



HOPE IN FOCUS

Community Survey

Understanding the LCA Community

We are conducting a community survey to get a better understanding of the needs of people living with and affected by Leber congenital amaurosis (LCA). The survey responses provide us with insight and information into the resources and educational support that are needed and that may currently be missing in the LCA community.

We asked the LCA community about:

- Demographic Information
- Disease Education
- Genetic Testing
- Patient Registries
- Support Groups
- Expenses & Educational Resources
- Current Care, and more

We greatly appreciate everyone who contributed their valuable insight, and we are proud to share with you what we learned so far.

We Heard from 50 Individuals Across 14 Countries!



Survey participants typically sought out LCA-related information through **online resources, non-profit groups/advocacy organizations**, or the **doctor/specialist who did not make the diagnosis**.



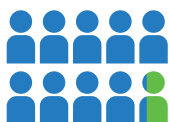
Participants commonly consumed information through webinars/virtual events and social media. **Facebook** is the most common social platform used by the survey participants, followed by **YouTube**.



More than 90% of participants took part in genetic testing to **learn about their mutation, what to do with the results**, and to identify **other associated symptoms or syndromes**.



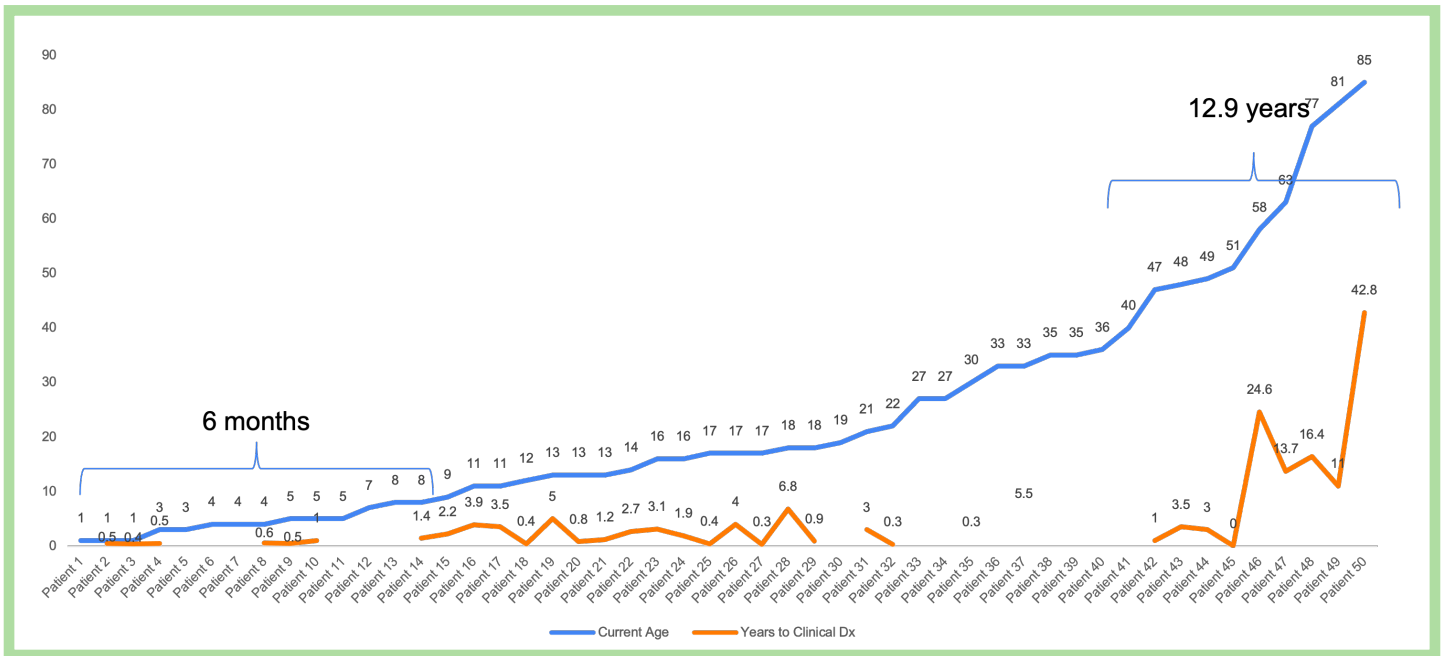
Survey respondents cited interest in taking part in clinical trials, with their main motivation being **restoring vision**.



92% of affected individuals with LCA do not participate in a support group related to LCA, primarily due to **lack of awareness**.

The Amount of Time to Receive an Accurate Diagnosis Has Steadily Decreased Over Time

For individuals born before 1975, an LCA diagnosis took an average of about 13 years. For individuals born between 2015-2022, an LCA diagnosis took an average of just 6 months.



Immediately following diagnosis, the community wants more information on:

- LCA progression & progression of symptoms
- Resources for newly diagnosed individuals
- Available treatments
- Clinical trials
- General information about LCA

Currently, the community wants more information on:

- Current research
- Participating in clinical trials
- Available treatments
- Advocating for research & treatment options
- Disease progression

We have reopened the survey and would love to hear from you! Hope in Focus will be summarizing these anonymous responses to gain insight into education needs surrounding topics within LCA and how individuals prefer to receive this information.



Please help us by scanning this code or visiting the link below and sharing with your LCA network.

