

## Q1 2022 Update from IPA

### Announcement International Pompe Day Activity at April 15 2022

#### International Pompe Voices

For International Pompe Day we are asking to contribute a short podcast or video illustrating the strength and resilience through friendship. We are asking you to record a conversation with, for example, a friend, family member or someone within the Pompe community, talking about your life with Pompe, and how interacting with others, together, makes you, or your child, a stronger person. The subject of your conversation can be anything you like.

We would encourage you to record the conversation in your native language. We will then use YouTube or some other platform to transcribe it (sub-titles) into other languages. An example of a Pompe Podcast is that of Pompe Support Network at: <https://pompe.uk/pompe-voices-podcast>

Please encourage members of your national Pompe community to record their International Pompe Voices; remember, **“Together we are Strong!”**.

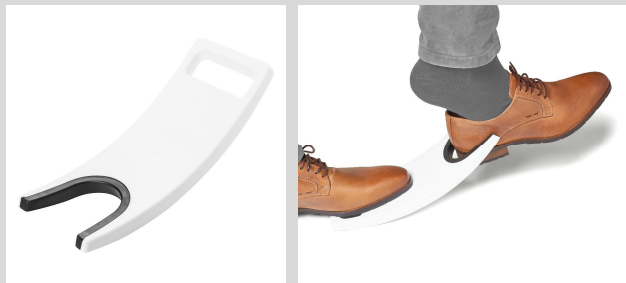


Together We Are Strong  
International Pompe Day

*NB: Technical details on how to submit the Podcast and in what format will be provided later.*

#### Support and Auxiliary Items

The IPA Board has started this item to support you and your members with practical items that might be interesting. We try to be as International focussed as possible, but we also know it might not always be feasible. Please let us know when you find the same or similar items on other websites in your region of the world. We then can adapt it on our website and inform others about it.



A **Shoe remover**, for taking off shoes without bending over. If you can't bend down, it is difficult to put on and take off shoe. You can use an extended shoehorn to put on shoes without bending over. But if you can't bend over to put on your shoes, you can't bend over to take them off. The shoe remover makes it possible to take off shoes or boots (without zip) in a simple way without having to bend over. You clamp the heel of the shoe or boot against the puller. With the other foot you stand on the puller, by moving the foot up you can take off the shoe or boot.

It can be bought at **Vitality International B.V. (vitality.com)** and look for **Shoe remover**

#### Scientific Article Abstract on Pompe Disease

Nutrition and Exercise in Pompe disease

by Mark A. Tarnopolsky and Mats I. Nilsson

Annals of Translational Medicine, 2019 Jul; 7 (13): 282

Nowadays enzyme replacement therapy is the first option to provide to people with Pompe disease. Exercise and nutrition are often considered as extra treatment options. It's important to check the nutritional intake in patients with Pompe disease with disability because of the decrease in strength and limited use of energy. Therefore the overall amount of energy (the amount of kilocalories intake) must be reduced to avoid obesity. One should avoid, though, that the intake of protein and micronutrients also is reduced. To prevent Pompe patients getting a deficiency in nutrients (protein, Vitamin D, Vitamin B12 etc.), these nutrients should be tested for and if needed replaced. Furthermore, given the role of cell regeneration in Pompe disease, it's important to look into nutritional timing and amino acid intake (L-arginine, L-leucine) as therapies.

In several other studies exercise interventions have been shown to improve six-minute walk testing distance. Exercise therapy can also activate the process of cell regeneration, just as nutrients do. Overall, exercise training appears to be a safe, effective and inexpensive intervention to improve functional metrics of importance to the health of Pompe patients.

If you no longer wish to receive this Update, please let us know by email to [info@worldpompe.org](mailto:info@worldpompe.org)