

Capitol Watch

Reports from the Courant's politics staff

Rare Disease Day Brings Advocates to the State Capitol

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Wednesday was Rare Disease Day at the state Capitol, giving advocates for those afflicted a high-profile forum to shine a spotlight on their concerns.

According to [the National Organization of Rare Disorders](#), rare diseases are those that affect less than 200,000 people. The group estimates there are nearly 7,000 diseases and disorders that fit that definition.

The event, held at the legislative office building, aimed to raise awareness at the state level by educating legislators and other policy-makers.

Among those attending was Kelly Brown, assistant executive director of the CdLS Foundation, a national advocacy group based in Avon that provides help to people with Cornelia de Lange Syndrome. The congenital disorder causes a range of physical, cognitive and developmental disabilities and occurs in about 1 in 10,000 live births. The disorder can result in a number of medical issues, including heart defects, gastro-esophageal reflux disease and seizures.

For more information, please visit the group's website: www.CdLSusa.org

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