



Complex Child E-Magazine

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The Global Genes Project: All Kids Deserve To Have Hope For A Cure by Janis Marie

According to the National Institutes of Health (NIH), 30 million Americans are afflicted with a rare disease, or one in ten people. The National Organization of Rare Disorders (NORD) estimates that of the 30 million people in the United States suffering from rare diseases, approximately 50 percent, or 15 million, are children. Many rare diseases appear early in life, and about 30 percent of children with rare diseases will die before reaching their fifth birthdays.

The Global Genes Project is a new campaign of the Children's Rare Disease Network, and is a grassroots effort to increase awareness about the prevalence and lack of treatments for rare diseases worldwide. As a method of raising awareness, Global Genes uses the connection between the pairs of jeans we wear and the genes that make up our 23 pairs of chromosomes. More than twenty corporations, as well as numerous hospitals, non-profits, and rare disease organizations support the Global Genes Project. For more information, visit <http://www.crdnetwork.org/> or <http://www.globalgenesproject.org>.

A staggering 250 million people worldwide are estimated to suffer from approximately 7,000 different forms of rare diseases, for which there are limited drug treatments. In the United States, statistics show that approximately 350 new drugs have been developed for the entire rare disease patient population since the passing of the Orphan Drug Act in 1983, despite incentives put in place by the federal government. All kids deserve to have a cure!

Global Genes Projects

This past February, Global Genes organized a campaign to raise awareness for Rare Disease Day by encouraging everyone to wear jeans that day. In addition, they created a "Jean Ribbon" that could be added to websites, or printed and distributed for a \$1 donation.

Ongoing events to increase awareness include "Denim and Genes" parties hosted throughout the country, fashion shows, a project to create 7000 jeans-themed bracelets (to represent the 7000 rare diseases), and purchasing products, such as shirts and jewelry, through their website.

Kids with Rare Diseases Become “Ambassadors for Hope”

A major project of the Global Genes Project is the development of the Global Genes Fund in conjunction with rare disease groups and families. This fund will not only increase awareness about rare diseases, but will also promote research and the development of treatments and therapies for children who have rare diseases.



In order to help kick-start this fund, Global Genes has created a Vote4Hope campaign throughout the month of September 2010. Pictures, stories and videos of children living with rare diseases will be featured on a daily basis on the Vote4Hope website: <http://www.vote4hope.org/>. Called the “Ambassadors for Hope,” these children represent the 7000 different rare conditions, and suffer from diseases including Ataxia-Telangiectasia, Autosomal Recessive Polycystic Kidney disease, Batten disease, Branchiootorenal Syndrome, Canavan disease, Cystic Fibrosis, Dravet Syndrome, Duchenne Muscular Dystrophy, Fibrous Dysplasia, Joubert Syndrome, Mitochondrial Encephalomyopathy, Niemann Pick Type C, Hutchinson–Gilford Progeria, Spinal Muscular Atrophy, Subcortical Band Heterotopia, Tay-Sachs and Type 2 Gaucher’s disease.

Vote4Hope refers to voting to obtain a \$250,000 grant through the Pepsi Refresh Project. The Pepsi Refresh Vote4Hope campaign began September 1 at <http://pep.si/ivote4kids> and will continue through September 30. Supporters can Vote4Hope by voting directly at the Pepsi site, texting 102614 to Pepsi (73774), or using the Pepsi Facebook voting application.

The Vote4Hope Rare Disease campaign is designed to help drive awareness for the unmet medical needs of the global rare disease community, and to support the development of the Global Genes Project.