Hello everyone,

It is two days from now, **Thursday 22 September at 8:30 a.m. Eastern USA time**, that we host our EL-PFDD event Voices of the People: The Alström Syndrome Journey.

The purpose of this hybrid meeting is to hear directly from individuals living with Alström Syndrome and their caregivers about their lived experience of Alström Syndrome symptoms and subsequent daily impacts, their experiences with available treatments and outcomes, and to hear their preferences for future therapies. We are sharing these stories and challenges directly with the FDA, academic investigators, clinicians, healthcare providers, industry partners and medical product developers.

This is an opportunity for YOU to tell your story. We encourage you to participate, to speak, to listen and to make your voice heard.

**PLEASE REGISTER NOW, EVEN IF YOU ALREADY REGISTERED AT EVENTBRITE!**

This is the link that will allow you to access our meeting virtually, from anywhere in the world, beginning at 8:30 a.m. Eastern USA Time on Thursday 22 September. Please join us and fellow Alström Family members for a chance to gather, share stories, discuss and listen.


You will need to register for this event: Click the link above and then do the following:

1. Scroll to the bottom of the page and click **REGISTER**
2. You will land on a page that asks for your **NAME, EMAIL, PHONE NUMBER**.

![Register Form](image)

3. You must also create a **PASSWORD**.

4. When you successfully complete this form, “Chime-Go” will send you a text or email with a 6-digit code to verify your identity.

5. Once you have verified your identity you will be asked to agree to a privacy notice...

![Privacy Notice](image)

...and then you will land on the welcome page for the event and see the agenda for the day. This is the site where presentations, panelists, speakers and polling will take place: you are invited to participate in all of these virtually, via your computer, tablet or mobile phone.

![Agenda](image)

We look forward to interacting with you, and hearing your perspectives and experiences about living with Alström Syndrome!