



About Max (age 6)

Genetic disorder: HED (Hypohydrotic Ectodermal Dysplasia)

Likes: Transformers, playing Nintendo Wii, West Ham football team.

Dislikes: Hot cars, nuts, wearing his false teeth.

Home town: Corringham, Essex

Unaffected siblings: Thomas (aged 11)

Mum: Tracey

Dad: David

About H.E.D.

- HED stands for **Hypohydrotic Ectodermal Dysplasia**.
- Children have **no teeth**, **can't sweat** and have **very little hair**.
- **Dentures** are often worn to help with **eating and speech** and some children wear **wigs**.
- **Air conditioning**, **cooling vests** and **cold drinks** are often used to **prevent overheating**.
- The most common form of the condition is caused by a **faulty gene** on the **x-chromosome**, of which boys have one (XY) and girls two (XX).
- A **developing embryo** is made up of **three layers**, each of which gives rise to different parts of the body. The gene mutation in people with HED affects a layer called the '**ectoderm**' which develops into the **hair, teeth, and sweat glands**.
- The condition is **not usually life threatening**, provided **body temperature is controlled**.

GENETIC DISORDERS

- **Genes** are made out of **DNA** and most contain **instructions for making proteins**.
- A **genetic disorder** happens when a **change** in one or more genes causes **vital proteins** in the body to be **missing or faulty**.
- An estimated **1 in 25 children** in the UK are born with a **genetic disorder**.
- Some other examples of genetic disorders include **Cystic Fibrosis**, **Sickle Cell Anaemia**, **Huntington's Disease** and **Haemophilia**.

CURRICULUM LINKS

- **Foundation:** Knowledge and understanding of the world; Personal, social and emotional development.
- **KS1 Science:** Ourselves; Human variation.
- **KS2 Science:** Teeth and eating; Evaporation and sweating.
- **KS1/2 PSHE and Citizenship:** Respecting the differences between people; Community cohesion; Disability rights.

USEFUL LINKS

- **The ED society:** www.ectodermaldysplasia.org
More about living with Ectodermal dysplasia.
- **Kid's Health:** <http://kidshealth.org>
Learn about health and how the body works.
- **GOSH Kids:** www.childrenfirst.nhs.uk
Age-appropriate information about hospital life.

FOR MORE RESOURCES LIKE THESE, AND TO SIGN UP FOR JEANS FOR GENES DAY, VISIT US AT WWW.JEANSFORGENES.COM

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