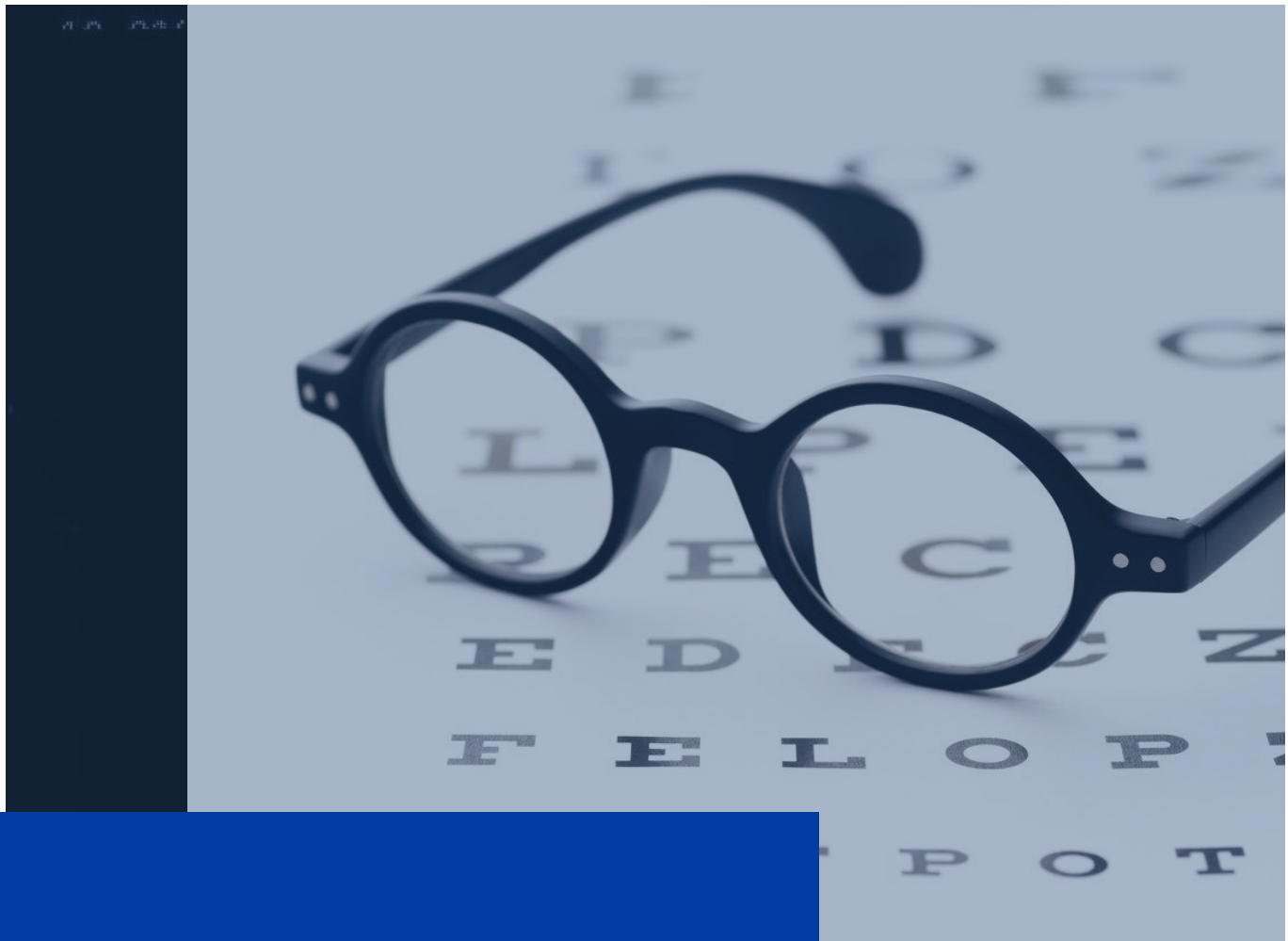

# A CURE IN SIGHT

## Impact Report

2022

aCUREINSIGHT™.org
ocular melanoma

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# Introduction

A Cure In Sight was founded by a group of Ocular Melanoma patients in 2012. It was initially started to provide aid to patients who couldn't afford treatment. Over the years, it has grown and developed to include many other programs and people. It has been an approved 501(C)3 nonprofit since 2014.

## Our Mission

To bring clarity, support, and compassion to the darkness of Ocular Melanoma

What exactly does that mean?

As an organization founded by patients for patients, A Cure In Sight knows how difficult it can be to be diagnosed with Ocular Melanoma. ACIS was founded to support the patients and families that are going through this challenge.

Because of the rarity of their disease, Ocular Melanoma patients often face their diagnosis with very little information. To address this, A Cure In Sight works with premier Bioscience companies, Pharmaceutical companies, and doctors to facilitate conversations and create accessible resources.

ACIS strives to be a hub where any patient can come for information, friends, and hope. A cancer diagnosis is difficult enough on its own; no one should have to face it without help.

## Our Purpose

A Cure in Sight (ACIS) supports families who have ocular melanoma and focuses on research for a cure. Through public and private partnerships, we provide clear and reliable education information and access to a community for patients and their supporters.

ACIS educates the public about ocular melanoma, treatment options, and clinical trials that may improve a patient's prognosis, making it less overwhelming. ACIS is dedicated to ongoing research.

aCUREINSIGHT™.org
ocular melanoma

# Our Team

By Patients, for patients

ACIS has remained focused on serving the needs of patients facing this difficult disease. The following individuals are crucial to this cause:

## Board Members

Melody Burchett- President

Loren Seaman-Vice President

Suzanne Lescure -Secretary

Marlene Day-Treasurer

Jack Odell-Director of Research

## Staff

Danet Peterson
Social Media Manager, Content Creator, and host for the Eye Believe Podcast

Hanna Hulick
Director of Communications and Community Engagement

Kevin O'Neil
Research consultant

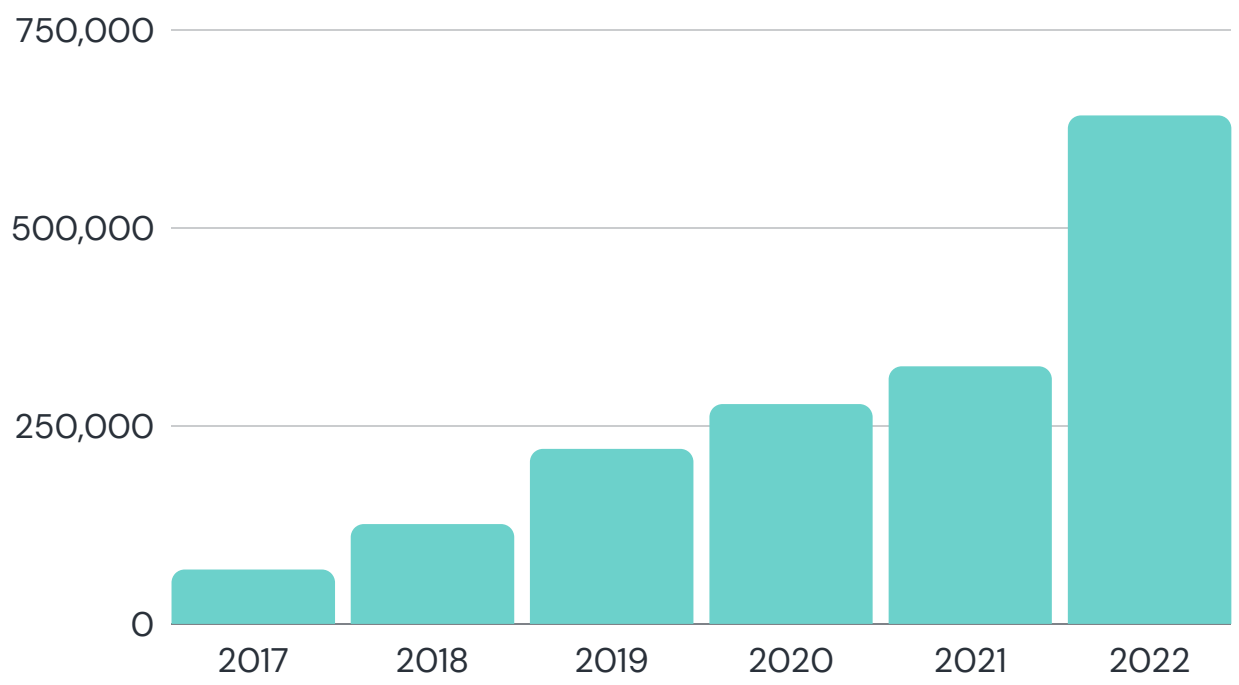
# Partnerships & Affiliations

# 2022 Growth

Despite ongoing COVID complications as well as other challenges, A Cure In Sight grew substantially in 2022.

$641,475 was raised from a combination of grants, contributions, donations, and fundraisers.

## Total Revenue 2017-Present



# Financial Assistance

Assistance offered to new patients of Ocular Melanoma or Metastatic disease. Patients qualify by submitting an application along with a statement of need. A committee reviews the applications and awards assistance based on the application.

"The financial assistance I was awarded has allowed me to travel to Philadelphia for my metastatic treatment. I believe my treatments with Dr. Sato's team is keeping me alive. ACIS is a blessing to all of us, ocular melanoma patients"
- Joan, Florida.

In 2022, ACIS spent $38,696 on direct patient support

A Cure In Sight is a global nonprofit, serving OM patients from around the world. While Ocular Melanoma is a cancer that primarily affects Eastern European/Caucasian peoples, ACIS makes every effort to be inclusive in caring for patients in need, regardless of race, color, income, or religion. The largest patient base is located in the United States, with growing communities around the world. Our financial assistance program is open to all.

# Patient Education

In addition to helping patients make connections and navigate the financial challenges of OM, A Cure In Sight has created several programs to provide information for patients

- Eye Believe Survivorship Seminar
- Online Webinars
- Podcast*
- Website
- Newsletter
- Patient connections
- Youtube

ACIS allocated $61,884 to patient education in 2022.

Another $119,846 went to the ACIS Eye Believe Survivorship seminar and webinar series

Patient education includes all projects designed to inform the patient community about research projects, physician information, clinical trials, and other resources related to dealing with and treating ocular melanoma.

*For more information about the podcast, see page [12]

# Research

Research is a key focus at A Cure In Sight. Since the foundation of the research program, ACIS has provided funding for projects that would have otherwise been stalled and never completed. Medical research grants are vetted individually by our research committee and Cancer Navigator Hartmut Stecher, PhD, MS. Strict contractual terms must be adhered to for funding.

In 2022, ACIS spent $4,109.00 on research projects outlined below. There is an additional $33,000 previously set aside for a project that has been delayed into 2023. A Cure In Sight currently has the dedicated funds in reserve, ready to deliver upon the project's commencement. ACIS has also set aside $50,000 that will go towards a joint MRA/ACIS award in 2023.

In general, A Cure In Sight's 2022 research contributions were not as large as they have been in the past. Research projects are still facing pandemic related delays, making the processes of contributing to research more difficult. However, ACIS has hope for more fundable research in 2023.

## Insight Registry

The A Cure In Sight Insight Registry is a powerful opportunity for Ocular Melanoma patients to contribute directly to research. It remains the largest patient input registry for Ocular Melanoma. There are currently 703 enrolled respondents, and 514 active participants. In 2022 alone, 707 patients began the process of enrolling and 526 surveys were completed.

The Insight Registry has made it possible for Dr. Afshar of UCSF to publish abstracts. The completed surveys will continue to provide researchers with essential biodata to fuel OM research.

In 2023, ACIS plans to launch a biobank connected to the Insight Registry. With the help of HonorHealth and Dr. Moser's team, they will begin collecting biopsied metastatic tumor cells to divide and research. These cells will be linked to the patient profile associated with the biopsy to provide revolutionary context to the research done on the cells. This will be the first biobank in Ocular Melanoma research.

733

enrolled respondents

514

active participants

# Medical Research

A Cure In Sight has also worked on or funded several other medical research projects:

### Steps for Sight Research Project

In 2022, ACIS held the first Steps for Sight campaign, encouraging participants to get 7,000 steps each day to recognize the 7,000 new patients diagnosed each year world wide.

281 people participated and completed 46,269,281 steps over the course of the month. **$53,934 was raised during this campaign.**

**Melanoma Research Alliance generously offered to match the funds raised by ACIS. Throughout 2022, ACIS and MRA carefully selected a research project to contribute to. The project will be announced to the public soon.**

### Jefferson Health Research Project

A Cure In Sight also contributed to a research project at Jefferson Health studying immune triggered cell death. This contribution allowed the project to continue when it otherwise wouldn't have been able to. The lab's progress report had this to say about the project:

"We are pleased to share that funding from A Cure In Sight allowed [Dr. Aplin's team] to study inflammatory cell death in uveal melanoma. This additional grant funding would not be possible without [ACIS]....

"Thank you for your generous support which is critical to understanding and treating this disease. Because of A Cure In Sight's partnership, we are progressing research that has the potential to have a transformative impact on uveal melanoma patients."

# Community outreach

## New Patient Packets

When a patient is first diagnosed, they can sign up for a free patient packet that includes informational brochures. Physician and industry information can also be added. Patient packets are designed to help patients feel connected to ACIS and the resources it offers.

In 2022, ACIS spent $8,306 to send new patient packets to 175 individuals as well as multiple physician offices.

The 2022 total expenses for all social media was $8,574. Over $35,000 was raised through Facebook marketing.

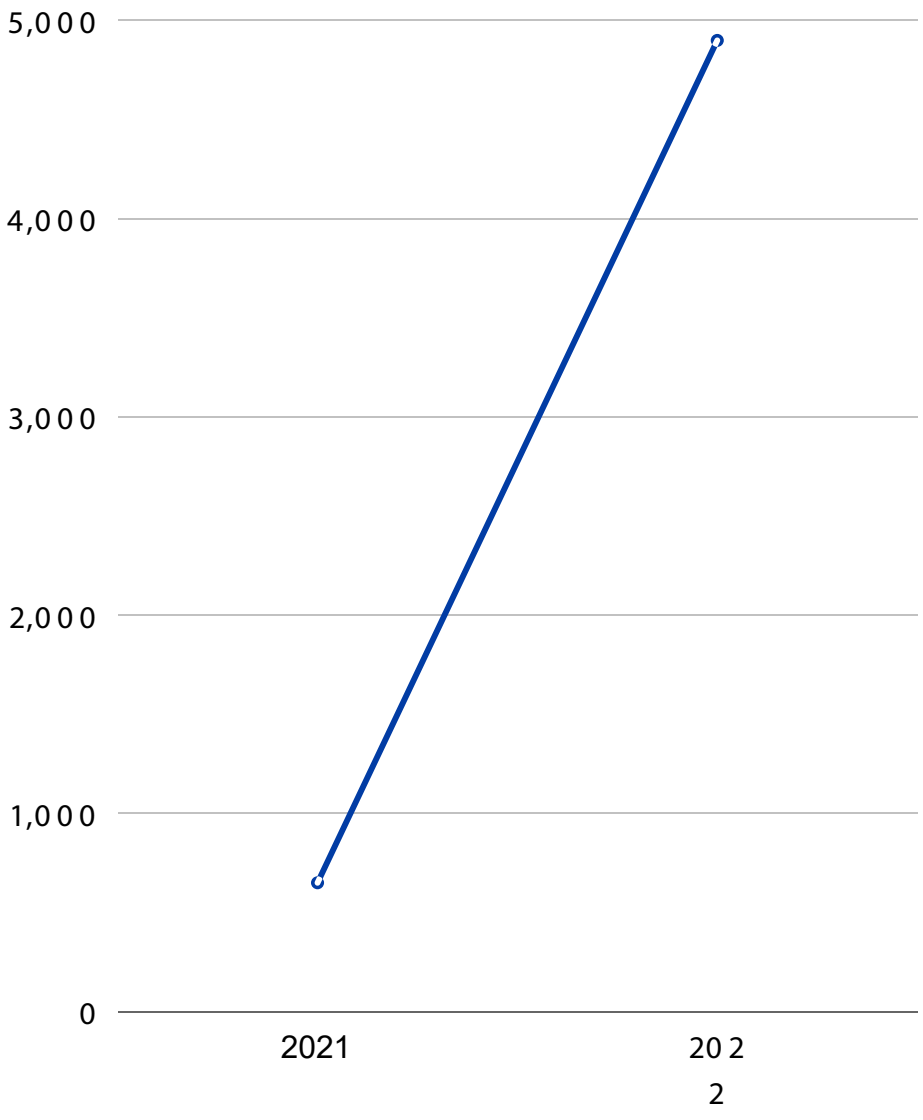
## Social Media

ACIS posts current updates on Ocular Melanoma research, trials, interviews, and patient stories on Facebook, Twitter, TikTok, and Instagram. In 2022, A Cure In Sight's cumulative number of followers across all social media channels reached 7,488. All channels had 6,913 direct clicks to the ACIS website or related registration pages. In general, ACIS posts exceeded 93,800 engagements, and reached 738,291 impressions. The overall engagement rate rose by 4.4% in 2022.

# The Eye Believe podcast

The Eye Believe Ocular Melanoma Podcast features patient stories, research updates, genetic testing information and professional mental health discussions. In 2022, the Eye Believe Podcast added 33 published episodes.

The episodes rotate from inviting guest experts and patients to talk about their experience. Pharmaceutical companies have taken an interest in the Eye Believe podcast and also occasionally record updates for the projects they are working on.




The podcast experienced exponential growth in 2022, growing from 679 downloads to 4,900.

# We thank you for your ongoing support of our program


## Acknowledgments and special thanks

Hanna Hulick and Danet Peterson for the conception and coordination

Our board and committee members for their leadership

To the donors, sponsors, and supporters without your help, this report wouldn't have been possible

The patients and patient supporters who trust us in their journey

Our colleagues and mentors for encouragement



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