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Can Private Money Buy Public Science? Disease Group Lobbying and Federal Funding for Biomedical Research

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Private interest groups lobby politicians to influence public policy. However, little is known about how lobbying influences the policy decisions made by federal agencies. We study this through examining lobbying by advocacy groups associated with rare diseases for funding by the National Institutes of Health (NIH), the world's largest funder of biomedical research. Disease group lobbying for NIH funding has been controversial, with critics alleging that it distorts public funding toward research on diseases backed by powerful groups. Our data reveal that lobbying is associated with higher political support, in the form of congressional "soft earmarks" for the diseases. Lobbying increases with disease burden and is more likely to be associated with changes in NIH funding for diseases with higher scientific opportunity, suggesting that it may have a useful informational role. Only special grant mechanisms that steer funding toward particular diseases, which comprise less than a third of the NIH's grants, are related to earmarks. Thus, our results suggest that lobbying by private groups influences federal funding for biomedical research. However, the channels of political influence are subtle, affect a small portion of funding, and may not necessarily have a distortive effect on public science.

Keywords: research and development; lobbying; earmarks; National Institutes of Health
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1. Introduction

Special interest groups commonly lobby politicians for favorable treatment. In the year 2012 alone, interest groups spent $3.3 billion and hired 12,000 lobbyists in the United States to advocate for their causes (Center for Responsive Politics 2015). But independent bureaucrats make many decisions that affect interest groups, with limited formal oversight from politicians. For example, scientists at U.S. federal agencies such as the Food and Drug Administration, the Environmental Protection Agency, and the National Institutes of Health (NIH) implement regulations and make funding choices that affect private entities without direct congressional guidance, typically through peer review. Does lobbying by interest groups mobilize political support for their causes? How can political influence affect the decisions of independent agencies, which have their own procedures for making funding decisions? What leads interest groups to lobby in the first place?

Political scientists, economists, and strategy scholars have considered the above questions, but they typically do so separately. For example, previous studies suggest that interest groups that stand to benefit from political influence also spend more on lobbying (Stigler 1971, Grier et al. 1994, Grossman and Helpman 1994). A different body of scholarship reports evidence that interest groups transfer resources to politicians in return for a variety of benefits, including favorable treatment in spending bills, regulatory legislation, lower tax rates, and the distribution of "pork" (e.g., Austen-Smith and Wright 1994, Kroszner and Stratmann 1998, de Figueiredo and Silverman 2006b, Richter et al. 2009, Bertrand et al. 2014). A third set of studies argues that elected representatives design a variety of institutions, structures, and processes, such as advisory committees, budgetary controls, and subcommittee hearings, to retain oversight of "independent" bureaucratic agencies (e.g., McCubbins and Schwartz 1984, McCubbins et al. 1987, Balla 1998, Balla and Wright 2001). Taken together, this literature suggests that although interest groups attempt to obtain private benefits by persuading politicians, the preferences of elected representatives and nonelected bureaucrats may not always align, thus posing a challenge for interest groups seeking to influence public policy.

Here, we study whether interest groups affect policy decisions by federal agencies through lobbying politicians with budgetary oversight over the agencies. We do so in the context of the NIH, the world's largest single source of funding for biomedical research (in 2010, Congress provided approximately $31 billion to the NIH to support biomedical research). The NIH allocates this money for research across hundreds of diseases and other biomedical fields, typically through the peer review process. The agency relies on scientific experts to evaluate the merit of research proposals. Congress generally does not include directives that set aside funds for specific projects, or "hard earmarks," in its appropriations for the NIH, in contrast to its appropriations for other agencies (e.g., the Department of Agriculture, the Department of Defense). Instead, Congress specifies "soft" earmarks in language that "urges" and "encourages" the NIH to support research on particular diseases. These soft earmarks do not have the formal force of law and are buried in the text of the congressional committee reports that accompany NIH appropriations bills (Hegde and Mowery 2008, Hegde 2009, Sampat 2012). According to some critics, these soft earmarks distort allocations away from the best science toward projects favored by powerful interest groups (e.g., Institute of Medicine 1998). However, disease advocates argue that the congressional appropriations process and soft earmarks provide them with a mechanism to align agency funding decisions, which primarily reward the technical merit of research proposals, with the public interest (Dresser 2001).

Motivated by this debate, we explore how lobbying responds to changes in important disease-specific characteristics such as disease burden and scientific opportunity. We then investigate whether lobbying mobilizes political support, in the form of soft earmarks, and whether earmarks are associated with more NIH funding for the diseases. Rather than all diseases, we focus on "rare" diseases because our large-sample analysis requires linking information on diseases from disparate sources, and doing so reliably requires the diseases to be well defined and unrelated to each other. Rare diseases tend to be discrete (typically genetic) conditions and can be uniquely mapped to the funding, earmarking, disease burden, and publication data used in our analyses. Since the private sector finds it unprofitable to invest in research and development (R&D) for diseases with low prevalence, public funding is considered critical for finding treatments for rare diseases (Ashbury 1985).[1]

[1] Various initiatives, such as the Orphan Drug Act of 1983, have attempted to create tax and market exclusivity incentives for stimulating private sector research on rare diseases.

Our analysis of 955 rare diseases between 1998 and 2008 reveals that interest group lobbying expenditures increase with disease burden (measured by deaths). Increased lobbying is associated with more congressional soft earmarks for the diseases. The relationship is strongest when lobbying is accompanied by increases in scientific opportunity (measured by the number of scientific publications) associated with the diseases. In general, although both lobbying and earmarks appear to respond positively to changes in our measures of disease burden and scientific opportunity, the estimated effects of the latter two variables are quite small. This could be due to the limitations of our measures and the study sample, which captures variation in disease attributes within a short span of time, of which there may be "too little" after controlling for unmeasured disease fixed effects in our regressions.

Specific types of NIH grants—for example, "requests for applications" (RFAs) and "program announcements" (PAs), which solicit research proposals in particular areas of research rather than unsolicited investigator-initiated research—are most strongly related to soft earmarking, suggesting the mechanisms through which political influence shapes NIH funding decisions. Since these special types of grants account for less than a third of the NIH's overall allocations, the overall effect of lobbying and earmarks on NIH funding appears small—in the range of 3%–15% of the agency's new spending on rare diseases each year.

These findings contribute to the emerging literature on firms' nonmarket strategies in several ways. First, we document and measure an understudied mechanism through which Congress influences independent agencies' funding decisions: soft earmarks. Much of the literature on earmarks, including work examining their effect on research funding, focuses on "hard" earmarks (e.g., Payne 2002, de Figueiredo and Silverman 2006b). But soft earmarks are becoming important well beyond the NIH context: after the curbs on hard earmarking imposed by the 2007 Congress ethics rules, media reports suggest that politicians are commonly relying on soft earmarks to influence various federal agencies (see Nixon 2012). However, there is little research on whether soft earmarks, which, unlike hard earmarks, do not have the formal authority of law, actually influence agency decisions. Here, we provide evidence suggesting that they do, in ways consistent with theories of "congressional dominance" (Fiorina 1981, 1982; Weingast 1981, 1984; Weingast and Moran 1982, 1983; Calvert and Weingast 1984; McCubbins 1985).

Second, our analysis complements previous work on public funding for biomedical research that treats the allocation process as a black box (e.g., Lichtenberg 2001, Bhattacharya and Packalen 2011, Cutler et al. 2012). We analyze the institutions that shape the

allocation process and provide evidence that interest groups indirectly influence the funding choices made by independent scientists. We also find some evidence that lobbying may reflect changes in disease-specific demand characteristics and may have an important role in communicating information about these characteristics to policy makers. Hence, our findings suggest that the conventional "private interest versus public good" distinction and the conclusion that interest groups distort allocation patterns away from the first best may be too simple.[2]

Third, although it is generally acknowledged that lobbying is among the most common nonmarket strategies pursued by interest groups attempting to benefit from public policy, evidence on whether lobbying succeeds is limited.[3] This lack of evidence reflects several measurement challenges: the path through which interest groups affect politicians, and politicians influence policy, does not show clear footprints, and counterfactual allocation patterns against which to assess the effects of interest groups typically do not exist. In addition to being important, the NIH allocation process allows us to address these challenges: we can link disease interest groups to their lobbying expenditures, we can control (albeit imperfectly) for disease characteristics (i.e., scientific opportunity and disease burden) that influence allocations for the diseases, and we can link congressional support for particular diseases (in the form of soft earmarks) to agency funding for the diseases through various grant mechanisms. Hence, we are able to examine not only whether but also how lobbying by interest groups influences public funding choices in a setting that affects the health and well-being of millions.

2. Institutional Context

2.1. The National Institutes of Health

The NIH is part of the U.S. Department of Health and Human Services and provides 85% of total federal support for research and development in the biological, medical, and psychological sciences (based on FY2008 federal obligations; see National Science Foundation, Division of Science Resources Statistics 2007). The agency is organized into 27 independent institutes and centers that specialize by disease (e.g., the National Cancer Institute), organ (e.g., the National Eye Institute), field of science medicine (e.g., the National Institute of General Medical Sciences), or stage of human development (e.g., the National Institute on Aging) (McGeary and Smith 2002). More than 80% of the agency's funding is awarded annually to researchers at over 3,000 universities, medical schools, and other research institutions.[4] NIH extramural funding for research increased from $1.95 billion in 1998 to $3.4 billion in 2008 for rare diseases and from $14.5 billion to $22.1 billion for other research during the same period (throughout this paper, all dollar figures are inflated to 2010 constant dollars).

The individual institutes at the NIH utilize a *dual peer review* process to evaluate proposals from researchers. In the first stage of this process, grant applications are evaluated by panels of external scientists from the relevant fields. These peers score applications based on their significance, technical merit, innovativeness, and investigators' qualifications. Acceptable applications are then assigned to the NIH institute or center best suited to fund the research, where they are reviewed by a "national advisory council" composed of scientists and public representatives. Each institute's (or center's) advisory council recommends applications for funding by considering priority scores and the proposed project's relevance to the institute's mission. The director of the institute/center makes the final funding decision based on the relevant advisory council's recommendation (National Institutes of Health 2008).

The NIH is viewed by some observers as an exemplar research agency because of its commitment to funding the highest-merit projects identified through its peer review process (Cook-Deegan and McGeary 2006). For example, (Drazen and Ingelfinger 2003, p. 2259) note that "the selection of research for funding [for investigator-initiated grants] is based solely on merit; politics has no place in this system."[5]

2.2. Congress

Annual congressional decisions concerning the NIH budget are made by the Labor, Health and Human Services, and Education and Related Agencies Subcommittee (LHHE) of the House and Senate Appropriations Committees. The bills reported to the floor of the House and Senate by each of these subcommittees indicate the total annual appropriation for each NIH institute and center. These bills, unlike those

[2] For example, Becker (1996) has argued that "the distribution of funds among diseases deviates greatly from the socially most desirable allocation," since "well-organized advocacy groups for particular diseases . . . use their political clout to get disproportionate shares of the research budget" (p. 18).

[3] The studies by Payne (2002) and de Figueiredo and Silverman (2006b) showing the effects of lobbying on the legislative actions of elected representatives, such as direct earmarking in appropriations bills and voting on regulatory policy, are notable exceptions.

[4] The rest of the funds support "intramural" research, i.e., work carried out by scientists at the NIH.

[5] Li (2012) studies NIH's peer review process and concludes that although peer reviewers are biased in favor of research proposals from their own subfield, the deleterious effect of this bias is trumped by the superior information the reviewers have about their fields, which allows them to make better funding decisions.

for other funding agencies, do not include earmarks. The former director of the NIH, Harold Varmus, suggests that congressional reluctance to include hard earmarks in the NIH's spending bills "represent[s] votes of Congressional confidence in the NIH's system of peer review" (Varmus 2009, p. 150). Yet members of the LHHE subcommittee seek to influence the NIH's disease-specific funding through soft earmarks, or language recorded in the annual appropriations committee's meeting reports that accompany the appropriations bills.[6] These earmarks have been the subject of considerable controversy. Some worry that earmarks target diseases without concern for the scientific feasibility of research and that this low-quality research crowds out funding for higher-quality peer-reviewed research (Greenberg 1998). Others argue that earmarks are the only channel through which "public interest" can be incorporated into the NIH's allocation process, which (they contend) is otherwise narrowly oriented toward rewarding scientific opportunity. For example, according to one disease advocate, "Patient groups believe the decision-making process at the NIH is basically a closed process where patient organizations are only consulted at later stages, when decisions in fact have already been made" (quoted in Dresser 2001, p. 80).

2.3. Disease Advocates

In the United States, disease interest groups have long been influential in mobilizing private and public resources against disease (for example, Lerner 2003 documents the critical role played by patient groups in educating the public and policy makers about breast cancer). Interest groups seek to increase funding for research on specific diseases though a number of channels: by lobbying Congress, by organizing testimony to persuade the congressional appropriations committee, and by mobilizing grassroots advocacy campaigns that, for example, encourage patient groups to inform their representatives of the importance of supporting research on particular diseases (Armstrong et al. 2006, Best 2012 describe factors that shape the intensity and success of disease advocacy). According to Dresser (2001), citizen groups started systematically lobbying for disease-specific earmarks in the 1980s, after successful campaigns by AIDS and breast cancer advocacy groups led to increased congressional support and NIH funding for the diseases.

One example of disease advocacy, which we will return to throughout the text, is provided by the case of Rett syndrome, a developmental disorder affecting approximately 1 in 10,000 children in the United States. The syndrome is primarily seen in females 6–18 months old, causing a loss of communication skills and, in severe cases, seizures, leading to death. In 1999, a discovery linking the disorder to mutations of the *MECP2* gene opened new avenues of research for a potential cure. In 2002, the International Rett Syndrome Association (IRSA) mobilized parents, friends of patients (including actress Julia Roberts), and scientists to lobby Congress to increase the NIH's funding for research on the disease. In response, the House Appropriations Committee included language in the reports accompanying its appropriations for NIH, "encouraging research" on Rett syndrome. In the following year, NIH grants for research on Rett syndrome increased by 65%, from $4.6 million in 2002 to $7.6 million in 2003.

Previous research on lobbying suggests that the size of groups, their ability to mobilize resources, and the expected benefits from lobbying are important determinants of lobbying intensity (de Figueiredo and Richter 2014). In our empirical analysis below, we assess whether the expected benefits of lobbying, resulting from changes in scientific opportunity and disease burden, influence the intensity of lobbying by interest groups, after controlling for other factors that are unlikely to vary over the time period we study with disease fixed effects.

2.4. Grant Mechanisms at the NIH

How does the NIH direct its funding, typically made through peer review of research proposals, to disease areas specified in congressional soft earmarks? Existing research (see, e.g., Lichtenberg 2001, Best 2012, Bhattacharya and Packalen 2011) is silent on the channels through which demand-side factors (including either politics or disease burden) can influence funding in an allocation process dominated by peer review of the scientific merit of investigator-initiated proposals (Sampat 2012).

However, as the Institute of Medicine (1998), Dresser (1999), and Sampat et al. (2013) suggest, some grant mechanisms at the NIH—particularly RFAs and PAs—are more focused and allow the NIH to steer the direction of research in response to congressional guidance. RFAs and PAs are solicitations by the NIH for grant applications that address a defined research topic. PAs are used by the NIH to announce its interest in building or enhancing research in specific areas

[6] For example, House Report 109-515 accompanying the Departments of Labor, Health and Human Services, and Education, and Related Agencies Appropriations Bill for FY2007 includes soft earmarks for interstitial cystitis (IC): "Research on IC is still in its infancy . . . the Committee encourages NIDDK [the National Institute of Diabetes and Digestive and Kidney Diseases] to place emphasis on IC-specific funding in order to focus on the basic science of IC and to attract and sustain research in the field" (pp. 94–95). The analogous Senate report 109-103 includes soft earmarks for Batten disease: "The Committee strongly urges the Institute to increase funding for Batten Disease research by actively soliciting grant applications and taking aggressive steps to assure that a vigorous research program is established" (p. 111).

considered to be of high priority. RFAs, similar to PAs, also specify an area of research, with suggested approaches to the research topic described in the announcement.

About RFAs, the Institute of Medicine (IOM) report notes, "Because of their directedness, such mechanisms tend to be specified by Congress in legislation or report language when Congress concludes that NIH should move more quickly to attack a particular disease or other problem" (Institute of Medicine 1998, p. 19). The former director of one of the NIH institutes (the NIDDK) also noted the importance of the RFA mechanism in responding to earmarks: "Use of RFAs is generally restricted to areas of congressionally directed earmarks. In addressing these earmarks, efforts are made to identify relevant, scientifically meritorious grants that are submitted through the regular grant application process, are reviewed and approved by standing study sections, and are within the projected pay-line. Often, however, it is necessary to stimulate additional grant applications through the RFA mechanism to meet the congressional earmark" (Gorden et al. 1993, p. 685).[7]

Nearly 30% of NIH funding associated with new grants for rare diseases during our study was funded via RFAs and PAs and the rest for unsolicited investigator-initiated proposals.[8] Below, we separately examine the effects of earmarks on these different types of research grants, with a view to illuminating the channels through which earmarks affect NIH funding. If one starts with the assumption that investigator-initiated grants are less amenable to political direction, then examining the effects of earmarks on such grants also serves as a falsification test of whether earmarks really affect funding or reflect omitted variables.

3. Specification and Sample

3.1. Empirical Specification

We ask three questions: (1) Does lobbying respond to changes in disease-specific characteristics? (2) Is increased lobbying associated with more congressional support, in the form of soft earmarks for diseases? And (3) are increases in lobbying and earmarking associated with more NIH funding for research on diseases?

To answer these questions, we focus our analysis around three regression models that respectively explain the lobbying expenditures of interest groups (L), the number of soft earmarks (E), and NIH funding (in dollars) for new research projects (G) as a function of disease-specific characteristics and control variables:

$$\ln L_{i,t} = \alpha_0 + \alpha_1 \ln M_{i,t-1} + \alpha_2 \ln P_{i,t-1} + \alpha_3 \ln K_{i,t-1} + \sum I_i + \sum T_t + e_{i,t}, \quad (1)$$

$$E_{i,t} = \beta_0 + \beta_1 \ln M_{i,t-1} + \beta_2 \ln P_{i,t-1} + \beta_3 \ln L_{i,t-1} + \beta_4 \ln K_{i,t-1} + \sum I_i + \sum T_t + u_{i,t}, \quad (2)$$

$$\ln G_{i,t} = \gamma_0 + \gamma_1 \ln M_{i,t-1} + \gamma_2 \ln P_{i,t-1} + \gamma_3 \ln L_{i,t-1} + \gamma_4 E_{i,t-1} + \gamma_5 \ln K_{i,t-1} + \sum I_i + \sum T_t + v_{i,t}. \quad (3)$$

For each disease (i), we observe and measure L, E, and G for each year (t) between 1998 and 2008. We focus on two disease-specific factors: the disease burden (M) and the scientific opportunity (P) associated with research on the disease. Our choice of these two factors draws on the model explaining cross-disease funding in Lichtenberg (2001), along with the views of previous analyses of how public biomedical R&D funding is (and should be) done (Institute of Medicine 1998).[9]

[7] Our survey of congressional reports revealed several instances when Committee members specifically requested the NIH to issue RFAs and PAs to support specific research areas. For example, FY2006 Committee report contains the following language: "The Committee encourages NIH to identify new research opportunities on CMT [Charcot-Marie-Tooth disorder] that could lead to a relevant program announcement or request for applications." The Senate report corresponding to NIH appropriations for FY1999 specifies, "Last year, the Committee and the conference committee called on the NICHD [National Institute of Child Health and Human Development] to support research on the prevalence, causes, and treatment of vulvodynia. To date, no RFA has been issued.... Also, the Committee encourages that additional funds be provided above the budget request in fiscal year 1999 for research on vulvodynia and expects NICHD to issue a RFA within the first quarter of fiscal year 1999." The Senate report corresponding to NIH appropriations for FY2007 specifies that "the Committee encourages NICHD to issue RFAs for NF [neurofibromatosis] research and aggressively pursue and expand funding of clinical trials for NF patients in the area of learning disabilities." A report by the U.S. Government Accountability Office, responding to Nevada Senator Harry Reid's queries about how the NIH responded to congressional report language on chronic fatigue syndrome (CFS), notes, "NIH develops extramural research on diseases, including CFS, primarily by creating program announcements for grant applications" (U.S. Government Accountability Office 2000, p. 21).

[8] RFA and PA awards also fund the establishment of "research centers" that support a wider range of activities, are more capital intensive, and involve more investigators than awards for investigator-initiated projects.

[9] For example, the main title of the 1998 IOM report on NIH funding patterns is "Scientific Opportunities and Public Needs." The IOM report also emphasizes other dimensions that this model does not, including equity considerations and the extent of market failure (Garber and Romer 1996). Note also that in 1997 the NIH itself stated the three most important criteria for determining NIH funding choices were "(i) public health need, as judged by the incidence, severity, and cost of specific disorders; (ii) the scientific merit of individual research proposals; and (iii) the potential for scientific advancement in different fields" (quoted in Dresser 1999, pp. 262–263).

In each of these models, we include a full suite of disease fixed effects ($\sum I_i$) to control for other attributes of diseases that are fixed over time. We are interested in whether changes in lobbying, earmarks, and measures of disease burden and scientific opportunity are important after accounting for these other fixed factors.[10] Funding levels during the past year may influence lobbying, congressional earmarking, and current-year NIH grants. Accordingly, we include NIH funding in the previous year (K) as a control variable, as well as year-specific indicator variables ($\sum T_t$) to control for time trends in some models. Lagged funding, K, also captures the NIH's own assessment of scientific opportunity and the effect of other attributes that the agency considers while making its allocations.

3.2. The Sample

Rare diseases have no official definition but are typically characterized as those with prevalence of fewer than 200,000 individuals. The National Organization for Rare Disorders (NORD) identifies 1,200 such diseases in its Rare Disease Database. Since some of these are not "true" rare diseases (e.g., HIV/AIDS), we focus on the subset of 955 that are also identified as rare diseases in an NIH database of rare diseases (National Institutes of Health 2011). Even this list includes some diseases that have high prevalence. Thus the NIH cautions that the list "should not be used as a reference or guarantee that a condition is rare" and that "[some] diseases with 200,000 or more affected individuals may be included in this list if certain subpopulations of people who have the disease are equal to the prevalence standard for rare diseases." We use the term "rare disease" in this paper to mean specifically a disease identified as "rare" in both the NORD and NIH rare disease databases.

The NORD database also provides all known synonyms for each disease, and we use each of the synonyms to collect and assemble data on the characteristics of each disease from five different sources as described below. The NORD data also include information on all organizations associated with each disease, allowing us to link them to data on lobbying expenditures.

3.3. Variables

3.3.1. Lobbying Intensity Measured by Lobbying Expenditures of Disease Interest Groups. The Lobbying and Disclosure Act of 1995 requires organizations that lobby Congress to disclose good-faith estimates of their lobbying-related expenditures, rounded to the nearest \$20,000, to the secretary of the Senate Office of Public Records (SOPR). Under the act, lobbying expenditures include money spent by the organization on lobbying by internal personnel and by hired external lobbyists. The Center for Responsive Politics (CRP) has collected these data for each organization that lobbied Congress and federal agencies in each year since 1998.[11] We identified in the CRP data any organization associated with the 955 diseases in our data as indicated by the NORD disease–organization correspondence. During this period, 98 unique organizations reported positive lobbying expenditures. The majority of these organizations are nonprofit professional and disease advocacy groups, such as the American Speech-Language-Hearing Association, the March of Dimes Foundation, and Autism Speaks. Many of these organizations are associated with lobbying for multiple diseases. In these cases, we divided the total lobbying expenditures reported by the organization by the number of diseases associated with the organization. We thus constructed the lobbying expenditures for each disease by totaling the lobbying expenditures of all the organizations associated with the disease for each year during 1998–2008.

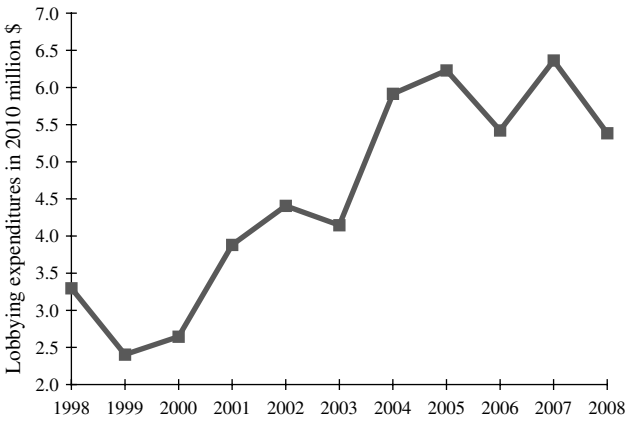
We do not know the extent to which the lobbying expenditures of organizations are directed at obtaining earmarks for research funding versus other activities (e.g., changing reimbursement rules for public insurers). Hence, we reviewed the websites of each of the 110 lobbying organizations in our sample (and, on occasion, when we could not find the websites, we searched news databases for mentions of the activities of the organizations) and identified a subset of 52 organizations as potentially interested in research activities and funding (see Table A1 of the supplementary appendix, available as supplementary material at http://dx.doi.org/10.1287/mnsc.2014.2107) lists these research-related lobbying organizations). We use only the lobbying expenditures of the 52 research-related organizations in our analyses. The lobbying expenditures of interest groups associated with research on rare diseases increased from \$3.3 million in 1998 to \$5.4 million in 2008 (Figure 1 shows trends in the lobbying expenditures).

3.3.2. Congressional Support for Diseases, Measured by the Number of Soft Earmarks. We collected data on all report language that mentioned support for the 955 rare diseases (and/or their synonyms) from the House and Senate LHHE subcommittee appropriations reports accompanying appropriations

[10] These other attributes of diseases may be correlated with our measures of M, P, and the dependent variables of interest in each of the above three equations and, if omitted from the ordinary least squares regressions, lead to biased estimates.

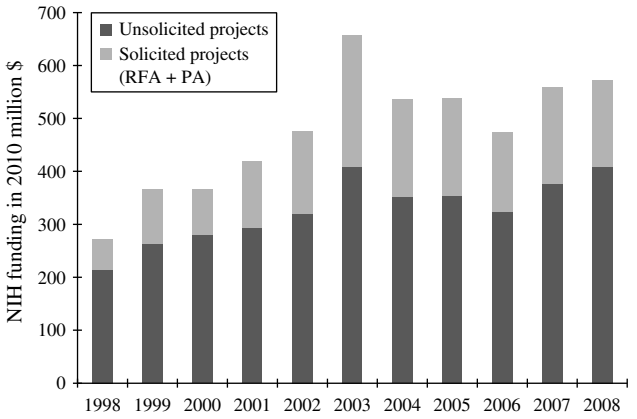
[11] An organization that spends less than \$10,000 in any six-month period does not have to report its expenditures. In those cases, the center treats the figure as zero.

Figure 1 **Lobbying Expenditures by Rare Disease Interest Groups, 1998–2008**



Notes. The figure shows the lobbying expenditures (in millions of 2010 dollars) of 52 research-related interest groups that were associated with at least one of the 955 rare diseases in our sample. Data on lobbying expenditures were gathered from the disclosures of lobbying organizations filed with the secretary of the SOPR and are available through the Center for Responsive Politics.

Figure 2 **NIH Grants for New Unsolicited Projects and Solicited Projects (RFAs and PAs) on Rare Diseases**



Note. The figure shows NIH funding (in millions of 2010 dollars) for new unsolicited investigator-initiated projects and grants for new projects through the solicited grant mechanisms.

bills between fiscal years 1998 and 2008. We read the reports for each year and chamber, and we coded as an earmark any mention of a rare disease in conjunction with words indicating support (mainly "urge," "encourage," and "direct"). Occasionally, diseases are mentioned in the report language for not one but multiple NIH institutes; in these cases we count each earmark as a separate instance of congressional support for the disease. Over the 1998–2008 period, House reports specified an average of 33 earmarks for rare diseases each year, and Senate reports specified an average of 51. Overall, the congressional reports specified an average of 84 earmarks annually, supporting 32 rare diseases on average each year. Approximately 90% of the 955 rare diseases in our sample did not receive a single earmark during the period of our study.

Rare diseases appear to receive a disproportionate number of earmarks. For example, in 2006, our House and Senate reports together specified a total of 310 earmarks, of which 140 (or 45% of earmarks) focused on rare diseases. By comparison, the 955 diseases in our data received approximately 15% of the NIH's overall funds in 2006 and account for roughly the same percentage of deaths in the United States from these diseases (based on data collected by the National Vital Statistics System of the National Center for Health Statistics) and the same percentage of NIH-funded publications associated with these diseases (as indexed by MEDLINE).

3.3.3. Agency Funding for Rare Diseases. We developed a text-matching algorithm to search the NIH's Computer Retrieval of Information on Scientific Projects (CRISP) database for the names of each of the 955 diseases and their synonyms in the abstracts of each of the 600,000 grants awarded between 1998 and 2008, associating a grant with a disease if any of the words in the abstract matched the primary name of the rare disease or any of its synonyms.[12] Overall, the 955 diseases mapped to 77,005 distinct grants during the period. We used a separate NIH database, Research Portfolio Online Reporting Tools, to collect information on the amount of funding associated with each grant, and we aggregated the funds received by each disease for each year. In an average year during 1998–2008, the 955 rare diseases in our sample together received 7,000 grants, or $2.8 billion in NIH funding.[13] Figure 2 shows trends in NIH funding for rare diseases (for new projects only) through the solicited (RFA/PA) and unsolicited (investigator-initiated) grant mechanisms.

3.3.4. Disease Burden Measured by Deaths Caused by Diseases. We measure disease burden as the number of deaths associated with each disease,

[12] Previous research (e.g., Lichtenberg 2001, Toole 2007) has used "thesaurus" keywords provided in the CRISP data to identify and measure funding for diseases. However, we found the thesaurus terms unreliable for rare diseases. For example, many grants referenced a rare disease in the title and abstract but not in the thesaurus keywords, and many rare diseases did not have entries in the CRISP thesaurus.

[13] Historically, the NIH has not reported data on funding by disease, but the agency's recent Research, Condition, and Disease Categorization (RCDC) initiative tabulates disease-specific funding data for a subset of diseases and for the years after 2007 (Sampat 2012, Sampat et al. 2013). For the 33 diseases in our sample also listed on the RCDC, we compared our funding numbers for the year 2008 to those available from the RCDC (see Figure A1 of the supplementary appendix). The correlation between the funding numbers obtained through our search and the numbers reported by the RCDC is 0.92, suggesting that our strategy generates numbers comparable to the official RCDC benchmark.

Table 1 Sample Descriptive Statistics

Panel A

Variable	Mean	SD	50th percentile	90th percentile	Maximum	Nonzero observations
Number of deaths	292.4	2,644.1	0.0	120.0	74,648.0	4,862
Number of publications	18.9	101.1	0.0	33.0	2,770.0	4,544
Research-related lobbying expenditures	4.8	16.4	0.0	16.7	567.5	2,463
Number of earmarks	0.1	0.6	0.0	0.0	13.0	358
NIH grants for new and continuing projects	2,991.4	18,572.8	0.0	4,233.5	488,617.2	4,684
NIH grants for new investigator-initiated projects	342.1	2,105.6	0.0	531.7	62,033.7	2,451
NIH grants for new projects via RFAs and PAs	156.5	1,143.1	0.0	39.2	31,526.5	1,096
NIH grants for new projects via PAs	57.1	510.0	0.0	0.0	21,593.0	758

Panel B

Variable	Number of earmarks = 0	Number of earmarks > 0
Lobbying expenditures = 0	634 (66.4%)	43 (4.5%)
Lobbying expenditures > 0	236 (24.7%)	42 (4.4%)

Notes. Panel A reports descriptive statistics for the 10,505 disease-year observations in the sample (955 rare diseases over an 11-year period from 1998 to 2008). Lobbying expenditures and NIH grants are in thousands of 2010 dollars. RFAs are grants through requests for applications, and PAs are grants through program announcements. Panel B shows, for the 955 rare diseases in our sample, the number and percentage (in parentheses) of diseases that did or did not receive at least one earmark conditional on being associated with zero or greater than zero lobbying expenditures during our study period.

as reported in the Multiple Cause of Death Mortality files, developed through the National Vital Statistics System of the National Center for Health Statistics. The mortality files provide data on deaths by disease, using disease categories from the 10th revision of the *International Statistical Classification of Diseases and Related Health Problems* (ICD-10; World Health Organization 2011). Accordingly, we determined the ICD-10 code for each disease in our data set (using their synonyms, where necessary) and constructed numbers of deaths from each disease. The 955 rare diseases in our sample account for between 13% and 15% of all deaths from disease (excluding accidental causes) between 1998 and 2008. The 955 diseases collectively are responsible for 307,182 U.S. deaths annually, on average. We also examine another measure of disease burden, the number of hospitalizations associated with diseases, in a robustness check.

3.3.5. Scientific Opportunity Measured by the Number of Scientific Publications in a Disease Field. Scientific opportunity is difficult to measure across diseases. Indeed, NIH peer reviewers spend hours evaluating scientific opportunity for individual applications. We use the number of publications associated with the diseases to measure scientific opportunity. We map each disease (and its synonyms) to a Medical Subject Headings entry in MEDLINE and construct disease-specific publication counts by year. The idea behind this measure is that disease areas where there is an increase (decrease) in opportunity should see a corresponding increase (decrease) in publications.[14]

On average, there were 19,836 rare-disease-related publications per year, roughly 15% of all MEDLINE publications related to diseases. Since simple counts of publications can be a noisy indicator of scientific output, we also examine quality-weighted publications as a more refined measure of output in robustness checks.

Table 1, panel A reports descriptive statistics on the variables used in the analysis, using the 10,505 disease-year observations (955 diseases over 11 years) in our sample. In addition to the variables discussed above, panel A also reports descriptive information for NIH funding through the different kinds

[14] Ideally, the scientific opportunity measure would capture advances in each disease field, such as the discovery of particular genetic mutations associated with a disease or the identification of mechanisms that can provide the basis for developing treatment. Although such a measure is difficult to construct for each disease in our data, we randomly selected 20 diseases from among the diseases with noticeable increases in associated publications during our study period, and we searched news archives for reports of scientific advances associated with the diseases. We were able to identify media reports on advances for 12 of the 20 diseases. Of the 12, for 9 diseases, the jump in publications appears to occur in the year, or immediately following the year, in which the media reported the advance. Table A2 of the supplementary appendix reports the years for the advances and provides references to the media articles reporting the advance. This exercise suggests that within-disease publication counts respond to, and can thus reasonably indicate, changes in scientific opportunity.

of grant mechanisms (RFA/PA grants and unsolicited investigator-initiated grants).

For most of our key variables, the median disease-year observation takes on the value 0, indicating the left skew of the variables (see Table 1, panel B). We log-transform lobbying expenditures and NIH funding after adding 1 to smooth their distribution and reduce variance before estimating the regressions. We also separately examine linear probability analogues of the main regressions (that is, models predicting any L, any E, and G as the dependent variables; the corresponding results are consistent with the ones reported here and available on request from the authors).

4. What Predicts Lobbying?

The Rett syndrome case discussed above suggests that disease advocates might lobby in response to changes in scientific opportunity and disease burden.[15] Next, we examine whether these factors indeed predict lobbying intensity in our large sample. We focus on disease burden (measured by the number of deaths) and scientific opportunity (measured by the number of publications) since these factors are commonly thought to affect funding in previous work on the NIH and would likely affect returns to lobbying. Other factors such as the demographic characteristics of the population affected by the disease and the ability of interest groups to mobilize resources for lobbying can have a bearing on the level of lobbying expenditures (Best 2012); these are difficult to operationalize in a large sample and are captured by disease fixed effects.

Table 2 shows estimates of the relationship between the lobbying expenditures of interest groups and one-year lagged measures of burden and opportunity. The three variables are log-transformed after adding 1 and are measured for each disease-year (955 diseases for each of the 11 years between 1998 and 2008; accounting for the one-year lag between the explanatory variables and lobbying yields 9,550 observations). We calculate and report standard errors clustered by disease to account for within-disease correlations among the observations. Column 1 suggests that a 10% increase in either deaths or publications increases lobbying expenditures by 0.6% in the pooled cross section. Deaths and publications explain 4% of the variation in lobbying expenditures.

Table 2 Relationship Between Lobbying and Disease Characteristics

	DV = *Log lobbying expenditures*			
	1	2	3	4
Log deaths (1-year lagged)	0.066**	0.051*	0.050*	0.050*
	[0.021]	[0.024]	[0.024]	[0.024]
Log publications (1-year lagged)	0.066**	0.041*	0.038*	0.025
	[0.021]	[0.017]	[0.016]	[0.017]
Log NIH grants (1-year lagged)			0.009**	0.005
			[0.003]	[0.003]
Constant	0.374	0.456	0.434	0.351
Disease fixed effects (955)	N	Y	Y	Y
Year fixed effects (10)	N	N	N	Y
Observations	9,550	9,550	9,550	9,550
Adjusted R^2	0.04	0.904	0.905	0.907

Notes. The table reports OLS estimates of the effect of explanatory variables on the lobbying expenditures of research-related interest groups. The unit of observation in the estimation sample is disease-year, and the sample has observations for 955 diseases for each year between 1998 and 2008. All SEs, in brackets, are clustered at the disease level. DV, dependent variable.
$^{+}p < 0.1$; $^{*}p < 0.05$; $^{**}p < 0.01$.

Adding disease fixed effects controls for attributes that systematically vary across diseases. This helps us to isolate the influence of changes in deaths and publications on lobbying. Strikingly, column 2 of Table 2 shows that adding disease fixed effects results in a model that explains 90% of the variation in lobbying expenditures and reduces the estimated effects of deaths and publications. Columns 3 and 4 show that adding past-year NIH funding for the disease and year fixed effects, respectively, further reduces the estimated effect of publications (primarily because of the high positive correlation between NIH funding and publications). Deaths, however, have a statistically significant effect on lobbying in all specifications.

The estimates suggest that the effects of our measures of disease burden and scientific opportunity on lobbying are small relative to the effects of unobserved disease-specific factors. What might some of these unobserved factors be? Previous research on the NIH suggests that the demographic characteristics of groups affected by diseases, such as their age, race, socioeconomic status, and gender, may affect both advocacy and funding (Lichtenberg 2001, Best 2012). The ability of advocacy groups to command attention, and the resources available to the groups, may also influence the intensity of lobbying, which is precisely why there are concerns that lobbying (if successful) could distort research agendas away from

[15] To get a sense of whether disease burden and scientific opportunity are considered important by a larger sample of disease advocates, we surveyed the websites of each of the 52 research-related disease advocates in our sample. We found that all of the advocates highlighted the reduction of disease burden on the affected individuals as their primary objective in their mission statements. We also searched archives of media articles for mentions of disease advocates surrounding years of noticeable jumps in their lobbying expenditures. The advocates typically appeared to be mentioned in the media in conjunction with new scientific advances related to the diseases, suggesting that they were active in disseminating information about the advances (references to these articles are available from the authors on request). These qualitative findings should be viewed with caution: given the stated importance of disease burden and scientific opportunity by funding agencies, one can argue, to an extent, that advocates can be expected to highlight these factors as key drivers of their activities.

Table 3 Relationship Between Soft Earmarks and Lobbying

	DV = *Number of earmarks*						
	1	2	3	4	5	6	7
Log lobbying expenditures (1-year lagged)		0.065*	0.043†	0.243*	0.243*	0.246*	0.689*
		[0.026]	[0.023]	[0.114]	[0.114]	[0.115]	[0.267]
Log deaths (1-year lagged)	0.040**		0.038**	0.007	0.007	0.008	−0.053
	[0.013]		[0.013]	[0.019]	[0.019]	[0.019]	[0.166]
Log publications (1-year lagged)	0.040**		0.037**	0.03	0.029	0.027	0.256
	[0.009]		[0.009]	[0.022]	[0.022]	[0.022]	[0.169]
Log NIH grants (1-year lagged)					0.001	0.001	0.025
					[0.002]	[0.002]	[0.039]
Constant	−0.065	0.052	−0.08	−0.135	−0.137	−0.14	−0.689
Disease fixed effects (955)	N	N	N	Y	Y	Y	Y (85)
Year fixed effects (10)	N	N	N	N	N	Y	Y
Observations	9,550	9,550	9,550	9,550	9,550	9,550	9,550
Adjusted R^2	0.05	0.014	0.056	0.604	0.604	0.606	0.57

Notes. The table reports OLS estimates of the effect of previous year lobbying expenditures of research-related interest groups, NIH grants, deaths, and publications on the number of current-year earmarks. The unit of observation in the estimation sample is disease-year, and the sample (corresponding to estimates in columns 1–6) has observations for 955 diseases for each year between 1998 and 2008. Column 7 reports estimates obtained by restricting the sample to only the 85 diseases that received an earmark in at least one year during our study. All SEs, in brackets, are clustered at the disease level. DV, dependent variable.

†$p < 0.1$; *$p < 0.05$; **$p < 0.01$.

the public interest (Best 2012). The theoretical literature on lobbying also emphasizes difficulty in organizing to overcome collective action problems (Olson 1965). It is also possible that different disease groups have different levels of access to powerful legislators (de Figueiredo and Silverman 2006a) or face different costs to organize (Olson 1965) or to lobby (Kerr et al. 2011). Finally, both disease burden and scientific opportunity are multifaceted and may include dimensions beyond those captured by our measures. Examining the effects of each of these factors on levels and changes in lobbying and allocations is important, although beyond the scope of our study. We emphasize for now that to the extent that the factors listed above are time invariant (as they are likely to be within the short span of our study), they are captured by the disease-specific intercepts in our regressions.

5. Does Lobbying Influence Political Support for Diseases?

5.1. Relationship Between Soft Earmarks and Lobbying

Table 3 reports estimates of the relationship between the number of soft earmarks and the explanatory variables in our sample of 9,550 disease-year observations. The explanatory variables are lagged by one year to account for the lagged relationship between disease characteristics and congressional response.[16]

[16] We experimented with different lag structures, including two-year lags and contemporaneous variables, but found one-year lags to yield the most robust relationship between earmarks and the explanatory variables of interest.

Column 1 shows that a 10% increase in past-year deaths and past-year publications are each associated with 0.4 additional soft earmarks for the disease (the effect is statistically significant at the 1% level). This baseline model explains 5% of the variation in earmarking across disease years.

Column 2 of Table 3 shows that, in a model with only lobbying on the right-hand side, a 10% increase in lobbying expenditures is associated with 0.6 additional earmarks. Column 3 shows that this estimated effect of lobbying goes down to 0.4 upon holding deaths and publications constant. Column 4 adds disease fixed effects and shows that a 10% within-disease increase in lobbying expenditures is associated with 2.4 additional earmarks for the disease. Incorporating disease fixed effects identifies the effect of lobbying using the 278 diseases in our sample with variation in lobbying expenditures across time (see Table 1, panel B), ignoring 677 diseases that were not supported by lobbying during our study. Given that the average disease in our sample receives 0.1 earmarks in a year, this estimated effect suggests that lobbying has a particularly strong association with earmarks "within" disease. Not surprisingly, the estimated effect of lobbying on earmarks is even higher when we limit the sample to the 85 diseases that received at least one earmark during our study (column 7 reports the corresponding estimates).

The estimated relationships between deaths and earmarks and between publications and earmarks are each statistically insignificant after including disease fixed effects and thus appear to be primarily driven by cross-disease variation. The model with disease

fixed effects explains nearly 60% of the variation in earmarking. Columns 5, 6, and 7 of Table 3 show that adding past-year NIH funding and year fixed effects does not significantly change the estimates.

The number of earmarks is a count variable ranging between 0 and 13, with a value of 0 for nearly 90% of the observations. Given this skewed distribution, we checked whether our results are robust to the following alternative specifications: ordinary least squares (OLS) with log(1 + *number of earmarks*) as the dependent variable, logit with a binary earmarks indicator as the dependent variable, and Poisson pseudo-maximum likelihood (PPML) with the number of earmarks as the dependent variable.[17] Table A3 of the supplementary appendix reports the corresponding estimates. In all specifications, we see a positive and (statistically and practically) significant effect of lobbying on earmarks.

5.2. Omitted Variable Bias

The OLS estimates suggest that congressional earmarking is associated with changes in the lobbying expenditures of disease advocates, even after including disease fixed effects. However, it is possible that changes in disease burden or scientific opportunity are not completely captured by our measures. Unmeasured changes in the severity of the diseases (not captured by deaths), or new scientific breakthroughs (not captured by publications), could be driving both lobbying and earmarks, and our estimates of the relationship between the two would be biased. The ideal experiment to identify lobbying's effect on earmarks would randomly assign lobbying dollars to a treatment group of diseases that are identical in every aspect to a control group and test whether lobbying increases earmarks for the treatment group. However, both our model and first set of empirical findings suggest that lobbying expenditures are not allocated randomly across diseases—in fact, measures of burden and opportunity are positively related to lobbying in the cross section of diseases. Hence, it is hard to think of a context in the sample that might approximate random assignment. Alternatively, one could either utilize quasi-natural experiments, such as exogenous changes in the political landscape that are unrelated to omitted disease-specific characteristics, or employ instrumental variables to isolate exogenous variation in lobbying to isolate its influence on earmarks. We use the former identification strategy below.

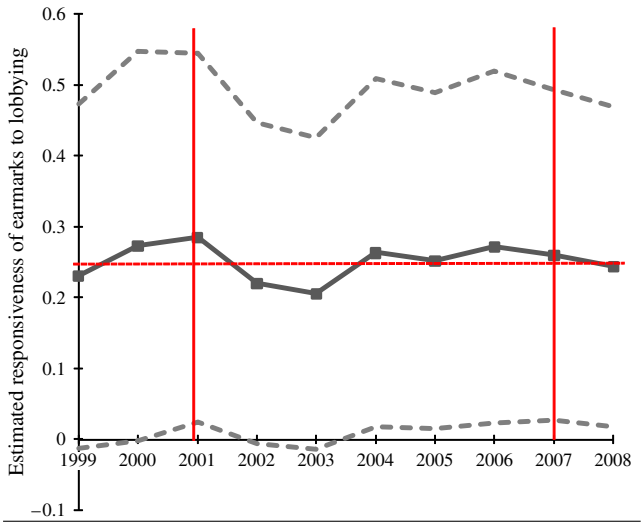
[17] Estimations of standard count models such as the Poisson or negative binomial do not converge in our sample because of a large number of zeros (in the dependent variable) and a number of dummy variables (disease fixed effects). PPML, developed by Santos Silva and Tenreyro (2010), automatically identifies and drops regressors that may cause the nonexistence of the maximum likelihood estimates and therefore solves problems of convergence encountered with the standard count model regressions.

5.2.1. Evidence from Appropriations Subcommittee Changes. We draw on institutional aspects of the U.S. Congress to assess whether the result that lobbying affects earmarks behaves as we would expect if the relationship were causal (as opposed to being driven by unobserved disease-specific factors). Accordingly, we analyze the effect of changes in the chairmanship of the LHHE subcommittee that makes appropriations to the NIH on the relationship between lobbying and earmarks. We focus on changes in chairmanship, since, as Savage (1991, p. 338) explains, "The chair's power stems from the drafting of the mark-ups [associated with appropriations to individual agencies], the timing of the release of the mark-ups to the subcommittee, and the management and control of the staff." LHHE chairmanship is determined by seniority, and changes in chairmanship result from either the incumbent's resignation (or defeat) or a change in the party controlling that branch of Congress (Cohen et al. 2011). The changes are unlikely to be related to changes in unobserved rare-disease-specific characteristics.

If the OLS estimates of the relationship between lobbying and earmarks were due to changes in omitted disease characteristics and not political influence, the estimates should not be systematically related to changes in LHHE chairmanship. If, on the other hand, the estimates capture the true influence of lobbying on earmarks, we would expect the relationship between earmarks and lobbying to be weaker in the years immediately following changes in the LHHE's chairmanship. This is because lobbyists and disease advocates cultivate connections with politicians over time, and these connections lose their value when political power changes hands (Blanes i Vidal et al. 2012). In other words, if earmarks truly respond to lobbying, we would expect to see a decrease in the responsiveness when connections between lobbyists and congressmen with the authority to earmark were disrupted.

We focus on 2001, when Ohio representative Ralph Regula replaced representative John Porter of Illinois as the chair of the House LHHE subcommittee, and Iowa congressman Tom Harkin replaced representative Arlen Specter of Pennsylvania as the chair of the Senate LHHE. We can examine the effectiveness of lobbying both committees for a reasonable span before and after the changes in 2001. Figure 1 shows that lobbying expenditures did not drop but instead increased after the change (Figure A2 of the supplementary appendix suggests that the composition of diseases that were the subject of lobbying did not change drastically in these years). This is consistent with the argument that lobbyists respond to subcommittee changes by increasing lobbying expenditures in order to cultivate the new connections necessary to eventually exert influence, even though the

Figure 3 **(Color online) Relationship Between Lobbying and Earmarking by Year**



	1999	2000	2001	2002	2003
House	Porter	Porter	Regula	Regula	Regula
Senate	Specter	Specter	Harkin	Harkin	Specter
	2004	2005	2006	2007	2008
House	Regula	Regula	Regula	Obey	Obey
Senate	Specter	Specter	Specter	Harkin	Harkin

Notes. The figure shows estimates of the responsiveness of current-year earmarks to one-year lagged lobbying expenditures by year. The dotted horizontal line represents the estimated average responsiveness across the years 1999–2008. The estimates are from the regression reported in Table A4 of the supplementary appendix. The dashed lines indicate 95% confidence intervals around the yearly estimates. The table below the graph indicates the chairmen of the House and Senate LHHE subcommittees by year. Vertical lines show years in which changes in subcommittee chairmanship occurred.

returns to lobbying may decrease after the changes (Eggers 2010).

Figure 3 plots estimates of the effect of lobbying on earmarks for each of the years during 1999–2008 obtained by interacting lobbying expenditures with indicators for each year (the regression estimates are also reported in Table A4 of the supplementary appendix). The figure shows that whereas the estimated responsiveness of earmarks with respect to lobbying is 0.28 in 2001, it drops to 0.22 and 0.20 for the two years following the 2001 changes but returns to 0.26 in 2004. The estimated elasticities for 2002 and 2003 are significantly different from the elasticities for 2001 and 2004 ($p < 0.10$).[18]

[18] Figure 3 also suggests a drop in the effects of lobbying in 2007 and 2008. Although this change is not as sharp as the one immediately after 2002, nor statistically significant, it coincides with another change in LHHE leadership: Wisconsin representative David Obey replaced Regula as the chair of the House LHHE subcommittee, and Harkin once again replaced Specter as the chair of the Senate LHHE in 2007. This drop in the effectiveness of lobbying in the years after chairmanship turnover is consistent with our argument that our estimates, in fact, represent the effect of lobbying on congressional support for diseases rather than omitted disease-specific characteristics.

5.2.2. Evidence from House and Senate Differences. According to congressional scholars (e.g., Fenno 1966), subcommittees of the Senate Appropriations Committee are more successful in influencing allocations through earmarks than their counterparts in the House. This is because the Senate subcommittees deliberate on agency appropriations after the House, and advocates approach senators if their interests have been ignored by House representatives. Also, senators serve larger constituencies (states), enjoy longer tenures, and are more accommodative of each other's interests, making it easier for them to accommodate requests for earmarks. Table A5 of the supplementary appendix supports this view in the context of earmarks for rare diseases: the Senate is nearly 1.5 times more responsive to lobbying than the House. This finding provides further confidence that the relationship documented between lobbying and soft earmarking is not spurious.

5.3. Favoring Powerful Groups or Responding to Information?

Critics of disease advocacy and earmarks implicitly view interest groups as seeking to draw funding away from diseases that impose a greater burden or are associated with greater scientific potential (e.g., Stigler 1971, Tullock 1980, Peltzman 1989, Becker 1996). But a large literature also suggests that interest groups may provide information to decision makers about the actual social benefits of different policy choices (e.g., Krehbiel 1991, Banks and Weingast 1992, Grossman and Helpman 2001).

We investigate these contrasting views about the role of interest groups in the NIH context by estimating the effect of changes in lobbying expenditures when accompanied by changes in either disease burden or scientific opportunity. Specifically, we test whether the within-disease interaction effects of lobbying expenditures and deaths, and the interaction of lobbying expenditures and publications, affect earmarks. Column 1 of Table 4 reports the corresponding estimates, which suggest that the estimated positive effect of lobbying on earmarks is positive and significant for diseases with more publications. The estimated main effect of lobbying in this model is essentially zero but is calculated for diseases with zero deaths and publications. Hence, we also estimate the effect of lobbying at more typical values of lobbying and deaths after subtracting out their respective mean values from the variables. Column 2 of Table 4 shows the corresponding result that the main effect of lobbying is positive and significant for diseases with "average" levels of deaths and publications. Thus, lobbying appears to have a significant effect on earmarking (over and above its positive interaction effect with publications) only for diseases with relatively "high" burden and opportunity.

Table 4 Interaction Effects of Lobbying on Earmarks

	DV = *Number of earmarks*	
	1	2
Log lobbying expenditures (1-year lagged)	0.039	0.157*
	[0.065]	[0.072]
Log deaths (1-year lagged)	−0.006	−0.006
	[0.040]	[0.040]
Log publications (1-year lagged)	−0.002	−0.002
	[0.028]	[0.028]
Log lobbying × *Log deaths*	0.012	0.012
	[0.028]	[0.028]
Log lobbying × *Log publications*	0.044*	0.044*
	[0.022]	[0.022]
Log NIH grants (1-year lagged)	0.001	0.001
	[0.002]	[0.002]
Constant	−0.022	−0.036
Disease fixed effects (955)	Y	Y
Year fixed effects (10)	Y	Y
Observations	9,550	9,550
Adjusted R^2	0.61	0.61

Notes. The table reports OLS estimates of the effects of lobbying expenditures (logged, and with a one-year lag) on the log of earmarks with two additional interaction terms (*lobbying* × *deaths* and *lobbying* × *publications*; interactions are also between one-year lagged variables). Column 2 presents estimates obtained at the mean values of logged deaths and logged publications. The unit of observation in the estimation sample is disease-year, and the sample has observations for 955 diseases for each year between 1998 and 2008. All SEs, in brackets, are clustered at the disease-level. DV, dependent variable.

$^{\dagger}p < 0.1$; $^{*}p < 0.05$; $^{**}p < 0.01$.

That Congress appears to respond to within-disease increases in lobbying only when accompanied by high scientific opportunity supports the view that lobbying influences congressional priority setting by providing information. This is consistent with the events described in the Rett syndrome anecdote in which the IRSA mobilized support for research on the disease following a scientific breakthrough. Taken together with our first set of results that lobbying itself responds to deaths, the results suggest that lobbying may help to provide important information about changes in burden or scientific opportunity associated with the diseases to Congress.

6. Does Politics Influence Agency Decisions?

6.1. Relationship Between Earmarks and NIH Funding

Finally, we examine the relationship between lobbying and earmarks and NIH funding for rare diseases. It is possible that soft earmarks are an inexpensive congressional response to lobbying and do not affect actual agency choices. As we note above, soft earmarks are specified in committee reports that, unlike appropriations bills, are not voted on by the full Congress and do not have the force of the law. Further, since many of them "urge" and "encourage" funding, rather than use more direct language, it is plausible that the NIH does not respond to these earmarks.[19]

In examining the effects of earmarking on funding, we focus on NIH grants for new projects, rather than grants for continuing projects that had previously received funding from the agency. Although funding for continuing projects comprises the bulk of NIH expenditures on rare diseases each year (83% of all funding over the 1998–2008 period), these continuation grants are annual disbursements for multiyear projects funded in previous years and create inertia in NIH allocation patterns. We focus on funding via new grants (accounting for about 17% of funding) since these are plausibly more responsive to changes in disease-specific attributes and earmarking.

Column 1 of Table 5 reports OLS estimates of the effects of past-year deaths and publications on current-year NIH grants for new projects (all variables are logged). The dependent variable in the regressions is NIH funding for a disease in year t. We find that a 10% increase in lagged deaths is associated with a 2.4% increase in funding and that a 10% increase in publications is associated with a 4.8% increase in funding (each of these estimates is significant at $p < 0.01$). These two variables together explain 21% of the variation in NIH funding. These results are consistent with the claim that burden and opportunity substantially affect NIH allocation decisions (Institute of Medicine 1998).

Column 2 of Table 5 shows that in the pooled cross section, earmarks and lobbying each have a significant effect on funding, after controlling for deaths and publications. Column 3 shows that when disease fixed effects are included, the effects of deaths and publications are not statistically different than zero (at $p < 0.05$). Including disease fixed effects sharply increases the explanatory power of the model, increasing the R^2 value by 47 percentage points. Unsurprisingly, across-disease variation has much more explanatory power than within-disease changes in our short panel.

Moreover, in the fixed effects models, neither lobbying nor earmarks appear to significantly predict NIH funding for new research projects overall (at the 5% level). Although this result challenges claims that private interest groups and Congress have a large impact on NIH choices (e.g., Becker 1996), it is less surprising in light of recent discussion that steering NIH research toward one disease is quite

[19] As we have already suggested, the responsiveness of agencies to soft earmarks is increasingly likely to be important even outside the NIH context, given the growth of scrutiny of hard earmarks.

Table 5 Relationship Between NIH Funding and Earmarks

	DV = *Log NIH funding*					
	1	2	3	4	5	6
	All	All	All	RFA + PA	PA	II
Earmarks (1-year lagged)		0.518**	0.055†	0.165**	0.216**	0.048
		[0.110]	[0.031]	[0.060]	[0.061]	[0.043]
Log lobbying expenditures (1-year lagged)		0.116*	−0.005	0	0.056	0.003
		[0.059]	[0.053]	[0.062]	[0.067]	[0.058]
Log deaths (1-year lagged)	0.235**	0.208**	−0.037	0.112	0.085	−0.028
	[0.043]	[0.042]	[0.077]	[0.098]	[0.073]	[0.072]
Log publications (1-year lagged)	0.478**	0.450**	0.072	0.092†	0.05	0.029
	[0.042]	[0.041]	[0.061]	[0.051]	[0.041]	[0.059]
Log NIH grants (1-year lagged)			−0.046**	−0.008	0	−0.035*
			[0.015]	[0.009]	[0.006]	[0.014]
Constant	0.215	0.207	1.838	0.353	0.323	1.727
Disease fixed effects (955)	N	N	N	Y	Y	Y
Year fixed effects (10)	N	N	Y	Y	Y	Y
Observations	9,550	9,550	9,550	9,550	9,550	9,550
Adjusted R^2	0.208	0.223	0.693	0.591	0.572	0.674

Notes. The table presents OLS estimates of the effect of past-year earmarks and logged lobbying expenditures on logged current-year NIH funding for new projects. Columns 1–3 report estimates of the effects of the explanatory variables on all new NIH grants. Column 4 reports estimates of the effects on RFAs (grants through requests for applications) and PAs (grants through program announcements). Column 5 reports the estimates for PAs, and column 6 reports on NIH allocations for unsolicited investigator-initiated (II) projects. The unit of observation in the estimation sample is disease-year, and the sample has observations for 955 diseases for each year between 1998 and 2008. All SEs, in brackets, are clustered at the disease level. DV, dependent variable.

†$p < 0.1$; *$p < 0.05$; **$p < 0.01$.

difficult (Sampat 2012, Sampat et al. 2013). We next focus on grant mechanisms that observers of the NIH and participants in the budget process suggest are more commonly used to target specific diseases: RFAs and PAs. Column 4 of Table 5 shows that one additional earmark for a disease is associated with a 17% increase in NIH funding through RFAs and PAs. Column 5 shows that one additional earmark for a disease is associated with a 22% increase in funding through PAs alone (both estimates are significant at $p < 0.05$).[20] By contrast, earmarks do not appear to have a statistically significant effect on NIH funding for investigator-initiated projects. Wald tests for differences in coefficients across regressions confirm that the estimated positive effect of earmarks on solicited grant mechanisms is statistically distinct from its estimated null effect on grants for investigator-initiated proposals (at $p < 0.06$ and $p < 0.001$ for RFA/PA and PA allocations, respectively). In addition to suggesting the mechanisms through which political influence shapes NIH allocations, these models are useful as falsification tests. If our results reflected some omitted factors other than earmarking, we would expect to see these effects for both investigator-initiated grants and RFAs/PAs. That we do not see an effect on investigator-initiated grants provides more confidence that the results for RFAs/PAs are not due to omitted variables.

[20] Grants made by the NIH through RFAs and PAs were nearly twice as large, on average, as grants for investigator-initiated projects and allocated funds for use over longer durations during the period of our study. Table A6 of the supplementary appendix provides statistics for the length and duration of awards by award type.

6.2. How Large Are the Effects of Lobbying?

The previous analyses show that the effects of lobbying on congressional soft earmarks, and earmarks on NIH allocations, are each statistically significant after controlling for unobserved disease-specific and year-specific influences. How practically significant are these effects? In other words, how many of the soft earmarks each year are related to lobbying, and how much of the NIH's funding for rare diseases is related to earmarks? Here, we provide a back-of-the-envelope estimate.

The aggregate additional soft earmarks for diseases associated with lobbying can be calculated as $\sum_i(\hat{\beta}_3 \times \ln L_{i,t-1} \times E_{i,t})$, where $\hat{\beta}_3$ is the estimated responsiveness of soft earmarks (E) to lobbying expenditures (L) obtained by estimating Equation (2). The aggregate additional NIH allocations for diseases associated with earmarking can be calculated as $\sum_i(\hat{\gamma}_4 \times \ln E_{i,t-1} \times G_{i,t})$, where $\hat{\gamma}_4$ is the estimated responsiveness of NIH grants through the RFA and PA mechanisms (G) to soft earmarks (E) obtained by estimating Equation (3).

Table 6 Estimated Effects of Lobbying and Earmarks

Year	1 Lobbying expenditures (in $ millions)	2 No. of earmarks	3 Estimated earmarks due to lobbying	4 RFA + PA allocations (in $ millions)	5 Total NIH allocations (in $ millions)	6 Estimated RFA + PA allocations due to earmarking (in $ millions)	7 Estimated NIH allocations due to earmarking (%)
1998	3.3	47					
1999	2.4	70	9.8	102.2	366.5	19.2	5.2
2000	2.6	79	16.1	86.8	367.1	18.3	5.0
2001	3.9	85	23.3	125.3	419.4	25.5	6.1
2002	4.4	42	12.3	156.4	475.6	68.3	14.4
2003	4.1	42	9.0	249.2	657.0	26.5	4.0
2004	5.9	93	46.4	185.1	537.4	14.7	2.7
2005	6.2	119	57.7	184.9	537.9	33.2	6.2
2006	5.4	140	71.6	150.8	474.6	63.6	13.4
2007	6.4	111	54.3	181.6	558.8	85.1	15.2
2008	5.4	99	50.0	164.2	572.4	60.6	10.6

Notes. The table uses the OLS estimates of the effect of lobbying on earmarks and OLS estimates of the effect of earmarks on NIH allocations for new research proposals (through RFA and PA grant mechanisms) to estimate the annual number of earmarks due to lobbying (column 3) and NIH allocations due to earmarking (columns 6 and 7). OLS estimates of the effect of lobbying on earmarks are obtained from the column 5 of Table 3 and estimates of the effect of earmarks on NIH allocations from column 4 of Table 5. Both RFA and PA allocations combined (column 4) and total NIH allocation (column 5) refer to NIH funding for new projects on rare diseases in the corresponding year.

Table 6 shows our calculations of the effect of lobbying on earmarks, and earmarks on NIH allocations, for the years 1999–2008 (we use $\hat{\beta}_3 = 0.243$ from column 5 of Table 3 and $\hat{\gamma}_4 = 0.165$ from column 4 of Table 5).[21] The numbers in columns 3 and 4 suggest that between 14% and 51% of the congressional soft earmarks each year are related to lobbying. Taken together, the numbers in columns 5 and 6 suggest that 8%–47% of the NIH's allocations through the RFA and PA mechanisms are related to earmarks. Given the small number of diseases for which advocates lobby and receive earmarks, and the dominance of grants for unsolicited investigator-initiated proposals (which are less influenced by lobbying and earmarking), the share of the NIH's overall funding for new projects on rare diseases that can be attributed to earmarking during the period of our study ranges between 3% and 15%. This calculation is rough and relies on a number of assumptions, but it provides an approximate range for the implied effects of lobbying on funding for rare diseases.

6.3. Robustness Checks

The number of deaths captures just one dimension of disease burden, and the number of publications is a noisy measure of opportunity since articles vary in their quality. To address these concerns, we first examined an alternative measure of burden: the number of annual hospital discharges associated with the diseases in our study. This is a cost-weighted measure of prevalence and captures morbidity associated with debilitating but nonfatal diseases. The data were obtained from the Healthcare Cost and Utilization Project (HCUP) of the Agency for Healthcare Research and Quality (AHRQ).[22] Second, we refined the scientific opportunity measure by weighting the publications by journal impact factors (JIFs) for the journals in which they appeared; i.e., articles published in top-tier journals such as *Science* and *Nature* are weighted more heavily than those published in lower-tier journals. Third, rather than one-year-lagged publications, we constructed five-year stocks of publications. The results obtained by using these alternative measures (displayed in Tables A7, A8, and A9 of the supplementary appendix) are qualitatively comparable to the main estimates we have reported here.

The Rett syndrome story, related in §2, might suggest that rather than the lobbying expenditures of interest groups, celebrity advocacy for a certain disease is another influence on congressional attention and earmarking toward that disease. For each disease, we searched for media reports (on Factiva) about a celebrity's advocacy for the disease, disclosure of a celebrity's affliction, or death of a celebrity or a close relative from the disease. We were able to identify nine diseases in our sample associated with significant celebrity-related events during the period of our

[21] Because 1998 is the first year for which we have data on lobbying expenditures, we are able to obtain estimates of the effect of lobbying on earmarks and earmarks on NIH funding starting in 1999.

[22] We collected information on all hospital discharges for each disease from the Nationwide Inpatient Sample (NIS) database, which was developed through the HCUP. The NIS data are aggregated at the ICD-9 year level and available at http://www.healthdata.gov/data/dataset/hcup-nationwide-inpatient-sample-nis (accessed January 1, 2013). We created a concordance from our 955 diseases to ICD-9, using disease names and synonyms. Of our 955 diseases, 593 reliably map to an ICD-9 code. With this concordance, we compiled information from HCUP on all discharges by disease for the diseases in our sample. The diseases without an ICD-9 code have discharges of zero for all years and drop out of the models with fixed effects.

study. We estimated the models in Tables 2, 3, and 5 after including a dummy variable to indicate diseases in the years immediately following the celebrity events. The results (not reported) suggest that controlling for celebrity involvement with a disease does not significantly affect our main findings.

7. Conclusion

Many federal agencies, particularly those in charge of publicly funded research in the United States, employ their own procedures for allocation decisions. The view that allocation decisions at such agencies (e.g., the NIH) are made purely on the basis of technical merit of the proposed research, and with very little political oversight, is widespread. Yet special interest groups frequently lobby Congress to fund their "pet" research projects. The large amount of resources invested in advocacy by interest groups naturally raises the question, can they obtain their desired allocations when agency experts are primarily responsible for the allocations? This question is of historical significance in U.S. science policy: at the end of World War II, Director of the U.S. Office of Scientific Research and Development Vannevar Bush argued that scientific agencies should be insulated from patronage politics and advocated peer review as a process for achieving the insulation (Kevles 1977). And, in the NIH's case, tension between the scientific and political allocation processes intensified in the 1990s as disease advocates attempted to obtain congressional support for research on particular diseases, bypassing the peer review process at the NIH. Although this advocacy has generated controversy, its effects on agency allocations have not been systematically investigated. Previous work has also puzzled over the mechanisms through which advocacy could influence a seemingly independent agency where most funding is awarded through peer review (Hegde 2009, Best 2012, Sampat 2012).

Our study suggests that disease interest group lobbying affects congressional soft earmarking and NIH allocations through special grant mechanisms that respond positively to these earmarks. We also find that lobbying itself responds to increases in disease burden, and the effect of lobbying on earmarks is most pronounced when accompanied by increases in scientific opportunity associated with the diseases. Although we do find an effect of earmarks on NIH funding, our rough calculations suggest that no more than 3%–15% of the NIH's allocations for rare diseases are influenced through advocacy-related political activity. Thus, although the NIH may not be completely insulated from politics—there are mechanisms for advocacy to have real effects on its allocations—concerns that disease advocacy has a large distortionary effect on public biomedical research funding in the United States may be overstated.

Our study also informs the emerging literature on nonmarket strategy that considers how special interest groups can obtain private benefits by influencing public policy. We uncover the importance of a subtle mechanism through which political influence flows—congressional soft earmarking. Soft earmarks may become increasingly more important for interest groups (beyond disease advocates) with the recent moratorium on congressional hard earmarks, and their effects on decision making may be amplified at agencies that historically have been less insulated from politics than the NIH.

Theories of interest group influence have debated whether politicians in committees favor powerful interest groups at the cost of the larger public or instead gather information from lobbying groups to make better decisions. Our findings lend some support to the latter view. Thus, interest group lobbying and congressional oversight may be complements to, rather than substitutes for, agency attempts to allocate funding based on scientific opportunity and disease burden. Although the lobbyists in our context are primarily nonprofit entities, the insights from our study also apply to profit-seeking corporations that lobby for policies that favor them over competing interests.

Supplemental Material

Supplemental material to this paper is available at http://dx.doi.org/10.1287/mnsc.2014.2107.

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