



**DATA  
COLLECTION  
PROGRAM**

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**User Guide**



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# Getting Started in the Data Collection Program (DCP)

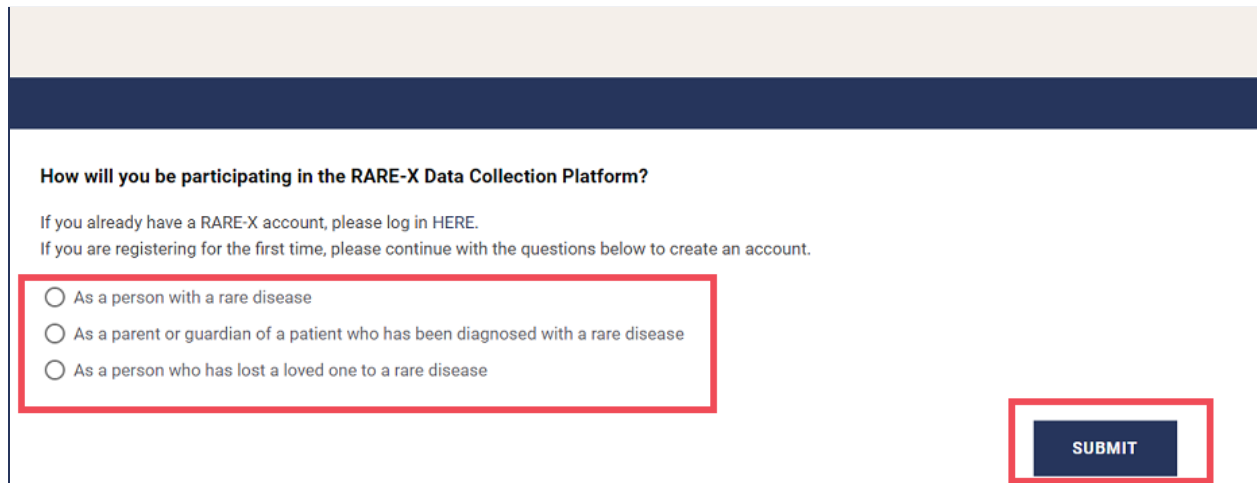
## Approved Browsers for Accessing the DCP

Chrome, Firefox, and Safari are the approved browsers for accessing the DCP.

Internet Explorer and Microsoft Edge are not approved browsers. Please do not use these when accessing the DCP.

## New to the DCP

Step 1 – Survey questions are role-based, so select the answer that best describes your relationship with the patient & click Submit.



The screenshot shows a registration form titled "How will you be participating in the RARE-X Data Collection Platform?". It includes instructions for existing and new users. Three radio button options are listed: "As a person with a rare disease", "As a parent or guardian of a patient who has been diagnosed with a rare disease", and "As a person who has lost a loved one to a rare disease". A red box highlights these options. A "SUBMIT" button is also highlighted with a red box.

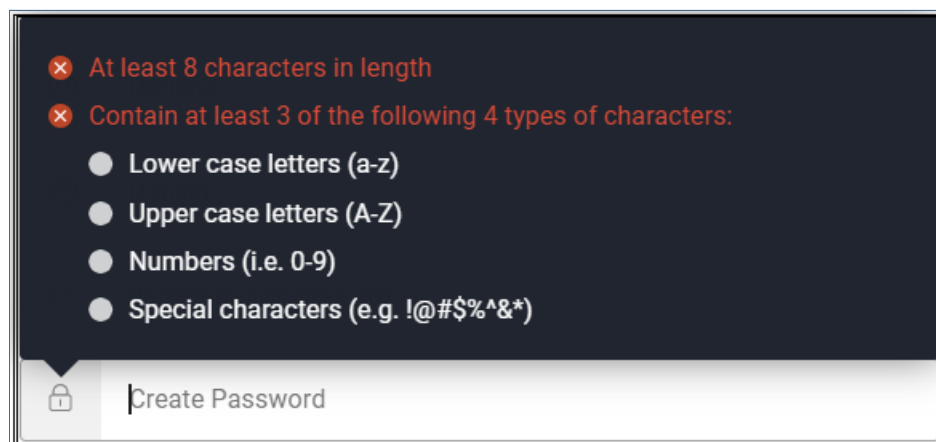
**How will you be participating in the RARE-X Data Collection Platform?**

If you already have a RARE-X account, please log in [HERE](#).  
If you are registering for the first time, please continue with the questions below to create an account.

☐ As a person with a rare disease  
☐ As a parent or guardian of a patient who has been diagnosed with a rare disease  
☐ As a person who has lost a loved one to a rare disease

**SUBMIT**


Step 2 – Complete your account information, including a password & click Submit.



The screenshot shows a dark overlay with password requirements. Two red 'x' icons indicate requirements: "At least 8 characters in length" and "Contain at least 3 of the following 4 types of characters:". The four types are listed with radio buttons: "Lower case letters (a-z)", "Upper case letters (A-Z)", "Numbers (i.e. 0-9)", and "Special characters (e.g. !@#%&\*)". Below this is a password creation field with a lock icon and the text "Create Password".

✗ At least 8 characters in length  
✗ Contain at least 3 of the following 4 types of characters:

- ☐ Lower case letters (a-z)
- ☐ Upper case letters (A-Z)
- ☐ Numbers (i.e. 0-9)
- ☐ Special characters (e.g. !@#%&\*)

 Create Password

**NOTE: You will receive email confirmation of your successful registration**

## Already Have a DCP Account

Step 1 - Click Log in or click the [HERE](#) link.

Powered by **RAREX**

Log In

**How will you be participating in the RARE-X Data Collection Platform?**

If you already have a RARE-X account, please log in [HERE](#).

If you are registering for the first time, please continue with the questions below to create an account.

☐ As a person with a rare disease

☐ As a parent or guardian of a patient who has been diagnosed with a rare disease

☐ As a person who has lost a loved one to a rare disease

**SUBMIT**

Step 2 – Enter your Email address and Password. Click LOG IN. You will be taken to the Participant Dashboard.

**RAREX**

**Please Sign In**

**G** LOG IN WITH GOOGLE

or

Email address

Password

[Don't remember your password?](#)

If you haven't registered yet, please [do so here](#).

For help, please contact [support@rare-x.org](mailto:support@rare-x.org).

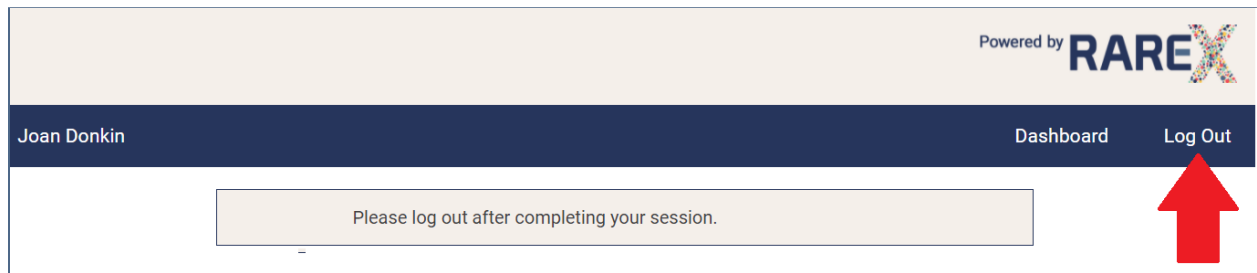
**LOG IN >**

# Participant Dashboard

## What is the Participant Dashboard?

The Participant Dashboard lists all family members that have been added to the DCP. This is where you will access each family member's data to complete, edit or respond to new surveys.

**Security! Security! Security! Security! Security!**

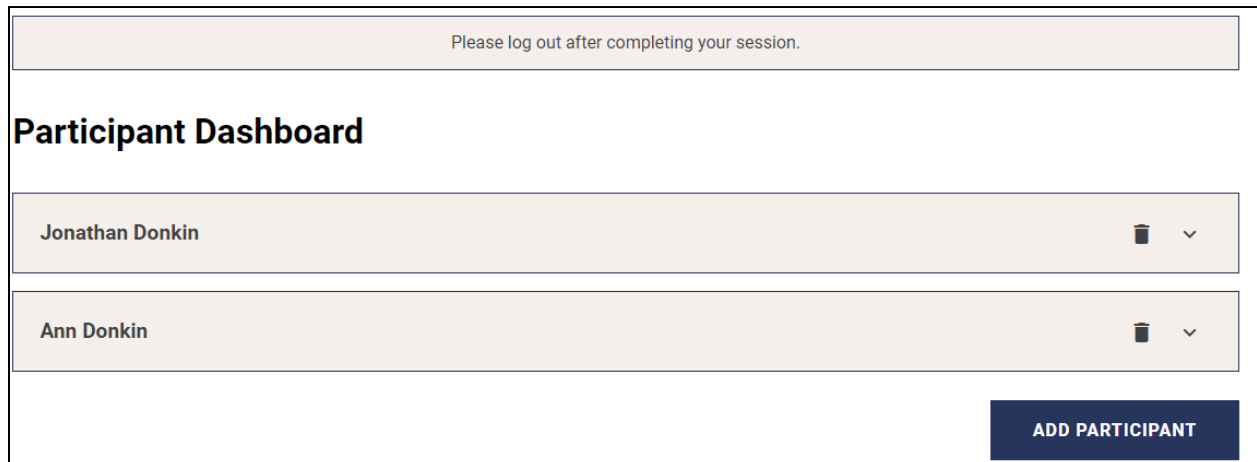


## Security and Confidentiality.

Suppose you are using a public computer, such as a computer at your local library or at a conference using a shared laptop. In that case, it is crucial to use Log Out when you have finished entering data. If you do not use the Log Out feature, your data will be visible to the next individual that uses the device.

## Dashboard Views & Navigation

### Dashboard Views





**COLLAPSED VIEW OF THE PARTICIPANT DASHBOARD**

## EXPANDED PARTICIPANT DASHBOARD

Please log out after completing your session.

### Participant Dashboard

Ann Donkin





Form	Summary	Created	Status	Actions
Research Consent Form - Parent or Guardian	Thank you for signing the research consent form.	05/17	Complete	<a href="#">VIEW</a>
Data Sharing Survey	Thank you for completing the Data Sharing Agreement.	05/17	Complete	<a href="#">VIEW</a> <a href="#">EDIT</a>
General Information Survey	Thank you for answering the General Information Survey.	05/17	19 / 20 questions	<a href="#">VIEW</a> <a href="#">EDIT</a>
Health and Development Survey	Please fill out the Health and Development Survey.	05/17	0 / 25 questions	<a href="#">START</a>
General Quality of Life Survey	Please fill out the Quality of Life Survey.	05/17	0 / 25 questions	<a href="#">START</a>

[ADD PARTICIPANT](#)

### Dashboard Navigation

The following actions will occur when clicking the associated button.

	To delete all data for the selected participant.
	To expand or collapse the participant's survey list.
<a href="#">VIEW</a>	To view the participant's survey in read-only format.
<a href="#">CLOSE</a>	Will close the survey and return the user to the Participant Dashboard.
<a href="#">BACK</a>	To go back to the previous page.
<a href="#">EDIT</a>	To open the survey for editing. Click NEXT to navigate to the page with the information to be edited. Then Click

	NEXT to navigate to the end of the survey and Click SUBMIT.
START	To open a survey.
CONTINUE	To open an incomplete survey.
ADD PARTICIPANT	To add an additional family member to the DCP.

### Adding a Participant

To add an additional family member to the DCP, follow the steps below.

Step 1 – Click the ADD PARTICIPANT button on the right side of the screen.

Step 2 - Complete the *Relationship with the Patient Page*. Additional questions may be presented based on the relationship selected.

Step 3 – Click Submit

**Note: All questions on this page are mandatory.**

## Consent

Informed consent is the process through which a researcher obtains and maintains the permission of a person or person's authorized representative to participate in a research study.

The navigation menu below shows you the progress you've made in completing the Consent form and is an easy way to navigate between pages where data has been entered.



### HORIZONTAL NAVIGATION BAR

- The blue circles indicate information on the page is complete.
- The green circle indicates the page you currently have open.
- The gray circles indicate information on the page has not been started.
- Click a blue circle to be taken to that page of the Consent. You can only navigate to pages where data has been entered using the navigation bar.

Each page of the Consent is essential. Please read them carefully. For additional information in each section, click [LEARN MORE](#).

**LEARN MORE** ↗

With your permission, the patient's de-identified data in the DCP can be shared with researchers (including researchers at drug companies) and approved patient organizations worldwide.

**BACK****I UNDERSTAND**

If you have questions about the RARE-X Data Collection Program or the Consent form, please contact us at [support@rare-x.org](mailto:support@rare-x.org). You may also call us at (716) 427-2739.



## Completing the Consent Form

Step 1 - For each page of the Consent review the information carefully.

Step 2 – If you have questions, please call, or email them to RARE-X using the contact information above. If you do not have questions, Click I UNDERSTAND. You will be taken to the next page of the Consent.

Use the BACK button to return to previous pages of the Consent.

Step 3 - Click Submit to finalize the Consent.

***Note: You will receive email confirmation of consent completion.***

## Consent Form Pages

Page 1 – Summary of the Data Collection Program (DCP)

Page 2 – Introduction & Purpose

Page 3 – Funding & Patient Responsibilities

Page 4 – Data Use & Confidentiality

This page explains who will have access to and how the data will be used.

Page 5 – Data Sharing

This page allows you to choose how your or your child's data is shared.

Page 6 – Benefits of Participating in the DCP

Explains the benefits and risks of participating in the DCP.

Page 7 – Can a Patient Quit the DCP

Explains how to withdraw from the DCP.

Page 8 – The Consent

Read the statements carefully—answer Yes or No to whether RARE-X may contact you with follow-up surveys or invitations to additional studies.

Answer Yes or No: A qualified patient organization may contact you if a researcher thinks you or your child may qualify for a clinical trial.

# Data Sharing Interest Survey

## De-Identified Data Research Choices

You must choose the type of research you would like the patient's data to be used for **before** the data can be shared. There are two types.

General Research – This is the broadest type of research. A more detailed description is included in the DCP.

Health/Medical/Biomedical Research – This type of research is narrower than General Research. A more detailed description is included in the DCP.

## Optional Limits on Research

*If you would like your data to be used for the broadest research, do not check these boxes, scroll to the bottom of the page, and click NEXT.*

The additional options are listed below with full descriptions in the DCP.

- Research solely for non-commercial purposes
- Only research that has been approved by an Institutional Review Board (IRB)

## Other Questions

The next group of questions focuses on biospecimens, medical records, and other studies/data collections you may have participated in. When the option is available to connect this information to your RARE-X data, you will be contacted.

The last question asks if you would like your contact information shared with patient advocacy groups that support your diagnosis(s).

## General Information

Step 1 - Verify/complete information about yourself. Questions will vary depending if you are the patient or your relationship with the patient.

Step 2 - Verify/complete information about the patient. This section includes a question asking if the patient is still alive. Answering No to this question will add a Legacy Survey to the Dashboard. This survey collects data specific to your loved one if you would like to share additional information.

Step 3 - Click SUBMIT. This may take a few minutes. When the submission is complete, you will be returned to the Participant Dashboard to start the next survey.

**Note: All questions on the General Survey are mandatory.**

# Completing Surveys

## Survey Tips

### Mandatory Questions

Mandatory questions are indicated with an asterisk. These questions must be completed before moving to the next page. If you click NEXT or SUBMIT prior to answering a mandatory question, you will be taken to the top of the page. Scroll down to find the question with the red error message. Complete the question to continue the survey.

**Were there any concerns about the patient's development? \***

☐ Yes

☐ No

Please choose yes or no

### Read-Only View

Opening a survey via the VIEW button from the dashboard opens the survey in read-only mode. This will not allow you to edit questions. To edit a survey, you must open the survey by clicking the EDIT button.

## Health and Development Survey

These are general questions reviewing various body systems. As RARE-X adds more detailed surveys to the DCP, you will be notified of the opportunity to participate in additional surveys based upon your answers to the general questions.

### Adding Diagnosis/Diagnoses

To help RARE-X identify and prioritize future groups of focused questions, please provide ALL known patient conditions/diagnoses/genetic diagnoses on this page.

Step 1 – Enter a condition/diagnosis on the line provided.

Joan Donkin

Research Consent Form - Parent or Guardian  
COMPLETE

Data Sharing Survey  
COMPLETE

General Information Survey  
COMPLETE

Health and Development Survey  
NEW

General Quality of Life Survey  
NEW

### Diagnosis/Diagnoses

General health and development questions were asked in this survey. To help RARE-X identify and prioritize future focused groups of questions, please provide ALL known patient conditions/diagnoses/genetic diagnoses below (one per line). If the patient is undiagnosed, please list "undiagnosed".

Autism

+ ADD ANOTHER DIAGNOSIS

BACK SUBMIT

Step 2 – To add another condition or diagnosis, click **+ ADD ANOTHER DIAGNOSIS**. Another line will be added to the page. Continue adding a line for each entry. To remove an entry, click the X.

### Diagnosis/Diagnoses

General health and development questions were asked in this survey. To help RARE-X identify and prioritize future focused groups of questions, please provide ALL known patient conditions/diagnoses/genetic diagnoses below (one per line). If the patient is undiagnosed, please list "undiagnosed".

Autism

Another diagnosis X

Epilepsy

+ ADD ANOTHER DIAGNOSIS

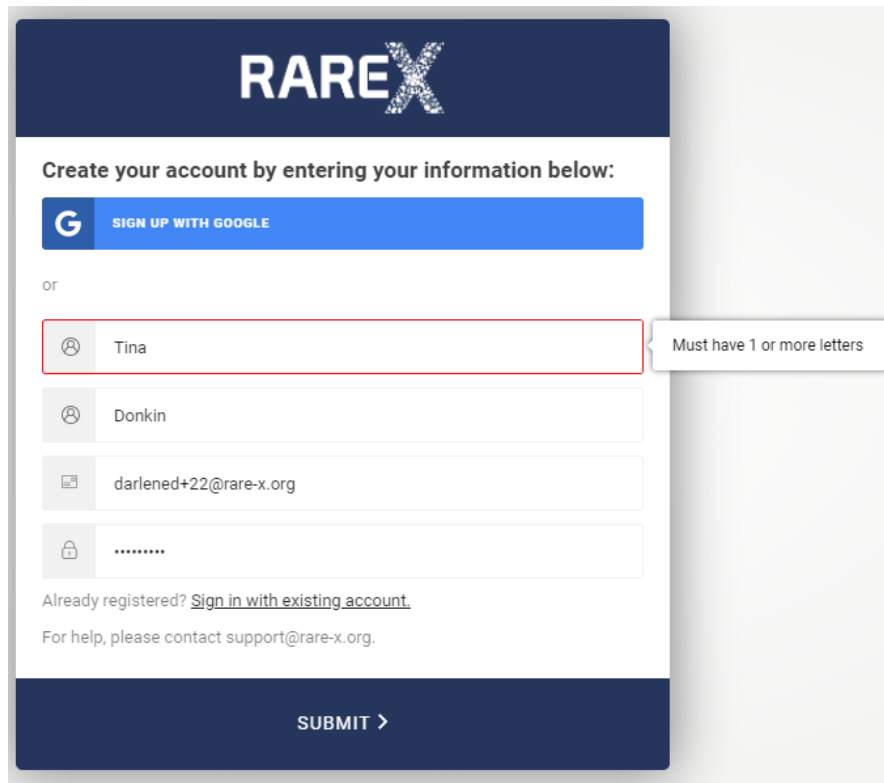
Step 3 – When all conditions and diagnoses have been added, click SUBMIT. You will be taken back to the Dashboard to open another survey or Log Out.

# Troubleshooting

## I am Getting an Error When Registering

I am getting a message stating I must have 1 or more letters in the name field when creating my account. I have entered my name in the field.

Make sure you have not accidentally added a space after your name. Delete the extra space and re-submit.

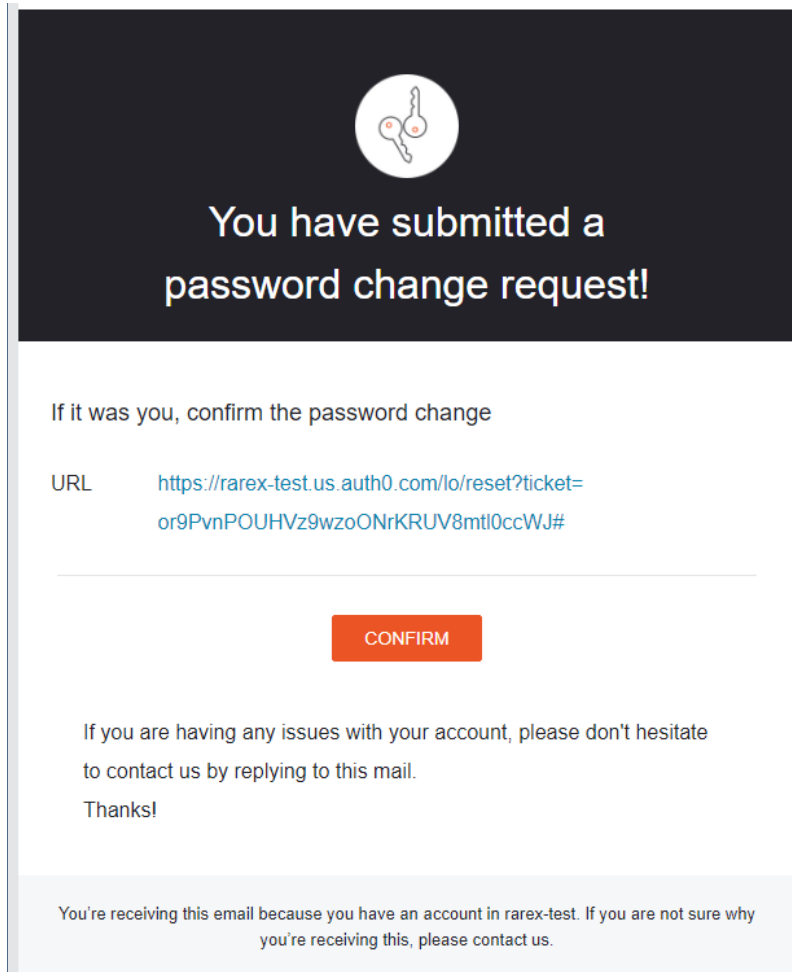


The screenshot shows the RAREX account creation interface. At the top is the RAREX logo. Below it, a heading says "Create your account by entering your information below:". There are two main options: "SIGN UP WITH GOOGLE" (a blue button with a Google 'G' icon) and a "or" separator. Below the separator are four input fields: a name field containing "Tina", a last name field containing "Donkin", an email field containing "darlened+22@rare-x.org", and a password field with masked characters. A red border highlights the name field, and a tooltip message "Must have 1 or more letters" points to it. Below the fields, there is a link "Already registered? [Sign in with existing account.](#)" and a note "For help, please contact support@rare-x.org.". At the bottom is a dark blue "SUBMIT >" button.

## I Forgot my Password

Step 1 - Click the [Don't remember your password?](#) link under the Password field on the Sign In page.

Step 2 – Enter the email address associated with your DCP account. You will be sent the following email.

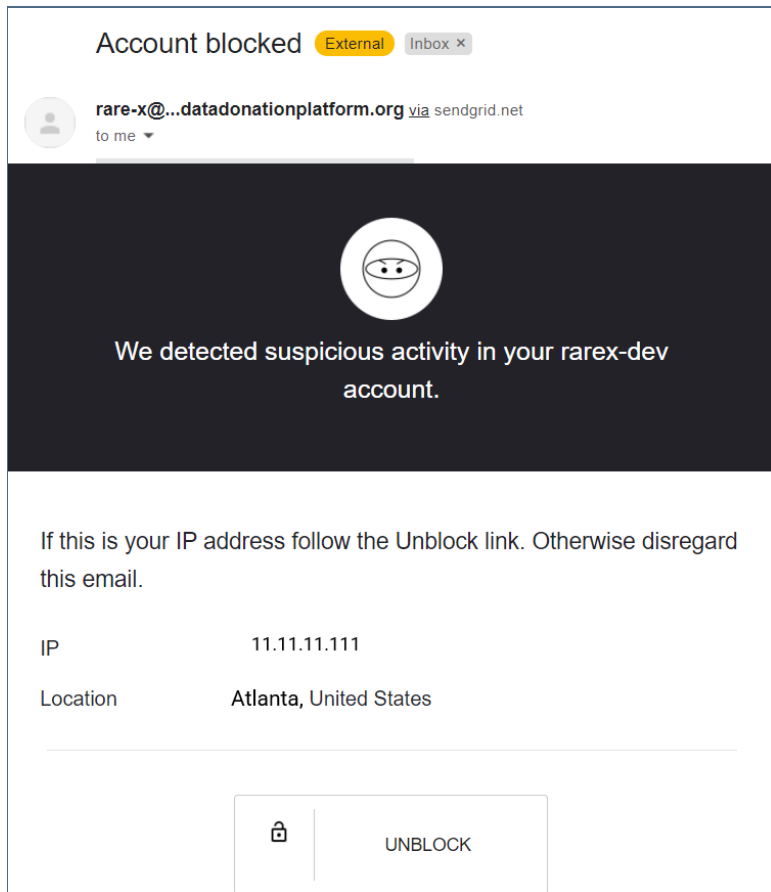


Step 3 – Click CONFIRM

Step 4 – Enter your new password. You will receive confirmation your password has been reset.


### **I've Locked Myself Out the DCP**


You will be emailed the message below if you have too many failed log-in attempts. To unlock your account, click UNBLOCK. You will receive an email in about an hour with instructions for resetting your password.



## My Screen is Frozen

There are several steps you can take to resolve this issue.

- Refresh the browser by clicking the  icon next to the address bar.
- Try logging out of the DCP and logging back in.
- If neither of these works, clear the cache on your computer by following these steps.

Step 1 - Open your browser's options menu by clicking the three dots at the end of the address bar. 

Step 2 - Select Settings from the menu

Step 3 - Scroll down to the Privacy and security section

Step 4 - Click Clear browsing data > Basic.

Step 5 - Click the Clear data button

### How Do I Return to an Incomplete Survey?

Step 1 – Log in to the DCP. You will be taken to your Participant Dashboard.

Step 2 – Open the survey list by clicking the arrow icon on the far right of the participant's name.

Step 3 – Click the CONTINUE button next to the survey needing completion. This will open the survey for data entry,