



Venture Philanthropy in Action: A Case Study of EB Research Partnership and ProQR

August 27, 2020

How are nonprofit organizations leveraging venture philanthropy to accelerate the development of treatments and cures? As part of The Research Acceleration and Innovation Network (TRAIN) webinar series, FasterCures takes a deeper dive into the venture philanthropy approach of [EB Research Partnership](#), the largest global nonprofit organization dedicated to treating and curing Epidermolysis Bullosa (EB). To date, EB Research Partnership has funded 80 research projects, which has led to 30 clinical trials, including 3 Phase III trials.

EB Research Partnership's venture philanthropy approach is simple: Invest in research projects to develop therapies and, in return, participate in the financial upside. Proceeds from successful projects are redirected into future research.

In 2019, EB Research Partnership funded the formation of Wings Therapeutics, a new company dedicated to developing treatments for EB. Its lead drug originated at ProQR Therapeutics, a rare disease company that sought a strategic partner to continue the development of its EB drug. In only two weeks, EBRP raised the capital and secured the management team to establish Wings Therapeutics.

In a discussion moderated by Michael Hund (CEO of EB Research Partnership), Alex Silver (Chairman of EB Research Partnership), Daniel de Boer (CEO of ProQR Therapeutics), and Mark de Souza (CEO of Wings Therapeutics) discussed the success factors that ultimately led to the creation of Wings Therapeutics. They include:

- **Building key relationships, especially with those who balance commercial interests with societal objectives** - Wings Therapeutics was born out of the strong relationships that Silver had developed with de Boer and de Souza; this trust, along with an alignment of interests, enabled the group to structure and form a new company with unprecedented speed.
- **Recognizing venture philanthropy is a nontraditional model that requires persistence and flexibility** - Venture philanthropy is a shift from the status quo. It requires tenacity and patience on the part of nonprofit organizations who should be prepared to face resistance from more traditional actors.
- **Evaluating commercial viability as a criterion in investment decisions** - Nonprofit organizations should evaluate investments with an eye toward its probability of commercial success. To do this, it will be crucial to have the input of drug development experts in the investment decision-making process.
- **Securing strong financial and legal expertise to advise on how to structure investments** - There are multiple options for how a deal can be structured, making it imperative that a nonprofit organization has access to financial and legal experts through their board or elsewhere. Legal services should be treated as a core investment and not given short-shrift.
- **Establishing a solid understanding of patient needs, the patient experience, and the disease** - Patient organizations need to establish themselves as leaders in their fields through their deep knowledge of the disease, establishment of patient registries that capture patient experience data, and their collaborations with researchers, key opinion leaders, and the patient community. These are assets that will aid in deal making, tech transfer, and drug development.

Silver challenged foundations to think about their role in a different way and to take risks that philanthropy is uniquely positioned to make: “Nonprofit is a tax status, not a business model.” Venture philanthropy, in his view, represents an evolution of both philanthropic *and* for-profit investment. Silver continued to say, “And when people tell you this isn’t what nonprofits do, tell them it’s exactly what nonprofits do.” Patient-driven foundations are focused on the asset that can’t be replaced—time.

This webinar was conducted as part of FasterCures’ TRAIN Program activities. TRAIN is an affinity network of foundations that are interested in utilizing venture philanthropy approaches to fund medical research. The TRAIN program offers a variety of networking and capacity-building programs for leaders of nonprofit, patient-centered research foundations. To learn more about TRAIN and how to join, visit the [TRAIN web page](#).