

(Insert Ring14 USA Outreach, Inc. logo)

Rare Disorder Website and Music Video Raise Awareness for Ring14

NEWBURY PARK, CA (April 11, 2012) -- In support of the mission to fund research for Ring 14, raise awareness of the rare genetic disorder through education, and provide support to patients and caregivers, a new website has been launched for Ring 14 USA Outreach, Inc. at <http://ring14usa.org/>. Concurrently, the 501 (c)(3) non-profit organization has also created a [Ring 14 music video](#) to introduce some of the patients and caregivers.

Ring 14 syndrome is a very rare genetic disorder that occurs randomly when one of the 14th chromosomes mutates in such a way that the ends of this chromosome fuse together to form a ring structure. Genetic material is often lost in this process. The consequences of this syndrome can be varied but are often profound. Children with this syndrome often have low muscle tone, slow growth, mild to severe learning disabilities, limited large and small motor skills, digestive problems, immune deficiencies and a severe form of epilepsy that is mostly drug-resistant. Children with other anomalies of the 14th chromosome, such as deletion, translocations and uniparental disomy (UPD), share many of these same problems.

"We are very pleased to be making such amazing progress to help spread the word about Ring 14," said Terri Granard, caregiver for her son, Elijah, who is one of fewer than 300 people worldwide diagnosed with this ultra-rare disorder. "We're collaborating with a wonderful team of people at [Ring 14 Onlus in Italy](#) who are leading the bulk of the research with children around the world who are affected by Ring 14."

Those interested in helping are encouraged to donate money since private donations are the primary source of funding for research. Parents with a child having an anomaly on the 14th chromosome are asked to [donate blood samples](#) to the Ring 14 international biobank to help expedite the research process. The organization is also looking for volunteers to donate their time, talent and professional services, such as singer/songwriter [Dan Coyle](#), and sponsor companies [Mainely Cole's](#) and [Cisco Equipment](#).

About Ring14 USA Outreach, Inc.

Ring14 USA Outreach, Inc. is a 501 (c)(3) non-profit charitable corporation founded in 2011 by a group mothers dedicated to improving the lives of their children diagnosed with Ring 14 and others living with the rare disorder. Their inspiration was the Italian organization, Ring14 Onlus (ring14.org), which was founded in 2002 and has proven that it is possible for a few people to raise significant money to fund critical research, provide vital education and change lives. The current partnership of the two organizations is built on a common goal to initiate and fund international research and provide unique opportunities for members to benefit from local services.

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