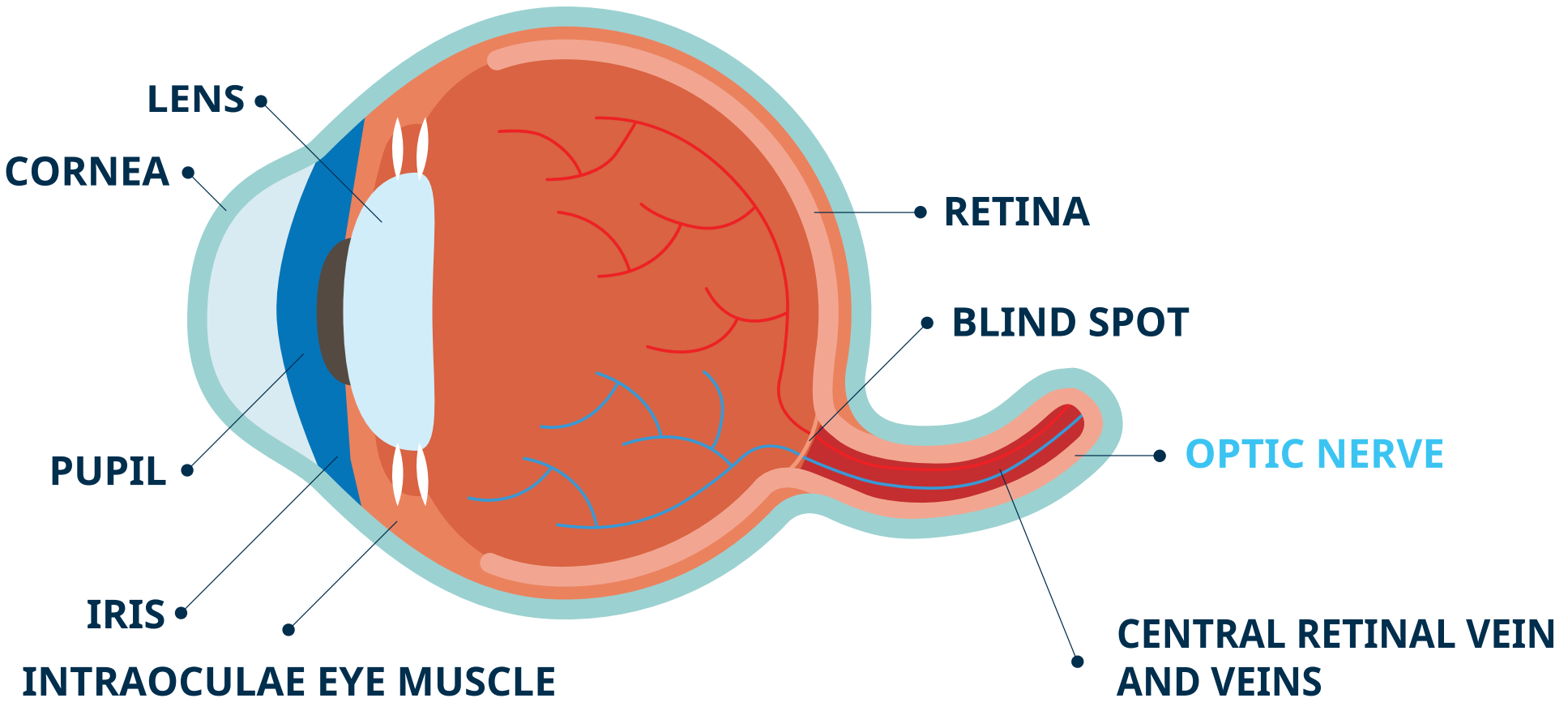
WHAT IS ADOA?

CURE ADOA FOUNDATION

This brochure is made for persons with ADOA or ADOA-plus.
It is published by the Cure ADOA Foundation.

What is ADOA?

ADOA is a rare disease that causes a decline in visual function due to issues with the optic nerves. The disease affects about 1 in 30,000 people. Some people have few or no symptoms, while others become almost completely blind. About 10-20% of people with ADOA have a form called ADOA-plus, that causes symptoms in other parts of their body as well.



How do you develop it?

ADOA(-plus) is caused by a change in the OPA1 gene. This gene makes proteins which help cells get energy. ADOA(-plus) is a hereditary disorder, meaning you inherit it from one of your parents. Anyone who carries the mutation can pass it on, even those who have no symptoms themselves. Of children born with ADOA(-plus), 95% develop symptoms. The symptoms typically start within the first ten years of life.

What does the Cure ADOA Foundation do?

Since 2018, the Cure ADOA Foundation has been helping people with ADOA(-plus) and their families. The foundation focuses on Scientific research, Advocacy, Raising awareness and Connecting the ADOA(-plus) community. The ultimate goal is to prevent and cure ADOA(-plus).

What are the symptoms?

Symptoms include:
- Decreased visual sharpness
- Blurred vision
- Reduced contrast
- Abnormal color perception
- Tunnel vision
- Abnormal pupil reactions

People with ADOA-plus may also have:
- Hearing loss
- Balance problems
- Muscle weakness
- Poor coordination.

The official name

In its full name, the disorder is called autosomal dominant optic atrophy. “Autosomal dominant” describes how it is inherited, and “optic atrophy” means the optic nerve is affected.

What treatments are available?

There is currently no approved treatment for ADOA(-plus), therefore, recommendations include regular eye exams. Measurements such as visual acuity, visual field, and color vision allow doctors to monitor visual function and see how the disease is progressing.

Glasses or contact lenses do not help persons with ADOA(-plus) to see better, because the problem is in the optic nerve and not in the eye. However, certain assistive devices can help individuals, such as glasses that filter light to prevent eye strain, and other aids for reading, cooking, learning, or navigating.

Scientists in various countries are actively conducting research on ADOA(-plus). Most researchers are working to develop a treatment that will stop or slow vision loss. For all research, it may be years before there is a cure.

What can you do for yourself?

Living a healthy life is important. This means:
- Eating a balanced diet
- Not smoking
- Avoiding alcohol and other addictive substances

An occupational therapist can help you manage your energy. Some supplements may support optic nerve health, but there’s no evidence yet.

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