

Dear Sir / Madam

We have been approached by [insert name of parent] regarding their child [insert child's name] who is in your school.

Whilst we cannot comment on [insert child's name] personally, we would like to explain a little more about Neurofibromatosis, (NF1)

NF1 is a genetic condition; it is permanent, incurable and progressive. NF1 can vary from child to child but many have a number of different medical, social and developmental complications. Many children with NF1 need plans put in place within the school environment to ensure they get the most from their school experience.

Around 70% have some degree of learning disabilities and nearly 50% show some signs of autism spectrum disorder and sensory issues with 25% meeting full diagnostic criteria. [insert child's name or delete as appropriate] like many children with NF1 displays some learning and sensory issues associated with NF1].

Neurofibromatosis causes, amongst many things, tumours to grow on the nerves anywhere in the body, which can cause extreme pain, and some cases blindness and cancer. These are largely inoperable and do not respond well to chemotherapy, if you can imagine a net of lemons, the tumours grow like the net, they grow in and around the nerve, so I am sure you understand can be very painful. The pain can come and go, it's pretty much like having an electric shock, which can happen when knocked or at seemingly random moments. Outwardly many children with NF1 look pretty much like anyone else and it's very hard to know what is going on inside. This causes many problems for them because they are often treated like anyone else when in fact they are dealing with an awful lot. [insert child's name or delete as appropriate] like many children with NF1 has such tumours].

There is no cure for NF1 and it's often pretty much a case of having to live with it. They do however need support as every day can be different and with NF1 nobody ever knows what is around the corner. They are not lazy or difficult, they live with an extremely challenging condition and would much rather be 'like anyone else'. It can be difficult to understand the variability of how the condition affects a child day to day or even moment by moment, but it is typically observed in children with NF1 that their energy peaks and troughs with the same child who could run and jump on one occasion not being able to even support their own weight on another. We do not understand exactly why this is but this pattern is very much observed in many children with NF.

If you would like any further information on NF1, please do not hesitate to contact us, we also have an assembly PowerPoint which can be used to explain a little bit more about NF1 to staff and pupils at the school if you would like to have this, please send us an e-mail and we can send you the link.

Kind regards

Vanessa Martin (Chair) [insert date]