

JANUARY 2016 Update from IPA

2016 International Pompe Day

On Friday, **April 15** we will celebrate the third International Pompe Day. The purpose of International Pompe Day is to show the world that 'Together We Are Strong'. While activities vary between countries and local communities, by using a consistent theme and message we are connected.



Together We Are Strong
International Pompe Day

Please stay tuned to the International Pompe Association website for updates on International Pompe Day and to learn about the Art Contest: <http://www.worldpompe.org/index.php/international-pompe-day>

We can also be found at Facebook: <https://www.facebook.com/InternationalPompeDay/?fref=ts> Please share your thoughts and ideas about International Pompe Day at this Facebook page.



2015 IPD activity: Workshop on Pompe Research at the Erasmus MC in the Netherlands.



2015 IPD activity: Opening of the 'Pompe Garden' at the Campus of the Medical University in Warsaw, a garden with rare plants.

Conference DVD's about the 2015 AMDA/IPA Conference

For the Conference DVD section, they will be available for purchase by February 26. The cost for a full set will be \$55 (USD) + shipping. The DVD set will include all of the presentations and Question and Answer Sessions from the Conference.



Ask The Experts:

What medications should Pompe patients avoid? What medicines are counter-indicated?

There have been many questions focussed on Statins, medicine used to reduce cholesterol. After a discussion among several experts on this topic it was concluded that Statins don't have a direct contra indication in Pompe disease, but that there is a likelihood of side effects. Therefore experts recommend that if Statins are prescribed for a Pompe patient, there should be careful monitoring.

Although patients asked for a list of medicines that Pompe patients shouldn't use, experts agreed that a list can't be made as for each patient there may be situations where it is correct and medically necessary to use medications that would otherwise not be used.



CLINICAL TRIALS IN POMPE DISEASE

At this moment several clinical studies, also called clinical trials, are done in Pompe disease are being performed by several industries and academic centres. If you are interested to learn more about these clinical trials to be informed or to consider participation if you meet the participation criteria, you can find information at the following site www.clinicaltrials.gov by entering 'Pompe disease' in the 'Search for Studies' line.