

Guide for Existing Users on Luna

How to Verify You Have a Child/Minor or a Ward Account

This is an account set-up guide for existing users.* This guide will help confirm that you have a *separate account for your child with a KCNT1 mutation*. If you do not, it will describe how to create one.

**This guide assumes that you already have your own adult or guardian account. If you do not, please see our guide for new users.*

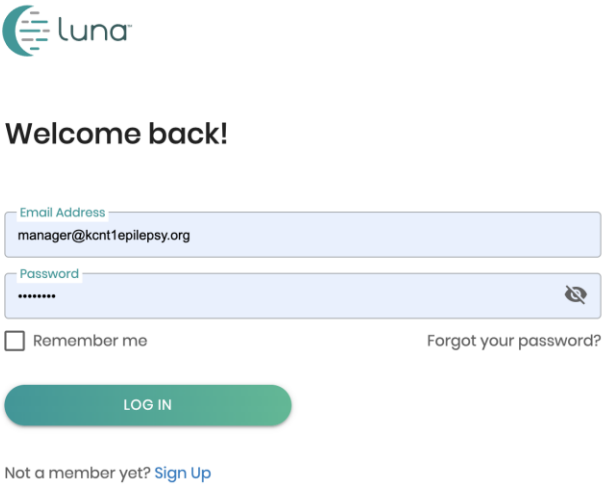
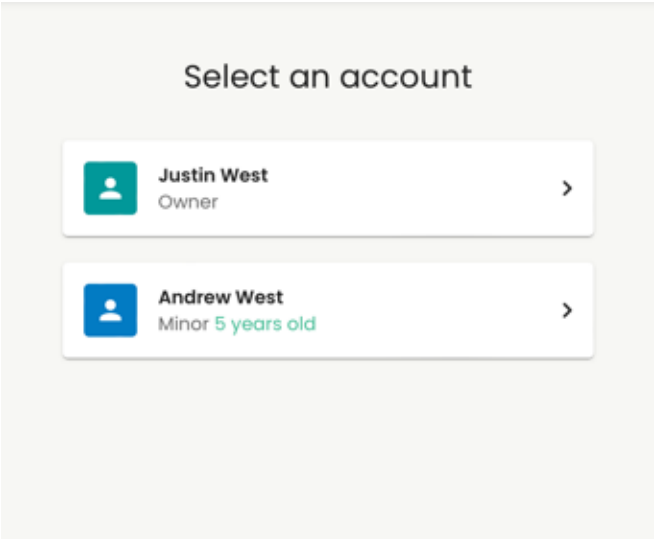
The KCNT1 Epilepsy Foundation uses the Luna platform to administer surveys to learn about how KCNT1-related epilepsy progresses over time, and how it impacts families' everyday living. New surveys will be added throughout the year.

Luna allows families to create accounts on behalf of children with KCNT1 mutations, both living and who have passed away. **Depending on when you originally set up your Luna account, you might not have had the opportunity to create an account on behalf of your child. You may only have a caregiver or guardian account. To ensure the best quality research going forward, we ask that you enter any information about your child with KCNT1 from an account *specific to that child*.**

Do you have a child account?

The following guide will review the steps to determine whether you already have an account set up for your child with KCNT1. If you do not, the guide will show you how to create an account for your child that you can manage from your existing caregiver or guardian account.

In Luna, we refer to accounts for children as **Minor** accounts and accounts for dependents (if your child is over 18) as **Ward** accounts.

<p>Click this Referrer Link: https://member.lunadna.com/study/273</p> <p>You will land on the KCNT1 Epilepsy Foundation Registry Welcome Back page.</p>	
<p>Log in to your account by entering your email and chosen password. You will then receive a 6-digit code to the cell phone or Google Voice number associated with your account. Enter that to proceed.</p> <p>If you have already created an account for a child or minor, you will see a screen like this after you log in. <i>(If you do not see this screen, go to the next step.)</i></p> <p>This screen will tell you to select the account that you would like</p>	

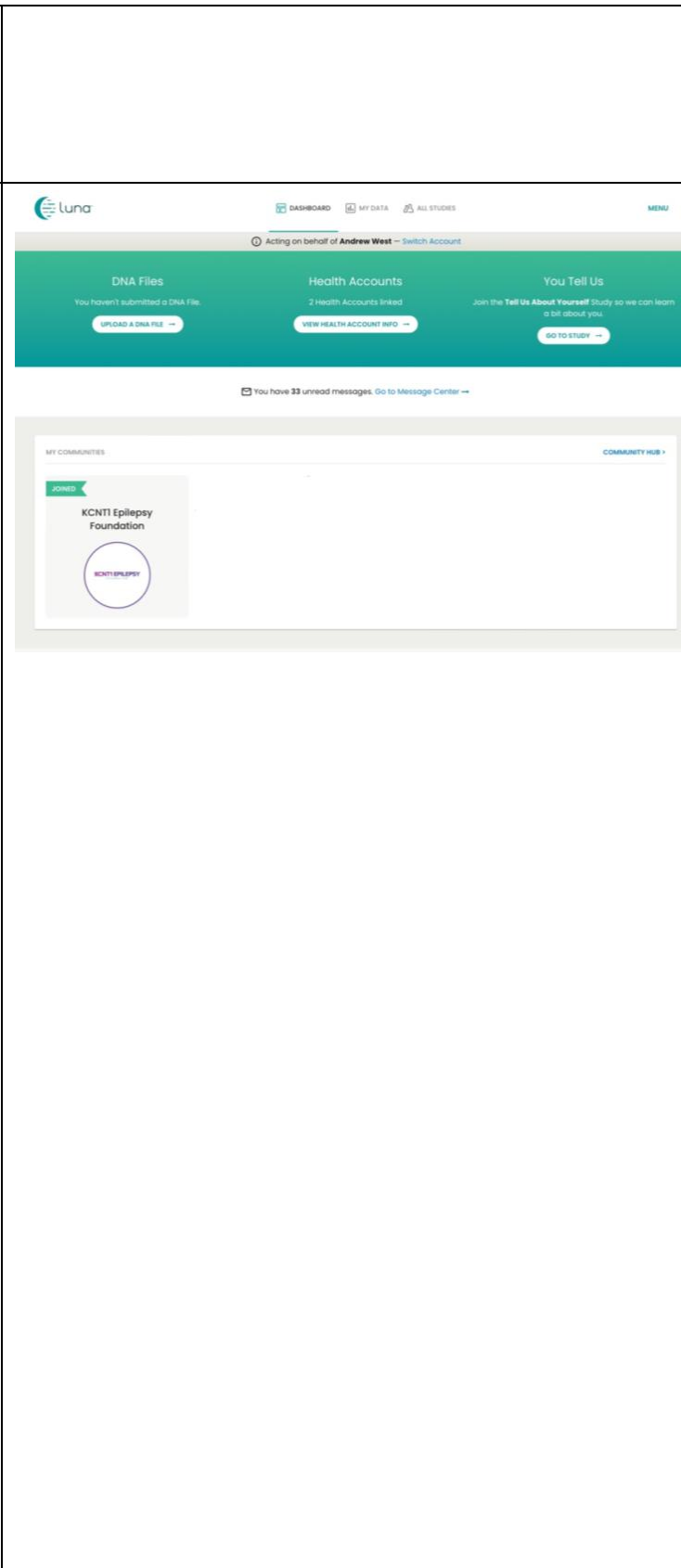
to use. Going forward, please be sure to enter information about your child **from your child's account**.

If you do not have accounts set up for multiple people, you will land on your Account Dashboard *instead* of the previous screen.

Check to see whether you see **“Acting on behalf of [Name of Minor or Ward]”** at the top of the screen.

1. If you see this, you are in logged in to an account **for your child and can use this account to enter information on their behalf in the registry.**
2. If you do NOT see a notice telling you that you are acting on behalf of someone else, you are logged in to **your own caregiver or guardian account and you will need to create an account for your child with KCNT1 mutations.**

To create an account for your child: click **“MENU”** (teal towards top right of dashboard).



In the Menu, click **“Settings”** -> **“View All.”**

On the **Settings** page, click **“Connected Accounts”** on the left-hand side.

In Connected Accounts: select **“Add Minor”** or **“Add Ward,”** depending on which you need to add.

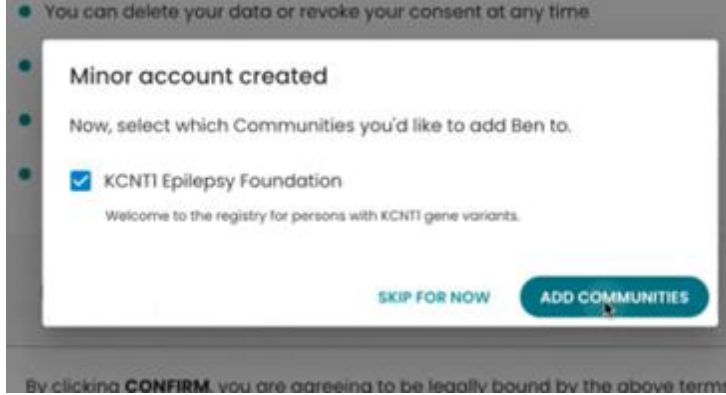
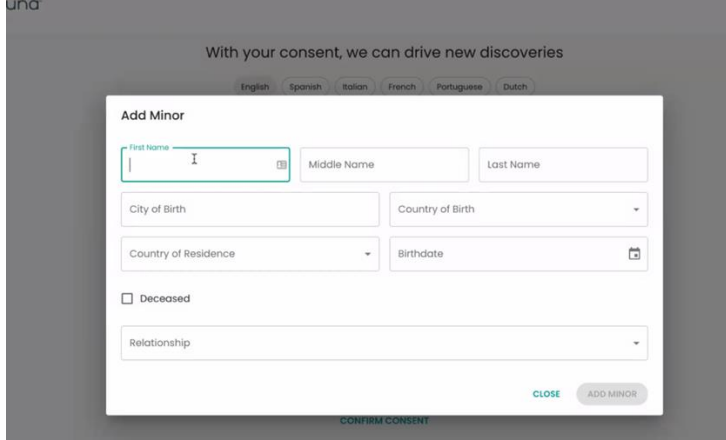
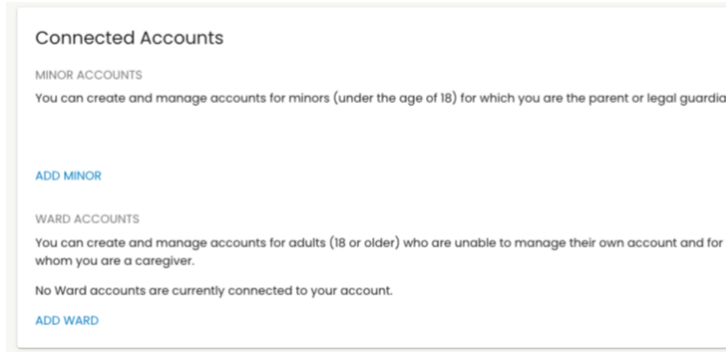
Enter information about your child for whom you are creating the Minor or Ward account.

(Note: Middle Name, City of Birth and Country of Birth are all optional.)

After you click **“Add Minor/Ward,”** you will be asked if you want to add the Minor/Ward to your Communities.

Please check the box for KCNT1 Epilepsy Foundation to ensure your parent account and your child’s Minor or Ward account are both added to the KCNT1 community.

Click **“Add Communities”** to save.

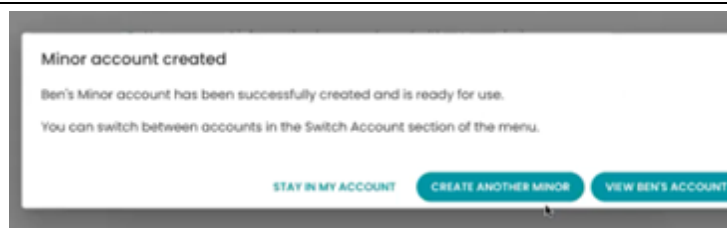


Next, you will be asked if you want to go to your child's Minor or Ward account.

Select **"View [Name of Child or Ward]'s Account"** on the far right.

Even if you have another child you wish to add, **go to the newly created account, first! This step is very important for the information to be useful in research.**

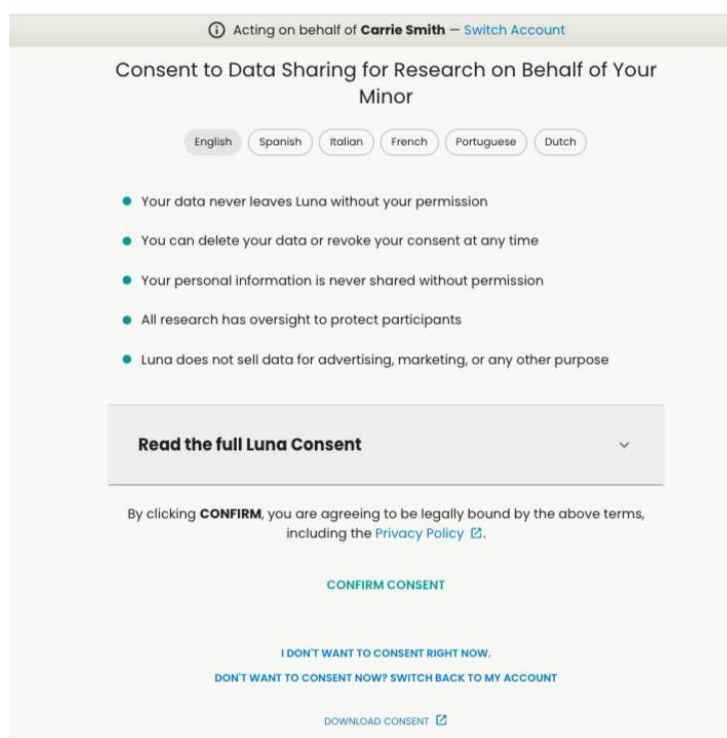
You will always be able to add additional children later in your account settings.



You will be taken to a **consent page**.

You will be **consenting ON BEHALF** of the Minor or Ward for whom you just created an account! You should see **"Acting on behalf of [Name of Child or Ward]"** at the top of the page.

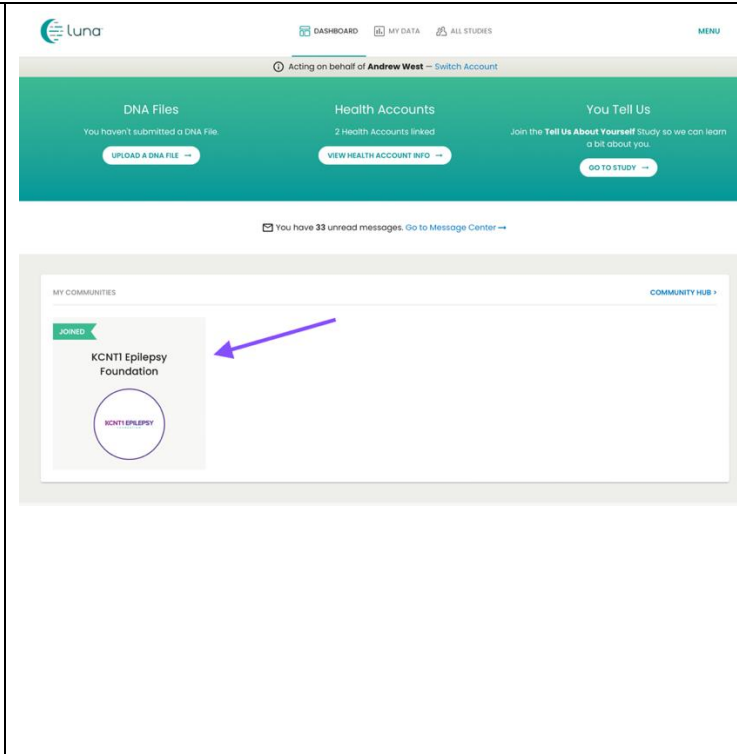
By clicking **"Confirm Consent"** you agree to share data on behalf of your child for research purposes. All data will be de-identified (name etc. removed from the data) for research and will not leave the platform without your consent.



After consenting, you should land back on your child's Minor/Ward account dashboard. Confirm this at the top of the page where it should say: **"Acting on behalf of [Name of Child or Ward]."**

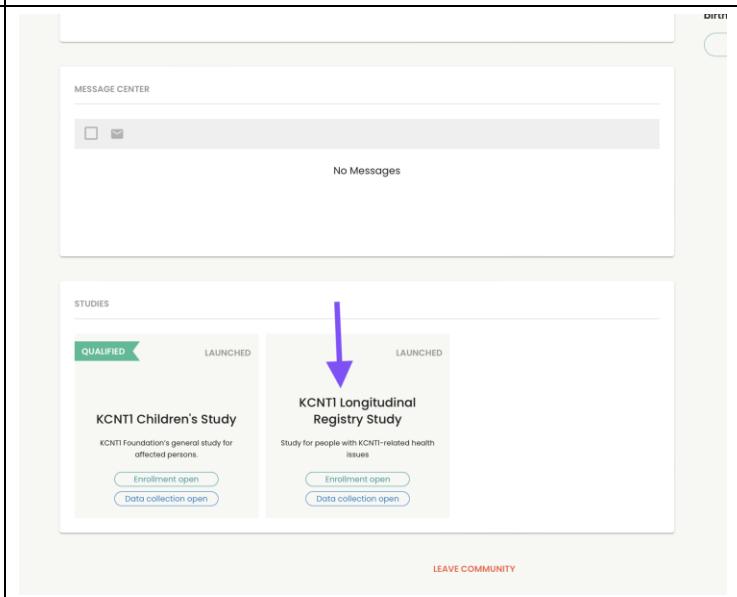
Scroll down a little to the **"My Communities"** section.

You will see a box for the **"KCNT1 Epilepsy Foundation"**. Click this box to go to the Foundation's Community Page.



On the Foundation's community page, scroll down to the **"Studies"** section.

You should see a tile/box for the **KCNT1 Longitudinal Registry Study**. Click the box to go to the study page.



Here you will **join the KCNT1 LONGITUDINAL STUDY.**

You can walk through the study flow.

Click: **Consents > Prerequisites > Data Requests (Survey[s]).**

Luna

DASHBOARD MY DATA ALL STUDIES MENU

ALL STUDIES > KCNT1 CHILDREN'S STUDY

STUDY ENROLLMENT OPEN DATA COLLECTION OPEN

157 STUDY PARTICIPANTS 128 WITH ANY SURVEYS 0 WITH ANY DNA FILES 0 WITH CONNECTED HEALTH RECORDS 3/13/23 LAST UPDATED

PARTICIPANT CODE: LN-49550R

OVERVIEW CONSENTS PREREQUISITES DATA REQUESTS

First things first – you'll need to join the study before you can proceed.

KCNT1 CHILDREN'S STUDY OVERVIEW

Status: **Launched**

KCNT1 Epilepsy Foundations' general study for children with mutations in KCNT1 to understand how this condition impacts their health and longevity.

Please note: this study is for children with genetic epilepsy with a causative mutation in the KCNT1 gene. You should be completing the information below ON BEHALF OF YOUR CHILD and from YOUR CHILD'S ACCOUNT.

JOIN STUDY

INSIGHTS

STUDY INSIGHTS UNAVAILABLE

Last step: Adjust your settings so the Foundation can confirm that you are in the study!

Select Menu > Settings > Privacy to toggle on the switch.

Toggle on the option for **"Contact/Profile Information Access."**

You can enable or disable special access to your contact information and your individual data for each group that you belong to.

KCNT1 Epilepsy Foundation

Contact Information Access

Allow KCNT1 Epilepsy Foundation to download my **contact information** (name and email address)