EURORDIS Newsletter Issue 19 December 06 Category: Learning from each other

A charity dressed in denim...

....the growing success of the Jeans for Genes trust

Summary:

Jeans for Genes is a UK one-day national appeal that was set up to raise funds for children with genetic diseases. The idea is simple and fun: everyone is invited to throw out the usual dress code, jump into their jeans and show they care by donating £1 or more. This fun charity has raised up to £24 million over a ten year period.

Article:

It would be an understatement to say that <u>Jeans for Genes</u> charity has been a popular trust since its very beginning. Launched in the UK in 1992 by the <u>Chronic Granulomatous Disorder</u> <u>Research Trust</u> (soon joined by the <u>Primary Immunodeficiency Association</u> and the <u>Society</u> <u>for Mucopolysaccaride Diseases</u>), the day when people ditch their regular dress code to wear jeans raised £860,000 in its first four years of existence.

The idea is simple and fun: people are asked to wear a pair of jeans on the first Friday of October and donate a minimum of $\pounds 2$ ($\pounds 1$ for children) to help genetic research. 'Until 1996, the Jeans for Genes day was on trial in schools in the western part of the UK only', says Rosalind Freeborn, Head of Communications at Jeans for Genes. 'Children loved the idea of wearing jeans instead of their regular school uniforms and the charities involved realised that they were onto something that could work on a greater scale. So they approached Great Ormond Street Hospital Children's Charity (GOSHCC).' With <u>GOSHCC</u> on board, the Jeans for Genes day raised a whooping $\pounds 3.5$ million in 2005 and over $\pounds 24$ million in only ten years of existence. 'Of course the fun-aspect and simplicity of the event is one of the main reasons for our success. But we realised that people also understood the message of the day very clearly and this is very important for a fund raising event,' explains Rosalind Freeborn. This popular campaign finds its most enthusiastic volunteers in children. 'We have always reached citizens in their young age – in nurseries, schools, colleges – and now, those who are in their 20s know this charity very well and are quite fond of it.'

One of the most popular achievements of Jeans for Genes happened in 2002. The campaign funded the first ever treatment and successful cure by gene therapy in the UK. Rhys Evans, an 18-month old boy was treated by a specialist team at Great Ormond Street Hospital (GOSH) for a rare immune deficiency disorder, called <u>Severe Combined Immunodeficiency</u>

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(SCI). This gene therapy developed in partnership with Professor Alan Fischer from Necker Hospital, Paris and supported by <u>INSERM</u> (France) and <u>AFM-Téléthon</u> (France) was a major breakthrough in validating the proof of concept of gene therapy for rare diseases. Often dubbed the 'baby in the bubble' syndrome, SCI, caused by a single mutated gene, forced the little Rhys to live in sterile conditions or risk picking up a life-threatening infection. 'Ten children have undergone gene therapy since then and donors on Jeans for Genes day know they are giving for something that can change a life forever. Rhys Evans is a normal school boy today,' says Rosalind Freeborn.

Jeans for Genes works like an umbrella charity. Every year, the trust invites projects from all over the UK and has the difficult task of picking some happy few 'guest charities' to share 10% of the money raised. The rest is returned to the founding charities. Today, Jeans for Genes is such a fully recognised brand that there is a Jeans for Genes day in <u>Australia</u> and in <u>Canada</u>, both meeting the same growing success as the British edition. 'We have been working steadily, building our brand carefully, step by step, and it's very easy to have a Jeans for Genes day in any country. A European network would be great actually,' says Rosalind Freeborn. Something Eurordis is seriously considering.

For its tenth year anniversary as an annual fund raising event, Jeans for Genes has moved into new premises. 'We are still very much linked to our founder charities but we now have 8 people working on a full-time basis for the trust.' Today, celebrities like *Robbie Williams* or the pop band *Blue* are on board, giving the charity a broader scale and more media attention. 2006 will be marked by new aspirations and expectations: making Jeans for Genes not only a day campaign, but a whole year-round fund-raising charity with balls, sporting events, challenges etc. Judging by its ongoing success, it should be only a matter of time before it rivals other popular trusts.

For more information:

Website of <u>Jeans for Genes</u> <u>Research projects</u> funded by Jeans for Genes