Local Elementary Schools To Recognize World Rare Disease Day With “Jeans for Genes” Event

*SCHOOLS SHOW COMPASSION AND HOPE FOR NEVADA CHILDREN AFFECTED BY RARE DISEASES ON FEBRUARY 22, 2013*

LAS VEGAS - February 22, 2013 - Students, teachers and staff at three Henderson elementary schools will take part in World Rare Disease Day activities helping to spread awareness among students and educate them on the science genetics play in these catastrophic conditions.

On **February 22, 2013**, students at Frank J. Lamping, John C. Vanderburg and Selma F. Barlett elementary schools will also create supportive notes for families of children affected by rare diseases and forgo their school uniforms to wear denim jeans to represent the “genes” that make up the genetic basis for many of the 7,000 rare diseases.

**Rare Disease Day Activities Planned:**
Lamping Elementary, approximately 1:10 – 2:10 pm  
Vanderburg Elementary, approximately 2:10 – 3:10 pm  
Bartlett Elementary, approximately 2:20 – 3:20 pm  
(Media covering the event are asked to call the School District for approval prior to event)

The goal of World Rare Disease Day is to increase awareness of rare diseases and the often unrecognized difficulties faced by Las Vegas Valley children and their families affected by these conditions. In recognizing this day, teachers are also helping students increase their compassion for children with disabilities by sending personal messages of hope. The messages will be shared with families affected by rare diseases and with the
Children’s Specialty Center of Nevada, a program of Cure 4 The Kids Foundation, where many of those affected by rare diseases receive medical treatment.

“One of the many heartbreaking frustrations of having a child diagnosed with a rare disease is that there is so little research and ultimately so few treatment options available,” said Carrie Ostrea, founder of Little Miss Hannah Foundation. “By recognizing World Rare Disease Day we hope to build awareness, understanding and ultimately research that will save the lives of children in the future.”

Ostrea gave birth to Hannah Ostrea in 2008 who was soon diagnosed with a life-limiting genetic metabolic disorder after birth called Gaucher’s Disease type 2/3. Hannah passed away on December 4, 2011 at the age of 3. Little Miss Hannah Foundation, along with the Global Genes Project, hope to encourage families affected by rare diseases to share their stories and show the world that they too deserve a chance at a full life.

Teachers at each school will spend the last hour of the school day focusing on rare diseases and will then allow each student to create a personal message on a 5 x7 card to be sent to a family who has a child battling a rare disease. Each card will have a denim jean ribbon attached.

Examples of past cards made for families can be found here:
http://cl.ly/image/3G3Q193x0515
http://cl.ly/image/2U0f3h0U1X1D

www.littlemisshannah.org
www.globalgenes.org
www.cure4thekids.org

For additional information:

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