Thank you so much for joining the ADLD Research Hub. Together, we can develop a cure for ADLD!

This document will walk you through the steps to share information as a family member or caregiver of an individual who has been diagnosed with ADLD. We welcome family members and caregivers to create accounts with the registry, either on their own OR as part of the process of entering information on behalf of an ADLD patient. By sharing information about your experience, you can help us develop new research studies to address your and your loved ones' needs – including the needs of individuals who may someday develop ADLD.

Looking for information about how to register an ADLD patient with the ADLD Research Hub? Please review our patient registration guide for additional instructions.

OPTION 1: Create your own account as a family member or caregiver, without also entering information on behalf of an ADLD patient.

Prefer a video walkthrough? Click here to see how to join!

- 1. Sign up for an account with Luna, our registry platform, using this link.
- 2. Complete the Luna platform consent.
- 3. Join our first study in the registry, "ADLD Research Hub: Get Started" and complete the study activities. As a family member or caregiver, you should complete the following activities:
 - Your Experience with ADLD: For Caregivers and Family Members. A few simple questions about the experience and needs of family members and caregivers.
 - **Demographics Survey.** Questions about you, your work, and your home life. These details are critical to understanding how our daily lives impact our experience
 - **Electronic Health Records.** An optional activity to connect your patient portals to the registry and share valuable information about how your health changes over time. You only need to connect your patient portal once after that, Luna does the rest! *Currently only available for participants in the United States.*

Do not take the "Your Experience With ADLD: For Patients" survey.

OPTION 2: Use the account you created to enter and manage information on behalf of an ADLD patient to enter information about your own experience.

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Family members or caregivers of ADLD patients can enter information on a patient's behalf if the patient is unable to do so themselves (see our *patient registration guide* for more information). Once you've created an account to information on behalf of an ADLD patient, you can use your credentials to enter information about your own experience, too. Just make sure that when you enter information about your experience that you do so in your account - not the patient's account.

- Log in to Luna, our registry platform, <u>using this link</u>. Use the credentials you created to enter information on behalf of an ADLD patient (or "ward") these are also the credentials you will use to manage your own account. *If you haven't entered information on behalf of an ADLD patient yet but you plan to, you can see how to do this in our patient registration guide*.
- 2. Once you have logged in, complete the Luna platform consent for research for your own account (versus the patient's account) if you have not done so already.
- 3. Choose your account from the account selection screen.
- 4. Click on "ADLD Research Hub" in the "My Communities" section. Don't see ADLD Research Hub listed as an option? Please <u>contact us</u> for support.
- 4. In the ADLD Research Hub page, scroll down to the studies section and click on the "ADLD Research Hub: Get Started" study. Review the study information, then click the "Join Study" button and complete the study activities. As a family member or caregiver, you should complete the following activities:
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The information you share as part of this study will help us build a picture of the ADLD community and their needs. This study is a starting point: over time, we will collect more detailed information about the ADLD community to aid our efforts to develop a cure. We'll be in touch with updates about what we're learning from this first study and what comes next soon!