

FEBRUARY 2017 Update from IPA

2017 International Pompe Day

International Pompe Day is coming up on April 15th. This will be the Fourth Annual International Pompe Day. At the IPA Annual General Meeting in November, we discussed different awareness themes that we could focus on this year. After a subsequent follow-up conversation on the IPA Member's Closed Group on Facebook, we decided to focus on

Healthy Living with Pompe Disease. The purpose of this awareness theme is to provide patients, their families, and doctors on all the ways that patients can take a proactive and positive approach to living healthy with Pompe—regardless of where they are on the disease spectrum. The IPA will collect patient stories to show all the ways we can achieve *our personal "healthy."* Please stay tuned to the IPA Member Updates, the IPA website, and the IPA Closed Facebook page for more information.



Together We Are Strong

International Pompe Day

<http://www.worldpompe.org/index.php/international-pompe-day>

<https://www.facebook.com/InternationalPompeDay/?fref=ts>

Talent of Pompe - ToP Awards 2017

To celebrate International Pompe Day on 15th April 2017, IPA has expanded the annual art contest to include any art form that shows off the talents of individuals living with Pompe and their family members. Choosing winners of the ToP Award will be a challenge in itself; but our aim is to celebrate the wide range of talents within the international Pompe community. All submissions will be displayed in a special section of the IPA website after the event.

ToP Awards Theme

There is no prescribed theme this year, your talent alone will illustrate how you transcend Pompe Disease; your work may like to reference the IPD slogan "Together we are Strong", but that is not mandatory.

Art forms

Your talent can be any visual art you like; it may include for example:

- | | | | |
|----------------|---------------|-------------------|---------------------|
| o Drawing | o Ceramics | o Performing arts | o Conceptual art |
| o Painting | o Sculpture | - Dance, | o Textile arts |
| o Printmaking | o Photography | - Music, | o Hairdressing |
| o Crafts | o Video | - Acting, | o Body art |
| - Woodwork, | o Filmmaking | - Comedy, | o Industrial design |
| - Jewellery, | o Literature | - Puppetry, | - Graphic design, |
| - Carving, | - Prose, | - Magic, | - Fashion design, |
| - Basketry | - Poetry | - Spoken word, | - Interior design, |
| o Architecture | | - Singing, | - Decorative art |
| | | - Mime | |

ToP Awards Submissions

Submissions are invited from all ages, there will be four age categories: **0-5; 6-10; 11-17 and 18+**

Submissions, images or videos of submissions, should be uploaded to the IPA website or sent via email. They should be sent electronically as either a text, graphic or video document, for example:

Text (DOC, DOCX, TXT, rich text: RTF); Web - HTML; Adobe PDF; Graphic (JPEG, PNG, GIF)

Full instructions, entry form and contest rules will be included on the IPA website shortly:

www.worldpompe.org/index.php/international-pompe-day

ToP Awards Deadline

The deadline for submissions is April 1st 2017. IPA hope to announce the **ToP Awards** in each age category on, or shortly after, International Pompe Day (15th April 2017).