

Clinical Research and the Disparities amongst Non-Profit Cancer Foundations

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Abstract

In this review, donor considerations relevant to supporting a particular cancer research organization are discussed. Moreover, middleman or intermediary non-profit cancer centers that do not actually conduct research, but instead, outsource this endeavor to another institution are discussed. Finally, assessment resources to which donors may refer are commented upon and select recommendations prior to supporting a specific non-profit cancer foundation are also conferred.

Keywords: Non-profit foundations; Cancer research; Overhead expenses

Introduction

The United States Government primarily funds scientific or clinical research grants through "intermediary or middleman" institutions (i.e. these intermediary organizations collaborate with secondary research institutions to accomplish their mission) (Internal Revenue Service (IRS) [1]. Surprisingly, most cancer foundations do not possess the necessary infrastructure to conduct clinical investigations; instead, they disperse funds to another entity or foundation that is capable of implementing actual clinical research.

When a financial gift is initially bestowed upon a middleman organization to conduct research, the original amount is potentially depleted, following a specified amount allocated to the foundation for overhead expenses. The bequest may be further diminished when the intermediary foundation distributes a predetermined amount of the donation to a secondary foundation who actually conducts the research (i.e. they may also deduct for their specific institutional overhead costs). Therefore, if the ultimate goal is to improve cancer cure rates [2], a donor should ascertain if the prospective cancer foundation to which he or she wishes to contribute, is a middleman organization or indeed, a functioning research organization that is involved in improving clinical outcomes [3].

Middleman Cancer Foundations

The American cancer Society (ACS) and Susan G. Komen for the Cure (Komen), despite their size and resources, do not actually have an "in-house" research group; thus, they can be categorized as middleman or intermediary foundations and therefore, must collaborate with academic and medical institutions to conduct cancer research. Hence, one could conjecture that the relatively low amount invested in cancer research by these two organizations with regard to their annual revenue, is attributed to their respective status as an intermediary organization [4].

The National Breast Cancer Research Center is also a middle man cancer foundation (or "a charity within a charity") for the Walker Cancer Research Institute (WCRI), an organization by whom the former entity is subsumed. The WCRI reported revenues of \$12.7 million in 2009, of which 52% was invested in fundraising and 4% on research [5]. Since the WCRI also raises funds in association with the National Breast Cancer Research Center, there may be some confusion vis-a-vis what proportion of a benefactor's original donation is

invested in clinical research and what percentage is allocated toward the two organizations' respective overhead expenses.

Alternatively, the Women's Cancer Research Foundation (WCRF), a non-profit cancer foundation exclusively dedicated to conducting cancer research, has a reasonably low overhead of 10%; they have been incredibly productive, consistently enrolling patients on research studies and publishing peer-reviewed medical publications, the hallmark of a successful research organization [6]. Moreover, the WCRF's relative 5-year patient survival rates are higher than the United States average [7].

Overhead Expenses

There are specific websites that evaluate non-profit organizations, to wit, Guidestar (www.guidestar.org) and Charity Navigator (<http://www.charitynavigator.org/>); the principal goals of these two organizations are to promote non-profit transparency and provide a central source of financial information (e.g. 990 Form), for approximately 6,000 charities in the United States. Since Guidestar and Charity Navigator assist in elucidating the manner in which non-profit agencies utilize their funds and illustrate the operating expenses that they incur, donors have a greater opportunity to make informed decisions prior to sponsoring a particular organization.

All cancer research organizations are confronted with overhead expenses, of which a significant amount comprises valuable services to patients and their families (e.g. public education, cancer screening and social services). Therefore, one could argue that lower overhead costs do not necessarily equate with increased productivity [3]. The ACS, in particular, has extensively conducted significant intramural epidemiologic and surveillance studies that have occasioned seminal findings. Consequently, operating expenses (e.g. soliciting and reviewing grant applications, administering and disbursing the funds

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over the term of a grant) are inherent to most national foundations, and thus, to a judicious extent, they should be anticipated.

Cancer Research Development

The reality is that the process between cancer research development and effectuating a cure is quite multi-faceted and protracted. For example, during the initial development phase of select cancer studies, specific biomarkers may be identified in conjunction with statistical modeling and simulation; the intent is to design a proof of concept, or a method in which to demonstrate an idea's feasibility and potential for success in the impending, confirmatory phase [8,9]. During the ensuing phase, the research design is applied to a larger-scale study, within the context of a specified patient population; subsequently, the medication is evaluated for safety and efficacy, wherein the optimal dose and treatment regimen are confirmed [8,9].

The Way Forward

The improvement of cure rates is of paramount importance in the field of cancer research [2,10]. The progress, however, in reducing cancer death rates since 1990, has only decreased by 5% since 1950 [11,12]. Therefore, potential benefactors who are exclusively interested in improving cure rates should investigate a prospective cancer foundation (i.e. are they a middleman organization, and how do they invest their financial resources?), to ensure that his or her intended goals coincide with the organization's mission.

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