



International Pompe Association

International Pompe Day 2026

Keep the Momentum Going – Join the Global Pompe Day Movement



Following the strong launch of this year's International Pompe Day campaign, we invite you to continue building momentum and mobilizing your communities worldwide.



From April 1–30 individuals across the globe are coming together for the "Run, Walk or Roll" initiative under the theme "Every Move Counts." This campaign is more than a symbolic gesture—it is a powerful reminder that every action helps raise awareness for Pompe disease, a rare and often underdiagnosed genetic

disorder that can lead to progressive muscle weakness and respiratory complications.

How your organization can amplify impact:

- Encourage your members to register and log their distance
- Share participant stories and local activities
- Promote visibility using campaign hashtags: #EveryMoveCounts
#PompeAwareness

New opportunities to engage your community:

-  Pompe Day T-Shirt Campaign: Encourage supporters to wear and share the official campaign shirt—globally available via download and local print options
-  Donations: Contributions directly support awareness, advocacy, and the global Pompe community

Find more information under <https://pompeday.com/>

Awareness remains critical. Early diagnosis can significantly improve outcomes, yet many patients still face long delays before receiving the correct diagnosis.

Together, we can ensure that no patient remains unseen or unheard.

Let's continue to move together.

Contribute to Pompe
Research
**MAKE YOUR VOICE
HEARD**



Are you 16+ and living with late-onset Pompe disease? The Pompe Survey would like to hear from you!

What is the Pompe Survey?

The Pompe Survey is an annual online questionnaire that collects information on the effects of Pompe disease and its treatment on patients' lives. The survey asks questions about physical health, quality of life, social participation, and treatment.

Why is the Pompe Survey important?

The information gathered in the survey provides insight into how Pompe disease impacts patients' lives and compares how different treatments can improve this. This can help identify which treatment is most beneficial for specific patient groups, highlight the ongoing challenges patients face, inform clinicians on how to best support them, and guide future treatment development.



Interested? Scan to
learn more



cipmz.nl/en/participating-in-the-pompe-survey

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IPA**

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