



**Childhood
Tumour
Trust**



**Manchester
Metropolitan
University**

What is Neurofibromatosis type 1 (NF1)?

School Assembly Version

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Neurofibromatosis Type 1 (NF1)

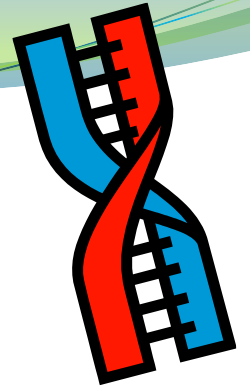
- Neurofibromatosis is a tricky word to say
- Can you say it?
- Neuro – Fibro – Matosis

• Neurofibromatosis



Neurofibromatosis is genetic

- Neurofibromatosis is caused by a mistake in one of our genes.
- Does any one know what genes are?



What are Genes?

- Genes are like ingredients in a recipe.
- If you are baking a cake you need to put in all the right ingredients like:

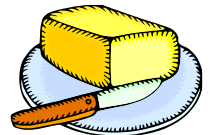
- Eggs



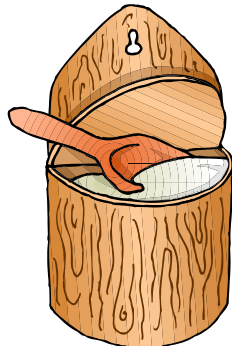
- Flour



- Butter



- Sugar



Oops

- But what happens if you don't put enough of the ingredients in?
- Some times in a cake you need two eggs, if you only put one egg in you still have a cake but it doesn't look or taste quite the same. Or perhaps you put in half the egg but dropped the other half on the floor, or maybe even put in a bit of the egg shell!

The missing ingredient

- This is what happens in NF₁, instead of people with NF₁ a little bit was missing from the recipe.
- One baby every day is born with NF₁

The missing ingredient

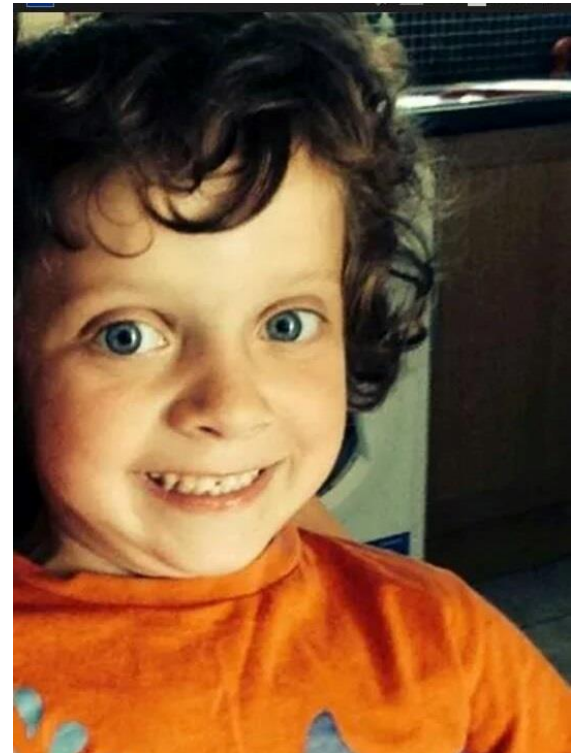
- Half the children with NF1 have it because their mummy or daddy has it and passed it on to them, there is a 50:50 chance of this happening this is like flipping a coin (heads or tails)



- For half the children the broken gene just happens when they are growing in their mummy's tummy

So what do Children with NF1 look like?

- They look like children – silly!!
- This is a child with NF₁,
- His name is Alfie-



Here are lots of children with NF1





How am I similar to children with NF1?

- They are just like any other children –
- 1) They love playing – hands up who likes playing!
- 2) most love chocolate – hands up who likes chocolate!
- 3) most love Disney – hand up who loves Disney!



A little bit different?

- Children with NF1 are also a little bit different, this is ok, we are all a bit different-
- What's your favourite colour?
- What's your favourite food?
- See we are all similar and all a bit different this is what makes us special.

What children with NF1 look like again

- Hands up who has freckles?
- Hands up who has birth marks?



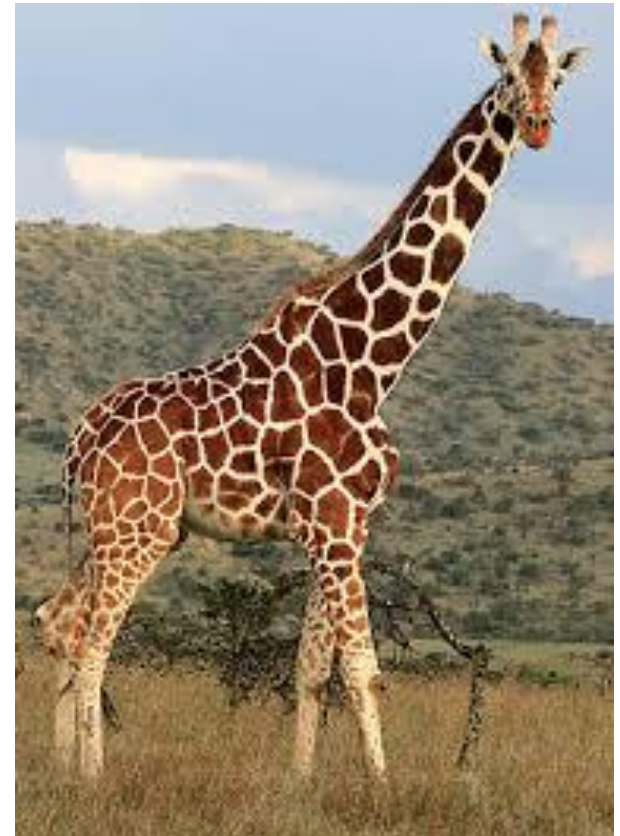
- See lots of us have freckles and birth marks – children with NF1 have lots and lots and lots of these!

Café au lait

- In children with NF1 the birth marks have a special name they are called café au lait (CALs), this means milky coffee because they are a light brown colour.
- This is a little girl with NF1, she has some big birth marks on her tummy, they don't hurt her they are just birth marks!
She likes her birth marks and calls them 'pretty'



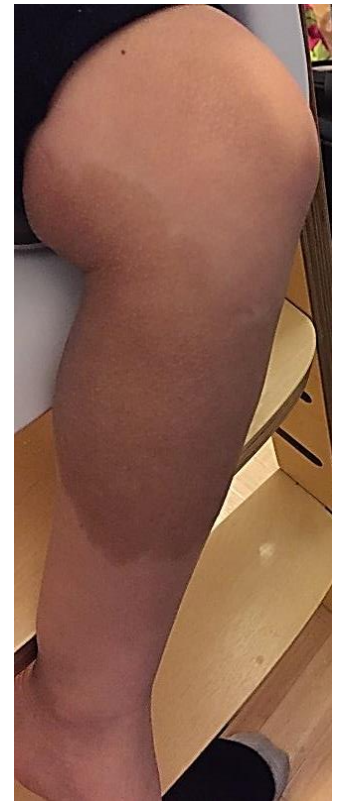
Some nice animals with brown patches (like in NF1)



Children with NF1 can be a bit poorly

- There are lots of different ways children with NF1 can be a bit poorly, sometimes they have tumours, these are lumps, this little girl has one in her leg.
- If you look carefully you can see the skin is a bit darker.

The tumour is causing her leg to grow a bit fast so it is longer than the other one, this makes her fall over but its ok we all fall over sometimes, hands up if you ever fall over!



NF1 can make walking hard

- If a child finds it hard walking because their legs get tired or they fall over a lot sometimes they get a special chair called a wheel chair (or a wheely)

Doesn't it look cool!





NF1 can make school a bit hard too

- Sometimes when we are tired we find it hard to pay attention because our brains are a bit sleepy.
- For a lot of children with NF1 their brains are a bit sleepy a lot of the time, and this can mean that they find it hard to listen to the teacher or make friends or sit still for a long time, this is ok, they are not being naughty, they are trying hard but their brains are just a bit sleepy.

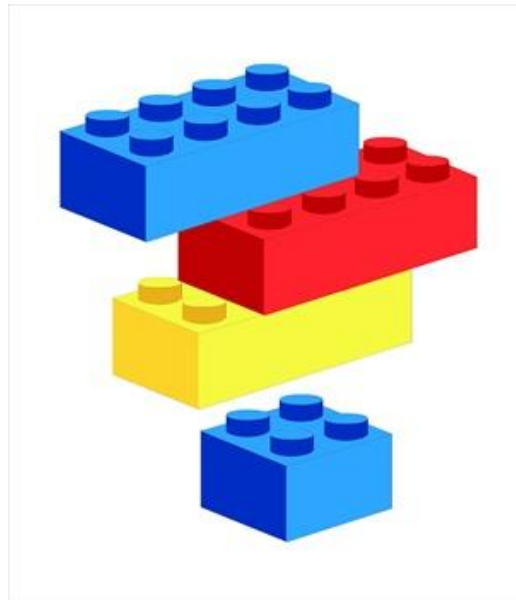
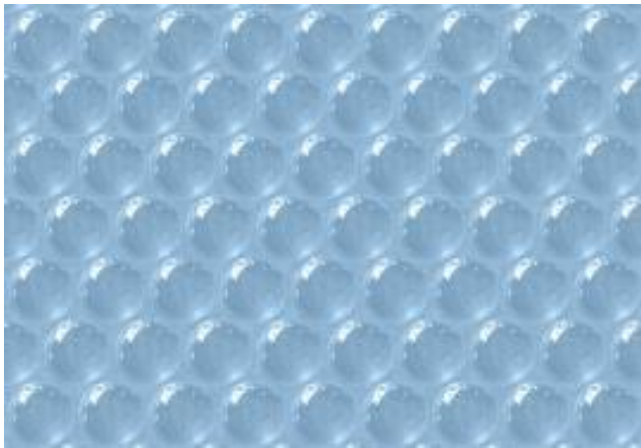


Funny Lumps

- When children with NF1 get a bit older and becomes a grown up they can get lots of little lumps and bumps on their skin.
- These are a bit like spots.
- This is a bit different to people without lumps and bumps but it is ok, its ok to look a bit different.

Funny Lumps

- I like bumps, lots of good things have lumps and bumps like bubble wrap bubbly chocolate and bricks



This is my friend Mandy

Mandy has lumps and bumps but a beautiful smiley face.

Mandy is a very nice lady

Sometimes people laugh at Mandy because she is a bit bumpy, this is very mean and silly because we are all a bit different and this is what makes us special.



How the Childhood Tumour Trust Helps

- Running camps for young people with NF1



How the Childhood Tumour Trust Helps

- Awareness raising
- Campaigning
- Research
- Family days out
- Children's parties
- Liaising with medical professionals



For more information please visit

<http://www.childhoodtumourtrust.org.uk/>

Disclaimer

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