Name

Address

Date

To ??

Re: Childs name, school and year group

**Parental input re EHCP Assessment.**

Dear ??,

**Introduction**

We are writing as the parents of the above child to support the assessment of my child’s special educational needs under the 2011Education Act.

It is our strong belief that childs name has complex educational and medical needs and is socially vulnerable to such a degree that he now requires constant support throughout the school day in order to access the curriculum fully. His needs are currently not being met.

Research in the US supports the idea that XXYY adults are significantly disadvantaged if early intervention and special educational support are not provided.

childs name attends ??primary school. He has a diagnosis of **XXYY Syndrome / autism traits etc**, a very rare chromosomal abnormality, which causes learning difficulties. We are including information on this condition and how it is currently manifesting.

**Current Situation**

We believe, and the school is in agreement, that his needs are not being met currently and his special educational needs are as follows:

* Difficulty with processing verbal instructions
* Difficulty understanding or using language
* Interprets instructions literally
* May not be able to ask for help when needed
* Has difficulty working in group settings
* Has impulsive behaviour
* Needs extra help to understand another person’s perspective
* Difficulty organising information
* Difficulty understanding abstract ideas
* Finds it difficult to predict and anticipate events
* Cannot process spoken information very well
* Finds transition between activities difficult
* Has difficulties managing own behaviour
* Has a lack of understanding of social rules
* Has confusion and fear of unexpected events
* Has physical co-ordination problems
* Has significant sensory processing problems leading to hypersensitivity to sensory input
* Has short attention span and is easily distracted
* Has difficulty staying on task
* Has low muscle tone and suffers with severe tiredness

Our reasons for believing that the school cannot make the provision required to fully meet our child’s needs, without additional resources, are:

* Teachers have repeatedly expressed concern that they are unable to meet his educational needs in the current setting, with the current resources available
* He has been withdrawn from activities such as assembly and other events in school, as currently the staff level and resources are not in place to enable him to be fully included at all times and gain positive benefit from certain situations.
* I have been asked to collect early, childs name ‘s staff feel he is unable to cope with certain aspects of the school day without one-to-one support.
* We feel that although we put much additional effort into helping him with his literacy and numeracy at home and school give all the support they can with current staff and resources, that he is now beginning to slip behind in some areas of the curriculum, and progress is slowing.
* He often comes home from school feeling exhausted and over stimulated and his behaviour then deteriorates due to his fatigue.
* Boys with XXYY syndrome have problems with Adaptive Functioning throughout their lives, and although some may have an IQ within normal range, they have difficulty accessing this IQ and translating it into social and life skills. As childs name spends a large amount of time at school this becomes an important place for developing these skills, and to do this he needs constant support in all aspects of the school day and not just the academic parts.
* Due to his unusual condition, no standard educational tool is available to guide us, or his school, in catering for his rare condition. We therefore feel that a plan for his education can only be properly formulated with the help and guidance of educational and medical professionals. This multi-disciplinary approach will give him the chance for his needs to be assessed, planned for, implemented and evaluated on an annual basis. We are certain it will be the only way to ensure he performs to his full potential and most importantly remains happy in his school life.

**XXYY Syndrome and childs name.**

childs name was diagnosed with XXYY in Date, via a chromosome blood test.

Hehas two extra sex chromosomes in every cell, and this has been shown in recent research to cause specific medical problems; learning disability, social interaction difficulties, various mental health problems and a lack of energy. He suffers with chest infections, Asthma and allergies. Due to the XXYY he will not have a normal puberty and will require testosterone treatment from his early teens for the rest of his life to help prevent the problems associated with little or no testosterone, such as bone problems and tall stature. XXYY can cause heart and neurological conditions and these will be investigated in time.

Boys with XXYY exhibit a very wide range in level of learning disability and therefore one cannot fully predict how childs name will develop at school. However, XXYY boys do encounter specific problems with reading and writing and also meeting the behavioural expectations of the school setting. He tires very quickly and has a short attention span so my concern is that as the intensity of work increases he will slip back further, and increasingly lose confidence and interest.

childs name also has an intension tremor making his hands shaky and therefore he finds writing difficult. We feel he will benefit from early introduction of a keyboard, as this tremor is likely to increase with age.

Boys with XXYY appear to be better visual learners and have problems processing auditory information. This is the case with our son. He is prone to sensory overload and responds better to one-to-one or small group work due to his sensory processing difficulties. He has a strong visual memory and can talk in detail about past events.

XXYY boys often have social and behavioural difficulties and childs name shows this as he can sometimes be anxious, feel insecure and lacks emotional judgement, he is also prone to outbursts of temper and emotional meltdowns. We have access to the 48XXYY Family Support Group UK (www.xxyy.co.uk) who work very closely with the Americans between them we are kept up-to-date with information about the condition and relevant research.

childs name also has a diagnosis of Autistic Spectrum Disorder (ASD) and we are keen to see what the Educational Psychologist feels about this and how this will impact on his education.

We are very lucky to have a relatively early diagnosis of his conditions. This should enable school and the Education Authority to act quickly in providing a comprehensive psycho-educational assessment to decide how best to help him, his teachers and peers. It is well documented that early intervention for ASD has the most positive outcomes.

An organisation called Unique Rare Chromosome Disorders has information on XXYY boys in education. Many start out in mainstream with one-to-one support where needed. Very few remain in mainstream secondary and generally if they do they need a dedicated resource teacher. Most boys attend second education in special schools or learning centres.

childs name is a very happy boy who enjoys life to the full. He is inquisitive, loving, excitable and interested in life and the world around him. He sees, hears, feels, smells and tastes the world differently from most of his school friends and from us. This fact is causing issues at school, meaning he is not able to fully access the curriculum. This is not a problem to be solved, but a situation to be managed. With the help and support of experienced people, who can maximise on his strengths and support him in his difficulties, we can ensure he enjoys his education and time at school, giving him full access to the curriculum. This will help ensure he benefits from a positive experience, affecting his future for the good.

Yours Sincerely

Your name