



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.

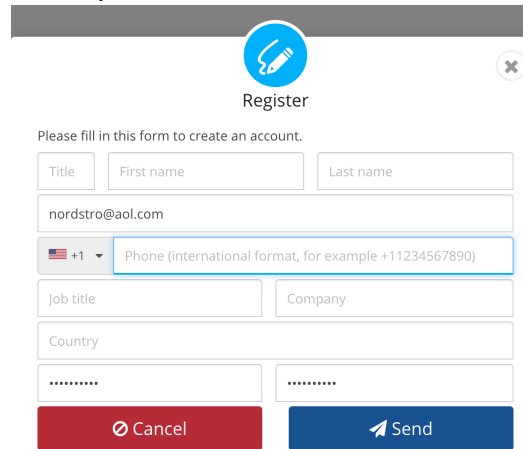
<http://alstrom.us.chime.live/>

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

A screenshot of the Alström Syndrome International registration page. At the top center is the ASI logo. Below it, the text reads: 'Welcome to VOICES OF THE PEOPLE THE ALSTRÖM SYNDROME JOURNEY!'. There are three input fields: 'Email/Username', 'Password', and a grey 'Log In' button. Below the 'Log In' button are two links: 'Forgot password?' and 'Register Need help?'. The 'Register' link is highlighted in blue.

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.

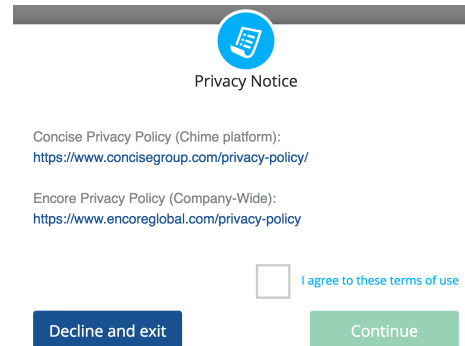


The image shows a registration form titled "Register" with a blue pencil icon. Below the title is a close button (X). The form asks to "Please fill in this form to create an account." and includes fields for Title, First name, Last name, Email (pre-filled with nordstro@aol.com), Phone (with a dropdown for country code +1 and a placeholder for international format), Job title, Company, and Country. There are two password fields with dots for characters. At the bottom are "Cancel" and "Send" buttons.

3. You must also create a PASSWORD.

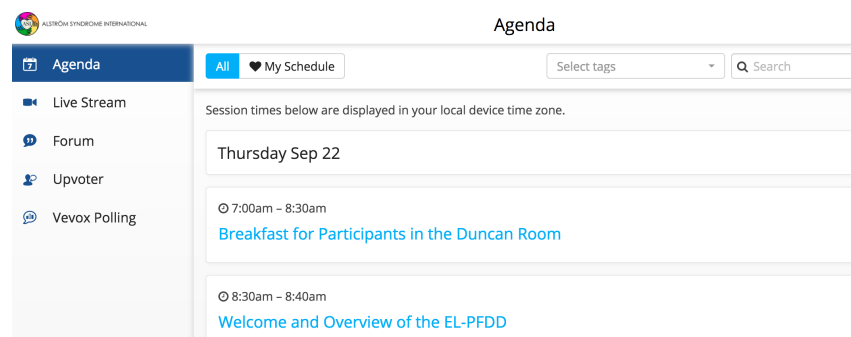
4. When you successfully complete this form, “Chime-Go” will send you a text or email with a 6-digit code to verify your identity.

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



The image shows a "Privacy Notice" screen with a blue document icon. It contains two links: "Concise Privacy Policy (Chime platform): https://www.concisegroup.com/privacy-policy/" and "Encore Privacy Policy (Company-Wide): https://www.encoreglobal.com/privacy-policy/". Below the links is a checkbox labeled "I agree to these terms of use". At the bottom are "Decline and exit" and "Continue" buttons.

...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.



The image shows an "Agenda" page for "ALSTRÖM SYNDROME INTERNATIONAL". The page has a navigation menu on the left with options: Agenda, Live Stream, Forum, Upvoter, and Vevox Polling. The main content area shows session times for Thursday Sep 22. The first session is from 7:00am to 8:30am, titled "Breakfast for Participants in the Duncan Room". The second session is from 8:30am to 8:40am, titled "Welcome and Overview of the EL-PFDD". There are filters for "All" and "My Schedule", a "Select tags" dropdown, and a search bar.

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