

PRESS RELEASE



Global Genes Project Launches to Raise Awareness for Millions of Children Living With Rare Disease

Campaign Symbolized by Blue Denim Jeans Ribbon, Brings Together Support from over 90 Corporations, Non-Profits, Advocacy Groups, Research Institutions, Hospitals and Government Agencies

DANA POINT, CA – February 1, 2010 – Hope – It’s In Our Genes.™ The Children’s Rare Disease Network (<http://www.crdnetwork.org>) today announced the Global Genes Project (<http://www.globalgenesproject.org>), a new campaign designed to raise awareness about the prevalence of rare diseases that afflict millions of children worldwide. Rare disease advocates organizing the campaign selected a blue denim jeans ribbon as the international symbol of hope for children suffering from life threatening and chronically debilitating rare diseases.

More than 90 corporations, non-profit foundations, research institutions and children’s hospitals have signed on to support the Global Genes Project including: 23andme, Amicus Therapeutics, Better Health, BioMarin, CheckOrphan, CollabRx, Counsyl, Coriell Institute, DonateGames.org, FasterCures, FreeForm, Genetic Alliance, Geni.com, Genzyme, Hide and Seek Foundation, Kakkis EveryLife Foundation, Knome, Lili Claire Foundation, Life Technologies, Mayo Clinic, Jackson Laboratory, and Shire. Numerous rare disease foundations from Australia, Argentina, Belgium, Canada, China, Denmark, New Zealand, Philippines, UK and the United States have also joined the awareness effort.

“The Global Genes Project is providing a new platform to help unite people under a common goal and to make a difference for all children suffering from rare diseases,” said Nicole Boice, Founder, Global Genes Project. “In many ways, this is not so much a campaign, it’s a global movement. We want to create a world where children suffering from rare disease have equal access to life saving drug treatments.”

Growing Public Health Concern; Inequity Exists

Rare disease is an important and growing global public health concern that can no longer be ignored. While each disease may be rare when considered by itself, rare disease collectively impacts the lives of millions. According to estimates from the National Institutes of Health (NIH), approximately 6,800 rare diseases exist, many of which are genetic in origin, and impact over 25 million Americans or approximately 1 in 10 people. In Europe, the number affected is almost identical.

Approximately 75% of those affected by rare disease are children, making the rare disease category one of the most deadly and debilitating for children worldwide.

Despite the success of the Orphan Drug Act of 1983, pharmacologic treatments exist for only a small fraction of rare diseases, or approximately 200 of the 6,800 rare diseases according to the NIH. After 25 years of orphan drug regulations and legislation, the development path to approve new drugs has not stimulated orphan drug development for rare diseases with low prevalence.

Current studies suggest that it takes more than a dozen years and hundreds of millions of dollars to take a potential drug from discovery to the marketplace. As a result, a severe inequity exists in access to care and treatment for millions of rare disease patients.

Denim Blue Jeans Ribbon Campaign

Leading up to the annual World Rare Disease Day at the end of February, the Global Genes Project will help facilitate a series of denim awareness events, charitable activities and engage corporate sponsors, government officials, celebrities and the media to help spread its lifesaving message of hope.

“Blue is the color of strength and our blue denim jeans ribbon is a symbol that expresses solidarity,” added Boice. “Genes and jeans are a natural fit – both are universal, come in pairs and are unique to the individual.”

The Global Genes Project is asking rare disease advocates and stakeholders across the world who want to raise awareness for the millions of people living with rare disease to wear denim jeans and blue denim jeans ribbons the week of February 22 and leading up to World Rare Disease Day 2010. The organization is also asking supporters to display the blue denim jean ribbon symbol on their websites and to actively invite co-workers, friends and family members to join in spreading its global message and denim symbol.

Blue denim jeans ribbons can be obtained by visiting www.globalgenesproject.org. Denim jeans and ribbon wearing supporters can submit digital photos on Facebook: <http://www.facebook.com/group.php?gid=214263320931&ref=mf>. To join the growing list of supporters, visit <http://www.globalgenesproject.org/sponsors.php>.

About The Global Genes Project

The Global Genes Project is a campaign of the Children’s Rare Disease Network and a grassroots effort with the goal to increase awareness about the prevalence of 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 www.globalgenesproject.org.

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