained that just like parents could pass on their eye or hair colour, sometimes they could pass on a diagnosis too. And even though there wasn't anyone else in Patches' family with their diagnosis, there were lots of other animals who had NF1, so Patches was definitely not alone.

The doctor said that maybe one day they could all talk or even meet each other! That would be so much fun! Meeting new friends was so exciting and they would have such a lot to talk about together. They all had a very special diagnosis.

"So NF1 means I have some brown marks on my skin and some new friends who are just like me?" Patches asked. This didn't sound so bad after all!

"That's right. It also means you'll be having more visits to the hospital too. NF1 can cause some other changes to your body, so we have lots of clever doctors here to look after you. They will keep checking to make sure that you are staying happy and healthy," explained the Doctor .

And that was that.

After that not-quite-so-normal day Patches went home with Mum and Dad (and their new diagnosis) and things mostly went back to normal. Patches played with the other animals in the grasslands, learned lots of new things at school and ate lots of yummy green leaves. Those things all stayed just the same as before.

But some things had changed too. After learning about those big funny words, diagnosis and Neurofibromatosis, Patches went to the hospital regularly for special appointments and was happy to see all the lovely doctors and nurses lots and lots. But the very best change of all was making some very special new friends, just like the Doctor said they might! Thanks to having the NF1 diagnosis, Patches was now part of a very special group of very special NF Warriors - just like Patches.

(Manuela, Croatia)

Even though Patches accepted her diagnosis she felt lonely.

(Petra, Croatia)

Patches had a fight with her parents because she didn't want to be different from the others. She said: "Find a cure for it now or I'll be sad."

(Dorotea, Croatia)

She felt at a loss because she was different from all her friends and she thought she was the only one

(Aurora, Italy)

After she realized (again) that she was not the only one with that disease, she started to feel a little better because she saw that the popular giraffes also suffer from NF.

(Lana, Croatia)

Having yelled at her parents before, she immediately went to apologize and said that she understood that it was actually normal because many giraffes suffer from this disease.

(Dagnius, Lithuania)

After a few days Patches started eating healthier because she thought she could cure it on her own.

(Aironas, Lithuania)

That did not help and she accepted that she has NF and she could not change that. After that, she found new friends with the same diagnosis and felt special.

(Vygandas, Lithuania)

She stopped worrying about NF and thought that this was cool and did not want to change it anymore.

(Kotryna, Lithuania)

She thought it was a good opportunity to have new friends and that they had something to share.

(Vanessa, Italy)

She started wearing more bright coloured clothes which were attention grabbing.

(Augustina, Lithuania)

A couple of months later, Patches went to school. She was surprised to see a new face in class.

(Rusnė, Lithuania)

The new giraffe had also a diagnosis, he had heterochromia. That means that he had different coloured eyes,

(Gabija, Lithuania)

Patches loved his eyes because they had different colors!

(Sebastiano, Italy)

One of his eyes was light green and the other was blue like the sky. Patches immediately loved those eyes.

(Maria Teresa, Italy)

Patches decided to befriend him. Turns out his name is Matches and because of his diagnosis he was scared to make eye contact.

(Eva, Lithuania)

Patches introduced Matches to her friend group.

(Arnas, Lithuania)

They all thought he was cool and friendly and they accepted him into their friend group.

(Dovydas, Ignas, Domantas, Lithuania)

They were friendly with him too.

(Thomas, Italy)

It was the first time that Matches had so many friends at once.

(Nina, Poland)

After some time, Matches started acting very weird for no reason. Patches with her friends were asking what's the reason for his behavior. It turned out that it was caused by his family.

(Zosia G, Poland)

Matches told his friends about his problems. His story shocked everyone.

(Nina, Poland)

His parents are moving to foreign country. They got a new well paid job. So he had to leave with them.

(Zosia G, Poland)

His friends turned out to be very supportive. They made him feel better, but sadly they couldn't change his situation.

(Zosia O, Poland)

A difficult family situation forced Matches to leave. All of his friends felt helpless and couldn't accept it.

(Christina D, Greece-Irakleio)

Matches left some days later but his friends texted him everyday. This made him very happy.

(Irene, Italy)

One day Patches was very happy and without patches because a doctor patched her up until heavy rain broke out.

(Joanna, Greece-Ilion)

At that moment her patches started to appear again. Patches was very upset, because she thought she was cured of the NF1 disease, but in the end she was still sick.

(Misha, Poland)

When Patches came home, she was very upset. But when she talked with her relatives about her diagnosis, they all supported her.

(Angelina, Greece-Ilion)

Luckily, among the relatives there was a cousin of Patches who knew the best doctor for her diagnosis and gave her the doctor's phone number.

(Maksymilian, Poland)

When Patches got the doctor's number, she called him right away. During the conversation, it turned out that there is an operation that can fix it, but Patches may lose her sight.

(Natalia, Greece-Ilion)

In a few minutes, the doctor found a new solution to help Patches. She had to travel to another country to do a very painful operation.

(Jim, Greece-Ilion)

Patches didn't mind traveling long distances, so she decided to go wherever she could find a cure!

(Sharon, Italy)

The country in which she would perform the operation was Germany. So she packed her bags and full of anxiety and hope, started her journey.

(Bill, Greece-Ilion)

The journey was quite long but she was so excited because she knew she could finally find therapy. Moreover, she loved traveling and visiting new places so different from the one she lived in!

(Gabriele, Italy)

Patches and her family made it safely to Germany and life for them at first was going well. A few weeks later, the day had finally come, the day that Patches had to go to the hospital.

(Zosia O, Poland)

Patches went to see the doctor who explained to her how the surgery would go. Moments before surgery, Patches was extremely stressed.

(Jakub, Poland)

Patches was very afraid that the operation might not go well and panicked.

(Nick, Greece-Ilion)

Four hours later the surgery was successfully done. After an hour she woke up and saw that her patches were gone.

(Eva, Greece-Ilion)

After the operation Patches returned home happy because she would have a better quality of life.

(Misha, Poland)

Following the doctor's advice, she went to the pharmacy, bought a lot of medicine and felt well for a long time.

(Veronika, Ukraine)

Patches was very happy that her patches were finally gone, but she still thought they might come back.

(Jakub, Poland)

Exhausted, she returned home and went to sleep.

(Christina, Greece-Ilion)

Next morning Patches woke up after a long sleep. While trying to process things, her NF1 experience seemed to be a big weird dream. She felt truly relieved!

(Polina, Ukraine)

Patches played with other animals in the meadows, studied hard at school and ate a lot of delicious green leaves.

(Maritenia A, Greece-Irakleio)

After this weird "adventure", Patches understood how important it is for us to be healthy and we must always enjoy every moment of our life. But what about the animals that actually have this disease?

(Joanna, Greece-Irakleio)

After two months since she is healthy, she found many friends who love and care about

her without making fun of her.

(Philip, Greece-Irakleio)

Patches realized how badly people with problems were treated in today's society and decided that helping people with problems will be her lifelong dream to accomplish.

(Achilleas, Greece-Irakleio)

After her "experience", she also learned to appreciate what she has got. Also, Patches understood that she must love and accept herself however she is.

(Dima, Ukraine)

Now Patches understands sick animals. She wants to make friends with diagnoses so that they are not sad.

(Melina, Iliion-Greece)

She understood that she had to do something, to become active and help other giraffes who face the same disease.

(Irene, Greece-Irakleio)

So she went to multiple hospitals, and met other animals that had NF1, and made lots of friends. She tried to support them and make them feel less bad about the disease they had. Meanwhile there was a surprise for her. A very happy one in fact. Matches would come to visit her after a long time!

(John, Greece-Irakleio)

Patches' life certainly changed after all that experience. Through time, she understood that finding a cure and also helping others with the same symptoms was the main purpose of her life! So she promised herself to study to become a Neurologist and eliminate this disease.

(Nadia, Greece-Irakleio)

She knew how one could feel because of this disease since she had lived the same situation. She decided she would work hard to achieve this goal!

(Alessandro, Italy)

After a week Matches came to visit Patches all the way from Norway.

(Evelina, Greece-Irakleio)

Patches was very happy to see him. She told him about her plans to become a Neurologist and he supported her. Matches stayed for a week. They talked about their adventures and had a great time. But the farewell was very difficult for both of them.

(Daria, Ukraine)

Matches returned to Norway. After a few years he went to the USA and opened his own business.

(Semen, Ukraine)

When Patches grew up, she became a Neurologist. She worked very hard to find a cure for the disease, Matches supported her in everything.

Finally Patches managed to find a complete gene-therapy for NF1. For that she was awarded the Nobel prize in medicine.

(Vasile, Italy)

Now she is a famous researcher and she is all determined to discover therapies for other diseases that still cannot be cured.

The end