

We empower the rare disease patient community to advocate for impactful, science-driven legislation and policy that advances the equitable development of and access to lifesaving diagnoses, treatments, and cures.

My story: Actress to advocate



Lymphedema
Diary

SHARING ADVICE, COMFORT
& POSITIVE THINKING



Advocacy is...storytelling with a purpose.



“As a patient advocate, I am enthusiastic about making sure that the home health and telemedicine options that have been expanded due to the pandemic continue to remain in place.”



“Establishing a Rare Disease Center of Excellence at the FDA would go a long way to address the barriers inherent in developing treatments for small patient populations, and that would profoundly advance our efforts.”

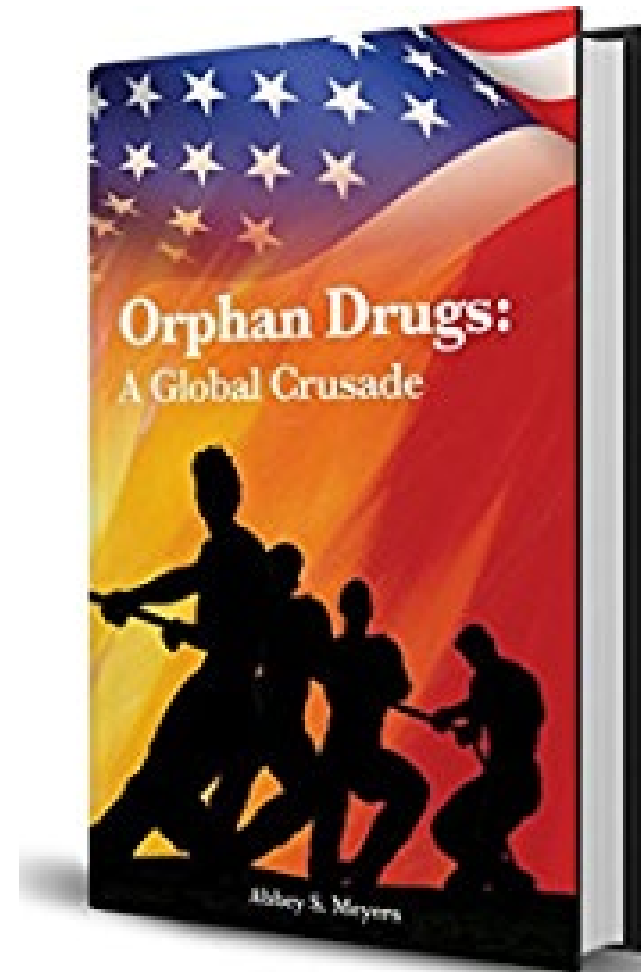


“The only hope for MPS kids like mine is to be able to detect the disease before symptoms emerge, and newborn screening is the most cost-effective way to do that.”

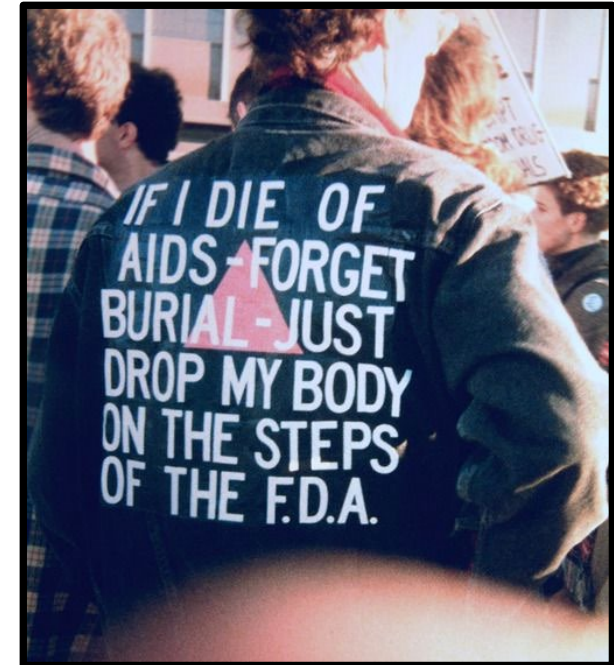
Advocacy 40 years ago: The Orphan Drug Act of 1983



Photo credit: abbeysmeyers.com



U.S. patient advocacy roots: The HIV/AIDS movement





RARE DISEASE WEEK ON CAPITOL HILL



February 28 – March 2, 2023

Stay in touch

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