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PRESIDENT’S LETTER

Dear Friend of the Foundation,

“With CRF, our vision is the future!” We’re so grateful for your support in enabling this vision, both as today’s breakthroughs and as tomorrow’s landmark achievements.

I’m incredibly pleased and gratified to present the CRF’s first Annual Report to you, our loyal donors and supporters. I’m grateful to those of you who have supported the Foundation financially, and to those of you who have also shared your time and expertise to carry forward our mutual achievements.

As you’ll discover in the following “Highlights,” Fiscal Year 2017-18 has been a tremendously exciting period at CRF – a time when we’ve witnessed increases in new patients and our patient registry enrollment, the arrival of new CRF staff to drive research and programming, and record attendance at the 2018 conference in Dallas.

I’d like you to join me in celebrating the breadth of our achievements together – from a Strategic Plan reaffirming our Mission of research, education, and engagement; to varied and proactive strategies for research; family engagement and new patient outreach; advocacy and awareness; organizational growth for Mission impact; and partnering to leverage our strengths, both internationally and here in the U.S.

And in closing, I invite you to share this news of our work and investment together – with friends and family, neighbors and colleagues, and all those who can join us in our Mission and our quest.

Thank you once again for your ongoing support!

Christopher Moen, MD,
President of the Board
2018 ACHIEVEMENTS

Research

Early and ongoing investments and efforts are moving us closer to effective treatments for Choroideremia (CHM). As of 2018, we have awarded over $2.5 million to support research on causes and potential treatments. The CRF-funded biobank created from CHM patient samples is being used by researchers and sponsors in the US, Europe, and Canada. Two key collaborative projects are exploring the retina degeneration process to identify other treatment options, and new approaches for delivery of improved therapeutic agents for CHM.

Gene Therapy Clinical Trials

There are now clinical trials in several stages. Nightstar Therapeutics is now in phase 3 studies; Spark Therapeutics has completed phase 1-2 studies; and 4D Molecular Therapeutics expects to begin clinical trials in 2019. The CRF works with companies to connect them with our community; we play an essential role in recruiting study participants and study sites; we provide the patient voice to investigators to aid in study design; and we actively provide family and patient support.
2018 ACHIEVEMENTS

Partnering for Advocacy and Awareness

There are now over 30 entities working on various aspects of CHM studies and trials. We are working to build upon relationships with key figures at the FDA, EMA and the National Eye Institute and will be more than doubling the size of our Scientific Advisory Board. On Capitol Hill, CRF joined in advocacy that resulted in the recent $31 million increase in federal funds for retinal research. Our staff presents at conferences and panels across the U.S. and internationally. We represent patient needs as we address regulatory challenges for ongoing retinal disease research.

Million Dollar Bike Ride

In a fundraising event hosted by University of Pennsylvania's “Orphan Disease Center,” Team CHM surpassed the $50,000 match challenge, raising $76,000 plus, for a total of $126,000. The Million Dollar Bike Ride brings over 500 cyclists and volunteers to Penn’s campus to ride several circuits across the Greater Philadelphia region. In four years, the MDBR’s 25+ teams have raised over $6.4 million to fund research grants on the diseases they represent. Team CHM volunteers are slated to compete here again on June 8, 2019.
2018 ACHIEVEMENTS

Biannual Conference
Last June’s Dallas Conference was our most successful to date, showing dramatic growth in both offerings and attendance – over 250 attendees. The event provided an incredible opportunity to learn about treatments in the pipeline, gain a more in-depth understanding of CHM, and connect with an amazing network of individuals and families who are also impacted by Choroideremia. Presenters included industry leaders such as NightStar, SPARK Therapeutics, 4D Molecular Therapeutics, Roche, and PTC Therapeutics.

Retinal Specialist Outreach
We empower specialists providing critical information for newly diagnosed CHM families. We’ve designed an innovative project to connect with patients through retinal and allied health specialists across the U.S., enabling us to welcome as many new families as possible and to support them as early as possible in their experience with Choroideremia.
2018 ACHIEVEMENTS

Regional “CHM Family” Meetings
We’re now reaching out to our American CHM family through three regional meetings around the country. These highly-personalized, patient- and family-centered events share CHM research news, provide tools and support, greet new CHM families, and engage affected CHMers and families in creating solutions in their communities.

Partnering for Impact
We continue to capitalize on strong relationships. With support from 4D Molecular Therapeutics, a world-leader in the discovery and development of next-generation gene therapy products, CRF is now building an initial partnership with Roche Pharmaceutical, the world's largest investor in pharmaceutical research and development. We continue to work with Spark Therapeutics, Nightstar Therapeutics, and other companies with active CHM programs, and we are continually networking with others whose work could translate to a treatment for Choroideremia.
2018 ACHIEVEMENTS

International Role
CRF’s mission is international in scope, serving Choroideremia patients worldwide. We convene and sponsor CHM research in many countries, include international representatives on our Board of Directors; and travel and partner to share our mission globally. Fiscal Year 2017-18 saw the launch and promotion of CRF’s new international CHM patient registry (CHMregistry.org), as well as plans for presentations at the CHM Frankfurt conference and three major, global summits in the U.S.

CRF’s 2019 International Choroideremia Symposium
2018 saw initial planning for our biannual scholarly Symposium in Philadelphia, PA. The Symposium aims to advance discourse and collaborative thinking among international experts in Choroideremia and related inherited retinal dystrophies.

Organizational Growth
With our recent Strategic Plan, CRF’s Board set the course to build organizational capacity, focusing on increased mission impact and long-term sustainability. We’ve engaged additional staffing to further develop infrastructure and maximize the potential for reaching established goals.
CRF HELPED BRING ME FROM A PLACE WHERE I WAS ALONE INTO A FAMILY THAT WAS THERE TO HELP.

My first introduction to the CRF was at the Chicago Conference in 2006. Since my experience at that conference, I felt accepted, understood, and included. I was not alone facing a rare eye disease that was stealing my vision, I was now part of something bigger. The CRF helped to bring me from a place where I was facing CHM alone into a family that was there to help. The CRF is more than a group of CHMers getting together to raise money for research, it's also a family that provides support, advocacy, and hope. I have had the privilege of watching the CRF grow over the years, and each time we get together at a conference, we get bigger and stronger. There is great strength in a group of individuals getting together for a common purpose. As a CHMer, you are 1 in 50,000. With the CRF, you are a part of an international organization that was formed to help. This incredible group of individuals has taken our cause to a whole new level, and we have already taken huge steps in the right direction. It has gone from "sorry there is nothing that can be done for you" to ground-breaking research that brings us closer to a cure each day! It's great to be a part of it!

Brian Mayer, Member of the Board of Directors (& Affected CHMer)
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Director of Fund Development

H. Eric Hartman
Director of Advocacy

Beth Foss
Director of Operations

Cory MacDonald
CHM Family Engagement Director
## FINANCIAL SUMMARY

Financial Summary, July 1, 2017 – June 30, 2018

<table>
<thead>
<tr>
<th>Revenue</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Revenue</td>
<td>$568,000</td>
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</table>

<table>
<thead>
<tr>
<th>Operational Expenses</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Research and Grants</td>
<td>$213,000</td>
</tr>
<tr>
<td>Research &amp; Education Conference</td>
<td>$68,000</td>
</tr>
<tr>
<td>Programming and Outreach</td>
<td>$72,000</td>
</tr>
<tr>
<td>Administration &amp; Fundraising Costs</td>
<td>$83,000</td>
</tr>
<tr>
<td>Total Expenses</td>
<td>$436,000</td>
</tr>
</tbody>
</table>

Net Balance for Capacity Building and Future Operations $132,000
Being involved with the Choroideremia Research Foundation has brought so much hope to my family. As the mother of a child affected by CHM, it means so much to be connected to other mothers and fathers who are on the same journey. We support each other through tough times and remind each other of all of the amazing research and progress being made towards a cure!

Stephanie Sims
DONORS

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July 1, 2017-June 30, 2018
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July 1, 2017-June 30, 2018

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Dealing with the thought of going blind can be an overwhelming and lonely experience, but I am extremely thankful to the CRF for giving me multiple ways to handle that experience. At the CRF’s biannual conferences I have shared stories, frustrations, and laughs with other men affected by Choroideremia who in turn showed me that I was not alone in my struggles. That experience is unique and healthy, and I encourage everyone to attend! Additionally the CRF has given me the opportunity to stay current and support research towards a cure which is exciting and gives me great hope for the future!

Peter Boone, Affected CHMer
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Paolina Atanassova
As a wife to a man that has CHM, the word ‘caregiver’ wasn’t a label I associated myself as being. I didn’t think too much about it. In fact I often forget Lin is blind because he is so independent. When Lin found the CRF, he was so ecstatic in finding others like him. No one should ever be alone. My purpose in being a better wife has been repurposed through the CRF by knowing other wives/caregivers. I was given a caregiver book by Beth Foss’ mom at one our conferences. I have cherished this book and made me realize we have a deeper purpose in supporting our guys. There is an invisible strong hold among us wives and yet we don’t need to talk about; but just know the support is there.

Laura Ogg, CRF wife and former Treasurer
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Every effort has been made to recognize each donor 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.