



# Philanthropy, Medical Research, and the Role of Development

The funding of medical research is in flux, with private financiers increasingly providing primary support, their gifts rivaling or even surpassing federal grants in scale. Greater availability of philanthropic dollars coincides with decline in growth of National Institutes of Health (NIH) grant making. In real terms, total NIH funding increased 49% from 1990-1995, 59% from 1995-2000, and 60% from 2000-2005. It then leveled off with a 9% increase during 2005-2010, and decreased slightly in 2011 and 2012.<sup>1</sup> Compound inflation-adjusted annual growth decreased from 7.8% during 1994-2003 to 3.4% from 2003-2007.<sup>2</sup> In academic medical centers, where federal sources provide 65% of biomedical research funds,<sup>2</sup> this slowdown is dire.

Meanwhile, staggering wealth is amassing in the hands of the few. From 1987-2012, the number of billionaires in the US increased from 41 to 425.<sup>3</sup> The Forbes 2013 Billionaires List names 1426 individuals worldwide, with a record net worth of \$5.4 trillion; 442 billionaires are American.<sup>4</sup>

We are witnessing the rise of a new social class, the “gigaphilanthropists.” Their names have become household words—Bill and Melinda Gates, Paul Allen, Warren Buffett, Michael Bloomberg—associated with philanthropic activities as well as affluence. According to a report produced by the Giving USA Foundation and Indiana University Lilly Family School of Philanthropy, individual Americans donated \$228.9 billion in 2012.<sup>5</sup> Even in an economically distressed year, 2008, the *Chronicle of Philanthropy* estimated total charitable contributions in the US at \$135.8 billion.<sup>6</sup>

The rise in exceptional philanthropy is not a purely American phenomenon. The Frankfurt-based Hertie Foundation donated over €90 million (US\$122 million) to neuroscience from 2000-2007, tripling its contributions in the previous quarter century, which totaled €30 million.

Charities fund more than half of the United Kingdom’s biomedical research enterprise, led by the Wellcome Trust, with £746 million (US\$1.15 billion) given in 2012, up from £484 million in 2006.<sup>7,8</sup>

Are we handling this mode of funding responsibly? The NIH two-phase peer review system is designed to safeguard scientific accountability and quality. Scientific Review Groups (“study sections”) perform rigorous scientific evaluation; National Advisory Councils, separately, make funding recommendations. Though faulted for various reasons—conservatism, lengthy review timelines, bias toward established investigators—NIH study sections perform crucial evaluative functions. No comparable system exists to ensure that medical research funded through philanthropy has high quality, integrity, and importance.

Some gigaphilanthropists create charitable organizations that evaluate scientific merit and institute accountability. For example, the Prostate Cancer Foundation, established by the former head of Drexel Burnham Lambert, and prostate cancer survivor, Michael Milken, is guided by a Scientific Advisory Board of over 100 scientists representing Harvard, Johns Hopkins, Memorial Sloan-Kettering, and other institutions; Milken serves as the board’s Chairman.

Within academic medical centers, scientific oversight of research-focused philanthropic activity is less clear. In a typical scenario, a grateful patient makes a gift to support his/her doctor’s research. A proposal is written in lay language, discussed, and agreed upon between donor, family, physician, and development officer. Although the proposal may take the place of a research grant, the decision-making process lacks peer review or competitive selection between candidate proposals, and there is minimal scientific oversight of the ensuing research activity. Gifts are primarily shepherded by development officers, who oftentimes oversee proposal development as well as communications with the philanthropic funder.

Development officers’ competencies lie primarily in management, communications, relationship building, negotiation, and strategic planning rather than science, though they collectively direct billions of dollars toward scientific purposes. In this context, several concerns arise. First is scientific merit. For research projects sponsored by philanthropy, there are few if any processes to evaluate study design, methods, or relevance. Scientific merit and technical quality are addressed

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mainly by the investigator him/herself. Institutional review boards (IRBs) provide feedback, typically after the benefactor has pledged funds, and focus primarily on safety and protection of human subjects. Usually, investigators are not bound by IRB suggestions for strengthening study methods or reframing the scientific plan.

A second concern surrounds fairness. Philanthropic support for research is typically directed to a specific individual and his/her studies; other qualified scientists in the same area lack comparable access to these funds. In some institutions, clearance policies heavily control investigators' approaches to potential donors, restricting opportunity to certain physician-scientists. Clinicians who care predominantly for disadvantaged patient populations are far less likely to garner significant financial support from grateful patients. Conceivably, the NIH could reduce allocations to areas well funded through philanthropy, thereby further limiting other investigators' access to grants in those areas.

Third is control of the research agenda. Philanthropists function like policy-makers when they provide major gifts that set the course of research. For example, Microsoft co-founder Paul G. Allen launched the Paul Allen Institute for Brain Science with a gift of \$100 million; Allen focused the Institute's efforts on developing a free and open-access "brain atlas." With vast financial infusions funneled toward philanthropists' personal research interests, there is no guarantee that highest societal priorities in medical research are addressed, or that the quantity of funding directed to a purpose is appropriate and matched to actual scientific needs.

Fourth is societal equity. In medical philanthropy, decisions important to the health of large patient populations can be made by individuals or boards who lack not only scientific expertise, but also a desire to maximize the public good. The National Committee on Responsive Philanthropy monitors the extent to which private foundations support vulnerable and underserved populations. No similar organization examines grateful patient philanthropy, ensuring that vulnerable populations and greatest medical needs receive a just share of available resources.

Philanthropy, nonetheless, offers advantages for both researchers and donors. The Philanthropy Roundtable,<sup>9</sup> a national association, enumerates the benefits of the current environment for donors interested in medical research, among them the freedom to "think boldly," pursue unconventional hypotheses, support orphan conditions, and fund whomever they choose, including early-career investigators. The Roundtable notes that the mobility and flexibility of philanthropic funding can accelerate progress from laboratory to market because "private donors do not answer to voters or shareholders, and they are not constrained by the peer-review protocols that dominate government funding."<sup>9</sup>

In a challenging economy, medical development offers a vital pathway toward research funding. To safeguard the quality and integrity of medical science underwritten by philanthropy, and to ensure equitability in access to philanthropic funds, academic institutions might consider two pathways: 1) developing institutional strategies or guidelines to minimize the above hazards, while maximizing the impact of gifts and honoring donors' intentions; or 2) establishing pathways through which development officers can gain basic scientific literacy, enabling them to think intelligently about medical research, ask relevant questions related to integrity, relevance, and quality, and participate with faculty and donors in conversations related to scientific merit and value.

Philanthropic support of research will undoubtedly continue to result in tremendous advances in biomedical science, and in discoveries that will revolutionize patient care. Thoughtful consideration about how best to shepherd this precious investment should focus on assuring maximal benefit for all stakeholders.

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