

# WEAR JEANS, CHANGE LIVES

Sonny, Elvi and their mum supporting Jeans For Genes Day



## DID YOU KNOW?

Genes carry instructions that tell your body how to make all the proteins it needs to survive and grow. Scientists hope to better understand how the body works by studying genes. They believe this will eventually lead to more effective medicine and treatment for everyone.

Elvi and her friends Daisy and Izzy



IT'S time to make sure your school is signed up for Jeans For Genes Day this year. Here one brother explains what it's like to have a disabled sister and how you can get involved.

Hi, I'm Sonny and this report is about my sister Elvi, who has a genetic disorder. That means her genes, the instructions for her body, don't work properly.

Elvi was born in 2001. She had, and still has, a rare syndrome called RCDP (rhizomelic chondrodysplasia punctata). There are 4,000 known genetic disorders but only three other children in Britain have the same one as Elvi, so it's pretty rare.

RCDP means she can't walk, speak properly or do other things that you and me take for granted. However, Elvi can still make herself understood and she can let us know what she wants and doesn't want, by saying "yes" or "no" to options that we give her.

Me: Crisps, Elvi?

Elvi: Yes.

Me: Apple, Elvi?

Elvi: No!

Whenever our family goes out of the house, Elvi has to be wheeled around in her (fabulous) wheelchair. We had to buy a special van for the wheelchair to fit in. All of us take turns pushing Elvi.

A lot of people stare at Elvi, because maybe they've never seen someone like her, or they find my sister just plain interesting. It makes me feel quite angry. Please remember that Elvi is still a young person like you, and always think: "Would I like people staring at me every time I go out?" or "Would I like it if I was afraid of going out on a walk?". Always think of those questions, and anyway, she's a really nice teenager to know!

Elvi's best friends are both disabled. Sadly, one of them, Daisy, died earlier this year aged 12, from a genetic disorder called Costello syndrome. Elvi's friends can all play together well and they love each other like sisters. They go to a special needs school near us, which is adapted for wheelchairs and has special lessons. She loves it.

Every year, schools across the country, including mine and Elvi's, have Jeans For Genes Day, where you wear jeans to school and bring in one pound. If your school doesn't take part in Jeans For Genes Day, please ask your teachers, head teacher and maybe even your parents to take part in this important fundraising campaign. All of your money will go to the Jeans For Genes charity, which provides equipment and days out, and really just makes life better for families with a child that has a genetic disorder. Thank you for taking your time reading this report. Peace out.

## Your school can help!

This year's Jeans For Genes Day is on Friday 22 September. You could be the one who persuades your teacher or school council to take part!

The money your school raises if every pupil brings in one pound to wear jeans could stretch really far. £100 could go towards the cost of a sports wheelchair for a child who loves football but can't walk.

£200 could help provide a specialist nurse at a fun day for children where they can meet others with their syndrome for the first time.

£300 could go towards creating a booklet for kids like me, to understand more about their brother or sister's condition.

Find out more at [jeansforgenesday.org](http://jeansforgenesday.org).

## DID YOU KNOW?

One in 25 children is born with a genetic disorder and 500,000 children in Britain live with a genetic disorder. There are more than 6,000 different genetic conditions and scientists find more all the time, because this is a really new and exciting field of research for them.

Find out more now at [jeansforgenesday.org](http://jeansforgenesday.org)