

OC FAMILY

IN OUR COMMUNITY

Fashion show to
raise awareness
of rare diseasesBY NICOLE LYONS
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World Rare Disease Day is Friday. There are 7,000 identified rare diseases, and 350 million people worldwide are affected by a rare genetic disease.

The inaugural Especially Beautiful Fashion Show in Orange County will take place on Sunday at Peppino's in Foothill Ranch from 11 a.m. to 1 p.m. to raise awareness about rare diseases.

The models, all of whom have a rare disease, will showcase Rove Clothing on the catwalk. Proceeds from the event will go to the UC Irvine Division of Genetics and Metabolism to help fund the center's ongoing research.

The event will be hosted by the Spooner family - sisters Cali, 15, and Ryann, 4, are two of four individuals worldwide to suffer from mitochondrial complex 1 - and the UC Irvine Division of Genetics and Metabolism.

"We are excited and hopeful that the Especially Beautiful Fashion Show will bring together members of our community to support rare disease (research) and thrust us forward with additional research to find a cure, not only for our two beautiful daughters, but also for other undiagnosed children," said Cristy Spooner, the girls' mother.

"After a 14-year struggle of going undiagnosed, we know how difficult it can be for children and their families impacted by a rare disease. The fashion show will showcase how being rare is in fact so beautiful."

The National Institutes of Health estimates 50 percent of people affected by rare diseases are children and 95 percent of all rare diseases do not have an FDA-approved drug treatment, making the work of researchers critical in finding treatments and cures.

During the fashion show, Noelle Kirby, who has cystic fibrosis, will speak about how she tackles living with the disease. Dr. Virginia Kimonis, who works at UC Irvine Division of Genetics and Metabolism, will talk about her research and how it has benefited the Spooner children.

For more information about the event, visit [facebook.com/spoonerfund](https://www.facebook.com/spoonerfund).