

## Pompe Disease Patient-Focused Drug Development Virtual Meeting



### Virtual PFDD Participation Instructions

Thank you to those who have registered for the Pompe disease Patient-Focused Drug Development virtual meeting! Below are ways for patients and caregivers to participate in the event, which begins at 12pm ET on July 13<sup>th</sup>.

**How to join the broadcast:** If you haven't already registered for the virtual PFDD meeting, [please visit our website](#) and sign-up before June 12th! As we get closer to the event, instructions on how to log into and watch the virtual event will be sent to each registrant via email. The event can be viewed both on a mobile device or computer, but we do recommend a stable internet connection, so you don't miss the video testimonials and live discussion.

**Make sure your voice is heard:** The virtual meeting will give those in the Pompe community multiple ways to their share day-to-day experiences living with Pompe and viewpoints on the benefits and risks of treatments for Pompe with both the Food and Drug Administration and biopharmaceutical companies. Once the broadcast starts, moderators will give more information on how to participate, but here are the five ways we are making sure the voice of this community is heard loud and clear.

1. Panelist presentations: A pre-selected group of Pompe community members will share their experiences on the broadcast with pre-taped video testimonials.
2. Live video participants: A handful of pre-selected patients and caregivers will give live feedback over video conferencing to the topics at hand.
3. Call into the program: All patient and family participants watching the event can call into the program and share their experiences living with Pompe and views on current and future treatments. There will be nearly 3 hours of discussion for the community to join by calling into the meeting.
4. Write-in your experiences: Before and during the event, all participants can submit written comments about how Pompe affects you or your family. We suggest attendees submit their remarks early on our [PFDD website](#). We will address as many comments as we can live on the broadcast.
5. Live Polling: Throughout the event, community participants will answer live polling questions to provide quantitative feedback on the topics.

[Please visit our PFDD website](#) for more information on the event and details on submitting your written comments! If you have any questions, please email us at [advocacy@mdausa.org](mailto:advocacy@mdausa.org).