

Venture Philanthropy: It Takes More Than Money

Robert J. Beall

Former President and CEO
Cystic Fibrosis Foundation



Through patience, commitment and clear communication, venture philanthropies can enter into innovative partnerships to accelerate new therapies.

During the last decade, many nonprofit organizations have explored and adopted the concept of venture philanthropy to accelerate the development of new therapies for their respective patient community. The resulting relationship with the biotech industry has resulted in a number of successes, but in turn there have been a number of disappointments.

The Cystic Fibrosis Foundation (CFF) has been successful in using venture philanthropy to accelerate the development of several new disease-modifying therapies for individuals with cystic fibrosis (CF) and has created a robust pipeline of potential new therapies. Outside of traditional financial investment, there are elements worth consideration

and adoption that might enhance the chances of success in the translational effort with industry.

There have been a number of organizations that are beginning to focus their efforts on the possible financial results of a successful alliance with a venture philanthropy partner. This opens up chances for failure. The goal of venture philanthropy is acceleration of new therapies, not necessarily assuring financial return to the organization.

All parties need to set clear-cut scientific goals as milestones during the negotiation process. Early on in a project, a Scientific Advisory Committee (SAC) needs to be established with the biotech partner. In the CFF alliances, the SAC met

frequently, and there was open discussion of the progress and challenges of the effort.

CFF looked to this group to inform us of the completion of research milestones during the project performance. Later, as progress continued into the development phase, CFF was represented by clinicians and others familiar with the pathophysiology of the disease and in elements of clinical trials for CFF. The synergy between these groups and the willingness to share were critical and contributed to the overall success of our alliances.

Another critical component to the success of the venture philanthropy program was access to patients and their data. In CF, we are fortunate to have about 90 percent of our patients seen in a network of CF care centers throughout the United States. In 1998, we initiated a clinical trials network in the United States that has completed more than 125 trials since its launch. Coordinated by a team at Seattle Children's hospital, this network, which now has more than 80 sites, has worked to ensure the completion of well-designed trials. The network works closely with academics and industry to assure the best use of our valued patient community. A common Data and Safety Monitoring Board has been established for all CFF clinical trials in the network.

“ The goal of venture philanthropy is acceleration of new therapies, not necessarily assuring financial return to the organization. ”

The network has been mirrored throughout other CF communities in Europe and Pacific nations. The network is prepared to begin more than 25 clinical trials in 2016 in an amazing partnership with industry.

Once these networks are established, the next step is the collection of appropriate clinical data. The CFF patient registry was established in 1965, and virtually all of the patients seen allow both demographic and clinical data to be collected. Anything that can be provided to the Food and Drug Administration and industry that documents the natural history of the disease will certainly accelerate the translational process. Fortunately, there are a number of efforts on the part of the National Center for Advancing Translational Sciences at the National Institutes of Health to assist organizations to begin this important data collection.

Patience and commitment by all elements of the awarding institution are critical to the success of venture philanthropy. “Venture Philanthropy is not for the faint of heart,” is a phrase frequently shared with organizations that are contemplating entering this space. There will be disappointments along the way, and the timetable to achieving the goals of each collaboration is often long. Everyone — boards, clinicians and, most of all, the patients — must be committed to the program. That institutional commitment will help carry the project through both the good times and bad times that are experienced with any drug discovery endeavor.

For venture philanthropy to be successful, it truly takes a faithful community. The awarding of the project and the excitement that result are only the beginning of a journey that, if successful, will work to change the course of the disease.

The network of CF care centers was founded in 1998

125 trials launched since network's founding

25 trials launched in 2016 alone