LHON Collective: LHON Data Collection Program Tips and Recommendations

LHON Data Collection Program, in partnership with RARE-X

Before you Start

The LHON Data Collection Program can be reached at the following website, RARE-X.org/LHON. Use only Google Chrome or Apple Safari version 14 or higher.

Reach out to connect@lhon.org or rarexsupport@globalgenes.org with questions, concerns, or feedback.

Tips and Tricks

Additional Assistance

If you would like assistance registering successfully, you can contact us directly at connect@lhon.org or use the scheduling app linked here to set up a video or phone call whenever works best for you.

What role to assign yourself

Whether you are affected by LHON vision loss, an unaffected carrier, or LHON Plus, enroll as a "Patient". In other words, if you carry an LHON genetic mutation, enroll as a "Patient."

What role(s) to select at the initial point of registration

Consider that you may one day want to enroll a deceased loved one or a minor child - select ALL potential role(s) on the Request Access page at the beginning of your enrollment and at the end of the Informed Consent. This will give you the flexibility to add others at a later date.

A second email may be needed to enroll

If you have enrolled in the mitoSHARE Registry or another registry that uses the Matrix platform, you will need to provide two email addresses for registration in both.

General information section

In the General Information section, the bottom of the form is not immediately visible. To complete this page, keep scrolling down until you reach and complete all the required fields, and then click on the "Save" button to save your answers.

For caregivers or those adding information about a deceased loved one

After you have enrolled and created an account, you will be brought to the RARE-X homepage. There is a tab that says, “Add Patient”. Select the Add Patient tab to get started. If you have more than one person to add to the DCP, you will do this for each person you register.

Expanding surveys for participants entered by a caregiver

Once the patient is added, click on the “Dashboard” tab in the column under the patient’s name. This will populate all the available surveys to be filled out in the center of the screen under the tab, “New/In-Progress”.

Important Notes and Instructions

Head-to-Toe Survey

This is a very important survey. Everything you answer “Yes” to will then create a more detailed survey called a Level 2 Survey for that identified issue. The Level 2 surveys can then be found on your dashboard after completing this survey.

Any symptom or diagnosis you have can be included in this section, even if you don’t think it is related to LHON. You never know what commonalities we could learn when we put all the data together, looking at each person from head to toe.

Where to input specific non-vision loss symptoms that are fairly commonly reported with LHON

- Migraine: answer “yes” to “Brain and/or Nervous System”
- Central Auditory Processing Disorder: answer “yes” to “Ears and/or Hearing” and describe in Other.
- Tremors or Peripheral Neuropathy: answer “yes” to “Brain and/or Nervous System” and describe in Other.

Addition of a Genetic Report to substantiate your LHON Diagnosis

If a genetic report is available, please upload it to the LHON Data Collection Program (DCP) so health information can be associated with genetic information in the Documents section of the website.

Consenting

If you are a patient reporting on your own behalf, you will consent only once. If you are a caregiver, you will be asked to consent for yourself and then also for your minor child or deceased loved one once you add them as a patient. If you have multiple registrants, you will need to consent for each of them.

Frequently Asked Questions

How long will this take?

It may take around 45-60 minutes for account creation, enrollment, consent, and then completing all the surveys.

Can we do it on our mobile phones or tablets?

Yes, you can use your mobile phone or tablet, but a desktop or laptop computer has a better interface than either a phone or tablet.

Do I have to live in the United States to participate?

No. This is a global form that can be completed anywhere in the world. However, if you are outside the US, you will need to agree to an additional consent question. The goal of this is to establish a global database that includes all individuals with LHON.

What languages are available?

Currently English. If you understand English (even if it is not your primary language) or have someone who can assist you and translate, we encourage you to participate.

When will other languages be added?

We don't have firm dates. The next languages to be added to the platform will be Spanish, Portuguese, and French.

Why aren't there specific questions about LHON?

The RARE-X platform is built for all rare diseases and uses standard surveys. The data is in a format that is research-ready and can be understood across diseases. This provides an opportunity to attract greater interest from researchers and pharmaceutical companies, as more people with various diseases can share their diagnoses in a combined format, creating a critical mass.

How often are we expected to enter data?

The goal is for everyone to visit the LHON DCP once a year to review and make any necessary updates, particularly if a new symptom has developed. If specific surveys relevant to LHON are added, we will notify you and hope you will complete the relevant survey. Once you have enrolled, every subsequent log-in will be significantly easier and less time-consuming, as you no longer need to enroll or provide consent.

Who owns the data?

You (the patient or caregiver) always have full control of your data. It is owned by you and enabled by RARE-X.