



## **GLOBAL GENES PROJECT ANNOUNCES “WEAR THAT YOU CARE™” DENIM AWARENESS CAMPAIGN FOR RARE DISEASE DAY 2011**

**Statistics Show 95% of Rare Diseases Have No FDA Approved Drug Treatments; Only 352 New Drugs Developed and Approved For Tens of Millions of People Since 1983**

**DANA POINT, Calif. – January 26, 2011** – Monday, February 28, 2011, is the 4<sup>th</sup> annual Rare Disease Day — a day when people worldwide will show their support for the millions of people suffering from rare diseases and disorders. According to statistics from the National Institutes of Health (NIH), there are approximately 7000 different rare diseases that together affect over 25 million Americans and about 250 million people globally. It is estimated that 80% of rare diseases are caused by gene defects, and according to the Kakkis EveryLife Foundation, 95% of rare diseases do not have any FDA approved drug treatments. Since the Orphan Drug Act was enacted 28 years ago in January 1983, only 352 new drugs have been approved by the FDA for all rare diseases combined despite incentives by the federal government.

The Global Genes Project ([www.globalgenesproject.org](http://www.globalgenesproject.org)), a leading nonprofit rare disease advocacy organization, today announced the “Wear That You Care™” Denim Campaign in support of Rare Disease Day 2011 and to call attention to the global drug development crisis facing millions of people afflicted with rare diseases. The Wear That You Care™ Denim campaign is simple — all across the world people can participate in supporting the rare disease movement on Rare Disease Day 2011 by wearing a Denim Jeans Ribbon™ and their favorite pair of jeans -- also known as vaqueros , cowboybuckers, niuzaiku, farmernadrág and dungarees in other countries.

“Spurring development of new treatments for thousands of rare diseases is one of the most pressing health care challenges we face in the world today,” said Nicole Boice, Founder, Global Genes Project. “The goal of our effort is to create synergy among all constituents committed to finding treatments for the millions of people living with rare diseases and to educate the public on how genetics can influence their health or lead to chronic or life threatening diseases.”

Since the launch of the Global Genes Project and Hope – It’s In Our Genes™ awareness campaign in February 2010, more than 150 leading corporations, organizations, hospitals and nonprofits have signed up to support rare disease awareness and educational efforts. Organizations that recently joined the effort include: Angelman Syndrome Foundation, Batten Disease Support and Research Association (BDSRA), Biotechnology Industry Organization (BIO), Children’s Hospital Research Center Oakland, Healthline, Illumina, Medpedia, MLD Foundation, National Society of Genetic Counselors, Pfizer, Progeria

Research Foundation and RemedyMD. The Global Genes Project has also added new supporters from China, Serbia and Turkey.

“Many rare disease foundations are starting to understand our core message -- we’re all in the same boat when it comes to drug development for our individual rare diseases and there are few options in sight for millions of people,” added Boice. “It’s time to band together to make our voices heard and to push for major legislative initiatives that provide novel incentives to researchers and industry so they will invest the time and capital needed to develop new treatments.”

A number of “Wear That You Care” denim awareness events are currently being organized around the world and hundreds of volunteers, coordinated by the Global Genes Project, are working on a multitude of outreach activities leading up to Rare Disease Day 2011. Some of the events and activities in progress for Rare Disease Day 2011 are as follows:

- The National Institutes of Health Office of Rare Diseases Research (ORDR), in association with the Global Genes Project, is encouraging all attendees to wear their favorite pair of jeans to their day-long Rare Disease Day 2011 celebration at the Lipsett Amphitheater at the NIH Clinical Center. Dr. Francis S. Collins, Director of the National Institutes of Health and one of the leaders of the Human Genome Project (HGP), is expected to address attendees.
- Pfizer’s rare disease research and development unit based in Cambridge, MA, will be encouraging attendees at their Rare Disease Day 2011 event to wear jeans to help raise awareness. In June 2010, Pfizer established a new research unit devoted to developing new biologics to treat rare diseases.
- Shire, one of the world's leading specialty biopharmaceutical companies, will encourage employees to wear jeans to work and plans to hand out over 5000 denim blue ribbons to employees at various corporate locations worldwide.
- Over 200 volunteers, including numerous children, have made over 20,000 Denim Jeans Ribbons™ that will be distributed to rare disease patient advocacy groups, pharmaceutical companies, biotech firms, schools and hospitals on Rare Disease Day 2011. Blue denim ribbon making efforts will continue leading up to February 28, 2011, with a goal of reaching 50,000 handmade ribbons.
- Over 300 volunteers ranging from jewelry designers to crafters are working on the 7,000 Bracelets for Hope™ campaign. These blue denim inspired “cause bracelets” will be distributed on Rare Disease Day 2011 to children and families battling rare diseases and serve as symbol of hope to find treatments and cures.
- A number of schools have signed up to host “Wear That You Care™” denim awareness days and plan to distribute Denim Jeans Ribbons™ in an effort to support the rare disease community.

For more information on how to get involved and support Rare Disease Day 2011 in your local community or to get your Denim Jeans Ribbon™, visit the Global Genes Project at [www.globalgenesproject.org](http://www.globalgenesproject.org).

## **About The Global Genes Project**

The Global Genes Project is a leading nonprofit rare disease advocacy organization that educates the public about the prevalence of rare diseases worldwide. To see our full list of supporters, visit <http://www.globalgenesproject.org/sponsors.php> or follow us on Facebook at <http://www.facebook.com/group.php?gid=214263320931#!/group.php?gid=214263320931>.

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