Choroideremia
RESEARCH FOUNDATION

2024
Annual Report

SAVING SIGHT IS OUR VISION.
BUILDING HOPE IS HOW WE'LL GET THERE.

A Fresh Look for CRF, Thanks to Princeton10 (P10)!

Thank you to P10's strategic marketing consultancy for graciously providing pro bono support to help us enhance our brand and outreach efforts.

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A Letter to the CHM Family

Dear Readers:

We would like to thank all our CHM family members who have participated in uplifting our community throughout the past year. Participation has included many different activities, ranging from joining in on one of our online chat conversations; reading our weekly e-newsletter; following, liking and sharing our social media pages; volunteering to coordinate an event; partaking in research studies; attending an in-person program; making a financial donation; or calling/texting/reaching out a fellow CHM community member and having a conversation on any topic at all. There are many ways to help move progress forward as we work towards potential treatments and build engagement amongst our CHMers and family members. All of them make a difference.

We would also like to thank our dedicated researchers who have gathered in person and virtually on multiple occasions over the past year to network and accelerate CHM science with each other. This includes being involved in events such as the ARVO vision research conference in Seattle; the France Choroideremie Scientific Symposium in Montpellier; CRF patient and family regional meetings in Dallas and London; joining virtual webinars; coordinating small group calls; publishing papers and data findings; and other actions. We are so grateful for all our researchers who take time away from their medical practice, and their own families, to spend time with our community, because they truly care and want to help put an end to vision loss caused by CHM.

We are very much looking forward to this coming June 25-28, 2025, when after a three-year hiatus, we will be holding our next CRF International Conference, which will unite both our CHM patient and family community and our scientific community to join in better understanding the causes and impacts of CHM and developing and supporting treatment options. Collectively, we can put all the pieces of the CHM puzzle together and solve its mystery.

All the best to everyone in our CHM community, and thanks again for all that you do to keep us moving closer to understanding and conquering choroideremia.

Neal Bench
CRF President

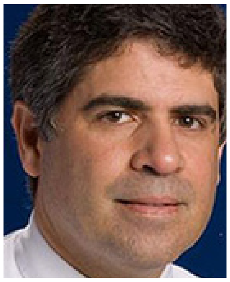
Kathi Wagner
CRF Executive Director

Jess L. Thompson, MD, MS
CRF Chair, Science Advisory Board

2023-2024 Research Funding

Since the inception of the Choroideremia Research Foundation in 2000, the organization has provided over $5.5 million to date in research grants to find treatment options and a cure for CHM.

Recent grants have included:



Researcher: Tomas S. Aleman, MD, Director of the Retinal Structure and Function Laboratory, Perelman Center for Advanced Medicine, Perelman School of Medicine

Institution: University of Pennsylvania, Philadelphia, PA

Project Title: Gene Therapy for Choroideremia: Redefining Cellular Targets and Treatment Windows

Researcher: Malia Edwards, PhD, Associate Professor of Ophthalmology

Institution: Wilmer Eye Institute, Johns Hopkins Medicine, Baltimore, MD

Project Title: To Study the Potential for Collagen Mimetic Peptides to reduce progressive damage to the Bruch's-RPE-Photoreceptor Complex in Choroideremia - funded in partnership with the Penn Orphan Disease Center Million Dollar Bike Ride

Researchers: Bhanu P. Telugu, DVM, PhD, President & CSO

Institution: RenOVAte Biosciences, Inc., Reisterstown, MD

Project Title: CHM Porcine Animal Model Development year 3

Researcher: Mariya Moosajee, MBBS, BsC (Hons), PhD, FRCOphth, Consultant Ophthalmic Surgeon and Clinical Academic Ophthalmologist

Institution: University College, London, UK

Project Title: Further development of CHM nonsense mutation readthrough compounds and maintenance of the CHM Mouse Colony

Researcher: Robert James Casson, MB, BS Hons, Professor of Ophthalmology, University of Adelaide and Kiora Pharmaceuticals

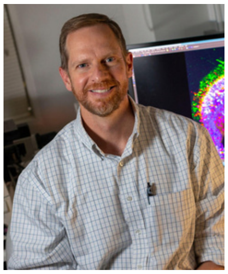
Institution: Kiora Pharmaceuticals, Encinitas, CA

Project Title: Validation of functional vision testing in a population of patients with retinitis pigmentosa & choroideremia (ABACUS-1)

Researcher: Kathleen Boesze-Battaglia, PhD, Professor of Biochemistry and Biophysics

Institution: University of Pennsylvania, Philadelphia, PA

Project Title: Assessment of Metabolic Homeostasis in the CHMnull/wtmouse, implications for novel therapeutic interventions



Researchers: David Gamm, MD, PhD, Director, McPherson Eye Research Institute; Associate Professor, Ophthalmology and Visual Sciences

Institution: University of Wisconsin, McPherson Eye Research Institute, Madison, WI

Project Title: Optimization of AAV vectors for ace-tRNA readthrough therapy for choroideremia

Researcher: Shalhevet Izraeli, MSc Student

Institution: Hadassah-Hebrew University Medical Center, Jerusalem, Israel

Project Title: RANDY WHEELOCK RESEARCH AWARD: Using suppressor transfer RNAs to correct CHM nonsense mutations

Researcher: Dror Sharon, PhD; Division of Ophthalmology and Shay Ben Aroya, PhD, Faculty of Life Sciences

Institution: Hadassah-Hebrew University Medical Center, Jerusalem, Israel and Bar-Ilan University, Israel

Project Title: In-vitro and in-vivo RNA editing of CHM nonsense mutations, year 2

Visit curechm.org/research/#funded to view a full list of research funded to date.

International Advocacy Efforts

One of CRF's primary goals is to advocate on behalf of CHM patients and family members in both the rare disease and vision communities.

The CRF's 2024 advocacy efforts continued to support our mission and strategic efforts with federal regulators, pharma, researchers and national and international patient advocacy allies, including in person and virtual meetings. Director of Advocacy, H. Eric Hartman attended several international events to discuss the diverse areas of CHM research funded by the CRF along with expanding our global patient support network.

In February, the CRF participated in Rare Disease week through virtual meetings hosted by the FDA, NIH and the US Congress Rare Disease Caucus. This joint effort allowed CRF to engage with other rare disease patient organizations like NORD, Global Genes and Every Life Foundation to support legislative advocacy letters regarding a number of important issues, including accelerated pathways for rare disease therapeutics, newborn screenings, equitable access to approved treatments, and improved strategic endpoints for clinical trials with the involvement of the patient community in that process.

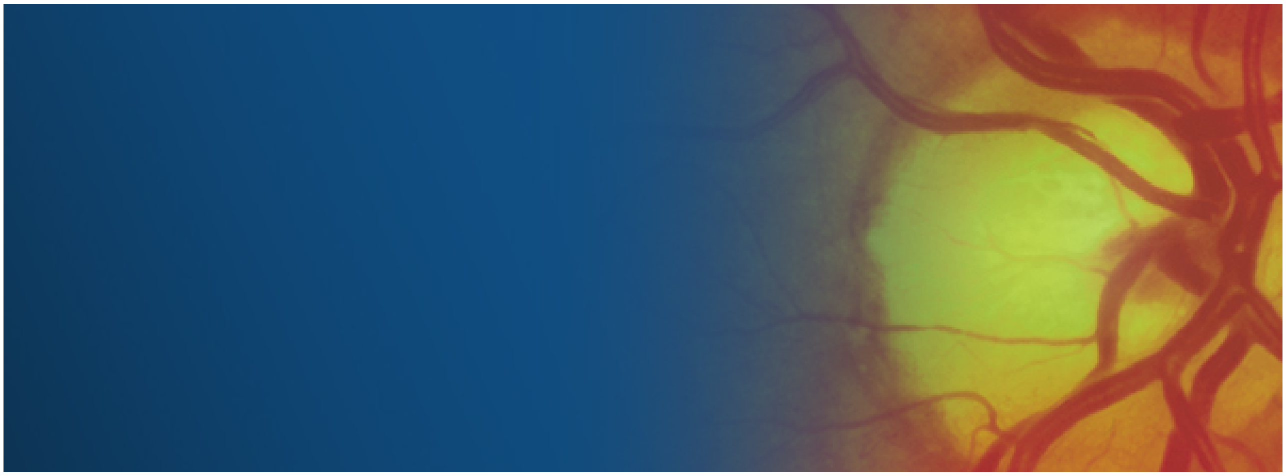
At the May 2024 Association for Research in Vision and Ophthalmology (ARVO) conference in Seattle, CRF joined other rare advocates at meetings hosted by Global Genes's RareX Vision Consortium and Retina International's Science Advisory Board Meeting. CRF also exhibited at this event for the second year in a row. Over 11,600 basic science researchers, clinical researchers, clinicians, surgeons, ophthalmology educators and students, and clinicians-in-training attended this international convening.

At the 2024 Dublin, Ireland, Retina International World Congress, Eric was an invited speaker on the role that patients play in advocacy and research. In June, Eric also attended the Foundation Fighting Blindness (FFB) Conference in Chicago. The FFB will be hosting the Retina International Conference in 2026 in the United States.

In October, Eric attended the National Organization for Rare Disorders (NORD) Patient Breakthrough Summit. This is an important gathering for rare patient advocates to help build collaboration and support to strengthen each members' organizations. NORD has partnered with the FDA's Critical Path Institute to help facilitate the use of patient data to advance research. Together they have formed an entity called the Rare Disease Cures Accelerator – Data and Analytics Platform (RDCA-DAP).

Immediately following the NORD event, Eric was invited to attend BIO's 13th Annual Patient & Health Advocacy Summit in Washington, DC. This was the CRF's first participation in this event which brings together stakeholders from industry and patient advocacy. Eric was able to sit down one on one with several leading pharma companies to discuss CHM research and potential avenues for collaboration.

CRF's Director of Patient Engagement Cory MacDonald also presented at a virtual meeting of the International Association of Audio Information Services (IAAIS) to educate their members about choroideremia. IAAIS is a volunteer-driven membership organization of radio and online audio information services that turn text into speech for people who cannot see, hold or comprehend the printed word and who may be unable to access information due to a disability or health condition. IAAIS currently represents 80-some services and developing services. CRF also provided members with several written and audio public service announcements the stations could read or play for their members to learn about CRF and choroideremia.



CHM Natural History Data

The CRF's greatest advocacy achievement for 2024 was collaborating with Biogen to upload its depersonalized CHM natural history data into the Rare Disease Cures Accelerator Data and Analytics Platform (RDCA-DAP). As a result, researchers from around the globe can now gain access to this data after participating in a stringent review process. This advancement was informed by extensive discussions between RDCA-DAP and the Choroideremia Research Foundation, identifying the critical need to improve understanding about CHM progression and make that information freely available to international scientists.

The two studies that are now available online include:

Efficacy and Safety of BIIB111 for the Treatment of Choroideremia (STAR)
Data Contributor: Biogen
Study ID: NCT03496012
Sponsor ID: NCT03496012

Natural History of the Progression of Choroideremia Study (NIGHT)
Data Contributor: Biogen
Study ID: NCT03359551
Sponsor ID: NCT03359551

If you are a researcher who seeks to access this data, please create an account here: **https://portal.rdca.c-path.org/**

2024 CRF Program Highlights

In Person:

During April 2024, CRF hosted a Regional Meeting for approximately 50 patients and family members in Dallas. In October 2024, a similar meeting was held in London for 100 attendees. At both meetings various speakers shared more information about CRF’s services, the latest research updates, and locally available supportive services for our visually impaired community members.

CRF also coordinated two research meetings over the past year including a Breakfast for members of our International Choroideremia Research Network (ICRN) at the Association for Research in Vision and Ophthalmology in May 2024. Around 50 scientists from around the world attended to hear four presentations by CRF’s funded researchers, as well as to network and discuss potential collaborations.

Shortly following that meeting, CRF helped to plan and support a CHM Scientific Symposium in Montpellier, France in conjunction with allied nonprofit organization France Choroideremie. This event was held in honor of FC’s 20th anniversary and featured an evening networking reception, a full day of scientific presentations, and a half day patient and family meeting. Twenty-seven researchers from 6 countries participated in the program.

CRF will also be hosting its next International Conference for patients and family members June 25-28, 2025, at the Radisson Blu, Mall of America, Minneapolis, MN. More information will be available soon – we hope you can join us!

2024 CRF Program Highlights

Online:

In total CRF has over 260 total videos posted with over 55,000 views on its Cure CHM YouTube Channel to date! Visit youtube.com/curechm to subscribe to updates today!

2023-2024 scientific webinars included:

- Outcome Measures in CHM Clinical Trials
- Photoreceptor Structure-Function Relationships in CHM
- Retinal Oxygen Metabolic Function in Choroideremia
- Improving Vision with Non-invasive Bioelectricity – A New Hope
- Investigating patterns of gene expression in choroideremia iPSC-RPE
- Intracortical Visual Prosthesis (ICVP) Research Study
- Biogen CHM Clinical Trial Findings! Meet Dr. Robert MacLaren
- Meet Samarendra Mohanty with Nanoscope Therapeutics
- Kiora Pharmaceuticals and the CRF

CRF also offers a variety of monthly opportunities to socialize online with fellow CHM family members via Zoom.

Regularly scheduled events include:

- Music Trivia
- Sports Trivia
- Beer Appreciation Club
- Book Club
- Moms of CHMers Chats
- CHMer Convos (twice a month! Europe and North American time zones)

All are welcome! Contact corymacdonald@curechm.org to register for future events!

Patient and Family Services

SOCIAL MEDIA

Facebook.com/curechm

2,500
Facebook Followers

X.com/curechm

3,200
X Followers

Instagram.com/curechm

536
Instagram Followers

LinkedIn.com/company/curechm

1,520
LinkedIn Followers

WHO WE SERVE

We currently communicate with **4,379** total CHM family members from nearly **60** countries! While there may be some overlap between groups, as many people fall into more than one category, this includes:

854 CHMers
521 Female Carriers
641 Parent of CHMer or Female Carrier
152 Child of Adult CHMer or Female Carrier
390 Spouse/Partner of CHMer
91 Spouse/Partner of Carrier
2,731 Other Relatives
(siblings, cousins, aunts/uncles, grandparents, grandchildren, etc.)

HOUSEHOLD MEMBERSHIPS

Last Year in Parenthesis

Free Members - **333** (310)
Annual Members - **67** (89)
Lifetime Members - **391** (341)
Total Members - **791** (740)

INDIVIDUAL MEMBERSHIPS

Last Year in Parenthesis

Free Memberships - **209** (209)
Annual Memberships - **23** (56)
Lifetime Memberships - **205** (205)
Total Memberships - **437** (470)

WE ARE IN TOUCH WITH CHM FAMILY MEMBERS FROM:

Algeria, Argentina, Australia, Austria, Bangladesh, Belgium, Bolivia, Bosnia and Herzegovina, Brazil, Canada, Chile, Columbia, Costa Rica, Croatia, Curacao, Czech Republic, Denmark, Dominican Republic, Finland, France, Germany, Great Britain, Greece, Hungary, Iceland, India, Iran, Iraq, Ireland, Israel, Italy, Jamaica, Kazakhstan, Kenya, Lebanon, Luxembourg, Mexico, Mongolia, Netherlands, New Zealand, Nigeria, Norway, Pakistan, Poland, Portugal, Russian Federation, Saudi Arabia, Serbia and Montenegro, Slovakia, South Africa, Spain, Sweden, Switzerland, Thailand, Turkey, Ukraine, United Arab Emirates, United States

Patient and Family Resources

One of the primary foundations of the CRF is its' network of support groups, resources and opportunities to network and connect and with CHM Family members, both one on one and in small groups. These include:

FACEBOOK

Over 1,500 CHM Family from around the world network, share experiences, support and resources. It's a great place to ask questions and get feedback from people who know what you are going through. Search for "Choroideremia (CHM)" on Facebook to subscribe to this private group.

WHATSAPP

For those not on Facebook, the CRF also has a private group via WhatsApp. Contact Cory MacDonald at corymacdonald@curechm.org to get the subscription link.

PATIENT TOOLKIT

On our website, you can learn about Home Adaptation, Lifestyle, Technology and other subjects related to a life with CHM. It can be found in the "For Patients and Families" section of the CRF website.

PRODUCTS AND SERVICES

Also in the “For Patients and Families” section, we have listings for suggested lighting, mobility and a host of other products and service to aid you in your day to day living.

CONNECTING WITH CHM FAMILY MEMBERS

Would you like to connect one on one with other CHMers, Carriers or Spouses of CHMers in your area? Contact Cory MacDonald to find out who may be near you.

More Information and Support: If you would like more information on any of the above, or would just like to speak to another CHMer, give us a call at
800-210-0233, extension 1.

WE ARE HERE TO HELP YOU!

CHM Family Accomplishments

Congratulations to CHMer and CRF Board Member Dr. John-Ross Rizzo who received a 2024 DOTTY Award presented by the Intelligent Transportation Society of New York.

Drs. Botond Roska and José-Alain Sahel have been awarded the 2024 Wolf Prize in Medicine for their pioneering work on restoring vision to blind patients using optogenetic therapy.

CHMer Aaron Everitt Published Turning a Blind Eye to the World Book.

CHMer Sam Harding finished 8th in the PTVI Triathlon at the Paralympic Games in Paris 2024.

The Thompson Family supported the Mesa Sprint Triathlon in honor of Team CHM and the Choroideremia Research Foundation.

Team Blake participated in the Smith Point Triathlon and collectively raised over $5,000 to support the CRF!

Christina Kostecki raised over $13,000 for CRF in an online fundraiser

Jon and Rachel Salois raised over $7,500 from a fitness fundraiser to support his New York Marathon run for Team CHM. Jon also finished the marathon with a personal best of 2:57:16!

The Holbrook family raised over $15,000 by coordinating a fitness class for donations and hosting a bake sale fundraiser!

Victoria, Andrew, Felix, Atticus & Talia have raised nearly $6,000 in their Absorb the Light fundraiser as they travel the world raising awareness of CHM!

At 46 years old, CHMer Tom du Preez hit a 225-lb clean PR at his first Adaptive CrossFit Games in the Men's Vision Division.

CHMer Pieter du Preez achieved a Bronze medal in Hand Cycle at the Paralympic Games in Paris 2024.

2024 11th Annual Million Dollar Bike Ride (MDBR) - Team CHM

Over $35,000 was raised by Team CHM in the 2024 MDBR, which was then matched with $30,000 from the Penn Orphan Disease Center to support research funding!

2024 TCS New York Marathon - Team CHM

31 runners and one guide represented TEAM CHM in the TCS New York City Marathon and raised over $110,000 to benefit CRF!

Financial Summary

Fiscal Year Financials

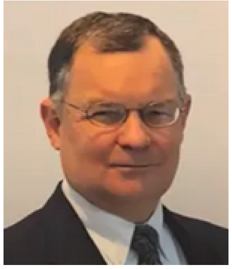
	Without Restrictions	Research Restricted	Fiscal Year 2024	Prior Year 2023
Revenue				
Direct Public Support	$611,406	$48,985	$660,391	$536,725
Investment Income, Net	$19,772	$18,887	$38,659	$24,108
Total Revenue	**$631,178**	**$67,872**	**$699,050**	**$560,833**

Expenses		
Patient and Family Education and Advocacy	$186,525	$238,673
Research Funding	$363,127	$359,320
Fundraising	$86,578	$90,989
Management	$53,248	$56,518
Total	**$689,478**	**$745,500**

Net Assets		
Total Net Assets Without Donor Restrictions	$381,801	$440,101
With Donor Restrictions		
• Research Restricted	$86,451	$39,096
• Peter G. Boone Endowment Fund	$342,559	$322,042
Total Net Assets With Donor Restrictions	$429,010	$361,138
Total Net Assets	**$810,811**	**$801,239**

(July 1 - June 30)

2023-24 Board of Directors



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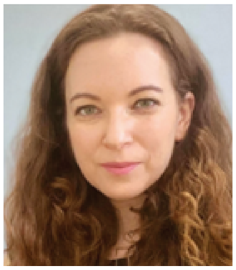

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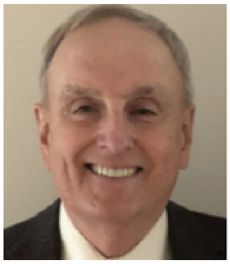

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Jacksonville, Florida

Liza Zumsteg, CPA
West Chester, Pennsylvania

2023-24
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Chair, Science Advisory Board, Choroideremia Research Foundation; Cardiothoracic Surgeon, Yavapai Cardiac Surgery

Prescott, Arizona

Chris Moen, MD

Accomplished Rare-Disease Patient Advocate & Healthcare Operations Executive, Choroideremia Research Foundation;

Wilmington, Delaware

Tomas Aleman, MD

Director of the Retinal Structure and Function Laboratory, Perelman Center for Advanced Medicine, Perelman School of Medicine, University of Pennsylvania

Philadelphia, Pennsylvania

Lauren Ayton, B. Optom, PhD, GCOT, FAAO

Principal Research Fellow Optometry and Vision Sciences at the University of Melbourne.

Melbourne, Australia

Brian Ballios, MD, PhD, FRCSC, DABO

Assistant Professor in the Department of Ophthalmology and Vision Sciences at the University of Toronto

Toronto, Canada

Kathleen Boesze-Battaglia, PhD

Professor, Assistant Dean for Academic Initiatives, Department of Basic and Translational Sciences, University of Pennsylvania, School of Dental Medicine

Philadelphia, Pennsylvania

Kim Edwards

Graduate Research Associate, Cellular and Molecular Pathology, Waisman Center (VCRGE), Gamm Lab, University of Wisconsin

Madison, Wisconsin

Malia Edwards, PhD

Assistant Professor of Ophthalmology, Johns Hopkins Medicine

Baltimore, Maryland

Rachel Huckfeldt, MD, PhD

Academic Vice Chair, Science Advisory Board, Choroideremia Research Foundation; Physician and Surgeon and Director, Inherited Retinal Degenerations Fellowship, Massachusetts Eye and Ear; Assistant Professor of Ophthalmology, Harvard Medical School

Boston, Massachusetts

Jasleen Kaur Jolly, DPhil, MSc, BSc (Hons), MCOptom

Senior Clinical Research Fellow, Oxford Neuroscience

Cambridge, UK

Vasiliki Kalatzis, PhD

Group Leader of “Gene Therapy of Retinal Dystrophies” within the Team 01 “Genetics of Retinal and Optic Nerve Blindness” directed by Pr Christian Hamel at the Institute of Neurosciences of Montpellier

Montpellier, France

Maureen McCall, PhD

Academic Chair, Science Advisory Board, Choroideremia Research Foundation; Professor & Vice Chair for Research, Department of Ophthalmology & Visual Sciences, School of Medicine, University of Louisville

Louisville, Kentucky

Ruchi Sharma, PhD

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Bethesda, Maryland

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Sharon Lab, Department of Ophthalmology, Hadassah-Hebrew University Medical Center

Jerusalem, Israel

Divya Sinha, PhD

Scientist I, David Gamm Laboratory, Waisman Center, University of Wisconsin

Madison, Wisconsin

Stephen Tsang, MD, PhD

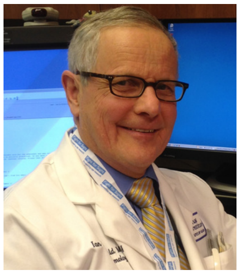
Professor of Ophthalmology and Professor of Pathology and Cell Biology, Columbia University

New York, New York

Ajoy Vincent, MBBS, MS

Staff Ophthalmologist, Ophthalmology and Vision Sciences; Medical Director, Visual Electrophysiology Unit; Associate Scientist Genetics and Genome Biology Research Institute, The Hospital for Sick Children

Toronto, Canada



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Professor Emeritus, Department of Ophthalmology and Visual Sciences, University of Alberta; Director, Department of Ophthalmology, University of Montreal

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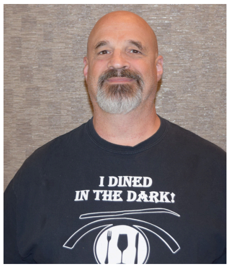

Cory MacDonald

Engagement Director

Springfield, Massachusetts

2024 Great Non-Profits “Top Rated” Charity Status

Highest Platinum Rating from Charity Watchdog Group Candid/Guidestar

100 of 100 score from Charity Navigator – “Give with Confidence”

Thanks to Our Fundraisers!

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Every effort has been made to recognize donors correctly. We apologize for any omissions or errors. If we need to make corrections to your listing, please call us at 800-210-0233, ext. 1 or email us at info@curechm.org.

Planned Giving

Remember the Choroideremia Research Foundation in your estate or with a planned gift to strengthen research efforts to find treatments and a cure so that future generations may never experience vision loss caused by CHM. For more information on making a bequest, gift of stock, gift of life insurance or IRA, please contact Kathi Wagner, CRF's Executive Director, at kathiwagner@curechm.org or (800) 210-0233, Ext 5.

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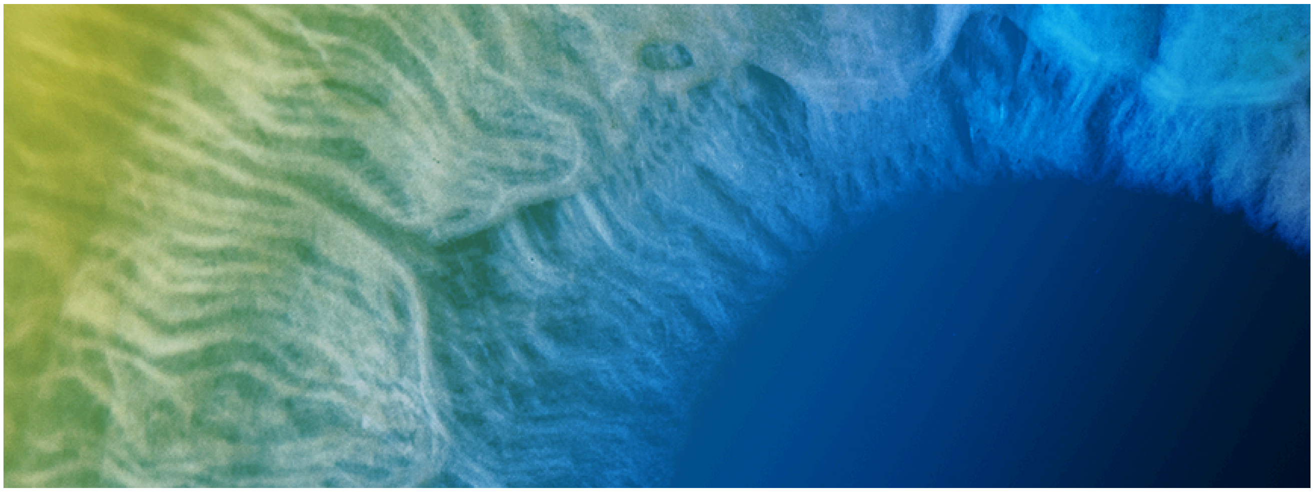
- Bequests
- Stocks
- Life Insurance
- IRA Charitable Contribution

> "CRF is a fantastic organization for both research and community-building for those living with Choroideremia. They are truly passionate about their mission and bring so much hope to families who need it."
>
> —— General Member of CRF, Sept. 2024
>
> ★★★★★



Eye Donation Program

As an eye donor, gifting your eyes for choroideremia (CHM) research after your death is a heroic act. By studying this donated tissue, researchers will better understand the disease pathology and strive to develop new treatments and a cure for CHM.

To facilitate this effort, the Choroideremia Research Foundation has initiated a new collaboration with Eversight, a nonprofit organization whose mission is to restore sight and prevent blindness through the healing power of donation, transplantation, and research. Via Eversight, male CHM patients and female CHM carriers can donate their eyes for research in the states of MI, IL, OH, NJ and CT. Eye donation in other states or countries may be arranged through local eye banks that are members of the Eye Bank Association of America and the Lion Clubs InternationalEye Banks.

To learn more about becoming a CHM eye donor, visit
https://www.curechm.org/research/#eye

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Choroideremia
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