

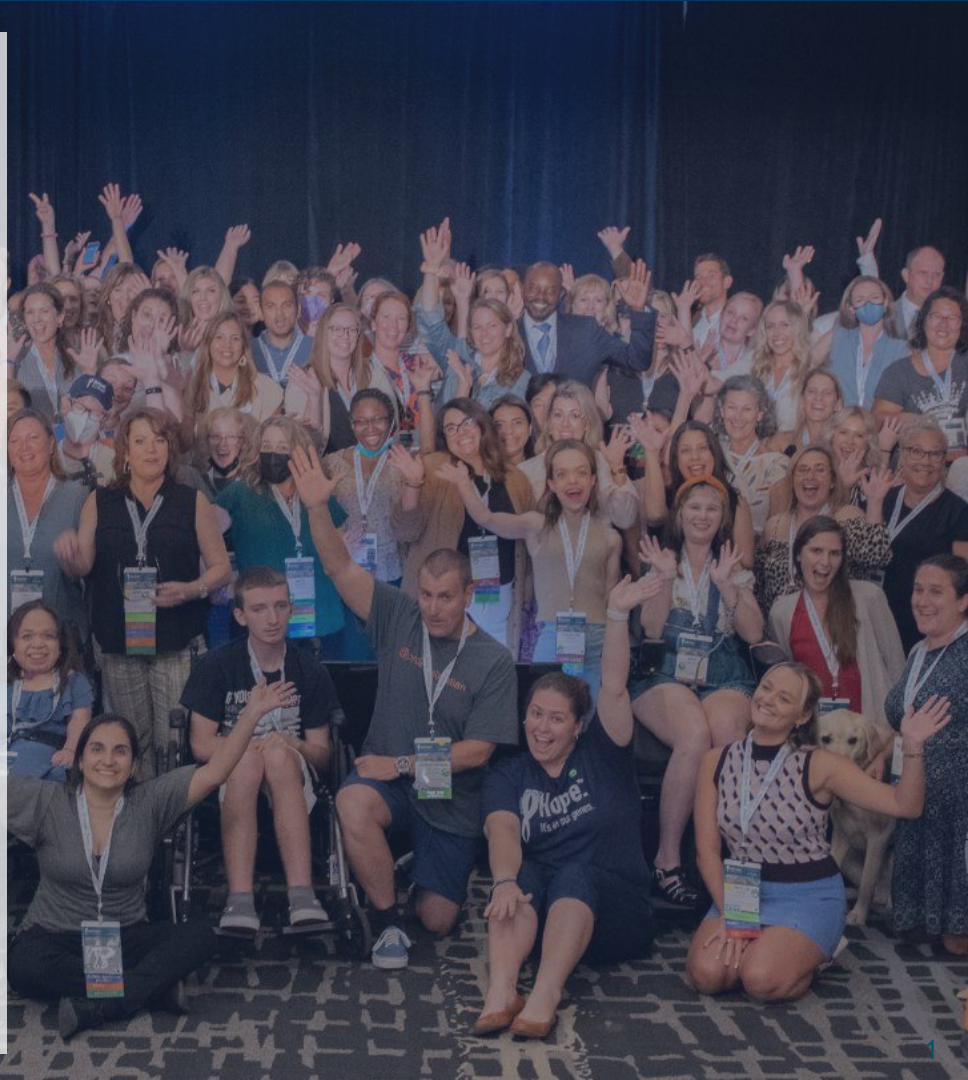


**Global Genes®**  
Allies in Rare Disease



# DeSanto-Shinawi Syndrome (DESSH) Data Collection Program

November 18, 2023



# What Is RARE-X?

- RARE-X is a program of Global Genes created to accelerate rare disease research and treatments by removing barriers for data collection and sharing
- RARE-X is a platform to collect, connect, and share data

RARE-X is **not** a replacement for any current research or clinician-sponsored patient registries.



# What Are We Solving For?

The speed and productivity of innovation in rare disease is limited by cost and lack of access to standardized, structured patient data



Data exists, but is captive within silos



Data is not in a structured, standardized format that is useful to research/patient communities



Data doesn't yet exist; most groups don't have the resources to collect data properly

## Why did DESSH Leaders Choose RARE-X?

- GLOBAL data collection
- Patient owned and managed - not organization managed
- No cost to patients or organizations
- No cost to researchers (scientists/pharma)
- Structured, standardized Q&A
- Governance is handled
- Streamlines researcher access to data - de-identified data is made available in Federated Data Access Platform
- Speeds up research and drug development
- Ability to connect to existing data sources



# What is the benefit for patients/caregivers/families?

- **Collecting data on ALL systems of the body will allow a better understanding of the disease**
- **Summary data returned to the community so you can compare your symptoms to others with the same disease**
- **The chance to participate in clinical trials**
- **Ability to update a change in symptoms at any time**
- **Reach more researchers worldwide**
- **Ability to manage who uses your data**



# Patient Journey in the Data Collection Portal (DCP)

## Patient Dashboard

Potential Survey Topics (Domains)

Patient Community



Community Page  
Get Started

Welcome  
Privacy Policy  
Terms of Use

Enroll in  
DCP

Verification email is sent to you - letting you add a password and complete your registration

Matrix  
Terms of Use

Patient  
Consent &  
Data  
Sharing  
Preference  
Survey



General Info



Gen Medical



Neuro Gen



Quality of Life



Eye



Kidney



Heart



Lung



Skin



Endocrine



Med Usage



Ear

# How To Access Data Collection Program

DESSH

[HOME](#)

[GETTING STARTED](#)

[FAQ](#)

Powered by **RAREX**

## DESSH - Data Collection Program



DeSanto-Shinawi Syndrome (DESSH) patients, families, and communities are excited to participate in data collection to expand and improve medical research. By coming to this site, you can begin the first step in making your patient information available to researchers. By generating the most comprehensive DeSanto-Shinawi Syndrome (DESSH) Data Collection Program, we can accelerate research and the development of new drugs, devices, or other therapies. Only you hold the key to unlock future discoveries.

Start Your Journey

GET STARTED

Already Enrolled?

LOGIN



### Why Should You Participate?

<https://dessh.rare-x.org/>

# What Do You Need To Get Started?


- **Email address and Create a password**
- **An approved Browser**
  - **Google Chrome, or**
  - **Apple Safari version 14 or higher**
  - **Microsoft Edge**
- **Do not use an unapproved Browser**
  - **Internet Explorer**
  - **Mozilla**
- **What you do NOT need to get started?**
  - **A Lot of Time**
  - **To Finish It All At Once**



# First-time Login Page (Pre-Qualifications Page)

Caregivers should also check the “Patient Participant” box if:

- they are diagnosed with the disease
- they are a “carrier” of the disease



## Request Access

Join us and get connected today!

**Your Information:**

*This information will be used to create access credentials for the patient who will be accessing the platform themselves, or the caregiver/guardian who will be providing information on behalf of a patient.*

Your First Name \*

Your Last Name \*

Enter Letters Only

Email \*

Mobile Phone \*

Your Date of Birth \*

Enter Numbers Only

In order to proceed with your account creation, please acknowledge the following:

I am at least 18 years of age (or at least the Age of Majority in my State/Country)

I acknowledge that I am located in the United States; OR

I acknowledge that I am located outside of the United States, and that the information I am providing will be transmitted to the United States for account creation.

**Please check all that apply:**

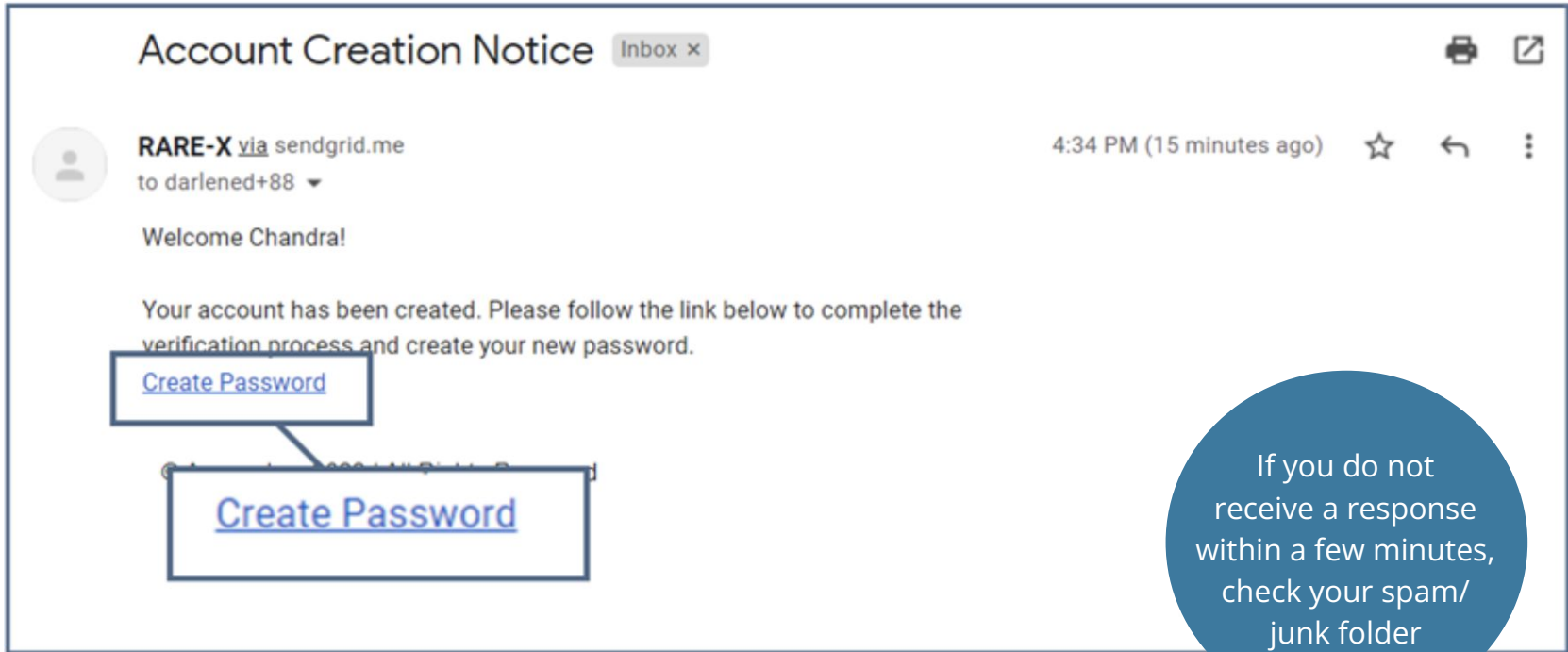
**Patient Participant**  
*A Patient Participant is a person with a rare disease (already diagnosed or still on their diagnostic journey) who will be able to answer surveys and provide information about themselves.*

**Caregiver Participant**  
*A Caregiver Participant will be able to answer surveys and provide information on a patient(s) with a rare disease, for whom they are the Parent or Legally Authorized Representative.*

**Person who has lost a loved one to a rare disease**  
*This user will be able to answer surveys and provide information on a loved one with rare disease who is now deceased.*

[PRIVACY POLICY](#) [TERMS OF USE](#) [GO TO LOGIN](#)

# Receive Account Creation Email



# Email Verification (multi-factor for your privacy)

1. Request your verification code

## Create Password

*Enter Your Email Address*

Send verification code

Continue

Cancel

2. Confirm your verification code

## Create Password

Verification code has been sent to your inbox. Please copy it to the input box below.

*Your Email Address*

527545

Verify code

Send new code

Continue

Cancel

3. Create your password

## Change Password

The password must be between 8 and 64 characters.  
The password must have at least 3 of the following:

- a lowercase letter
- an uppercase letter
- a digit
- a symbol

.....|

Confirm New Password

Continue

Cancel

# Privacy Policy & Terms of Use for RARE-X

*Login to the DCP*



Sign in with your email address

Forgot your password?

Sign in

[PRIVACY POLICY](#)

[TERMS OF USE](#)

You can access these documents anytime by clicking on them

# Technology Platform Terms of Use

The screenshot shows a web interface for RAREX. At the top, there is a dark blue header with the RAREX logo. Below the header, the user's name "Haley Jameson" is displayed. The main content area is titled "Terms of Use" and contains the text: "You must first read, agree to, and accept the following Terms of Use in order to gain access to this software application." Below this text is a large white box containing the "Matrix Terms of Use" document. The document title is "Matrix Terms of Use" with a subtitle "Last Updated December 23, 2021". The text of the document begins with: "These Terms of Use constitute a legally binding agreement made between you, whether personally or on behalf of an entity ("you") and Across Matrix, Inc. ("Matrix," "we," "us," or "our"), concerning your access to and use of our website and other technologies located at [www.acrossmatrix.com](http://www.acrossmatrix.com) as a component of your use of other hosted services (the "Service(s)"). Matrix is providing the Services as a service provider for a third party to whom we provide the Services ("Host Site"). You agree that by..." At the bottom right of the document box, there are two buttons: "DENY" and "ACCEPT". The "ACCEPT" button is highlighted with a red border. Below the document box, there are two buttons: "PREVIOUS" and "NEXT". On the left side of the interface, there is a sidebar with the RAREX logo and a menu with "Terms of Use" (highlighted), "Caregiver Informed Consent", and "General Information".

# Informed Consent

8 Pages of Detailed Q&A to Ensure Understanding

**RARE X**

We encourage you to [download](#) a PDF version of the Consent form and read it carefully.

**Who is funding the DCP?**  
RARE X, a non-profit organization, is paying for the DCP.  
[LEARN MORE](#)

**How long will the DCP last?**  
The DCP does not have an end date. In fact, over time participants and caregivers may be asked to update their data to improve rare disease research.  
[LEARN MORE](#)

**Who is eligible to take part in the DCP?**  
All participants and families who have or may have a rare disease(s) may take part in the DCP.  
[LEARN MORE](#)

Participants and families who may take part include:

- Any person who has been diagnosed with a rare disease, or who is looking for a diagnosis.
- A parent or legal guardian of a child with a rare disease may register a child who is a minor (a "minor" is a child under the age of 18, in most states).
- The legally authorized representative of an adult with a rare disease who cannot physically or mentally answer the surveys may enroll the affected participant.

**Do I or my child have to take part in the DCP?**  
Taking part in the DCP is voluntary. This program is for research purposes only. The only alternative is to not participate in this program.  
[LEARN MORE](#)

**What will I have to do if I take part and give permission for my child to take part in the DCP?**  
We will ask you to create a secure, password-protected account. You will have the chance to answer a set of questions (surveys) about your child's health, health history, treatment and care, and the impact of having a rare disease on your household.  
Your child will not be asked to do anything for the DCP at this time.  
It is likely that in the future, DCP will expand to include the collection of biocamples such as saliva or blood. At that time, RARE X would request an additional consent and

[PREVIOUS](#) [NEXT](#)

# Informed Consent

Check all that  
apply

**I am taking part in the RARE-X DCP for one or more of the following reasons (Check all that apply) \***

- You have stated that you have or may have a rare disease.
- You are the Parent or Caregiver of a person who has or may have a rare disease.
- You are the legally authorized representative of a person who has or may have a rare disease.
- You are the family member, other than a parent, caregiver or legally authorized representative of a person who has or may have a rare disease.
- You have lost a person who had or may have had rare disease.

Check the boxes below to indicate if you agree to the following options. *If you check "no" to any given option, you can still take part in the DCP.*

**RARE-X may contact me with follow-up research surveys and invitations to take part in additional studies. I may choose to ignore these surveys/invitations. \***

- Yes
- No

**RARE-X or a qualified patient organization may contact me if a researcher thinks that I qualify to be part of a clinical trial/study. \***

- Yes
- No

# Informed Consent

If you are a caregiver of a patient, be sure to provide your info and the child's info in the correct places

My signature below indicates:

- I am the parent or legal guardian of the child whose name is listed below.
- I have read this consent and permission form. I understand the information in this form. I have had the opportunity to ask questions related to the DCP and do not have any unanswered questions.
- I agree to take part and give my permission for my child to take part in the DCP.
- I agree to allow the collection, use, and sharing of my child's data as described above.
- By signing and dating this form, I do not give up any of my or my child's legal rights.
- I understand I will get a signed and dated copy of this consent and permission form.

Your child's complete legal given (first) name \*

Kathleen

Your child's complete legal family (last) name \*

Lynch

Your child's middle/second or additional (if your child has one) name

Battista

Your complete legal given (first) name \*

Isabel

Your complete legal family (last) name \*

Lynch

Your middle/second or additional (if you have one) name

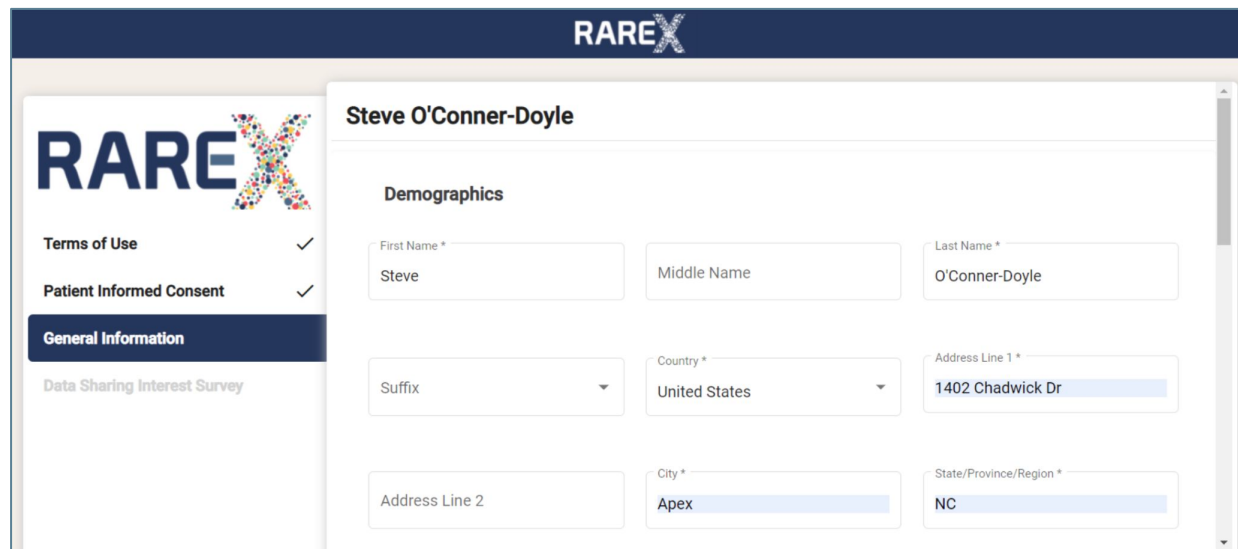
Gormley



# General Information

## *Demographics*

Demographic information collected on both patients and caregivers



The screenshot displays the RAREX patient profile interface. The header features the RAREX logo. The profile is for Steve O'Conner-Doyle. A left sidebar contains navigation options: 'Terms of Use' (checked), 'Patient Informed Consent' (checked), 'General Information' (selected), and 'Data Sharing Interest Survey'. The main content area is titled 'Steve O'Conner-Doyle' and 'Demographics'. It contains several input fields: 'First Name \*' (Steve), 'Middle Name', 'Last Name \*' (O'Conner-Doyle), 'Suffix' (dropdown), 'Country \*' (United States), 'Address Line 1 \*' (1402 Chadwick Dr), 'Address Line 2', 'City \*' (Apex), and 'State/Province/Region \*' (NC).

Steve O'Conner-Doyle		
<b>Demographics</b>		
First Name *	Middle Name	Last Name *
Steve		O'Conner-Doyle
Suffix	Country *	Address Line 1 *
	United States	1402 Chadwick Dr
Address Line 2	City *	State/Province/Region *
	Apex	NC


# General Information

## Demographics

Demographic information collected on both patients and caregivers

**Other Information**

Race *	White	Ethnicity *	Not Hispanic or Latino
Gender At Birth *	Female	Gender Identity *	Woman (or girl, if patient is child)
Birthplace: Country *	USA	Birthplace: State/Province/Region *	DC
Estimated Household Income *	Prefer Not To Answer	Does this participant have health coverage of any type? *	Yes
Does this participant have health coverage of any type? *	Yes	What type of coverage does the participant have? (Select all that apply) *	Private Health Insurance (e.g. HMO, PPO, HSA, Fee for Service, POS, etc.)
Is Patient Living? *	No	Rare Disease(s) - Select all that apply	Non
Is Patient Living? *	No	Rare Disease(s) - Select all that apply	Nonsense Mutation Related Disorder
Is Patient Living? *	No	Rare Disease(s) - Select all that apply	Other
Is Patient Living? *	No	Rare Disease(s) - Select all that apply	Unsure
Is Patient Living? *	No	Rare Disease(s) - Select all that apply	Undiagnosed



# Data Sharing Preference Agreement

By selecting General Research, your participant's data will reach the most researchers (recommended)

## **Type of research**

You choose the **type of research** you would like the participant's data to be used for. You must choose **one** of the following two types of research:

1. General Research

This is the broadest type of research. When you choose General Research, researchers may use the participant's data for:

### **a. Health/Medical/Biomedical Research**

Researchers can access and use the participant's data to learn more about a health condition, its causes, symptoms, progression, and treatments. This type of research could include research on any health condition, even if it is not a rare disease.

*and*

### **b. Other kinds** of studies that are not related to health such as

- Research on age, race, and ethnicity
- Research studying traits such as how long people live or how easily they may get sick
- Research about genetic traits of different populations
- Studies to develop survey questions to improve research

**OR**

2. Health/Medical/Biomedical Research

This type of research is narrower than type 1, General Research. If you choose just Health/Medical/Biomedical Research, ***the participant's data may be used for fewer types of research studies than if you choose General Research.***

# Data Sharing Preference Agreement

Optional: Setting  
Restrictions

## **Other Limits on Research - Optional**

You do *not* have to put any additional limits on how the participant's data is used for research. If this is your choice, you can stop now and go to the end of this form.

But if you would like, you may choose to further **limit** how the participant's data is accessed and used for research. You can select *one* or *both* options below.

Research solely for non-commercial purposes.

If you choose this limit, it means the participant's data may **NOT** be used by any researcher to do studies to develop a drug, treatment, or device that might later be sold to make a profit. For example, if you choose this limitation, a drug development company (biotech or pharmaceutical) would not be allowed to access or use the participant's data for research to develop a drug, treatment, or device that they will sell.

Only research that has been approved by an Institutional Review Board (IRB).

If you choose this limit, it means that only researchers that have had their studies reviewed by an Institutional Review Board (IRB) may access the participant's data for their research. An IRB is a type of committee that reviews research studies and methods to make sure they are not harmful to people. Most of the people who are on an IRB have professional expertise to be able to review the research. The IRB has scientists and nonscientists as part of the committee. When you make this choice, a researcher must present written proof of the IRB's approval, or proof of exemption, of their study before they can access the participant's data for their research.

Page 2 of 3

PREVIOUS

NEXT

# Data Sharing *Preference Agreement*

**Mary Lucus**

GLOSSARY

Data Sharing Interest Survey



## **Biospecimen(s)**

**Do you know if there are biological samples that you have given for research purposes? \***

- Yes
- No

**Are you interested in the collection of biological samples for research (saliva/spit, blood, bodily fluids, etc)? \***  
You will be contacted when this option is available.

- Yes
- No

# Data Sharing Preference Agreement

## Patient Community Connections

Do you want to share your **contact information** with patient advocacy groups that support your diagnosis(s)? \*

- Yes  
 No

Contact Information = Name and email only

## Including Your Data in Summaries on the RARE-X DCP Data Dashboard

We combine data from Participants, remove all identifiers from the combined data, summarize it and present the summary data to others on a "dashboard" that is used to display RARE-X DCP data. This summary might be made available to users of the RARE-X DCP and the general public. May we include your information in the dashboard data? \*

- Yes  
 No

# Caregiver Dashboard

## *Adding a Patient*

The screenshot shows the RAREX Caregiver Dashboard. On the left is a sidebar with the user name "Britany Lane CAREGIVER" and navigation links: Dashboard, General Information, Messages, Documents, Resource Center, and Contact Us. The main area is titled "My Patients" and contains an "ADD PATIENT" button circled in red. A red callout box points to this button with the text "Click ADD PATIENT to add a participant". To the right, another red callout box points to a book icon in the top right corner of the patient list table, with the text "Click the book icon to open the participant's Dashboard". The table below has columns for First Name, Last Name, DOB, Rare Disease, and Last Login. One patient is listed: Brad Lane, DOB Jun 15, 2021, Rare Disease Lennox-Gastaut Syndrome (LGS), Unsure, Last Login Not Available. The bottom right of the table shows "Items per page: 5" and "1 - 1 of 1".

First Name	Last Name	DOB	Rare Disease	Last Login
Brad	Lane	Jun 15, 2021	Lennox-Gastaut Syndrome (LGS), Unsure	Not Available

The screenshot shows the RAREX Caregiver Dashboard with the "My Patients" section. The "ADD PATIENT" button is circled in red, with a red callout box pointing to it that says "Click ADD PATIENT to add a participant to your Dashboard". Below the button, the RAREX logo is displayed. Underneath the logo, the text reads: "As a Caregiver, you currently have no patients associated with your account. To get started, please select the ADD PATIENT button above to begin adding and associating Patients to your Caregiver account." The bottom right of the page shows "Items per page: 5" and "0 of 0".

# Caregiver Dashboard

*Navigating Between Caregiver & Patient*

The screenshot shows a user interface for a caregiver dashboard. On the left is a dark sidebar with navigation icons and labels: a home icon for 'Dashboard', a calendar icon for 'General', an envelope icon for 'Messages', and a folder icon for 'Documents'. The main content area is light-colored and displays a user profile for 'Marilynn Lucus' with the role 'CAREGIVER' and 'Viewing: Macy Lucus'. Below this is a table with columns 'New/In-Progress' and 'Completed'. The table lists 'Surveys/Studies - Level 1' with a 'Diagnosis Survey' entry under the 'New/In-Progress' column and a 'Health and Development Su...' entry under the 'Completed' column. A red callout box with white text points to the 'Diagnosis Survey' entry, stating 'Indicates whose survey data you are currently viewing'. Another callout box, identical to the one above the profile, is positioned over the profile information.

Marilynn Lucus  
CAREGIVER  
Viewing: Macy Lucus

Indicates whose survey data you are currently viewing

Dashboard  
General  
Messages  
Documents

Marilynn Lucus  
CAREGIVER  
Viewing: Macy Lucus

New/In-Progress      Completed

Surveys/Studies - Level 1

Diagnosis Survey

Health and Development Su...



# Surveys Health & Development

You should choose the  
Diagnosis Survey to provide  
more detailed information  
about the diagnosis

The screenshot shows the RARE dashboard for user Bridget Michaels (CAREGIVER). The dashboard is divided into two tabs: 'New/In-Progress' and 'Completed'. Under the 'New/In-Progress' tab, there are two sections: 'Health and Development' and 'Demographics'. The 'Head to Toe' survey is highlighted in yellow and circled in red. The 'Demographics' section lists three surveys: 'Race and Ethnicity Concepts Survey', 'Other Names Survey', and 'Additional Participant IDs'.

Health and Development		Published On	Expiration Date	Time To Complete (minutes)	Questions	Status
Head to Toe		Aug 08, 2023		10 - 15	43	START

Demographics		Published On	Expiration Date	Time To Complete (minutes)	Questions	Status
Race and Ethnicity Concepts Survey		Jul 03, 2023		5 - 8	2	START
Other Names Survey		Jul 20, 2023		2 - 4	1	START
Additional Participant IDs		Jun 12, 2023		5	3	START

# Surveys Head to Toe

Click on the "X" to  
save & exit

**GLOSSARY** ✕

**Have you had issues with your HEAD/FACE/NECK? \***  
Please note that we are asking about SIGNIFICANT issues with these areas, problems that the patient has seen a doctor for or had surgery for, or problems that you don't notice often in other people. The doctor may have used the term "dysmorphic" in describing some features of the patient's face. Examples: Cleft lip/palate, large or small head size, fused skull bones, sparse hair, etc. We will ask specifically about eyes and ears later.

Yes  
 No  
 Unsure

**Have you had issues with your EYES and/or VISION? \***  
Examples: Vision loss, dislocation of lens, cataracts, a "lazy eye," nearsighted- or farsightedness. You may have seen an optometrist or ophthalmologist (eye doctors) for these issues.

Yes  
 No  
 Unsure

**Do you have SLEEP**...  
Examples: trouble falling asleep, snoring, restless legs, bruxism, or narcolepsy.

Yes  
 No  
 Unsure

Page 4 of 8

**PREVIOUS** **NEXT**

You should choose  
"YES" for  
HEAD/FACE/NECK

Answering  
Yes or Unsure  
will trigger Level 2 Surveys if  
they are available

# Genetic Testing Information

## Health and Development Survey



*In this survey, "participant" refers to the patient with the rare disease. If you are a Caregiver viewing an associated patient's record (i.e., you see "Viewing:" followed by the patient's name directly below your name in the upper left corner), then the "participant" referred to in this survey is the patient you are currently viewing.*

Did you have genetic testing? \*

- Yes
- No
- Unsure

What was the reason for your genetic testing? \*

- I have had symptoms of a genetic condition.
- The doctor/I wanted to confirm a diagnosis that was suspected based on my symptoms.
- I have a family history of a genetic disorder and was showing symptoms of that disorder - wanted to confirm diagnosis.
- I have a family history of a genetic disorder and was NOT showing symptoms of the disorder - wanted to assess my risk.
- I am healthy and wanted to be proactive about my health.
- Unsure

Do you have genetic reports or summaries to upload? \*

\*\* Instructions for uploading a copy of your genetic test report(s) will be provided after you complete this survey.

- Yes (I have had testing and I have a copy)
- No (I have had testing but I do NOT have a copy)

# Genetic Testing Information

## Updating a Genetic Report

## 1- Documents

Katelyn Peters  
CAREGIVER  
Viewing: Jake Peters

Dashboard  
General Information  
Messages  
Documents  
Resource Center  
Contact Us

### Documents

Search Documents UPLOAD

**RAREX**  
You currently do not have any documents  
To get started click the UPLOAD Button above.

Items per page: 5 0 of 0

## 2- Upload & Tag

Upload a Document

Please select a file for upload  
File Size Limit: 50 mb

UPLOAD

Please combine all pages belonging to the same report before uploading.

When tagging a document, please note that we can only accept the following file types for upload: JPG, JPEG, GIF, PNG, APNG, TIF, TIFF, BMP, PDF.

Please select a tag below if this document is one of the following files:

Audiology Report  
Genetic Test  
Vineland

CANCEL SAVE SAVE AS

## 3- Save & View

Name	Uploaded By	Date Added	Tag	384.65 KB/5 GB
JakePetersGeneticReport.pdf	Katelyn Peters	Jul 13, 2023	Genetic Test	# ↓ 🗑️

Items per page: 5 1 - 1 of 1

# Surveys

## *Level 2 Survey*

### *Example*

More detail than Head to Toe, but not a “deep dive”

Always able to provide additional details in “free text” section at the bottom (do not use patient’s name or other identifiers)

Dashboard	
New/In-Progress	Completed
Surveys/Studies - Level 2	
Behavior Survey	
Bone, Cartilage and Connective Tissue Survey	
Brain and Nervous System Survey	
Digestive System Survey	
Ears and Hearing Survey	
Endocrine System (including Hormones) Survey	
Head, Face, and Neck Survey	

# Surveys Answering Level 2 Surveys

RAREX

GLOSSARY X

What specific **EYE/VISION** issues has the participant had? At what age did the **EYE/VISION** issues begin, and when were they diagnosed by a healthcare provider?

	Do you see this symptom *	Age symptoms first appeared	Age at Diagnosis
<b>Eye movement issues</b> - Eyes have unusual movement such as "lazy eye" (strabismus), or eye tremors (nystagmus), etc..	Yes <input type="button" value="v"/>	2 years old <input type="button" value="v"/>	2 years old <input type="button" value="v"/>
<b>Visual Impairment</b> - Vision loss that cannot be corrected by conventional means, such as refractive correction, medications, or surgery.	Unsure <input type="button" value="v"/>	Unsure <input type="button" value="v"/>	Unsure <input type="button" value="v"/>
<b>Difference in eye size</b> - Eye size differs from what is usual such as a small eye size (microphthalmia) or lack of eye development (anophthalmia), etc.	No <input type="button" value="v"/>		
<b>Unusual Iris</b> - The colored part of the eye, called the iris, has freckles/spots or eye color differs between eyes.	No <input type="button" value="v"/>		
<b>Coloboma</b> - A notched pupil.	Unsure <input type="button" value="v"/>	8 - 11 months <input type="button" value="v"/>	8 - 11 months <input type="button" value="v"/>
<b>Lens issue</b> - Can be classified as:	Unsure <input type="button" value="v"/>	Choose... <input type="button" value="v"/>	Choose... <input type="button" value="v"/>

# Surveys

## *Adding Symptoms Not Mentioned in Level 2 Surveys*

Are there any other specific **HEART/BLOOD VESSEL** issues the participant has had that were not listed above? Please include at what age the **HEART/BLOOD VESSEL** issues began, and at what age were they diagnosed by a healthcare provider.

**Additional Issues? \***

Yes

No

**Please Describe: \***

Aortic root dilation

**Please try not to put an identifying information in the free text area!**

# Surveys

## *Vineland Survey*

You do not have to complete the Vineland Survey in 1 sitting, but you do have to complete it within 30 days of starting

### Dashboard

New/In-Progress

Completed

Patient Reported Measures (1)

Published On

PEHLS Epilepsy - Caregiver Report

Observer-Reported Communication Ability (ORCA) Measure

Vineland-3 Comprehensive Parent/Caregiver Form

Neuro-Quality of Life - Proxy

Eating Assessment Tool (EAT-10) Proxy

A Sleep Questionnaire for Children with Severe Psychomotor Impairment

VIEW: Category

The Vineland Adaptive Behavior Scales Third Edition is a standardized assessment tool to measure adaptive behavior and support the diagnosis of intellectual and developmental disabilities, autism and developmental delays. It can be used to determine eligibility or qualification for special services, plan rehabilitation or intervention programs and track and report progress.

When you click "Continue", the Vineland will open in another tab in your browser. When you are done with the Vineland, you will be told on-screen to close the tab to be returned to RARE-X. If you inadvertently close all of your windows, simply log back into RARE-X at any time to continue the Vineland, or review your results once available.

Once your assessment is scored, the results will be available on the "Completed" tab on your Dashboard. Results are typically available within one hour.

Please click "Continue" to go on to complete the Vineland."

Continue



# Dashboard Completed Tab

Bridget Michaels  
CAREGIVER  
Viewing: Lila Michaels

- Dashboard
- General Information
- Messages
- Documents
- Resource Center
- Contact Us



## Dashboard

Click the ellipsis to View, Edit, or Email completed surveys

New/In-Progress	Completed	Head to Toe	Published On	Completed On	Type	
		Health and Development Survey	Aug 08, 2023	Aug 16, 2023	PATIENT	⋮
		Health and Development Survey	Jan 17, 2023	Jun 28, 2023	PATIENT	⋮
Demographics		Published On	Completed On	Type		
		Other Names Survey	Jul 20, 2023	Jun 22, 2023	PATIENT	⋮
		Additional Participant IDs	Jun 12, 2023	Jun 28, 2023	PATIENT	⋮
High Priority Data		Published On	Completed On	Type		

- View
- Retake
- Email

Powered By: Matrix

**If you have questions or technical issues...**

**Email:**

- [rarexsupport@globalgenes.org](mailto:rarexsupport@globalgenes.org)

**Thank You!**

