



FUNDING SCIENTIFIC RESEARCH

A GIVING SMARTER GUIDE



MILKEN INSTITUTE



## AUTHORS

### LEAD AUTHORS

Maureen Japha, JD  
Erik Lontok, PhD

Ebony Mosley  
Danielle Salka

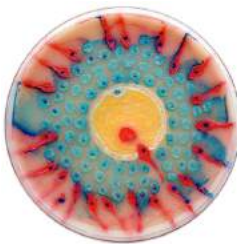
### CONTRIBUTING AUTHORS

LaTese Briggs, PhD  
Sonya Dumanis, PhD  
Heather Fields

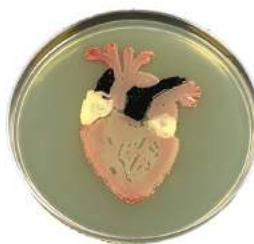
Yoori Kim, MS  
Ekemini Riley, PhD  
Melissa Stevens, MBA

### COVER

In partnership with the American Society for Microbiology (ASM), the Philanthropy Advisory Service created the report cover with submissions by ASM members to the 2015 and 2016 Agar Art Contests. All submissions are living organisms plated on agar—a growth surface for microorganisms—and speak to the creativity of the academic research field. ASM launched Agar Art as a public outreach program to promote the work of their scientific members, humanize scientists, and highlight the role of microbiology in our lives.



*The First Race*, (1st Place 2016) by Md Zohorul Islam, Graduate Student of University of Copenhagen, Denmark



*The Anatomical Heart*, 2016 by Natalie Stringer et al, Teaching Faculty, Montgomery College - Germantown



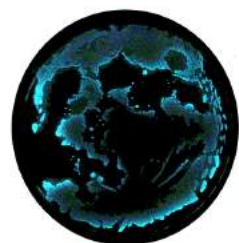
*Bacteria at Birth*, 2016 by Julie Torruellas Garcia, Associate Professor, Michelle Duddy, Undergraduate Student Artist, Veronique Cote, Photographer, Nova SE University



*Fight the Bite*, 2016 by Supram HS, Graduate Student, Manipal College of Medical Sciences



*Mushrooms*, 2015 by Maria Peñil Cobo, Mixed Media Artist and Mehmet Berkmen, PhD, Staff Scientist, New England Biolabs, USA



*Near Side of the Moon*, 2016 by Michelle Williams, Graduate Student, University of Missouri



*Neurons*, (1st Place 2015) by Maria Peñil Cobo, Mixed Media Artist and Mehmet Berkmen, PhD, Staff Scientist, New England Biolabs, USA



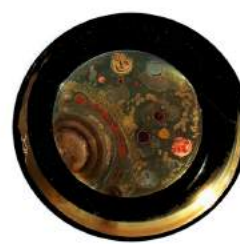
*The Violet Louis Pasteur*, 2015 Dharshika Jayasuriya, Graduate Student, University of Colombo, Sri Lanka



*Cell to Cell*, (People's Choice 2015) by Maria Peñil Cobo, Mixed Media Artist and Mehmet Berkmen, PhD, Staff Scientist, New England Biolabs, USA



*Bacteria: they have a mind of their own*, 2016 by Elizabeth E. Tremblay, Infection Control Practitioner, Univ. of Florida Health Shands Hospital



*Microcosmos*, 2015 by Maria Peñil Cobo, Mixed Media Artist and Mehmet Berkmen, PhD, Staff Scientist, New England Biolabs, USA



AMERICAN  
SOCIETY FOR  
MICROBIOLOGY

## ACKNOWLEDGEMENTS AND CONTRIBUTORS

We graciously thank the nonprofit, foundation, and philanthropic leaders who kindly shared their time, experience, and expertise to help to complete this landscape analysis of philanthropic funding of scientific academic research. The contributors' stories of challenges, opportunities, and successes guided our writing and will hopefully inform the work of current and future philanthropists in this space. This report was supported by the Apex Foundation's LGMD2i Research Fund (see About).

**Gina Agiostratidou, PhD**

Program Director, T1D  
The Leona M. and Harry B. Helmsley Charitable Trust

**Meredith Haupt**

Director, Research Partnerships  
The Michael J. Fox Foundation

**Elizabeth Cheung, MPP**

Senior Program Officer, Domestic Programs  
Conrad N. Hilton Foundation

**JayEtta Hecker**

Executive Director  
Wishes for Elliot

**General Peter Chiarelli (Ret.)**

Chief Executive Officer  
One Mind

**Kathy Hudson, PhD**

Deputy Director for Science, Outreach, and Policy  
National Institutes of Health

**Louis J. DeGennaro, PhD**

President and Chief Executive Officer  
The Leukemia & Lymphoma Society

**Betsy Myers, PhD**

Program Director for Medical Research  
Doris Duke Charitable Foundation

**Sandy Finucane**

Senior Advisor  
Epilepsy Foundation

**Plavi Jain Mittal, PhD**

President and Chief Executive Officer  
Jain Foundation

**Rachel Flax**

Executive Director  
Weiss Family Foundation

**Rebecca Oberman**

Executive Director  
ML4 Foundation

**Maryrose Franko, PhD**

Executive Director  
Health Resources Alliance

**Louise M. Perkins, PhD**

Chief Scientific Officer  
Melanoma Research Alliance

**Simone Friedman**

Head of Philanthropy and Impact Investing  
Emanuel J. Friedman Philanthropies

**Kathy Russell**

Consultant

**Kathy Giusti**

Founder and Executive Chairwoman  
Multiple Myeloma Research Foundation

**Josh Sommer**

Executive Director  
Chordoma Foundation

## TABLE OF CONTENTS

<b>AUTHORS</b> .....	<b>2</b>
<b>ACKNOWLEDGEMENTS AND CONTRIBUTORS</b> .....	<b>3</b>
<b>STANDOUT EXAMPLES OF SCIENTIFIC PHILANTHROPY</b> .....	<b>5</b>
<b>ABOUT</b> .....	<b>6</b>
<b>FOREWORD</b> .....	<b>7</b>
<b>EXECUTIVE SUMMARY</b> .....	<b>9</b>
<b>1. WHAT ARE MY PHILANTHROPIC GOALS?</b> .....	<b>11</b>
<b>2. WHAT IS THE CURRENT STATE OF THE RESEARCH AND EXISTING SUPPORTERS OF RESEARCH?</b> .....	<b>14</b>
NONPROFITS AND FOUNDATIONS.....	14
GOVERNMENT .....	16
SUBSCRIPTION-BASED RESOURCES .....	17
<b>3. GIVEN THE STATE OF RESEARCH, WHAT ARE THE MECHANISMS TO ACHIEVE MY GOALS?</b> .....	<b>18</b>
GIFTS VERSUS SPONSORED RESEARCH AWARDS.....	18
GRANT MECHANISMS .....	19
<b>4. HOW DO I FIND RESEARCH PROPOSALS?</b> .....	<b>22</b>
WRITING AN RFP .....	22
ADVERTISING YOUR FUNDING OPPORTUNITY .....	24
<b>5. HOW DO I JUDGE THE MERIT AND POTENTIAL OF A POTENTIAL PROPOSAL?</b> .....	<b>25</b>
ENGAGING EXPERTS IN THE FIELD.....	26
WHAT TO CONSIDER IN A RESEARCH PROPOSAL .....	27
<b>6. HOW DO I WRITE A RESEARCH GRANT AGREEMENT?</b> .....	<b>29</b>
PRINCIPLES FOR EFFECTIVE COMMUNICATION .....	29
KEY ELEMENTS OF INCLUSION IN A GRANT AGREEMENT .....	30
OTHER PROVISIONS TO CONSIDER.....	31
<b>7. HOW DO I MONITOR A RESEARCH AWARD?</b> .....	<b>34</b>
GRANT MONITORING AND PROGRESS REPORTS .....	34
FINAL GRANT REPORT.....	36
<b>8. HOW DO I MEASURE SUCCESS?</b> .....	<b>37</b>
MEASURING THE TANGIBLE IMPACT OF A RESEARCH PROJECT .....	38
MEASURING THE SCIENTIFIC MERIT OF A RESEARCH PROJECT .....	38
MEASURING THE IMPACT FOR YOUR FOUNDATION .....	39
<b>CONCLUSION</b> .....	<b>40</b>

## STANDOUT EXAMPLES OF SCIENTIFIC PHILANTHROPY

1. Chordoma Foundation: Targeting a Crucial Unmet Scientific Need Page 10
2. Conrad N. Hilton Foundation: Expanding the Field of Multiple Sclerosis Research Page 13
3. Epilepsy Foundation (EF): De-Risking the Clinical Pipeline Page 14
4. The Kenneth Rainin Foundation: Supporting Innovative, Proof-of-Concept Research Page 17
5. Doris Duke Charitable Foundation (DDCF): Developing the Clinical Workforce through Mentorship Page 18
6. Bladder Cancer Advocacy Network (BCAN): Convening Leaders to Define Strategic Priorities Page 19
7. Melanoma Research Alliance (MRA): Funding Collaborative Research Page 21
8. The Jain Foundation: Developing the In-house Expertise to Advance Philanthropic Scientific Research Page 23
9. Wishes for Elliot (WFE): Leveraging Strategic Partnerships Page 24
10. Michael J. Fox Foundation (MJFF): De-Risking Innovation Page 35

## ABOUT

### About the Milken Institute

The Milken Institute is a nonprofit, nonpartisan think tank determined to increase global prosperity by advancing collaborative solutions that widen access to capital, create jobs, and improve health. We do this through independent, data-driven research, action-oriented meetings, and meaningful policy initiatives.

### About *FasterCures*

*FasterCures* is a DC-based center of the Milken Institute driven by a singular goal—to save lives by accelerating and improving the medical research system. In working toward this goal, *FasterCures* focuses on cutting through the roadblocks that slow medical progress by spurring cross-sector collaboration, cultivating a culture of innovation, and engaging patients as partners. *FasterCures* works across sectors and diseases to accelerate the process through which great advances in science and technology are translated into meaningful medical solutions for patients. Our programs identify what works and what does not work across the research ecosystem and share that knowledge so that every sector—and every patient—can benefit.

### About the Center for Strategic Philanthropy

The Milken Institute Center for Strategic Philanthropy designs smart giving strategies to accelerate philanthropic goals and progress. It is focused on maximizing the return on philanthropic investment by ensuring that innovation used to address one social issue is translated to another, best practices and metrics guide new and existing giving programs, and resources are invested to optimize outcomes.

As the flagship program of the Milken Institute’s Center for Strategic Philanthropy, the **Philanthropy Advisory Service (PAS)** counsels philanthropists, family offices, wealth advisors, and foundations seeking to make transformative philanthropic investments. Expert advisory boards, in-depth due diligence, and an objective framework for evaluation shapes our analysis. PAS works in partnership with *FasterCures* to provide comprehensive, digestible information that helps philanthropists evaluate research efforts and funding opportunities in various disease areas.

### About the Apex Foundation’s LGMD2i Research Fund

The mission of Apex Foundation’s LGMD2i Research Fund is to find a cure for Limb Girdle Muscular Dystrophy 2I (LGMD2I) and to enhance the patients’ quality of life. The Research Fund accomplishes its mission by building a comprehensive view of the entire LGMD2I research landscape, advocating for application of new technologies to the field of LGMD2I research, financially supporting the most promising research, and bringing a level of collaboration and management to the scientific process.

Our strategy relies on the six complementary programs: (1) Supporting medical research, (2) Building solid relationships with scientists/clinicians, (3) Connecting patients, scientists, and drug developers, (4) Facilitating patient identification, (5) Increasing patient input into therapy development, and (6) Raising awareness of LGMD2I. We achieve our strategy by concentrating on four objectives: Clinical Trial Readiness, Disease-modifying and Curative Solutions, Quality-of-Life Improvement, and Patients Molecular Data related to Disease Presentation.

## FOREWORD

Apex Foundation, the family foundation for Bruce R. McCaw, has been pleased to work with the Milken Institute Center for Strategic Philanthropy and *FasterCures* in creating this guide. We are grateful to all who contributed their insights and wisdom. Hopefully, it is a useful read for anyone considering investing in research. The goal of producing a useful guide for prospective philanthropists was driven by our desire to share what we've learned from 20 years of experience in the field. We've learned a lot through the course of funding various academic and medical research initiatives, and through trial and error of granting many millions of dollars to research projects. A guide of this sort would have served us well as we set our course, and in considering questions that came up along the way.

A major focus of our current work is on identifying new approaches to diagnose, treat, and cure limb girdle muscular dystrophy via translational research. At this stage of research, new understandings of disease mechanisms gained in the laboratory are converted into the development of new methods for diagnosis and therapy.

As we think about innovation and leverage, we are always seeking ways to be more strategic by fostering greater collaboration and trust among researchers and institutions, and across disciplines and sectors by applying leadership and management to the science that can help drive progress. Given the changing stakeholder landscape and less predictable funding climate of our day, there is increasing need for smarter philanthropy in R&D. We believe this primer paves the way for funders and the research community to accomplish their respective goals faster and more effectively.

Based on our own experience, our advice for funders and expectations for researchers are the following:

### Advice for Funders

- **Be clear about what you want to accomplish.** Put it in writing in your grant agreement, but be flexible. We structure the grant to enable changes based on emerging data during the grant period.
- **Tie grant payments to project milestones.** We have found this helps to keep the research focused on objectives and to maintain accountability.
- **Ask yourself if you are using your financial resources in the best way to see results.** If we are not seeing strong results, good or bad, we are prepared to help troubleshoot problems or pull the plug.
- **Promote collaboration and tear down silos between grantees.** We do this by rewarding institutional behaviors that facilitate team science and real-time data sharing.
- **Consider your options for having influence over intellectual property developed with your grant funding.** We have found there are positions that foundations can take to help promote the dissemination of knowledge to benefit society and advancement of research towards commercialization.
- **Look for opportunities to leverage your investment for all stakeholders.** Our funding alone will not develop a new therapy, but other stakeholders—patients and families, healthcare payers, regulators, funders and patient advocacy organizations, biotech, pharma, medical researchers, and the media—can use and build on the findings from our investment.

- **Consider engaging in advocacy efforts.** We've seen that policy solutions at the local, state, national, and global levels can complement our funding programs and help to advance our mission.

#### Advice for Researchers

- **Focus on not just the “what” but on the “how” to integrate your findings into improving patient care and advancing cures.** We believe all stakeholders have a responsibility to ensure that applicable research does not end up on the shelf but is put to productive use.
- **Know your audience when communicating results.** We find that when outcomes are communicated in easy-to-understand language, we, as well as all other stakeholders, can be better partners, advocates, and supporters.
- **Treat funders as full partners, not just patrons.** We've found it tremendously productive to work collaboratively with our grantees and for them to share all data/results, good or bad, in real time, so that we can be helpful in overcoming obstacles or moving promising research to the next step. We appreciate the time, attention, and respect our grantees show us. It makes us want to be even more committed collaborators.
- **Participate in efforts that promote open science.** We believe that democratizing data and science can yield greater medical progress for us all. We hope you will be part of the movement too.

When philanthropy, science, business, program, and advocacy groups present a united front and speak with a collective voice, we make the most progress on policy and program changes that will lead to the preventions, treatments, and cures for all diseases. With each of your voices and leadership, policy changes, and the allocation of scarce resources, we can, together, accomplish what science tells us works and is the right thing to do.

Craig Stewart  
President & Trustee  
Apex/Bruce R. McCaw Family Foundation



## EXECUTIVE SUMMARY

A philanthropist's decision to invest in scientific research and development may be driven by an array of factors. Their giving may be motivated by personal experience with a specific disease, the desire to help improve health and save lives, or the aspiration to improve the status quo. Regardless of one's motivations, strategic philanthropic investments in medical research require a careful consideration of the philanthropist's priorities and an understanding of the current state of research to amplify the impact of their giving.

With support from the Apex Foundation's LGMD2i Research Fund, the Milken Institute Philanthropy Advisory Service conducted a landscape analysis of current and best practices for funding scientific research, which was informed by interviews with foundation leaders, philanthropy advisors, and government stakeholders. In this Giving Smarter Guide for Funding Scientific Research, we provide a pathway for defining your philanthropic priorities, aligning them with the unmet needs of a research field and the existing funding ecosystem, and effectively deploying philanthropic capital to universities and research institutions.

The report is structured to provide points of entry into the pathway of funding scientific research primarily conducted in an academic or medical setting. Written for individual philanthropists and foundations who may be new to scientific research, this report will walk you through the process with a series of questions and key takeaways.

1. What are my philanthropic goals?
  - Understand the stages of scientific research (from basic science to clinical trials) and how they align with your goals.
  - Create a well-defined vision, mission, strategy, and objectives to guide your philanthropy, and also clearly and consistently communicate your interests to the scientific research community and relevant stakeholders.
2. What is the current state of the research and who are existing supporters of research?
  - Identify potential research partners – from academics, nonprofits, and industry – in the disease research ecosystem to help determine the research gaps your philanthropy can address.
3. Given the state of research, what are the award mechanisms I can use to achieve my goals?
  - Explore which mechanism is right for you - a university-directed gift or a sponsored research award.
  - Tailor the award to focus on the specific research gaps, such as scientific unknowns, segments of the research workforce, or research infrastructure to enhance the capabilities of the entire research ecosystem.



4. How do I find research proposals?
  - Craft a Request for Proposals (RFP) to communicate your strategic priorities to the wider research community and highlight the research questions and objectives you wish to address.
  - Widely disseminate your RFP to maximize the number of proposals addressing your specific research question.
5. How do I judge the merit and potential of a submitted proposal?
  - Consider both the quality and merit of proposals, as well as the ability of the researcher to successfully complete the work.
  - Engage disease research experts as part of the review and selection process.
6. How do I write a research grant agreement?
  - Upon identifying the proposal you wish to fund, craft a grant agreement, which is the legal document that outlines the terms, conditions, and goals of the grant.
  - Effective communication with the grantee and research institution is critical to advancing your foundation’s stated mission and strategy.
7. How do I monitor a research award?
  - Progress and final grant reports are key checkpoints of the funding process, and should capture the roadblocks and proposed solutions of the awarded project.
8. How do I measure success?
  - Measuring the success of awarded grants involve both tangible and intangible impact metrics.
    - Tangible metrics include fruitful collaborations and follow-on funding, as well as research infrastructure development and workforce directly supported by the award.
    - Intangible metrics include development of new and innovative thinking for the field, and whether the work demonstrates the kind of scientific ambassadorship your foundation wishes to project.

Throughout the report, we also highlight standout examples of philanthropic support for scientific research, ranging from a focus on novel research without existing data by the Kenneth Rainin Foundation, workforce development by the Doris Duke Charitable Foundation, to the collaborative project review and modification model employed by the Jain Foundation (see page 5 for complete list of case studies).

Scientific research is a noble endeavor—one that many advocate for and professionally pursue. However, difficulties remain in how to identify the best philanthropic process and opportunities to support research. Our goal with this report is to identify common approaches and best practices to address the potential pitfalls and challenges that come with supporting scientific research in academic institutions.

However, as with all things in science, you cannot know what will or will not work until you perform the experiment.



# 1. WHAT ARE MY PHILANTHROPIC GOALS?

## KEY TAKEAWAYS

- Understand the stages of scientific research (from basic science to clinical trials) and how they align with your goals.
- Create a well-defined vision, mission, strategy, and objectives to guide your philanthropy, and also clearly and consistently communicate your interests to the scientific research community and relevant stakeholders.

There are viable and effective treatments for only 500 for the approximately 10,000 known diseases. Thus, there are many opportunities for medical philanthropy to advance progress—from researching causes of Crohn’s disease to developing treatments for Alzheimer’s disease—with no one-size-fits-all approach. Given the array of options, it can be difficult to decide which avenues to pursue. The initial step is to define your funding priorities, which will require an articulation of your philanthropic goals, followed by an understanding of the research process, the risks involved, and ultimately informed the current state of the scientific field.

First, you should identify your philanthropic goals and ask what is the ambitious change you want to see in the world? Do you want to cure a rare neurological disease? Do you want to develop novel diagnostic tools for blood cancers? Or do you want to build a research field for an underserved disease? Articulating your goals serves as a strong foundation to strategically deploy your philanthropy.

Next, you should understand the research process and identify the unmet needs that are impeding progress. Simply stated, the medical research pipeline has three stages: basic research, translational research, and clinical research (see right).

Philanthropy can support research throughout the pipeline by advancing the science and/or improving the system.

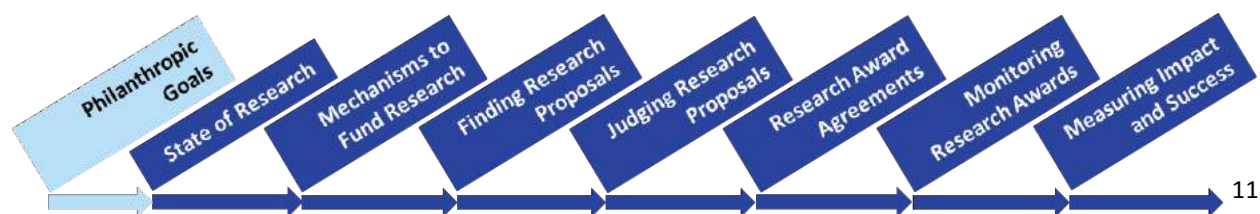
- Advancing the science centers on addressing a specific research question, such as understanding the biological underpinnings of a disease or testing the clinical efficacy of a new drug.
- Improving the system means creating tools, resources, or infrastructure that help scientists answer research questions. Examples include building patient registries and sample biorepositories for research, or developing the research workforce.

### Stages of Scientific Research

**Basic research** aims to advance knowledge, without a specifically envisaged or immediately practical application, and serves as the foundation of translational and clinical research. Basic research projects focus on improving the scientific theories that explain or inform what may cause, drive, and impact a disease.

**Translational research**, often referred to as bench-to-bedside research, serves as the bridge between basic and clinical research. Translational research projects apply an iterative and multidirectional process to (a) transform basic research discoveries into new drugs, devices, and interventions and (b) utilize findings from the clinic to inform new research to refine or expand an innovation.

**Clinical research** addresses disease prevention, treatment, diagnosis, and relief from disease-related symptoms in human subjects. Clinical research projects focus on the safety and effectiveness of medications, devices, diagnostics, and treatment regimens intended for human use.



Regardless of which research stage you choose to support, scientific progress is often uncertain and riddled with risk. However, one of the key advantages of a scientific philanthropy is the ability to assume a higher risk profile than funders such as the NIH. Thus, it is important to understand your risk tolerances and how to tolerate the risk other funders may not.

An appetite for higher risk and higher social reward should drive philanthropists to consider nontraditional and innovative approaches, while aiming to fill gaps in the funding and science landscape that have been avoided by industry, government agencies, and other nonprofits.

Finally, a landscape assessment of the research field will help identify the unmet needs that can be addressed to advanced towards your goals. Methods for conducting the due diligence necessary to determine the current funding and scientific landscape will be addressed in the next section: “What Is the Current State of the Research and Existing Supports of Research?”

---

## Chordoma Foundation: Targeting a Crucial Unmet Scientific Need

---

### Mission and Strategy:

---

*The Chordoma Foundation is working to accelerate the search for a cure by initiating and funding high-impact research, facilitating information exchange and collaboration among researchers, and providing scientific resources to study chordoma, a rare cancerous tumor that can occur along the bone and soft tissue anywhere along the spine.*

---

### Program:

---

*The Cell Line Prize—Cell lines are critical for understanding chordoma and developing new treatments. Until 2010, only one valid chordoma cell line had been created, which prevented researchers from confirming their findings and many researchers from undertaking chordoma research projects altogether. Thus, the Foundation’s Scientific Advisory Board and attendees of its research workshops identified development of new chordoma cell lines as one of the highest priorities for advancing chordoma research.*

*In response to this clear message, the Foundation set a goal to develop 10 validated chordoma cell lines and make them easily accessible to the research community. However, how to develop these cell lines and who to fund was not obvious; many attempts had been made by top-notch labs in the past to little avail. Needed were different approaches, more trial and error, and perhaps some luck. Rather than focus limited resources on a small number of labs, the Foundation encouraged as many labs as possible to bring their efforts and unique approaches to bear on the problem by offering a \$10,000 prize for each valid chordoma cell line that is submitted to the Chordoma Foundation Cell Line Repository.*

*To date, the Cell Line Prize has led to nine validated chordoma cell lines, all of which are available to researchers in the chordoma scientific community.*

---





Once you identify your funding priorities, your foundation should define a vision, mission, and strategic plan to delineate long-term goals and the short-term objectives employed to achieve them. Doing so will help your foundation maintain focus and an internal sense of purpose, while facilitating communication and engagement with external stakeholders throughout the funding process.

- Your foundation’s **vision** is the end goal—such as a world free of the disease, or a world where the disease is curable, chronic, and/or manageable.
- The **mission** supports the vision and should focus on the unmet needs and barriers that your foundation seeks to address. The mission should be broad enough to accommodate adjustments in strategy over time, but specific enough to clearly define and communicate your work to external stakeholders.
- **Strategic priorities** define the tools that your foundation will utilize and the angles from which your foundation will chip away at the larger problem. In other words, your strategy defines the steps needed to achieve your mission.
- **Objectives** set specific goals that help maintain focus and measure the efficacy of your strategy through individual projects or initiatives. Your foundation’s vision and mission will not be achieved overnight, as scientific research progress is nonlinear and fraught with risk. Strategic priorities and objectives set a short-term, nimble agenda that can respond to internal factors such as your foundation’s capacity and available resources or external factors such as the actions of other funders and the evolution of the current state of the science.

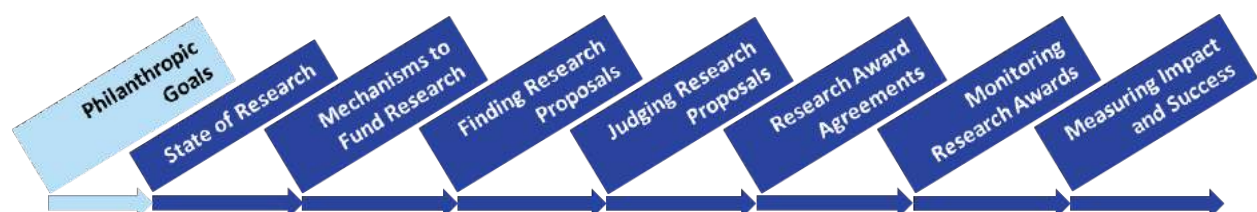
---

FOR FURTHER READING:

[Getting Started: A Medical Research and Development Primer](#)

[Crossing Over the Valley of Death: Translational Research](#)

[Honest Brokers for Cures: How Venture Philanthropy Groups are Changing Biomedical Research](#)



## 2. WHAT IS THE CURRENT STATE OF THE RESEARCH AND EXISTING SUPPORTERS OF RESEARCH?

### KEY TAKEAWAY

- Identify potential research partners—from academics, nonprofits, and industry—in the disease research ecosystem to help determine the research gaps your philanthropy can address.

The ideal next step in focusing your philanthropy is better understanding who is playing in the same sandbox. The following section enumerates resources that can expand your view of the disease research ecosystem, from nonprofits and foundations, government resources, and subscription-based platforms.

### NONPROFITS AND FOUNDATIONS

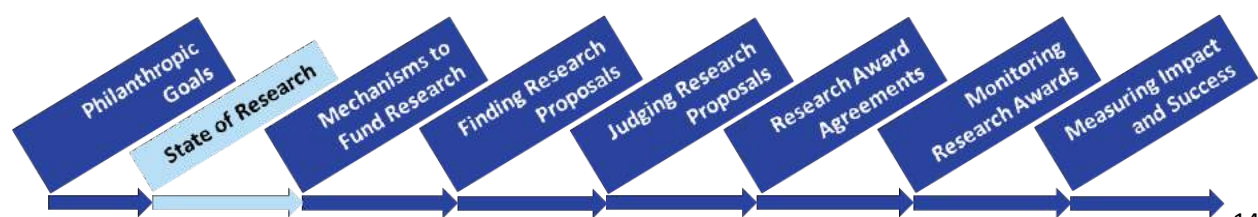
[Charity Navigator](#) is the nation's largest and most utilized evaluator of charities. Its analysts examine thousands of nonprofit financial documents to develop a numbers-based rating system to assess more than 8,000 of America's best-known and some lesser known, but worthy, charities.

[Foundation Directory Online](#) is a fee-based service of the Foundation Center that maintains a database of all U.S. private foundations and associated grant opportunities.

[Genetic Alliance](#) is a leading nonprofit health advocacy organization that includes a network of 1,200 disease-specific advocacy organizations, as well as thousands of universities, private companies, government agencies, and public policy organizations. Genetic Alliance manages the Genetic Alliance Registry and Biobank that provide a variety of resources and publications about registries and biobanks developed specifically members and other disease advocacy organizations.

[GuideStar](#) is the largest source of information on nonprofit organizations. A user can find organizations whose titles include the name of your disease space. Along with mission and contact information, GuideStar provides recent IRS documents (990 forms) that detail organizational revenue, assets, expenses, and grantmaking.

[Health Research Alliance \(HRA\)](#) is a membership organization with representation from more than 70 nongovernmental funders of health research. HRA members routinely share best practices and ideas about how to facilitate operational processes of grant-making. Its semiannual member meetings provide members with the opportunity discuss the topics of interest to the grant-making community. The list of member organizations might give insight into other nonprofit funders in your disease space.



**National Health Council (NHC)** brings together diverse stakeholders within the health community to work for health care that meets the personal needs and goals of people with chronic diseases and disabilities. The NHC's core membership includes the nation's leading patient advocacy organizations, whom altogether develop public policy positions with the goal of bringing about a health care system committed to putting patients first.

**National Organization for Rare Diseases (NORD)** provides networking and research services for patients and their families, rare disease patient organizations, medical professionals, and those seeking to develop new diagnostics and treatments.

**The Research Acceleration and Innovation Network (TRAIN)** is a *FasterCures* program that convenes dozens of forward-thinking foundations to learn from each other and share their novel solutions with the rest of the medical research system. The list of participating TRAIN organizations might give insight into other nonprofit funders in your disease space.

---

## Conrad N. Hilton Foundation: Expanding the Field of Multiple Sclerosis Research

---

### Mission:

---

*The mission of the Conrad N. Hilton Foundation is to provide funds to nonprofit organizations working to improve the lives of disadvantaged and vulnerable people throughout the world. Within this scope of work, the Foundation prioritizes scientific support for researchers and clinicians hoping to discover the cause and a cure for multiple sclerosis (MS), impact its prevention and treatment, to ultimately improve the quality of life of patients who suffer from its debilitating effects.*

---

### Strategy:

---

*The Foundation targets its scientific funding portfolio toward two primary aims: support and enhancement of existing funding efforts in the field, and identification of innovative research that is not supported by current funding programs. Through the Marilyn Hilton Award for Innovation in MS Research, the Foundation leverages its existing relationship with clinical care networks to identify new researchers, with the goal of directing funding toward innovative and risky research projects with the potential to create significant change.*

*Through this effort, the Foundation aims to avoid duplication of existing research, while also identifying new, exciting projects that might otherwise go unfunded.*

---



## GOVERNMENT

**NIH RePORTER**—The National Institutes of Health (NIH) is the primary agency of the U.S. government responsible for biomedical and health-related research, as well as the largest public funder of biomedical research in the world, with annual investments of more than \$32 billion a year. NIH RePORTER is a tool to assess existing research awards using multiple filters such as research field, university, project parameters, and principal investigators (the primary researcher on the award). The tool can help you understand the ongoing research efforts in the space, as well as the research leaders and principal investigators who might serve as ideal points of contact. Although NIH RePORTER can help to identify leading research and experts in the field, it should not serve as the only tool to assess the research landscape. In the context of a constrained government funding environment, established investigators are favored to receive NIH funding because of their track records or ability to generate relevant pre-award data. Younger investigators may bring a novel perspective to research questions but can be disadvantaged by the NIH process due to their lack of pre-existing data.

**Clinicaltrials.gov**—Understanding a disease’s clinical pipeline is a vital step to assessing the scientific landscape of the research. As a registry and results database of publicly and privately supported clinical studies of human participants conducted around the world, maintained by the National Library of Medicine, Clinicaltrials.gov can greatly aid this process. If your disease area has promising therapies in the clinical pipeline that need additional support, funding clinical studies might be a worthy investment with high-impact potential. Understanding the state of the clinical research can also inform translational research opportunities by delineating the gaps between the basic science and clinical applications.

Although Clinicaltrials.gov is a tool that captures the existing efforts in the space, it does not facilitate support of specific trials, as industry, such as biotechs and pharmaceutical companies, play a considerable role in funding clinical trials of potential drugs and medicines.

---

### Epilepsy Foundation (EF): De-Risking the Clinical Pipeline

---

#### Mission and Strategy:

---

*EF’s mission is to lead the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives. In pursuit of this mission, EF works to overcome the barriers to successful translation of promising new research insights.*

---

#### Program:

---

*Through the Epilepsy Therapy Project, EF analyses the clinical pipeline and provides financial support and scientific and business direction to promising new therapies that have progressed beyond the basic science discovery stage. Preference is given to proposals that already have a commercial partner engaged to assist with development and/or have committed or matched funding from a third-party source.*

---





## SUBSCRIPTION-BASED RESOURCES

**[UberResearch, Dimensions for Funders](#)**—This fee-based platform provides philanthropists with a comprehensive view of the past and ongoing efforts in specific research fields. Drawing from a global award database covering 200 funders and more than \$900 billion in historical awards, users can instantly compare internal funding applications and their philanthropic interests against the global funding landscape.

**[Online Partnership to Accelerate Research \(OnPAR\)](#)**—Research funders can utilize this fee-based platform to support proposals that were reviewed but not funded by the NIH. NIH has historically supported around 30% of submissions; however, in this constrained research funding environment, that rate has dropped to less than 20% of submissions. Thus, many worthy research proposals go unfunded. OnPAR aims to connect these high-scoring, unfunded proposals with potential foundation, philanthropic, and industry funders, serving as the matchmaker between funder and potential grantee.

**[BioCentury Online Intelligence \(BCIQ\)](#)**—This fee-based service provides information and analyses of various components within the clinical development space. BCIQ allows the user to analyze therapeutic product pipelines, public and private financing activity, and the relevant biotech and industry players in their desired research space. Understanding the dynamic and evolving landscape that shapes clinical development empowers the funder to make more strategic giving decisions.

---

### FOR FURTHER READING:

[Consortium Sandbox: Building and Sharing Resources](#)

[Consortia-pedia: A project to better understand the breadth and scope of approaches that a wide range of consortia have adopted to bring together non-traditional partners with a shared R&D goal.](#)



### 3. GIVEN THE STATE OF RESEARCH, WHAT ARE THE MECHANISMS TO ACHIEVE MY GOALS?

#### KEY TAKEAWAYS

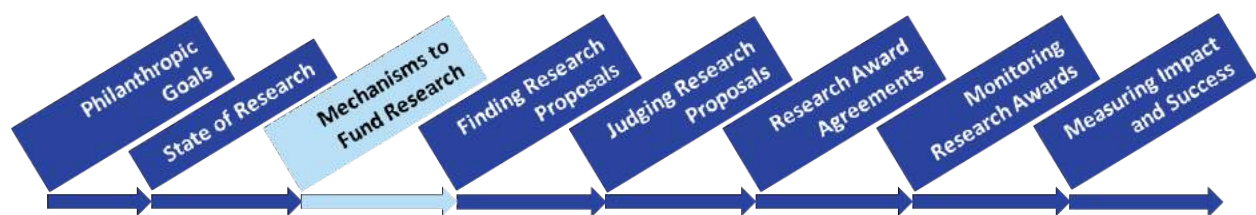
- Explore which mechanism is right for you - a university-directed gift or a sponsored research award.
- Tailor the award to focus on the specific research gaps, such as scientific unknowns, segments of the research workforce, or research infrastructure to enhance the capabilities of the entire research ecosystem.

There are multiple factors to consider when determining the funding mechanisms that align with your philanthropic goals. The following section is informed by a survey of the current mechanisms and programs utilized by members of the *FasterCures* TRAIN program (see section 2 for a description of TRAIN).

#### GIFTS VERSUS SPONSORED RESEARCH AWARDS

An initial consideration is how to engage with the academic institutions, because externally supported university research is classified as either a gift to the university or a sponsored research project. Gifts are defined as any item of value given to a university by a donor who expects nothing of significant of value in return, other than recognition and disposition of the gift as desired. Sponsored research projects involve a grant, contract, or cooperative agreement between the university and the sponsor, along with a detailed statement of work and a commitment to a specific project plan. Both award structures differ in their level of financial accountability and project oversight. The following table provides a brief comparison of the two award mechanisms.

	Gifts	Sponsored Research Award
<b>Purpose</b>	Donor specifies an area of interest to be addressed by the gift	Sponsor specifies how the funds should be used, as outlined in the grant or statement of work
<b>Reporting</b>	The university has little to no obligation to report to the donor how the gift is used. Required reporting is limited to details of how, when, and to whom to funds were disbursed	Sponsor requires performance of specific duties such as research deliverables, budget reports, progress reports, and return of unused funds
<b>Document</b>	Letter of Donation or Gift Agreement	Award Letter and/or Grant Agreement
<b>Deadline and Terms</b>	Typically, no time period is associated with the use of funds	Agreement outlines a specific time period to conduct the project
<b>Facilities &amp; Administrative Cost Rates (Indirect Costs)</b>	None	Varies by institution and usually a percentage of the total award value
<b>University/Academic Institution Contact</b>	Development Officers and Foundation Relations Office	Sponsored Programs Office as well as Research/Program Directors



## GRANT MECHANISMS

Depending on what you want to accomplish with your research award, certain grant mechanisms may be more suitable than others. For well-studied diseases, more impactful awards lie in targeted research initiatives that address a gap in the field, such as drug development or innovative approaches to disease research. Other disease areas may benefit from workforce development; thus, financial support for early-stage investigators may be a better fit. Below are considerations in choosing grant mechanisms based on your research priorities.

- 1) First, your foundation should first consider the research gap you wish to address.

### The Kenneth Rainin Foundation: Supporting Innovative, Proof-of-Concept Research

#### Health Mission:

*The Kenneth Rainin Foundation supports cutting-edge research projects that are potentially transformative to diagnosing, treating and curing inflammatory bowel disease.*

#### Program:

*The Innovator Awards program provides \$100,000 grants for one-year research projects, which because of their ground-breaking nature may not be suitable for funding from more traditional sources, such as the NIH. Applicants are not required to have pre-existing data, and grant proposals are weighed against the following criteria: innovation, scientific merit, strong evidence of collaboration, and the investigator's capability to execute the project. To date, the Foundation has awarded 36 Innovator Awards, of which 27 were successfully validated and received follow-on funding through the Foundation's Breakthrough Awards mechanism.*

Grant Mechanism	Purpose	Range of Award Size (per year)	Range of Award Duration
<b>Innovative Research Award</b>	Supports innovative research with <i>minimal existing data</i> but addresses questions beyond currently accepted paradigms	\$40,000-\$150,000	1-2 years
<b>Targeted Initiative Award</b>	Targets identified research needs, <i>e.g.</i> , biological and genetic signals of disease (biomarkers), drug discovery and delivery	\$25,000-\$600,000	1-3 years
<b>Bridge Funding</b>	Supports research projects that have been submitted to the NIH but have not yet received NIH funding	\$25,000-\$50,000	1-2 years
<b>Research Tools Award</b>	Targets the development of tools to support disease research <i>e.g.</i> animal models, imaging techniques, and tissue culture cell lines	\$25,000-\$50,000	1-2 years



- 2) Another potential consideration is the segment(s) of the research workforce you wish to support. Within a given funding cycle, your foundation can fund more than one type of scientist. The following table describes some common practices related to workforce grants.

Workforce	Definition	Award Size (per year)	Range of Award Duration
<b>Undergraduate Fellowship</b>	For researchers currently enrolled in an accredited undergraduate program	\$2,500-\$4,000	<1 year
<b>Predocctoral Fellowship</b>	For researchers enrolled in a master's or doctoral program	\$30,000-\$41,000	1-2 years
<b>Postdoctoral Fellowship</b>	For researchers with a graduate degree	\$35,000-\$60,000	1-5 years
<b>Early-Stage Investigators</b>	For principal investigators in the early stages of their career	\$20,000-\$100,000	1-5 years
<b>Established Investigators</b>	For principal investigators 10 years or more post their graduate degree	\$100,000-\$150,000	1-5 years
<b>Team Science</b>	For >2 investigators across multiple research disciplines	\$100,000-\$300,000	1-5 years

The considerations described in the Mechanism and Workforce tables are not mutually exclusive and can be mixed and matched to align with your philanthropic priorities.

---

## Doris Duke Charitable Foundation (DDCF): Developing the Clinical Workforce through Mentorship

---

### Medical Research Mission:

---

*The mission of the Medical Research Program is to advance the prevention, diagnosis, and treatment of human disease by strengthening and supporting clinical research.*

---

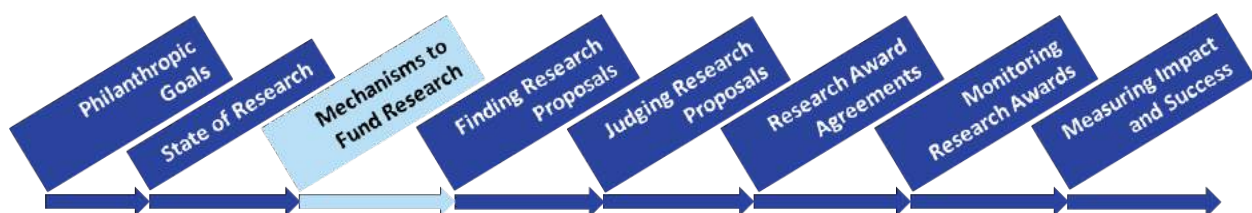
### Strategy and Program:

---

*The Clinical Research Mentorship program provides previously funded DDCF investigators with the opportunity to foster the next generation of clinicians by mentoring a medical student for one year.*

*Scientific mentoring is a personal, one-on-one relationship between an experienced scientist and a scientist-in-the-making. The Clinical Research Mentorship program supports the establishment of a relationship between a medical student and a talented and successful DDCF-funded clinical investigator and role model. Students will become involved in a research project that has already met the high standards of peer review, while DDCF investigators will receive the opportunity to teach and train the next generation of researchers. Their work will not only boost their mentoring skills, but also benefit from the student's energy and ideas.*

---





	Award Type	Purpose	One Time Award Size
3) Another potential consideration for rare diseases and new research fields is to support general awareness and dissemination of research findings via conference and meeting attendance.	<b>Meeting or Conference Support</b>	Funds meetings or conferences related to disease-specific research	\$5,000-\$20,000
	<b>Travel Awards</b>	Funds for researchers to attend conferences or facilitate collaborations	\$1,000-\$2,500

---

### Bladder Cancer Advocacy Network (BCAN): Convening Leaders to Define Strategic Priorities

---

#### Mission:

---

*BCAN sets the agenda for bladder cancer by promoting and funding collaborative and cutting-edge research programs and providing critical patient support and education services.*

---

#### Strategy:

---

*In 2006, BCAN started the Bladder Cancer Think Tank, the first scientific conference solely focused on bladder cancer. Hosted annually, the event is the only scientific conference that convenes leading oncologists, urologists, researchers, and patients to enhance collaboration among those dedicated to the prevention, diagnosis, and treatment of bladder cancer.*

*The meeting has focused on identifying obstacles and creating solutions in bladder cancer research and helps to define BCAN's strategic funding priorities while advancing bladder cancer research. A key outcome of the Think Tank was the launch of the Bladder Cancer Genomics Consortium, which is a cooperative effort between BCAN and eight major medical centers recognized for their expertise in bladder cancer research and treatment.*

---

FOR FURTHER READING:

[Entrepreneurs for Cures: The Critical Need for Innovative Approaches to Disease Research](#)

[Expanding the Science of Patient Input: Building Smarter Patient Registries](#)



## 4. HOW DO I FIND RESEARCH PROPOSALS?

### KEY TAKEAWAYS

- Craft a Request for Proposals (RFP) to communicate your strategic priorities to the wider research community and highlight the research questions and objectives you wish to address.
- Widely disseminate your RFP to maximize the number of proposals addressing your specific research question.

#### Tools for Philanthropy: Grant Management Software

Many grant management platforms can aid in the development, receipt, review, and tracking of awards throughout their funding lifecycle. In 2016, the nonprofit Idealware published a comprehensive review of commercially available grant management software. The "[Consumer's Guide to Grants Management Systems](#)" categorizes platforms based on four attributes: low cost for simple needs, flexible relationship management, comprehensive online data collection, and comprehensive application review.

### WRITING AN RFP

After setting your goals and identifying the most appropriate grant mechanisms, the next step is to solicit research proposals. This process starts by writing an RFP, also referred to as Request for Applications (RFA), which communicates your strategic priorities to the wider research community. It should highlight the objectives you wish to address given the current state of the research. RFPs can follow a variety of approaches to predetermine which researchers or types of projects will be funded, or both. The outline below delineates the key elements that your foundation might include in an RFP.

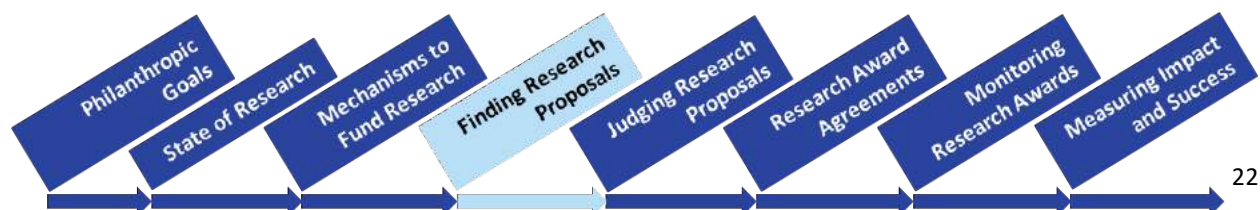
1) **Statement of Research Purpose:** As the most significant section of the RFP, the statement of purpose clearly defines the goals you seek to advance in the context of unmet needs and the larger research landscape.

*Elements of your strategy may include:*

- Stage of research: basic, translational, or clinical.
- Targeted patient population (such as gender or age group).
- Risk profile above the threshold for the NIH or other traditional funders (such as minimal requirement of pre-existing data).

*Intended goals may include:*

- Innovative and new methods of research and discovery.
- Identified research needs, such as biological and genetic signals of disease (biomarkers), drug discovery and delivery.
- Bridge funds, or funding support for NIH submitted proposals that have not yet received NIH funding.
- Increased awareness about your disease space (meeting support or travel grants).



2) **Submissions:** This section describes the administrative components of grant selection and implementation and may include:

- Desired format/page length for the grant proposal.
- Timeline of the review process and when researchers might expect a response.
- Expected to start and end of funding for selected proposals.
- Timeline for release of funding over the course of the grant.
- Access and availability of university resources to accomplish the proposed work.

3) **Eligibility:** The eligibility section defines the types of researchers your foundation hopes to support. Depending on your priorities, you may limit eligibility to, or encourage applications from:

- Undergraduate researchers.
- Trainees.
- Early-stage postdoctoral researchers.
- Early-stage or established principal investigators in the beginning stages of their career.
- Academics with industry partnerships (for translational projects).
- Research teams across multiple scientific disciplines (such as clinicians and basic researchers) or across multiple research fields.
- Consortia—existing research efforts characterized by cross-sector collaboration, often with multiple stakeholders, in the pursuit of a unified research mission.

---

### Melanoma Research Alliance (MRA): Funding Collaborative Research

---

#### Mission:

---

*To end suffering and death due to melanoma by collaborating with all stakeholders to accelerate powerful research, advance cures for all patients, and prevent more melanomas.*

---

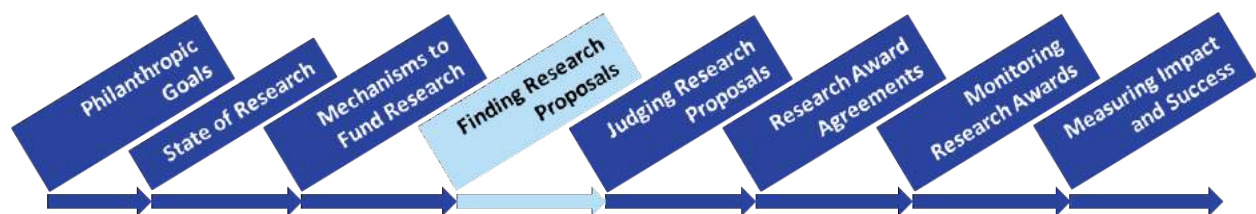
#### Program:

---

*The Team Science Award Program is the centerpiece of MRA's research funding portfolio and fulfills one of MRA's primary goals—to foster a collaborative research process. Multidisciplinary teams consist of principal investigators with complementary expertise who may be from the same institution, inter-institutional, and/or international.*

---

4) **Range of Grant Awards:** This section defines the monetary scale of the grant based on your desired granting mechanisms (see section 3). Your RFP can state that the award sizes and timelines will be determined by the stated justified needs of the submitted proposal. Alternatively, your RFP can state a predetermined dollar amount tied to a set timeline of release (tranches of funding).



To better understand the range of award sizes for each stage of research, we surveyed publicly available information on the websites of 57 TRAIN members (see section 2). The table (right) provides broad parameters of award sizes for each research stage and provide context as your foundation solicits proposals and decides on funding amounts. Although the ranges are wide, there is a clear progression in award size based on advancement through the research pipeline.

Stage of Research	Range of Award Size (per year)
Basic	\$10,000-\$250,000
Translational	\$40,000-\$500,000
Clinical	\$50,000-\$3,000,000

**5) Review Process:** This section describes how your foundation will select proposals and processes for internal and external review by scientific experts. It also suggests criteria for use during proposal evaluation. The section titled “How Do I Judge the Merit of and Potential of a Submitted Proposal?” presents best practices to engage experts in the field and metrics to assess the researcher and research proposal.

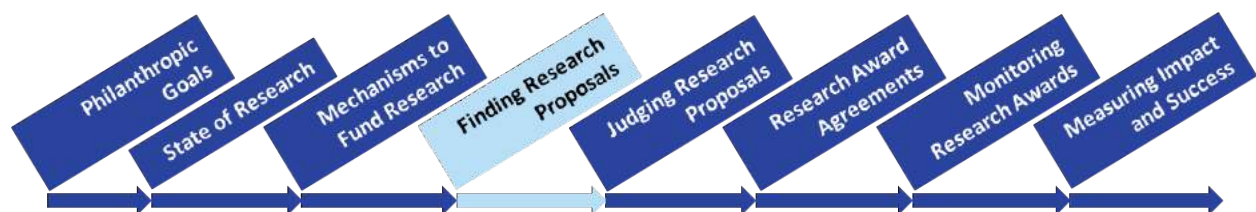
## ADVERTISING YOUR FUNDING OPPORTUNITY

To attract as large an applicant pool as possible, your foundation should broadly disseminate its RFP. Advertising opportunities exist on a variety of web portals with a reach far beyond your foundation’s website. Below are several options worth exploring:

[Foundation Directory Online](#) is a fee-based service of the Foundation Center that maintains a database of all U.S. private foundations and associated grant opportunities. Because most major universities have subscriptions to this database, Foundation Directory Online is an effective way to market your grant opportunities to academic researchers.

[COS Pivot](#) is a searchable database that enables researchers to identify funding opportunities from government, private foundation, and international sources. Although Pivot is a fee-based service for researchers and universities, there is no charge to submit funding opportunities. Most major universities have subscriptions to this database.

[Disease-specific grant databases](#) are centralized resources that advertise funding opportunities from government, foundations, and industry that pertain to specific diseases. These databases are usually coordinated and managed by nonprofits. Depending on your foundation’s disease area, there might be a disease-specific database to advertise funding programs. If none exists for your disease, your foundation might consider coordinating one. The [Epilepsy Research Connection](#) is an example of this type of database.





## 5. HOW DO I JUDGE THE MERIT AND POTENTIAL OF A POTENTIAL PROPOSAL?

### KEY TAKEAWAYS

- Consider both the quality and merit of proposals, as well as the ability of the researcher to successfully complete the work.
- Engage disease research experts as part of the review and selection process.

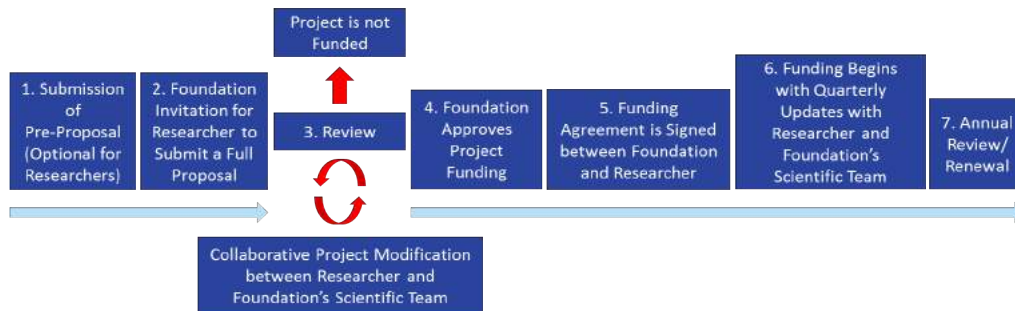
The sections below address how to engage experts, evaluate the quality of a researcher, and assess the scientific and strategic merit of the proposal.

### The Jain Foundation: Developing the In-house Expertise to Advance Philanthropic Scientific Research

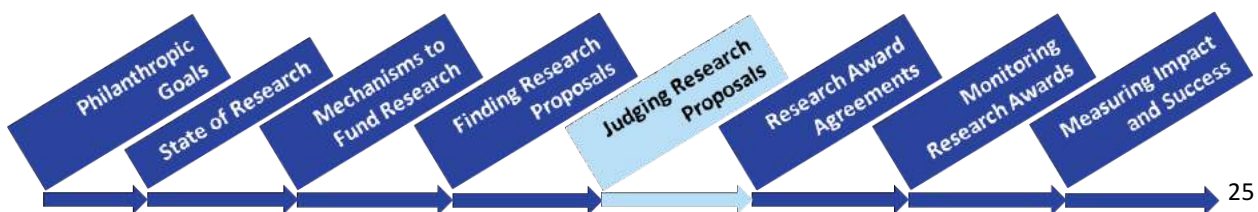
#### Mission:

*The Jain Foundation's mission is to cure muscular dystrophies caused by dysferlin protein deficiency.*

#### Funding Model:



*The Jain Foundation employs an interactive project management process, driven by the Foundation's in-house, full-time scientific team. In contrast to the commonly used external scientific advisory board, which evaluates stacks of submitted proposals, the Jain Foundation's scientific team identifies areas of need, solicits proposals from experts in the relevant fields, evaluates each proposal while working with the researcher to optimize the aims to improve the proposal's chances of success and alignment with the Foundation's goals, and then works with the researcher to ensure that the project is executed effectively and completed to its logical conclusion. A key innovation of the funding model is the review period's "collaborative project modification" that occurs between the Foundation's scientific team and researchers who have submitted proposals. The Foundation and researchers work together to refine the proposal, obtain the required research materials, and build a relationship of mutual respect between grantor and grantee. This relationship is invaluable throughout the grant review, monitoring, and renewal process and leads to a heightened level of intellectual engagement by both parties that moves research forward. A final key advantage of the Foundation's scientific team is its focused expertise to identify and eliminate research roadblocks due to lack of research materials or expertise, by mediating collaborations among researchers.*



## ENGAGING EXPERTS IN THE FIELD

Many of the foundations interviewed for this report engage a network of scientific leaders as external reviewers. These reviewers assess the merit of a proposal utilizing a foundation-issued rubric or metrics to ensure that evaluations are standardized and tailored to the foundation's interests.

In addition to external reviewers, your foundation should consider hiring an internal scientific advisor or director – often referred to as a Chief Scientific Officer – to oversee proposal evaluation and grantee selection, as well as to help to define the scientific and strategic priorities advanced by your funding programs.

If your foundation is interested in translational research, you should also consider engaging an advisory board of reviewers with business expertise to evaluate the commercial viability of an investment opportunity. These reviewers can also help to identify opportunities for strategic partnerships with industry to facilitate the translation of research from the bench-to-bedside.

In addition, when selecting reviewers, it is important to take measures to maintain objectivity and avoid conflict of interest. If your foundation is working in a rare disease landscape with limited researchers or in an otherwise insulated community, you may need to exercise extra caution to deter conflict of interest during the review process. This would involve seeking out a broader, interdisciplinary pool of experts who might be one or two steps removed from your disease area, in addition to the main players in your disease area.

The surveyed foundations engage reviewers on a volunteer basis or with an annual honorarium ranging from \$1,000-\$5,000, depending on the level of the engagement.

---

### Wishes for Elliot (WFE): Leveraging Strategic Partnerships

---

#### Mission:

---

*WFE is a family-based, nonprofit organization dedicated to supporting scientific research to improve the lives and prognoses of children struggling with SCN8A mutations, an extremely rare form of epilepsy.*

---

#### Strategy:

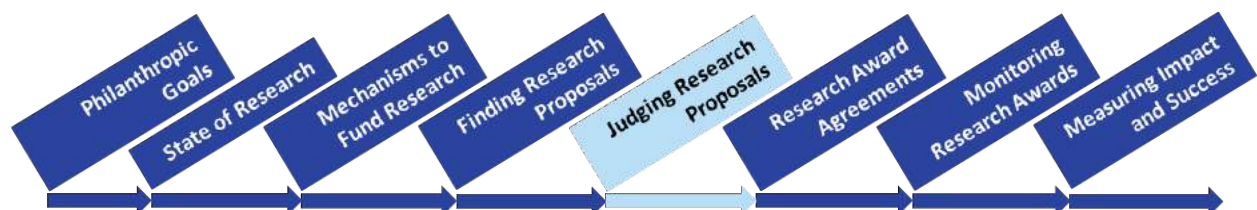
---

*As a small foundation lacking in-house scientific expertise, WFE pursued an alternative strategy to develop a competitive, peer-reviewed process for identifying promising research opportunities. WFE partnered with the American Epilepsy Society (AES), a leading nonprofit supporter of epilepsy research, to gain access to AES's expertise and peer review infrastructure.*

*Under the terms of the partnership, AES's peer review panels evaluated proposals for SCN8A research along with other proposals for AES Early Career Research Funding programs and recommended two proposals for funding. WFE funded one proposal, and AES funded the other proposal (for which WFE provided 15% of the costs).*

*Through this strategic partnership, WFE was able to achieve a high level of scientific rigor in its selection process as well as successfully channel additional funding to SCN8A research.*

---



## WHAT TO CONSIDER IN A RESEARCH PROPOSAL

Research proposal review is a two-step process. First, your foundation should assess the submitted proposals for scientific merit. Next, your foundation should assess the proposals that pass this first threshold for strategic merit, or how well the proposed research fits with strategic funding priorities.

**Scientific Merit:** Your scientific review board should first conduct a baseline evaluation of the proposal’s scientific merit, perhaps using the following key metrics:

Metric	Key Questions and Measures
<b>Background and Support for Hypothesis</b>	<ul style="list-style-type: none"> <li>Does the proposal clearly define a hypothesis that is supported by the current body of literature in the field?</li> </ul>
<b>Research Objectives</b>	<ul style="list-style-type: none"> <li>Is it clear what knowledge or advancement this research seeks to achieve?</li> <li>Do research objectives address unmet needs and align with your foundation’s mission?</li> <li>How likely is it that these objectives will be achieved?</li> </ul>
<b>Study Design and Methodology</b>	<ul style="list-style-type: none"> <li>Does the study design and methodology clearly tie back to the hypothesis?</li> <li>Does this design include appropriate controls and a means to gather measurable quantitative and/or qualitative data?</li> </ul>
<b>Data Analysis and Interpretation</b>	<ul style="list-style-type: none"> <li>Will the proposed analysis procedures yield objective results that have clear implications for the hypothesis?</li> </ul>
<b>Schedule and Milestones</b>	<ul style="list-style-type: none"> <li>Does the proposal establish a strategic plan with clear milestones and monitoring checkpoints?</li> <li>Is the proposed timeline feasible and in line with the grant parameters and your foundation’s goals?</li> </ul>
<b>Budget and Budget Justifications</b>	<ul style="list-style-type: none"> <li>Is there a clearly stated budget with justifications that make sense and adhere to your foundation’s funding policies?</li> </ul>
<b>Collaboration (if a foundation priority)</b>	<ul style="list-style-type: none"> <li>Does the proposal take a collaborative, team-oriented approach?</li> <li>Will the proposed collaboration advance the scientific research field?</li> </ul>
<b>Resource Building (if a foundation priority)</b>	<ul style="list-style-type: none"> <li>Does this research aim to develop tools or resources that will expand the infrastructure and capabilities of the field? Are these tools congruent with our foundation’s overall mission?</li> <li>Will these tools contribute to the accountability, collaboration, and research effectiveness in the field (see section 7)?</li> </ul>



**Strategic Merit:** Your scientific review board should next evaluate the proposals deemed to be of scientific merit for strategic merit, i.e., the potential of the research to positively impact the field and advance your foundation’s mission. Below are questions to consider when assessing strategic merit.

Alignment with Your Foundation’s Strategic Priorities

- How well does the proposal fit with your foundation’s funding priorities and mission?
- How significant would your funding be to the researcher, i.e., will your grant be a high priority in the context of the researcher’s total portfolio?
- If your foundation chose not to fund this work, would this research be funded by other sources?
- Does this proposal fit with your foundation’s risk tolerance and desired timeframe for results?

Potential to Impact the Field

- How likely is it that the proposed research will positively impact and contribute to the field?
- Will this proposal aid in the development new resources and infrastructures for the field?
- How well does the proposal capitalize on existing resources and infrastructures in the field?
- Does the research seek to form strategic partnerships with industry, nonprofits, universities, other researchers, and/or international research initiatives?
  - If so, will the proposed collaboration advance the scientific research field?
- How likely is it that the proposed research will succeed in attracting additional resources and other sources of funding?
- If the applicant is a former grantee of your foundation, how well did they perform during previous engagements?

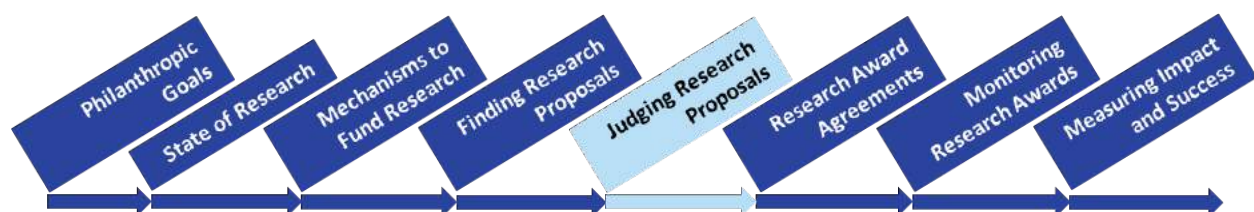
**Other Considerations:** The availability of institutional resources to execute the proposed research is another consideration. We emphasize that institutional resources are a secondary consideration to scientific and strategic merit, as good research can be conducted at research institutes and universities with fewer resources. The main question is not how much capital the university has, but whether the researcher has access to the tools and resources needed to conduct the proposed research. Accordingly, the proposal should describe not only the tools necessary to complete the research but also how the researcher will gain access to those tools.

---

FOR FURTHER READING:

[Measuring and Improving Impact: A Toolkit for Nonprofit Funders of Medical Research](#)

[Giving Smarter: Building a High-Impact Medical Philanthropy Portfolio](#)



## 6. HOW DO I WRITE A RESEARCH GRANT AGREEMENT?

### KEY TAKEAWAYS

- Upon identifying the proposal you wish to fund, craft a grant agreement, which is the legal document that outlines the terms, conditions, and goals of the grant.
- Effective communication with the grantee and research institution is critical to advancing your foundation's stated mission and strategy.

This section provides an overview of the elements common to most grant agreements, as well as additional topics a foundation may want to consider addressing through the grant agreement.

### PRINCIPLES FOR EFFECTIVE COMMUNICATION

Regardless of the details of your funding agreement, your foundation should adopt strategies and policies that facilitate positive and effective interaction with university partners.

Before entering negotiations, your foundation should confirm its ability to clearly articulate its goals and limitations to the other party. In addition, it should set a deadline for finalizing decisions, building in time to address unexpected issues that may arise as negotiations progress.

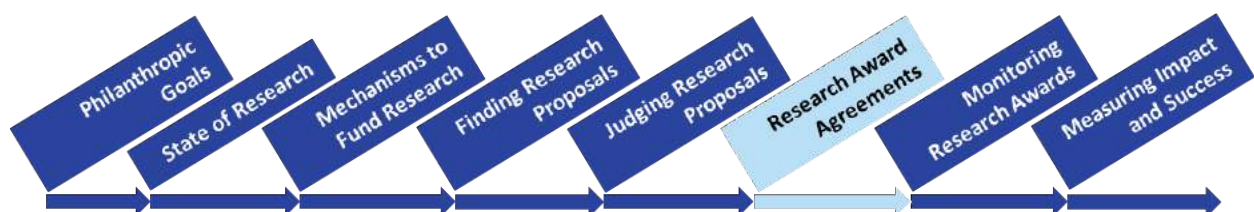
From interviews for this report and discussions among university and foundation leaders hosted by *FasterCures* in July 2012 and November 2015, we have identified three key principles to guide both foundations and universities in grant agreement negotiations.

#### Principle 1: Enter into Partnerships for Purpose

- Although their priorities and expectations may differ, universities and foundations are mission-driven organizations working to serve the public good. The negotiation process should be mindful of the common goal to deliver safe and effective therapies to patients as efficiently as possible.
- Through experience, resources, and contacts, your foundation can add value to the process far beyond the amount of funding supplied. Clearly communicate that value to university stakeholders with the aim of forming a sustainable partnership rather than a one-time transaction.

#### Principle 2: Communicate Early and Often

- Establishing a single point of contact for your foundation and the university facilitates internal coordination and avoids multiple, potentially conflicting conversations between the funder, researchers, technology transfer office ("TTO"), research administration, and other entities.
- Setting expectations for when your foundation should be notified of certain developments. For example, establishing that the university must notify your foundation within 60 days of receiving an invention disclosure for an invention funded at least in part by your foundation.





### Principle 3: Be as Transparent as the Process Allows

- When licensing of the funded technology to a third-party is possible, your foundation should ask to review the institution’s diligence terms and requirements.
- If interested in supporting the sharing of early-stage research or resources, your foundation should ensure that the university’s sharing policies are reasonably tailored for the technology and research stage.
- If seeking a share of any licensing revenue, your foundation should articulate your goals and determine the terms for a fair allocation. This allocation could take the form of a proportional share, flat rate, threshold requirement, and/or a cap.

### KEY ELEMENTS OF INCLUSION IN A GRANT AGREEMENT

Depending on the depth and breadth of its research portfolio, your foundation may need different agreements for different research projects. Trusted legal counsel should review the grant agreement to ensure satisfaction of the the legal requirements specific to your organization and research grant. However, the elements listed below will likely be included in any academic grant.

- **Amount and purpose of the grant:** Although it may seem obvious, the agreement should include this information so that all parties are clear about the expectations before the research begins.
- **Coverage of indirect costs:** The agreement should state whether indirect costs will be covered, and if so at what rate. Indirect costs, also known as “facilities and administration costs,” are expenses that cannot be directly attributed to a particular project (e.g., labs, classrooms, offices, libraries, office supplies, departmental administrative staff, utilities, maintenance, and research administration staff and offices). Federal agencies such as the NIH may pay indirect cost rates of 50% or more depending on the research institution. Foundations that elect to cover indirect costs typically do so at a much lower rate. A 2014 survey of organizations conducted by *FasterCures* and the Health Research Alliance revealed a median indirect cost rate of 10%.
- **Grant term and payment schedule:** The agreement should outline how and when the grantee will receive funds. Funding can be administered in installments tied to the grantee meeting certain milestones outlined in the research plan.
- **Reporting expectations:** The agreement should specify whether the grantee should submit interim reports or only a final report. In addition, to ensure that reports are comprehensive yet digestible at a lay level, the agreement should provide guidelines about the type of information to report. Updates via teleconference could serve as alternatives to written reports. If a report reveals that events are not unfolding as planned, your foundation should help the grantee to make course corrections to ensure effective use of your funding. Key considerations for grant reporting will be covered in Section #7, “How Do I Monitor a Research Award?”
- **Publication and publicity:** The agreement should outline the expectations for publishing results and clarify how the grant itself will be publicized (if at all).
- **Confidentiality:** The agreement should clarify how both the grantor and grantee will handle and exchange confidential information.



- **Budget:** The agreement should set forth the budget and state how changes to the budget can be made and addressed if necessary.
- **Provisions for terminating the grant:** It is common to allow for termination where, for example, the grantee’s tax-exempt status is changed or revoked, or the grantee fails to abide by the terms of the grant agreement.
- **Intellectual property:** Foundations and grant-making organizations are typically not structured to manage intellectual property. Academic grants usually state that ownership of intellectual property resides with the university. However, foundations are becoming increasingly interested in playing a role in how the intellectual property moves forward, or in sharing any revenue. We discuss these approaches in the following section.

## OTHER PROVISIONS TO CONSIDER

The decision to include the provisions discussed below in the grant agreement will vary across organizations, and even across projects within the same organization. For example, a foundation that funds basic research may place a high priority on data and resource sharing and include provisions designed to facilitate such sharing. In contrast, a foundation that funds later stage or translational research may focus more on helping to move any intellectual property generated toward commercial application.

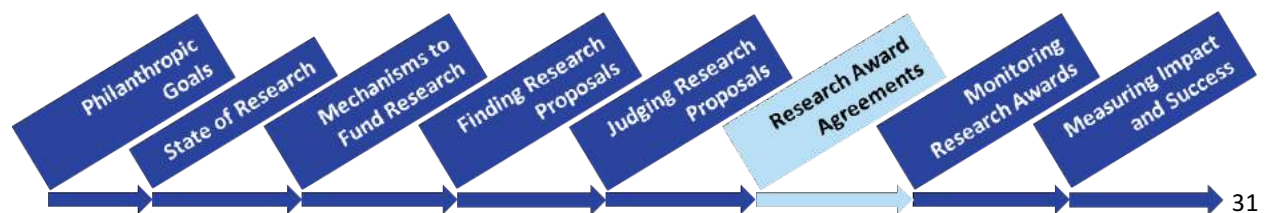
Through discussions with representatives from both universities and patient foundations at *FasterCures*, we *identified* three road blocks frequently encountered in grant agreements:

- Sharing of resources in basic research
- Intellectual property and role of the funder
- Revenue sharing

**Sharing of Basic Research and Resources:** Many foundations that fund scientific research, particularly early-stage research, want to ensure that researchers across institutions work collaboratively so that discoveries move forward efficiently. Foundations can promote their collaborative policies through their grant agreements and may condition future funding on the degree of cooperation and collaboration demonstrated by an investigator. Below are possible provisions for consideration.

**Participation in Workshops or Collaboration:** Some foundations, particularly those focused on a specific disease area, require its funded researchers to discuss and share information and tools with each other. This condition is often employed by funders in a disease area with relatively few researchers or with a large portfolio of researchers working on a similar type of project.

**Publication:** Academic researchers are highly motivated to publish their work in academic journals. However, it takes time to prepare an article for publication in a prestigious journal, which can be critical to career advancement. Moreover, academic researchers may not be eager to share results from failed experiments. Many funders recognize these challenges and require publication of all results, within a reasonable amount of time, as a condition of funding. Funders may also consider provisions that reserve their right to publicly release the results of the research if the researcher fails to do so within a reasonable amount of time.



**Sharing Data, Tools, and Resources:** Access to research tools is widely acknowledged as a critical component to scientific advancement. At the same time, reasonable restrictions may be necessary to preserve opportunities for commercial development. Therefore, funders should be careful to balance the needs of the scientific community with the requirements of product development when crafting provisions.

**Research-Use Only License:** A research-use only license authorizes the licensee to use intellectual property for research purposes only. This type of license facilitates research, without compromising ownership of the underlying intellectual property. It may be particularly useful when research is in a relatively early stage, such that the benefits of sharing outweigh the risks. Furthermore, this license preserves the rights of the university to offer exclusive commercial rights to a third-party company that is interested in the technology. These licenses can take different forms. Early communication with the grantee will ensure an approach that is acceptable to both sides.

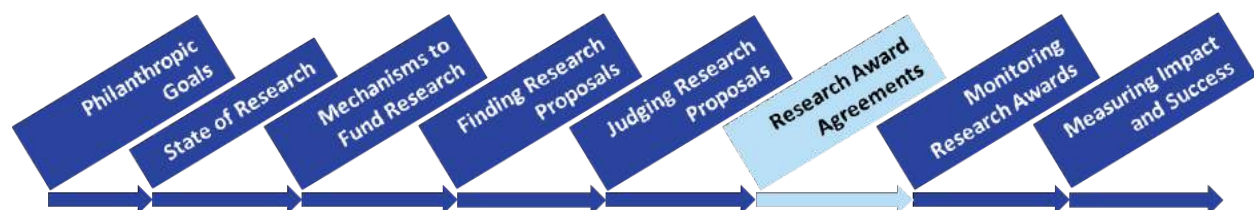
- **Option A:** Grantor requires grantee to extend a nonexclusive, sub-licensable license back to the grantor, which the grantor may then distribute solely for research purposes.
- **Option B:** Grantee agrees to extend a nonexclusive, royalty-free license to a limited number of institutions who will have permission to use intellectual property generated with foundation-funded research solely for research purposes.

**Intellectual Property and the role of the Funder:** Many foundations place high importance of working with institutions that are equally dedicated to moving promising technology forward, including after licensing to a third party (e.g. such as biotech or industry partners). They may be concerned about the dedication of all industry partners to advance therapeutic development within their disease space. Therefore, selecting a licensee with the capability, expertise, and motivation to move a product forward is critical and foundations increasingly want to play a role in the selection process.

Moreover, foundations with broad networks and subject matter expertise may be able to contribute to the identification of potential licensees. Indeed, many surveyed universities and TTOs indicated that they would welcome input from funders. However, grant provisions that remove final decision-making authority from the university or give the foundation the right to “march-in” and take control of the intellectual property if the licensee is not advancing the technology can be problematic. Specifically, such provisions may have the unintended consequence of discouraging promising licensees or derailing negotiations. However, foundations can play an important oversight role and should work with the grantee to develop a collaborative and coordinated licensing effort.

**Identify Interest in Commercialization Process:** Funders who desire a role in the commercialization process should clearly communicate this intent in the grant agreement. Example text is as follows:

“Given Foundation’s network and expertise, both parties recognize that Foundation can be a valuable partner in the search for a licensee of technology funded by this grant. Accordingly, the parties agree that within 30 days of the decision to pursue patent protection, the Foundation will be offered an opportunity to confer with the Institution to identify and suggest potential licensees.”



In addition, foundations should identify a contact person within the office responsible for commercializing inventions, usually the university's TTO. Although universities and foundations are aligned in their goal to move technology move forward, foundations can exercise some oversight by requiring the university to share its diligence terms early in the process so that it can identify potential vulnerabilities. Building into the agreement a requirement for regular communication with the university about licensing efforts, even after the grant term has ended, will not only keep the foundation informed but also enable the foundation to identify as yet untapped resources or potential partners.

**Require Notification of Inventions:** Foundations who desire a role in the commercialization process should also require notification when intellectual property is developed with foundation funds. To reduce the administrative burden on institutions, these reporting requirements should be consistent with those established by the NIH.

**Revenue Sharing:** Many foundations are exploring revenue-sharing provisions to generate more sustainable funding streams. These provisions are particularly appealing for funders of later stage research because the likelihood of generating intellectual property with commercial potential is much higher. Different institutions are likely to have different policies regarding revenue sharing. Many surveyed institutions indicated that revenue sharing is an appropriate and reasonable strategy, but it must be in line with the foundation's contribution to the research. Although revenue-sharing provisions can take many forms, the following are two current examples:

- Revenue is distributed in amounts proportional to the funder's contribution, which is the fairest allocation.
- The funder receives a flat royalty rate, capped at a reasonable multiple of the award, which is appealing because of its straightforward application.

The reasonableness of the negotiated rate will depend on other deductions or contributions made by the foundation, as well as the specific research being funded. For example, because universities devote resources to filing for patents for many inventions—not just those that generate royalties—a foundation that offers to cover patenting costs may be able to negotiate a higher royalty rate.

Regardless of the approach employed, foundations should consider stating a threshold that must be reached before the its right to share kicks in. Such a threshold ensures that a foundation shares in any big winners, but avoids the administrative burden of dividing small amounts of revenue. A threshold also give the university a chance to recoup some of its indirect costs that may not have been covered by the foundation.

---

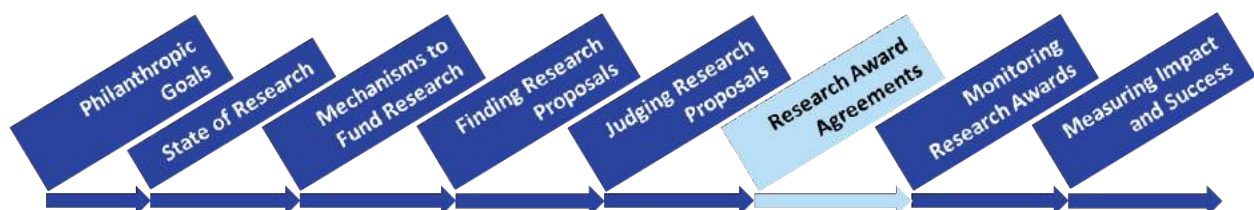
FOR FURTHER READING:

[TRAIN Foundation-University Partnerships Toolkit](#)

[Unlocking Intellectual Property: Principles for Responsible Negotiation](#)

[University-Foundation Relations: From Transactional to Transformative Partnerships](#)

[Key Research Agreement Terms & Definitions](#)



## 7. HOW DO I MONITOR A RESEARCH AWARD?

### KEY TAKEAWAY

- Progress and final grant reports are key checkpoints of the funding process, and should capture the roadblocks and proposed solutions of the awarded project.

Like any investment, choosing who and how to fund is only the first stage of the process, with the next decision being whether to continue funding a specific research project. Scientific research is not linear, with roadblocks a hallmark of the process. An award's progress and final grant report are key materials that should capture these challenges and demonstrate the researcher's ability to continue research advancement. The following section discusses how to regularly monitor research progress, identify potential challenges, and assess whether a project merits continued and/or possible renewed funding.

### GRANT MONITORING AND PROGRESS REPORTS

Depending on the length of a grant, your foundation can solicit progress reports every six months or annually. The following template can facilitate the review of research progress. Progress reports are required for sponsored research awards, but are not regularly required for gifts to a university (see Section #3).

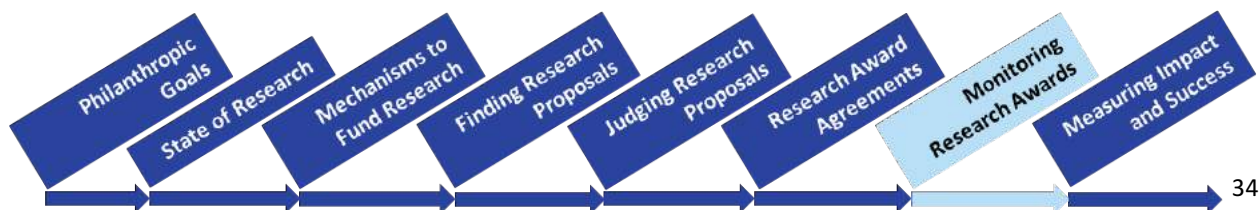
#### PROJECT AIM:

#### Accomplishments since last progress report

#### Challenges encountered

#### Proposed solutions

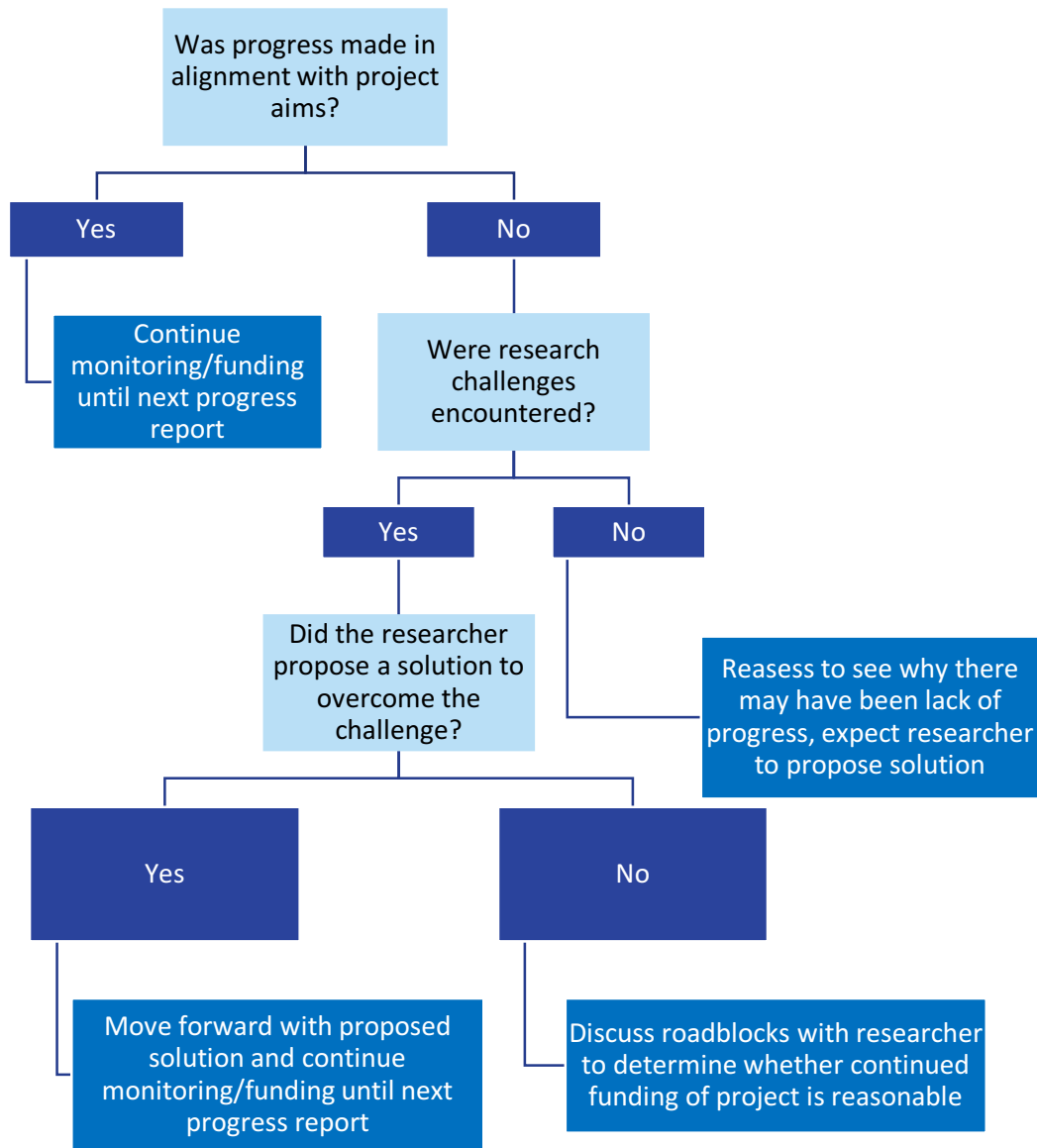
#### Anticipated milestones for next reporting period





Because a project’s success cannot always be predicted at its outset, we encourage you to consider the ability of a grantee to adapt to research challenges and generate reasonable solutions to continue to advance the project’s aims. The flowchart below serves as a guide to quickly assess a research grant’s progress. Warning signs include the following:

- Continued lack of progress in project aims.
- Lack of feasible proposed solutions to encountered challenges.
- “Mission creep” or appearance of new aims not previously discussed and/or with limited validity to original project hypothesis.



## FINAL GRANT REPORT

At the conclusion of the funding period, your foundation should request a final report that describes the project's outcomes and impact. You can structure the final report in terms of four metrics: Accountability, Collaboration, Research Effectiveness, and Resource Building. Although the progress report format can serve as an outline, the final report should provide greater detail about the successes and failures of the research project. The questions and metrics below can assist in requesting the project information most important to you.

**Accountability:** The degree to which a grantee transparently details project execution to the foundation.

- Do the specific aims and activities outlined in the final report match those agreed upon in the original work plan?
- Were each of the project aims addressed, and what were the relevant outcomes?
- What were the encountered challenges, and how were they overcome?
- Was the project completed within the agreed upon timeline?
- Was the project completed within budget guidelines? If not, is there a good explanation?

**Collaboration:** The degree to which the grantee engages and builds relationships to accelerate the overall funding and research supported by the foundation.

- Were academic or industry collaborations initiated/facilitated by the project?
- Were any interdisciplinary collaborations initiated during the project?

**Research Effectiveness:** The degree to which the grantee's conducted research yields sufficient data and deliverables in alignment with their proposal's stated objectives and aims.

- Has the project raised new pointed research questions to pursue?
- Did the project employ novel concepts, approaches, or methods?
- Do project results challenge existing paradigms?
- Do project results develop new methodologies or technologies?
- How were research results disseminated?
  - Number of published articles in peer-reviewed journals or abstracts presented at conferences.
  - Number of seminars held for non-academic audiences.
- Did the project result in other deliverables such as products or patents?
- Has follow-on funding been awarded to support research related to the awarded project?

**Resource Building:** The degree to which the grantee's research contributes critical resources and infrastructure to the greater scientific community.

- How many trainees were supported by this award (if applicable)?
- Did the project result in tools or infrastructure that benefits the research field?
- How were project results (published or negative data) shared with the field?

---

### FOR FURTHER READING:

[Measuring and Improving Impact: A Toolkit for Nonprofit Funders of Medical Research](#)

[TRAIN Foundation-University Partnerships Toolkit](#)



## 8. HOW DO I MEASURE SUCCESS?

### KEY TAKEAWAYS

- Measuring the success of awarded grants involve both tangible and intangible impact metrics.
  - Tangible metrics include fruitful collaborations and follow-on funding, as well as research infrastructure development and workforce directly supported by the award.
  - Intangible metrics include development of new and innovative thinking for the field, and whether the work demonstrates the kind of scientific ambassadorship your foundation wishes to project.

The lack of linearity in scientific research may make mapping success difficult, but does expand the ways to measure the impact of a completed research award. Although it is straightforward to ask whether the specific milestones of a project were met, the ability to gauge the long-term impact and benefits for the field is often limited at the end of a funding period.

The first goal of this section is to make sense of all the information collected from the progress and final reports. The second goal is to provide a framework of questions to help you to evaluate whether to renew a research award. We approach this evaluation by considering the impact of the stakeholders involved in a signed sponsored research agreement.

---

### Michael J. Fox Foundation (MJFF): De-Risking Innovation

---

#### Mission:

---

*MJFF is dedicated to finding a cure for Parkinson's disease (PD) through an aggressively funded research agenda and to ensuring the development of improved therapies for those living with Parkinson's today.*

---

#### Strategy and Impact:

---

*MJFF invests in high-risk, high-reward research targets, with the goal of de-risking the Parkinson's field and making it as attractive as possible for all researchers, particularly industry groups that play a significant part in commercializing therapies.*

*In 2005, MJFF began supporting novel research at Vanderbilt University to develop an entirely new class of treatment for PD, focused on the glutamate system as a means to bypass dopamine replacement altogether, with a focus on the glutamate receptor called mGluR4.*

*In 2012, on the heels of nearly \$5 million in MJFF investment, Vanderbilt University announced a major collaboration with Bristol-Myers Squibb for development of a potential first-in-class symptomatic treatment for PD. Typically, the timeline for translating a research discovery into a new treatment for a disorder such as PD can take as many as 20 years. With MJFF's support, the funded research group was able to radically accelerate this process.*

---



## MEASURING THE TANGIBLE IMPACT OF A RESEARCH PROJECT

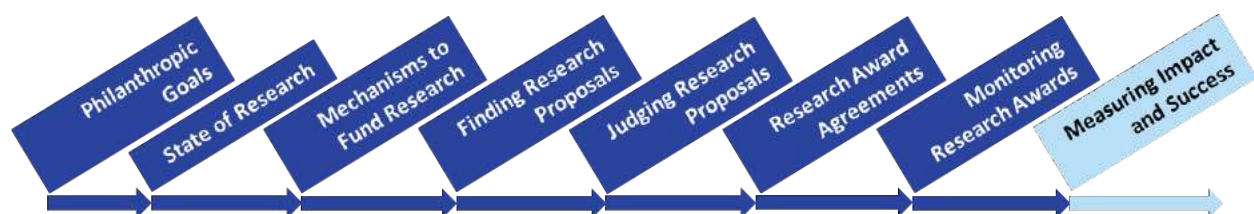
The basic currency of the academic research field lies in scientific publications and presentations. Researchers who successfully communicate their research findings through peer-reviewed manuscripts and scientific conferences and seminars are generating impact. However, impact can also be measured in terms of collaborations with academic and industry partners, follow-on funding, and workforce development.

- **Collaborations:** Impactful collaborations include engagement with researchers within the grantee's university and partners in other institutions. For late-stage basic, translational, and clinical projects, engagement of industry collaborators exemplifies a researcher applying their work beyond the bench.
- **Follow-on Funding:** Follow-on funding is an indirect measure of the value of the work to the field and a direct measure of the researcher's ability to capitalize and advance the work in an environment of limited research funding. The follow-on funding agency is also an important consideration, as it represents new financial collaborators that can span federal, industry, and other nonprofit/foundation funders.
- **Workforce Development:** Recruitment of new researchers into a field is a critical factor for continued and better research. With the focus on research advances and new medical products, the importance of educating the next generation of scientists to become the new experts and leaders in their field is often overlooked. Thus, you might assess the researcher's ability to not only educate undergraduate, predoctoral, and postdoctoral trainees, but also support their transition to and success in the next stage of their scientific careers.

## MEASURING THE SCIENTIFIC MERIT OF A RESEARCH PROJECT

The final research report should discuss the scientific merit of the completed work and should provide a sense of its value to the entire field. Measurements of the work's impact include its expansion of scientific knowledge, innovative and applied potential, and overall benefit to the research field. Answering a research question often begets only more questions, and before renewing funding, you should consider the relevance and direct impact of next-stage questions to your disease area and your foundation's mission and objectives.

- Did the project result in a new and innovative way to approach research in your disease area?
  - Do project results direct researchers to a new way of thinking or propose novel approaches to solve disease-related problems?
  - Do project results point to a novel diagnostic tool, or possibly a new therapy to benefit persons affected by disease?
- Did the project lead to new tools or infrastructure that will benefit the entire research field? Such tools or infrastructure might include new animal models, experimental assays and designs, and research databases that facilitate the sharing of data and initiation of collaborations.



## MEASURING THE IMPACT FOR YOUR FOUNDATION

Because the landscape of scientific research is diverse, it is difficult to assemble a broadly applicable set of metrics to assess the success of an award. Therefore, the assessment must attempt to answer the following questions:

- Do the project results support and advance your foundation’s mission?
- Does the grantee’s work demonstrate the kind of scientific ambassadorship your foundation seeks to project?
- Might the new research questions raised by the grant impact and guide your foundation’s strategic objectives?

---

### FOR FURTHER READING:

[Measuring and Improving Impact: A Toolkit for Nonprofit Funders of Medical Research](#)

[Giving Smarter: Building a High-Impact Medical Philanthropy Portfolio](#)





## CONCLUSION

Philanthropy accounts for only 3% of the overall funding for scientific research, but it can have an outsized impact by targeting knowledge gaps and building needed research infrastructure. In addition, although measuring the success of funding scientific research has been described as “you will know it when you see it,” our interviews with nonprofit funders of research revealed several contributors to a successful venture into scientific philanthropy:

- The need to maintain a laser-like focus on the foundation’s goals.
- The importance of assessing the gaps in research with the help of subject matter experts.
- The willingness to employ multiple funding approaches to achieve a foundation’s strategy and objectives.
- The value of identifying and facilitating multidisciplinary academic and industry research partnerships.
- The benefit of maintaining open communication and transparency between the grantor, grantee, and academic institution.

Scientific research is a noble endeavor—one that many advocate for and professionally pursue. However, difficulties remain in how to identify the best philanthropic process and opportunities to support research. Our goal with this report is to identify common approaches and best practices to address the potential pitfalls and challenges that come with supporting scientific research in academic institutions.

However, as with all things in science, you cannot know what will or will not work, until you perform the experiment.