DISEASE ON THE HILL: PATIENT ADVOCACY GROUPS AND THEIR LOBBYING EFFORTS

by
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A thesis submitted to Johns Hopkins University in conformity with the requirements for the degree of Master of Arts in Government

Baltimore, Maryland
August, 2015

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Health and medicine are some of the most complex issues that Congress faces, especially since currently only 17 of 535 members of Congress have a medical degree. At the same time, however, members of Congress are themselves patients or have friends and family members who are patients, which gives them a personal interest in health care. Furthermore, members of Congress know that their constituents (and voters) are patients or the friends and family members of patients, so they also have an electoral reason to understand and support these issues. In this thesis, I explain how patient groups educate Congress about their disease using three main tactics: coalitions with other disease groups, appropriations report language, and celebrity testimony. These efforts, and Congress’ resulting support for the patient group and the disease, can affect the American public by leading to additional research, treatments, and hopefully cures for some of our country’s most pressing health problems.

Readers: Jacob Straus and Kathy Wagner Hill

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Lobbying by Colorectal and Lung Cancer Advocates in 2012
INTRODUCTION
TOO BIG TO IGNORE

In today’s political environment, where the issues are very complex and Congress has less time, less staff and less funds, interest groups play an increasingly important role in providing Congress with information. As Hall and Deardoff argue, these lobbying groups “freely but selectively provide labor, policy information, and political intelligence to likeminded and resource-constrained legislators.”¹ This legislative subsidy is particularly helpful for scientific and medical issues. These are some of the most complex issues that Congress faces, especially since only 17 of 535 members of Congress have a medical degree.²

At the same time, however, members of Congress are themselves patients or have friends and family members who are patients, so they find this information valuable. Furthermore, the member of Congress knows that his constituents (and voters) are patients or the friends and family members of patients, so they have an electoral reason to understand and support these issues. They also recognize that illness affects the society as a whole because of the economic costs of caring for the ill and the burden of lost wages and productivity.³ This means, “in other words, [that] diseases garner attention in the public arena precisely because they have real consequences for individuals and for

¹ Richard L. Hall and Alan V. Deardoff, “Lobbying as Legislative Subsidy,” The American Political Science Review 100, no.1 (February 2006): 75.
This thesis will explain that patient groups draw the attention of members of Congress by using three tactics to explain to members of Congress how the disease affects individuals and the society as a whole. Those three lobbying tactics include: forming coalitions with other disease groups, advocating for appropriations report language, and having celebrities testify before Congress.

Who are Patient Advocates and Why Study Them?

Patient advocates are “activists speaking for people with a particular disease or injury.” These advocates work with patient advocacy groups, which are “any group organized around a particular disease, health impairment, or disability that allows those with the disease to join as members or to engage in the organization’s activities by volunteering for the organization.” Maureen Casamayou defines the work of patient advocacy groups as collective entrepreneurism, which is “an effort at political mobilization by a group of risk takers...who had vision and initiative and who sacrificed their time and energy to form an organization.” This mobilization process is important to study because these groups (unlike occupational-based groups that represent doctors and researchers or industry-based groups that represent health care businesses) enable patients to join the organizations and advocate for themselves and their interests. The patients’

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8 Keller and Packel, “Going for the Cure,” 332.
proxies (including their family members and doctors) are also part of the organization,\textsuperscript{9} but patients are the core. Also, as Rachel Grob explores, some of the patients not only become members of the organizations, but high-profile leaders of them.\textsuperscript{10}

The number of patient groups grew from less than 400 in 1991 to more than 1,000 in 2003.\textsuperscript{11} These groups have been successful in mobilizing patients and their caregivers to such an extent that they are now “too big to ignore…and have grown apace in numbers and scale…They employ many thousands of staff, and their combined memberships run into the millions.”\textsuperscript{12} Their lobbying activities have also grown, with expenditures rising from less than $0.5 million in 1991 to $2.5 million in 2003.\textsuperscript{13} Rachel Kahn Best finds that every $1,000 spent by patient groups on lobbying results in a $25,000 increase in research funds for the disease.\textsuperscript{14} This increase in funds is possible because the groups’ lobbying efforts have encouraged Congress to think of patients (and not doctors, researchers, or businesses) as the beneficiaries of research funds.\textsuperscript{15} Patient advocacy group lobbying has therefore had a large impact, and their influence continues to grow.

This study of patient advocacy groups is critically important because the work of patient advocacy groups affects everyone. Medical research is one of the few bipartisan and bicameral issues in Congress because as Representative Cathy McMorris Rodgers

\textsuperscript{9} Nancy Tomes and Beatrix Hoffman, introduction to \textit{Patients as Policy Actors}, ed. Hoffman et al. (New Brunswick: Rutgers University Press), 5.
\textsuperscript{13} Kahn Best, “Disease Politics and Medical Research Funding,” 781.
\textsuperscript{14} Ibid., 787.
\textsuperscript{15} Ibid., 784.
(R-Washington) explains, “this goal is not political or partisan. It is personal.”16 Almost every American will be a patient or the friend or family member of a patient (or both) at some point in their life. Even if the patient is not a dues-paying member of that group, the lobbying activities of that group can affect the patient by resulting in more research on that disease or in Medicare coverage of the patient’s medication.

Members of Congress themselves-most of who are older and prone to diseases affecting the elderly-can have a personal interest in the group. This was the situation that Senator Edward Kennedy (D-MA) faced when he was diagnosed with (and ultimately died from) a brain tumor. Or, sometimes, the members of Congress’ friends and family members are the ones who are the patient. Senator Mark Warner (D-VA)’s mother died of Alzheimer’s, which inspired his work on the Bipartisan Congressional Task force on Alzheimer’s disease.17 Their staff members’ families could also face this situation, as Steven Brill explains when he tells the story of the staffer largely responsible for writing the Affordable Care Act. That staffer’s mother was not been able to get health insurance due to a preexisting condition, a situation which led to provisions in the act that did not allow insurance companies to exclude people for having those conditions.18

Even if the disease does not personally affect the Congressman or his staff, they realize the importance of these issues to their constituents. For example, Rep. Elsie Stefanik knows that “whether it is a child caring for an elderly parent who is suffering, a spouse receiving disheartening news about the health of their loved one, or a parent

tearfully listening to devastating news about their child’s diagnosis, every single family in our district has faced health challenges.” This realization about every family in every Congressional district has made patient advocacy groups very successful in their lobbying efforts. As Congressman Fred Upton (R-Michigan) the Chairman of the Congressional Committee responsible for setting medical research policy, said, “We have all said too many early good-byes to the people we love and treasure. Every single person has a common goal: we want more time with those we love.”

Congressman Upton was talking about every single one of his constituents, as well as the constituents of his fellow members of Congress, all of whom are being lobbied by patient advocacy groups. For example, two young girls from his district who suffer from a genetic disease called Spinal Muscular Atrophy (SMA) influenced Congressman Upton’s work on the 21st Century Cures Act. The SMA group educated the Congressman on the disease and honored him at their Congressional events. By doing so, they inspired Rep. Upton to introduce legislation that would “accelerate the discovery, development, and delivery of promising new treatments and cures for patients.” In order to fully understand how the SMA group and other patient groups were able to influence Congressman Upton, it is first necessary to look at the theoretical frameworks of interest groups.

*Theoretical Frameworks*

Theorists trace the growth of interest groups in the 1960s to the “Great Society” initiatives of the same time period. Interest groups were formed in response to the growth of these programs and helped to ensure that these initiatives would continue.\textsuperscript{23} Scholars who agree with this view also believe in the pluralist theory of interest group formation, which says that these groups form from “elements of society [that] possess common needs and share a group identity or consciousness.”\textsuperscript{24} Patients possess those common needs (they need effective treatments and cures) and identity (they identify as a person with AIDS, or breast cancer, or a rare disease). Mancur Olson challenged the pluralists by identifying the collective action problem, whereby “the rational individual in the large group in a socio-political context will not be willing to make any sacrifice to achieve the objectives he shares with others.”\textsuperscript{25} In other words, individuals will not be willing to sacrifice their time and money to participate in an interest group if they are confident that others will do so for them. However, as will be explored in this thesis, patient groups are able to overcome this problem by providing people with solidarity benefits (partnerships with other patients like them) and purposive benefits (joint advocacy efforts with those other patients). The current literature fails to fully examine how patient advocacy groups overcome the collective action problem and succeed in their efforts.

\textit{A Review of the Literature}

The literature generally falls into three main categories, all of which have their limitations and fail to fully capture the impact of patient advocacy. These categories

\textsuperscript{24}Ibid., 8.
include: 1) literature that does not recognize the impact of patient groups and instead concentrates mainly on other health care groups, including those representing doctors, pharmaceutical companies, or insurance companies, 2) literature that discusses patient advocacy groups from a non-political science perspective and does not look closely enough at the groups’ advocacy efforts on Capitol Hill, 3) literature that focuses on case studies of single disease groups, especially HIV/AIDS and breast cancer.

Rebecca Dresser argues that “research advocacy...brings interest group politics to biomedical research policy.” However, this perspective has often been missing in the literature, and “general texts on groups rarely mention patients’ associations, even in passing.” Jeffrey Berry’s overview of interest groups makes a common error: even as he breaks from the traditional scholarship in acknowledging the growth of citizen groups as opposed to corporate lobbies, he fails to mention patient advocacy groups as one of those citizen groups. Furthermore, his discussion of the reform of the Food and Drug Administration (FDA) drug approval process fails to mention the recipients of those drugs: the patients. Similarly, even as Gary Andres emphasizes that “health care lobbying is a valuable prism through which to view strategic choices in advocacy,” he mainly looks at groups representing hospitals and health insurance companies.

Additionally, Anthony Nownes discusses health care reform in great detail, but does not include patient groups in that discussion. Jacob Hacker also discusses health care reform, insurance coverage, and Medicare and Medicaid, but does not mention if patient

26 Dresser, When Science Offers Salvation, 7.
groups have been involved in the debates over these issues.\textsuperscript{32} He is therefore following the lead of many other writers in not mentioning patient organizations. This scholarship argues that “the only organizations that are capable of marshaling the resources to do [lobbying] effectively are business organizations.”\textsuperscript{33} However, this is flawed. Congress may view “disease advocates more favorably than other lobbyists because disease advocates do not directly profit from medical research expenditures,”\textsuperscript{34} unlike doctors, pharmaceutical companies, or insurance companies. Patient groups have found ways to lobby and gain a great deal of influence within their specialized niche, and those three ways will be outlined throughout this thesis.

Even when scholars do mention patient groups, this attention is not universal across all fields. Unfortunately, “disease-related patients’ associations have received particularly scant attention from political scientists.”\textsuperscript{35} Instead, these groups have been studied by other social scientists, including sociologists (who focus on the groups’ patient support role) and social change scholars (who focus on how the groups have historically built social movements). For example, sociologist Steven Epstein places the study of patient groups within the larger field of science and technology studies (STS),\textsuperscript{36} and argues that STS scholars can influence other fields (but does not mention political science as one of those fields).\textsuperscript{37} Similarly, Rachel Kahn Best looks at how patient advocates have worked to change the political landscape, but does so from a social movement

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\textsuperscript{34} Kahn Best, “Disease Politics and Medical Research Funding,” 794.
\textsuperscript{35} Wood, \textit{Patient Power?}, 8.
\textsuperscript{37} Ibid., 504.
\end{flushright}
perspective.\textsuperscript{38} As Jeffrey Berry argues, this perspective is flawed because while “these movements had their origins in challenges to the political system…most of them quickly passed from the stage of representing marginalized interests and became full and conventional participants in the policymaking process.”\textsuperscript{39} The social change literature plays an important role in understanding how and why these groups form, and one cannot evaluate the lobbying activities of the groups without first understanding this literature. However, the political science literature’s failure to fully investigate patient groups’ work on Capitol Hill is problematic because increased governmental attention to disease is a major reason why these groups continue to be active. The literature must therefore reflect their participation in the political process.

Patient groups have been active in the political process since the 1940s (when the March of Dimes and the American Cancer Society were prominent),\textsuperscript{40} but these organizations really started to grow in number in the late 1960s and 1970s. The groups that formed in the ‘60s and ‘70s were unique because “they construct[ed] identities in relation to particular disease categories and assert[ed] political and scientific claims on the basis of these new identities.”\textsuperscript{41} At that time, the “upsurge of health-and disease-based organizing reflects the prevalence…of more skeptical attitudes toward doctors, scientists, and other experts.”\textsuperscript{42} Those skeptical attitudes emerged because as the “Civil Rights movement and other movements for self-determination broadened, the assault on medical paternalism gained momentum.”\textsuperscript{43} A prominent strain of thought in the literature draws on

\textsuperscript{38} Kahn Best, “Disease Politics and Medical Research Funding,” 795.
\textsuperscript{39} Berry, \textit{The New Liberalism}, 42.
\textsuperscript{40} Epstein, “Patient Groups and Health Movements,” 500.
\textsuperscript{41} Steven Epstein, \textit{Impure Science: AIDS, Activism, and the Politics of Knowledge} (Berkeley: University of California Press, 1995), 347.
\textsuperscript{42} Epstein, “Patient Groups and Health Movements,” 500.
\textsuperscript{43} Tomes and Hoffman, introduction to \textit{Patients as Policy Actors}, 11.
those movements to study organizations dealing with HIV/AIDS and breast cancer. As will be explored below, the HIV/AIDS groups framed that disease as a gay rights issue, while the breast cancer groups viewed that cancer as a feminist issue.

The HIV/AIDS organizations worked to turn private issues-sexuality and disease-into public problems. To do this, the HIV/AIDS movement “capitalize[d] on a well-organized and active membership to make successful policy demands on various actors and organizations in the federal government.”44 This membership was unique because the HIV/AIDS epidemic was “the first social movement in the United States to accomplish the large-scale conversion of disease victims into activist-experts.”45 These activist-experts disproportionately came from groups stigmatized by the rest of society, especially gay men.46 These activists were able to successfully challenge the FDA by smuggling in medicines from Mexico and Asia that were not approved for use in the United States.47 The advocates also “clamored for entry into clinical trials, insisting, in the process, on their right to serve as guinea pigs.”48 These trials-and the guinea pig patients- did lead to the development of antiviral HIV/AIDS medicines. Furthermore, the HIV/AIDS activists achieved a legislative victory with the Ryan White CARE Act, which has become “the centerpiece of the federal government’s efforts to improve the quality and availability of care for medically underserved individuals and families affected by HIV/AIDS.”49 These

44 Keller and Packel, “Going for the Cure,” 333.
45 Epstein, Impure Science, 8.
successes have been well studied by Steven Epstein, Randy Shilts,\textsuperscript{50} Patricia Siplon, and Jonathan Kwitny. These scholars then often generalize from HIV/AIDS to the breast cancer movement.

Women with breast cancer framed that disease as a problem that needed attention from members of Congress through the appropriation of increased funding for research.\textsuperscript{51} Steven Epstein traces the literature’s focus on that disease to “the distinctive impact of feminist theory and politics on several generations of STS [science and technology studies] researchers.”\textsuperscript{52} This literature argues that the breast cancer movement was successful because these advocates “were of a generation that experienced a greater political presence for women. They also lived with a new set of cultural mores that placed greater emphasis on the quality of living. Moreover, the sexual revolution of the 1960s, the increased health consciousness of Americans in the 1980s, and general increases in societal enlightenment about matters of this sort...worked together to diminish any taboos against publicly discussing the disease.”\textsuperscript{53} These patients were successful in diminishing the taboos to such an extent that the ‘pink ribbon’ symbolizing breast cancer is now used to market everything from yogurt to watches.\textsuperscript{54} The grassroots activism of the breast cancer advocates also succeeded in getting rid of the taboo of discussing the disease on Capitol Hill. This resulted in increased funding for breast cancer research at the National Institutes of Health (NIH) and the Department of Defense (DoD).\textsuperscript{55}

\textsuperscript{50} Randy Shilts, \textit{And the Band Played on: Politics, People, and the AIDS Epidemic} (New York: St. Martin’s Press, 1987).
\textsuperscript{52} Epstein, “Patient Groups and Health Movements,” 504.
\textsuperscript{55} Susan Halebsky Dimock, “Demanding Disease Dollars: How Activism and Institutions Shape Medical Research Funding for Breast and Prostate Cancer,” (Ph.D. diss., University of California, San Diego, 2003), ix-x.
Like the above examples on HIV/AIDS and breast cancer, the literature on patient groups mostly focuses on case studies of single groups.\textsuperscript{56} This means that “most social science research on the process of allocating attention to disease has focused on a single disease at a particular point in time.”\textsuperscript{57} By failing to explore multiple groups these scholars “neither document advocacy’s effects by statistically comparing outcomes across diseases nor observe the overall effects of the increase in disease advocacy.”\textsuperscript{58} This means that the literature on single disease groups fail to fully capture the impact of patient advocacy.

Smaller groups that do not focus on HIV/AIDS or breast cancer are often referred to in the literature as ‘kitchen table groups.’\textsuperscript{59} These organizations represent patients with rare diseases and are started by the patient or his or her family member (usually someone without previous experience in medicine or advocacy). That term implies that the groups’ small size is a disadvantage. However, “small size alone does not mean failure. Indeed, small groups may enjoy maintenance advantages over large ones.”\textsuperscript{60} This is illustrated by the groups that celebrate their founding status as a kitchen table group.\textsuperscript{61} Furthermore, the Internet has enabled kitchen groups to grow their influence.


\textsuperscript{57} Armstrong, Carpenter, and Hojnacki, “Whose Deaths Matter?” 730.

\textsuperscript{58} Kahn Best, “Disease Politics and Medical Research Funding,” 781.

\textsuperscript{59} Mary Dunkle, “A 30-Year Retrospective: National Organization for Rare Disorders, the Orphan Drug Act, and the Role of Rare Disease Patient Advocacy Groups,” \textit{Orphan Drugs: Research and Reviews} 4 (February 17, 2014): 19.

\textsuperscript{60} Foreman, “Grassroots Victim Organizations,” 46.

Patient groups “exist in large numbers on the Internet, combining mass communication with what is generally a small-group phenomenon.”62 The Pew Internet Project found that 18% of all Internet users went online to find other people with the same disease.63 This phenomenon has enabled even patients with extremely rare diseases to find one another all across the country and the world.64 As one mother said, “when a disease is so rare and there are no folks in your town, and few in your state, who are going through what you are going through, you need a support group that encompasses people from all over the world.”65 The Internet gives patients the ability to form that worldwide support group. The groups’ Internet pages and social media feeds enable their members to share information with one another, as well as educate others about the disease. As a result, “the birth and development of the Internet is another crucial background condition that explains much about how and why patient groups and health movements have taken particular forms in recent years.”66 The Internet has been especially successful in enabling these groups to engage in grassroots lobbying.

Patient advocacy groups participate in grassroots lobbying “to do one or both of the following: 1) to influence people’s opinions and 2) to encourage people to contact policymakers and make their opinions known.”67 Edward Walker argues that the first goal

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66 Epstein, “Patient Groups and Health Movements,” 514.
has become increasingly commercialized and professionalized as organizations turn to paid consultants to mobilize the public.\textsuperscript{68} For example, the Lung Cancer Alliance contracted with an ad agency to design a public advertising campaign that had the slogan certain people (hipsters, cat lovers, and others) ‘deserve to die.’ These satirical ads got the public’s attention (and the attention of the news media). People then went to the Alliance’s website (or listened to the local news broadcast) and learned about the true message of the campaign-no one deserves to die, not even people who get lung cancer as a result of smoking.\textsuperscript{69} However, as will be explained in Chapter 1 of this thesis, the Lung Cancer Alliance also used other (less commercialized) forms of grassroots advocacy, including emails from patients to their members of Congress and grassroots lobby days on Capitol Hill. These grassroots advocates are found through the Internet, social media, and patient hotlines-not the professional firms discussed in Edward Walker’s book.

\textit{Outline of Thesis}

This thesis will explain why patient groups have evolved into a powerful lobbying force. The first chapter is a comparative case study of two different types of patient groups, lung and colorectal, and finds that the key difference between the two groups’ advocacy efforts is the lung cancer community’s alliance with another disease (pancreatic cancer). The second chapter looks at a broader range of disease groups and argues that these organizations advocate for appropriations report language to influence the NIH’s research on their disease. This language then becomes a ‘soft earmark’ for the patient group. The third and final chapter looks at celebrity testimony before Congress, and


finds that the testimony can lead to governmental support of the patient advocacy group working with the celebrity.
CHAPTER 1
CANCER, COALITIONS, AND CONGRESS

In this chapter, I undertake a comparative case study of patient groups working on two different types of cancer-colorectal and lung-in order to better understand how those organizations advocated for Congressional support of cancer-related legislation. As Chubin and Struder argue, “cancer, of course, is much more than an area of scientific research; it is a highly visible symbol and thus peculiarly vulnerable to political abuse.”\(^70\)

Not all types of cancer receive the same level of visibility and political attention. To determine why, this study will look at the strategies that the lung and colorectal cancer groups used during 2012 in order to advance their goals on Capitol Hill. Identifying these strategies will allow for a comparison as to why the advocates working on lung cancer were successful in their efforts to get legislation signed into law while the colorectal cancer advocates were not. This comparison will find that the varying levels of success were due to the legislative alliance that the lung cancer group built with the pancreatic cancer community, which in turn allowed the lung cancer advocates to gain additional Congressional supporters and overcome the stigma of their disease.

*The Theoretical Frameworks of Interest Group Coalitions*

Kevin Hula believes that different groups belonging to the same coalition are similar to one another,\(^71\) while another school of thought thinks that there are often large differences between the groups that can lead to the strange-bedfellow problem.\(^72\)

Depending on the analysis, these differences can inhibit the groups from effectively

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\(^{72}\) Berry, *The Interest Group Society*, 190-192.
framing their policy agenda,\textsuperscript{73} or they can raise the comfort levels of lawmakers by joining together groups that lawmakers are familiar with groups that they do not know.\textsuperscript{74} Coalitions also enable members of Congress to avoid having to make hard choices between groups—if two groups are working together as part of the same coalition, then a member of Congress can support both groups at the same time.\textsuperscript{75} This chapter will argue that it was this last characteristic of coalitions that enabled the lung and pancreatic cancer coalition to succeed. Even though the two diseases have very different biologic characteristics (and different levels of stigma) they share a high mortality rate, a fact that the advocacy groups emphasized in their lobbying efforts. Members of Congress did not want to have to make a hard choice between two types of dying patients, so they supported legislation that would assist both.

As explained in the introduction to this thesis, members of Congress often have an interest in patient advocacy because of their experiences or their friends and family members’ experiences. However, different members of Congress have interests in different diseases. Additionally, advocates face time constraints that make it difficult for them to meet with every Congressional office, even though their goal is to reach all of these offices and convince them to support the patients’ goals. Coalitions give patients that opportunity, and “a hallmark of coalition strategies is that membership enables the workload to be spread out.”\textsuperscript{76} These coalitions are attractive to patient advocacy groups because they enable them to share their resources, expand their expertise, and add

\textsuperscript{75} Hula, \textit{Lobbying Together}, 28.
\textsuperscript{76} Hula, \textit{Lobbying Together}, 27.
credibility to their lobbying campaigns.\textsuperscript{77} This was the case for the pancreatic and lung cancer communities. Lawmakers like Senator Sheldon Whitehouse (D-RI), \textsuperscript{78} Representative Anna Eshoo (D-CA),\textsuperscript{79} and Representative Frank Pallone (D-NJ)\textsuperscript{80} who were familiar with and supportive of research for pancreatic cancer (because a family member or close friend had that disease) then learned more about lung cancer through the efforts of the coalition.

\textit{Definitions}

Jeffrey Berry defines a successful coalition as one that has several factors, including: 1) the coalition is temporary, 2) is limited to one specific issue, 3) the issue has some immediacy and has good chance of government action, 4) the coalition is run informally, and the lobbying is done by the coalition members’ staff rather than a separate coalition-only staff, 5) the coalition members are part of the same issue network and have experience working together, 6) the coalition members take turns being in the leadership, and 7) the coalition will not become so visible that any lobbying success will be attributed to the coalition rather than to the individual members.\textsuperscript{81} The coalition between the lung and pancreatic cancer communities had those qualities. However, Godwin, Ainsworth, and Godwin term ad hoc efforts without a dedicated staff or office space (which the lung and pancreatic alliance did not have) as ‘cooperative lobbying

\textsuperscript{77} Berry, \textit{The Interest Group Society}, 188.
\textsuperscript{78} Sheila Ross, interview by author, Washington, DC, March 27, 2013.
\textsuperscript{80} House Committee on Energy and Commerce, \textit{Markup of HR 1206, HR 6118, HR 1063, HR 6163, HR 4124, and HR 733}, 112th Cong., 2d sess., 2012, 60.
\textsuperscript{81} Berry, \textit{The Interest Group Society}, 193-194.
efforts’ rather than coalitions. This chapter will use the term coalition as that was the term used by the pancreatic and lung cancer groups themselves.

The Method of Analysis

The colon cancer groups mentioned in this study were chosen because they are involved in Capitol Hill advocacy. Although Fight Colorectal Cancer takes the lead on advocacy, the Colon Cancer Alliance also attends Fight Colorectal Cancer’s events on Capitol Hill. Despite their names, the Colon Cancer Alliance and Fight Colorectal Cancer both work on colon and rectal cancer, and the screening test for both diseases is the same (colonoscopy). In addition, colon and rectal cancers have a very similar genetic basis. This study therefore groups colon and rectal cancer advocates together, since that is also how they organize and view themselves.

The chapter also analyzes the Lung Cancer Alliance’s efforts because it is the first and only lung cancer group to focus on advocacy. The other lung cancer groups mostly work on fundraising, and the patients who join the Lung Cancer Alliance are interested in Capitol Hill advocacy.

As a comparative case study, this work examines the differences between the lobbying efforts of two patient communities (lung and colorectal cancer) during the same time period (2012). Steven Epstein agrees that, when it comes to patient advocacy

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84 Carlea Bauman, interview by author, Alexandria, Virginia, April 2, 2013.
86 Bauman, interview.
87 Ross, interview.
88 Cecilia Izzo, personal communication to author, April 22, 2013.
groups, “many of the questions....could best be answered by close comparative analysis.”\textsuperscript{89} Using what Tarrow terms a most-similar analysis,\textsuperscript{90} the similarities between the two groups are the control, while the key difference is the alliance that the lung cancer group formed with the pancreatic cancer community. This alliance led to joint efforts by the two communities on behalf of the Recalcitrant Cancer Research Act, which authorized research on both lung and pancreatic cancer, and was signed into law as part of the Defense Authorization Act. The colorectal cancer community did not form an alliance with another disease on their goal of removing barriers to cancer screening (though they formed alliances on other issues). This difference is what accounts for their failure in 2012 to achieve their goal of removing barriers to colorectal cancer screening.

The primary method of analysis for this study is interviews with advocates who lobby on Capitol Hill on behalf of lung and colorectal cancer patients. These interviews took place in March and April of 2013 because at that time the events of 2012 were still fresh in the advocates’ minds. To make the advocates as comfortable as possible, the interviews were held at their offices or at a location nearby. If the advocate was unable to participate in an in-person interview, then it was done by phone or email. The conversations were unstructured and lasted about an hour each. Although the interviews were unstructured, they covered several general topics including: 1) background on the organization, 2) background on the advocate’s interest in the disease and how they got involved in the organization, 3) the history of the organization’s lobbying efforts on Capitol Hill, 4) the organization’s involvement in coalitions, and 5) the organization’s victories on Capitol Hill and the method by which they were achieved.

\textsuperscript{89} Epstein, “Patient Groups and Health Movements,” 525.
The study also looked at primary source documents. These documents included materials published and distributed by the patient advocacy groups, such as websites, brochures, newsletters, and legislative action alerts. In addition, I examined transcripts of Congressional hearings and markups, as well as press releases, speeches, and Congressional Record statements by members of Congress. These primary sources helped to verify the information gathered from the interviews. The materials published by the groups provided additional background on their advocacy tactics and strategies, while the Congressional documents helped to reveal why those advocates were effective.

Results of the Comparative Case Study

Table 1: Lobbying by Colorectal and Lung Cancer Advocates in 2012

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<th>Colorectal Cancer Advocates</th>
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<td>Background Characteristics</td>
<td>Stigma associated with disease</td>
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<td>Yes</td>
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<td>Cancer screening is an effective way of finding the disease early before it spreads</td>
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<td>Asked their grassroots networks of patients to contact Congress in support of their lobbying efforts</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>Used professional lobbyists to educate and meet with Congressional offices</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>
Table 1

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Colorectal Cancer Advocates</th>
<th>Lung Cancer Advocates</th>
</tr>
</thead>
<tbody>
<tr>
<td>Formed a coalition with another disease group to advocate for legislation that crossed disease boundaries and was research-focused instead of screening-focused</td>
<td>No</td>
<td>Yes</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Colorectal Cancer Advocates</th>
<th>Lung Cancer Advocates</th>
</tr>
</thead>
<tbody>
<tr>
<td>In 2012, legislative priorities were included in legislation that was passed by Congress and signed into law by the President</td>
<td>No</td>
<td>Yes</td>
</tr>
</tbody>
</table>

The above table shows that, despite the many similarities between the colorectal and lung cancer advocates, the key difference between their outcomes was whether or not they worked with other disease groups to support research-oriented legislation.

Background Characteristics

As seen in Table 1, there are several similarities between the lung and colorectal cancer communities. This section of the chapter will go through those characteristics and explain how they allow for a comparative case study of the final outcome.

Both diseases face a stigma. For colorectal cancer, this is due to the disease’s location in the body, as well as its invasive screening tests.\(^\text{91}\) As Congressman Donald M. Payne, Jr. (D-New Jersey) noted, “There is a stigma around colorectal cancer screenings as many people tell me the process is too invasive...but my response to them is be a man. Get tested.”\(^\text{92}\) Similarly, lung cancer patient advocates often face a stigma because of the

\(^{91}\) Crawford Clay, interview by author, Washington, DC, March 27, 2013.
connection between smoking and the disease.\textsuperscript{93} This study examines how the lung cancer community was able to overcome the stigma of their disease and convince Congress to support research on its disease, much as the HIV/AIDS groups had done two decades earlier. This study therefore extends the work done by sociologist Rachel Kahn Best, who wrote before the Recalcitrant Cancer Research Act was passed, and who argues that lung cancer received less funding as a result of its stigma and association to smoking. Kahn Best acknowledges that “the history of AIDS activism reveals complexities in the relationship between disease advocacy and stigma,” but fails to see how the lung cancer community learned from those groups’ example.\textsuperscript{94}

Although colorectal and lung cancer are very different diseases, the groups’ similar focus on screening as a means of catching the disease early allows for a good comparison of their advocacy efforts on this subject. For example, Medicare coverage for colonoscopies is a major focus of colorectal cancer advocacy on Capitol Hill. Screening is also important to lung cancer advocates, especially after the National Lung Screening Trial (NLST) found a 15 to 20\% decline in lung cancer deaths among current or former heavy smokers who were screened through the use of CT scans versus X-rays.\textsuperscript{95}

The lung and colorectal groups were both started and led by survivors of the disease. Even if one of the group’s staff members is not a survivor themselves, they emphasized their friends or family members’ connections to the disease.\textsuperscript{96} These staffers in turn encouraged other patients to become involved in grassroots advocacy, which can be difficult to do because dead or dying patients often lack the energy to become

\textsuperscript{93} Ross, interview.  
\textsuperscript{94} Kahn Best, “Disease Politics and Medical Research Funding.” 793.  
\textsuperscript{95} National Cancer Institute, “National Lung Screening Trial,” \url{http://www.cancer.gov/types/lung/research/nlst} (accessed July 20, 2015).  
\textsuperscript{96} Bauman, interview.
involved in advocacy. However, these groups tried to encourage patients to become involved by drawing a connection between their efforts on Capitol Hill and the advocacy that they do on behalf of their own health. As one rectal cancer patient noted, “When I first started advocating for my own healthcare, I felt productive....when I started advocating on the Hill or in my hometown, I left their offices knowing I was making a difference.”

In addition, both the colorectal and lung cancer groups set up patient information hotlines that patients can call when in need of advice or assistance. When these callers asked about Congress, the groups encouraged the patients to become grassroots advocates. Similarly, patients who were searching the Internet for information on their disease often found the Facebook pages and Twitter feeds of the advocacy groups, which also encouraged the patients to become involved in Capitol Hill advocacy. Even if the patients were too sick to contact the advocacy groups or get involved in their work, their family members, caregivers, and physicians did so on their behalf, and this helped to grow the pool of potential advocates.

The colorectal and lung cancer groups worked to train these patients and their allies in grassroots advocacy. Fight Colorectal Cancer’s Advocacy Handbook is an example of the educational materials published by these groups. This handbook begins by explaining the group’s mission and defining how Congressional advocacy fits into that mission by emphasizing that “Fight Colorectal Cancer demands a cure for colon and rectal cancer.” To do this, “they push for changes in policy that will increase and improve research and empower survivors and those touched by colorectal cancer.” The brochure

97 Ross, interview.
98 Bauman, interview.
then outlines the legislative process and the group’s legislative priorities, including the removal of the Medicare coinsurance requirement for patients whose colonoscopy uncovers polyps. The handbook also provides quotes and tips from advocates who have lobbied Congress in the past. For example, Eric Hausman gives advocates the following advice about members of Congress and Congressional staffers: “the people you will talk to are interested in what you have to say….your personal story is important and more effective than a script.” Similarly, Doug Sharp reminds advocates that “your legislative members’ schedules are very fluid. You may not see your representative or they may be called away in the middle of your meeting for a vote. If this is the case you will meet with one of their legislative aides. This is ok; be patient, and don’t be frustrated by this.”

These and other advocacy tips reminded patients not to be frustrated by the legislative process, and encouraged them to remain involved.

The Lung Cancer Alliance’s website has similar information, including a reminder that “advocacy is one of the three pillars of our mission. Advocacy is about standing up, being visible, and being heard. It is about promoting change and not accepting the status quo.” The website also lists past advocacy victories, as well as its current legislative priorities. The Alliance emphasized that those types of victories were only possible through sustained advocacy, and reminded their members that change in Washington rarely happens in a day or even a year.

102 Ross, interview.
In addition to educating their members about the importance of advocacy, these websites also provide patients with a way to contact their members of Congress directly. They do so because they believe that “when we are not fairly heard, the government—which is the single largest funder of all cancer research-forgets about us.” The groups ensure that their patients are heard by including a system on their websites where patients can send an email to their members of Congress in just a few clicks. One lung cancer advocate noted the success of these emails by pointing out that they overwhelmed a Senator’s email system until she agreed to support lung cancer-related legislation.

The patient groups also emphasized the importance of in-person grassroots advocacy. Through the aforementioned handbooks and websites, the patient groups give advice to advocates for their meetings with members of Congress and congressional staffers. These tips are necessary because both the colorectal and lung cancer groups organized congressional visits and lobby days for their advocates. These events encouraged advocates to come to Washington from all over the country and “meet with the offices of their members of Congress…Advocates attend these meetings in groups, taking turns sharing their stories and asking for support.” By forming a visible presence on Capitol Hill these patients and their supporters helped remind Congress to pay attention to their disease. For example, Fight Colorectal Cancer asked all of its “Call-on Congress” attendees to wear T-shirts with the group’s logo. These advocates wore

105 Mike Stevens, personal communication to author, April 22, 2013.
their T-shirts while visiting more than 100 congressional offices,¹⁰⁷ and these visits helped remind Congress why the patients were in Washington. In addition, these Capitol Hill days energized advocates and gave them an opportunity to see the legislative process firsthand. Long-term survivors often led new advocates on these visits and trained them in the basics of advocacy.¹⁰⁸ Those advocates then came back to D.C. the following year and trained even more advocates.

In addition to grassroots advocates, patient groups have professional lobbyists who share the group’s message on Capitol Hill. A lobbyist is defined legally as someone who 1) is employed or retained by a client for financial or other compensation, 2) makes more than one lobbying contact in a quarterly period, and 3) spends at least 20% of one’s time engaged in lobbying activities. For example, in 2012 Fight Colorectal Cancer retained lobbyist Camille Bonta,¹⁰⁹ who made lobbying contacts and spent at least 20% of her time on issues relating to federal budget and appropriations, Medicare and Medicaid, and general health care.¹¹⁰ Lobbyists like Camille employ background lobbying tactics such as “sending press releases, or policy papers, or monographs, or e-mail messages to legislators and their aides.”¹¹¹ The Lung Cancer Alliance did this when it distributed a fact sheet to Congressional offices that explained that the disease was the leading cause of death among all ethnic groups.¹¹² In addition, the lobbying activities include in-person

¹⁰⁷ Bauman, interview.
¹⁰⁸ Stevens, personal communication.
¹¹¹ Nownes, Total Lobbying, 90.
meetings with members of Congress and Congressional staffers.\textsuperscript{113} These meetings are important and effective because they give lobbyists a chance to make an impression with the Congressional staffers and get information from Congressional offices.\textsuperscript{114} This information goes both ways-Congressional offices also gain a lot from their meetings with lobbyists, including background information on the issue, technical information about the disease, and the electoral consequences of supporting or not supporting the patient group.\textsuperscript{115}

The patient groups’ lobbyists found that members of Congress and congressional staffers were not initially talking about colorectal or lung cancer, but once the groups started being active on Capitol Hill members of Congress and Congressional staffers often shared that they had a personal connection to the disease.\textsuperscript{116} For example, Congressman Donald Payne, Jr. (D-NJ) became a colorectal cancer advocate after his father (also a Congressman) died from the disease. Congressman Payne noted his family’s connection to the disease when discussing his introduction of a congressional resolution honoring National Colorectal Cancer Awareness Month. The Congressman emphasized that “after witnessing my father’s heartbreaking battle with this fatal, yet very preventable and treatable cancer, it became my mission to raise awareness.”\textsuperscript{117} Similarly, Congressman Rick Nolan (D-MN) added an extra $1 million for lung cancer research at the Department of Defense after his daughter was diagnosed with the

\textsuperscript{113} Ross, interview.
\textsuperscript{114} Nownes, \textit{Total Lobbying}, 90-91.
\textsuperscript{115} Ibid., 93-95.
\textsuperscript{116} Ross, interview.
The colorectal and lung cancer groups worked with their key legislative supporters to advocate for the groups’ legislative priorities.

The colorectal cancer groups asked Congress to support screening-related legislation that applied to that disease only. Colonoscopies can prevent colon cancer by finding and removing polyps. This procedure is covered under Medicare, but if a precancerous polyp is found during the test then the patient must pay a copayment. In 2012, Congressman Dent (R-PA) introduced the Removing Barriers to Colorectal Cancer Screening Act, which would get rid of that copayment. Even though this bill gained 48 cosponsors in the House of Representatives, companion legislation was not introduced in the Senate and the legislation did not pass either house of Congress.

Although the colorectal cancer groups support medical research, they focus much of their legislative efforts on colonoscopy and other forms of screening. The group was founded for that reason. However, cancer screening is a contentious and pricey issue, while research “has gained eminence as the premiere medical endeavor because it perpetuates the power vested in modern medicine and is lucrative to the industry as a whole.”

The Lung Cancer Alliance realized this, and targeted their advocacy efforts towards research.

The Lung Cancer Alliance’s efforts in 2012 were part of an ongoing advocacy push on research-oriented legislation. In 2005, the Lung Cancer Alliance furthered its legislative goals by ensuring the Senate passage of a non-binding Congressional

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119 Removing Barriers to Colorectal Cancer Screening Act of 2012, HR 4120, 112th Cong., 2d sess.
120 Bauman, interview.
resolution that asked the President to declare lung cancer a national research priority.\textsuperscript{122} Both houses of Congress passed a similar resolution in 2007.\textsuperscript{123} \textsuperscript{124} The Lung Cancer Mortality Reduction Act, which called for a comprehensive research plan on the disease, was first introduced in 2009 in both the House\textsuperscript{125} and the Senate,\textsuperscript{126} but it did not pass Congress at that time. As will be explained below, this changed in 2012.

\textit{Treatment: Coalitions}

At the same time that the lung cancer community was building support for the Lung Cancer Mortality Reduction Act, the pancreatic cancer community was advocating on behalf of the Pancreatic Cancer Research and Education Act. Pancreatic cancer patients do not face the same smoking-related stigma as lung cancer.\textsuperscript{127} There is also no reliable screening test for pancreatic cancer, so they do not face the same stigma as colorectal cancer patients do for the invasive screening test colonoscopy. The pancreatic cancer group was able to use this lack of stigma to build support for their legislation. However, this legislation had a very high price tag (more than $160 million for the first year, and additional amounts in the following years).\textsuperscript{128} Realizing that this high price tag would make it difficult to gain support, the pancreatic cancer community expanded their base of support by forming an alliance with the lung cancer group. The two patient

\textsuperscript{122} A resolution expressing the sense of the Senate that the President should declare lung cancer a public health priority and should implement a comprehensive interagency program that will reduce lung cancer mortality by at least 50 percent by 2015, S. Res. 408, 109th Cong., 2d sess.

\textsuperscript{123} Expressing the sense of the House of Representatives with respect to lung cancer as a public health priority and the recommendations of the Lung Cancer Progress Review Group of the National Cancer Institute, H. Res. 335, 110th Cong., 1st sess.

\textsuperscript{124} Expressing the Sense of the Senate that the President Should Declare Lung Cancer a Public Health Priority and Should Implement a Comprehensive Interagency Program to Reduce the Lung Cancer Mortality Rate by at Least 50 Percent by 2015, SRes 87, 110th Cong., 1st sess.

\textsuperscript{125} Lung Cancer Mortality Reduction Act, HR 2112, 111th Cong., 1st sess.

\textsuperscript{126} Lung Cancer Mortality Reduction Act, S. 332, 111th Cong., 1st sess.

\textsuperscript{127} Ross, interview.

\textsuperscript{128} Ross, interview.
communities therefore coalesced around the idea of legislation that would advance research on the most lethal (recalcitrant) cancers, with a particular focus on lung and pancreatic cancer. Like the Lung Cancer Mortality Reduction Act, this recalcitrant cancer bill called for a comprehensive research framework for these cancers. However, the bill did not include the large price tag of the Pancreatic Cancer Research and Education Act.129

Although the lung and pancreatic cancer groups had first joined together several years before, at that time the partnership did not lead to the passage of lung cancer-related legislation. Congress was in the process of debating healthcare reform, and did not have the time to consider other healthcare-related legislation.130 This changed in 2012 when healthcare reform had passed Congress and the debate had shifted to implementation of healthcare reform on the state level. This gave Congress more time to consider other healthcare-related bills. However, even though Congress had that additional time they did not consider the colorectal cancer legislation. This is because the colorectal cancer groups did not have the coalition partners (and the expanded base of support in Congress that resulted from that coalition) that the lung and pancreatic cancer communities did.

The House of Representatives passed the Recalcitrant Cancer Research Act, which was a modified version of the pancreatic cancer bill and also applied to lung cancer, on September 19, 2012. When the bill passed the Senate it did so as an amendment to the Department of Defense Authorization Act, which is an omnibus bill. Omnibus bills cover a wide range of issues, are hundreds of pages long, and include

129 Recalcitrant Cancer Research Act, HR 733, 112th Cong., 2d sess.
130 Ross, interview.
budgetary appropriations. Due to the increased partisanship of Congress and the legislative body’s continued fights over the budget and healthcare spending, it is often difficult to get stand-alone legislation passed through Congress. Instead, patient advocacy groups find it easier to have their priorities included in omnibus legislation like the Defense Authorization Bill.

After the Recalcitrant Cancer Research Act was included as an amendment to the Senate’s version of the Defense Authorization Act, the amendment remained in the Omnibus bill as Congress negotiated over the legislation’s provisions. The amendment remained despite the objections of Senator Tom Coburn (R-OK). Throughout this process, the Lung Cancer Alliance was encouraging its advocates to contact members of Congress and thank them for supporting the legislation. This grassroots advocacy helped ensure that members of Congress would continue to support lung cancer research, despite Senator Coburn’s objections. In addition, the lung cancer group’s alliance with the pancreatic cancer community helped in this effort because Senator Sheldon Whitehouse (D-RI) negotiated with Senator Coburn and helped ensure the passage of the bill. Senator Whitehouse first became a supporter of the pancreatic bill because his mother died from the disease. But after the lung cancer advocates started working with the pancreatic cancer advocates, Senator Whitehouse revealed that his father had died from lung cancer, and this helped him to become an even stronger supporter of the legislation. As was explored in the introduction to this thesis, family members’

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133 Ross, interview.
134 Ibid.
experience with disease is a common way for members of Congress to become the allies of patient advocacy groups. The alliance between the colorectal and pancreatic communities therefore helped ensure Senator Whitehouse’s support, while also ensuring that Senator Coburn’s objections would not lead to the defeat of the bill.

Outcome

Without Whitehouse’s help and negotiation skills Coburn may have continued to hold up the Recalcitrant Cancer Research Act. Instead, when the President signed the omnibus Defense Authorization Act into law on January 2, 2013, it included the recalcitrant cancer research language.

Even after the bill passed, the Lung Cancer Alliance continued to recognize the efforts of its grassroots advocates and its pancreatic cancer partners. These groups were therefore recognizing the importance of the characteristics mentioned in Table 1. For example, the group thanked their grassroots advocates for their work by calling the Recalcitrant Cancer Research Act “a holiday gift for all the lung cancer advocates around the country who came to Washington in person, or called and emailed their representatives.”\(^\text{135}\) The Lung Cancer Alliance also thanked its partners at the Pancreatic Cancer Action Network for playing an instrumental role in the passage of the bill.\(^\text{136}\) Similarly, “the Pancreatic Cancer Action Network applaud[ed] the Lung Cancer Alliance for their efforts in advocating for the passage of the Recalcitrant Cancer Research


Both groups recognized that without their joint effort Congress might not have passed the legislation.

The title of the bill (Recalcitrant Cancer Research Act) did not directly mention the cancers involved, which therefore avoided any stigma associated with those diseases. This is similar to how the HIV/AIDS legislation was named after a teenager with hemophilia (Ryan White). Even “though children with AIDS comprised a mere 1.7 percent of people with AIDS…they were mentioned 41 percent of the time”¹³⁸ by members of Congress during the debate on the Ryan White bill. The vast majority of people with AIDS at that time were gay men or IV drug users, but children were more sympathetic so lawmakers mentioned them more often and named the legislation after them. As was mentioned in Table 1, in 2012, the lung cancer group achieved the same outcome by forming a coalition with the pancreatic cancer community to advocate for research-related legislation that would help both diseases. The research-related legislation did not mention lung cancer in its title, which helped it to avoid the smoking-related stigma of the disease. Instead, the legislation focused on the high mortality rates (the recalcitrant nature) of both cancers, which members of Congress found hard to argue or vote against. As Congressman Joe Pitts (R-PA) acknowledged during the markup of the Recalcitrant Cancer Research bill, “It is never easy to lose someone to cancer, but it is especially difficult when you are not given a fighting chance. Recalcitrant cancers with

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their low survival rates and poor outcomes have baffled researchers for decades.”  
Rep. Pitts and his colleagues knew they had to support this bill in order to support the additional research that would give their constituents a fighting chance against these cancers.

In contrast, the colorectal cancer group’s legislative priority in 2012 mentioned both the disease and screening in its title, and did not focus on research. Furthermore the legislation’s applicability to only colorectal cancer limited the group’s ability to partner with other cancer advocates. This focus on colorectal cancer also limited the legislation’s support in Congress. As this chapter explained, it is this lack of coalition and limited focus that led to the colorectal cancer community’s failure when compared to the successful lobbying efforts of the lung/pancreatic cancer coalition.

It is important to study the successes and failure of the lung, pancreatic, and colorectal groups, as their lobbying has the chance to greatly affect a large number of people. Combined, these three cancers had more than 400,000 new cases in the United States in 2015.  
When one includes the friends and family members of these patients, the number of people affected by these diseases grows even larger. Advocacy groups that lobby for legislation on these disorders are doing so on behalf of all of those Americans. If that lobbying is successful and the legislation passes, then scientists could potentially find a cure or physicians could screen thousands more patients for the cancer. But if the patient advocacy group lobbying is not successful, then these patients (and their friends

139 House Committee on Energy and Commerce, Markup of HR 1206, HR 6118, HR 1063, HR 6163, HR 4124, and HR 733, 112th Cong., 2d sess., 2012, 59.
and family members) will be kept waiting. The next chapter will look at another lobbying
tactic used by these patient advocacy groups on behalf of their waiting constituents.
CHAPTER 2

PATIENT ADVOCACY GROUPS AND REPORT LANGUAGE: A SOFT EARMARK FOR DISEASE RESEARCH AT THE NIH

While chapter 1 focused on only three groups, this chapter will include a much larger sample, including organizations representing both common and rare disorders (the NIH defines a disease as rare if it affects fewer than 200,000 people in the United States).\textsuperscript{141} This chapter will explore the lobbying these groups do to include language on their disease in the committee reports for the Labor-Health and Human Services (Labor-HHS) Appropriations Bills. Furthermore, the chapter will look at how the NIH responds to this language, and will conclude that that response makes this language a ‘soft earmark’ for the patient advocacy groups.

The Budgeting and Appropriations Process

This process starts with the release of the President’s budget, which occurs on the first Monday in February. However, the federal government agencies have to submit their requests to the President nine months prior to that. The Department of Health and Human Services, including the NIH, is one of the agencies that submits their requests and then is part of the President’s budget. For example, in Fiscal Year 2013, the President’s budget noted that his administration was “supporting research at the National Institutes of Health that will accelerate the translation of new discoveries in biomedical science into new therapies and cures.”\textsuperscript{142} To accomplish this goal, the President’s budget included $31 billion for the NIH. However, “the President’s budget is only a request to Congress;

\textsuperscript{141} National Organization for Rare Disorders, “Resources & FAQ,” \url{http://rarediseases.org/for-patients-and-families/information-resources/resources-faqs/} (accessed July 20, 2015).
Congress is not required to adopt his recommendations.” In recognition of this, patient groups will generally not individually lobby the President on his budget, although they will join umbrella organizations like the Non-Defense Discretionary United group (which represents a wide variety of medical research, public health, transportation, education, and other public service organizations) in issuing statements on the budget.

Following the release of the President’s budget, the NIH and the other agencies then testify before Congress about the President’s request. In doing so, they “are supposed to justify the President’s recommendations, not their own. OMB [Office of Management and Budget] maintains an elaborate legislative clearance process to ensure that agency budget justifications, testimony, and other submissions are consistent with presidential policy.” Patient groups attend these hearings and submit comments and questions for members of Congress to ask the NIH after the testimony. Congress considers this testimony and the question and answer sessions when developing the concurrent budget resolutions, and later the appropriations bills. The budget resolutions are not law, are not signed or vetoed by the President, and do not have the effect of statute. Instead, the “main purpose of the budget resolution is to establish the framework within which Congress considers separate revenue, spending, and other budget-related legislation.” The Appropriations Committees then fill in that framework.

The Congressional Appropriations Committees determine the funding levels of federal programs. In addition, the appropriations process gives members of Congress the

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146 Ibid.
opportunity to oversee federal agencies and influence their work. For Senators, “participation in the appropriations process is perhaps the most important way in which Senators can get specific preferences about biomedical research incorporated into law and into agency activity.”\(^\text{147}\) Similarly, Richard Fenno’s classic study of the House Appropriations Committee notes that the House expects the Committee to “keep itself and the rest of the House informed on the way[s] in which the executive agencies use the money granted to them.”\(^\text{148}\) Another way that Congress monitors and directs the executive agencies is through the use of the limitation provisions in appropriations bills, which Jessica Tollestrup argues can be used “to influence policy implementation through the denial of funds for specific purposes, as well as an additional high-stakes method of forcing the president to cooperate with the intentions of Congress in agency structuring and decision-making.”\(^\text{149}\) John Marini agrees that the budget “became the point of control over which the political parties and the political branches fell to fighting.”\(^\text{150}\) This divided government has led to the budget becoming “the focal point of the American administrative state—the place where political institutions and public bureaucracies accommodate the various interests and constituencies seeking a share of the national wealth.”\(^\text{151}\) For many years, the way that those interests tried to gain a share of the wealth given out by the agencies was through earmarks in the appropriations bills.

\(^{147}\) Richard Clarke Weston, “The Legislative Politics of Appropriations for Biomedical Research” (Dr. P.H. diss., University of Michigan, 1994), 73.


\(^{151}\) Ibid.
Scott Frisch and Sean Kelly criticize the common characterization of earmarks as ‘pork barrel spending’ because they believe that earmarks can support both the local and national interest.\footnote{Scott A. Frisch and Sean Q. Kelly, \textit{Cheese Factories on the Moon: Why Earmarks are Good for American Democracy} (Boulder: Paradigm Publishers, 2011), 51.} For example, when Congressman John Porter (R-Illinois) was Chair of the House Labor-HHS-Education Appropriations Subcommittee, he would encourage earmarks for small universities that wanted to build their research infrastructure. By using those earmarks to fund projects like new buildings and laboratories, the universities were then able to apply for NIH funding. Congressman Porter used those earmarks (the local interest) to gain the support of the members of Congress who represented the small universities. As a result, those members of Congress supported increases for the NIH as a whole (the national interest). Congressman Porter was Chair of the Subcommittee during the Republican Party’s Contract for America. But even in that time, when funding for many federal programs was cut, Congressman Porter was able to increase the NIH’s funding by building “a base of support in Congress and throughout the country for an institution in which he had an intense policy interest.”\footnote{Ibid., 58.} That institution was the NIH and medical research.

Earmarks are now largely banned, but members of Congress are still able to express their policy interests regarding the NIH. They do so through the use of language in the appropriations committee reports. By including this language, members of Congress are controlling the actions of the NIH and other federal government agencies, and ensuring that those agencies are acting according to Congress’ priorities.\footnote{Steven C. LaTourette, “The Congressional Earmark Ban: The Real Bridge to Nowhere,” \textit{Roll Call}, July 30, 2014, \url{http://www.rollcall.com/news/the_congressional_earmark_ban_the_real_bridge_to_nowhere_commentary-235380-1.html} (accessed July 21, 2015).}
Using Frisch and Kelly’s framework, much like earmarks for small universities (the local interest) gave members of Congress an incentive to support the NIH (the national interest), so has report language on specific diseases given members of Congress who have an interest in that disease the incentive to support the NIH as a whole. The literature rarely mentions this part of the appropriations process. The work of Susan Halebsky Dimock is an exception to this rule. However, Halebsky Dimock only focuses on two patient groups: the National Breast Cancer Coalition and the National Prostate Cancer Coalition. She finds that the Breast Cancer Coalition was much more successful in inserting report language.155 Groups working on a wide range of diseases, including all types of cancer as well as non-cancer illnesses, advocate for NIH report language. To fully examine this language, the scholarship must include this range of groups, not just two.

Deepak Hegde and Bhaven Sampat look at the report language on a bigger sample of diseases,156 however they only focus on rare disorders (those affecting less than 200,000 people in the United States) and do not examine whether their conclusion holds true for more common ones as well. Since the appropriations committee reports include language on many different rare and common diseases, it is important to look at both types of diseases. Hegde and Sampat also find that rare disease patient group advocacy influences 15% of funding at the NIH.157 However, they fail to take into account the other effects of report language on the NIH besides funding, including the resulting conferences and plans of study that result from that language. Those conferences and

155 Halebsky Dimock, “Demanding Disease Dollars.”
157 Ibid.
plans of study are mentioned in the NIH’s Significant Items Report, and these reports are
a way for the Institutes to reassure the Congressional appropriators that they are
following their directions. The article by Hegde and Sampat that fails to look at the
Significant Items Report is therefore missing a key piece of the analysis: the response of
the NIH to the Congressional directives.

Background and Methodology

This study will fill critical gaps in the scholarly literature on patient groups, as
well as the literature on the appropriations process, by analyzing the report language (and
the NIH’s response to that language) on a wide range of rare and common diseases. By
doing so, it will find that patient groups have a large impact on the appropriations process
and the NIH’s research activities. This finding brings up a neglected question in health
ethics and policy: What is a just allocation of resources for biomedical research?”¹⁵⁸ As
those resources become even more limited due to Congressional budget cuts to the NIH,
this question becomes ever more important. Critics of the report language process have
argued that “if advocacy groups play a more significant role in funding allocation, groups
with the resources and expertise to mount the most effective lobbying campaigns could
obtain substantial sums for research.”¹⁵⁹ This study will demonstrate that patient groups
do use their financial resources to lobby for report language on their diseases.
Furthermore, the study will explain that this language has an impact on determining the
NIH’s research priorities.

Patient advocacy groups are able to have this type of impact on the NIH because
“even a small or new group can cultivate friends in high places, and it does not take many

¹⁵⁹ Ibid., 93.
such friends to have a discernible impact. A single congressional advocate can offer visibility for the group agenda and sometimes more tangible victories.” To find these advocates, the patient groups hire professional lobbyists who visit Congressional offices. These lobbyists specifically target members of Congress who might have an interest in the disease (because they, their staff, or their family member suffer from the same condition). Patient groups also look for congressional champions by drawing a connection between the Congressman’s district and the disease in question. If a member of Congress represents the district where the patient group’s office is located, that member might become a great champion for the disease. By carefully choosing, and working closely with, these Congressional policy entrepreneurs, patient advocate lobbyists are able to find champions for their cause. Together, these members of Congress and lobbyists ask the Appropriations Committee to support report language on the disease.

The Appropriations Committee staff might edit the language, but the patient groups (and their Congressional champions) work closely with the committee to ensure that the language’s central message is not lost. This strategy is particularly effective if the Congressional champion is a member of the Appropriations Committee. However, even members of other committees are able to influence what language is included in the Appropriations Committee report. For example, at the National Fragile X Foundation’s urging, members of the House and Senate wrote letters to their Appropriations Committees that asked those Committees to support report language that would “create

160 Foreman, “Grassroots Victim Organizations,” 43.
161 Spencer Perlman, interview by author, Washington, DC, July 11, 2014.
163 Perlman, interview.
greater synergy and efficiency among the Fragile X and Autism research tracks to accelerate translational research toward a better understanding of both conditions and ultimately bring more effective treatments for both conditions to market.”¹⁶⁴ Rep. Gregg Harper (R-MS), whose child has Fragile X, ¹⁶⁵ led the House letter.

The appropriations committee “reports are filled with running comments about the appropriations being recommended for an agency. They contain reasons for past Committee action plus suggestions and admonitions for the future.”¹⁶⁶ To determine the impact of these suggestions and admonitions, this study will look at the report language in Fiscal Year 2012 and Fiscal Year 2013 (FY12 and FY13) for a range of Institutes that work on different issues and different parts of the body, including everything from the National Institute on Mental Health Institute to the National Institute of Diabetes, Digestive, and Kidney Diseases. Because the House of Representatives’ Labor-HHS Appropriations Subcommittee did not release a committee report in those years due to conflicts between the committee’s Republicans and Democrats on overall spending levels and other controversial provisions unrelated to the NIH, this study will look at the Senate’s language. The Senate leadership did not change between FY12 and FY13 (the Democrats remained in power) so studying those two years provides a consistent picture of the Senate’s work on the NIH during that time.

The report language is not in the main text of the legislation and is therefore not legally binding. However, it still plays an important role in influencing the work of

¹⁶⁶ Fenno, The Power of the Purse, 292.
federal agencies, including the NIH. This is because the NIH understands that if they do not follow the directives laid out in the report language, they will face the anger of the members of Congress during the appropriations hearings the following year.\textsuperscript{167} Even if the House does not issue a report, the consolidated appropriations bill passed by both the House and Senate (which includes the Labor-HHS bill as well as other appropriations bills) includes an explanatory statement saying that language in the Senate Labor-HHS report should be followed even if not directly mentioned in the consolidated bill.\textsuperscript{168} The NIH knows that as long as the Senate’s language is not directly mentioned or contradicted in the consolidated bill, then the Senate’s language has the force of law. As a result, “when a particular item is mentioned by the committee, there is a strong expectation that the agency will adhere to the instructions.”\textsuperscript{169} This study will look at how and why the agency adheres to those instructions.

Materials published by the patient groups (including press releases, websites, and annual reports) are used in this study to give background on the development of the report language. Additionally, interviews with the patient groups’ lobbyists are used to give context to their work on Capitol Hill, and interviews with two former Appropriations Committee staffers give background on the appropriations process and the influence of patient groups. The NIH’s response to the report language is analyzed through the examination of the NIH’s Significant Items report, which is part of its budget justification for the following fiscal year. When the NIH Institutes “send up their justifications for their budget estimates each year, some of them include a report of precisely what action

\textsuperscript{168} Telephone interview, July 14, 2014.  
\textsuperscript{169} Heniff, Lynch, and Tollestrup, “Introduction to the Federal Budget Process.”
they took regarding each relevant item in last year’s Committee report.”

These Significant Items reports serve as a way for both Congress and the patient groups to determine what the NIH did and did not do. Susan Halebsky Dimock argues that these Significant Items Report serve the principal-agent relationship between Congress and the NIH because Congress can use the reports to track the NIH’s response, and it gives the NIH the opportunity to educate Congress on the scientific rationale behind its decisions. As mentioned previously, this examination of the NIH’s reaction to the report language is missing in the current literature on patient advocacy groups. This study will look at the report and at the NIH’s justifications for their actions in order to determine the extent of patient groups’ influence on both Congress and the Institutes.

An Examination of the FY12 and FY13 Report Language on the NIH

In FY12, approximately 105 (out of a total of 136) of the items mentioned in the Labor-HHS Appropriations Bill report language on the NIH dealt with specific diseases or conditions. The other items mentioned in the report language on the NIH were not disease-specific, but instead were related to other areas of science and healthcare policy, including the use of chimpanzees in research and mobile healthcare technology. The numbers and topics in the FY13 report language were similar, with 120 (out of a total of 150) of the items mentioned in the report language on the NIH being related to disease. The fact that, in both years, around 80% of the report language was disease-specific shows the impact of patient groups on the appropriations process.

This language is arranged in the Appropriations Committee report by Institute. The Appropriations Committee allocates a specific amount of funding for each Institute,

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170 Fenno, The power of the Purse, 292.
171 Perlman, interview.
but does not give funding amounts to each disease studied by that Institute. Instead, the report language serves as a way for Congress to direct the NIH’s research priorities on certain diseases. For example, the FY12 report’s section on the National Heart, Lung, and Blood Institute (NHLBI) includes language on asthma, cardiovascular disease, Chronic Obstructive Pulmonary Disease, Marfan Syndrome, pulmonary hypertension, and sleep disorders.173 Meanwhile, the FY13 report’s section on the National Institute of Neurological Disorders and Stroke (NINDS) includes language on diseases studied by that Institute, including Amyotrophic Lateral Sclerosis (ALS), dystonia, epilepsy, headache disorders, spinal muscular atrophy, and stroke.174 The bolded diseases in the above examples are rare diseases (they affect less than 200,000 people in the United States and are listed in the NIH’s rare disease database).175 As can be seen in these examples, in both FY12 and FY13, the Institutes’ report language dealt with both rare and common diseases, and the examples in this chapter will also include both kinds of diseases.

Through the “use of a set of coded words and phrases…committee members adjust the forcefulness of the language in reports to signal to the agency how important the issue is to Congress.”176 By using words like ‘commends’ and ‘applauds,’ the report language thanks the NIH for the work that it has done on that disease. For example, in FY12 the Senate Committee report included the following language on the National

Institute of Allergy and Infectious Disease (NIAID) and Hepatitis B Virus (HBV) research

The Committee *applauds [emphasis added] NIAID’s efforts to pursue the development of new classes of drugs that are safe and effective in treating HBV. The Committee urges continued HBV research [emphasis added] on different courses of treatment as well as ways to support efforts to identify new cellular and antiviral targets to develop new strategies for intervention. The Committee also urges an increased focus on pregnant women and pediatric cases of HBV.*

In FY13, the Senate Committee report included similar language on diabetes prevention research at the National Institute of Diabetes, Digestive, and Kidney Diseases (NIDDK):

The Committee *applauds NIDDK [emphasis added] for its continued efforts to build on the successes of the Diabetes Prevention Program and encourages the use of additional resources [emphasis added] to improve prevention and treatment of diabetes.*

This report language format (at first supportive of the work that the NIH has done so far, and then asking the NIH to expand its research (and allocate additional resources to that research) is one of the key ways that the Labor-HHS-Education Appropriations Subcommittee uses its report language to influence the NIH.

The report language can also take a more concerned tone about the NIH’s budgeting decisions. For example, in FY13 the Committee wrote that it was

*concerned [emphasis added] that the NIH spends only 1 percent of its budget on stroke research and strongly urges [emphasis added] NINDS to expand its stroke portfolio.*

Even the concerned language, however, still maintains the same general format as the supportive language. For example, in FY13, the report language about premature mortality in people with mental illness reads

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177 Senate Committee, *FY12 Appropriations*, 93.
178 Senate Committee, *FY13 Appropriations*, 83.
179 Ibid., 85.
The Committee continues to be concerned [emphasis added] about premature mortality and lower life expectancy experienced by adults living with serious mental illness as a result of treatable medical conditions such as cardiovascular, pulmonary, endocrine, and infectious diseases. The Committee urges NIMH [emphasis added] to continue its collaborations with other Institutes…to pursue research to better understand the causes and interventions needed to address this crisis. The Committee requests an update in the fiscal year 2014 congressional budget justification.180

This language, although more direct, is similar to the supportive language in that it ends by asking the NIH to expand its research. The NIH recognized that the Senate was asking the Institutes to expand its research in this way, and in its Significant Items Report (the congressional budget justification) the following year, the NIH noted that it was listening to the Committee’s request. The Institutes therefore reported that they were supporting research that

aim[s] to improve the general health of persons living with SMI [severe mental illness] and comorbid physical illnesses. These studies cover a broad range of treatable conditions associated with SMI that harm the health of these individuals.181

Congress learns about the NIH’s response to SMI and other illnesses by reading the Significant Items Report.

Just as importantly, the patient groups learn about the NIH’s efforts on their disease by reading this report. The Significant Items Report (and its outline of areas of NIH success and areas where NIH needs to do further research) therefore helps patient organizations to plan their advocacy efforts for the following year. For example, the Tuberous Sclerosis Alliance noted in its annual report that the Alliance “successfully advocated for the inclusion of National Institutes of Health report language…This

180 Ibid., 96.
language calls on various Institutes at the NIH to augment existing research efforts with new initiatives examining the many manifestations of TSC [tuberous sclerosis complex].”

The Alliance will work to ensure that the NIH implements those new initiatives. Similarly, the National Fragile X Foundation, another patient group, noted the success of their efforts in urging for “strong congressional directives [that] resulted in the National Institutes of Health nearly doubling its yearly investment…in basic science and translational research aimed specifically at bringing targeted treatments for FX [Fragile X] to market.”

The NIH knows that patient groups will complain to Congress (and especially to members of the Appropriations Committee) if the Institutes do not follow Congress’ directives by establishing these new initiatives and doubling research efforts. The NIH therefore is careful to follow Congress’ directives (and to outline how they did so in the Significant Items Report). This process is particularly effective for diseases that the NIH had previously not been devoting many resources.

This lack of resources changes because of the lobbying efforts of patient groups, and this change can be seen in the report language and significant items report. As one lobbyist remarked, “That’s the reason for report language. Something they [NIH] don’t want them to do and someone wants them to do it.”

The NIH often responds to these Congressional directives by emphasizing that they have found a promising line of research and are encouraging researchers to work in

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185 Lyle Dennis, telephone interview by author, July 28, 2014.
that area. For example, in response to the above request from the Fragile X Foundation, the NIH noted in its Significant Item Report that

*in another promising line of research* [emphasis added], scientists have found that a class of drugs called P13 kinase inhibitors could help improve learning and cognition in individuals with Fragile X syndrome.\(^\text{186}\)

The NIH is implying that if they receive additional funds from the NIH they could fulfill the promise of this new research. In its response to the FY12 report language on sleep disorders, the NIH also noted that it was supporting new and exciting research on those conditions. The NIH assured the Appropriations Committee that its new trans-NIH Obesity Research Plan highlights *emerging opportunities [emphasis added]* to study the role of sleep in the development of obesity.\(^\text{187}\)

Similarly, in its FY13 Significant Items response on pediatric cardiomyopathy, the NHLBI noted that the Institute is strongly committed to pediatric cardiomyopathy research and continuously identifies gaps and opportunities [emphasis added] in basic and clinical research in the area through on-going reviews and conversations with investigators and patient advocacy groups.\(^\text{188}\)

The patient groups note these gaps and opportunities, and work with the NIH to ensure that they advance in the research in those areas. In addition, the groups ask Congress to follow up on the advances in research by including report language the following year.

The influence of patient advocacy groups can also be seen in the fact that both the Appropriations Committee and the NIH refer to these groups in the report language and the resulting Significant Items report. The appropriations bills do not mention the group directly by name (since that would violate the Congressional earmarking rules), but they

\(^{186}\) U.S. National Institutes of Health, *FY13 Significant Items Report*.
\(^{188}\) U.S. National Institutes of Health, *FY13 Significant Items Report*. 
are mentioned indirectly through terms like ‘patient groups’ or ‘patient health organizations’ or ‘patient communities’ or ‘advocacy groups.’ Both the Committee and the NIH know exactly which groups are behind the language, which can be seen by the fact that the NIH Significant Items Report (which does not face the same earmark rules as the Congressional appropriations bills) does mention these groups by name. The NIH knows that Congress wants them to work with certain groups, and the NIH reassures them that they are doing so through the Significant Items Report. This understanding makes the report language a ‘soft earmark’ for those groups. For example, the FY12 Senate Appropriations Bill included the following language on chronic pelvic pain:

> The Committee is pleased by the progress made in the Multidisciplinary Approach to the Study of Chronic Pelvic Pain [MAPP] Research Network, particularly the inclusion of male subjects, as the research plan continues to focus on the natural history of interstitial cystitis. The Committee encourages the MAPP Research Network to collaborate closely with patient health organizations [emphasis added].

In its response, the NIH reported that it followed the Appropriations Committee’s recommendation to work with patient advocacy groups (and mentions the specific groups by name, which illustrates that the NIH does know which groups asked Congress to include the language). This response emphasized that

> The success of the MAPP Research Network’s efforts thus far has been helped by the Institute’s collaborations with patient health advocacy organizations, including the Interstitial Cystitis Association and the Prostatitis Foundation [emphasis added]. For example, patient advocacy organizations have publicized the MAPP study on their Website to help bolster recruitment, and have provided feedback on the Network’s activities through attendance at Steering Committee meetings and through other avenues of communication.

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189 Parikh, interview.
190 Dennis, interview.
191 Senate Committee, *FY12 Appropriations*, 90.
Similarly, the FY13 Appropriations Report asked the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) to support natural history studies that will facilitate efforts by advocacy groups and medical professional societies to develop clinical practice guidelines for adults living with OI [osteogenesis imperfecta] and to increase research on emerging issues. The Committee encourages NIAMS to work with relevant stakeholders from government, medical professional societies, and advocacy groups [emphasis added] on this matter and to provide an update.¹⁹³

In its update in the Significant Items Report, NIAMS responded that it was following Congress’ recommendation by providing grant funding for a conference hosted by the advocacy group the OI Foundation. The NIH also noted that the conference organizers have agreed to share insights gained at the conference with a wider audience through venues such as the OI Foundation website, the OI Foundation newsletter, and submission of a workshop report to a peer-reviewed journal.¹⁹⁴

The NIH is therefore explaining to Congress that it has worked with patient advocacy groups like the OI Foundation. Not only has the NIH funded the organization’s conference, but the conference’s research insights will be shared with the organization’s members (the patients) through their website and newsletter.

Like the above example on OI, one of the common ways that Congress asks the NIH to take action is by hosting a conference or workshop on the disease in question. Even though the federal government is encouraging federal agencies to reduce travel expenses,¹⁹⁵ disease-specific report language has continued to request that the NIH hold these conferences.¹⁹⁶ These requests show the continuing power of patient groups that

¹⁹³ Senate Committee, FY13 Appropriations, 91.
are eager to be part of the conferences. For example, the FY12 bill’s language on hereditary angioedema (HAE) asks the NIH Office of Rare Disease Research (ORDR) and relevant Institutes and Centers to expand research on HAE, a rare and potentially life-threatening genetic condition. In particular, the Committee urges ORDR to support a scientific conference on HAE [emphasis added], with the goal of identifying research opportunities and priorities for this disease.\(^\text{197}\)

Similarly in FY13, the Committee’s language on mucopolysaccharidoses (MPS) include a recommendation that the NIH Institutes and Centers and ORDR continue funding research consortia and conferences on MPS and other lysosomal diseases, such as the annual Lysosomal Disease Network WORLD meeting and the Gordon research conference [emphasis added].\(^\text{198}\)

The NIH noted these recommendations and acted accordingly. In its Significant Items Report, the Institutes said that they continue to support scientific conferences that bring together researchers on MPS and other storage diseases. NINDS and ORDR also supported the 2011 Lysosomal Disease Gordon Research Conference. In addition, NICHD [National Institute of Child Health and Human Development], NINDS, and NIDDK supported the 8th Annual Lysosomal Disease Network’s WORLD (“We’re Organizing Research for Lysosomal Diseases”) Symposium in February 2012, and NINDS and NIDDK are supporting the 9th WORLD Symposium in 2013 [emphasis added]. This is one of the preeminent forums for researchers to share their work on the diagnosis, management, and treatment of lysosomal storage disorders, including MPS.\(^\text{199}\)

Conferences like the ones on MPS are valuable to patient groups because they can attend these events and be involved in the discussions. As one group reported on its website, the “Coalition for Pulmonary Fibrosis participated in a landmark meeting at the National Institutes of Health’s National Heart, Lung, and Blood Institute this week that promises to pave the path forward to finding answers to the deadly lung disease, Pulmonary Fibrosis. The Idiopathic Pulmonary Fibrosis Strategic Planning Workshop...is

\(^{197}\) Senate Committee, FY12 Appropriations, 108.
\(^{198}\) Senate Committee, FY13 Appropriations, 104.
\(^{199}\) U.S. National Institutes of Health, FY13 Significant Items Report.
the first NIH meeting in 11 years to discuss the state of lung fibrosis research in the U.S.”200 Even if physicians and researchers sometimes dominate these conferences, they can still have a positive long-term impact on the patient group and its research priorities. For example, as Elizabeth Mitchell Armstrong and Eugene Declercq note, a 2006 NIH conference on cesarean sections (C-sections) was formatted to showcase the work of physicians and researchers, and was antagonistic toward patient questions and comments. However, four years later the NIH held a conference on vaginal births after C-sections at the request of patient advocates who attended the first event.201

These workshops are also critical because they help the NIH to develop a research plan for the disease. These plans of study are often reflected in the report language as well. For example, in FY12, the Committee asked the NHLBI to research chronic obstructive pulmonary disease by working

with community stakeholders and other Federal agencies, including CDC [Centers for Disease Control and Prevention] to develop a national action plan [emphasis added] to respond to the growing burden of this disease.202

Similarly, in the Fiscal Year 2013 Labor-HHS Appropriations Bill language on pancreatic cancer, the Committee requested that that the National Cancer Institute (NCI) create a comprehensive, long-term research strategy [emphasis added] for this disease that focuses on increasing survival. The plan should not be simply a summary of recent and ongoing research activities. Rather, it should set out concrete goals [emphasis added] for the future.203

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202 Senate Committee, FY12 Appropriations, 88.

203 Senate Committee, FY13 Appropriations, 79.
One former appropriations committee staffer noted that report language requiring the NIH to set out concrete goals for studying the disease is a very effective type of report language, more so than general language commending or encouraging the NIH for its research. This is because the Committee is helping to ensure that the NIH staff will devote time to the disease by developing a specific research plan, supporting and conducting the research, and reporting back to Congress on the success of that plan. This was the case for one rare condition, polycystic kidney disease (PKD). In FY12, the Appropriations Committee urged the NIDDK to collaborate with other institutes and leverage discoveries from its portfolio of PKD grants for the purpose of developing a comprehensive strategic plan for PKD [emphasis added].

The NIDDK responded that it is conducting a ‘Kidney Research National Dialogue,’ an effort to strategically plan its future research focus for kidney disease, including PKD [emphasis added]. This effort is designed to strengthen both the Institute’s kidney research program as well as the broader nephrology research community. Development of a ‘Blueprint for Kidney Disease Research’ will inform future NIDDK kidney disease research planning and program management.

The report language on PKD thus encourages the NIDDK to plan its future research on this disease, a plan that did not exist before. Similarly, in FY13, Congress asked the NIH “to develop a strategy [emphasis added] for enhancing research” on pulmonary fibrosis (PF). In response, the NIH noted that

In November 2012, NHLBI convened a workshop to develop a strategic plan [emphasis added] for PF research. Representatives from NIH, pharmaceutical companies, the FDA, and patient advocacy groups joined PF researchers to discuss research priorities and potential collaborations.

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204 Telephone interview, July 14, 2014.
205 Senate Committee, FY12 Appropriations, 91.
207 Senate Committee, FY13 Appropriations, 81.
This response from the NIH not only said that it was developing a strategic plan, but also that it held a conference and did so in collaboration with other stakeholders, important aspects of report language that were discussed earlier in this chapter.

As in the pulmonary fibrosis example, requests for cross-institute and cross-agency collaborations are a common feature of the disease-specific report language. This language can include a request that one NIH Institute to work with other NIH Institutes to coordinate research efforts. Congress included such a request in FY12 when it directed the National Institute of Dental and Craniofacial Research (NIDCR) to research temporomandibular joint (TMJ) disorders by collaborating with other Institutes and Centers at the NIH regarding

the etiology and pathogenesis of TMJ disorders that solely or predominantly affect women. In particular, NIDCR should work with NIAMS [National Institute of Arthritis and Musculoskeletal and Skin Diseases] and NIBIB [National Institute of Biomedical Imaging and Bioengineering] [emphasis added] to develop research opportunities in the area of joint pain.209

In its Significant Items Report, the NIDCR assured Congress that it was following the legislators’ directives and working with the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) and the National Institute of Biomedical Imaging and Bioengineering (NIBIB) to enhance research efforts on this debilitating disorder. In one example, NIDCR is working with NIAMS [emphasis added] to conduct a careful analysis of the TMJ-associated pain measures included in the NIAMS-led Osteoarthritis Initiative [emphasis added], a multi-center, longitudinal, prospective observational study aiming to facilitate the scientific evaluation of biomarkers for disease onset and progression. NIDCR research efforts are also complemented by NIBIB studies [emphasis added] in tissue engineering and repair of TMJ articular cartilage.210

209 Senate Committee, FY12 Appropriations, 89.
In addition to asking an Institute to collaborate with other Institutes, Congress can also ask an Institute to coordinate its research efforts with other federal government health care agencies. For example, in FY13, the Appropriations Committee urged NHLBI to increase research on and awareness of asthma, and to collaborate with the FDA, NIAID, NICHD, NIMHD [National Institute of Minority Health and Health Disparities], and OMH [Office of Minority Health] in this regard [emphasis added].

Not only was the Committee asking the NHLBI to collaborate with other NIH Institutes and Offices (NIAID, NICHD, and NIMHD) but also with other federal government agencies and offices (the FDA and OMH). In its Significant Items Report, the Institute responded that

collaboration with other NIH Institutes and Centers and Federal Agencies provides opportunities to accelerate testing and refinement of asthma treatments. For example, NICHD includes NHLBI and NIAID in discussions about setting research priorities in its Best Pharmaceuticals for Children program with the FDA [emphasis added].

This Significant Items language served as a way for the NHLBI to reassure Congress that it was following their directions and also working with other government agencies to ensure that those agencies were doing the same.

Conclusion

In 1998, when the NIH budget was increasing rapidly, the Institute of Medicine said that the report language’s “typical directive—‘the Committee encourages the Institute to expand its support of x research’—is usually not problematic because, given NIH’s normal rate of budget growth, research on x is going to grow anyway, without any special

\[211]\text{Senate Committee, FY13 Appropriations, 80.}

\[212]\text{U.S. National Institutes of Health, FY13 Significant Items Report.}\]
steps being taken.”213 The current budgetary climate in Congress has not allowed for the same kind of increases for the NIH in recent years. In fact, when accounting for inflation, the NIH’s budget is 20% lower than it was a decade ago.214 However, the same kind of report language persists, and this is due to the influence of patient groups on Congress, and especially on the Appropriations Committee. This report language has become a soft earmark for the patient groups.

The NIH has argued that Congressional report language does “not allow NIH to adjust for the different probabilities of scientific progress against each health problem.”215 In addition, as former NIH Director Harold Varmus believes, “directives to alter allocations for disease-oriented programs are especially problematic if they occur abruptly or come at the expense of research on another disease. The situation may be further complicated if the directives are demands from powerful people rather than consensual decisions.”216 Report language comes from powerful people (members of Congress) as opposed to the consensus decisions developed by the NIH peer review process.

Under the peer review system, the NIH judges “the merit of applications for financial support of research by impaneling experts from the extramural research community to evaluate and rank grant proposals.”217 The NIH is therefore taking the money appropriated by Congress and giving it to researchers based on the

217 Ibid., 150.
recommendations of those researchers’ peers. These peer review committees are authorized by the Federal Advisory Committee Act (FACA), which “was designed to…make advisory bodies in the executive branch more transparent.”

However, the membership of these peer review committees is largely scientists, and those scientists are appointed by the Director of the NIH and the Secretary of Health and Human Services (not by Congress). This leads Congress to argue that the peer review system is flawed because “scientists’ intellectual curiosity and desires for professional advancement have produced allocation choices that deviate from public preferences and the overall public good.”

By including report language on diseases, the Appropriations Committee reports are steering the NIH towards what members of Congress (and the patient groups that they work with) see as research for the public good, and not what the peer review scientists think is the public good. Therefore, report language serves the interests of members of Congress in two ways, both to “respond to advocacy group demands and [to] communicate their interest to agency administrators.”

Congress is communicating those interests to the administrators to ensure that the administrators do not listen solely to the interests of the peer review committees.

M. Boyce Ginieczki believes that by communicating their interests to the agency, appropriators are taking a more active policymaking role, more like that of an authorizing committee than an appropriations committee. The results of this active role can be seen

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220 Dresser, When Science Offers Salvation, 96.
221 Halebsky Dimock, “Demanding Disease Dollars,” 224.
222 M. Boyce Ginieczki, “Are Appropriators Actually Authorizers in Sheep’s Clothing? A Case Study of the Policymaking Role of the House and Senate Appropriations Subcommittees on Labor, Health and
in the fact that these requests have an impact in generating scientific workshops and plans of study at the NIH. Rather than just responding to scientific opportunity, as Sampat and Hegde believe, these workshops and plans of study also create that opportunity.223 These workshops and plans of study create that opportunity by discovering new areas of research, coming up with potential new therapies for disease, and fostering collaboration between patient groups, industry, and academia. Former NIH director Harold Varmus argues that it is often difficult to determine if these conferences and plans of study result in more funding for the disease.224 However, additional funding is not the only possible outcome, and a focus on that sole outcome is a major flaw of the existing literature on this subject. Raising awareness and knowledge about the disease (which in turn reduces its stigma), and encouraging the NIH to develop a plan of study on that disease, can be just as valuable an outcome as additional dollars.225 By holding “meetings at which researchers, clinicians, and advocates discuss areas they perceive as underfunded.... NIH officials decide when affirmative steps are needed to encourage research interest in a particular area.”226 In fact, “one of the potential strengths of the NIH is its ability to encourage scientists throughout the country to pay greater attention to underserved and deserving problems, even when the new opportunities may not be obvious.”227 Patient groups recognize this opportunity, and lobby Congress to ensure that the NIH pays that kind of attention to their cause through the use of report language. This language effectively becomes a soft earmark for disease research.

Human Services, Education, and Related Agencies” (Ph.D. diss., Virginia Polytechnic Institute and State University, 2010), 10.
223 Hegde and Sampat, “Can Private Money Buy Public Science?”
225 Ibid.
226 Dresser, When Science Offers Salvation, 78.
When actor Seth Rogen testified before Congress in February 2014 in support of Alzheimer’s research, he was disappointed to find that he was mostly speaking to an empty room. After the hearing, he tweeted “Not sure why only two Senators were at the hearing. Very symbolic of how the Government views Alzheimer’s. Seems to be a low priority.” In order to determine if Rogen’s testimony is likely to have an impact on Congressional support of Alzheimer’s, this chapter will look at prior examples of celebrity advocacy on many different diseases. By doing so, the chapter will find that celebrity advocacy raises public awareness of the disease, and this awareness can help result in Congressional action. The audience for this testimony is thus both the general public (the celebrity’s fans who hear about the testimony through tweets or other forms of media coverage) and members of Congress. Celebrity advocacy’s power lies in the fact that they are able to reach both audiences.

Patient advocacy groups actively search for and recruit celebrity advocates with an interest in their disease. Online guides explain how to recruit these advocates, including tips on how to ensure the celebrities stay on message and do not embarrass the

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228 Ken Lombardi, “Seth Rogen Pleads with Congress Over Alzheimer’s, Slams Low-Senator Turnout,” 


organization.\textsuperscript{232} Despite these potential drawbacks, patient groups work with celebrities because of their ability to raise funds and public awareness.\textsuperscript{233} This is especially true for organizations “representing still-stigmatized diseases…[that] actively sought celebrities who could provide needed cachet and attention.”\textsuperscript{234} Chapter 1 of this thesis explored how the Lung Cancer Alliance worked to overcome the stigma of their disease by forming a coalition with another cancer group, while Chapter 2 showed how appropriations report language reduces the stigma of disease by making the NIH pay more attention to the disease and develop a plan of study for it. As will be seen in this chapter, another way that patient groups reduce stigma is by recruiting and cultivating celebrities with a personal interest in the disease (because they, their family member, or a friend have suffered from it). These celebrities then educate public about the disease and reduce its stigma. They do this because they believe that “one of the greatest attractions of political activism is the opportunity to shift the blinding and dehumanizing glare of celebrity that follows them onto a worthy cause that might otherwise remain obscure.”\textsuperscript{235} Many of the diseases discussed in this chapter would have not gained public attention and would have remained obscure without the celebrity (either because the disease is rare or because the common disease faces a stigma).

This stigma is reduced because “instances of celebrity health activism…spark public dialogues about issues related to a particular illness or injury such as preventative

care, testing, diagnosis, research, and/or general awareness.” In other words, “these public illnesses-featured in newspapers and magazines, in television news programs and documentaries and in book-length biographies-were compelling and often heart-breaking tales that Americans followed, discussed, and debated.” As Beck et al. argue, the celebrity and the public thus co-narrate a story about illness-a story that then works to convince Congress to support patients with that disease. While the literature on celebrity advocacy has studied this narration process, it generally leaves out the role of patient advocacy groups.

The Literature on Celebrity Advocacy

Scholars like Barron Lerner argue that celebrities are able to raise public awareness and reduce stigma by “democratiz[ing] the subject of illness. Because television, radio, newspapers, and tabloids reach all classes and races in society, information about celebrity illnesses is readily available.” When celebrities go public with their stories of illness, and that information becomes widely known, their fans take note. After all, “if you’re interested in the lives of celebrities who are healthy and their marriages, and their divorces, and their movies, and what they’re wearing on the red carpet-when they become sick, why not be interested as well?” While Brockington and Henson argue that celebrity advocacy alienates the general public, they focus on

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237 Lerner, When Illness Goes Public, 3.
238 Beck et al., Celebrity Health Narratives and the Public Health, 17.
239 Lerner, When Illness Goes Public, 273.
international aid issues.\textsuperscript{241} The literature on disease advocacy and celebrities in the United States generally agrees that celebrity advocacy can positively impact their fans’ health. An example of this impact is actress Angelina Jolie.

One study found that after Angelina Jolie revealed that she carried the BRCA gene and had had surgery to reduce her risk of developing breast and ovarian cancer, the number of women being tested for that gene increased by nearly 40\%.\textsuperscript{242} These fans found out about Jolie’s diagnosis and surgery through her op-ed in the New York Times,\textsuperscript{243} which is an example of how celebrity patients use the media to draw attention to their disease. This op-ed brought about “an unprecedented level of awareness about hereditary cancer, making words like mutation and mastectomy common terms.”\textsuperscript{244}

Furthermore, the patient group advocating for people with the BRCA gene (Facing Our Risk of Cancer Empowered, or FORCE) built on Jolie’s op-ed by being quoted in other media outlets about their work and the importance of advocacy. For example, FORCE pointed out that the Affordable Care Act’s requirements for genetic testing do not apply to men with the BRCA gene. At the conclusion of that article, the authors suggest that Jolie should testify before Congress.\textsuperscript{245} She has not yet testified, but the article’s mention


of that possibility shows the impact that celebrity testimony has on the media and on patient groups’ lobbying efforts.

When a disease is represented by groups that are registered to lobby that disease is more likely to gain media attention.\(^{246}\) This is because, as scholar Gary Andres explains, “the emergence of a hyper media age also has altered the structure, style, and substantive methods of lobbying.”\(^{247}\) It is for that reason that Jeffrey Berry’s “data on hearings and newspaper citations show that citizen groups have become prolific and enduring participants in legislative policymaking. Their success in getting their views before policymakers and the public is evidence of their acceptance as a normal part of interest group politics.”\(^{248}\) As Berry points out, Congressional hearings and media attention are important parts of advocacy, and patient groups (and the celebrities that they work with) are involved in both. While Thrall et al. argue that “rarely do even the most famous celebrities get sustained attention from mass media news organizations,”\(^{249}\) they are looking too broadly at all types of advocacy. By not limiting their sample to Congressional testimony, Thrall et al. are finding that all forms of celebrity advocacy have a combined impact that is less than expected. Their argument is flawed since the media sees Congressional testimony as being more newsworthy.

Furthermore, unlike Thrall et al., my study on celebrity testimony will focus only on patient-related topics, which is important because these topics are seen as particularly newsworthy since “they frequently attract the attention of celebrity advocates and may be

\(^{247}\) Andres, *Lobbying Reconsidered*, 120.
\(^{248}\) Berry, *The New Liberalism*, 32.
associated with notable people.” As this chapter explains, those notable people include both celebrities and members of Congress. It is the interaction of these two groups on matters of disease advocacy that draws media attention. The patient groups can provide the media with “an authentic voice or face on a story they cover to give it human interest.” But this is a reciprocal relationship: the patient groups also gain a lot from the media attention. Publicity such as that generated by media coverage of celebrity testimony works to create a positive image for the group.

The event of the celebrity testimony plays a key role because “properly portrayed, [it] can attract the attention of the mass media and inspire stories and photos that ultimately influence the attitudes of millions of readers and viewers.” Patient groups seek this type of attention because “they recognize that media coverage is a critical instrument for gaining public acceptance, political interest, and research funding.” Especially when televised, this testimony enables “prominent advocates to articulate their views before national audiences.” In this way, the testimony affects the public, members of Congress, and Congressional staffers.

Rebecca Dresser refers to the appropriations subcommittee hearings on the NIH as Mother Teresa’s waiting room, where the sick and afflicted wait for their turn to speak. Before the 1980s “when these groups testified before Congress, they rarely

253 Randall M. Packard et al., introduction to Emerging Illnesses and Society: Negotiating the Public Health Agenda (Baltimore: The Johns Hopkins University Press, 2004), 17.
254 Ginsberg, The American Lie, 58.
255 Dresser, When Science Offers Salvation, 73.
competed with each other.” The literature agrees that this changed when the “HIV/AIDS and breast cancer communities drew media attention to the importance of research funding for their causes. When these groups achieved success…some advocates began to complain that their constituents had been shortchanged in the funding process and a competitive environment emerged.” As a result of this competitive environment, patient groups sought to have celebrities testify on their behalf. These groups look for celebrity advocates because like Barron Lerner, they believe that “if you’re more of an A-list celebrity, you can get more money for disease, which seems like a crazy way to allot money for diseases, but that’s the way it is.” This study modifies Lerner’s theory by arguing that celebrity patient advocacy does not automatically result in a large increase in funding for the disease, but patient groups still use it as a lobbying tactic because it builds public awareness of the disease that can eventually translate into governmental action. In addition to increased dollars, governmental action on disease can take many different forms, including executive orders, appropriations report language, legislation authorizing governmental research programs, NIH-led meetings and symposiums, and patient advocacy group collaboration with other federal government agencies like the Centers for Disease Control and Prevention. These governmental programs might not be possible if it were not for the public awareness raised by the celebrities, awareness which decreases stigma and increases information.

A full analysis of this interplay between celebrity testimony, public awareness, and governmental action is lacking in the literature on celebrity advocacy. Furthermore,

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256 Kahn Best, “Disease Politics and Medical Research Funding,” 781.
257 Dresser, When Science Offers Salvation, 74.
even when the literature does mention celebrity testimony, if often leaves out the role that patient groups play in asking Congress to have these celebrities testify and then using that testimony in their lobbying efforts. This chapter will correct those deficiencies.

Methodology

This study comes uses media reports in the LexisNexis database and Congressional hearing transcripts in the ProQuest Congressional hearing database. By doing so, I compiled a collection of celebrity testimonies on disease from 2000-2014. I chose to focus on individual examples of celebrity testimony because, as Barron Lerner believes, the scholarship on “individual persons experiencing illness can also be done well…[these] stories remain as powerful as ever.”259 This study will add to that scholarship by looking at celebrities who not only personally experience that illness, but who experience it indirectly through their friends and family members. This indirect experience is important because it can still lead the celebrity to want to testify before Congress, and the stories portrayed in that testimony are still so powerful that they have an impact on Congress.

Celebrities speak about their disease experience in many different ways, including press conferences, briefings, commercials, and public appearances. Furthermore, as Linda Demaine notes, celebrities also lobby by giving campaign contributions and by meeting with lawmakers.260 However, this study focuses on testifying before Congressional committees (which unlike other forms of advocacy or lobbying becomes part of the permanent Congressional record). These “hearings play an important role in the federal

259 Lerner, When Illness Goes Public, 18.
lawmaking process,\footnote{Ibid.} and patient groups and celebrities are eager to be a part of that process. They know that “testifying at hearings helps to legitimize a group’s participation in the policymaking that follows”\footnote{Berry, \textit{The New Liberalism}, 19.} and so patient advocacy group lobbyists submit testimony requests to Congressional Committees on behalf of the celebrities. These lobbyists also know that in a crowded Congressional calendar, with many testimony requests, members of Congress and Congressional staff are more likely to respond positively to a request from a patient advocacy group if it involves a celebrity. Celebrities are therefore able to influence the testimony selection process, and then they influence Congress even more during their testimony.

However, these celebrities do not influence Congress on their own. Sometimes the celebrity has started their own patient advocacy group, and sometimes they work with one that was already in existence, but either way these celebrities always have a group behind them. As has been argued throughout this thesis, patient groups are becoming increasingly influential on Capitol Hill. Celebrities realize this, and know that to affect governmental change they must work with a group. Not only do the groups submit testimony requests on behalf of the celebrity, but they also follow up on the testimony by meeting with Congressional offices, ensuring continuing media coverage of the disease, and incorporating the celebrities’ testimony into all of their lobbying work.

My study will find that celebrity testimony occurs in both houses of Congress, in different Congressional committees, and in different periods of Congressional leadership. The celebrities include people who are famous for different reasons (actors, athletes, and musicians), as well as people who achieved recent fame and who have been well known
for a long time. I look at both rare and common diseases, and at celebrities who testified on conditions they personally suffered from as well as ones they became involved with because of their friends or family members. Taken as a whole, my analysis of these examples will show that the reaction to celebrity disease testimony is similar independent of these other factors. Celebrity disease testimony builds public and media awareness of the disease, and over time this awareness leads to governmental action.

Christopher Reeve

Actor Christopher Reeve, the founder of patient advocacy group the Christopher Reeve Paralysis Foundation, spoke before a Senate subcommittee in 2000 on stem cell research. During his speech, he emphasized that stem cells’ “extraordinary potential is a recent discovery. And much basic research needs to be done before they can be sent to the front lines in the battle against diseases.” Senator Specter, the Chairman of the Committee holding the hearing, wanted that basic research to become a reality. However, due to objections from pro-life Senators, he had to remove the stem cell research provisions from the appropriations bill in order to pass that bill. So Reeve’s testimony did not immediately result in research on stem cells. However, his testimony did generate media attention, and Christopher’s speech is mentioned in the media as an example of successful celebrity advocacy. This media attention resulted in public awareness, and eventually, governmental action. Nine years after Reeve’s testimony (and five years after his death), President Obama highlighted the actor’s activism when signing the executive order lifting the ban on embryonic stem cell research. The President emphasized that “as

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we restore our commitment to science and expand funding for promising stem cell research, we owe a debt of gratitude to so many tireless advocates…people like Christopher and Dana Reeve, who we wish could be here to see this moment.”  

Unfortunately they were not there, but their work still had an impact on stem cell policy.

*Ben Affleck*

Actor Ben Affleck testified before the Senate in 2001 during a hearing on “The Promise of the Genomic Revolution.” Mr. Affleck spoke about Joe Kindregan who he met while filming a movie and who suffers from a rare genetic disorder called ataxia-telangiectasia (A-T). The actor then worked with patient advocacy group the A-T Children’s Project to raise awareness of the disease by testifying before Congress. The actor called on Congress to double the NIH budget while also giving A-T “a bigger piece of the NIH pie…the support of the Congress and the investment of the NIH in A-T research is vitally important if kids like Joe are to have their hopes and dreams fulfilled.” The media praised Ben for raising awareness about this rare disease. The NIH budget did double between Fiscal Year 1998 and Fiscal Year 2003. Although, A-T was not mentioned in the appropriations bill the year Ben testified, in Fiscal Year 2003 (the last year of the doubling) the appropriations bill included report language on this disease. As was seen in the second chapter of this thesis, appropriations report language can have an impact on the NIH and create scientific opportunity on the disease by encouraging the Institutes to hold workshops and conferences. This was the case for A-T.

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The NIH held a workshop in 2004 on drug screening for that disease, and the patient group the A-T Children’s Project participated in that event.

Muhammad Ali and Michael J. Fox

In 2002, boxer Muhammad Ali and actor Michael J. Fox, both Parkinson’s disease patients, attended a Congressional hearing on this disease (Fox testified, but because the disease affects Ali’s voice, his wife read his testimony for him). In their report on the hearing, CNN noted the patients’ symptoms and mentioned that it was difficult to watch them struggle during the hearing. By doing so, this media outlet was educating its viewers about the problems suffered by Parkinson’s disease patients.

In his testimony the founder of the Michael J. Fox Foundation for Parkinson’s Research urged Congress and the NIH to support patients with that disease. He specifically urged the NIH Director to immediately appoint a permanent director of the NINDS. The NINDS had had a revolving door of Directors in the years leading up to the hearing. Although the NIH did not immediately name a permanent Director as requested by the actor, when it did do so a year later that Director would stay in office for more than a decade. That new Director, Story Landis, emphasized in her first budget request to Congress that “when I began as Director about six months ago, one of my first priorities was to meet with voluntary groups representing patients and their families.” That budget request also emphasized that NINDS was developing a comprehensive

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271 Senate Subcommittee on Labor, Health and Human Services, and Education, Committee on Appropriations, Parkinson’s Disease Research, Special Hearing, 107th Cong., 2d sess., 2002, 6-42.
translational research program, one that would meet Michael J. Fox’s goals of “an aggressive, proactive Bunsen burner to bedside approach to creating cures not just research.” Dr. Landis’ support of research that would translate to the bedside (despite her own background as a basic scientist focused on Bunsen burners) might not have happened without the Congressional appearance by Muhammad Ali and Michael J. Fox.

Dr. Landis also knew that in order to get Congress’ support of the NINDS, she had to support with patient groups like the Michael J. Fox Foundation, and that is why she made meeting with these types of groups a top priority.

David Hyde Pierce

Actor David Hyde Pierce, famous for his role as Niles in the TV show Frasier, testified before the Senate Appropriations Committee in both 2001 and 2002 on Alzheimer’s research. The actor became involved in this issue and worked with the patient group the Alzheimer’s Association due to his father and grandfather’s struggles with the disease. Mr. Pierce asked that Congress “escalate the war on Alzheimer’s disease by increasing funding to $1 billion within three years.” This speech received coverage in the Associated Press and CNN, which educated the public about this disease and Congressional action on it. And following the actor’s testimony, the Appropriations Bill released by the Senate included report language saying that “the Committee’s goal is to increase the NIH commitment to Alzheimer’s research to

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273 Senate Subcommittee on Labor, Health and Human Services, and Education, Committee on Appropriations, Parkinson’s Disease Research, 107th Cong., 2d sess., 6-42.
274 Senate Subcommittee on Labor, Health and Human Services, and Education, Committee on Appropriations, Alzheimer’s Disease FY02 Special Hearing, 107th Cong., 1st sess., 2001, 28-44.
$1,000,000,000 as soon as possible.”276 The House did not include the same recommendation,277 and Alzheimer’s did not receive that level of funding, but Mr. Pierce did have an impact on the Committee before which he testified.

**Julia Roberts**

Actress Julia Roberts testified before a House Committee in support of Rett Syndrome research in 2002.278 Rett Syndrome is a genetic disorder that mostly occurs in females and causes problems in brain function.279 The children eventually lose their ability to walk, speak, and use their hands. Julia Roberts became close to Abigail Brodsky, a young girl who had the disorder, and who unfortunately died before Roberts was able to testify.280 This experience led the actress to testify on behalf of the patient group the International Rett Syndrome Association. During her testimony, Ms. Roberts explained that “each of these innocent little girls begins life with unlimited potential, but once this disorder takes hold their lives take on incredible hurt and challenge.”281 This speech attracted attention in media outlets that do not usually cover rare diseases, including *People Magazine*282 and *Entertainment Weekly*.283 Because Julia Roberts was

involved, these publications that normally focus more on who celebrities are dating, explained that “Ret Syndrome leaves its victims unable to communicate and control their body movements, rendering many of its patients severely disabled by the age of three.”

These articles therefore educated the general public about a rare disease that only affects 3,000 people in the United States.

The actress also educated Congress. During her testimony Julia had asked Congress to increase the funding for Rett Syndrome research to $15.5 million in the next fiscal year. Although they are not fully meeting Julia Roberts’ funding request, research on Rett Syndrome has grown from $3 million at the time of her testimony to $12 million today. Adjusted for inflation, that is an increase of $8 million.

Julianne Moore

Tuberous sclerosis complex (TSC) is “a genetic disorder that causes non-malignant tumors to form in many different organs, primarily in the brain, eyes, heart, kidney, skin, and lungs.” Actress Julianne Moore is not personally affected by TSC, but after meeting a child with this disease (Tommy Lindsey) she became an advocate for the disorder. Tommy’s father recognized the power of celebrity advocacy and when he ran into her on the street he told her about his son’s struggles and used “the chance

encounter in the hopes of persuading Ms. Moore to help the Lindseys heighten awareness of TSC.”

She agreed to do so, and her role as the spokesperson for patient advocacy group the Tuberous Sclerosis Alliance has helped the group to get press coverage. This is because the story of her meeting with the child provided a human-interest angle to an article about a rare disease. Newspapers like USA Today would not have written about a disease like TSC if it were not for Julianne Moore’s involvement, and the readers of that paper might not have wanted to read the article if they had not seen her name in the headline. The article raised awareness about TSC by educating readers about the symptoms and giving them links to other resources.

Julianne Moore raised the same type of awareness when she testified before Congress on the disease. During her testimony, she explained how she became involved with the patient group “when [she] realized that there were 50,000 Americans diagnosed with this debilitating disorder, [and] wanted to do everything in my power to fight for a cure.” She asked the House Appropriations Committee to join in this fight by funding TSC research at the Centers for Disease Control and Prevention (CDC). While the Committee did not give the Alliance the $2 million they hoped for, the Appropriations Bill did include report language directing the CDC to look into the feasibility of an initiative with the Alliance to “collect and analyze data from a network of TSC clinics;

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support surveillance and epidemiological studies; and to educate health care professionals and teachers who come into contact with TSC patients.” Julianne Moore’s testimony therefore raised awareness of the Alliance’s work and of the importance of research on TSC.

Fran Drescher

Actress Fran Drescher, famous for her role in the TV show *The Nanny*, spoke before a Senate Committee in 2005. In her testimony, Fran told the Senators that “this June 21, I will be 5 years well from uterine cancer. But for 2 years and eight doctors, I was misdiagnosed and mistreated for a perimenopausal condition that I did not have.” In addition to her Congressional testimony, Fran told her story by writing a book and founding her own patient advocacy group, Cancer Schmancer. By doing so, she was raising awareness for gynecological cancers, and letting women know to be aware of the symptoms while being wary of misdiagnosis. These educational efforts also helped to dispel the stigma of diseases that are often not talked about because of their location in women’s bodies. Fans of the actress read the book and visited her group’s website to learn more about gynecological cancers. Congress also listened to her testimony and learned more. After her testimony, they passed a law that created a public awareness campaign about the diseases.

Bradley Whitford

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Actor Bradley Whitford was a college friend of Jonathan Shestack, whose son has autism and who founded the patient advocacy group Cure Autism Now.296 Bradley Whitford helped his friend to raise public awareness of this disease by incorporating autism into an episode of Bradley’s hit TV show The West Wing. The episode even had a poster from the patient group Cure Autism Now poster displayed in the background. In addition, the actor testified on the disease before Congress and said that he became an advocate because “these children have no voice and this seems an appropriate use of the attention that actors get to bring voice to them.”297 Specifically, Whitford gave voice to autistic patients by asking Congress to fully fund the Combating Autism Act by appropriating $168 million in federal funding for autism research. After his testimony, Congress did appropriate these funds in FY08.298

Sheryl Crow

Singer Sheryl Crow, a breast cancer survivor, testified before the House Energy and Commerce Committee in support of the Breast Cancer and Environmental Research Act. Her testimony was part of the National Breast Cancer Coalition’s efforts to pass that legislation, and during her testimony Sheryl explained that the leader of that group, Fran Visco, had asked her to learn about the bill. In doing so, the singer came to believe that the legislation was important “because I want to know what causes this disease—for me, for the 2.3 million others who share this disease with me, and especially for all those who

297 Senate Committee on Appropriations, FY08 Labor, Health and Human Services, and Education Appropriations Act, 110th Cong., 1st sess., 2007, 259-311.
are at risk, or putting themselves at risk without even knowing it.” She urged Congress to take action by saying that “the public cares deeply about the environment and about breast cancer. And they look to you to help solve these problems. Don’t let us down.”

The public might no have known that Congress was letting them down if it were not for Sheryl’s testimony. However, because of that testimony, Congress knew they had to take action. This legislation, which authorized federal research into how the environment relates to breast cancer, became law a few months after Sheryl’s testimony.

*Lance Armstrong*

Tour de France winner Lance Armstrong is a testicular cancer survivor. Even media reports that speak negatively about his doping speak positively about his cancer activism, and his ability to raise awareness. For example, the media talks about the efforts of his patient advocacy group, the Lance Armstrong Foundation, especially that group’s Livestrong bracelets that have raised millions of dollars for cancer.

Recognizing his influence, Senators Kay Bailey Hutchison (R-TX) and Ted Kennedy (D-MA) had him testify in support of their comprehensive cancer legislation. During his testimony, the cyclist urged Congress to “be ruthless and relentless. I encourage all of us to do that. Renew the war on cancer…and ultimately make sure that our kids and our grandkids don’t have to face this.” The war on cancer legislation did not pass Congress, but

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300 Ibid.


provisions of the bill regarding insurance coverage for clinical trials were included in the Affordable Care Act. 305

**Nick Jonas, Mary Tyler Moore, and Sugar Ray Leonard**

Singer Nick Jonas, part of the teenage pop group the Jonas Brothers, suffers from Type 1 Diabetes, as do actress Mary Tyler Moore and boxer Sugar Ray Leonard. In 2009 they took part in a lobbying effort by patient advocacy group JDRF. This organization brought children from all over the country to DC to lobby Congress on Type 1 Diabetes. Nick Jonas, Mary Tyler Moore, and Sugar Ray Leonard served as an inspiration to the non-celebrity children with diabetes who attended the event to lobby their members of Congress. These celebrities (especially Nick Jonas) also grew public and media awareness of this issue. For example, the local media in the kids’ hometowns wrote articles highlighting the fact that the child went to DC and met Nick Jonas and this meeting helped give the child the confidence necessary to live with the disease and advocate on its behalf. 306 The readers of those local newspapers may have been fans of Nick Jonas but they would not have known much about Type 1 Diabetes before reading those articles.

Nick Jonas, Mary Tyler Moore, and Sugar Ray Leonard also advocated on the disease by testifying before the Senate Homeland Security and Government Affairs Committee. Nick Jonas asked the Committee “to join me in supporting the renewal of the Special Diabetes Program next year so that researchers can continue to find a cure for our


306 For example, see Eric Lindquist, “Meeting Obama Not as Cool as Hugging a Jonas; Diabetic Children Get Chance to Meet the President and Connect with Other Diabetics.” *Eau Claire Leader-Telegram*, June 28, 2009. Also Melanie Creamer, “Seeking a Cure for Diabetes; Two Mainers Testify Before Congress and Get to Meet President Obama and Nick Jonas.” *Portland Press-Herald*, July 8, 2009.
disease. My life depends on it. All our lives depend on it.”

This testimony was successful because although the stand-alone bill to reauthorize the Special Diabetes Program did not pass, the program was reauthorized as part of a larger bill extending several provisions of the Medicare and Medicaid programs. This bill passed because of the continued lobbying efforts of JDRF even after the celebrities’ testimony.

Louis Gossett, Jr.

In 2010, actor Louis Gossett, Jr. (famous for his role in the movie An Officer and a Gentleman) testified before Congress during a hearing on prostate cancer screening. Mr. Gossett is a prostate cancer patient, and during the hearing he emphasized that “there is a percentage of African-American men who do get [prostate cancer], and they also cannot afford to see a doctor.” His goal was to help them by going “public with the fact that I have prostate cancer…I am a gentleman of service these days, and to serve all of the people who have prostate cancer who like to keep it a secret, I came out of the closet and said so.” He said so by publishing a book and by working with his foundation, Eracism. Through this activism, he was raising public awareness of the disease and the health disparities facing African-American men.

Louis Gossett was also educating Congress about these issues. The member of Congress leading that hearing, Rep. Edolphus Towns (D-NY), introduced prostate cancer legislation in both 2010 and 2011. This legislation included language directing the

308 A bill to amend the Public Health Service Act to Reauthorize the Special Diabetes Programs for Type 1 Diabetes and Indians Under That Act, S 3058, 111th Cong., 2d sess.
310 House Committee on Oversight and Government Reform, Prostate Cancer: New Questions about Screening and Treatment, 111th Cong., 2d., 2010, 36-37.
311 Ibid.
Secretary of Health and Human Services, the Secretary of Veterans Affairs, and the Secretary of Defense to direct a research program that would “better understand the etiology of the disease…in different ethnic, racial, and socioeconomic groups.”312 This research program would include African-American men, as Louis Gossett had urged.

Jean Smart

Actress and Type 1 Diabetes patient Jean Smart testified on that disease before the Senate Special Committee on Aging in 2013. Unlike Nick Jonas, who also testified on that disease, Ms. Smart’s appearance was likely to appeal to an older generation who watched her on shows like Designing Women and Frasier. Type 1 Diabetes used to be known as Juvenile Diabetes, but Ms. Smart’s testimony was part of a larger effort by the patient group to educate the public that people with this disease are living longer. In fact, that group changed its name from the Juvenile Diabetes Research Foundation to just JDRF.

During her testimony, the actress thanked Congress “for all you’ve done to promote Type 1 Diabetes research and ask that you please continue your efforts.”313 Like Nick Jonas, Ms. Smart’s testimony had an impact. The hearing discussed the Special Diabetes Program (SDP) and its reauthorization. Senator Collins, the leader of the committee, noted that she had helped pass an extension of this program 6 months previously. However, it was due for another extension in 2014. This 2014 extension passed as well.314

313 Senate Special Committee on Aging, Diabetes Research: Reducing the Burden of Diabetes at All Ages and Stages, 113th Cong., 1st sess., July 10, 2013.
Findings from the Study on Celebrity Patient Advocacy

Jean Smart’s testimony is an example of how even if celebrity activism does not immediately result in a legislative victory for patient advocacy groups, their testimony can still be part of a long-term strategy. In their testimony, celebrities “portray what they are doing—their act-as giving voice to the voiceless.” These celebrities give their voice to the patients suffering from the disease, but they also give their voice to the groups representing those patients. Patient advocacy groups use the celebrity testimony to garner media attention, and “getting a star can mean the difference between whether a hearing gets on the evening news or not.” In addition to the evening news, celebrities use popular magazines like People, TV dramas, books, and social media to build public awareness. These efforts reduce stigma by showing that even famous people (and their friends and family members) can suffer from these diseases. Members of Congress read these media reports too, and combined with the testimony, this press coverage helps Congress to become more aware of the patient advocacy group’s legislative priorities.

Scholars Deepak Hegde and Bhaven Sampat look at whether celebrity advocacy has more of an influence on Congressional attention to disease than patient advocacy group lobbying, but they fail to see that patient advocacy groups use those celebrities as part of their lobbying efforts. Patient advocacy groups recruit these celebrities, they work with the media to have coverage of the hearings, and they follow up with the Congressional offices that hear the celebrity testimony to ensure that those offices

317 Hegde and Sampat, “Can Private Money Buy Public Science?”
continue to remember the testimony. This process thus shows the continuing influence of both celebrities and patient advocacy groups. Celebrities are not the only lobbying tactic used by patient groups (as chapters 1 and 2 showed) but they play an important role in building awareness and affecting change (among both the general public and members of Congress). This helps elevate these diseases so they become a priority on Capitol Hill.

Seth Rogen’s quote at the start of this chapter indicated that he thought Alzheimer’s was a low priority for Congress because only two Senators attended his hearing. However, Seth’s testimony and tweets generated media attention from *Time Magazine*, *The New York Daily News*, *Good Morning America*, and many more. This attention helped with his goal (and the goal of the patient groups he worked with, the Alzheimer’s Association and Hilarity for Charity) of reducing “the shame and stigma associated with the disease.” His fans heard his testimony and learned not to be ashamed about their own family members’ struggles with the disease. Congress also listened to his plea and a year later the Senate committee before which he testified proposed a 60% for Alzheimer’s research at the National Institute on Aging (NIA).

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This is the single largest increase in Alzheimer’s funding to date. It will remain to be seen if additional patient advocacy groups invite celebrities to testify as a result of the Alzheimer’s victory. If they do, future patient advocacy group researchers should interview the members of Congress, the leaders of patient groups, and their celebrity advocates to see if this testimony has an impact.

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CONCLUSION

PATIENT ADVOCACY NOW AND IN THE FUTURE

This thesis explored three ways that patient groups have been successful: by forming a coalition with another disease, by using appropriations report language to encourage the NIH to support research on their disease, and by having celebrity advocates testify on Capitol Hill. These efforts are successful because these groups provide information and insight on a topic that touches all Americans (including members of Congress): how to deal with disease when it strikes you or a loved one. As Maureen Casamayou notes, “disease lobbies have a built-in advantage with their particular area, because life-threatening disease tends not to discriminate, so often there are people in positions of power who have already experienced—directly or indirectly, through spouses, siblings and friends—the devastation, pain, and suffering from such a disease.” When struck by a serious disease, people want more information, research, and access to treatment options—and Congress is no exception to this rule. Only 17 members of Congress are physicians, but all 535 are patients or the friends and family members of patients. In addition, all 535 have constituents who are patients and the friends and family members of patients. Knowing this, Congress turns to patient groups for information, who they are familiar with because of the patient groups’ lobbying efforts (including forming coalitions, advocating for appropriations report language, and using celebrities to build public and governmental awareness). This process enables patient groups to reduce the stigma of their disease on Capitol Hill. The groups’ resulting influence on Congress and the NIH is also why patient groups are an important research topic.

Future researchers may want to look at the potential downsides of patient advocacy. Paul Starr examines how patients with mental illness were among the first to challenge physicians and the medical establishment. This movement “represented the extreme edge of what became a broader, more moderate kind of health consumerism in the 1970s.” Partly as a result of these advocates, as well as the support of fiscal conservatives who wanted to lower the costs of running the hospitals, the number of mentally ill patients in public psychiatric hospitals decreased from 885,010 in 1955 to 71,619 in 1994. However, the decrease in the number of hospital patients has not been because of a decrease in the number of mentally ill people. Instead, these patients are now often homeless or in jail. In fact, 40% of mentally ill patients have been in jail or in prison. Advocacy helped release them from the public hospitals, but homelessness or jail are not better options.

Another downside of patient advocacy is that in their efforts to get donations, grow their membership, and advocate to Congress, patient groups can sometimes contribute to the “pervasive misunderstanding about the slow pace of clinical research and its frequent failure to deliver.” As Rebecca Dresser concludes in her study of the ethics of patient advocacy, “thanks to research advocacy, patients have more freedom to

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seek help from promising but unproven interventions.” These unproven interventions pose a possible threat to patient health. However, the materials published by patient advocacy groups rarely mention “the possibility that research interventions might prove ineffective or more risky than standard therapy.” Patients do not have the scientific know-how to weigh the risk-benefit equation fully, and faced with a possible threat to their life, these patients are willing to take almost any step. This is what happened in the 1980s when more than 100,000 women with advanced breast cancer underwent a bone marrow transplant. Unfortunately, clinical trials later showed that this treatment was killing women faster than the cancer itself. These trials ironically took longer than normal to complete because women were reluctant to enroll—instead they got the bone marrow transplants from physicians outside of the trials who could guarantee that they would not be in the control group. If breast cancer advocacy groups had not promoted these treatments and urged insurance companies to cover it, the women might have lived longer and not suffered through an extremely burdensome treatment.

Congress also lacks scientific know-how. In his memoir, former NIH Director Harold Varmus recounted the dilemma he faced when Senator Tom Harkin (D-Iowa) called him to urge for the creation of the National Center for Complementary and Alternative Medicine (NCCAM). Senator Harkin became a supporter of alternative medicine because he believed that bee pollen cured his allergies. However, this treatment

331 Ibid., 58.
has not been proven to work and can cause life-threatening reactions in some people.\textsuperscript{334} As Dr. Varmus found, though, “Resistance…[was] especially difficult because the advocates are among the agency’s best friends.”\textsuperscript{335} Senator Harkin was one of the NIH’s strongest Congressional advocates, and Dr. Varmus therefore had no choice but to agree to form the NCCAM. An investigation by the \textit{Chicago Tribune} found that since it’s founding, the NCCAM “has spent millions of taxpayer dollars on studies with questionable grounding in science.”\textsuperscript{336} Similarly, in debates over the Affordable Care Act, Senator Barbara Mikulski (D-MD) urged that the law include mammography coverage for women aged 40-50, even though there is scientific evidence that mammograms for women in that age range produced “so many false positives, compared to lifesaving diagnoses, that they caused more expense, more needless treatments, and more scares than they were worth.”\textsuperscript{337} Future patient group scholarship should look at efforts to reduce those types of unnecessary treatments.

One example of an initiative to reduce unnecessary treatments is the House of Representatives Energy and Commerce Committee’s 21st Century Cures Initiative. This Initiative “takes a comprehensive look at what steps we can take to accelerate the pace of cures in America.”\textsuperscript{338} The Committee is examining all stages of the medical research process—from basic science, to drug and device development, to the delivery of treatments to patients. This legislation will be a fruitful area of research for scholars of interest

\textsuperscript{335} Varmus, \textit{The Art and Politics of Science}, 173.
\textsuperscript{337} Brill, \textit{America’s Bitter Pill}, 167.
groups, and especially patient advocacy groups. Patient advocates have been involved in the drafting of this legislation by submitting comments and by participating in forums and hearings. The questions for scholars will include how Congress will react to those suggestions and incorporate them into the legislation, and what this process says about the impact of patient advocacy.

The 21st Century Cures Act envisions that that the legislation will enable medical scientists to develop new treatments for disease. However, questions remain as to who should get these new treatments and when. In an era of limited budgets, with health care costs rising, should all patients get the newest (and most expensive) treatments? One example of this controversy is Sovaldi, the new treatment for Hepatitis C, which sells for $1,000 a pill in the United States. A typical three-month course of treatment costs $84,000. Since many patients with this disease are on Medicaid, the cost of this treatment will fall on the state and federal government. Will those governments be able to provide the drug to all patients with Hepatitis C? Will patient advocacy groups and the government be successful in pressuring the makers of Sovaldi to lower its price?

Similar questions will be raised for many other expensive diseases and treatments. Given these economic uncertainties, patient advocates may look to other funding models for medical research and drug development. For example, the venture philanthropy model pioneered by the Cystic Fibrosis Foundation and Vertex Pharmaceuticals led to the

The development of the first treatment aimed at the genetic cause of that disease. The Foundation invested $75 million in that drug, but in return it asked for a percentage of the sales. Other nonprofits, such as the National Multiple Sclerosis Society, took note of the success of the Cystic Fibrosis group, and are now pursuing similar strategies. More research by patient advocacy scholars will be needed to see how Congress will react to this new model, and whether funding for the NIH and other federal government programs will be affected as a result.

Another area of future interest group research is Congressional and patient advocacy on diseases caused by the Human Papilloma Virus (HPV). This virus can lead to cervical, anal, throat, vaginal, vulvar, and penile cancers. There are vaccines that can protect against this virus. However, there is also controversy over whether to require children to have the vaccine, and if so at what age. Like HIV/AIDS, HPV can be sexually transmitted and thus faces a stigma. In the 1980s, the advocacy efforts of the HIV/AIDS patient groups “led to the establishment of new mechanisms for regulating drugs, such as expanded access and accelerated approval. Their arguments have brought about shifts in the balance of power between competing visions of how clinical trials should be conducted.” As a result of these new drugs and clinical trials, HIV/AIDS has been transformed from a quick death sentence to a chronic but manageable disease. Other

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patient groups learned from this example and became activists as well using the steps outlined in this thesis, and the HPV groups would be wise to do the same in the future.

As the HIV/AIDS groups showed, when patient advocacy results in the development of new drugs and treatments this can affect millions of Americans by reducing the burden of disease and disability. The advocacy described in this thesis therefore has the potential to transform lives. Members of Congress learn about this potential through the groups’ lobbying efforts (including coalitions, appropriations report language, and celebrity testimony) and realize the possible impact on all patients (including themselves, their friends and family members, and their constituents). This realization is why they support these groups.
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Curriculum Vitae

Roxanne Yaghoubi was born in Phoenix, Arizona on September 10, 1983. Following her graduation from Swarthmore College in 2005, she moved to Washington, DC where she started her career as a health care lobbyist at the consulting firm the Health and Medicine Counsel of Washington. After two years at that firm, she worked on Capitol Hill for Congressman Michael Arcuri (D-NY) from 2007-2010. She currently works at the Academy of Radiology Research/Coalition for Imaging and Bioengineering Research, where she educates the public about the benefits of imaging research. In addition, she advocates before Congress on the importance of supporting that research at the National Institutes of Health. In this role, she works closely with patient advocates who depend on imaging for the diagnosis and treatment of their illnesses. This experience led to her interest in patient advocacy groups and their lobbying work on Capitol Hill, and to the writing of this thesis.