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The Choroideremia Research Foundation (CRF) Marks 25 Years of Progress, Research, and Community Support

The CRF marks 25 years of research and global support. Founded in 2000, CRF has funded $6M in research and connected families in 60 countries.

SPRINGFIELD, MA, UNITED STATES, September 17, 2025 / EINPresswire.com/ -- The Choroideremia Research Foundation (CRF), the world's largest organization solely focused on choroideremia (CHM), proudly commemorates its 25th Anniversary this year. Since its founding in 2000, CRF has raised millions to fund groundbreaking research, fostered a strong global network of families and scientists, and provided unwavering hope to those living with CHM.

CRF leaders and researchers unite to drive progress in choroideremia research. Pictured (left to right): two collaborating researchers with H. Eric Hartman, CRF Director of Advocacy; Cory MacDonald, CRF Engagement Director; and Jason McKinney, MBA, Board of Directors.

What is Choroideremia?
Choroideremia (CHM) is a rare, inherited retinal-degenerative disease that causes progressive vision loss and eventual blindness. Affecting approximately 1 in 50,000 people, CHM primarily impacts males due to its X-linked inheritance pattern, though female carriers may also experience vision problems.

Our Challenges Don't Define Us. Our Actions Do.

Founded by a small group of individuals affected by CHM, CRF was built on determination, collaboration, and the belief that progress is always possible. Today, the foundation continues its mission:

- To raise funds in support of scientific research leading to a treatment or cure.
- To educate families affected by CHM.
- To inform the public and build global awareness.

25 Years of Milestones

Since 2000, CRF has achieved extraordinary impact, including:

- 25 years of community and support
- $6 million invested in research
- 100+ research grants awarded
- 4,375+ CHM family members connected
- CHM families in 60 countries
- 7,375+ social media followers
- Recognition as the #1 CHM organization worldwide

“Our progress over the past 25 years would not be possible without the incredible dedication of families and supporters. Every donation, every fundraiser, and every post shared on social media helps move our mission forward.” — Reagan Devinney, CRF Communications and Development Manager

Research and Achievements

Over the past two decades, CRF has funded pivotal early-stage research projects that helped establish the foundation for today’s clinical trials—including the first CHM mouse model, induced pluripotent stem cell (iPSC) models, and the creation of a human CHM cell biobank. These investments directly supported the launch of three clinical trials in gene therapy.

Guests and supporters gathered for CRF’s Dining in the Dark — one of the Foundation’s most impactful and inspiring fundraising events.

Team Blake members of Team CHM gather for a celebratory selfie at the Smith Point Sprint Triathlon, showing their strength and unity in the fight against choroideremia.

In 2021, CRF spearheaded the International Choroideremia Research Network (ICRN), now composed of nearly 140 multi-disciplinary vision researchers across 25 countries. This alliance accelerates collaboration and advances scientific understanding of CHM.


CHM families come together at a regional CRF meeting, connecting, sharing experiences, and building community.

Looking ahead, CRF is exploring cutting-edge avenues such as pharmaceutical therapies, optogenetics, neuroprotection, RNA/DNA editing, stem cell therapy, bionic vision technologies, and sight replacement therapies.

Beyond research, CRF has hosted patient and family conferences, scientific symposia, regional events worldwide, and ongoing webinars to provide resources, education, and community support.

Membership: Fueling the Future
As CRF celebrates its 25th year, it is calling on families, advocates, and allies to join its mission by becoming members:

Free Membership: Stay informed with no financial commitment.
Standard Membership ($60/year or $5/month): Includes voting rights, discounts, and personal outreach.
Lifetime Membership ($600 one-time): Includes all benefits plus a welcome swag pack and exclusive invitations.

“Becoming a CRF member is a powerful way to fuel research, connect with the CHM community, and stay informed,” said Cory MacDonald, CRF Engagement Director.

Learn more or become a member: https://www.curechm.org/for-patients-families/#membership
Make a 25th Anniversary donation: https://curechm.salsalabs.org/crf25

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About Choroideremia:

Choroideremia (CHM) is a rare inherited form of blindness affecting approximately 1 in 50,000 people. Due to its x-linked inheritance pattern males are most severely affected with females usually experiencing much milder visual impairment. Symptoms begin in early childhood with night blindness and restriction of visual field being the earliest noticeable effects, eventually progressing to complete blindness. An estimated 6,000 people in the United States and 10,000 in the European Union are impacted by Choroideremia. There are currently no approved treatments for Choroideremia. For more information, visit curechm.org/#choroideremia

About the Choroideremia Research Foundation Inc.:

The Choroideremia Research Foundation was founded in 2000 as an international fundraising and patient advocacy organization to stimulate research on CHM. Since its inception, the CRF has provided approximately $6 million in research awards and is the largest financial supporter of CHM research worldwide. Research funded by the CRF has led to the development of a CHM animal model, the pre-clinical production of gene therapy vectors currently in clinical trials, and the CRF Biobank which stores tissue and stem cell samples donated by CHM patients.

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