### Tuberous sclerosis in children
(or TS for short)

#### What is it?
In TS there can be skin changes and lumps or cysts in the body. Some have epilepsy or problems with behaviour, sleep or learning. About 1 in 7000 babies born in the UK has TS.

#### What is the cause?
TS is due to a defect in a gene (you say gene like jean). We do not know why the defect happens. You are born with it. You do not catch it like the flu. It doesn’t go away. There isn’t a cure. But problems can be treated.

#### Is it passed on in the family?
TS can be passed on. But for about 75% of children with TS (3 out of 4) neither parent has it. There is a 50% chance (1 in 2) that a person with TS will pass it on to their child. The risk stays the same no matter how many children they have. We may be able to test a mother’s baby before birth.

#### How do you find out if a child has TS?
Your doctor may see things in the skin, mouth or eyes. Scans may show lumps or cysts in organs like the brain or kidneys. Knowing that a parent has TS can help. In the skin there can be a red lumpy rash on the cheeks and nose. Tiny patches of white skin may be seen. There can be a smooth raised red area on the forehead or scalp. A thick coloured area may be found on the back. There can be skin tags and small lumps in the nails. There can be tiny pits in the teeth and small lumps on the gums. There can be small lumps at the back of the eye.

#### What can happen?
Every child with TS is different. You cannot tell how it will affect a child by looking at their parents. Some stay well and it doesn’t affect them much. Some do not know they have it. About 75% of children with TS have epilepsy or problems with behaviour, sleep or learning. If epilepsy starts in the first year it is often hard to treat. It can affect how a child develops in the future. Most of the skin changes, lumps and cysts tend to occur in older children or adults. It is rare for them to cause any problems or need treatment. Sometimes lumps or cysts in the kidney cause blood pressure or bleeding. A lump in the brain may cause raised pressure. This can lead to headache, double vision, vomiting, poor balance or sleepiness. Babies may have lumps in the heart. These tend to be harmless and go away. Rarely, lung cysts are found. This is mostly in adult women. They can cause shortness of breath or a sudden air leak. This can happen with an anaesthetic or air travel.

#### What needs to be done?
Tests are done such as scans of the brain and kidneys. Problems such as epilepsy will be treated. Most lumps or cysts only need checking and can be left alone. Help may be needed for problems with behaviour, sleep or learning. It is best for your child to see the children’s doctor at least once a year. Even if they are well. A doctor who knows a lot about gene defects and how they are passed on can see your family. Parents may need some tests. Ask about claiming benefit.
Where can I find more help and information?


**Contact a Family**, 209-211 City Road, London EC1V 1JN, 0808 808 3555, e-mail info@cafamily.org.uk, www.cafamily.org.uk.

**King’s Mill Hospital**
Patient Advice and liaison Services
(PALS) on 01623 672222

**Newark Hospital**
Patient Advice and Liaison Services
(PALS) on 01623 685692