Over 500+ Patients, Advocacy Leaders, Biotech and Pharmaceutical Executives, Healthcare Philanthropists and Celebrities to Gather in Newport Beach for Rare and Genetic Disease Awareness Benefit

ALISO VIEJO, Calif., Sept. 12, 2013 /PRNewswire-USNewswire/ -- Global Genes | RARE Project today announced that Emmy-nominated recording artist,
Andrew McMahon
, a singer and songwriter best known for his vocals, piano and lyrics for the bands
Something Corporate
and
Jack's Mannequin
, will perform at the sold-out
2nd Annual RARE
Tribute To Champions of Hope
™ benefit
on
Saturday, September 21, 2013
, at the Balboa Bay Club in
Newport Beach
, CA.

McMahon, who is nominated for a Primetime Emmy Award for his work on "I Heard Your Voice In A Dream" from NBC's hit musical drama SMASH, has a personal connection with the struggles facing rare disease patients due to his diagnosis of Acute Lymphocytic Leukemia (ALL) in 2005. In 2006, McMahon created the "Dear Jack Foundation" to advocate and support initiatives that directly benefit adolescents and young adults diagnosed with cancers.

"We are expecting an amazing and magical evening as the global rare and genetic disease community unites together to honor each other's achievements," said Nicole Boice, President & Founder of Global Genes | RARE Project. "My hope is, as more people understand the unique

set of healthcare challenges facing rare disease patients and their families, they are inspired to take action and get actively involved in this movement."

In addition to a performance from McMahon, Cimorelli, an all-girl sister band popularized on YouTube and signed to Universal Music's Island label, will also perform live at the event. Many celebrity guests are also expected to take part in the event including Eileen Grubba (*Hung, The Closer, Cold Case, Sons of Anarchy, Monk, CSI*
and
The Five Year Engagement)
and
Carmen Argenziano
(
House, Young and the Restless
and
CSI
).

"Children with rare illnesses are very close to my heart, because I was one of those kids," said Eileen Grubba
. "I know firsthand what children experience, and I am determined to help create a more welcoming world for those suffering from rare and genetic conditions. I am deeply honored to be part of
Tribute to Champions of Hope
™ event as a presenter and look forward to recognizing these truly rare champions."

It is estimated that it takes on average five to seven years for a patient suffering from a rare disease to receive a proper diagnosis. According to the Shire Rare Disease Index Report , rare and genetic disease patients generally receive up to two or three misdiagnoses, draining hope and finances from affected patients and their families. Money raised at this year's
Tribute to Champions of Hope
™ benefit will fund tools and resources to support the global rare and genetic disease community, and will also support efforts by Global Genes | RARE Project's partners in the area of diagnosis and research.

Sponsors of the 2013 RARE *Tribute to Champions of Hope*™ include Aegerion Pharmaceuticals, Alexion Pharmaceuticals, Ambry Genetics, Amicus Therapeutics, Audentes Therapeutics, Auxilium Pharmaceuticals, Bayer Healthcare, Biotechnology Industry Organization (BIO), Biogen Idec, BioMarin, Cambridge Biomarketing, Center for the

Advancement of Science in Space (CASIS), Centric Health Resources, Engage Health, Cincinnati Children's Hospital Medical Center, EveryLife Foundation, Feinstein Kean Healthcare, Genzyme, GlaxoSmithKline, IDIS, Jazz Pharmaceuticals, Ewing Marion Kauffman Foundation, Illumina, Lumena Pharmaceuticals, InterMune, Novartis Pharmaceuticals, Patient Crossroads, Patient Services Incorporated, PatientsLikeMe, Pfizer, PhRMA, Raptor Pharmaceutical Corporation, Recordati Rare Diseases, Sarepta Therapeutics, Shire, Sigma-Tau Pharmaceuticals, Siren Interactive, Vanda Pharmaceuticals, Vertex Pharmaceuticals, Vidara Therapeutics, ViroPharma Incorporated, Walgreens and Watson Land Company.

Numerous awards will also be presented at the 2nd Annual RARE *Tribute to Champions of Hope™* to recognize the key innovators and pioneering leaders in the rare and genetic disease community including the *Henri Termeer Lifetime Achievement Award*, the *RARE Champion Award for Patient Driven Science*, and the *RARE Champion Award for Advocacy*.

In addition, the 2nd Annual RARE *Patient Advocacy Summit*™ is being held the day prior to the *Tribute to Champions of Hope*™ benefit to bring together rare and genetic disease patients, parents, advocates, clinicians and key stakeholders for a series of best practices panels and policy driven discussions.

For more information about the 2013 RARE *Tribute to Champions of Hope*™ benefit or the RARE *Patient Advocacy Summit*™, visit the following links:

Web: http://globalgenes.org/ Facebook: https://www.facebook.com/globalgenesproject Twitter: @GlobalGenes - https://twitter.com/GlobalGenes

About Global Genes | RARE Project

Global Genes | RARE Project is a leading rare and genetic disease patient advocacy organization. The Foundation's mission is to unify the international rare and genetic disease community by providing connections and resources to ease the burdens of affected patients and their families. Recognized worldwide by the Blue Denim Genes Ribbon™, Global Genes | RARE Project unites experts, advocates and patients of all ages to stand together in hope for treatments and cures for the estimated 7,000 rare and genetic diseases that impact approximately 30 million Americans and over 250 million people worldwide. For more information, visit http://globalgenes.org/ .

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