

# Join Kellie's Team

March 26th Boulder Fundraiser for Rare Gene Research

Support Kellie by donating and joining us for a 5K walk!

On March 26, 2016, the Boulder community can support the Second Annual Denim Dash 5K, a worldwide fundraising event for research toward treatment and cure of diseases caused by rare genetic disorders.



## About Kellie

Kellie Taylor is a 15-year-old Boulder County resident, who has a rare disease called Sanfillipo Syndrome. Sanfillipo Syndrome is a genetic flaw resulting in a lack of one enzyme. It causes a buildup of cellular waste that kills cells and clogs major organs and joints, leading to death when those with the disorder are only in their teens.

Kellie has been practicing Iyengar Yoga to help maintain her structural alignment in hopes that she will never have to use a wheelchair. She is easy-going, hard-working, determined, smart, and strong – and beautiful! She handles her disease with ultimate grace. Learn more about Kellie at <http://relevantstories.org/stories/kelli>

There is no treatment or cure for Sanfillipo Syndrome, but thanks to generous support, a new drug is now in early trials. Her family and friends hope that Kellie will benefit from future access to treatment.



## How You Can Help

- **Walk** with Kellie and her team on **March 26th at 2:00pm starting at the Iyengar Yoga Center of Boulder** at 2299 Pearl Street. After the walk, refuel and reconnect with food and drinks provided by Cured, Glacier, and WonderPress.
- **Cheer** the team along the walk route!
- **Donate** online to support Kellie's Team at: <https://www.crowdrise.com/kellie-denimdash/fundraiser/lauraantelmi>
- **Raise Awareness** by using the hashtag #Dasher2016 on social media. Teams around the world are 'dashing' between March 19th & March 27th. Net proceeds will go directly to the rare disease community through the Global Genes RARE Patient Impact Grant (<https://globalgenes.org/raregrants/>).

## Why Care About Rare?

- In the United States, a condition is considered 'rare' if it affects fewer than 200,000 persons
- 30 million people in the United States are living with rare diseases. This equates to 1 in 10 Americans or 10% of the U.S. population
- According to the Kakkis EveryLife Foundation, 95% of rare diseases have not one single FDA approved drug treatment
- During the first 25 years of the Orphan Drug Act (passed in 1983), only 326 new drugs were approved by the FDA and brought to market for all rare disease patients combined



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