

# Patient-led advocacy has changed how US government funds medical research

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Patient-led advocacy has created a shift in the way the U.S. government has prioritized funding for medical research, and significantly changed the way policymakers think about who benefits the most from these dollars, a University of Michigan School of Public Health fellow in the Robert Wood Johnson Foundation Scholars in Health Policy Research Program found.

In "Disease Politics and Medical Research [Funding](#): Three Ways Advocacy Shapes Policy," a paper published in the October issue of the [American Sociological Review](#), Rachel Kahn Best analyzed data on 53 diseases over a 19-year period from 1989-2007.

She found that those diseases tied to strong advocacy organizations received millions of dollars more in research funding over the period than others whose advocates were not as strong. She also found an increasing number of these organizations, from about 400 large [nonprofits](#) working on disease advocacy in the early 1990s to more than 1,000 by 2003.

In addition, Best noted another fundamental shift in policy brought about by advocacy. Where policymakers once focused on providing dollars to the scientists who made the best case for funding—with the general population thought of as the beneficiaries of their research—the government began to think of patients with particular diseases as the recipients of the research funds. This resulted in funding based on "perceived moral worthiness."

"The downside is not every disease has this potential for strong advocacy," Best said. "In addition to things like [lung cancer](#) and [liver disease](#), which lose out because of the [social stigma](#) tied to those diagnoses, there are diseases like pancreatic cancer, whose patients often don't live very long after diagnosis and, therefore, don't have time to tell their stories.

"In the years I studied, the National Institutes of Health budget was expanding rapidly. But in more recent years, we've seen a leveling off of what funding is available. It will be interesting to see if, after the time period I studied, disease advocates have become more competitive in their efforts to secure a share of the dollars."

Best also found that advocacy groups created political pressure to have funding allocated in line with mortality rates. After activists mobilized against an initially weak response to AIDS, it eventually received more research funding than any other disease.

Subsequently, advocates for other diseases protested that they were receiving fewer "dollars per death." Policymakers then pressured the NIH to bring the funding distribution more in line with mortality, even though NIH officials preferred to set priorities based on scientific criteria.

To reach her conclusions, Best collected data from the NIH and the Department of Defense—Congressionally Directed Medical Research Programs to determine dollars spent on various diseases. She gathered tax data on disease-related nonprofits and collected data on congressional hearings at which disease advocates gave testimony. She also reviewed mortality data for the 53 diseases that ranged from various cancers and influenza to hypertension and diabetes.

Provided by American Sociological Association

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