HARVARD | BUSINESS | SCHOOL
Kraft Precision Medicine Accelerator

WHITE PAPER

WHAT ARE DISEASE FOUNDATION LEADERS FOCUSED ON RIGHT NOW?

CONTINUED FOCUS ON THEIR MISSION WHILE CREATIVELY NAVIGATING A TREACHEROUS FUNDING LANDSCAPE

KRAFT ACCELERATOR LEADERSHIP FORUM

At this unique moment, what are the most significant challenges being faced by leaders of disease foundations? The top priorities? The most important actions?

Those were among the topics discussed at the first Kraft Accelerator Leadership Forum, held virtually, with leaders from several innovative disease-focused foundations. The organizations represented ranged from large foundations with multiple chapters, hundreds of employees, and budgets in excess of $100 million to small, nimble startups focused on one specific disease. (Forum participants listed on page 5)

A key takeaway, summarized by one participant: “We have to stay focused on our priority initiatives at a time when budgets are constrained . . . we have to listen and respond to the groundswell of issues being raised by our employees without going off strategy and off mission.”

Massive Workforce Challenges

Like leaders of most organizations, over the past few months, foundation leaders have had to oversee a rapid shift to working remotely, with technological, operational, and cultural complexities. Leaders have had to sustain their foundations’ operations, morale, and culture during a time of high employee uncertainty and stress. Add to this a groundswell among some employees who are passionate about racial inequities and social justice issues—and want employers to take visible, concrete actions.

Leaders have navigated these challenges by listening to employees, being flexible, and engaging in frequent, transparent communication. Also, in this constantly changing environment, leaders have tried to be decisive by clearly stating, for example, “Here is our policy and our plan through the end of 2020.”

While foundation leaders have taken immediate steps to try to address these issues in the short term, they expect these workforce-related challenges to persist longer term —at least into 2021, making these issues a top priority for months or even years to come.

Prioritizing the Mission

In wrestling with multiple challenges over the last several months, a common theme among disease-focused foundation leaders has been the importance of defining and prioritizing their organizations' most critical strategic initiatives. These are the strategic imperatives that enable a foundation to fulfill its mission. These imperatives—which differ for each organization—might be continuing to offer significant grants, executing a high-profile clinical trial, creating a registry or biobank, or delivering more direct support for patients in need.

Multiple CEOs emphasized the need for tremendous focus. One explained, "The one thing we're focused on right now—it sounds blatantly obvious—is how do we accelerate our mission? . . . COVID has forced us to crystallize what's in the center of the bullseye. We're not doing anything else."

Consistent with this focus on mission, a survey of disease-focused organizations conducted by the National Health Council (NHC) in August 2020 found that only 20-30% had postponed planned research trials during January through June of 2020 (meaning that 70-80% did not postpone any trials) and almost no planned research trials have been cancelled for the rest of 2020 or 2021.

Focusing on Finances

While shifting to remote work and maintaining the organization's morale and culture, the overriding priority for leaders of disease-focused foundations right now is dealing with challenging financial realities.

This situation is grim. A July 31, 2020 STAT article,[1] "Medical Nonprofits Are Hard-Hit as the Pandemic Upends Crucial Fundraising," stated:

- Medical nonprofits are facing a funding shortfall that has forced many to cut staff, scale back operations, and decrease grant funding.
- The Christopher and Dana Reeve Foundation projected its 2020 revenue to be down 60%.
- The JDRF, falling 40% short of its expected revenue, cut its staff by 40%, reduced grants, and cut its chapters from 60 to 29.
- The American Cancer Society laid of 1,000 staffers as part of a 30% budget cut.

A few Forum participants cited the NHC's survey of 37 disease-focused organizations, which projected n average a 16% decline in 2020 revenue compared to 2019. Among respondents in this survey, the only sources of revenue expected to increase are major gifts and corporate contributions from life sciences companies. In addition, 22% of NHC survey respondents don't expect revenue lost during the pandemic to ever return; 38% believe it will take two years and 27% expect it to take three years for revenue get back to pre-pandemic levels.

Sentiments among Leadership Forum participants are even more pessimistic, with several reporting revenue declines of 25% to 50%. These organizations have been forced to cancel fundraisers, such as galas, walks, and other live events that represent significant sources of revenue. Also, they see major donors giving less, as major donors are being asked to support numerous causes, all of which have significant needs. These financial shortfalls and an overall sense of uncertainty make the current moment an extremely difficult situation.

As a result, dealing with their immediate financial pressures is the top priority for these leaders, with also rethinking their longer-term financial and operating models

[1] "Medical Nonprofits Are Hard-Hit as the Pandemic Upends Crucial Fundraising," Rebecca Robbins, STAT, July 31, 2020.

Short-Term Financial Actions

Amid this crisis, healthcare nonprofit leaders aren't standing still. They are taking immediate, short-term tactical steps to address their financial situation, including steps to reduce costs and boost revenue.

Cutting Costs

To fulfill their missions amid decreased revenues, foundation leaders have had to make difficult decisions about cutting costs. Among the actions taken:

- Furloughing or laying off staff, reducing salaries, and shifting to job sharing (to avoid layoffs)
- Reducing chapters
- Decreasing programming
- Downsizing grants
- Slashing fixed costs such as office space
- Decreasing operating costs including travel, consultants, and conference-related expenses

These actions by Forum participants are largely consistent with results from industry research.

Boosting Short-Term Revenue

The range of actions being taken varies from relatively simple and straightforward to visionary and complex.

The most obvious action being taken by most organizations is transitioning already scheduled in-person fundraising events to virtual events. This includes fundraisers such as 5Ks as well as major annual galas. The idea is to reach and engage donors, even if virtually, and maintain the relationship. A virtual 5K is easy to execute; there are no geographic boundaries, meaning more people can participate and the expenses are lower, with no need for permits or event planning companies. But virtual 5Ks lack a sense of community and are not sustainable without face-to-face energy. A virtual gala may lack the same appeal as an in-person event but can still include entertainment (such as a celebrity musical guest) and can have a broad range of content. While the amount of funds raised through virtual events may not be as high as in previous years, because of low or no expenses the net contribution to the organization from these events can still be important.

In some instances, foundations are thinking creatively and taking their virtual events to a broader audience. For example, EB Research Partnership (EBRP) turned its in-person poker fundraiser into a digital virtual event. EBRP kept registration fees low and was successful in attracting more participants than in previous years, as participants weren't constrained by location. The result from this and other digital events has been equal or higher net income for EBRP, with lower or minimal expenses.

And, some disease-focused organizations are viewing the current moment as a unique opportunity to think big. A significant initiative by MDA (Muscular Dystrophy Association)—which has been hit hard by the pandemic—is reimagining and relaunching the famed MDA Telethon to provide a significant fundraising boost to MDA. The MDA Telethon, being hosted by Kevin Hart on October 24, 2020, will be livestreamed on YouTube and other platforms.

MDA has recruited sponsors and has partnered with Salesforce to provide technology to support ongoing donor care. MDA has secured the legal rights to own the content that is created and will be repurposing this content in multiple ways after the Telethon to extend this event's fundraising potential. This is an example of going back to the organization's fundraising roots and leveraging celebrity to reignite the brand, engage sponsors, and build a new base of donors.

Common themes in shifting from in-person to virtual/digital events:

- Think creatively about events to engage the most possible people.
- Go big by thinking out of the box and engaging prominent celebrities.
- Partner with major organizations such as YouTube, Amazon, and Salesforce.
- Secure the rights to the content and repurpose it broadly.
- Leverage these events to secure sponsors and to generate new donors.
- Use technology to capture donor information and nurture new donors.

These activities demonstrate how necessity is the mother of invention, creativity, and resourcefulness.

Longer-Term Strategic Reassessment

While nonprofit leaders are quickly adapting their short-term fundraising plans, they are also rethinking elements of their strategy and revenue model. Leaders recognize that with such a major disruption in funding, their foundations must think and operate differently, which goes beyond just shifting from in-person to virtual events. Among the strategic actions mentioned by Forum participants were:

- **Formulating strategies to keep their brand relevant.** In the current landscape, which is dominated by COVID and where so many organizations are fighting for attention, it is difficult to break through. Disease-focused organizations must become effective brand marketers, using modern PR and marketing techniques to stay top of mind through relevant, compelling brands.
- **Accelerating the transition to going digital.** In conjunction with amplifying the organization's brand, in this virtual era, the successful disease-focused organizations will become great digital storytellers and marketers. They will develop in-house digital expertise, will adopt CRM systems, and will make digital a core competency. Those organizations that don't prioritize digital risk being left behind.
- **Further increasing the focus on major donors.** In the current fundraising crisis, relationships with major donors are more important than ever. In the survey mentioned earlier, revenue from major donors is one of the few areas where disease-foundations project revenues to grow in the rest of 2020 and in 2021. In a recent *Harvard Business Review* article the author said in a K-shaped recovery, wealthy individuals have fared well and still have the ability to make major donations. This makes it critical to engage these individuals, strengthen relationships with them, give them clarity on how their donations will accelerate a cure, and convince them through compelling PR and outreach that they are supporting a winning team.

- Leveraging your data to generate revenue. Foundations that have made significant investments in patient registries and biobanks are aggregating valuable data that is extremely important to pharmaceutical companies. Some leading organizations are looking for opportunities and models to leverage this data to generate new revenue streams.

  To offset the significant costs of registries and data collection infrastructure, some foundations have previously solicited upfront funds from philanthropists and industry (often pharmaceutical companies through pre-competitive consortia) and then make the data available to consortia participants or even more broadly.

  What is now occurring is that some innovative foundations such as the Multiple Myeloma Research Foundation (MMRF) are exploring ongoing subscription models where pharmaceutical companies subscribe to receive access to some data. Such models have the potential to generate millions of dollars per year for foundations, offsetting some of the costs of these registries and creating diversified, sustainable revenue streams. Also, some foundation leaders see potential in capturing and monetizing data from phase 4 post-FDA approval follow-up studies, which have increasingly become a requirement for many drug companies.

  However, to retain their position as a trusted third party, foundations will have to avoid conflicts of interest, which may entail limiting the amount and percentage of funding derived from industry.

- Considering setting up venture philanthropy funds. Organizations such as JDRF through its T1D Fund, MMRF, and EBRF have created venture philanthropy funds to make equity investments in early-stage companies. The intent is to provide capital to promising companies to help accelerate a cure while also helping these companies by providing expertise in a specific disease area, access to a clinical network, and help identifying patients, partners, and collaborators. These funds aim to attract additional investors and generate returns for the disease foundation that will then be used to make additional investments.

  While setting up a venture philanthropy fund is a significant undertaking, requiring the right culture, commitment, and expertise, an increasing number of disease foundations are considering this idea.

- Partnering and building multi-stakeholder coalitions. In seeking to accelerate a cure, going it alone is extremely difficult. Recognizing this, disease-focused foundations see value in creating critical mass through various types of partnerships (including public-private partnerships) that bring multiple organizations together to collectively pursue a shared goal. As an example, one organization is working to reimagine its relationship with the NIH to increase the amount of research funding devoted to its disease. If successful, these funds won't necessarily increase revenue for the foundation, but it could represent a substantial increase in research funding for the disease, which supports the foundation's mission.

Other major strategic efforts being pursued that aren't necessarily related to funding include leveraging technologies to increase the support for patients in need. This might include telemedicine, monitoring technologies, or new types of online education or community building.

Conclusion

It is an extremely difficult time for disease-focused foundations. The challenge is maintaining a laser-like focus on the organization's mission and on those key initiatives that will accelerate a cure while navigating financial and organizational complexities.

Leaders are urgently reexamining their strategies and revenue models to survive in the near term, to continue to make progress in fulfilling their foundation's mission, and to be prepared for the post-COVID environment. Success may involve rethinking the organizational structure, diversifying revenue streams, and increasing the use of technology.

Leadership Forum Participants

KATHY GIUSTI

Founder and Chief Mission Officer, MMRF

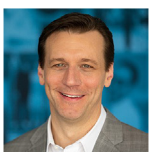
Faculty Co-Chair, HBS Kraft Accelerator

RICHARD HAMERMESH

Faculty Co-Chair, HBS Kraft Accelerator

MIKE ANDREINI

Chief Operating Officer, MMRF

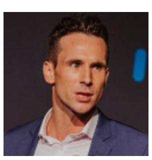


MICHAEL BOYLE, MD

President and CEO, Cystic Fibrosis Foundation

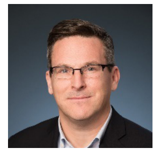
SUDHEER DOSS, PHD

Chief Data Officer, PanCAN



MICHAEL HUND

CEO, EB Research Partnership



AARON J. KOWALSKI, PH.D.

President and CEO, JDRF

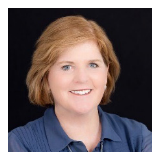
NICOLA MENDELSOHN

Vice President. Facebook EMEA

Founder and Chair, Follicular Lymphoma Foundation

TODD SHERER

CEO, The Michael J. Fox Foundation for Parkinson's Research



LYNN VOS

President and CEO, Muscular Dystrophy Association