



International Pompe Day 15 April 2022

International Pompe Voices

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



Together We Are Strong

International Pompe Day

- You can make the recording on a mobile phone or using an App such as Zoom; you can record your conversation with cameras switched on or off, whichever you prefer.
- We would encourage you to record the conversation in your native language. We will then use YouTube* to transcribe it (create sub-titles) and translate into other languages.
- Please try to keep the conversation to about 5 minutes or less.
- All recordings will be published on the **IPA YouTube channel** and will be available on our **website** on International Pompe Day.

**Please note: We cannot accept Audio files because they cannot be easily published on YouTube, but you may like to send a video recording that does not show the people speaking.*

Instructions sending IPD 2022 video files:

Please follow one of the five following methods to send us your video file, or a link to the file

Send small video files as email attachment - your email system may not allow files bigger than 10 or 20 MB.

OR

Upload your video to YouTube, Vimeo, or another video platform.

OR

Upload your video file to Dropbox, Google Drive, Microsoft OneDrive, or another cloud storage system.

OR

Send the file using WeTransfer, Filemail or another large file transfer system

OR

Request a link from us to our shared drive to upload your video file (Use email address below)

Email your video files or links to ipd2022submissions@worldpompe.org

When you send the file, or a link, please include a short description of the conversation, or send it in a separate email.

Using Zoom to record a conversation:

This is our suggested method to follow (a free Zoom account can host the meeting):

1. *Arrange a Zoom meeting with someone*
2. *Join the meeting together with each person:*
 - a. *Unmuted*
 - b. *Video on or off (your preference)*
3. *Press the record button on the control panel when you are ready*
4. *Stop recording when you have finished your conversation.*
 - a. *Try to keep the recording to less than 5 minutes.*
5. *End the Zoom call*
6. *Zoom should, after processing, show you the video file location*
 - a. *The Zoom App will also show your Recordings under 'Meetings' in the top menu*
 - b. *You can also find the recording on your Zoom Dashboard (in a browser window)*
7. *Please send the recorded video file (e.g., zoom_0.mp4) as instructed above*

If you require further help or clarification, please contact us at ipd2022submissions@worldpompe.org

We look forward to hearing your conversation!

If you no longer wish to receive this Update, please let us know by email to info@worldpompe.org