A Reflection on the Increasing Importance of Private Capital in Medical Research

Private philanthropic foundations are emerging as a revolutionary source of innovative medical research and development funds. Though the amount of private philanthropic donations as a percentage of medical research spending, is still at a nascent stage, the reality of stagnating federal and state contributions to research and development enterprises[1] is indicative of the future impact that private dollars may have on the field.

Philanthropy & Neglected Diseases

Funding for a disease is often scarce when the condition only affects a small portion of the population, or is considered to be less severe than other diseases in its class. Philanthropic medical research donations can target and drive medical advancements in these fields or with these diseases which are relatively neglected.

For example, Michael Goldberg, founding partner at the personal injury law firm Goldberg Weisman Cairo, and his family started the Goldberg Nathan Myotonic Dystrophy Type 2 Fund to encourage medical research into myotonic dystrophy type 2 (a rare genetic disorder characterized by muscular dystrophy).

The Goldberg endowment donated $1.25 million gift to the University of Rochester School of Medicine and Dentistry. The gift will be used to establish a center that will specifically study myotonic dystrophy type 2. Donations from private individuals who have loved ones or family members afflicted with rare genetic conditions are invaluable.

While muscular dystrophy disorders are researched and funded more broadly, rare variations, such as myotonic dystrophy type 2, lack funding and research resources. It is precisely in these circumstances that private donations are revolutionizing how cures and vaccines for rare diseases and conditions are pursued and developed.

Venture Philanthropies

FasterCures, a Center of the Miliken Institute, designates nonprofit medical research foundations as *venture philanthropies,* and credits them with offering new and valuable sources of funding for medical research institutions in both the private and public sector.

As funding for medical and research agencies like the National Institutes of Health (NIH) and the National Science Foundation (NSF) among others, remain largely stagnant,[2] private and philanthropic dollars can bridge the gaps in funding shortfalls for medical research and development spending.

While large for-profit pharmaceutical and biotechnology firms have the financial wherewithal to develop cures and vaccines, they focus exclusively on widespread or high-profit diseases. In cases where a vaccine or a cure is projected to lack significant profit margins, philanthropic research dollars are

[1] http://www.researchamerica.org/uploads/healthdollar12.pdf
[2] http://www.researchamerica.org/uploads/healthdollar12.pdf

imperative. In this regard, partnerships between private philanthropic foundations and medical research institutes has the potential to transform the world. Moving forward, venture philanthropies will play an increasingly important role in evaluating the medical research landscape and identifying gaps in research and development.

Recommendations

What the changing funding terrain means for universities and other medical research institutes is still being defined. Nevertheless, some broad lessons can readily be identified. First, medical research institutes would likely benefit by developing research and development proposals in rare and underfunded disease categories; leveraging initial donations to attract larger donations; and, partnering with venture philanthropies in order to access the human and research capital resources of such organizations.

Funding from private individuals and entities allows research foundations to take greater risks in the development and research of life-saving technologies. With funds from philanthropic organizations, research institutions can devote money to procedures, studies and vaccines that are high-risk or still in the initial research stages. Private funders are also more willing to take greater risks by providing vital seed money to clinical trials.

While funding an entire clinical trial is beyond the means of most private philanthropic foundations[3], many are able and willing to provide seed money for Phase 1 or Phase 2 trials. This seed money can be leveraged to attract additional donors, as well as proving the viability of the research to other potential donors. Using private seed money to take advantage of this snowball effect is one of the most effective ways that private and philanthropic donations are changing the terrain of medical research and development.

Additionally, private foundations and endowments, often driven by familial and personal connections to rare conditions and diseases, have intimate connections with a cadre of patients who are interested in and available for clinical trials and research. The sheer amount of patient and medical history already catalogued by such foundations is a vital, though non-financial, contribution to existing medical research and development.

The Future of Funding Medical Research

Universities and hospitals would be well-advised to build multi-faceted relationships with funding organizations to leverage both the financial and non-financial contributions such organizations have to offer.

Ultimately, increased medical and health research and development funding is critical to the United States' ability to remain competitive in the global economy while simultaneously improving healthcare at the individual, community and national levels.

[3] http://www.fastercures.org/assets/Uploads/PDF/HonestBrokers.pdf