## **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 <u>existing users</u>.\* 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.

Click this Referrer Link: https://member.lunadna.com/stud	Eluna
<u>y/273</u>	Welcome back!
You will land on the <b>KCNT1</b> Epilepsy Foundation Registry	Email Address manager@kont1epilepsy.org
Welcome Back page.	Password
	Remember me Forgot your password?
	LOG IN
	Not a member yet? Sign Up
entering your email and chosen	Select an account
password. You will then receive	
a 6-digit code to the cell phone or Google Voice number	Justin West >
associated with your account.	
Enter that to proceed.	Andrew West
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</i>	
this screen, go to the next step.)	
This screen will tell you to select	
the account that you would like	

to use. Going forward, please be sure to enter information about your child <b>from your child's</b> account.			
If you do not have accounts set up for multiple people, you will land on your Account Dashboard <i>instead</i> of the previous screen.	DNA Files Too haven't submitted a DNA File Unicida a data that —	Asting on behalf of Andrew West - Switch Account     Health Accounts     Wire Matth Accounts Initial     Wire Matth Accounts Initial     Wire Matth Accounts Initial	Vicu Tell Us Pro Tell Us a bit about four-sell Study so we con learn a bit about you contro study -
Check to see whether you see <b>"Acting on behalf of [Name of</b> <b>Minor or Ward]"</b> at the top of the screen.	KONTERNIE KONTERNIE Foundation		COMMUNITY HUB >
<ol> <li>If you see this, you are in logged in to an account <u>for your child</u> and can use this account to enter information on their behalf in the registry.</li> <li>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 <u>caregiver or guardian</u> <u>account</u> and you will need to <u>create an</u> <u>account for your child</u> with KCNT1 mutations.</li> <li>To create an account for your child: click "MENU" (teal towards top right of dashboard).</li> </ol>			

In the Menu, click " <b>Settings</b> " -> " <b>View All</b> ."	
On the <b>Settings</b> page, click " <b>Connected Accounts</b> " on the left-hand side.	Connected Accounts MINOR ACCOUNTS You can create and manage accounts for minors (under the age of 18) for which you are the parent or legal guardia
In Connected Accounts: select " <b>Add Minor</b> " or " <b>Add Ward</b> ," depending on which you need to add.	ADD MINOR WARD ACCOUNTS You can create and manage accounts for adults (18 or older) who are unable to manage their own account and for whom you are a caregiver. No Ward accounts are currently connected to your account. ADD WARD
Enter information about your child for whom you are creating the Minor or Ward account. ( <i>Note: Middle Name, City of Birth</i> <i>and Country of Birth are all</i> <i>optional.</i> )	With your consent, we can drive new discoveries
After you click " <b>Add</b> <b>Minor/Ward</b> ," you will be asked if you want to add the Minor/Ward to your Communities. Please <u>check the box for</u> <u>KCNT1 Epilepsy Foundation</u> to ensure your parent account and your child's Minor or Ward account are <u>both</u> added to the KCNT1 community.	<ul> <li>You can delete your data or revoke your consent at any time</li> <li>Minor account created</li> <li>Now, select which Communities you'd like to add Ben to.</li> <li>KCNTI Epilepsy Foundation Welcome to the registry for persons with KCNTI gene variants.</li> </ul> SKIP FOR NOW ADD COMMUNITIES By clicking CONFIRM, you are gargeing to be legally bound by the above terms
Click " <b>Add Communities</b> " 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.	Minor account created Ben's Minor account has been successfully created and is ready for use. You can switch between accounts in the Switch Account section of the menu. STAY IN MY ACCOUNT CREATE ANOTHER MINOR VIEW BENS ACCOUNT
Even if you have another child you wish to add, <b>go to the</b> <b>newly created account, first!</b> 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 c <b>onsent</b>	Acting on behalf of Carrie Smith - Switch Account
page.	Consent to Data Sharing for Research on Behalf of Your Minor
You will be <u>consenting ON</u>	English Spanish Italian French Portuguese Dutch
<u>BEHALF</u> of the Minor or Ward	Your data never leaves Luna without your permission
for whom you just created an	• You can delete your data or revoke your consent at any time
account! You should see	Your personal information is never shared without permission
"Acting on behalf of [Name of	All research has oversight to protect participants
Child or Ward]" at the top of	<ul> <li>Luna does not sell data for advertising, marketing, or any other purpose</li> </ul>
the page.	Read the full Luna Consent 🗸 🗸
By clicking "Confirm Consent"	By clicking <b>CONFIRM</b> , you are agreeina to be legally bound by the above terms.
you agree to share data on	including the Privacy Policy 2.
behalf of your child for research	CONFIRM CONSENT
purposes. All data will be de-	I DON'T WANT TO CONSENT DUALT NOW
identified (name etc. removed	DON'T WANT TO CONSENT NOW? SWITCH BACK TO MY ACCOUNT
from the data) for research and	DOWNLOAD CONSENT
will not leave the platform	
without your consent.	

	CE DARMONARD EL MYDATA (A ALL STUDIES MENU
After consenting, you should	Acting on behalf of Andrew West – Switch Account  DNA Files Health Accounts You Tell Us
land back on your child's	You hoven't submitted a DNA File 2 Health Accounts linked Join the <b>Tell Us About Yourself</b> Study so we can learn URIONS & DNA FILE - URIVIEALTH ACCOUNT RIFO - a Dit about you
dashboard	
Confirm this at the top of the	You have 33 unread messages. Go to Message Center
page where it should say:	MY COMMUNITIES COMMUNITY HUB >
"Acting on behalf of [Name of	
Child or Ward]."	Foundation
Scroll down a little to the <b>"My</b>	KONTIEKUESY
<b>Communities</b> " 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	MESSAGE CENTER
page, scroll down to the	
Studies Section.	NO Messages
You should see a tile/box for the	
KCNT1 Longitudinal Registry	STUDIES
<b>Study</b> . Click the box to go to the	QUALIFIC LAUNCHED LAUNCHED
study page.	KCNTI (children's Shudy Booletty Shudy
	KCHTI fundational study         KCHT fundational special study in people study for people stu
	Enrollment open     Enrollment open       Data collection open     Data collection open
	LEAVE COMMUNITY



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

## Select <u>Menu > Settings > Privacy</u> to toggle on the switch.

