Agenda

- What is RARE-X?
- Mission & Values
- What are we solving for?
- The RARE-X Data Collection Portal
- Data Governance
Agenda

- Benefits of the Data Collection Program
- Getting Started
- DCP User Journey
- Other Tips
- How this data collection is different
What Is RARE-X?

- RARE-X is a NONPROFIT created to accelerate rare disease research, treatments, and cures by removing barriers for data collection and sharing
- RARE-X is a platform to **collect**, **connect**, and **share** data

- **RARE-X does not own, sell, or do research with the data they collect**
Why did Usher Leadership Choose RARE-X?

- Participant owned
- Data security/privacy
- No cost to participants
- No cost to researchers
- Structured, standardized
- Data on all body systems
- Streamlines researcher access
- Speeds treatment development
- Ability to connect to existing data sources

Non-confidential
What is the benefit to YOU?

- You will get data BACK to you in de-identified summary
- You may have the chance to participate in clinical trials
- Reach more researchers worldwide
- Update symptoms at any time
- Manage who uses your data
- Speed up treatment development
Why Providing The Broadest Data Sharing Is Critical

Participants  Researchers  Participants  Researchers

RAREX
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
- No need to finish it all at once
Participant Journey in the Data Collection Portal

Community Page - Welcome, Privacy, Terms of Use, Start

Data Collection Program User ID Page

Participant Consent

Data Sharing Preference Survey

Survey Topics (Domains)

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

Participant Dashboard
Individuals with Usher syndrome, their families, and the broader Usher community 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 Usher Syndrome 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

Already Enrolled?

By clicking Get Started, you are agreeing to the RARE-X Terms of Use.

By clicking Login you are leaving the RARE-X site and entering the data.

https://ushersyndrome.rare-x.org/
All biological parents of underaged children with Usher syndrome would be considered “carriers” and should also choose “Patient Participant” in addition to “Caregiver”
Receive Account Creation Email

If you do not receive a response within a few minutes, check your spam/junk folder
Email Verification (multi-factor for your privacy)

1. Request your verification code

2. Confirm your verification code

3. Create your password

Create 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
Login to the DCP
Terms of Use

You must first read, agree to, and accept the following Terms of Use in order to gain access to this software application.

Matrix Terms of Use

Last Updated December 25, 2021

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 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 accessing the Service and/or any other hosted services of the Host Site, you have read and understood and agree to be bound by these Terms of Use. You further agree that if you use the Service and/or any other hosted services of the Host Site, you will be bound by the terms and conditions of service of the Host Site, and you hereby agree to comply with those terms and conditions of service. If you do not agree to these Terms of Use, you must immediately cease all use of the Service and/or any other hosted services of the Host Site.
Informed Consent - 8 Pages of Detailed Q&A to Ensure Understanding
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
Demographic data is collected on both caregivers and participants.
Select Usher from the drop-down list. If you have other conditions select Other from the list and enter the disease name in the text box that opens.
Data Sharing Preference Agreement

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.

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By selecting General Research your participant’s data will reach the most researchers (recommended)
Data Sharing Preference Agreement

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.
Data Sharing Preference Agreement

Mary Lucus

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
Medical Records

Are you interested in having your medical records connected to the data you provide on RARE-X? *
You will be contacted when this option is available.

- Yes
- No

Other Possible Data Sources

We know that you may have participated in other studies/data collection. Are you interested in having the data from those studies connected to your data in RARE-X? *
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

My Patients

Click ADD PATIENT to add a participant

Click the book icon to open the participant's Dashboard
Adding a participant to Your Caregiver Dashboard

Click ADD PATIENT to add a participant to your Dashboard.
Caregiver Dashboard

Indicates whose survey data you are currently viewing
Choose the Diagnosis Survey to provide more detailed information about the diagnosis.

Complete the Health & Development Survey first.

<table>
<thead>
<tr>
<th>Survey/Study</th>
<th>Published On</th>
<th>Expiration Date</th>
<th>Time To Complete</th>
<th>Questions</th>
<th>Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis Survey</td>
<td>Aug 22, 2022</td>
<td></td>
<td>15-30 minutes</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>Health and Development Survey</td>
<td>May 24, 2022</td>
<td></td>
<td>15-20 minutes</td>
<td>43</td>
<td></td>
</tr>
<tr>
<td>Other Names Survey</td>
<td>Jan 05, 2022</td>
<td></td>
<td>2-4 minutes</td>
<td>1</td>
<td>START</td>
</tr>
<tr>
<td>Race and Ethnicity Concepts Survey</td>
<td>Jan 05, 2022</td>
<td></td>
<td>5-8 minutes</td>
<td>2</td>
<td>START</td>
</tr>
<tr>
<td>Additional Parent Questions</td>
<td>Aug 16, 2022</td>
<td></td>
<td>2-4 minutes</td>
<td>4</td>
<td>START</td>
</tr>
<tr>
<td>Interventional or Medical Diets Survey</td>
<td>Jun 09, 2022</td>
<td></td>
<td>2-5 minutes</td>
<td>5</td>
<td>START</td>
</tr>
</tbody>
</table>
Health and Development Survey

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. 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.

- Yes
- No
- Unsure

Have you had issues with your EYES and/or VISION? *
Examples: Vision loss, dislocation of lens, cataracts, a “lazy eye”, redness, dryness, irritation, etc. We will ask specifically about vision and eye issues.

- Yes
- No
- Unsure

Do you have SLEEPING issues? *
Examples: Trouble falling or staying asleep, excessive sleeping

- Yes
- No
- Unsure

Answering Yes or Unsure to a question will trigger Level 2 Surveys if they are available
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/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.
- 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)
Uploading a Genetic Test Report

Step 1: Open Documents

Step 2: Click UPLOAD

Step 3: Select Genetic Report & UPLOAD the report from your device
# Level 2 Surveys

## Dashboard

<table>
<thead>
<tr>
<th>Surveys/Statits</th>
<th>Level 1</th>
<th>Published On</th>
<th>Expiration Date</th>
<th>Time To Complete</th>
<th>Questions</th>
<th>Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis Survey</td>
<td>Feb 17, 2022</td>
<td>15-30 minutes</td>
<td>13</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Names Survey</td>
<td>Jan 05, 2022</td>
<td>2-4 minutes</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Race and Ethnicity Concept</td>
<td>Jan 05, 2022</td>
<td>5-8 minutes</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Surveys/Statits</th>
<th>Level 2</th>
<th>Published On</th>
<th>Expiration Date</th>
<th>Time To Complete</th>
<th>Questions</th>
<th>Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ears and Hearing Survey</td>
<td>Jan 05, 2022</td>
<td>5-8 minutes</td>
<td>9</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eyes and Vision Survey</td>
<td>Jan 05, 2022</td>
<td>10-15 minutes</td>
<td>13</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kidney, Bladder, and Genit...</td>
<td>Jan 05, 2022</td>
<td>5-10 minutes</td>
<td>12</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Answering Level 2 Surveys

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?

<table>
<thead>
<tr>
<th>Eye movement issues - Eyes have unusual movement such as &quot;lazy eye&quot; (strabismus), or eye tremors (nystagmus), etc.</th>
<th>Do you see this symptom *</th>
<th>Age symptoms first appeared</th>
<th>Age at Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>2 years old</td>
<td>2 years old</td>
<td></td>
</tr>
</tbody>
</table>

| Visual Impairment - Vision loss that cannot be corrected by conventional means, such as refractive correction, medications, or surgery. | Unsure | Unsure | Unsure |

| Difference in eye size - Eye size differs from what is usual such as a small eye size (microphthalmia) or lack of eye development (anophthalmia), etc. | No |  |  |

| Unusual Iris - The colored part of the eye, called the iris, has freckles/spots or eye color differs between eyes. | Yes | 4 - 7 months | 1 year old |

| Coloboma - A notched pupil. | Choose... |  |  |

| Lens issue - Can be classified as: | Choose... |  |  |
**Level 2 - Eyes/Vision Survey (partial)**

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?

<table>
<thead>
<tr>
<th>Eye movement issues</th>
<th>Do you see this symptom *</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eyes have unusual movement such as &quot;lazy eye&quot; (strabismus), or eye tremors (nystagmus), etc.</td>
<td>Choose...</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Visual Impairment</th>
<th>Do you see this symptom *</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vision loss that cannot be corrected by conventional means, such as refractive correction, medications, or surgery.</td>
<td>Choose...</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Difference in eye size</th>
<th>Do you see this symptom *</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eye size differs from what is usual such as a small eye size (microphthalmia) or lack of eye development (anophthalmia), etc.</td>
<td>Choose...</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Unusual Iris</th>
<th>Do you see this symptom *</th>
</tr>
</thead>
<tbody>
<tr>
<td>The colored part of the eye, called the iris, has freckles/spots or eye color differs between eyes.</td>
<td>Choose...</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Coloboma</th>
<th>Do you see this symptom *</th>
</tr>
</thead>
<tbody>
<tr>
<td>A notched pupil.</td>
<td>Choose...</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Lens issue</th>
<th>Do you see this symptom *</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can be classified as:</td>
<td>Choose...</td>
</tr>
<tr>
<td>• Cataracts</td>
<td></td>
</tr>
<tr>
<td>• Abnormality of lens shape</td>
<td></td>
</tr>
<tr>
<td>• Aplasia/Hypoplasia of the lens</td>
<td></td>
</tr>
<tr>
<td>• Ectopia lentis</td>
<td></td>
</tr>
<tr>
<td>• Pseudophakia</td>
<td></td>
</tr>
<tr>
<td>• Phakodonesis</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Major vision issues</th>
<th>Do you see this symptom *</th>
</tr>
</thead>
<tbody>
<tr>
<td>Issues may include blindness, color blindness, night vision problems, floaters, or light sensitivity, etc. Please do NOT include minor nearsightedness or farsightedness.</td>
<td>Choose...</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Farsightedness</th>
<th>Do you see this symptom *</th>
</tr>
</thead>
<tbody>
<tr>
<td>Also called hyperopia or hypermetropia; things up close look fuzzy.</td>
<td>Choose...</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Nearsightedness</th>
<th>Do you see this symptom *</th>
</tr>
</thead>
<tbody>
<tr>
<td>Also called myopia; things in the distance look fuzzy.</td>
<td>Choose...</td>
</tr>
</tbody>
</table>
Level 2 Surveys - Adding Additional Symptoms at the Bottom

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

Additional Issues? *
- Yes
- No

Please Describe: *

Some of the above symptoms are a result of Usher Syndrome and others are not. (Explain more in this open text area)

Age at Diagnosis *
- Choose...
What specific **EAR/HEARING** issues has the participant had? At what age did the **EAR/HEARING** issues begin, and at what age were they diagnosed by a healthcare provider?

<table>
<thead>
<tr>
<th><strong>Ear shape difference (includes outer or inner ear)</strong></th>
<th>Do you see this symptom</th>
<th>Age symptoms first appeared</th>
<th>Age at Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Part or all of the ear may be over or under developed; can include issues such as an ear structure that is missing or underdeveloped, a copped ear shape, or an overly-large appearance of the ear, etc.</td>
<td>Yes</td>
<td>1 year old</td>
<td>1 year old</td>
</tr>
</tbody>
</table>

**Conductive hearing loss** - Hearing loss or impairment due to an issue with the ear canal, ear drum, or the bones in the middle ear

- **Sensorineural hearing loss (SNHL) or impairment** - Hearing impairment or loss in one or both ears due to an issue with the nerves in the inner ear or connecting ear to the brain

- **Mixed hearing loss or impairment** - A combination of both conductive and sensorineural hearing loss

- **Ringing in the ears** - Also called tinnitus.

- **Hyperacusis** - Reduced tolerance and increased sensitivity to everyday sounds in your normal environment.

- **Vertigo** - Abnormal sensation of spinning/dizziness while the body is not moving

Are there any other specific **EAR/HEARING** issues the participant has had that were not listed above? Please include at what age the **EAR/HEARING** issues began, and at what age were they diagnosed by a healthcare provider.
Level 2 Brain - Nervous System Survey

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

<table>
<thead>
<tr>
<th>Condition</th>
<th>Do you see this symptom</th>
<th>Age symptoms first appeared</th>
<th>Age at Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cerebral Palsy (CP)</td>
<td>Choose...</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognitive impairment</td>
<td>Choose...</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Headache or Migraine</td>
<td>Yes</td>
<td>0 years old</td>
<td>16 years old</td>
</tr>
<tr>
<td>Coordination issues</td>
<td>Choose...</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Abnormal EEG</td>
<td>Choose...</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hypertonia</td>
<td>Choose...</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hypotonia</td>
<td>Choose...</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Memory impairment</td>
<td>Choose...</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unusual movements</td>
<td>Choose...</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

A formal medical "Diagnosis" may have occurred at a later time than the symptom appeared.
Diagnosis Survey

General health and development questions are asked in this survey. To help RARE-X identify and prioritize future focused groups of questions, please provide ALL known participant conditions/diagnoses/genetic diagnoses below, starting with the most current diagnosis (one condition/diagnosis/genetic diagnosis per line).

What is the participant’s diagnosis (please list one at a time - you will have the opportunity to add more later). *
Include any diagnosis or symptom that you have not reported on yet or feel you need to provide more detail about.

What was the participant’s age in years when the formal diagnosis was made? *
5 years old

What was the participant’s age in years when they first began experiencing symptoms of this diagnosis? *
Unsure

What test(s) did physicians or other health professionals do to make the rare disease diagnosis? (Select all that apply.) *
- [ ] Audiology
- [ ] Cytogenetics
- [ ] CAT Scan
- [x] Electrocardiac (e.g., EKG, EEC, Holter)
- [ ] Hematology
- [ ] Blood Gases
- [ ] Chemistry
- [ ] Cardiac Catheterization
- [ ] Electroneuro (EEG, EMG,ERPSPG)
- [ ] Bedside ICU Monitoring
- [ ] Blood Bank
- [ ] Cytopathology
- [ ] Cardiac Ultrasound
- [ ] Genetics
- [ ] Immunology

You can add any diagnosis or symptom that you were not able to report in previous surveys.
# Quality of Life - Examples of Questions

During the past 30 days, for about how many days have you felt WORRIED, TENSE, or ANXIOUS? *

<table>
<thead>
<tr>
<th>Number of Days</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
</tr>
</tbody>
</table>

- None
- Don't know/Not sure
- Prefer not to answer

During the past 30 days, for about how many days have you felt you did NOT get ENOUGH REST or SLEEP? *

<table>
<thead>
<tr>
<th>Number of Days</th>
</tr>
</thead>
<tbody>
<tr>
<td>20</td>
</tr>
</tbody>
</table>

- None
- Don't know/Not sure
- Prefer not to answer

Anxiety

In the past 7 days...

- I felt fearful...
  - Never
  - Rarely
  - Sometimes
  - Often
  - Always
  - Prefer not to answer

Are you LIMITED in any way in any activities because of any impairment or health problem? *

- Yes
- No
- Don't know/Not sure
- Prefer not to answer

What is the MAJOR impairment or health problem that limits your activities? *

- Eye/vision problem

For HOW LONG have your activities been limited because of your major impairment or health problem? *

Please select below which unit of time your response will be in

- Days
- Weeks
- Months
- Years
- Don't know/Not sure
- Prefer not to answer

Number of Months *

<table>
<thead>
<tr>
<th>Number of Months</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
</tr>
</tbody>
</table>
Dashboard – Completed Tab

Click the ellipse to View, Edit or Email completed surveys

<table>
<thead>
<tr>
<th>Study Title</th>
<th>Published On</th>
<th>Completed On</th>
<th>Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health and Development Study</td>
<td>May 24, 2022</td>
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<tr>
<td>Consents and Data Sharing Preference</td>
<td>Feb 18, 2022</td>
<td>May 27, 2022</td>
<td>PATIENT</td>
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<td>Data Sharing Interest Survey</td>
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<tr>
<td>Informed Consent</td>
<td>Feb 10, 2022</td>
<td>May 27, 2022</td>
<td>INFORMED CONSENT</td>
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</tbody>
</table>
How is this data collection different from other data collection programs?

- Comprehensive across all body systems
- This is YOUR community’s data collection program
- Ability to do cross-disease research
- Return of de-identified summary data to community
- Complement other studies
- Ability to update over years and years - showing progression of disease
Use TalkBack to browse the web with Chrome

You can get spoken feedback when you use TalkBack in the Chrome browser.

To learn more, complete the TalkBack tutorial.

Contents

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Explore pages with a keyboard
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Explore pages with reading controls

To cycle through the reading controls:

1. In Chrome, open a page.
2. Swipe down then up, or up then down, until you reach the setting that you want.
   - You can choose a setting like Headings, Links, or Words.
   - On devices with multi-finger gestures, you can also three-finger swipe.

Use the Accessibility Shortcuts panel on Mac

The Accessibility Shortcuts panel offers shortcuts to quickly turn on or turn off common accessibility features such as Zoom, VoiceOver, and Sticky Keys.

Open the Accessibility Shortcuts panel

Press these keys together: Option (⌥), Command (⌘), and F5. On laptop computers with a Touch Bar, you might need to press the Fn (Function) key as well.

On laptop computers with Touch ID, triple-press Touch ID. If you press and hold the Command key while doing this, VoiceOver turns on or off.

Accessibility—
for everyone

Windows 11 built-in accessibility features empower every person to discover and do the things they love.
If you have any questions, experience and technical issues, or want to provide any feedback please send an email to:

support@rare-x.org

and cc: n.odonnell@usher-syndrome.org
Thank you!

Questions?