



The Global Genes Project Aims to Battle Rare Disease Through The 'Vote4Hope' Campaign and Pepsi Refresh Competition

Over 15 Million Children in America Are Estimated To Suffer From 7000 Unique Rare Diseases; Children Unite As 'Ambassadors of Hope' To Win \$250K Pepsi Grant For The Global Genes Fund

DANA POINT, CA – September 1, 2010 – *All Kids Deserve To Have Hope For A Cure – The 'Vote4Hope' Pepsi Refresh Rare Disease Campaign starts today.* The Children's Rare Disease Network (www.crdnetwork.org) and The Global Genes Project (www.globalgenesproject.org) are inviting the public, as well as caregivers, family and friends of the millions of children who suffer from rare diseases and disorders, to 'Vote4Hope' throughout September during The Pepsi Refresh Project.

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. The Pepsi Refresh 'Vote4Hope' campaign opens today at <http://www.refresheverything.com/fundhopeforsickkids> and will continue through September 30.

"We entered The Pepsi Refresh grant competition with the goal of continuing education surrounding rare diseases and to generate the global awareness the rare disease community deserves," said Nicole Boice, founder and president, Children's Rare Disease Network and the Global Genes Project. "Many rare diseases affect small numbers of patients and because of the rarity of each condition, the public is often unaware of these chronic and life threatening conditions. However, collectively millions of people worldwide have rare diseases and everyone knows an adult or child suffering from a rare condition."

If the Global Genes Project wins The Pepsi Refresh grant competition, funding will go to support further development of the Global Genes Fund. The Global Genes Fund is an innovative platform, which promotes a number of rare disease initiatives including 'in-a child's-lifetime' research and therapy development. The development of the Global Genes Fund will provide tremendous value to the millions of children, families and rare disease organizations that support them.

Time To Refresh Rare Disease Facts

A staggering 250 million people worldwide are estimated to suffer from approximately 7,000 different forms of rare diseases with the vast majority having no therapies at all. In the United States, FDA 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.

According to the National Institutes of Health (NIH), 30 million Americans are afflicted with a rare disease, or 1 in 10 people. The National Organization for Rare Disorders (NORD) estimates that of the 30 million people in the United States suffering from rare diseases, 50 percent or approximately 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 birthday.

Rare Kids Become ‘Ambassadors of Hope’

Throughout the month of September and during the “Vote4Hope” Pepsi Refresh Rare Disease Campaign, 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 of Hope’, these children are representing 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. To submit a child with a rare disease to the Ambassadors of Hope program, please visit the Vote4Hope website at <http://www.vote4hope.org/>.

“The ongoing lack of treatments for thousands of rare diseases has created an immense burden on the U.S. healthcare system and leaves millions of children and their families in despair,” added Boice. “At the Global Genes Project, our focus is on creating a unified voice and a platform for hope for this community, with continued efforts on educating the public and our government leaders on the importance of creating a national strategic plan for rare disease.”

About The Global Genes Project

The Global Genes Project is a campaign of the Children’s Rare Disease Network and is a grassroots effort with the goal to increase awareness about the prevalence and lack of treatments for rare diseases worldwide. The Children’s Rare Disease Network is a registered

501c3 non-profit organization. For more information, visit <http://www.crdnetwork.org/> or <http://www.globalgenesproject.org>.

About The Pepsi Refresh Project

The Pepsi Refresh Project is giving America the power to decide how to fund good ideas, big and small, that help refresh our world. In an effort to support those who generate innovative, optimistic ideas, the Pepsi Refresh Project <http://www.refresheverything.com>, will award more than \$20 million in 2010 to move communities forward. Each month, The Pepsi Refresh Project accepts 1,000 ideas and asks America to choose which ideas will win a Pepsi Refresh Grant.

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