# FIGHTING BLINDNESS

# Driving the Research for Treatments and Cures for Blinding Retinal Diseases.

October 2024





# Together, We Are Making a Difference!



Today, we continue to see progress through our funding of innovative global research with a strong potential for treatments and cures for blinding diseases.

As a trusted resource, we bring passionate blind and low vision communities together.

With your support, we will further the science that leads to success.



# The Path to Ending Blinding Diseases





# The Foundation Beginnings and Mission



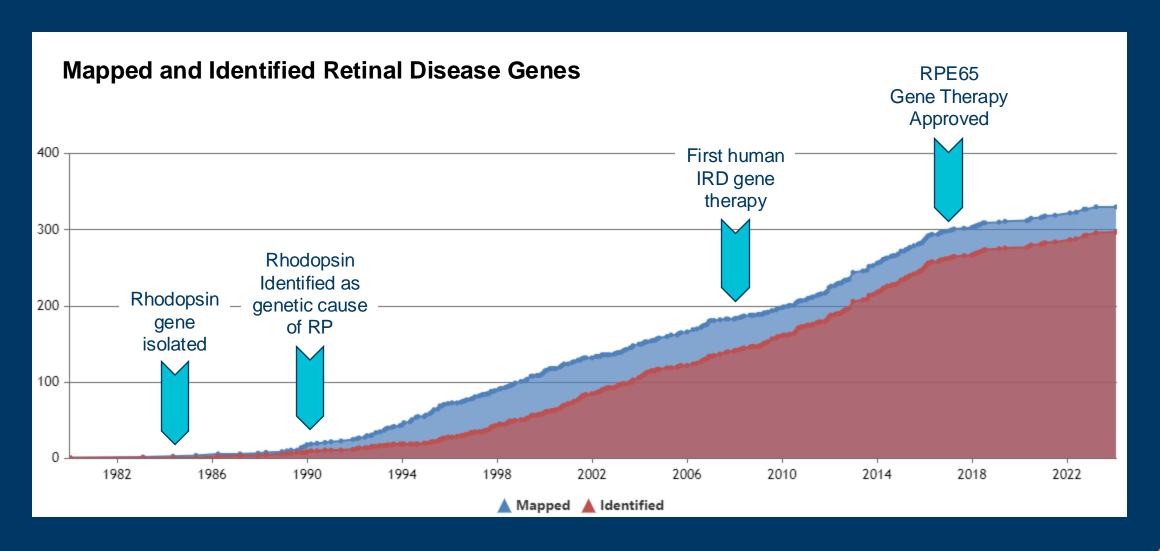
The Retinitis Pigmentosa
Foundation was founded in 1971
by Gordon and Lulie Gund,
Bernard and Beverly Berman,
and other dedicated families and
leaders to find cures for retinal
degenerations — at a time when
very little was known about those
vision-robbing diseases.

In 1995, Retinitis Pigmentosa Foundation was renamed to the Foundation Fighting Blindness. The urgent mission of the Foundation Fighting Blindness is to drive the research that will provide preventions, treatments and cures for people affected by retinitis pigmentosa, age-related macular degeneration, Usher syndrome and the entire spectrum of retinal degenerative diseases.



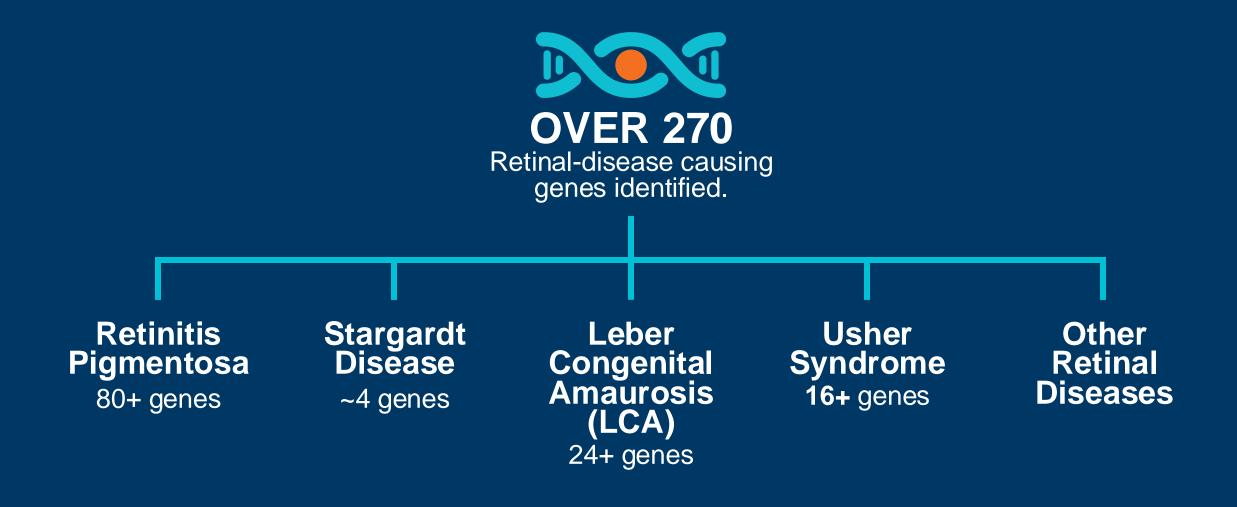
## **Understanding the Genetic Basis of Diseases**

We can identify the gene in ~65% of retinal disease.





## **Identifying Inherited Retinal Diseases**





# The Impact of a Blinding Disease\*



Non-Affected Vision

Severe Peripheral Vision Loss





Severe Central Vision Loss

<sup>\*</sup> This is for representational purposes only. The impact of vision loss will vary by disease and by patient.



# **Epidemiology of Inherited Retinal Diseases (IRDs)**

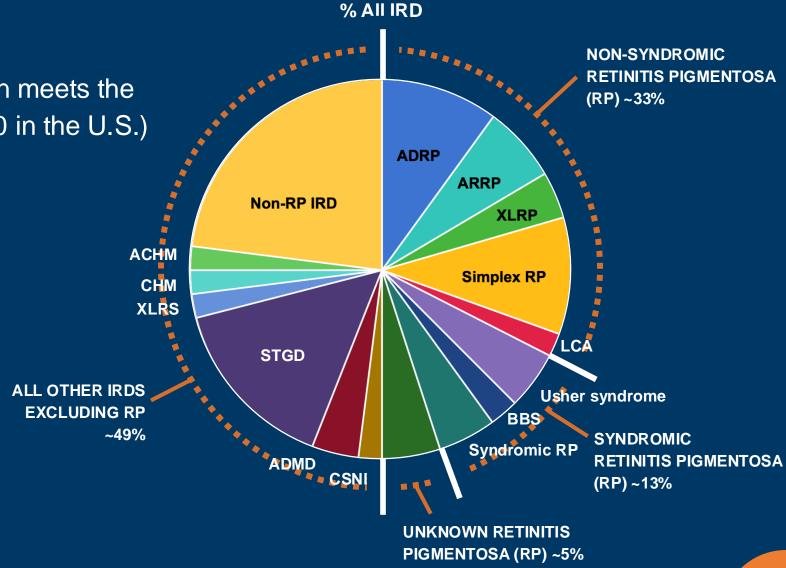
For IRDs individually, each condition meets the criteria of orphan disease (<200,000 in the U.S.)

US = 200,000

- RP = 100,000
- Stargardt = 30,000
- Usher = 25,000

**EU + US combined = 670,000** 

World = 4.5 million





# **Impact & Insights**



# \$915+ MILLION

Raised for retinal research and public health education since the Foundation Fighting Blindness began in 1971.



#### 80% OF TOTAL EXPENDITURES

Spent on research and public health education this year.



1 IN 33

People in the U.S. are affected by a blinding disease – IRDs and AMD.

1 IN 53 globally





93 GRANTS FUNDED GLOBALLY IN 2023

• 96 investigators • 71 institutions



# TOP CLINICAL CENTERS IN OUR CONSORTIUM

Throughout the U.S., Australia, Canada, England, France, Germany, Italy, Israel, Mexico, and the Netherlands.



## Signature Programs, Initiatives & Subsidiaries

#### **45+ Volunteer Chapters**

A national network that raises funds, increases public awareness and provides support to communities.



42 clinical centers of excellence with experience in IRDs and with standardized assessment protocols.

## RD FUND

Launched in late 2018, the retinal disease venture philanthropy fund drives emerging therapies that are moving toward, or in, clinical trials.

Patient registry with 28,000+ profiles – global, free, secure, easy-to-use patient-controlled.



#### **Grants & Awards**

Supports clinical studies and pre-clinical research applicable to a broad range of retinal degenerative diseases.



Over 200,000 walkers, donors, and corporate sponsors have raised more than \$66 million through over 30+ VisionWalk events.

### **Dinners, Galas and Events**

A variety of custom and unique events in cities across the nation to raise awareness and research funding.

### VISIONS

The Foundation provides a supportive learning environment through conferences seminars and workshops.

### **BioBonds (Advocacy)**

The Long-term Opportunities for Advancing New Studies (LOANS) for Biomedical Research Act.



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# FIGHTING BLINDNESS

# Thank You

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