LHON Collective

Vision Hope Now



Our Mission

LHON Collective is a global initiative dedicated to accelerating progress toward a cure for Leber Hereditary Optic Neuropathy (LHON) while improving the lives of people living with LHON.

When Lindsey lost vision at age 24, she and her mom, Rhonda, learned that all three generations are at risk of LHON vision loss. LHON families are fighting for a cure for themselves and future generations.

Leber Hereditary Optic Neuropathy (LHON) is a rare mitochondrial disease causing sudden, irreversible vision loss, often in adolescence or early adulthood. Most patients become legally blind, facing significant personal and financial challenges. Despite its impact, there is no cure or effective treatment yet.

LHON affects tens of thousands worldwide, yet its mechanisms remain only partly understood. Limited and inconsistent funding has hampered research, delaying progress toward therapies. A coordinated, well-funded effort is essential to advance treatments and improve outcomes for those affected by LHON.



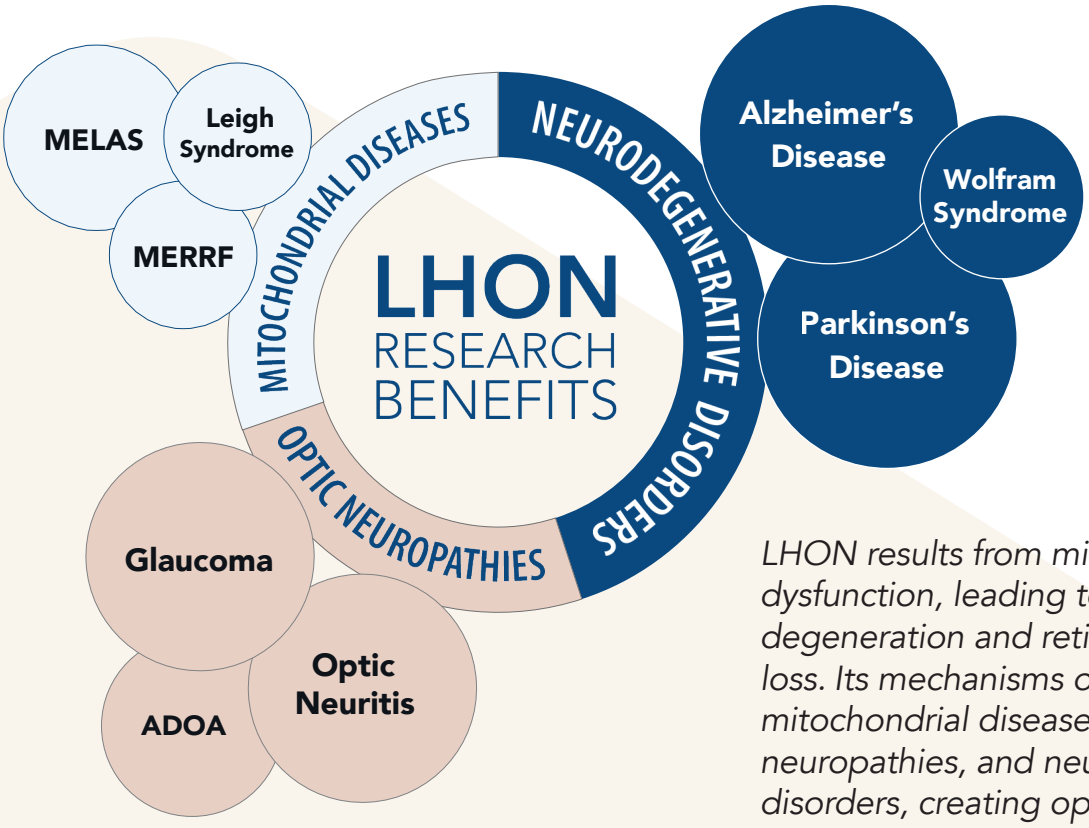
Healthy vision



LHON vision

The Broader Impact of LHON Research

Investing in LHON research can advance understanding and treatments for other diseases, leveraging shared mechanisms to accelerate progress across fields.



LHON results from mitochondrial dysfunction, leading to optic nerve degeneration and retinal ganglion cell loss. Its mechanisms overlap with other mitochondrial diseases, optic neuropathies, and neurodegenerative disorders, creating opportunities for cross-disciplinary research.

Vision Hope Now Campaign

LHON Collective has partnered with the Milken Institute to identify core areas of strategic philanthropic investments to significantly advance LHON research:

Goal 1 Biological & Data Resources

Collect natural history data and biological samples in a globally accessible biorepository.

LHON biological samples are rare and the patient data that exist are fragmented across clinics and patient registries around the world.



Featured Projects

1a: LHON Biorepository & iPSC Library

1b: LHON Natural History and Biostatistics Program

Goal 2 Scientific Models

Develop research tools for the field, beginning with models.

Current LHON models are insufficient. More available and better-suited models are needed, including those derived from human eyes and iPSC lines.

Featured Projects

2a: Mitochondrial Gene Editing Models

2b: Patient-Derived Cell Models



Goal 3 Therapeutic Discovery

Fund basic discovery, development and repurposing research to advance the pipeline of therapeutic candidates.

The underlying mechanisms of how and why mitochondrial mutations lead to vision loss in only a subset of individuals are not fully understood. This limits the development of precisely targeted therapies.

Featured Projects

3a: Collaborative Research Awards

3b: AI-Driven Therapeutic Repurposing

3c: Optic Nerve Protection and Restoration



Goal 4 Community & Scientific Engagement

Invest in raising awareness and building knowledge among LHON families and the broader scientific community through education and advocacy.

Demystifying LHON is needed to help empower families, expand scientific understanding, and foster opportunities for collaborations.



Featured Projects

4a: LHON Community Conference

4b: Scientific Engagement & Partnership Development

4c: Global Scientific Strategy Summit

Goal 5 Funding Progressive Innovation



Accelerate breakthroughs by investing in LHON Collective's Sustainable Research Funding Model, where proceeds from successful therapies are reinvested to fund the next generation of treatments.

The rare disease funding landscape leaves promising LHON research projects underfunded and vulnerable to interruption.

Featured Project

Sustainable Research Fund



Join Us

- By donating cash, stock, or crypto at VisionHopeNow.org
- By providing a foundation or corporate grant
- By donating via your donor-advised fund
- By donating via your retirement account
- By leaving a legacy gift

For more info and giving opportunities, please contact:
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LHON Collective

Ways to Give

Follow the Journey

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