The Choroideremia Research Foundation’s Mission

To raise funds in support of scientific research leading to a treatment or cure of choroideremia, a hereditary retinal-degenerative disease that causes blindness; to educate people affected by the disease; and to inform the public.

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President’s Letter

I would like to thank all of those who donated to the CRF throughout the year and those who offered their time in support of continuing our efforts in research and patient programming. We only move forward with everyone’s help. A special thanks is in order for Dr. Chris Moen, our President over the last five years, who stepped down in June. Chris guided us into the gene therapy trials, and was instrumental in moving us ahead as an organization.

This year has seen a number of significant transitions, some by choice and some not. We witnessed the passing of Randy Wheelock in March, 2019. Randy, and his tireless work for the CRF, were and still are a driving force behind the research networking and communication that has and will benefit all CHM patients. The CRF has created an annual CRF Randy Wheelock Research Award, with plans to select recipients who are doctoral candidates or post-doctoral scientists working on CHM. We miss you, Randy.

In June, the CRF was fortunate to find and add Kathi Wagner to our organization as our Executive Director and fundraiser. She has extensive experience in both the non-profit medical and research arenas. She is a pleasure to work with and in just a few months has advanced the CRF both internally and externally. The CRF created a position of Chief Medical Officer, and was very pleased that Dr. Chris Moen agreed to be the first to represent the CRF in that role.

We look forward to following up our most recent International Science Symposium held in Philadelphia last June, with CRF 2020, our biennial International Conference that will take place June 24 – 27 in Rochester, NY. It is our 20th year of working towards a cure. We hope to enjoy record attendance and I hope to see many of the CRF family there.

Neal Bench
CRF President
Striving for 180 degrees of Vision
Executive Director’s Letter

When I first became aware of the Choroideremia Research Foundation last spring, I was immediately impressed with how much the organization had accomplished since its inception, especially considering it had been operated primarily as a volunteer-driven entity for the past 20 years.

Further, when I had the chance to meet board members personally, they were all so friendly and welcoming, so receptive to new ideas and forward-thinking, that I knew right away I wanted to become a part of this community.

I see so much hope on the horizon as exciting new scientific discoveries in gene and cell therapy are accelerating the pace of clinical trials. As CRF continues to expand its communications and marketing, more funding is becoming available, and additional collaborations are being established to further our global impact.

As CRF enters its 20th year of service, there have been many remarkable achievements to date. I am honored to have been accepted into the CHM “family” and look forward to building on this momentum to make the organization’s next 20 years of service even more successful.

Kathi Wagner
Executive Director
Chief Medical Officer’s Report

2019 marked another successful year for CRF in its support of research activities toward a treatment for CHM. The year kicked off with the announcement of the first awardee through the Million Dollar Bike Ride program, a matching grant program sponsored by the University of Pennsylvania.

CRF leadership held its second International Scientific Symposium in Philadelphia bringing together experts from around the globe to share ideas and further support the CRF research vision.

The Foundation attended a number of meetings and scientific conferences, meeting with academic and industry leaders to support ongoing research activities and begin identifying new, promising opportunities. CRF also took the step to rejuvenate its Science Advisory Board, bringing in fresh faces and new ideas to guide the Foundation toward its goal of ending blindness from CHM.

Lastly, CRF continues to fund high-quality research programs from exemplary, internationally respected scientists who have dedicated themselves to helping us better understand CHM and develop potential treatment options. In short, we close the year of great productivity and look toward continued progress into 2020.

Christopher Moen, MD
Chief Medical Officer
2019 Achievements

Research, Clinical Trials and Ongoing Studies

Since the inception of the Choroideremia Research Foundation in 2000, CRF has provided 45 grants totaling over $3 million in research funding to find treatment options and a cure for Choroideremia (CHM). Recent grants have included:

**$40,000**

2018 David Gamm, MD, PhD, Director, McPherson Eye Research Institute; Associate Professor, Ophthalmology and Visual Sciences Waisman Center, University of Wisconsin, Madison, WI

Determining the Downstream Consequences of Endogenous REP1 Activity in Human RPE and Photoreceptor cells

**$107,823**

2018 Miguel Seabra, MD, PhD, Professor, CEDOC, Chronic Diseases Research Center Nova Medical School, University of Lisbon, Portugal

How CHM Defect Affects Cross Talk Between Organelles and Cellular Functions such as Mitochondria, Lysosome, Autophagy, and Proteostasis
2018-19 Fiscal Year Achievements

$100,000
2018 Jason A. Mills, PhD and Kathleen Boesze-Battaglia, PhD, MDBR Grant Program, Orphan Disease Center, University of Pennsylvania
Targeting Phagosome Maturation to Restore Dysfunctional Retinal Pigmented Epithelium in CHM (in conjunction with University of Pennsylvania Orphan Disease Center’s Million Dollar Bike Ride)

$75,000
2019 David Gamm, MD, PhD, Director, McPherson Eye Research Institute; Associate Professor, Ophthalmology and Visual Sciences Waisman Center, University of Wisconsin, Madison, WI
Elucidating the function of REP1 in human pluripotent stem cell-derived RPE and photoreceptor cells

$101,983
2019 Miguel Seabra, MD, PhD, Professor, CEDOC, Chronic Diseases Research Center Nova Medical School, University of Lisbon Portugal
Mechanisms of Cell Death in Choroideremia

To view a full list of research funded to date, visit: https://curechm.org/research/#_funded
As part of the $3 million provided in research funding to date, CRF has supported crucial research that led us to where we are today with gene therapy.

In Fall 2019, the final patients in Biogen’s Phase III STAR gene therapy clinical trial (formerly operated by Nightstar Therapeutics) were treated. These patients, like all those before them, will be followed for one year. At that point, the data will be compiled and brought before the FDA for review and potential approval in 2021. Biogen is also continuing the GEMINI Phase 2 study to determine the safety of bilateral sequential gene therapy for choroideremia.

Spark Therapeutics continues to follow and collect data from their Phase I/II Gene Therapy Clinical Trial participants.

4D Molecular Therapeutics concluded their Natural History Study in early 2019, and has developed a novel viral vector for their gene therapy which is scheduled to begin a Phase I Clinical Trial in 2020.

Participation in CRF's Patient Registry increased 52% between 2018 and 2019 and CHMers from 37 countries are now represented! Individuals who sign up for the registry will be notified about new clinical trials and studies and provided with the opportunity to participate in research surveys. To join the registry, visit: curechm.org/get-involved/#registry
2018-19 Fiscal Year Achievements

Advocacy and International Outreach

During 2018 and 2019, CRF represented the voice of choroideremia patients at 17 different advocacy and education events either as an attendee, speaker, exhibitor, or sponsor. Events included:

- American Academy of Optometry Conference
- American Society of Gene and Cell Therapy International Conference
- Association for Research in Vision and Ophthalmology Conference
- Classy Collaborative
- Envision Conference
- Food and Drug Administration Public Hearing on Rare Disease Patient Perspectives and Finding Commonalities
- Global Genes Rare Patient Advocacy Summit
- Harvard Medical School Symposium on Ocular Cell Restoration
- National Eye Institute 50th Anniversary Panel for Education Initiative Inherited Retinal Disorders
- National Institutes of Health Rare Disease Day
- National Society of Genetic Counselors
- National Organization for Rare Disorders (NORD) Rare Disease and Orphan Drug Summit
- Ocular Genetic Counselors Conference
- Ophthalmic Genetics Study Club San Francisco
2018-19 Fiscal Year Achievements

- Pro Retina Frankfurt Germany Choroideremia Patient Symposium
- Rare Disease Film Festival
- Rare Disease Week on Capitol Hill with RDLA
- UK Eye Genetics Group Meeting Glasgow
- USA Today article interview “Eye Want To Know“
- World Orphan Drug Congress

In addition to participation in the above outside meetings, CRF hosted three of its own meetings including the Duke Regional Meeting in April 2019, the International Scientific Symposium in Philadelphia in June 2019, and the UK Regional Meeting in London in November 2019. These events helped to provide education, networking and collaboration opportunities for CHMers, family members and researchers alike.
2018-19 Fiscal Year Achievements

Moving Forward

As CRF enters its 20th year of service in 2020, the organization has become well-poised for further success. In addition to the development of a comprehensive Strategic Plan in 2018 (view at https://curechm.org/who-we-are/#financials), CRF hired its first full-time Executive Director in June 2019, appointed a Chief Medical Officer, and expanded the Science Advisory Board to 13 members.

Towards the end of 2019, the organization launched a new, more robust website, and enhanced its infrastructure by purchasing a new integrated database, transaction processing, and email tool that will significantly improve the ability to communicate with constituents. Grant funding was also received from Allergan and Biogen to allow CRF to train staff and volunteers to facilitate educational webinars in 2020. This new decade will also begin with the hosting of CRF’s 2020 International Conference in June, the addition of one new part-time marketing staff member, and exciting new fundraising opportunities including bibs for the 2020 NYC Marathon and other Team CHM events. CRF also hopes to update its membership program to provide new incentives and benefits for those who commit to participation.

The future is extremely bright and hopeful with CHM patients as new treatment options may soon be on the horizon. As an organization funded nearly 100% by charitable donations, the Choroideremia Research Foundation is incredibly grateful for the ongoing and continuing support of our generous donors.
Fundraising

CRF fundraising efforts have been trending upwards thanks to our generous recurring donors, event coordinators, and special appeal contributors:

**Calendar Year Giving**
January 1 - December 31, 2019

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Testimonials

“CHM has given me a better appreciation of life and I have learned to celebrate the good things. Instead of thinking “someday” I’ll do that, I say “let’s do it now while I can”. I am absolutely thrilled to continue to hear about the ongoing research from so many different avenues. When we were diagnosed 10+ years ago, gene therapy trials were a distant goal but we are now there and I truly believe there will be a treatment soon.”

Barb Cameron
New Berlin, Wisconsin

“CHM has to some extent constrained my independence and makes it increasingly necessary to rely on others. It motivated me to educate myself and eventually start the CRF, with which I have been working since the beginning. Founding the Choroideremia Research Foundation has meant hope for my daughter, my brother, and my friends. Now, CRF needs to accomplish the mission and not get sidetracked by anything or anyone.”

John Oster
Rochester, New York
Testimonials

“Roughly 2 years ago, Jason was told the name of his disease and that he would eventually lose his vision. My heart sinks a little every time he says he doesn’t want kids if he can’t see them. I will always be there for him to count on, but I don’t want him to lose confidence when struggling to do things he has done all his life. The CRF has been extremely supportive, they are family and a community that understands what you’re going through. CRF makes me HOPEFUL!”

Jason Folie and Krista Kramer
Waseca, MN

“Learning to use a mobility cane and letting go of my pride to be able to use the cane was the first major hurdle. It was difficult to openly show the world I was “broken”. I have gone from hoping for a treatment, to the point that I expect there to be a treatment that will keep new generations of CHMers from losing their sight. This is all thanks to the CRF. It brings tears to my eyes as I consider the extended family the CRF has offered me. The ability to contribute to research efforts and be informed of the latest developments is incredible.”

Lin Ogg
Bedford, Texas
Staff

Beth Foss  
Director of Operations

Eric Hartman  
Director of Advocacy

Cory MacDonald  
Engagement Director

Kathi Wagner  
Executive Director

Board of Directors

Neal Bench  
President  
Chapel Hill, NC

John Trott  
1st Vice President  
Westfield, NJ

Michael Mullen  
2nd Vice President  
Carmel, IN

Tara Cassidy-Driscoll  
Treasurer  
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Brian Mayer  
Secretary  
Brookfield, IL

Chris Moen, MD  
Chief Medical Officer  
Wilmington, DE

Jason McKinney  
Officer At-Large  
Gilmer, TX

John Oster  
Officer At-Large  
Rochester, NY
Directors

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Washington, NJ

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Swampscott, MA

Tim Galvin, PhD
Australia

Sue Kazmierczak
Hammond, WI

Michael Langsfeld
Germany

Dan Peterson
Trimont, MN

Bob Pettipaw
Sublimity, OR

Angela Ricketts
St. Louis, MO

Craig Rowley
Jay, ME

Stephanie Sims,
MD
Jacksonville, FL
Scientific Advisory Board

Ian Macdonald, MD (Chair)
Professor, Department of Medical Genetics,
University of Alberta
Edmonton, Alberta, Canada

Tomas Aleman, MD
Associate Professor of Ophthalmology
at the Hospital of the University of
Pennsylvania, Perelman School of Medicine,
University of Pennsylvania
Philadelphia, Pennsylvania

Kapil Bharti, PhD
Senior Investigator, Ocular and Stem Cell
Translational Research Unit, National
Institutes of Health, Intramural Research
Program
Bethesda, Maryland

Sanford Boye, MS
Associate Scientist, Department of
Ophthalmology, Shannon E. Boye
Laboratory, University of Florida Health
Gainesville, Florida

Shannon Boye, PhD
Associate Professor, Department of
Ophthalmology, Shannon E. Boye
Laboratory, University of Florida Health
Gainesville, Florida

Frans Cremers, PhD
Professor, Ophthalmogenetics, Department
of Human Genetics and Donders Institute
for Brain, Cognition and Behaviour,
Radboud University Medical Center
Nijmegen, Netherlands

Jacque Duncan, MD
Professor in Ophthalmology, University of
California San Francisco
San Francisco, California

Rachel Huckfeldt, MD, PhD
Associate Surgeon and Director, Inherited
Retinal Degenerations Fellowship,
Massachusetts Eye and Ear; Assistant
Professor of Ophthalmology, Harvard
Medical School
Boston, Massachusetts

Alex Iannaccone, MD, MS, FARVO
Director, Center for Retinal Degenerations
and Ophthalmic Genetic Diseases, and
Professor, Ophthalmology, Duke University
Department of Ophthalmology
Durham, North Carolina

Mark Pennesi, MD, PhD
Assistant Professor in Ophthalmic Genetics,
Oregon Health and Science University
(OHSU) Casey Eye Institute
Portland, Oregon

Stephen Tsang, MD, PhD
Professor of Ophthalmology and Professor
of Pathology and Cell Biology, Columbia
University Department of Pathology and Cell
Biology
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, Ontario, Canada

Michael Young, PhD, FARVO
Associate Professor of Ophthalmology,
Co-Director, Ocular Regenerative Medicine
Institute; Director, Minda de Gunzburg
Center for Retinal Regeneration, Harvard
Medical School; Associate Scientist,
Schepens Eye Research Institute of
Massachusetts Eye and Ear
Boston, Massachusetts
## Financial Summary

**Financial Summary, July 1, 2018 – June 30, 2019**

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| Change in Net Assets                  | $60,560 |
| Net Assets (Beginning of Year)        | $833,614 |
| Net Assets (End of Year)              | $894,174 |
Donors

July 1, 2018-June 30, 2019

$10,000 & Above
4D Molecular
  Therapeutics
Hugh Hutchison
Mary Porter
Jennifer Rakvin

$5,000- $9,999
Jeff Benelli
Ed Lucas Foundation
John Oster
PayPal Giving Fund
Matthew Ricketts
David Rumpel
Joe Salois
Cassey Smith
Spark Therapeutics
Mihails Zeligmans

$1,000- $4,999
Amazon Smile
Stephen Appelbaum
Apple, Inc.
Atlas Distributing, Inc.
Bank Of America
  Foundation
Stuart Banks-Innes
  Barbara Barr
William Bauer
  Maria Bautista
Chris Bellon
Bruce Bench
  Neal Bench
Jean Bennett
Stephanie Benson
Glyn Boone
Daniel Boren
Milly Boren
Jay Boyle
Stephen Brennan
  Sheila Briscoe
Keith Cameron
Marilyn Cassidy
Steve Cole
Cornell Dubilier
  Electronics, Inc.
Daniel Crossland
Jeani Cunningham
Christopher
  Development
Edgemere
  Development, Inc.
Ruth Edwards
  Eyecare Partners LLC
Kelly Fayer
John Fenner
Andrew Foley
  Bob Foss
Gannett Foundation
Scott Garrison
George E. Walker Trust
Ann Gillespie
Charles Gleason
Kimberly Heitert
Sondra Hoffman
Daniel Houlihan
Michael Kane
Josh Kunz
Landry Commercial
Cory MacDonald
Kevin McCarthy
Thomas McMullen
Meidinger Family
  Charitable Fund
Alisa Moen
Michael Mullen
Laura Ogg
Loron Oster
Dan Peterson
  Bob Pettipaw
Bernice Pettit
John Polkowski
PTC Therapeutics
Marty Reiss
Louise Richards
Ross Rizzo
Earl Russell
Cathy Salois
Joanne Salois
Joe Salois
Mary Schulte
Schwab Charitable
Suzanne Sullivan
Sarah Thompson
Vrishali Thorat
Mick Throssell
John Trott
Daniele Vetere
Jeff Warner
Well's Fargo
  Philantropy Fund
Marna Whittington
William Richard
Wilson
### Donors

**$500-$999**

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