

# Measuring and Improving Impact

A Toolkit for Nonprofit Funders of Medical Research

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## INTRODUCTION

For much of its existence, *FasterCures* has been interested in the unique, powerful role philanthropy can have in jump-starting new models of innovation needed to accelerate progress in medical research and development (R&D).

We have analyzed the system-wide impediments to faster progress in the war against disease.<sup>1</sup> We have studied the innovative approaches being employed by a new breed of more strategic nonprofit foundations funding medical research, sometimes called “**venture philanthropies**,” to address many of those impediments.<sup>2</sup> We have created tools to help individual philanthropists understand the R&D landscape and strategically guide their investment into high-impact research opportunities.<sup>3</sup>

This document represents *FasterCures*’ latest effort to maximize philanthropic investment in medical research, by giving nonprofit foundations that fund medical research **a common framework for assessing and improving their organizational effectiveness**, based on many of the best practices we have observed in the field.

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<sup>1</sup>See *FasterCures*’ white papers *Entrepreneurs for Cures*, 2008 ([www.fastercures.org/objects/pdfs/white\\_papers/FastercuresWP\\_Innovation\\_052808.pdf](http://www.fastercures.org/objects/pdfs/white_papers/FastercuresWP_Innovation_052808.pdf)) and *Crossing Over the Valley of Death*, 2010 ([www.fastercures.org/documents/pdfs/VOD-TranslationalResearch.pdf](http://www.fastercures.org/documents/pdfs/VOD-TranslationalResearch.pdf))

<sup>2</sup>See *FasterCures*’ TRAIN Central Station Web site, [www.fastercures.org/train](http://www.fastercures.org/train)

<sup>3</sup>See *FasterCures*’ Philanthropy Advisory Service program ([www.fastercures.org/Programs/PAS.php](http://www.fastercures.org/Programs/PAS.php)) and the *Giving Smarter* toolkit ([www.fastercures.org/Publications/Giving-Smarter.php](http://www.fastercures.org/Publications/Giving-Smarter.php))

## WHAT IS VENTURE PHILANTHROPY?

Venture philanthropy is a concept very much in vogue but without a commonly agreed upon definition. In the strictest sense, venture philanthropy connotes nonprofit organizations that invest directly in for-profit companies. But we find that definition limiting, leaving out many disease research organizations that are taking a new, more outcomes-driven approach to philanthropy, whether or not they are investing in for-profit entities.

Wikipedia has a broader definition with which we generally agree, saying venture philanthropy “**takes concepts and techniques from venture capital finance and high technology business management and applies them to achieving philanthropic goals.**” It lists among the elements of venture philanthropy:

- Willingness to experiment and try new approaches;
- Focus on measurable results—donors and grantees assess progress based on mutually determined benchmarks;
- Readiness to shift funds between organizations and goals based on tracking those measurable results;
- Giving financial, intellectual, and human capital;
- Focus on capacity building, instead of programs or general operating expenses; and
- High involvement by donors with their grantees.<sup>4</sup>

Another analyst says that “at the center of this model is the concept of treating funding as an *investment* rather than as the traditional concept of a charitable *grant*, with corresponding expectations of return on investment, operating efficiencies, and management oversight.”<sup>5</sup> Return on investment may be *financial* (in the case of an investment in a for-profit company), to be reinvested in the foundation’s research agenda, but it is also importantly a *social* return on investment—the advancement of a promising therapy down the pipeline toward patients.

We also agree with the observation of a venture philanthropist of our acquaintance, who believes venture philanthropy is synonymous with a shift from reactive to proactive philanthropy. She calls it “**philanthropy with an opinion.**”

## THE CHALLENGES OF MEDICAL RESEARCH

Despite decades of medical and technological advances, from the decoding of the human genome to stem cell science, from health information technology to targeted cancer therapies, our ability to translate exciting new discoveries into products that can help patients is severely lagging behind the pace of discovery. A formidable list of diseases for which there are no cures or even meaningful treatment options remains.

The medical research enterprise is facing a serious productivity gap. The amount of money invested by all sources—government, industry, philanthropy—has been increasing while the number of new products approved is decreasing or stagnant.<sup>6</sup> It takes too long—on average 15 years from discovery to patients. It costs too much—well over \$1 billion to develop a successful drug, including the cost of failures along the way. And the risks are high—only 1 out of more than 5,000 compounds that enter the drug discovery pipeline will become an approved therapy. This trajectory is simply unsustainable.

Science is undeniably complex; for many diseases, the answers to even the most basic biological questions remain elusive. That being said, science is not the only reason for the slow momentum in clinical discovery and application. Among the many challenges that *FasterCures* has identified over the years are:

- Increasing conservatism on the part of the largest investors in medical research—the federal government (through the National Institutes of Health, or NIH) and the biotech and pharmaceutical industries;
- Significant cultural barriers in the academic research infrastructure and environment; and
- A widening gap—referred to by some as a “valley of death”—in funding and support for **translational research**, which moves basic science down the path toward treatments and feeds critical clinical information back to the laboratory for investigation. While the costs at this stage of research are relatively low, the risk of failure is high.

**Change is slow, and innovative efforts outside the NIH and industry are needed now more than ever to create a parallel track of disease research that complements existing efforts while aggressively pursuing innovative research agendas and approaches.**

<sup>4</sup> en.wikipedia.org/wiki/Venture\_philanthropy

<sup>5</sup> From remarks by Bruce Sievers, “If Pigs Had Wings: The Appeals and Limits of Venture Philanthropy,” November 16, 2001, Waldemar A. Nielsen Issues in Philanthropy Seminar Series, Georgetown University ([cpnl.georgetown.edu/doc\\_pool/Nielsen0103Sievers.pdf](http://cpnl.georgetown.edu/doc_pool/Nielsen0103Sievers.pdf))

<sup>6</sup> FDA did approve 35 new medicines in fiscal year 2012, a significant increase over the trend of the past decade. <http://www.fda.gov/AboutFDA/ReportsManualsForms/Reports/ucm276385.htm>

## Cystic Fibrosis Foundation

### PHILANTHROPY'S CRITICAL ROLE

Although private philanthropy is only a small share of overall spending on medical R&D in the United States (less than 3 percent), its flexibility and focus on outcomes can have an outsized impact on the medical research enterprise. Free of the pressures of publication and career advancement in academia and the bottom-line imperatives of the private sector, and driven by the desire to deliver results to the patients they represent, nonprofit foundations are ideally positioned to make relatively high-risk investments that could significantly move a field of research forward and increase the likelihood that other parties will also invest.

*FasterCures* has identified many ways in which foundations are already doing this; among them are:

- Developing pre-clinical tools that benefit the field and aid in translation, such as biomarkers and animal models;
- Bringing focus, management, and accountability to academic research;
- Creating strategic partnerships with industry—in some cases directly investing in companies; and
- Providing access to a patient community and resources through registries, biorepositories, and clinical trials networks.

By providing financial incentives, along with other benefits, such as access to patients and disease expertise, nonprofit foundations that fund research can change the culture and structure of the medical research enterprise. But philanthropy's true potential can be realized only through informed, strategic, and measurable investment strategies.

**By understanding the role nonprofits play along the R&D spectrum and the practices that position them to be most effective, your organization can maximize its “return on investment” and make a sustainable impact in the search for cures.**

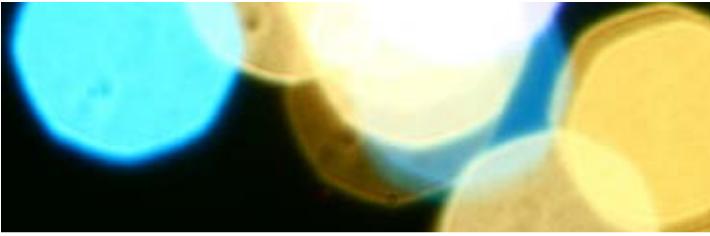
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Medical philanthropy can play an outsized role in catalyzing and jumpstarting innovation.

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One of the biggest research headlines of 2012 was the Food and Drug Administration's approval of Vertex Pharmaceuticals' drug Kalydeco to treat the underlying genetic cause of a subgroup of patients with cystic fibrosis. The Cystic Fibrosis Foundation (CFF), a venture philanthropy pioneer, was critical to that success; it invested \$75 million in the Vertex program over the years, helped the company maintain its focus on and commitment to the program even after the original biotech was acquired, and brought scientific guidance and trial subjects to the research.

With almost 30 products in its pipeline to treat the causes and the symptoms of the disease, CFF continues to invest significant sums of dollars in drug development, most recently with an almost \$60 million co-investment with Pfizer. While CF is a rare disease—and Kalydeco can treat only 1,200 patients—the Foundation has had an outsized impact with its funding and its drive toward outcomes for its patients.



## WHAT'S YOUR BUSINESS MODEL?

In *Entrepreneurs for Cures*, we asked the question, “What if you were in the business of curing a disease—not ‘discovery’ or ‘research,’ or of selling a product—but of curing a disease? What would your business model be?” In our view, the current R&D system doesn’t add up to a “business model” that can achieve the end we all have in mind.

The following definition of a business model neatly describes the role we see foundations increasingly interested in playing: “A business model describes the rationale of **how an organization creates, delivers, and captures value**. And a disruptive business model is one where a non-traditional industry player enters the mix and threatens to **disrupt the status quo**.<sup>7</sup>

While philanthropies are not fundamentally businesses, many of the venture philanthropies we have encountered are distinguished by their **business-like approach** to their philanthropic work. The Michael J. Fox Foundation for Parkinson’s Research refers to its role in its disease space as that of a “portfolio manager,” having a secure grasp of the landscape of activities across sectors and a well-educated view of where philanthropic funds should be invested to have greatest impact. They think about themselves in business terms and communicate in ways that make sense to people in that world.

A business sensibility is also in many cases reflected in the people engaged; increasing numbers of foundations are hiring staff with MBAs or backgrounds in industry, some are creating business or management advisory boards to complement their scientific advisory boards, and as organizations grow they are beginning to hire senior staff in a business- or alliance-development type role to help drive partnerships.

These social entrepreneurs recognize that new treatments for patients ultimately come via private markets, and they view their role as addressing the **market failures** that prevent those markets from serving the needs of the patients they care about. And like all good entrepreneurs, their efforts begin with a robust **landscape analysis** or needs assessment to help them craft their strategies.

## HOW DID WE COME UP WITH THIS SET OF METRICS?

In our view, the most effective medical research foundations are those that are addressing not only the **scientific needs of their field** but also the **systemic obstacles to progress**.

The framework of metrics presented in this document represents a marriage of *FasterCures*’ understanding of the systemic challenges in medical research with our understanding of the best practices among the innovative nonprofit medical research foundations that are part of our **TRAIN (The Research Acceleration and Innovation Network)** program.

Created initially for use in *FasterCures*’ **Philanthropy Advisory Service (PAS) program**, these metrics were developed in consultation with a panel of expert advisors from the nonprofit strategy, medical research, and venture capital fields, as well as other thought leaders. They were originally designed to help philanthropists understand the R&D landscape and apply the same rigorous analysis and expectations to their not-for-profit investments as they do to their for-profit endeavors. The first application of the metrics was in a series of 2009 PAS reports that objectively analyzed more than 20 foundations in Alzheimer’s disease, malaria, multiple sclerosis, and tuberculosis.

We believe that the PAS metrics also have value to thoughtful, creative innovators in the nonprofit space who are directly involved in medical research program development and evaluation, and have an interest in building efficient and effective organizations. This iteration of the metrics, an evolution of those originally developed for PAS, are intended to provide nonprofit disease research organizations with a self-evaluation framework by which to assess and improve organizational effectiveness.

<sup>7</sup> [www.openforum.com/idea-hub/topics/innovation/article/the-9-elements-of-an-ironclad-business-model](http://www.openforum.com/idea-hub/topics/innovation/article/the-9-elements-of-an-ironclad-business-model)

## THE AUDIENCE

We view the audience for this document as being what might be called “sophisticated start-up” disease research foundations, those setting their strategies for the first time, as well as more established foundations seeking to refresh their strategies and to ensure they are leveraging as much change as possible with their relatively limited resources.

These metrics are not intended to dictate the strategies or tactics of every medical research foundation. **There is no one-size-fits-all roadmap that works for every organization in every disease area.** Organizations of different sizes, ages, histories, and with unique scientific needs will want and need to pursue different means to the end that they do share in common—getting new treatments to the patients they care about.

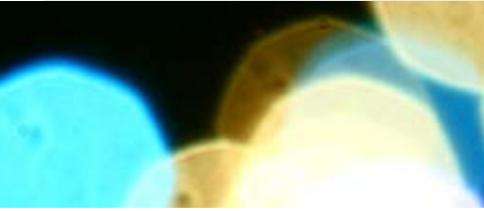
Rather, this document is intended to give you a set of questions and considerations that can help guide the decision-making and priority-setting within your organization in ways that can maximize its value and impact.

### GET ON BOARD THE TRAIN

TRAIN is an informal affinity group of medical research foundations seeking to play a more strategic role in their disease areas and leverage greater change with their relatively small investments. The **TRAIN Central Station** Web site ([www.fastercures.org/train](http://www.fastercures.org/train)) is an online platform for sharing information and resources among the groups to increase their individual and collective impact.

In 2012, FasterCures created a first-of-its-kind inventory<sup>8</sup> of the more than 50 groups participating in TRAIN, designed to help potential collaborators better understand the landscape of nonprofit disease research foundations and engage in meaningful partnerships with them. Using a set of common metrics, it highlights key details about each organization’s research portfolio, collaboration efforts, and financials. In all, these groups provide more than half a billion dollars in medical research grants in a year, and are worth more than \$2.2 billion. One in three TRAIN groups has supported at least one clinical trial. Nearly 9 out of 10 groups partner in some way with biotechnology and pharmaceutical companies.

<sup>8</sup> [www.fastercures.org/traininventory](http://www.fastercures.org/traininventory)



## KNOW YOUR DISEASE LANDSCAPE: PERFORMING A NEEDS ASSESSMENT

Most venture philanthropies we know agree that performing a robust needs assessment in your disease area is a critical first step in building a high-impact strategy and organization. This includes understanding both the research landscape—current scientific challenges and opportunities—and the market needs—where in the pipeline your involvement is most likely to have an impact.

- Have you held a research workshop? Does your organization have a clear grasp of the trends, challenges, and funding gaps in your disease area?
- What is the burden of disease and the state of scientific knowledge? Is your disease mechanism understood? Are there adequate models?
- Who are all the relevant stakeholders in your disease area (government, academic, nonprofit, industry), and what are their assets and capabilities?
- What is the current state of investment in the disease, in both science and in infrastructure and resources needed to facilitate research? What are believed to be the priority areas for research and infrastructure investment? Where are the gaps?
- What is the commercial landscape and the current pipeline of potential new therapies, to the extent that is knowable?

## DEFINING YOUR ORGANIZATIONAL PRIORITIES

THE DECISION TO START OR GET INVOLVED with a medical research foundation is often an emotional one, sparked by a personal experience or a family member's or friend's with disease. The stakes for patients are high, and investing philanthropic dollars in medical research is serious business, requiring a careful assessment of priorities and preferences as well as considering decisions within the context of the R&D process.

The process involved in bringing new drugs, diagnostics, devices, and vaccines to market is long and riddled with uncertainty. It is difficult to predict whether a project or approach is likely to succeed and, if it does, what its eventual value might be. There are many parties involved—from government to academic institutions to for-profit companies—with diverse viewpoints and incentives, almost all of whom will have to be engaged at some point in the life cycle of a research project if a treatment is to reach a patient.

Familiarizing yourself with the R&D process and arming yourself with information can help your organization objectively assess opportunities.

### KEY QUESTIONS TO ASK

1. Do we have a clear and current view of the disease landscape—both scientific and market needs?
2. How important is supporting research to our organization, relative to other priorities such as patient education and advocacy?
3. Are we interested in prevention, diagnosis, or treatment?
4. Do we know which stage of the R&D pipeline we want to support?
5. Are we interested in funding investigator-initiated (bottom-up) ideas or being more directive (top-down) in our grantmaking practices?
6. Are we interested in funding R&D for new products, and/or development of tools and resources to support R&D (e.g., health information technology systems, training)?
7. How much scientific and financial risk are we willing to take?

**When we invest our money, we look for the best ROI (return on investment); when we donate it, shouldn't we look for the best ROP (return on philanthropy)?**

#### **Prepare to Be Measured**

Philanthropists are becoming more engaged and outcomes-oriented than ever before. They want to see change in their lifetimes, and they are increasingly equipped with the desire and the tools to scrutinize their options for giving.

**Nonprofits will increasingly need to be prepared to make their case for support based on their ability to demonstrate sound strategy and the achievement of important milestones of success.** Simplistic measures, such as the percentage of revenue spent on programs versus overhead, are no longer sufficient.

The metrics in this document can help your organization be better prepared to make its case to potential donors and other collaborators.

# Chordoma Foundation

With the input of its scientific advisory board and participants in its research workshops, the Chordoma Foundation created a comprehensive research roadmap, identifying the places where the Foundation's resources were needed and would have the greatest impact in catalyzing further research and development.

#### **RESOURCE DEVELOPMENT**

Develop and share critical resources needed to study the biology of chordoma.

- Patient registry, biobank, cell lines, xenografts, transgenic animals

#### **DISCOVERY**

Analyze chordoma using the most advanced technologies and approaches to uncover the molecular underpinning of the disease.

- Genetic epidemiology, multidimensional genomics, functional proteomics, and high throughput screening.

#### **TARGET IDENTIFICATION**

Identify and functionally investigate genes and pathways that drive chordoma.

- Biomarker discovery, investigate relevant genes and pathways

#### **TRANSLATION**

Identify and test targeted therapies in models of chordoma, and generate preclinical data needed to initiate trials.

- Assay development, cell line testing, animal testing, clinical trials

## THREE STAGES OF MEDICAL RESEARCH: OPPORTUNITIES FOR PHILANTHROPY

**1. Discovery research** is the earliest stage of research, carried out for the advancement of knowledge, without necessarily any regard to its application to practical problems.

### WHAT CAN FOUNDATIONS DO?

- Invest in rare or neglected disease research unsupported by other forms of capital
- Support novel scientific approaches considered high-risk by other funders
- Fund collection of data necessary to apply for other sources of funding such as NIH, particularly by young investigators
- Fund researchers at institutions that have the right policies in place to facilitate translation of discovery research into real benefit for patients

**2. Translational, or “preclinical,” research** is the process of applying ideas, insights, and discoveries generated through basic scientific inquiry to the treatment and prevention of human disease—the critical bridge between basic research and clinical research. It includes intermediate steps such as identification of biomarkers, target and pathway validation, and development of and testing in animal models.

### WHAT CAN FOUNDATIONS DO?

- Support efforts to improve the tools and resources available to researchers, including developing better animal models to predict the behavior of compounds in humans, identifying biomarkers to help make testing products more effective and efficient; and creating interoperable research databases, comprehensive biobanks, information technology platforms, and data standards and protocols
- Advance potential new treatments to the point where industry may be willing to take up their development

- Invest in training and career development opportunities to attract and empower new scientists to conduct translational research
- Fund research into improving the processes required for translating discoveries into medical solutions, across diseases

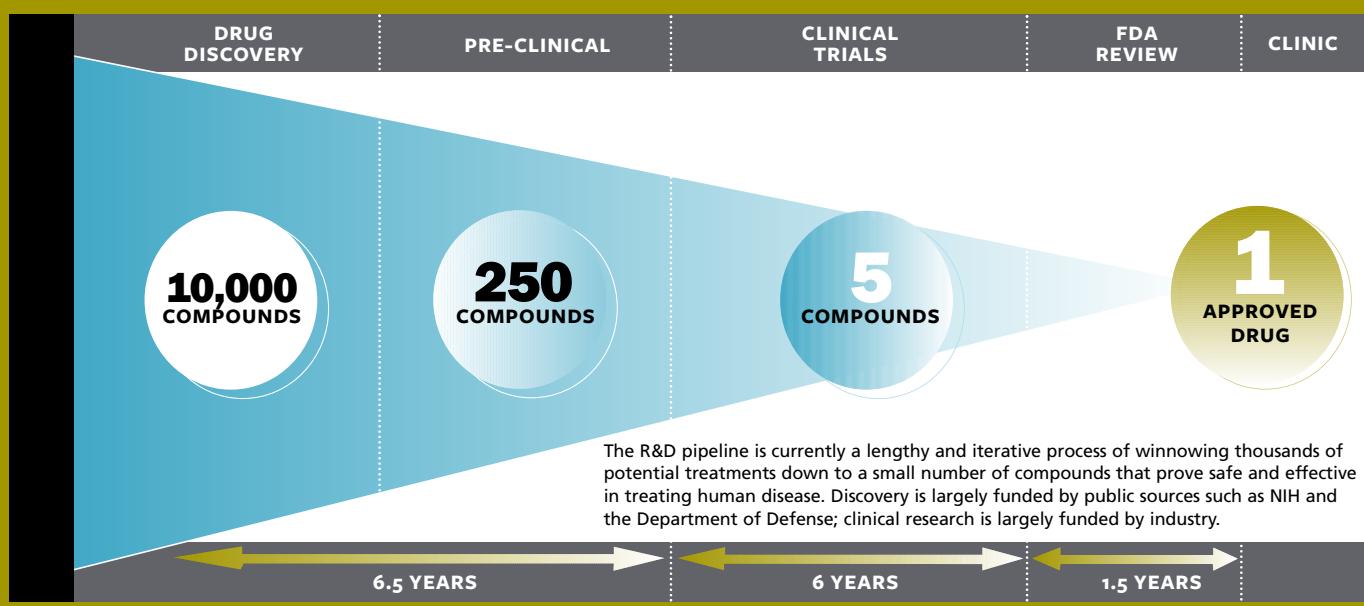
**3. Clinical research** is research in human subjects aiming toward approved treatments for patients. Clinical research is broken into three key phases: Phase I examines the safety of the product, usually in a very small group of healthy volunteers; Phase II assesses the efficacy and correct dosing in a larger group of patients; and Phase III tests the product in a much larger, more diverse population to determine broader efficacy, develop usage guidelines, and compare with existing products for the same indication.

### WHAT CAN FOUNDATIONS DO?

Some foundations, particularly those with substantial R&D budgets and those in rare and neglected disease areas where incentives for others to invest are low, do provide some support for clinical research activities. Nonprofit groups also contribute in critical ways to clinical research by supporting the process. Such investments include:

- Registries and databases to help connect patients and researchers;
- Improvements in clinical trials infrastructure, technology, and standards to ensure that the data collected through trials is comparable and high-quality;
- Training and career development programs to help build a cadre of capable physician-scientists to conduct clinical trials; and
- Building clinical trials networks and supporting coordinators at those centers to facilitate conduct of trials.

SOURCE: “ENTREPRENEURS FOR CURES,” “GETTING STARTED,” FASTERCURES, 2008 & 2010



SOURCE: NATIONAL INSTITUTES OF HEALTH

## EVALUATING YOUR ORGANIZATION'S PERFORMANCE

THE **FASTERCURES** METRICS MEASURE an organization's **operational processes** as well as its **contribution to the field** of disease research. To measure the impact of each organization, we focused our evaluation efforts on four key drivers of organizational success:

- 1. Accountability**
- 2. Collaboration**
- 3. Research Effectiveness**
- 4. Resource Building**

Within each category are several specific metrics. In this section we will define each category, and for each specific metric we will describe it and its importance and offer specific questions you might ask yourself to evaluate your performance in that area.

### **FasterCures Assessment Metrics Measure Operational Performance and Contribution to the Field**

<b>Operational Performance</b>	<b>Accountability</b> <ul style="list-style-type: none"><li>• Strategy &amp; Planning</li><li>• Milestones &amp; Monitoring</li><li>• Management</li><li>• Financial Sustainability</li><li>• Technology Transfer and Commercialization</li><li>• Community Engagement</li></ul>	<b>Collaboration</b> <ul style="list-style-type: none"><li>• Knowledge Sharing</li><li>• Cooperative Research</li><li>• Strategic Partnerships</li><li>• Global Research</li></ul>
<b>Field Contribution</b>	<b>Research Effectiveness</b> <ul style="list-style-type: none"><li>• Strategic Achievements</li><li>• Portfolio Congruence</li><li>• Scientific Advancement</li></ul>	<b>Resource Building</b> <ul style="list-style-type: none"><li>• Tool &amp; Resource Development</li><li>• Training &amp; Career Development</li></ul>

**How should you “score” your performance on any individual metric?**  
**Ask yourself the following questions:**

- Are our organization's activities in a given area consistent and in alignment with our stated strategy and profile (e.g., size, age, etc.)?
- Are our activities well-planned and executed?
- Can we demonstrate impact?
- Are we preparing appropriately for activities that will be key elements of future phases of our strategy?
- Are our activities aligned with the needs of the field?

What are some incremental ways of measuring impact, short of finding a cure for your disease? For the Alzheimer's Drug Discovery Foundation, it's how well you're moving programs through the development pipeline. In a 2008 progress report, it measured its impact in the following ways:

- Of the 94 drug discovery programs reported on, 38 **advanced at least two key stages** in the drug development process;
- Of the 94 reported programs funded, 56 percent **secured new intellectual property**, 17 percent have **generated licenses**, and investigators have applied for or been granted intellectual property rights covering several patent families;
- An **increasing ratio over time** of progressive forward movement through the stages of drug discovery for each dollar invested;
- Funded investigators have **published** hundreds of peer-reviewed articles; and
- Funded programs attracted hundreds of millions of dollars in **follow-on funding**, from government grants to initial public offerings.

# Adenoid Cystic Carcinoma Foundation

The Adenoid Cystic Carcinoma Research Foundation (ACCRF), a small foundation directed at a rare cancer, has crafted a focused research agenda appropriate to its profile and informed by a set of meaningful guiding principles, including:

## Venture philanthropy approach.

ACCRF sees its role as a provider of seed capital to advance pre-clinical drug discovery and development to the point where clinical trials are supported by the NIH and private sponsors.

## Portfolio management perspective.

ACCRF seeks to build a diversified portfolio of promising research projects.

## Multi-institutional cooperation.

The specimens and models are too rare, the technology platforms are too expensive, and the leading experts are too dispersed for any one institution to carry the burden alone.

## Proactive project selection.

ACCRF's Scientific Advisory Board proactively drives the research agenda, suggesting high-impact projects and identifying the leading researchers with the capacity and interest to carry them out.

## Accelerating practices.

ACCRF pushes for rapid and wide dissemination of research findings and delineates expectations for deliverables and timeframes in each project.

## ACCOUNTABILITY

**ACCOUNTABILITY** measures show that an organization engages in planning, demonstrates transparency, and upholds its responsibilities to stakeholders. It is comprised of six specific metrics:

- 1. Strategy and Planning**
- 2. Management**
- 3. Milestones and Monitoring**
- 4. Financial Sustainability**
- 5. Technology Transfer and Commercialization**
- 6. Community Engagement**

### Strategy and Planning

Organizations taking a proactive approach to understanding their position in the disease landscape and to developing a strategic plan for managing a portfolio of research projects are better able to target their research “investments” where they will have the most impact in understanding and curing disease. Those organizations that incorporate feedback loops from patients and key constituencies ensure that their plan is relevant to their stakeholders and responsive to the needs of the field.

#### KEY QUESTIONS AND MEASURES

1. Do we have a current strategic plan that articulates measurable goals and responds to the needs of the field?
2. Does the plan detail the activities that will help achieve those goals?
3. Is the strategy consistent with our mission and resources?
4. Do we seek out unbiased advice on our strategy from a diverse set of experts?
5. Do we produce a scientific agenda, as part of or independent of our strategic plan, that is updated to capture new scientific advances?
6. Do we publish regular financial statements, whether through an annual report or other mechanism, to ensure transparency with internal and external stakeholders? If so, do those reports clearly articulate how much of our budget goes to research grants/activities?

### Management

Nonprofit disease research organizations are increasingly led by management teams of qualified, diverse professionals, and have established active advisory boards that provide external, objective guidance at regular intervals.

Organizations with strong leadership teams bring experience in performing bench research, developing products, managing nonprofits and even for-profit businesses,

# Michael J. Fox Foundation for Parkinson's Research

and dealing with patient populations that benefit their organizations. They can convene scientific, clinical, business, and other advisory boards to validate research excellence as well as provide guidance in developing and executing their organizational strategies.

It should be noted that even very small organizations with mostly volunteer leadership can build strong networks of advisors with a variety of backgrounds and skill sets beyond the traditional scientific advisory board. The goal is to have access to expertise and relationships across the research ecosystem that will be needed to advance projects through the process.

## KEY QUESTIONS AND MEASURES

1. Do we have a diversity of management, business, scientific, and industry experience, either in-house or through advisory boards or networks?
2. Are our advisory boards (governing, scientific, business, etc.) active and engaged? Do they provide meaningful input to leadership decisions (e.g., research agenda, funding priorities and milestones, partnering policies), and are they regularly refreshed with new members?
3. Do we convene our management team and external advisors frequently?
4. Do we regularly report progress against our strategic goals to management, both internal and external?
5. Does our management work to create a collaborative, accountable culture?
6. Is our leadership sustainable over the medium- to long-term?

## Milestones and Monitoring

High-performing disease research organizations regularly evaluate their performance against the goals and objectives outlined in their strategic plans. They set milestones for staff and grantees so they are able to measure and manage advancement against their research plans and programmatic goals. Milestones for grantees can be scientific (e.g., synthesis of compounds, or establishment of cell-based assays) or operational (e.g., are key personnel in place, has IRB approval been secured) and may have “go/no-go” decisions tied to them.

Organizations that take a proactive approach to monitoring research portfolios and require achievement of milestones for funding are better able to ensure that focus is maintained on key activities and that vital resources are appropriately distributed to efforts and researchers demonstrating progress.

The Michael J. Fox Foundation for Parkinson's Research manages its grantees (whether from academia or industry) more closely than most foundations. Its awards are milestone-based and linked to go/no-go decisions along the way. The Foundation's internal scientific staff check in regularly with grantees to ensure they are making progress and to identify and try to address roadblocks early to help move the research along. Some specific examples of deliverables and milestones have included:

### Project deliverables

- Determine whether data collected at initial clinical presentation predict disease progression
- Determine whether non-traditional assessments at initial presentation predict disease progression

### Milestones

- Key personnel are in place as of second month of project
- IRB approval has been secured as of [DATE]
- Database is locked to perform analyses as of third month of project

### Project milestones with go/no-go indications

- Synthesis of compounds: Demonstrate that some compounds are neuroprotective. If compounds do not show neuroprotection, project is terminated.
- Establish one-to-two cell-based assays, first cohort of transgenic mice grown: Assays are fully operational at [DATE] and mice should be six months old by end of year.
- Screen top lead compounds for best “drugability” features, continue growing transgenic mice to reach 12 months: Identify top X compounds to be used in animal testing studies based on analysis of all functional, “drugability,” safety and pharmacokinetic data. Mice should be ready for in vivo testing. If no satisfactory compounds are identified, project may be terminated.

# Fast Forward

Fast Forward, the venture philanthropy arm of the National Multiple Sclerosis Society (NMSS), has partnered with EMD Serono (now part of Merck KGaA) on a **Collaborative Fund** of \$19 million to invest in promising translational programs identified by Fast Forward in academia or small companies. EMD Serono has the first option to in-license the compounds at the end of the project period, providing Fast Forward with an “exit strategy” for those programs, creating an external pipeline of potential new products for EMD Serono, and giving the funded organizations the opportunity for early engagement with a possible commercial partner.

Tim Coetzee, president of Fast Forward, emphasizes that “patient advocates need to be willing to adopt a tough-minded pharmaceutical development approach if they are to succeed in collaborative partnerships” like this one, and that “finding solid programs with secured intellectual property [IP] and developable targets or compounds” is a greater challenge than one might think.<sup>9</sup> Having a robust IP position is as important a qualification for funding as scientific merit in this effort, because the Foundation knows this is critical to its ability to hand off promising science to commercial partners for the lengthy and expensive clinical development phase.

## KEY QUESTIONS AND MEASURES

1. How and how often do we track our overall progress? Is there a set of metrics in place by which we evaluate the impact of each investment?
2. Is funding of grants or other investments tied to the achievement of milestones?
3. Are milestones defined in terms of outcome or process (e.g., “fund development of animal model” v. “develop animal model”)?
4. Are milestones specific and measurable (e.g., “collect tissue samples” v. “collect 1,000 high-quality tissue samples in 18 months”)?
5. Are milestones relevant to the goals laid out in our strategic plan?
6. Are projects designed with the flexibility to allow for mid-course corrections such as funding adjustments, time-frame extensions, corrective actions, or project termination?
7. Are scientific experts, internal or external, engaged in monitoring progress on an ongoing basis?

## Financial Sustainability

**FINANCIALLY STABLE ORGANIZATIONS** have detailed funding strategies that articulate their financial sustainability approach and goals. They seek broad-based support from government grants, private foundations, individual donors (small and large), and/or corporate sponsors.

Organizations that set specific goals for levels of funding from different sources and actively work to ensure a diversified funding base are less susceptible to changes in donor priorities or other external circumstances.

## KEY QUESTIONS AND MEASURES

1. Do we receive funding from a diverse set of donors?
2. Do we have a fundraising plan that sets out goals and strategies for attracting a diverse set of donors?
3. Are our revenue sources sustainable? Do any represent multi-year commitments?
4. Is the strategy aligned with R&D planning to prevent lags in activities due to funding shortages?
5. Do we have “exit strategies” for the initiatives our organization undertakes, plans for how they will move forward beyond the stage at which we can financially support them?

<sup>9</sup> Fast Forward—EMD Serono Collaboration presentation, Partnering for Cures 2010, [www.partneringforcures.org/2010\\_innovators/23\\_ff.html](http://www.partneringforcures.org/2010_innovators/23_ff.html).

## **Technology Transfer and Commercialization**

**PATIENT-DRIVEN FOUNDATIONS** have an interest in seeing knowledge shared to reduce time and duplication of effort, as well as ensuring that promising research is developed into products and marketed to patients by industry. Intellectual property (IP) is an important consideration when sharing knowledge among researchers as well as when attracting industry for drug development.

Whether or not your organization has any desire to benefit financially from IP, it should have established and documented an actionable IP policy aligned with its organizational mission, strategy, and goals.<sup>10</sup> It should have policies in place to promote knowledge sharing among researchers but also aid in the transfer of promising research results to industry for commercialization. (Implementation of strategic partnerships to promote commercialization will be addressed below; this section addresses organizational policy and planning.)

### **KEY QUESTIONS AND MEASURES**

- 1.** Do we have an IP policy that is consistent with our mission?
- 2.** Do our licensing practices support our ability to participate in collaborative research efforts?
- 3.** If applicable, do we have a development plan for each product in its portfolio that lays out the activities, partners, and timeline required for commercialization?
- 4.** Do we engage partners from academia, government, and industry to secure the right balance of skills and expertise for each stage of a product’s development, and have we built long-term strategic relationships with partners in all sectors?

## **Community Engagement**

**CANDIDATE THERAPIES** are not effective if they cannot reach the target patient population. There are several obstacles that impede access to interventions including insurers’ reimbursement policies, lack of appropriate facilities and professionals trained to administer care, and political will. Organizations with missions of delivering novel therapies will need to implement strategies for ensuring that access and delivery obstacles can be overcome in a timely manner.

Engaged organizations are in tune with community leaders focused on addressing the affected communities’ priorities—from access to affordability. They build

<sup>10</sup> See FasterCures’ white paper *Unlocking Intellectual Property: Principles for Responsible Negotiation* ([www.fastercures.org/documents/pdfs/IP-Principles.pdf](http://www.fastercures.org/documents/pdfs/IP-Principles.pdf)).



awareness and advocacy around the disease and new products when they are introduced. Clinical trials also provide a key opportunity for the organization to interact with patients, caretakers, and other affected populations. Growing numbers of patient organizations are also making an effort to educate the Food and Drug Administration about patients' priorities and about the science needed to make informed judgments about new product approvals.

#### **KEY QUESTIONS AND MEASURES**

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- 1.** Do we have deeply rooted ties to the communities we serve and have mechanisms in place to regularly communicate with them?
- 2.** Do we conduct activities aimed at understanding the needs of affected communities?
- 3.** Does a representative of the affected community sit on our board, or is there a separate community/patient advisory structure?
- 4.** Do we work to connect patients to appropriate clinical trials? How do we measure the effectiveness of that effort?
- 5.** Do we have a strategy in place to address issues of access to and affordability of therapies?
- 6.** Do we effectively utilize the social media tools frequented by our community members?

## COLLABORATION

**COLLABORATION** is the degree to which an organization can engage and nurture relationships with a wide range of partners that accelerate the overall funding and research cycle. Given the complexity of science and the research process, collaboration among researchers, disciplines, and sectors is critical to successful innovation in disease research, and patient-driven foundations can serve as an ideal nexus for convening and coordinating efforts.

The collaboration category comprises the following four metrics:

- 1. Knowledge Sharing**
- 2. Cooperative Research**
- 3. Strategic Partnerships**
- 4. Global Research**

### Knowledge Sharing

Incentive systems for academic and industry researchers do not usually reward early sharing of information; patient foundations can often provide the impetus needed for in-person sessions such as scientific retreats as well as open-access publishing (of positive and negative results) to expedite the knowledge-sharing process and reduce the information dissemination cycle. Organizations should consider policies and practices to facilitate sharing of data, experiences, and resources from projects funded by the organization—both internally, with other researchers funded by the foundation, and externally—consistent with the need to reasonably protect intellectual property for potential future development.

#### KEY QUESTIONS AND MEASURES

- 1.** Do we have a documented knowledge-sharing policy?
- 2.** Do we create and leverage opportunities to share knowledge among researchers and organizations to accelerate the research process, including conferences and symposia, online platforms for discussion, and data repositories?
- 3.** Do we require grantees to present and publish knowledge generated from the sponsored studies in reasonable timeframes?
- 4.** Have we considered requiring grantees to contribute data to public repositories, or to share negative results?
- 5.** Do we make an effort to transparently share our knowledge with industry (e.g., bringing scientific staff/advisors to companies)?

# Melanoma Research Alliance

The Melanoma Research Alliance (MRA), founded in 2007, is the largest private funder of melanoma research, focusing on translational research with the potential for near-term clinical impact. From its inception, it has prioritized funding team science to foster collaboration among academic researchers, and in 2010 it instituted a new **Academic-Industry Partnership Award**, to facilitate public-private partnerships. Under this mechanism, the academic researcher is the primary driver of the project, but an industry partner agrees to match MRA's funding in cash or supplies and services, and may collaborate scientifically in the research project. These awards catalyze synergistic interactions between corporate and academic researchers, leverage MRA funds with corporate investments, expedite early sharing of research information, and help accelerate the contracts process should development move forward.



## Cooperative Research

The complexity of science and of the research process means that effective research is becoming more interdisciplinary, multi-institutional, and multi-sectoral. Organizations funding team science can facilitate collaboration among leading research stakeholders, focus innovation that benefits patients, and shorten the cycle of discovery and development.

Organizations can create funding mechanisms to support goal-oriented, team-based science with a translational endpoint, in addition to single-investigator projects. They can prioritize grant applications from multidisciplinary teams both within an institution and among multiple institutions and sectors.

### KEY QUESTIONS AND MEASURES

1. Do we have a specific mechanism for funding team-based R&D?
2. Do we actively encourage involvement of industry researchers in funding programs?

## Strategic Partnerships

Organizations engaging in partnerships, particularly with industry, can accelerate the translation of discoveries made by basic scientists at the lab bench into clinical application in the market. Partnership arrangements may differ and include instances of nonprofit venture funding of for-profit research.

Patient foundations can form arrangements to engage with industry in product development or have other mechanisms and strategies for moving research through translation and toward commercialization. They can convene and participate in roundtable discussions and other meetings that bring together various sectors to support existing efforts and develop new solutions. They can contribute non-financial assets such as patient registry data or tissue samples to academic or industry research efforts.

### KEY QUESTIONS AND MEASURES

1. What kinds of strategic partnerships do we have in place to help advance our mission? Have we sought out partners best positioned to help us achieve the outcomes we seek?
2. What kinds of relationships, formal and informal, do we have with the NIH and with industry?
3. What non-financial assets do we have to contribute to strategic partners (including access to disease expertise and patient cohorts)?

- 4.** If we are interested in supporting drug development, have we considered creating a separate subsidiary for engaging in those activities?
- 5.** If we do not have industry partnerships, do we have a plan for aiding in the commercialization of promising research we fund?
- 6.** Do we have a feedback loop from our partners?

### **Global Research**

In an increasingly global R&D environment, it is important for organizations to build international relationships among top researchers, industry partners, funders, and others, as appropriate. This need increasingly encompasses not just Western Europe but also growing research capacity and infrastructure in Asia, the Middle East, South America, and other parts of the globe.

Nonprofit foundations can fund or collaborate on international research initiatives. They can seek out research proposals globally to ensure they continue to fund cutting-edge, forward-thinking ideas. They actively create opportunities to engage the international research community through conferences, special events, scientific working groups, and advisory boards.

### **KEY QUESTIONS AND MEASURES**

- 1.** Does your organization fund or otherwise work with top researchers, institutions, industry partners, and funders around the world? If not, are there mission or capacity-related reasons why?
- 2.** Is your organization developing tools to help international researchers collaborate more readily, such as databases and discussion platforms?



## RESEARCH EFFECTIVENESS

AS IN ANY FIELD, having the right policies and practices in place is important, but even more crucial is the ability to demonstrate effectiveness and impact both on the scientific landscape and ultimately on patients' well-being. Research effectiveness is the degree to which an organization's research portfolio yields sufficient data and deliverable returns to achieve its stated mission. What is the demonstrated or potential value of its scientific contributions?

The following three areas of evaluation can help your organization assess its research effectiveness:

- 1. Strategic Achievements**
- 2. Portfolio Congruence**
- 3. Scientific Advancement**

### Strategic Achievements

Strategic achievement describes an organization's ability to accomplish the goals it has set for itself. Organizations that have a process in place for measuring and managing the performance of their research portfolios are in a stronger position to make a significant contribution to their scientific fields than those that take a passive approach to reporting by their grantees.

#### KEY QUESTIONS AND MEASURES

- 1.** Do we have a demonstrated history of achieving the milestones we have established for ourselves and our grantees?
- 2.** When milestones have not been met, can we reasonably explain why?
- 3.** Are we capable of adjusting course with our scientific portfolio when warranted?

### Portfolio Congruence

Organizations should strive to construct a research portfolio that is congruent, or in alignment, with their mission, goals, and objectives, demonstrating that they are appropriately stewarding their research funding in efforts to achieve desired outcomes. For organizations with missions to deliver novel products to the market, their portfolio must add value to the overall pipeline of products for the disease and purpose.

### **KEY QUESTIONS AND MEASURES**

- 1.** Do the R&D programs we fund support our overall mission?
- 2.** Do we review our portfolio regularly to ensure that it aligns with our organizational priorities?
- 3.** Do the numbers of projects in terms of the stage (discovery, translational, clinical) and type (disease understanding, prevention, diagnosis, treatment) of research seem to align with our mission, goals, objectives, and stated activities?

### **Scientific Advancement**

Scientific advancement describes not only whether an organization is making progress against the goals it has set for itself but whether it is addressing the needs of the field (which one hopes would be in alignment). All organizations should hope to be able to demonstrate results in the generation of new data and knowledge for the field, and of scientific deliverables (e.g. assays, targets, pathways, biomarkers). Knowledge that drives the advancement of ideas through drug development is particularly valuable to the field. There is currently much concern that many basic scientific discoveries published in peer-reviewed journals are not reproducible, and some patient foundations are attempting to address that problem by, for instance, funding experiments to reproduce published results or to validate cell lines.

Research projects that produce deliverables and advance candidates through the R&D pipeline per their project plans demonstrate the ability of the organization to identify capable investigators and to bring together the necessary resources and coordinate the activities to achieve the desired outcomes.

### **KEY QUESTIONS AND MEASURES**

- 1.** What are our most important scientific milestones?
- 2.** Do outside experts consider these to be significant contributions to moving the field forward?
- 3.** Can we quantify the scientific deliverables from the research we have sponsored?
- 4.** What is the rate of projects moving through the R&D pipeline? Is this faster or slower than we anticipated? How many projects have advanced, and how many have been terminated? At what stage?
- 5.** How many annual presentations, publications, and citations have resulted from the research we have funded?"

<sup>"</sup>While the number of academic publications and citations may not be sufficient endpoints in and of themselves, they remain important incentives for academic investigators and can help your organization demonstrate production of valuable knowledge. Foundations can play an important role, however, in encouraging the use of alternate means of measuring impact.



# Multiple Myeloma Research Foundation

A central feature of the Multiple Myeloma Research Foundation's (MMRF) pioneering model is its **Multiple Myeloma Research Consortium** (MMRC) of 16 leading academic medical centers that functions as a plug-and-play clinical trials network for academia and industry alike. MMRF provides support, or what it calls "business solutions," in the form of scientific leadership, standardized clinical contracts, on-site project management resources, and protocol quality assurance. The Foundation has shown that trials opened through the consortium were activated 30 to 40 percent faster than comparable clinical trials in oncology, and that the MMRC has been able to decrease by an average of 100 days the time from the development and finalization of the trial's protocol to actual patient enrollment.



## RESOURCE BUILDING

MANY NONPROFIT ORGANIZATIONS that fund or conduct medical R&D also engage in efforts to fill critical resource gaps that limit scientific progress in their fields. Needs vary by field, of course, and each organization should work to identify what, if any, investments in this area are most likely to advance its own mission. But this can be an area of critical need that foundations are very well positioned to fill.

This Resource Building category represents an organization's commitment and capacity to contribute resources and infrastructure to scientific advancement, including:

- 1. Tools and Resource Development**
- 2. Training and Career Development**

### Tools and Resource Development

Nonprofit foundations are ideally situated to fund the creation, maintenance, and expansion of infrastructure and resources to meet the needs of their fields, such as predictive animal models, interoperable research databases, comprehensive biobanks, patient registries, clinical trials networks or infrastructure, information technology platforms, and data standards and protocols.

Effective research tools and resources are essential to expand available datasets and analytical capabilities that are necessary to accelerate and drive research from discovery to the clinic. Other research funders often lack incentives to develop such tools and resources that benefit the entire field. And patient-driven foundations are often in the best position to engage patient populations in research and to know where and how they are being treated.

Understanding and engaging patient populations is essential to developing effective treatments. Patient enrollment in clinical trials is one of the most significant hurdles for conducting clinical research for new therapies. Efforts like registries that organize patients and potential research participants enable expedited study enrollment and overall acceleration of the research process. These registries also provide data to better understand the patient population and thus design effective clinical trials.

Clinical trials networks create a group of research sites that are connected through common informatics systems to share data, employ consistently trained clinical trials coordinators and staff, are attractive for industry partnerships, and thus are able to more quickly advance the clinical development of promising compounds. Clinical trial network development that incorporates business and project management training is particularly valuable.

# New York Stem Cell Foundation

## KEY QUESTIONS AND MEASURES

1. Does our organization's mission or strategy include developing tools and resources as a priority? If not, why not?
2. Have we conducted interviews and in-depth research with experts in the field to identify critical gaps in tools and resources that would limit its ability to achieve its mission?
3. What percentage of our total grant funding is dedicated to tool/resource development?
4. Are the tools and resources developed available to the broader research community, and is there evidence that they are being used by outside parties?
5. Can we articulate the contribution that the tools and resources you have supported have made to the field (e.g. number of high-quality tissue samples or cell lines, number of sites in a clinical trial network, increase in speed of patient accrual to clinical trials)?
6. Do we have an understanding of the patient profile as evidenced by the segmentation of patient population (by genetic subtype, geography, ethnicity, etc.)?

## Training and Career Development

Training is required to develop researchers who have the multidisciplinary skills necessary for an R&D environment focused on translational and clinical research. Support is also needed for young investigators seeking to demonstrate the value of their ideas and build their careers; such support is vital when other funders are becoming increasingly conservative with their grantmaking (e.g., the average age of a first-time NIH investigator-initiated grant recipient is more than 40).

Nonprofit foundations can support the training and career development needs of investigators, clinicians, and support staff in ways that will support their missions. This might include funding training programs to develop a new cadre of translational researchers, or supporting young investigators who might find it difficult to compete for funding from other sources.

## KEY QUESTIONS AND MEASURES

1. Does our mission or strategy include supporting training and career development as a priority?
2. Do the training and career development opportunities supported address critical gaps identified by experts in the field?
3. Do we have a funding stream targeted at young investigators?
4. What is the percentage of total funding dedicated to training and career development activities?
5. Can we characterize the contribution our training/career development funding has made to the field?

A growing number of disease research foundations now target young investigators for grant funding, recognizing that scientists in their 20s and 30s can have difficulty getting support for their work, particularly as federal resources grow more constrained. Such early-career funding can also be an important means of attracting new researchers into their disease areas. The New York Stem Cell Foundation has taken this strategy a step further, recognizing that a year or two's worth of grants under \$100,000 are often not enough to help promising young scientists establish themselves. So in addition to its more typical Fellows program, it has initiated an **Investigators Program**, which provides five years of seed funding (up to \$1.5 million) to support awardees as they move beyond their postdoctoral training to cultivate their independent research and establish their own laboratories.





## KEY TAKEAWAYS

AS WE'VE ALREADY NOTED, there is no one-size-fits-all formula for success in medical philanthropy. We have tried, however, to provide you with a framework and a panoply of ideas, questions, and models to help guide your strategic and tactical choices. Here in closing, however, are a few overarching points to remember.

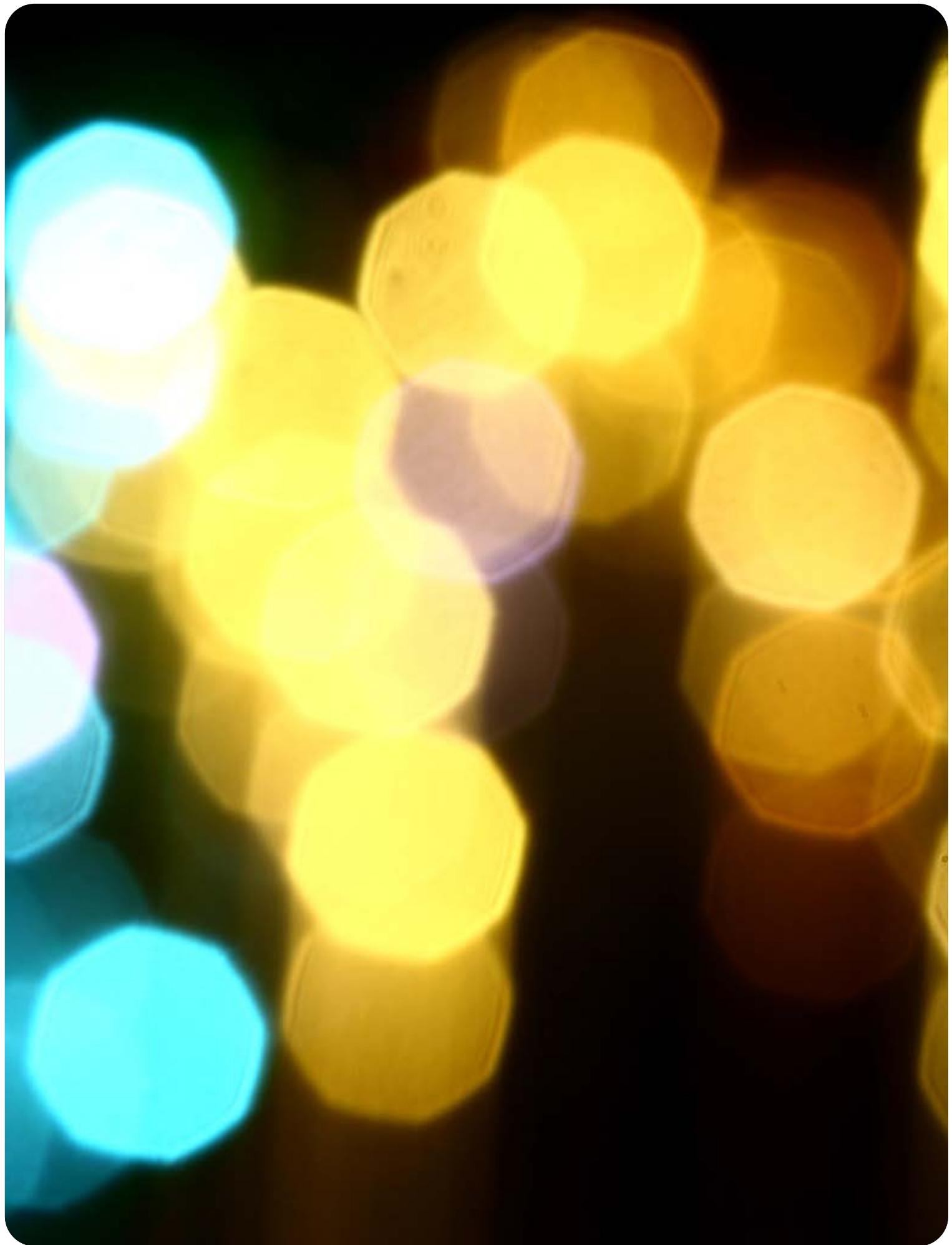
- 1. Begin with the end in mind.** The most important and unique asset that patient-driven foundations bring to the table is their singular focus on getting treatments to patients faster. Whether or not your organization is capable of helping carry the ball across the finish line, your strategies and tactics should always reflect an understanding of what it will take to make that happen.
- 2. Knowledge is power.** Passionate patient advocates are powerful, but informed patient advocates who can participate in the research and development process as peers are even more powerful.<sup>12</sup> Come armed not only with a checkbook but with knowledge of the process, your patient population, and the disease landscape (scientific and commercial). Know where in the pipeline you want to have impact and stay focused.
- 3. Size matters, but culture matters more.** It can be difficult for new or small foundations to relate to the success of larger, more established groups like the Cystic Fibrosis Foundation, but organizations such as the Chordoma Foundation are also having an outsized impact in their disease fields due to their focused and disciplined approach.
- 4. You get what you measure, so measure what matters.** Measure your performance by whether you are contributing to patient-relevant outcomes, not necessarily by traditional measures of progress (e.g., amount of money raised, number of grants dispensed, number of academic publications, etc.). And be prepared to act on what you learn.
- 5. He who pays, eats.** Foundations funding research can dictate the terms of their funding, and should think carefully about what conditions are important and responsible to attach to their support, from IP conditions to knowledge sharing requirements to milestones. Treat funding as an investment, not a gift.

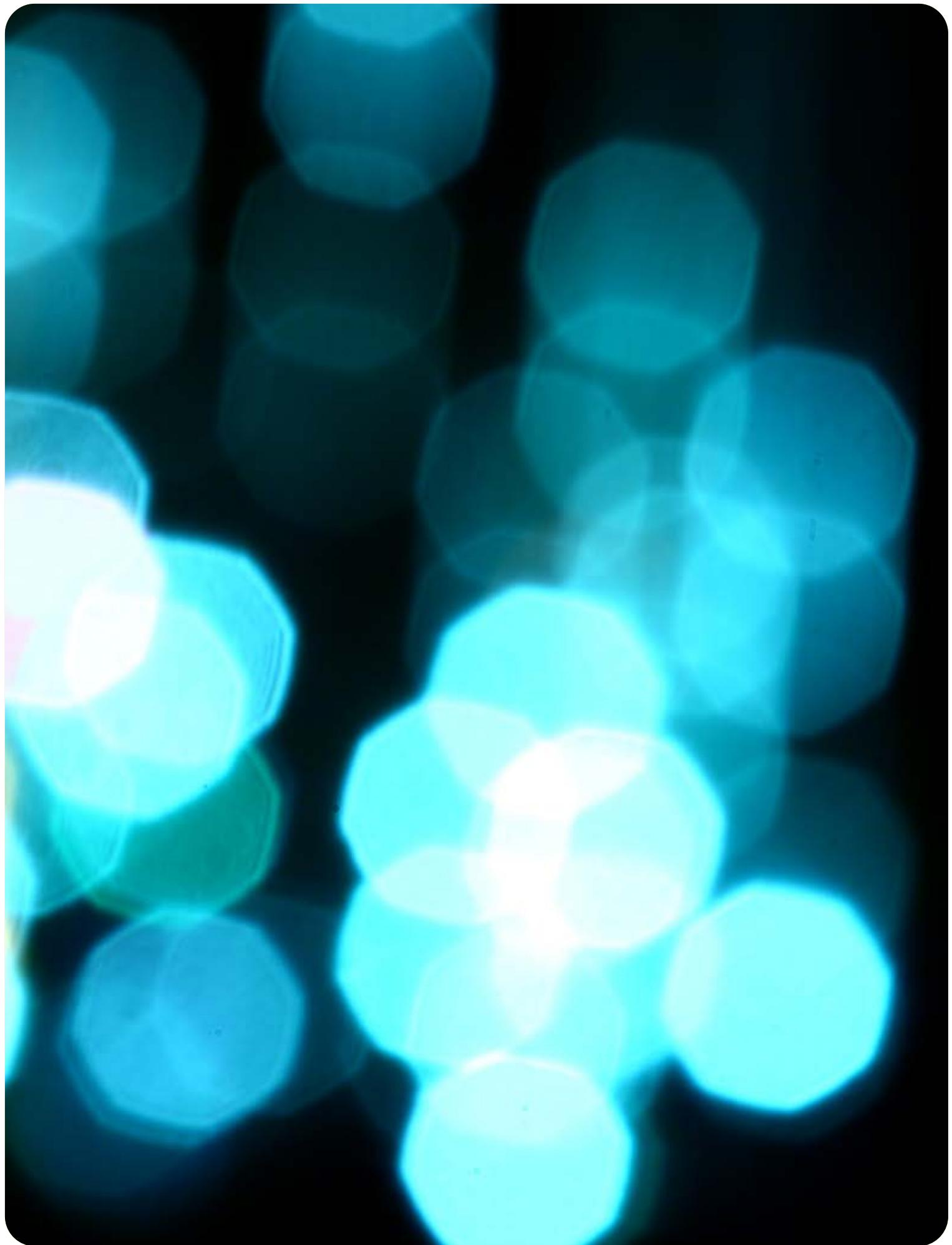
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<sup>12</sup> See FasterCures' white paper *Back to Basics: HIV/AIDS Advocacy as a Model for Catalyzing Change*, 2011, [www.fastercures.org/documents/pdfs/Back2BasicsFinal.pdf](http://www.fastercures.org/documents/pdfs/Back2BasicsFinal.pdf)

Medical research is badly in need of more innovative, high-risk approaches with high-reward potential. All sectors of the medical research enterprise—government, industry, nonprofit, and philanthropy—have critical roles to play in catalyzing these approaches.

For medical research foundations and the philanthropists who support them, informed and strategic decision-making can help ensure maximum return on philanthropic investment. By having performance measures and standards in place for accountability, collaboration, effectiveness, and resource building, organizations are cultivating a culture that is mission-driven, results-oriented, and focused on **the true bottom line: preventing, diagnosing, and curing disease.**





Check out these resources about venture philanthropies and medical research on *FasterCures*' Web site, [www.fastercures.org](http://www.fastercures.org), under "Publications".



To help philanthropists looking to make an impact, and organizations trying to improve their effectiveness, *FasterCures* created **Getting Started: A Medical Research and Development Primer** and **Giving Smarter: Building a High-Impact Medical Philanthropy Portfolio**.

These publications—**Crossing Over the Valley of Death**, **Trends in Translation: Models of Collaboration in Early-Stage R&D**, and **Fixes in Financing: Financial Innovations for Translational Research**—focus on the type of science that translates a basic discovery into a chemical or biological compound that is ready to be tested in humans.

In fighting disease, patience is not a virtue—patients are. These publications—**Banking on Trust: The Future of Research with Human Biological Materials**, **Still Thinking Research: Strategies to Advance the Use of Electronic Health Records to Bridge Patient Care and Research**, and **Back to Basics: HIV/AIDS Advocacy as a Model for Catalyzing Change**—focus on building a culture of participation in research.

**Entrepreneurs For Cures: The Critical Need for Innovative Approaches to Disease Research** lays out the critical need for innovative approaches to disease research.

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