



INNOVATIVE FUNDING MODELS TO DRIVE CURES

In our work at the Kraft Precision Medicine Accelerator, we have investigated numerous disease-focused nonprofits as well as for-profit companies. These organizations see and want to capitalize on amazing scientific discoveries to drive cures.

But science is not enough.

We have concluded the key success factors for cure-seeking organizations to make progress are strategy, leadership, and funding.

Our *Harvard Business Review* article, "[How Medical Nonprofits Set Winning Strategy](#)," outlined strategy basics for nonprofits. Tools on the Kraft Accelerator site guide nonprofits through the strategy development process. A future *HBR* article, "How to Lead Toward a Cure," focuses on leadership, as does the "Learn from Leaders" section on the site.

Yet even organizations with outstanding strategies and capable leaders can't make progress toward cures without SIGNIFICANT and SUSTAINED FUNDING.

**Harvard
Business
Review**

Investment & Venture Workstream

The Kraft Precision Medicine Accelerator's philosophy has been to bring together innovative first and second movers in an area, identify challenges and best practices, and then broadly disseminate knowledge. The Kraft Accelerator's Investment & Venture Workstream has involved experts from innovative foundations and nonprofits, for-profit companies, venture capital firms, investment banks, and other parts of the funding and drug development universe.



Convening of the Investment & Venture Workstream at HBS

The Funding Imperative

Significant funding is needed to exploit opportunities presented by precision medicine. That's because the research to develop a new treatment for a disease and bring it to market is highly uncertain, requiring multiple shots on goal through a portfolio of focused projects, which is extremely expensive. Success also requires early-stage nurturing.

Traditionally, funding innovative startups has been the domain of venture capitalists (VCs). The venture capital industry and many VC firms have great track records, which gives them the ability to raise and invest large amounts of capital. But the VC business model requires that firms diversify their investments to avoid concentration risk, which is the exact opposite of placing multiple bets to cure a specific disease.

While there is significant capital in the world, traditional approaches to funding the development of treatments are not adequate for the era of precision medicine. Fortunately, several nonprofit leaders are developing innovative funding models to fill the gaps.

The Role for Nonprofits

Historically, disease-focused nonprofits have mainly focused on providing support and advocacy; they haven't necessarily aspired to cure a disease as few can raise enough money to realistically contribute to finding a cure.

But a new generation of nonprofits is emerging whose missions and strategies are squarely focused on using precision medicine to develop treatments and cure a disease. Since these nonprofits are narrowly focused on one disease area, they know about the relevant research and science taking place, know about promising entrepreneurial activity, and can help attract attention, patients, and funding to the research and companies with the greatest potential for successful treatments.

These innovative organizations are staking out new ground in catalyzing investment to ensure that promising new therapies are getting enough funding.

Innovative Funding Models

Through our work, we have spoken with and learned from several innovators at disease-focused organizations that are raising significant amounts of capital and are developing sustainable funding models.

Three approaches to highlight are:

- 1 **Monetize everything (appropriately).** With research costing so much, we see some nonprofits adopting a more business-oriented mindset to try to develop new revenue streams. The intent is to recoup some of an organization's research costs to make these activities sustainable on an ongoing basis.

One example of a monetization activity that fits within a nonprofit's mission is building terms into grants to provide the nonprofit an opportunity for tangible value. This might include milestone payments or equity based on the intellectual property developed from a grant.

"WE NO LONGER WANT TO JUST WRITE CHECKS [FOR GRANTS] AND HOPE FOR THE BEST. WE ARE NOW MORE AGGRESSIVE WHEN NEGOTIATING RESEARCH GRANTS."

Other organizations are looking to generate revenue to help support the high costs of biobanks, registries, and data-banks by collaborating with industry in different ways. This can be done via a pre-competitive consortium of industry participants, where pharma companies participate in a cooperative investment model, or through an industry subscription model. Other nonprofits are exploring opportunities to secure payment from clinical research organizations (CROs) and industry for using data to identify and match appropriate patients for clinical trials.

The theme is that many nonprofits are developing more of a business orientation. They are looking for appropriate opportunities to leverage the organization's data and resources to recoup some costs in order to help sustain their research efforts.

MONETIZATION CASE STUDY

The Multiple Myeloma Research Foundation (the MMRF) — CureCloud®

Curing each of the 12 sub-types of multiple myeloma requires detailed clinical, genomic, and longitudinal data from thousands of patients. Since no single research center sees enough patients to generate the data that is needed, the Multiple Myeloma Research Foundation built the MMRF CureCloud.

CureCloud is the largest, most comprehensive bioinformatics platform—to speed the delivery of precision-based treatment to every multiple myeloma patient. The data in CureCloud will be used by researchers to discover new targets and by patients and providers to make more informed data-driven treatment decisions.

Creating CureCloud required investment of tens of millions of dollars. Financing came from philanthropy and a subscription model for industry partners. Participating industry partners have the ability to analyze the data in CureCloud, looking for insights to be used in drug development. Resulting development activities provide potential royalties for MMRF.

A SUBSCRIPTION MODEL FOR INDUSTRY PARTNERS IS AN IMPORTANT WAY TO RECOUP SOME OF OUR INVESTMENT IN CREATING MMRF CURECLOUD . . . WE HAVE AN INDUSTRY ADVISORY BOARD TO GUIDE US IN THE DATA WE ARE COLLECTING SO WE KNOW THERE IS VALUE [TO INDUSTRY] IN WHAT WE ARE BUILDING.



PAUL GIUSTI, CEO, THE MMRF



2 **Venture philanthropy.** Venture philanthropy is still philanthropy, where a donor gives money to a nonprofit and receives a tax deduction. But with *venture* philanthropy, a donor’s contribution is earmarked by the organization to invest in *for-profit* ventures. These are typically early-stage investments in startups where a nonprofit can provide value in adding its expertise, and where other funding may be harder to secure.

For multiple reasons—including management attention, governance, and fundraising focus—it is often appropriate for a nonprofit to set up a separate venture philanthropy fund to make these investments. Any investment returns generated by a venture philanthropy fund are not returned to the donors; they are recycled to the fund for additional investments.

Pursuing a strategy of venture philanthropy requires donors who understand that cures often come from entrepreneurial for-profit companies. These individuals understand and embrace the idea of making donations used to fund early-stage for-profit ventures. They buy into the mission of curing a disease, believe in the idea of venture philanthropy, and aren’t looking for a financial return on their donation. Some leaders from nonprofits with venture philanthropy funds note that having such a fund can even attract donors who otherwise wouldn’t contribute to the organization.

“VENTURE PHILANTHROPY IS IMPORTANT. IT ATTRACTS SOME NEW DONORS AND ATTRACTS SOME GIFTS WE WOULDN’T OTHERWISE GET.”

Examples of nonprofits that have launched venture philanthropy funds include the Juvenile Diabetes Research Foundation (JDRF) and the Multiple Myeloma Research Foundation (the MMRF).

JDRF raised \$90 million to launch its T1D Fund. To date, T1D has invested in 15 companies focused on type 1 diabetes, an area that had been neglected by researchers and companies. Importantly, T1D’s efforts have sparked far greater interest in type 1 diabetes research and have served to catalyze investment in this area. T1D’s efforts to catalyze investment are working, as T1D’s portfolio companies have successfully raised over \$200 million.

“BY USING A VENTURE PHILANTHROPY MODEL, THE T1D FUND IS UNIQUELY POSITIONED TO CREATE AN INVESTMENT MARKET IN T1D.”

SEAN DOHERTY, EXECUTIVE CHAIRMAN, JDRF



More recently launched, the MMRF’s venture philanthropy fund expects to raise \$50 million in its first five years and has already made several initial investments. Through its venture philanthropy activities, the MMRF has learned that its involvement in deals provides far more value to a portfolio company than just money. The MMRF has a biobank, data assets, a clinical network, access to patients, and deep expertise related to multiple myeloma. By partnering with early-stage companies, the MMRF can help these companies go further, faster.

In both examples, these cure-seeking organizations have raised money that allows them to partner with venture capital funds and make sure that the funding ecosystem is channeling capital to their disease.



Arjun Goyal, Vida Ventures, and Lisa Williams, Vice President, Goldman Sachs, at a meeting of the Investment & Venture Workstream

VENTURE PHILANTHROPY CASE STUDY

EB Research Partnership (EBRP)

Epidermolysis Bullosa (EB) is a rare genetic skin disorder estimated to affect 500,000 individuals worldwide. EBRP is the largest global non-profit focused on funding research that leads to commercially sustainable therapies and cures.

Since inception, EBRP has raised over \$40 million and used this money to fund more than 80 projects. EBRP has pioneered an innovative venture philanthropy approach and even formed multiple EB companies.

**ALL OF OUR RESEARCH
IS FUNDED UNDER A
VENTURE PHILANTHROPY
MODEL.**

**MICHAEL HUND, CEO, EB RESEARCH
PARTNERSHIP**



Operating similarly to an early-stage investor, but focused solely on EB, EBRP earns returns from successful projects that it uses to fund additional projects.

To identify potential opportunities EBRP calls for global research applications twice a year. A scientific advisory board (SAB) reviews and scores these applications based on multiple criteria, including a path to commercialization.

Once projects are approved by the SAB, EBRP approaches all negotiations with a partnering mentality. In addition to seeking to generate favorable returns, EBRP cares greatly that the research is fully funded and is completed for its intended cause. EBRP insists on certain control and other rights to ensure both patient needs and economic goals are met.

EBRP has already seen multiple positive outcomes from using this model and is able to direct the returns right back into funding more EB-focused research until a cure is found.



3 Impact funds. In contrast to a venture philanthropy fund where a donor gives a donation, takes a tax write-off, and doesn't receive any returns, with impact funds, investors desire and expect a *market-rate return*.

There is a tremendous interest in and appetite for impact investing, especially among many younger high net worth individuals who want to realize market rates of return while also making investments that have social impact. Today, the total market for impact investment is over \$225 billion, yet only 5% of impact investments are going to healthcare. A primary reason has been a shortage of healthcare-focused impact investing products. But that is beginning to change. Impact investments focused on precision medicine have the potential to bring capital to lifesaving treatments while producing attractive returns for investors.

Impact funds can be appropriate when the science for a particular disease is far enough along and there are multiple companies in a space that have advanced beyond their initial stages. We have seen the creation of several disease-focused impact investing funds that aim to earn market-rate returns.

One example is the Oncology Impact Fund, a \$471 million fund created by multinational bank UBS. Participants in this fund are UBS's high net worth clients, who each invest \$500,000 to \$1 million. These individual investors are attracted by the idea of making an investment that can produce meaningful impact in developing treatments for cancer, while simultaneously earning favorable returns.

UBS has partnered with MPM, a venture capital firm with healthcare expertise that leverages its domain expertise in oncology to invest these funds in private and public companies.



The UBS/MPM model of attracting a large amount of capital from individual investors who want to have impact, focusing on a particular disease area, and having the investments managed by a domain expert is a model that can be adopted by other investors and targeted at other diseases.



Angus Grant, CEO, Dementia Discovery Fund; James Flynn, Managing Partner, Deerfield Management; Detlev Giniszkiwicz, Executive Partner, MPM Capital, at a panel discussion at Harvard Business School

Another impact fund example is the Dementia Discovery Fund (DDF), which has raised \$350 million from sophisticated investors including seven leading pharmaceutical companies, AARP, and Bill Gates. DDF is focused on making investments for treatments in dementia and Alzheimer's. DDF is working with SV Health, an international venture capital firm with domain expertise.



In both examples, significant capital was raised, is being managed and invested with the assistance of experts, and is being invested in a highly focused way to take multiple shots on goal to cure a specific disease, while seeking to achieve market-rate returns.

These approaches highlight the importance of partnering with or bringing onboard scientific and venture capital experts who can lead a nonprofit organization in identifying the best investment opportunities and structuring the right deals.

Picking the Right Approach

Which of these approaches is right for your organization and how do you decide?

The answer is, "It depends."

The best answer for your organization depends on the maturity of the science for the disease you are trying to cure. It depends on the number of companies in the space, the maturity of the ecosystem, the mindset of the organization's board and donors, as well as the ability to attract top talent.



"THE TIME IS NOW FOR ACCELERATING PRECISION MEDICINE THROUGH INVESTMENT."
RICHARD HAMERMESH,
FACULTY CO-CHAIR, HBS
KRAFT PRECISION MEDICINE
ACCELERATOR

If the science is:

- **Early and immature**, the organization may be best served through grantmaking. In doing so it is important to embed creative, venture capital-like contract terms to try to create new revenue streams to recoup some of the organization's research-related costs.

- **More mature**, with some early-stage companies in the field, venture philanthropy may be the best approach. But to pursue venture philanthropy, your organization must be ready. You need support among donors and need the right team and organizational capabilities to be a credible partner for the ventures in which you invest.
- **Even further along**, with multiple credible companies and an ecosystem focused on the disease, the best approach may be to raise significant capital for an impact fund focused on pursuing market-rate returns. An impact fund may be appropriate for an umbrella organization that brings together several similar diseases.

Making the Funding Strategy a Strategic Priority

We see innovative nonprofits having success with each of the models we have discussed. Common themes are:

- **Focusing on cures:** Leading cure-seeking nonprofits want to do more than provide support and advocacy; they desire to be a catalyst for treatments and cures. In focusing on cures, they recognize the need for significant funding.
- **Making the funding strategy a top priority:** Innovative cure-seeking nonprofits are raising money in new ways. Whether pursuing a funding strategy focused on monetization, venture philanthropy, or impact investing, the funding strategy must be an integral part of the organization's overall strategy and must be a top organizational priority.
- **Putting in place the right people and partnerships:** Monetization requires legal and venture capital expertise; venture philanthropy and impact funds require domain experts and people with investing and deal experience. Since these capabilities are not common at most cure-seeking nonprofits, it is necessary to bring in or partner with the right people for the requisite skills. This might include partnering with a venture capital firm or adding board members with the requisite investment expertise.

While adopting new funding models can be challenging, it is exciting. When strategy, leadership, and funding are combined, nonprofit organizations are making a difference in spurring the development of new treatments, getting them to market, generating attractive returns, and reinvesting those returns to make further progress in realizing cures.



Participants at a 2019 HBS convening of the Investment & Venture Workstream