**Neurofibromatosis type 1 – Annual Review**

**Information for children aged 8-13**

**What is an annual review?**

The annual review is an appointment that happens once every year for children with neurofibromatosis type 1, which is also called NF1.

NF1 can have different effects, which might change as you get older. A doctor will see you once every year until you are an adult to keep track of how it is affecting you and to see what they can do to help you.

**What will happen at the appointment?**

There are different things that the doctor might do, depending on how NF1 affects you.

Look at your skin

* Children with NF1 have some lumps and bumps on their skin
* The doctor will check if you have any new lumps or bumps
* Usually they don’t cause any problems, but tell the doctor if they are bleeding or catching on your clothes

Look at your eyes

* When you were younger, you probably had appointments with an eye doctor (ophthalmologist) every year
* Now you are over 7 years old, these appointments might happen less often, usually once every 2 years
* The doctor will do some eye tests to check how clearly you can see
* Tell the doctor if you have noticed any problems with your eyes, like struggling to read small writing or to see the board at school

Measure your head size

* The doctor will use a tape measure to check the size of your head

Measure your blood pressure

* The doctor will inflate a band around your arm. This might feel a bit tight but does not hurt.

Measure how tall you are and how much you weigh

Talk about how you are behaving and getting on at school

* Some children with NF1 might have problems with learning at school, or might find it difficult to pay attention or concentrate at school and at home
* Sometimes children with NF1 find it difficult to make friends and to get on with other children at school
* Tell the doctor if you feel you have problems with these things, as they can find ways to help you

**What changes should I look out for?**

If you notice any of these changes you should tell your parents:

* Changes in the lumps and bumps on your skin
  + A lump quickly growing bigger
  + A painful lump
  + A change in how the lump looks or feels
* Changes in your eyesight
  + Difficulty seeing things clearly
* Headaches or being sick in the morning

It is important not to worry if you notice any of these things, but to make sure you tell an adult so they can arrange for a doctor to check everything is ok.

**Do I need to do anything before the appointment?**

* The appointment is a good time for you to ask any questions you have about NF1
  + You could bring a list of questions you might like to ask
* It is also a good time to talk about any worries you might have
  + Again, you could write these down if that helps you to remember them