LHON Deutschland e.V.

Visit our website

What is LHON and who is affected?

Leber's Hereditary Optic Neuropathy, or LHON, is a rare inherited mitochondrial eye disease that can cause sudden, painless loss of central vision. It often begins in adolescence or young adulthood and affects males more frequently than females, but families as a whole are affected by the uncertainty, diagnosis, and life changes that follow.

What is it like being affected?

LHON starts to impair one eye's vision first. Within a few weeks patients are legally blind with a blind spot at the center of their visual field. Vision usually stays severly impaired after minor improvements

Who are we?

LHON Deutschland e. V. is a non-profit patient organisation run mainly by people affected by LHON and their relatives. We inform, connect, and guide patients and families to the support they need.

THE BLIND SPOT

Imagine losing sight exactly where you try to focus.

Bridging the gap

We connect patients, families, clinicians, researchers, and support services — turning isolation into orientation and support.

What is our aim?

We support patients and families from the first signs of LHON onwards — helping with diagnosis, treatment options, assistive devices, emotional guidance, and contact with others who understand the condition.

What do we do?

Each year, our LHON meeting brings together patients, families, clinicians, and researchers to share knowledge, experiences, and support. Throughout the year, we provide information, answer enquiries, and connect people with the right medical, social, and peer-support contacts.