

Rare Disease Day Legislative Event to Raise Awareness of Rare Diseases in Colorado

On February 28th at 8:00 AM Colorado Rare will host Rare Disease Day at the State Capitol for legislators, policy makers, physicians, advocates and patients.

DENVER , COLORADO, UNITED STATES, February 13, 2018 /EINPresswire.com/ -- More than a half a million people in Colorado are living with a Rare Disease. Colorado Rare, a 501(c)3 nonprofit organization, along with the National Organization for Rare Diseases (NORD) will host a meeting for legislators, policy makers, physicians, advocates and patients to bring awareness to the needs of those living with Rare Disease in Colorado.

This event will take place on Wednesday, February 28th at 8:00 AM at the Colorado State Capitol in the Old Supreme Court Chamber and is open to the public.

Speakers include:

“

We may all have different rare disorders, but we share the profound need to be heard.”

Tara Bohle, President of Colorado Rare 501(c)3

Institute

Rare Disease Patient Advocate Lori Wise

The event is sponsored by Senator Irene Aguilar, of Colorado Senate District 32. Senator Aguilar has supported many bills that ensure the rights to health care and other quality of life services for individuals and families living with Rare Disease.



2018 Board of Directors and Junior Ambassadors

Colorado Rare Board Members and Junior Ambassadors connect with Rare Disease patients at Children's Hospital in February 2018

Former Miss USA Shawnae Jebbia living with a rare form of Meniere's Disease & hearing loss

Youth Rare Disease Patient Advocates 7 year old Lily Spletzer & 14 year old Cailee Crossley

Dr. Tim Benke, Director of Research-Neurosciences Institute

Dr. Scott Demarest, Assistant Professor Neuroscience

While individual Rare Diseases have small patient populations, collectively the Rare Disease community is larger than the AIDS and Cancer communities combined. Despite its impact on so many families, the Rare Disease community has lacked a unified voice--less than half of Rare Diseases have organizations or foundations providing support or driving research. Colorado Rare is a united voice in Colorado to support and represent the needs and challenges of all individuals living with rare diseases and their families.

Rare Disease statistics:

There are approximately 7,000 different types of rare diseases and disorders

30 million people in the US are living with a rare disease - this is equal to 1 in 10 people

In the US, a condition is considered rare if it affects fewer than 200,000 people

80% of rare diseases are genetic in origin

Approximately 50% of the people affected by rare disease are children

30% of children with rare disease will not live to see their 5th birthday

Colorado Rare is a 501(c)3 nonprofit organization with a mission to be a united voice in Colorado to support and represent the needs and challenges of individuals living with rare diseases and their families.

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Gracelyn, a Rare Disease Advocate, holds a sign for Rare Disease Day at an event at Children's Hospital, February 2018



Lily, a 7 year old Colorado Rare and Some 1 Like You Ambassador sings in the Seacrest Studios at Children's Hospital to promote awareness of Rare Disease Day.

This press release can be viewed online at: <http://www.einpresswire.com>

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