

Account Set-up Guide for New Users:

Creating an account on Luna for your child with a KCNT1 mutation

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. Only one caregiver or guardian per family should create an account with Luna on behalf of a loved one with KCNT1 mutations (meaning you should have only one account per child with KCNT1). When creating an account you will have the option to share your contact information with the KCNT1 Epilepsy Foundation. Please note that if you choose not to share this information, we will not be able to see your email address and verify that you have set up an account.

The following guide will review the steps to create an account for your child with KCNT1, that you can manage from your own caregiver or guardian account. In Luna, we refer to accounts for children as accounts for minors or for dependents or wards (if your child is over 18).

This guide assumes that you do NOT have your own caregiver or guardian account yet. If you do, please see our [guide](#) for existing users.

Click this Referrer Link:
<https://id.lunadna.com/referrer/kcnt1-longitudinal?studyName=kcnt1longtermregstudy>

You will land on the KCNT1 Epilepsy Foundation registry account creation page.

Enter **YOUR** email address, password, country of residence, and **YOUR** date of birth.

Next, click "Create an Account to Manage a Minor or Ward."

luna + KCNT1 EPILEPSY FOUNDATION

Welcome to Luna

Welcome to the KCNT1 Epilepsy Foundation! Welcome to the KCNT1 Epilepsy Foundation! To get started, please create an account to allow you to manage your child's account by selecting "Minor" or "Ward" (if 18yo +). Or, log into your existing account and then select your child's account (in dark blue).

After registration, you will be taken to the KCNT1 Children's Study study in Luna
KCNT1 Foundation's general study for affected children.

Email Address* Confirm Email*

Create Password* Confirm Password*

Between 8 and 100 characters Lowercase letter Uppercase letter Number Special character

Country of Residence* Month* Day* Year*

Date of Birth

CREATE AN ACCOUNT FOR MYSELF CREATE AN ACCOUNT TO MANAGE A MINOR OR WARD

Already a member? Link an existing account: [Log in](#)

A small window will open asking you to choose if you are creating an account for a minor or ward.

Select the appropriate option to continue.

Note: If you are creating an account for a loved one who has passed away, select minor or ward based on the age they were at the date of death.

Choose Account Type

CREATE MINOR ACCOUNT CREATE WARD ACCOUNT

- Under the age of 18
- You are the parent or legal guardian
- Living or Deceased

- 18 years or older
- You have the authority to act on their behalf
- Living or Deceased

If you are creating an account for a loved one who has passed away, please select minor or ward based on the age they were at the date of death.

You will receive an email which is sent to the email address you entered asking you to confirm your email address.

In your email, click the purple button to confirm.

This will take you to a webpage where you will set up two-factor

luna Your home for health discovery.

Check your inbox

We just sent a verification link to the email address:
deb+test500@lunadna.com
Don't see our email? Check your Spam folder or [resend it](#).

You're almost there!

WELCOME TO LUNA

We're glad to have you as part of the community, we just need you to verify your email address by clicking the link below.

Confirm Email

authentication to protect your and your minor or ward's accounts.

When you land on the "Set Up Your Two-Step Authentication" page, enter your cell phone or Google Voice number where you can receive texts.

Then click "Send Code".

You will receive a 6-digit text code to that number. Enter it in the "Code" field on the next page and click "Submit".

You will receive 10 recovery codes. Save these in a safe place. For example, take a screenshot of this page and rename the file as Luna Recovery Codes.

You can use each code ONE TIME to login in case you are in an area without cell phone reception, you don't have your phone with you and need to login, or you change your cell phone number and forget to update it in your account first.

The first screenshot is titled "Set Up Your Two-Step Authentication". It features the Luna logo at the top left. Below the title, it says "Please enter your phone number below to add an additional layer of security." There is a text input field with a red asterisk icon and a "SEND CODE" button. A "Notice" section at the bottom explains that two-step authentication is required for account security and that the phone number is used for verification.

The second screenshot is titled "Verify Phone Number". It also has the Luna logo. It includes a "Change phone number" link, a message stating "A verification code was sent to +1551234567", a "Code" input field, and "SUBMIT" and "RESIGN" buttons. A link for "Still no code? Contact support" is at the bottom.

The screenshot is titled "Recovery Codes" and features the Luna logo. It instructs the user to "Put these codes in a safe place." and notes that losing the device without these codes would result in losing access to the account. A list of ten alphanumeric recovery codes is provided: 4a8d32f8, e96be961, babbe763, 384a868f, 26e2ca16, ad7399f5, 7c2f2f8a, 1f2b5c15, a7fa5f4a, and 583a5765. A "CONTINUE" button is located at the bottom.

After you click “Continue”, you will be asked to enter information about your minor or ward for whom you are creating an account.

Enter the information to proceed. (Note: Middle Name, City of Birth and Country of Birth are optional.)

The screenshot shows the 'Add Minor' form on the UNDA website. At the top, it says 'With your consent, we can drive new discoveries' and lists languages: English, Spanish, Italian, French, Portuguese, Dutch. The form fields include: First Name (with a cursor), Middle Name, Last Name, City of Birth, Country of Birth (dropdown), Country of Residence (dropdown), Birthdate (calendar icon), a checkbox for 'Deceased', and a Relationship dropdown. At the bottom right are 'CLOSE' and 'ADD MINOR' buttons. A 'CONFIRM CONSENT' link is at the bottom center.

After you click “Add Minor” (or Ward), you will be asked if you want to add your minor or ward to your communities.

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

Click “Add Communities”

The screenshot shows a confirmation screen titled 'Minor account created'. It lists steps: 1. You can delete your data or revoke your consent at any time. 2. Now, select which Communities you'd like to add Ben to. 3. KCNT1 Epilepsy Foundation (checked). Below the list is the text 'Welcome to the registry for persons with KCNT1 gene variants.' At the bottom are 'SKIP FOR NOW' and 'ADD COMMUNITIES' buttons. A footer note says 'By clicking CONFIRM, you are agreeing to be legally bound by the above terms'.

Next, you will be asked which account you want to go to first or if you want to create another minor (or ward account).

Choose to go into the minor or ward’s account you just created (“View [Name of Your Child or Ward]’s Account”), even if you have another child you wish to add. You will be able to add additional children later from your account settings.

The screenshot shows a screen titled 'Minor account created' with the text: '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.' At the bottom are three buttons: 'STAY IN MY ACCOUNT', 'CREATE ANOTHER MINOR', and 'VIEW BEN'S ACCOUNT'.

You will be taken to a consent page, where you are consenting ON BEHALF of the minor or ward for whom you just created an account.

You will 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 minor or ward for research purposes. It will be de-identified (name etc. removed from the data) for research and will not leave the platform without your consent.

After consenting you will land on the study the KCNT1 Epilepsy Foundation is inviting your child or ward to participate in.

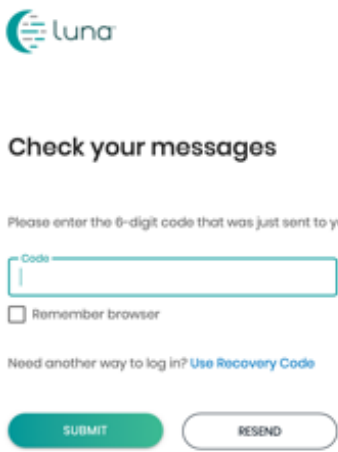
See other instructions for how to walk through the study itself, if needed.

The screenshot shows a consent page titled "Consent to Data Sharing for Research on Behalf of Your Minor". At the top, it says "Acting on behalf of Carrie Smith - Switch Account". Below the title, there are language selection buttons for English, Spanish, Italian, French, Portuguese, and Dutch. A list of bullet points outlines the terms: "Your data never leaves Luna without your permission", "You can delete your data or revoke your consent at any time", "Your personal information is never shared without permission", "All research has oversight to protect participants", and "Luna does not sell data for advertising, marketing, or any other purpose". A button labeled "Read the full Luna Consent" is present. Below this, a confirmation message states: "By clicking CONFIRM, you are agreeing to be legally bound by the above terms, including the Privacy Policy." A large "CONFIRM CONSENT" button is centered, with "I DON'T WANT TO CONSENT RIGHT NOW." and "DON'T WANT TO CONSENT NOW? SWITCH BACK TO MY ACCOUNT" as alternative options. A "DOWNLOAD CONSENT" link is at the bottom.

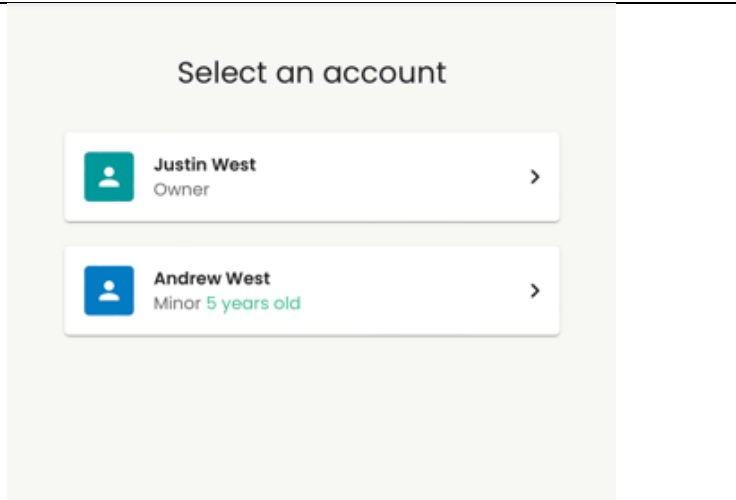
The screenshot shows the study overview page for "KCNT1 CHILDREN'S STUDY". The top navigation bar includes the Luna logo, "DASHBOARD", "MY DATA", "ALL STUDIES", and "MENU". The study title is "ALL STUDIES > KCNT1 CHILDREN'S STUDY", with status indicators for "STUDY ENROLLMENT OPEN" and "DATA COLLECTION OPEN". A summary bar shows "157 STUDY PARTICIPANTS" and "128 WITH ANY SURVEYS", "0 WITH ANY DNA FILES", and "0 WITH CONNECTED HEALTH RECORDS", with a "LAST UPDATED 3/13/23" timestamp. A progress bar shows four steps: OVERVIEW (active), CONSENTS, PREREQUISITES, and DATA REQUESTS. A message reads: "First things first - you'll need to join the study before you can proceed." Below this, the "KCNT1 CHILDREN'S STUDY OVERVIEW" section shows the status as "Launched" and a description: "KCNT1 Epilepsy Foundations' general study for children with mutations in KCNT1 to understand how this condition impacts their health and longevity." A note specifies: "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." A "JOIN STUDY" button is visible. The "INSIGHTS" section shows "STUDY INSIGHTS UNAVAILABLE" with a bar chart icon. A chat icon is in the bottom right corner.

Join the KCNT1 Longitudinal Registry Study

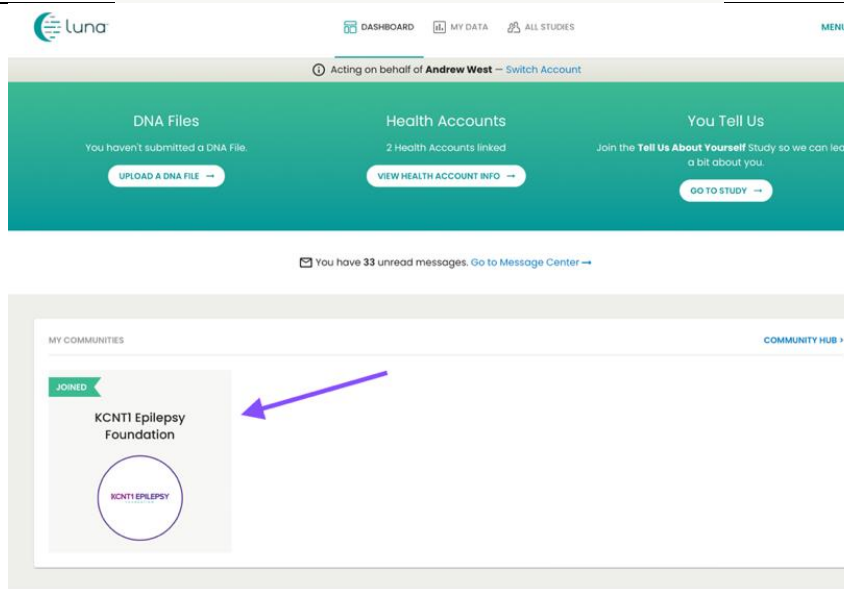
Now that you have registered and created an account for your child or ward, you can enroll in the KCNT1 Longitudinal Registry Study. If you are not already at the study page, follow these steps. If you are at the study, you can jump ahead to [the next section!](#)

If you have not already, go to LunaDNA.com and log in.	https://id.lunadna.com/referrer/kcnt1-minor?studyName=kcnt1-minor
Login to your account by entering the email and password for your account. 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>The screenshot shows the LunaDNA login interface. At the top is the LunaDNA logo. Below it is the heading 'Check your messages'. A prompt asks the user to 'Please enter the 6-digit code that was just sent to your phone.' There is a text input field labeled 'Code' with a cursor. Below the field is a checkbox for 'Remember browser'. At the bottom, there is a link for 'Need another way to log in? Use Recovery Code'. Two buttons are at the bottom: a green 'SUBMIT' button and a white 'RESEND' button.</p>

Select your minor account (in blue). If you do not have a minor account, see our account set-up guide for existing users. *It is very important to take surveys about your child's experience from within their account.*



You should land on your child's or ward's dashboard. Confirm this at the top of the page where it should say: "Acting on behalf of [Name of Child or Ward]."

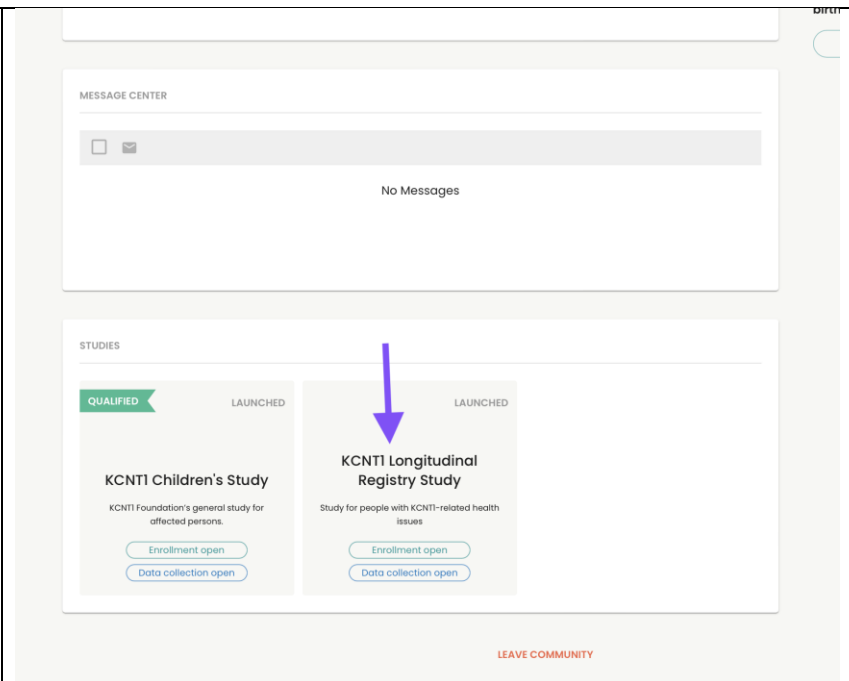


Scroll down a little to the "My Communities" section.

You will see a box for the "KCNT1 Epilepsy Foundation". Click the 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 or box for the **KCNT1 Longitudinal Registry Study**. Click the box to go to the study page.



Follow these instructions to join the study and take surveys.

If you have not already, make sure you are in your minor account. Then, from within the study, click the "Join Study" button. Then click through to the "Prerequisites" screen using the link at the top.

If you have already joined the study you can skip this step.

The prerequisite is a little different. We can replace this screenshot when it is live.

On the prerequisites screen, answer the question confirming whether your child or ward has a diagnosis with a KCNT1 variant. Next, navigate to the "Data Requests" screen to begin the surveys.

If you have already joined the study you can skip this step.

Luna

DASHBOARD MY DATA ALL STUDIES

ALL STUDIES > KCNT1 CHILDREN'S STUDY

STUDY ENROLLMENT OPEN DATA COLLECTION

157 STUDY PARTICIPANTS

128 WITH ANY SURVEYS 0 WITH ANY DNA FILES 0 WITH CONNECTED HEALTH RECORDS 3/13/2 LAST UPDATES

PARTICIPANT CODE: LN-495

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

Luna

DASHBOARD MY DATA ALL STUDIES

ALL STUDIES > KCNT1 CHILDREN'S STUDY

STUDY ENROLLMENT OPEN DATA COLLECTION

164 STUDY PARTICIPANTS

128 WITH ANY SURVEYS 0 WITH ANY DNA FILES 0 WITH CONNECTED HEALTH RECORDS 3/18 LAST UPDATES

PARTICIPANT CODE: LN-495

OVERVIEW CONSENTS PREREQUISITES DATA REQUESTS

0/1 complete

You need to complete all of the study's prerequisites listed here before you can move on.

PREREQUISITES

Diagnosis of Genetic Epilepsy Yes/no question

You need to pass this prerequisite to become qualified.

VIEW

CONSENTS DATA REQUESTS

This page shows what **surveys** or “Data Requests” are available to complete.

Click **Begin** on the KCNT1 Demographics and Genetics survey. (Available in German, Portuguese, Italian, Spanish, French and English. You can choose your language before beginning the survey.)

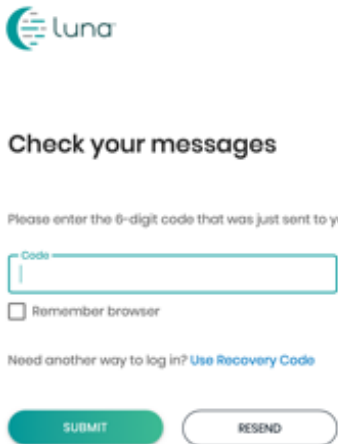
Once you have completed the KCNT1 Demographics and Genetics survey, please complete any other remaining surveys/data requests. Not all surveys are available in all languages. We will let you know as we add new surveys to the study!

The screenshot displays the Luna dashboard for the KCNT1 Children's Study. At the top, it shows the user is acting on behalf of Andrew West. The dashboard provides a summary of study participants: 150 total, with 112 having completed any surveys, 0 with any DNA files, and 0 with connected health records. A progress bar shows the user's completion status: Overview (1/1 complete), Consents (No consents), Prerequisites (1/1 complete), and Data Requests (1/2 complete). A message prompts the user to complete 2 data requests. Two survey requests are listed: 'Genetic Epilepsy in Minors' (Survey complete) and 'KCNT1 Top Tasks and Seizure Classification' (New Survey). The 'Begin' button for the new survey is highlighted with a purple circle.

How to Adjust Your Settings to Share Your Email Address with the KCNT1 Epilepsy Foundation

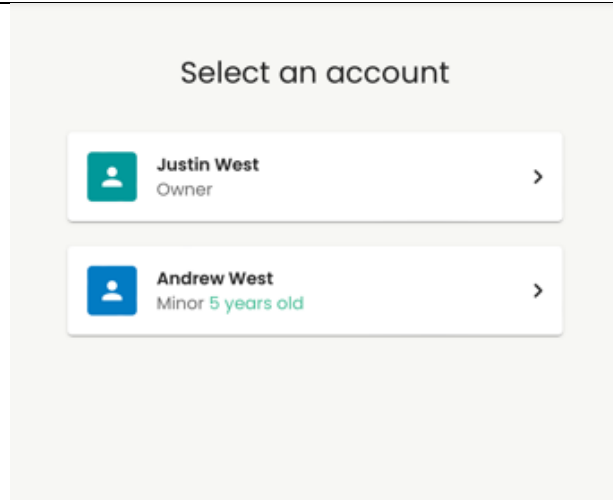
Sharing your contact/profile information allows us to see your email address so we know you are in this particular study. It helps us to connect the dots across multiple research studies, so that we know which studies you are participating in, and can provide you with easy-to-access, personalized information about new and existing research opportunities. Follow these instructions to share your contact information.

First, navigate to your minor account's Dashboard. If you have already reached your minor's Dashboard you can jump ahead to [the next section](#).

<p>If you have not already, go to LunaDNA.com and log in.</p>	<p>https://id.lunadna.com/referrer/kcnt1-minor?studyName=kcnt1-minor</p>
<p>Login to your account by entering the email and password for your account. 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>The screenshot shows the LunaDNA login interface. At the top is the LunaDNA logo. Below it is the heading 'Check your messages'. A message reads: 'Please enter the 6-digit code that was just sent to your phone.' There is a text input field labeled 'Code' with a cursor. Below the field is a checkbox labeled 'Remember browser'. At the bottom, there is a link: 'Need another way to log in? Use Recovery Code'. Two buttons are at the bottom: a green 'SUBMIT' button and a white 'RESEND' button.</p>

Select your minor account (in blue). You will be taken to your minor’s dashboard.

If you do not have a minor account, see our account set-up guide for existing users. *It is very important to take surveys about your child’s experience from within their account.*

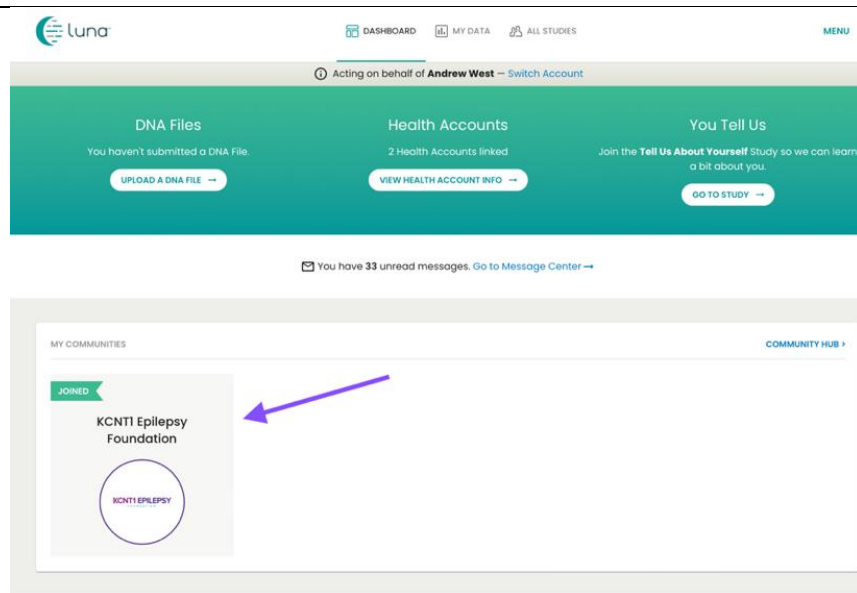


Once you have reached your minor’s Dashboard, follow these instructions to share contact information.

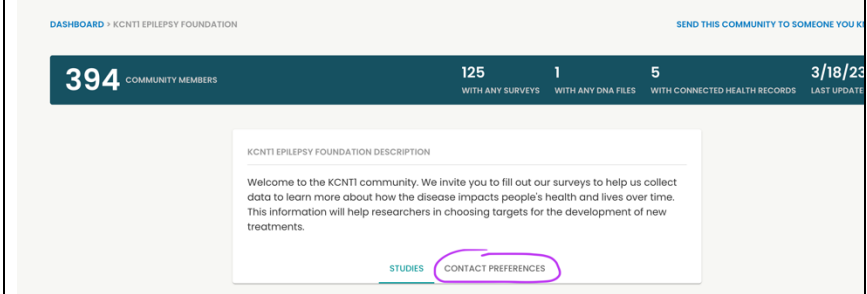
Confirm that you are at your minor or ward’s Dashboard. You can do this by looking at the top of the page where it should say: “Acting on behalf of [Name of Child or Ward].”

Scroll down a little to the **“My Communities”** section.

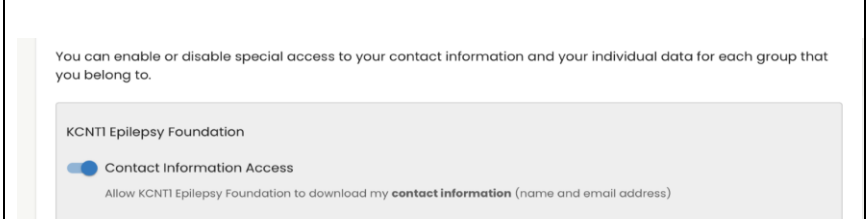
You will see a box for the “KCNT1 Epilepsy Foundation”. Click the box to go to the Foundation’s Community Page.



From the KCNT1 Epilepsy Community page, click into the **“Contact Preferences”** tab next to “Studies.”



Toggle on the option for “Contact/Profile Information Access.”



Alternately you can go to Menu > Settings > Privacy