

AUGUST 16, 2010 • VOLUME 1, ISSUE 1

GLOBAL GENES PROJECT E-NEWS

'WHAT'S HAPPENING'

Welcome to 'What's Happening' volume 1, and thank you for being an important part of the Global Genes Project. As you may know, the Global Genes Project began as an idea shared by numerous rare disease parents and advocacy groups, whose vision became real when Charleston|Orwig brought their creative expertise to the cause. In January 2010, the campaign was launched and in 4 short weeks over 150 organizations jumped in to become part of this grassroots campaign. Shortly thereafter, the slogan 'hope. it's in your genes' was translated into over 20 languages based on feedback and requests from all of you! Very exciting!

So here we are, almost 8 months later and we have a lot to share as we ready ourselves for upcoming fall events and activities, in addition to our preparation for World Rare Disease Day 2011 (February 28).

RECOJEANS, SEPT 9, 2010 DENIM FASHION SHOW:

recoJeans is hosting the first Denim Fashion Show and Charitable Auction to benefit the Global Genes Project and children affected by rare disease and disorders! At the start of fashion week Sept 9, 2010, in the fashion capital of the world, NYC, join recoJeans, for a sneak peek at some of their new designs, meet the team, and enjoy the festivities. Show your support for this campaign's 1st corporate supporter, and new champion for the rare disease community. Let's show our support for recoJeans and rally all our local friends and families to attend. For more information, and to purchase your tickets, please visit www.globalgenesproject.org/recofashionshow.php

GLOBAL GENES FUND: A WIN FOR RARE DISEASE

As part of the Global Genes Project, the Global Genes Fund is being developed to raise money and interest from new donors and the general public to support rare disease research initiatives. RARE Project recently announced the development of the Global Genes Fund which will promote innovative, collaborative, 'in their lifetime' research initiatives being developed for rare disease, in July 2010. Approximately 20 rare disease advocacy groups, and related organizations have joined the team to help direct and advise in the development



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of this fund. The Global Genes Fund will be made available at no charge to participating organizations! There exists an inherent need to develop a platform like this to benefit the community as a whole. The goal, to bring new awareness to rare disease, develop new supporters and new champions for this community in need! Expected launch, February 2011, for more information contact nicoleb@rareproject.org.

PEPSI REFRESH: SEPTEMBER, 2010 VOTE FOR THE GLOBAL GENES FUND

The team behind the recently announced Global Genes Fund has been accepted to participate in the Pepsi Refresh Grant Challenge September 1 – 30. The team is developing a strategy and plan of action to ensure a win in the amount of \$250K. The monies raised through Pepsi Refresh will go directly to the technology development and programming costs related to the build-out of this funding platform. This money would help accelerate the development of the fund, providing the ability to get more rare disease research initiatives out in front of the general public.

In order to win, the Global Genes Project team is asking for help from the over 200 rare disease and support organizations that have jumped on board as partners of this important initiative. Votes are needed daily to help ensure this campaign wins the funding. A win for Global Genes Fund will be a long term win for the rare disease community!

Janis Marie of Sneak Peek at Me blog and @sneakpeekatme will be leading our social media outreach for Pepsi Refresh on Facebook, twitter, as well as, reaching out to other key bloggers for support.

To get involved, please contact us at vote4hope@globalgenesproject.org

'7,000 BRACELETS FOR HOPE.' – CELEBRATING RARE KIDS

The Global Genes Project volunteer team is collecting blue jean/denim inspired bracelets for families living with rare diseases, disorders or conditions. The campaign is called “7,000 Bracelets for Hope.” To help raise awareness we’re asking 7,000 jewelry designers, volunteers from the craft community and various artists to donate one bracelet to this campaign to show their support of rare kids. This campaign will be ongoing through World Rare Disease Day on February 28, 2011. These bracelets will individually be donated to 7,000 rare families (parents/caregivers of rare kids). “How compelling to connect 7,000 new champions to our kids and their families”, stated Catherine Calhoun, program director for “7,000 Bracelets for Hope.” campaign. For more information or to participate, join us at www.globalgenesproject.org/7kbracelets.php

To get involved, please contact us at 7000bracelets@globalgenesproject.org



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WE WANT TO HEAR FROM YOU!

We will continue bringing you information, insights and news from the community monthly. We are hopeful that you will provide us with news about programs, events, ideas and best practices that we can share as well. We are also looking for innovators with big ideas – we want to hear from you! The Global Genes Project and Fund are collaborative initiatives that have been developed 'by the rare disease community, for the rare disease community'. This is your campaign – so get involved – make it your own, and keep us informed!

How are you using the denim ribbon and this unifying campaign to help your cause? Share your stories with us! info@globalgenesproject.org.

Don't forget to join the discussion on Facebook, and within the "Global Genes" channel of RARE Blog.

