Date: June 2017

**Violet Jeapes**

She is the happiest little girl, always full of smiles and cheekiness. She is an inspiration, her determination is amazing. She has the most fantastic bond with her twin brother Henry.

Violet has been diagnosed with a rare genetic disorder called 15q 13.3 micro duplication as well as quadriplegic dystonic cerebral palsy.

Violet has suffered from ill health from an early age and has failed to reach a lot of milestones parents often take for granted. Yet you would never know from her incredible zest for life and happy demeanour.

Violets muscle tone alternates between severe hypotonia in her trunk to hypertonia in all limbs. From floppy to rigid.

Violet was formally diagnosed in Jan 2017 with dyskinetic cerebral palsy - dystonic quadriplegia. This affects all four limbs.

Violet suffered from HIE - hypoxic ischemic encephalopathy, loss of oxygen to the brain around birth which caused brain damage. This was seen on an MRI completed in Jan 2017.

Violet attends a lot of appointments and works hard every day completing her physio exercises. She deserves to have as much fun as possible in between!

The goal for Violet:

The family would love to expand our beautiful girls world bringing as much happiness, fun and enjoyment into her life as possible.

Unfortunately a lot of the Special Educational Needs (SEN) equipment and toys are very expensive and we cannot afford to do this on our own.

As Violet develops and grows there will be new challenges and this will bring the need for new equipment and stimulation, most of which is either not available on the NHS or is out of our budget.

Currently the equipment needed for Violet is an specialist bed, which will accommodate her needs. The cost of this currently is over £4,000.

