

Pompe Alliance Hosts Town Hall on Budget Impacts for Rare Disease Patients

CLEVELAND, OH, UNITED STATES, September 23, 2025 /EINPresswire.com/ -- The Pompe Alliance

will host a virtual [Town Hall](#) on October 23, 2025 at 5pm EST to address how the current federal budget may affect patients living with rare diseases, including Pompe disease.

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This Town Hall is an opportunity to elevate the voices of patients and families who are too often overlooked in policy discussions, said Heather Shorten, Executive Director of the Pompe Alliance.”

Heather Shorten

The event will bring together patients, caregivers, advocates, and policy leaders for a timely discussion on healthcare access, equity, and the unique challenges faced by the [rare disease](#) community.

Featured Panelists:

- Paul Howard, PhD: Executive Director, Public Policy and Corporate Affairs at Amicus Therapeutics
- Baillie McGowan, MPH: Director of Policy Research at EveryLife Foundation for Rare Diseases
- John Brad Deane: Constituent Service Liaison Rep.
- Shontel Brown (OH-11)

- Paloma Juarez: Pompe patient caregiver

“This Town Hall is an opportunity to elevate the voices of patients and families who are too often overlooked in policy discussions,” said Heather Shorten, Executive Director of the Pompe Alliance. “We want to ensure that rare disease patients are not left behind in critical budget decisions.”

The event is free and open to the public.

□ Date/Time: October 23, 2025, at 5pm EST

□ Location: Virtual (Zoom)

□ Registration: <https://us02web.zoom.us/meeting/register/tgMcMC8aTLOV4ri0hz45LA>

About Pompe Alliance

The Pompe Alliance is a patient-led organization dedicated to supporting individuals and families affected by Pompe disease. Through education, advocacy, and community-building, the Alliance works to improve quality of life and ensure that the voices of patients are heard in healthcare

and policy decisions.

Heather Shorten

Pompe Alliance

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Pompe Alliance

Rare disease patients often face unique challenges in accessing care and resources. This Town Hall will highlight how budget decisions affect these communities and explore ways to ensure patients and families are supported.

This press release can be viewed online at: <https://www.einpresswire.com/article/851839312>

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