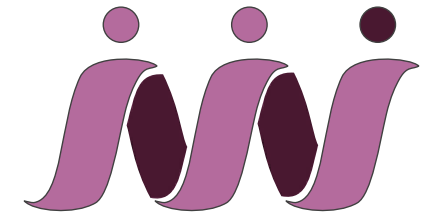


Balancing stakeholder expectations

HEALTH RESEARCH ALLIANCE
SEPTEMBER 22, 2020

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csO emerita llc

Agenda

- ▶ Non-profit Organization stakeholders
- ▶ Stakeholder drivers
- ▶ Case studies
- ▶ Summary

Stakeholder Universe



Stakeholder Drivers

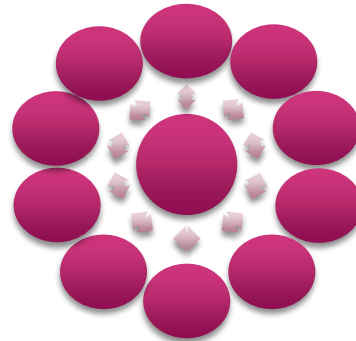
Mission Drivers “My NPO’s focused on”

Patients, Education, Research, Treatments
Financial Support and Sustainability

Cures

Reputational Drivers “I’m with”

Leading non-profit
Great researchers
Strong community
Industry leaders
Winners



Personal Drivers “I want work with my”

Condition
Doctor
Favorite institution
Local city
Idea

While well-intentioned, sometimes NPOs are driven to programs that don't work out as expected

The Case of the Broken Hearts

Donor-driven funding to a favorite clinician at a specific institution (2 NPOs)

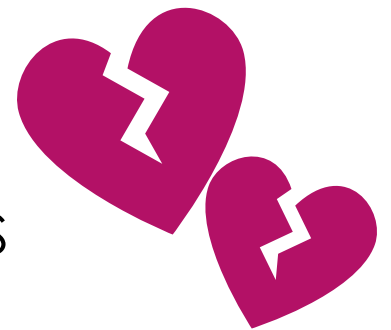
- ▶ After ~2 years, the projects did not advance
 - ▶ Funding was withdrawn

Disappointment and embarrassment

- ▶ Institutional leadership and researcher
- ▶ Donors/fundraisers and NPO

Key Takeaways

- ▶ Be honest about the risk when accepting \$ and making awards
- ▶ Can you mitigate risk by adding a second project to increase PTS



CoMMpass: A Matter of Balance

MMRF study of >1,000 newly diagnosed patients. Relied on \$MM from multiple pharma partners; institutional enrolment, sample collection and genomic research

- ▶ Critical need to offer companies equal access and a level playing field
- ▶ Academic researchers wanted option to see data & publish before industry
- ▶ Intellectual Property had to be addressed

Solutions arose after internal & external consideration

- ▶ Created Pre-competitive Consortium of companies with equal access
- ▶ Researchers had time-limited, first access to data
- ▶ Agreement that IP directly from study was dedicated to public domain



SarcID: Centers of Excellence

In 2017, the Foundation for Sarcoidosis Research (FSR) was funded by a Celgene Impact Award to identify multidisciplinary centers of excellence for sarcoidosis. Launched in 2018.

- ▶ Institutions apply for recognition
- ▶ Leading KOLs/clinicians of WASOG review and qualify centers
- ▶ One of three FSR programs to help patients find physicians

Work in-progress with future-looking questions

- ▶ Managing collaboration and ratings
- ▶ Clarifying three offerings: Physician vs Clinic vs Centers of Excellence
- ▶ Translating offerings to fundraising for FSR

<https://www.stopsarcoidosis.org/sarc-id/>
<https://www.stopsarcoidosis.org/sarc-id/sarcoidosis-clinics/>
<https://www.stopsarcoidosis.org/physician-finder/>



FOUNDATION FOR
SARCOIDOSIS RESEARCH

Summary

All NPOs have stakeholders with various drivers and expectations

- ▶ Founders, Board, Donors and Fundraisers, Corporate Partners, Researchers, Patients/Caregivers, Government Officials, Staff, Public
- ▶ Programming should harness stakeholder resources and enthusiasm; align with the mission; and protect NPO reputation
- ▶ Sharing experiences via HRA and developing novel approaches can make for success for NPOs and their supporters