CHOROIDEREMIA RESEARCH FOUNDATION

STRATEGIC PLAN

Document Revisions

<table>
<thead>
<tr>
<th>Date</th>
<th>Author</th>
<th>Board Approval Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>6/8/2018</td>
<td>Chris Moen</td>
<td>6/2018</td>
</tr>
<tr>
<td>9/8/14</td>
<td>Chris Moen</td>
<td>9/12/14</td>
</tr>
<tr>
<td>10/30/13</td>
<td>Chris Moen</td>
<td></td>
</tr>
<tr>
<td>1/9/13</td>
<td>RW for John Oster</td>
<td></td>
</tr>
</tbody>
</table>

CONTENTS

Overview 2

CRF Mission Statement 2

Strategic Planning Process 4

Strategic Plan Summary 5

Key Target Areas

A. Research
   i. Gene Replacement Therapy 8
   ii. Restorative Therapies 10
   iii. Therapies to Stop or Slow Progression of Choroideremia 12
   iv. Improved Understanding of Choroideremia 14
   v. Bio Bank and Registry 16
B. Meetings and Conferences 18
C. Fundraising 19
D. Marketing and Communications 20
E. Administration and Management 22
1. OVERVIEW

The Choroideremia Research Foundation is an international not-for-profit organization dedicated to supporting the Choroideremia community. CRF was founded in 2000 by individuals affected by Choroideremia and their families to generate research through grassroots fundraising efforts. Since that time, CRF has grown both in size and in stature, and has taken on additional initiatives including education, advocacy, and others to support families with CHM around the globe.

The CRF Strategic Plan was originally created in 2013 during an evolutionary time in the research interests of the Foundation. The goal of the document was to provide a clear vision for leaders of the organization as the research landscape became more diversified and required a more sophisticated approach. In the ensuing years, the Strategic Plan has evolved to represent all functions of the Foundation beyond research and development.

The purpose of the Strategic Plan is to structure the efforts of the CRF and to establish a common understanding of CRF goals in order to create a unified and efficient organization, as well as successful initiatives. The CRF strategy is layered from the organization’s Mission Statement to Objective to Initiatives to Funded Programs. Each layer is defined by a different set of requirements and responsibility levels; a graphical representation of this layering is given in Table A.

2. CRF MISSION STATEMENT

The Choroideremia Research Foundation has the following mission statement:

“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.”

The CRF is focused on the following research objectives as related to its mission statement:

Halt CHM Disease Progression
The CRF will support and fund research, development and commercialization of treatments which slow or halt the progression of CHM. This goal will be complete when an affordable treatment will be available to all patients at multiple treatment locations internationally, and when the treatment can guarantee to permanently halt CHM at all stages.

**Restore Sight in CHM Patients**

CRF will support and fund research, development and commercialization of treatments which can restore sight in CHM patients. The goal of this mission is to restore sight in CHM patients whose disease progression is already at a stage where it has an impact on the individual’s life, and/or when therapies to halt disease progression cannot be implemented. This goal will be completed when substantial sight restoration can be accomplished in patients at all stages, and when both a financially affordable mechanism and a sufficient number of treatment locations are available for CHM patients.

**Continued Organizational Growth**

CRF recognizes that, in order to achieve the previous two objectives, the Foundation will need to continue expansion. Reaching its goals will require increased fundraising to support research programs and a greater outreach effort to reach all individuals with CHM. In order for these achievements to happen, CRF will need to strengthen its organizational structure by including a robust staff of volunteers in its executive leadership and Director positions, and paid staff to fill key roles critical to the Foundation’s success. CRF will also need to continue developing its internal structure through Board of Directors development, utilization of technology, and other measures to ensure growth and success.
## TABLE A: STRATEGIC PLANNING PROCESS

### Mission Statement
- Well defined End Goals
- Link to Mission Statement

### Objectives

### Initiatives
- Created by Board to serve a Mission
- Lead by a member of the Executive Committee
- Work by the Executive Committee
- Accurate Goal with notional metrics
- Funding Envelope with a defined Timeline
- Definition of Program types to seek
- Produces RFP and funds programs

### Funded Programs
- Created by EC
- Lead by a member selected by EC
- Funded by Initiative Funding Envelop
- Result of an RFP selection
- Accurate Goals with metrics
- Monthly Report to EC
- Preferred Milestone based programs
3. STRATEGIC PLAN SUMMARY

<table>
<thead>
<tr>
<th>KEY TARGET AREA</th>
<th>GOALS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gene Replacement Therapy</strong></td>
<td>1. Continue collaboration with pharmaceutical industry partners to assist in clinical trial enrollment, outcome measure selection, and other items to achieve the most efficient and successful clinical trial.</td>
</tr>
<tr>
<td></td>
<td>2. Interact with members of regulatory agencies such as the FDA to provide disease-specific information about CHM.</td>
</tr>
<tr>
<td></td>
<td>3. Provide education to the CHM community regarding status of clinical trials to ensure that they are properly informed and have realistic expectations on timing and potential success of therapy.</td>
</tr>
<tr>
<td></td>
<td>4. Identify potential improvements to gene therapy with the ultimate goal of stopping the progression of retinal degeneration in CHM.</td>
</tr>
<tr>
<td><strong>Restorative Therapies</strong></td>
<td>1. Identify pre-clinical research projects that have specific relevance to CHM patients in accelerating the potential development of restorative therapies.</td>
</tr>
<tr>
<td></td>
<td>2. Monitor the advancement of potential restorative therapies that have relevance to treatment of CHM patients outside of those requiring funding.</td>
</tr>
<tr>
<td></td>
<td>3. Advocate for the inclusion of CHM patients in proposed clinical trials for restorative therapies.</td>
</tr>
<tr>
<td></td>
<td>4. Develop basic informational materials regarding currently approved retinal implant devices and of relevant active research projects that could be used in CHM patients.</td>
</tr>
<tr>
<td><strong>Therapies to Stop or Slow Progression of Choroideremia</strong></td>
<td>1. Identify high-quality research projects that could lead to treatments which would stop or slow the progression of disease in Choroideremia patients. This will be expanded as a greater knowledge of the molecular mechanisms of disease progression is understood.</td>
</tr>
<tr>
<td></td>
<td>2. Interface with leaders in the scientific community to identify projects that could lead to treatments useful for CHM patients.</td>
</tr>
<tr>
<td><strong>Improved Understanding of Choroideremia</strong></td>
<td>1. Improve understanding of molecular mechanisms of CHM by 2020.</td>
</tr>
<tr>
<td></td>
<td>2. Clearly define cell type(s) directly affected by REP1 loss of function by 2023.</td>
</tr>
<tr>
<td></td>
<td>3. Continue advocacy efforts to pharmaceutical companies involved in current and future natural history studies to promote public access to the data gained from these studies.</td>
</tr>
<tr>
<td></td>
<td>4. Define a mechanism to store natural history data when it is made available in a format that could be easily accessed by the research community.</td>
</tr>
<tr>
<td><strong>Bio Bank and Registry</strong></td>
<td>1. Establish an inventory of CHM cell models, antibodies, reagents, etc. to make available to entities engaged in CHM research and treatment.</td>
</tr>
<tr>
<td></td>
<td>2. Educate the research community on the availability of these scientific materials that could be accessed for use in research projects to make research programs more efficient and cost-effective.</td>
</tr>
<tr>
<td></td>
<td>3. Develop and promote a CRF registry with the goal of including &gt; 500 affected individuals internationally.</td>
</tr>
<tr>
<td><strong>Meetings and Conferences</strong></td>
<td>1. To host a biannual conference for the CHM community including patients and families, clinicians, scientists, ad members of industry.</td>
</tr>
</tbody>
</table>

Page 5 of 22
2. To support the development of regional CRF meetings to increase patient awareness and participation in the organization as well as education of ongoing CRF activities. These regional meetings are expected to occur in gap years.
3. To establish an international panel of retinal & CHM experts to collaborate and discuss avenues of research that lead to a treatment and cure of CHM.
4. To ensure an International Scientific Symposium every two years by working with other CHM organizations.

| Fundraising                                      | 1. Increase gross fundraising revenue by 10% annually. |
|                                                | 2. Establish the position of Fundraising Director who would be integrated with leadership and key committee chairs to understand funding needs of the organization. |
|                                                | 3. Build and manage Team CHM peer-to-peer campaigns. |
|                                                | 4. Pursue corporate sponsorships, grants, and/or matching gift programs. |
|                                                | 5. Search for potential grants that could be utilized by the CRF and identify grant writing expertise. |
|                                                | 6. Continue to refine the CRF Major Gift program. |
|                                                | 7. Develop and improve the process of donor retention. |

| Marketing and Communications                   | 1. Utilize available platforms for outreach to the public, including traditional mail, website, and social media platforms. |
|                                                | 2. Continue to provide a periodic newsletter to the CRF membership. |
|                                                | 3. Develop New Member materials to be provided to all new members of the organization. |
|                                                | 4. Perform annual re-evaluation of the curechm.org website to determine functionality and need for updating. |
|                                                | 5. Perform an annual review of the utilization of social media platforms to determine opportunities for improvement. |
|                                                | 6. Increase CRF general membership by 10% annually. |
|                                                | 7. Develop a CRF eye donor program and provide educational materials to the CHM community. |
|                                                | 8. Create a CRF patient registry with information that would be stored on a HIPAA-compliant database. |

| Administration and Management                  | 1. Identify and maintain key staff for the continued operation and success of the CRF. Key positions will be annually reassessed by the Board. |
|                                                | 2. Increase Board of Director involvement as key stakeholders in level of participation and strategic planning. |
|                                                | 3. Hold a staff development program annually for Directors, key staff members, and/or volunteers. |
4. Ensure that staff and administration have access to technological resources critical to the successful operation of the organization.
5. Perform an annual audit.
6. Develop an annual budget that is approved by the Board of Directors.

4. **KEY TARGET AREAS**

<table>
<thead>
<tr>
<th>A. THERAPY RESEARCH AND DEVELOPMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>i. <strong>Gene Replacement Therapy</strong></td>
</tr>
</tbody>
</table>

Choroideremia Gene Therapy is the product of research which has been initially funded by the CRF and other foundations with a focus on one particular research site, Imperial College, since 2000. The technology used is a gene replacement method with a viral delivery vector (AAV2), injected in the sub-retinal space via an elaborate surgical protocol. Multiple clinical trials are underway to test gene therapy’s efficacy in treating CHM. Trials have been sponsored by both pharmaceutical companies (Nightstar Therapeutics, Spark Therapeutics) as well as a number of investigator-sponsored studies around the world. Additional interest in CHM gene therapy has been expressed by Biogen. Gene therapy clinical trials for CHM would, in an ideal scenario, stop or slow the progression of vision loss but would not be expected to restore lost vision.

To date, CRF has played an active role in participating in the pre-clinical funding of gene therapy programs through researchers such as Prof. Miguel Seabra and Dr. Jean Bennett. CRF has developed relationships with key opinion leaders in the field regarding gene therapy, clinical trial development, and clinical outcome measures to present itself as a resource to interested academic and industry partners. Through these efforts, CRF has developed relationships with key leaders at Spark and Nightstar to provide the patient community’s stance on these topics and assist with their clinical trial program. CRF has also met with FDA Office of Cell, Tissue, and Gene Therapy in 2014 to educate the regulatory body about the impact of vision loss and the existing research available demonstrating disease natural history and clinical endpoints.

Highlighting the importance of research into gene replacement therapy, the CRF Board of Directors voted to provide $1 million in support of related research programs in 2013.
Goals

1. Continue collaboration with pharmaceutical industry partners to assist in clinical trial enrollment, outcome measure selection, and other items to achieve the most efficient and successful clinical trial.
2. Interact with members of regulatory agencies such as the FDA to provide disease-specific information, the impact on patients,
3. Provide education to the CHM community regarding status of clinical trials to ensure that they are properly informed and have realistic expectations on timing and potential success of therapy.
4. Identify potential improvements to gene therapy with the ultimate goal of stopping the progression of retinal degeneration in CHM. Examples of potential improvements are:
   a. Improved surgical techniques
   b. Improved delivery methods
   c. Improvements in safety
A. THERAPY RESEARCH AND DEVELOPMENT

ii. Restorative Therapies

In addition to developing treatments like gene replacement therapy to stop the progression of CHM, it is essential to support research programs that could restore vision to patients as well. A number of avenues are currently being pursued to achieve this goal, including the use of stem cell treatments, and/or transplantation, optogenetics, and retinal prosthetics. Many of these programs require significant amounts of funding and support beyond the current scope of CRF; as a result, the Foundation often positions itself

Optogenetics is a neuromodulation technique employed in behavioral neuroscience that uses a combination of genetic and optical methods to control specific events in targeted cells of living tissue. For patients with retinal degeneration, optogenetics could be employed by using a gene therapy approach on existing cell layers such as bipolar and ganglion cells to enable those cells to become light-sensitive and replace the function of lost photoreceptors. Successful optogenetics approaches may also require the addition of goggles or similar technology to assist with image processing. Optogenetics research is being explored by a number of organizations, including Allergan Pharmaceuticals, Gensight, and Dr. Sheila Nirenberg at Cornell University. It is anticipated that optogenetics could become a solution for patients with severe or end-stage CHM to provide them with some restoration of vision.

Retinal implants are another option for sight replacement for patients with CHM. Various approaches exist for the use of visual implants. Corresponding to the visual pathway itself, there are sub-retinal, epi-retinal, optic nerve and cortical visual implants. In principle, the sub-retinal implant replaces the photoreceptors in retinitis pigmentosa or other forms of retinal degeneration in which the inner retina and the rest of the visual pathway remain intact. Such a neurological implant converts incident light into an electrical signal which is then transmitted on to the bipolar cells. Two devices – the Argus II and the Alpha IMS – have obtained regulatory approval.

Retinal cell transplantation could also provide a treatment option for restoration of vision. Current research utilizes stem cells which can be differentiated into retinal progenitor cells (those which are further specialized and eventually form retinal cells)
and photoreceptors/RPE. These differentiated cells could then be transplanted into a patient in an attempt to restore lost vision. Several investigators have initiated clinical trials involving the transplantation of RPE cells into a human retina to determine the safety of such an approach and any potential vision improvement. More complicated transplants involving RPE and photoreceptors, or even choriocapillaris, will require more extensive research and development. CRF recognized the need for stem cell research and allotted $1 million in research funding in 2013. Large-scale transplantation efforts require funding far beyond the scope of our organization.

Goals

1. Identify pre-clinical research projects that have specific relevance to CHM patients in accelerating the potential development of restorative therapies, namely with respect to stem cell transplantation, for consideration of grant funding.
2. Monitor the advancement of potential restorative therapies that have relevance to treatment of CHM patients outside of those requiring funding from CRF.
3. Advocate for the inclusion of CHM patients in proposed clinical trials for restorative therapies.
4. Develop basic informational materials regarding currently approved retinal implant devices and of relevant active research projects that could be used in CHM patients.
A. THERAPY RESEARCH AND DEVELOPMENT

iii. Therapies To Stop or Slow Progression of Choroideremia

A primary goal of the CRF is to support the development of therapies that could stop or slow the progression of CHM, thereby halting vision loss in adults and preventing vision loss in children. While gene replacement therapy may successfully achieve this goal, we recognize that one therapy may not be suitable for every patient, or even successful. Identification of alternative treatment options to slow or stop the progression of CHM is essential to ensure that clinical development is in progress regardless of the success of gene replacement therapy.

An example of this potential approach is through the treatment of patients with a nonsense mutation in the CHM gene. These specific mutations can potentially be treated with medications called translational read-through drugs which assist the body’s mechanisms in identifying nonsense mutations and avoiding their effect. The most studied of these medications is Ataluren, which has been extensively studied in the Muscular Dystrophy and Cystic Fibrosis. Ataluren has been extensively studied in CHM zebrafish and in human CHM cells in vitro, with a plan for human clinical trials in the.

CRF is constantly evaluating the landscape of additional potential medications to search for other promising treatments. This includes performing a high throughput screening project through Drs. Mariya Moosajee and Jeffry Mumm testing CHM zebrafish against hundreds of currently approved medications. The Foundation also is considering the use of neuroprotective agents, molecules produced by cells like the RPE which promote the health of other cells in the brain and retina. Administration of a neuroprotective agent could be performed by directly administering the medication (oral, topical, injection) or by injecting stem cells into the eye’s vitreous chamber and allowing these cells to continually produce neuroprotective factors. Multiple clinical trials have been undertaken with other retinal degenerative diseases looking at these approaches; however no current treatment is available.

CRF believes that, long-term, a number of treatments will be offered to CHM patients. This may include alternatives to gene therapy in the early stages of disease to slow or prevent vision loss. This may also include a combination of gene therapy and other
modalities which work synergistically to prevent further deterioration of the retina and subsequent vision loss.

Goals:

1. Identify high-quality research projects that could lead to treatments which would stop or slow the progression of disease in Choroideremia patients. This will be expanded as a greater knowledge of the molecular mechanisms of disease progression is understood.
2. Interface with leaders in the scientific community to identify projects that could lead to treatments useful for CHM patients.
A. THERAPY RESEARCH AND DEVELOPMENT

iv. Improved Understanding of Choroideremia

While Choroideremia was first identified and described in 1872, the current understanding of Choroideremia stems back to the identification and cloning of the CHM gene in 1990 by Frans Cremers. The CHM gene encodes a protein called Rab Escort Protein 1 (REP1) which is responsible for the lipid modification of RAB27a through prenylation, and intracellular transport of these RAB27a molecules. Loss-of-function mutations in the CHM gene cause an absence of REP1 protein and its resulting function. Human DNA contains a REP2 gene which, depending on the level of expression, can compensate for the loss of REP1 in most human cell types. Research has also demonstrated suggestion of abnormalities in cells outside the eye, but no evidence exists that these abnormalities have clinical relevance. In the retina, absence of REP1 eventually leads to cell death in photoreceptors, Retinal Pigment Epithelium (RPE) cells, and choriocapillaris; it is unknown whether the absence of REP1 directly causes cell death in all three cell types, or whether RPE cell death leads to secondary loss of photoreceptors and choriocapillaris. Improving the understanding of these mechanisms of action could lead to additional potential avenues of therapy.

Natural history of CHM is another area of research that could benefit from greater understanding. A number of small natural history studies have been published in the medical literature, and the progression of patient symptoms is well understood. However, large-scale studies are required to better delineate natural history, specifically relating to the identification and characterization of potential outcome measure that could be used as endpoints in a clinical trial. As of the publication of this document, four separate natural history studies of Choroideremia patients have been undertaken, three by pharmaceutical sponsors. Aside from published data or conference presentations, none of this data has been made available to the CRF or the scientific community.

Areas of deficiency currently impacting CHM therapy development including but are not limited to:

- More specific understanding of the molecular basis of disease
  - Why cells die with REP1 loss of function
  - Which cell types are directly impacted by REP1 loss of function
  - Could REP2 upregulation promote health of retinal cells
- Natural history study data
Ø Public access will strengthen overall scientific community’s ability to design and test effective therapies
Ø Improved understanding of clinical endpoints to use in a clinical trial
Ø Understanding of population dynamics could create additional research opportunities

Goals

1. Improve understanding of molecular mechanisms of CHM by 2020.
2. Clearly define cell type(s) directly affected by REP1 loss of function by 2023.
3. Continue advocacy efforts to pharmaceutical companies involved in current and future natural history studies to promote public access to the data gained from these studies.
4. Define a mechanism to store natural history data when it is made available in a format that could be easily accessed by the research community.
v. BIOBANK AND REGISTRY

For the rare disease community, demographic and biologic information related to the disease becomes difficult to accumulate and thereby incredibly important. Scientists interested in studying Choroideremia collect blood and/or tissue samples for their laboratory to use for internal purposes like studying the disease, testing therapies, developing cell lines, etc. Within the Choroideremia scientific community, sharing these biologic samples has proven to be exceedingly difficult due to institutional and regulatory constraints that often override the beneficial interests of the individual scientists holding the samples. For example, a scientist interested in studying all of Choroideremia’s different mutation types may only have access to nonsense and deletion mutations in his or her lab; in order to study missense, splice site, or substitution mutations, that scientist would be forced to obtain samples directly from patients even if they exist in other laboratories. This work is duplicative, expensive, and takes unnecessary time to complete.

The CRF supports the development of shared information systems to aid in the research and development process. One of the strategic initiatives to meet this need was the development of the CRF Bio Bank. The Bio Bank provides scientists with a readily accessible and cost-effective resource for blood, tissue, and stem cell samples donated from CHM patients. The current CRF Bio Bank is housed at the Coriell Institute for Medical Research, which currently houses several cell lines including lymphocytes, fibroblasts, and stem cells. These cells are available for distribution to scientists at any time for a relatively minimal cost. CRF continues to support the promotion and the potential expansion of the CRF Bio Bank, in advance of research needs or to meet those needs when they arise.

CRF has also supported the development of a registry, directing patients to use the My Retina Tracker registry developed by the Foundation Fighting Blindness. While this registry is useful there is significant opportunity for improvement and expansion of the CRF network through internal development of a registry.

Goals
1. Establish in cooperation with other entities an inventory of CHM cell models, antibodies, reagents, etc. to make available to entities engaged in CHM research and treatment.

2. Educate the research community on the availability of these scientific materials that could be accessed for use in research projects to make research programs more efficient and cost-effective.

3. Develop and promote a CRF registry with the goal of including > 500 affected individuals internationally.
B. MEETINGS AND CONFERENCES

As a virtual organization representing a rare disease community, CRF must actively plan to bring together the community of affected individuals, supporters, and the medical and research community. These meetings are critical to the patient community. These individuals and their families struggle to obtain information regarding the disease and current research programs, or to learn coping mechanisms from their peers. CRF has traditionally held an international conference every 2 years to bring together the CHM community and provide education, outreach, and support to its membership.

Bringing together the community of CHM researchers and clinicians is equally as important to drive research and to understand CHM. The 1st International Choroideremia Research Symposium was held in Sommieres, France, in September 2011. Researchers and doctors from all over the world were invited to speak, collaborate and discuss CHM. The theme of this gathering was “Working Together toward a Therapy”. This initial meeting was followed by a second symposium, sponsored by CRF, in 2014 as well as a number of smaller

Goals

1. To host a biannual conference for the CHM community including patients and families, clinicians, scientists, and members of industry.
2. To support the development of regional CRF meetings to increase patient awareness and participation in the organization as well as education of ongoing CRF activities. These regional meetings are expected to occur in gap years.
3. To establish an international panel of retinal & CHM experts to collaborate and discuss avenues of research that lead to a treatment and cure of CHM.
4. To ensure an International Scientific Symposium every two years by working with other CHM organizations.
C. FUNDRAISING

As a research funding organization, fundraising has been a core element of the CRF since its inception. As is common in the rare disease community, research funding is often diverted to more prominent and common diseases, leaving rare diseases to stimulate their own research programs. CRF has demonstrated this to be true, by directly funding CHM research internationally since its inception and creating numerous programs that otherwise wouldn’t exist. In addition, CRF’s other initiatives and programs require financial support to ensure their success.

CRF was founded upon a model of grass-roots fundraising, built on the charitable contributions of affected individuals, their families and networks. While this model has been successful, continued expansion of CRF fundraising will require a more diversified approach to enable multiple additional revenue streams. This may include corporate sponsorships, family foundations, major gift programs, or other potential sources. Continued success of the program will require a structured and targeted approach to specific activities.

Goals

1. Increase gross fundraising revenue by 10% annually.
2. Establish the position of Fundraising Director who would be integrated with leadership and key committee chairs to understand funding needs of the organization.
3. Build and manage Team CHM peer-to-peer campaigns.
4. Pursue corporate sponsorships, grants, and/or matching gift programs.
5. Search for potential grants that could be utilized by the CRF and identify grant writing expertise to increase likelihood of successful grant application.
6. Continue to refine the CRF Major Gift program.
7. Develop and improve the process of donor retention.
D. COMMUNICATIONS AND MARKETING

To reach its mission, the CRF needs to increase the level of public awareness about Choroideremia and the potential for available therapies in the future. For a variety of reasons, the majority of people with Choroideremia currently are not members of the Foundation. It is believed that most of these individuals have not been properly diagnosed and therefore are unaware that they are affected by Choroideremia. Also, there is a significant population of individuals who have been diagnosed with Choroideremia but either have not found the CRF or have chosen not to become a member. The CRF endeavors to increase its reach to include these affected individuals to keep them apprised of CHM research developments in addition to improving its fundraising efforts by gaining their participation in the CRF.

In addition, a variety of activities and events occur throughout the calendar year to benefit Choroideremia patients and the CRF. Publicity plays a crucial role in the success of these events. Many of these are fundraising events hosted by members of the CRF, and the organization may want to promote certain events more actively. In addition, the CRF sponsors a bi-annual conference and plans to assist in the development of bi-annual scientific symposia, both of which present information relevant to the advancement of CHM research and greater public awareness of CHM. Additionally, the CRF can and must be prepared for, and potentially included in, the occurrence and publication of major research breakthroughs. To properly promote these major news events, the CRF may look to expand beyond social media by engaging a PR or Marketing firm to assist with these endeavors.

Goals

1. Utilize available platforms for outreach to the public, including traditional mail, website, and social media platforms. The professionalism and messaging of all communications will be consistent in branding, and serve the mission of the CRF.

2. Continue to provide a periodic newsletter to the CRF membership.

3. Develop New Member materials to be provided to all new members of the organization.
4. Perform annual re-evaluation of the curechm.org website to determine functionality and need for updating.
5. Perform an annual review of the utilization of social media platforms to determine opportunities for improvement.
6. Increase CRF general membership by 10% annually.
7. Develop a CRF eye donor program and provide educational materials to the CHM community.
8. Create a CRF patient registry with information that would be stored on a HIPAA-compliant database
E. ADMINISTRATION AND MANAGEMENT

The CRF historically has been, and continues to be, a Foundation primarily operated by volunteers. The Foundation has endeavored to keep costs and overhead low in an effort to maximize the percentage of donations provided directly to scientific research efforts. The growth of the CHM research platform, additional CRF initiatives, and the associated need for increased fundraising sparked evolution of that thinking. It has become more apparent to the Board of Directors that the CRF needs to dedicate funds to its organizational structure to manage the ever-increasing technology driven environment. As a virtual organization, a strong structure becomes increasingly important to keep its processes running efficiently and to stay competitive with other fundraising organizations.

In the past several years, CRF has begun to add paid staff positions to assist in the development and management of the organization. Starting initially with an Executive Director and Director of Operations, CRF expanded its team to include positions such as the Directors of Advocacy, Patient Engagement, and Fundraising in 2017 to aid the organization in meeting its goals. The CRF Board and Executive Committee is committed to ensuring these roles are filled by qualified and dedicated individuals, and to reassessing organizational needs on a regular basis.

In addition to manpower, the CRF requires several software and electronic systems to maintain its functionality. These include the CRF Website, fundraising platform, membership/donation database, newsletter production, and communications platform, to name a few. Periodic review of these resources is essential to determining the optimal utilization of these systems as technology continues to evolve. Particular attention must be paid to the accessibility of these software systems to the visually impaired members of the Foundation who will use them.

Goals

1. Identify and maintain key staff for the continued operation and success of the CRF. Key positions will be annually reassessed by the Board of Directors including annual performance review.
2. Increase Board of Director involvement as key stakeholders in level of participation and strategic planning.

3. Hold a staff development program annually for Directors, key staff members, and/or volunteers with an outside consultant and/or online educational resources.

4. Ensure that staff and administration have access to technological resources critical to the successful operation of the organization. Technology will be re-evaluated on an annual basis to ensure that organizational needs are met. This list of technology includes but is not exclusive to:
   a. Web-based fundraising platform
   b. Donor management software
   c. Accounting software

5. Perform an annual audit.

6. Develop an annual budget that is approved by the Board of Directors.