

International Pompe Association

International Pompe Day April 15

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The IPA is excited to announce it's plans for International Pompe Day. This year, we are focusing on *raising awareness of the importance of movement*. We all have different abilities and levels of disability, but the important thing to remember and focus on is that **"Every Move Counts."** We should celebrate what we can do, not focus on what we can't.



But we need your help! We want to show all the ways that individuals in the Community show that Every Move Counts. Do you have modified physical therapy that you can share? Do you keep moving by playing with your dog? Do you focus on music or other hobbies to keep yourself moving? The ways that we can show that Every Move Counts will be as diverse as our community! By sharing how YOU believe Every Move Counts, you can help others in our community! If you are interested in being part of this project, please reach out to us at info@worldpompe.org. Our plan is to collect these stories, videos, pictures, etc. and will then work with experts in the field to compile a set of resources that will be available on the IPA website. We will need representatives from all around the world, and across the disease spectrum so please consider joining our Project!

Every Move Counts also relates to developments in Pompe treatment and management, and our daily lives. Therefore, our SECOND project for International Pompe Day is that we are requesting submissions for a **2024 Calendar** that we will create. We would like to ask our community to submit artwork for a calendar that we will distribute to our members and to others in the community to remind us throughout next year to not give up—Every Move Counts! In research, in drug development, and in our lives. So please submit artwork to info@worldpompe.org that shows what Every Move Counts means to you!

Finally, the IPA will be developing an **awareness poster** that will be avilable on our website. Please feel free to download it and share it as much as you like to help raise awareness of Pompe. Perhaps at you physical therapy center, or gym, or school, or mosque or church. Wherever you want to share it, we encourage you to share it!



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