

The Political is Personal:

*Examining the Role of Personal Connection to
a Disease as an Access Point for Single-
disease Interest Groups*

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Entering the Conversation: Improving My Understanding of the Research Process

I chose to do a qualitative comparison of the ME Action Network and the MS Society because case studies of two single-disease interest groups advocating on behalf of patients with diseases that have a similar disease burden but very different levels of funding allowed me to isolate Congressional representatives with a personal interest in the disease as a single variable. This research design required data drawn directly from the two advocacy groups and theoretical research about the lobbying process.

Access to current academic journals through the library databases helped me place my research within the current academic conversation. Reading current and older journals revealed what questions had been asked and, equally crucial, what questions had not yet been investigated. Once I knew what other scholars had written, I focused on trying to fill one small gap in the existing research. I studied lobbying strategies that are effective specifically for interest groups that represent a single disease. Previous research had examined lobbying strategies, but no one had looked at the unique challenges facing interest groups with limited constituencies and little public recognition. I identified this gap only by reviewing political science journals through the library portal.

I learned to design a testable hypothesis and to collect and synthesize publically available information. This data was the basis of my research design and finding it taught me how to ask an answerable question about the bigger question of “How can a single-disease interest group lobby effectively when there are so many patient advocacy groups competing for funding?” Researching and writing this paper showed me the importance of building upon past research, establishing a sound theoretical framework, and then attempting to ask the question that has not yet been answered.

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Introduction:

Approximately 133 million Americans live with a chronic illness (“The Power of Prevention”). Government funding through the National Institutes of Health and other programs are an important source of research funding for the doctors and scientists who study and treat these diseases and syndromes. I am one of those Americans and live with a disease that very few doctors specialize in and for which few treatments options exist, at least in part because of lack of funding. This experience led me to ask what lobbying strategies are effective specifically for interest groups that represent a single disease. Lobbying strategies are well studied, but less research has been done to examine the strategies used by interest groups representing smaller and very specific constituencies, such as those affected by a single disease.

Reviewing general strategies of interest group lobbying and the research concentrated on single-disease interest groups shows a variety of ways in which interest groups can gain access to legislators, a necessary first step to legislative influence. This paper uses the structural framework of Hall and Deardorff’s theory of coalition-based success to argue that single-disease advocacy groups gain access to representatives when they target those Congressional representatives with a personal interest in the disease. Hall and Deardorff’s theory explains how groups and individuals unite based on shared interests. Rather than attempting to change a legislator’s stance on an issue, Hall and

Deardorff suggest that interest groups should and do focus on legislators who already hold a similar position to the interest group.

Three Approaches to Interest Group Lobbying:

In order to evaluate what lobbying strategy is effective for single-disease interest groups, the relevant interest group literature on the nature of lobbying may be divided into three schools of thought. Each school has its own theoretical and methodological subsets and disagreements. The first school in this paper focuses on the importance of identity in interest groups. Counter-mobilization theory is an important part of the research on the role of identity in interest groups (Truman 1960; Lowery, David et al. 2005; Boehmke, Bowen 2010; Abdelal, et al. 2006). The second school is exchange theory. Exchange theory may take many forms but its basis is always a transactional relationship between the interest group seeking support for a political goal and the legislator seeking re-election (Denzau, Munger 1986; Keiser, Miller 2009; Salisbury 1969). The third coalition-based success school of thought posits that disease-specific interest groups succeed when they are part of constellation of players collaborating on similar goals (Best 2012; Epstein 2016; Hall, Deardorff, 2006).

Each of these schools of thought provides a useful framework with which to analyze the extent to which lobbying helps disease-specific interest groups to succeed. However, the coalition-based success school of thought offers insights into the lobbying process of disease-specific interest groups that exchange theory and the theory of identity-based interest groups do not. The coalition-based success school of thought is the best fit for disease-specific interest group because disease-specific interest groups are usually (although not always) smaller organizations and have a greater need to form

coalitions. Therefore, this paper will focus on the coalition-based success school of thought.

The Theory of Identity-Based Interest Groups

Identity is an important component of single-disease organized interests because single-disease advocacy groups typically have well-defined constituencies of patients and their families, caregivers, and medical personnel involved with the disease. Many scholars (Truman 1960; Lowery et al. 2005; Boehmke, Bowen 2010; Abdelal, et al. 2006) have examined the role of identity in forming and continuing interest groups. David B. Truman was seminal thinker in this area. In his 1951 treatise, he argued that interest groups or political associations are a fact of human society and that they determine a person's experiences (Truman 1960). Truman also introduced the theory of counter mobilization at the same time (Truman 1960). Truman defines counter-mobilization as series of reactions in which an association responds to actions of other associations (Truman 1960). Truman argues that this mobilization happens in waves (Truman 1960). Applying this conceptualization of the interactions between different groups to single-disease interest groups highlights how the actions of a single-interest disease group may determine and be determined by decisions of researchers and the medical field, government entities (Congress, NIH, CDC, etc.), interest groups representing other constituencies with a stake in research funding such as medical professionals and pharmaceutical companies, and other single-interest disease groups. David Lowery has since criticized Truman's counter mobilization theory as unworkable because it is too broad to be useful as Truman presented it and too limited in its application when refined (Lowery et al. 2005).

While Truman and Lowery focus on the behavior of identity-based interest groups, other scholars have examined how shared identity forms interest groups (Abdelal, et al. 2006). Rawi Abdelal, Yoshiko M. Herrera, Alastair Iain Johnston, and Rose McDermott synthesize previous scholarship on the political nature of collective identity (Abdelal, et al. 2006). They suggest that collective identity in the political sphere is an important and necessary concept in examining a variety of social sciences but submit that its current definition is too broad to allow comparisons between scholars (Abdelal, et al. 2006). Defining identity as the reason for the group to form (content) and the degree to which members of the groups agree with each other would remedy this problem by establishing a definition that could be applied to almost any identity, including those identities formed by disability and disease (Abdelal, et al. 2006). Using Abdelal's definition of collective identity compliments Rachel Kahn Best's examination of the systemic, cultural effects of single-disease advocacy (her work is included in the coalition-based success school). It also helps to explain how the dollars per death metric, which uses mortality rates as a way to determine and compare funding levels between diseases, became popular with both lawmakers and a great number of single-disease interest groups (Best 2012). It is important to note that this mortality metric has decreased funding and skewed lawmakers opinions' of chronic illnesses that may have a low mortality rate but still have a significant impact on patients' daily life and ability to function at work and in their communities. Both multiple sclerosis (MS) and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) have low mortality rates and therefore the MS Society and ME Action Network, two disease-specific interest groups that lobby on behalf of patients with the named disease, do not use dollars per death as

way to communicate the seriousness of their respective diseases to lawmakers but they do exist in an environment accustomed to this metric and therefore are battling against it when they lobby representatives.

Exchange Theory:

Exchange theory has, in some way, influenced the development of all subsequent understandings of interest group lobbying. In 1969, Robert H. Salisbury theorized that interest groups create a principal-agent relationship in which the interest group supplies support and expertise as a means of gaining access to the legislator (Salisbury 1969). Arthur T. Denzau and Michael C. Munger accept the basic premise of exchange theory of lobbying that was expounded by Salisbury in 1969. They then refine exchange theory to suggest that the practice succeeds when interest groups seek out legislators whose constituents are not concerned by the proposed policy (Denzau, Munger 1986). This theory has significant implications for single-disease interest groups whose policy goals are likely to be of interest to only a small subset of the population. It offers a strategy that turns what could be a disadvantage, too few constituents concerned enough to mobilize, into an advantage; because few constituents are concerned with the policies of interest to single-disease interest groups legislators are more likely to grant access and follow the recommendations of single-disease interest groups that can provide expertise.

Hall and Deardorff reject the exchange theory of lobbying because they see the common interest between interest group and legislator as preceding, not giving birth to, any collaborative effort (Hall, Deardorff 2006). They argue that lobbyists assist those representatives whose interests already coincide with their own by assuming responsibility for favored projects that would not be financially feasible for the

legislator's office to complete. Hall and Deardorff refer to this phenomenon as a "form of legislative subsidy" and believe its recognition of budget constraints distinguishes it from exchange theory.

Coalition-based Success:

Hall and Deardorff's legislative subsidies fall under the umbrella of the coalition-based success school of thought. Forming a coalition of interest groups and legislators is an effective strategy because it matches the needs and goals of legislators and interest groups to create an interlocking puzzle of political and policy-based success (Hall, Deardorff 2006).

Rachel Kahn Best focuses specifically single-disease organized interests. She examines three areas of lobbying: direct benefits of advocacy, distributive changes resulting from advocacy, and systemic effects of advocacy (Best 2012). Each of the areas relies, to a greater or lesser extent, on the interest group's ability to enlarge its presence through alliances (Best 2012). She argues that the systemic, cultural effects of these organizations on public opinion and the funding process have been ignored and are an important aspect in understanding the effects of disease advocacy (Best 2012).

Steven Epstein follows the same path Best did to examine both the direct and systemic changes that result from the activities of single-issue disease advocacy (Epstein 2016). He argues that patient-centered groups are particularly effective in creating system-wide changes in research, management, and treatment of illness when they form alliances with other patient-advocate groups instead of focusing exclusively on alliances with experts within a disease (Epstein 2016).

Coalition-based success is the most useful lens with which to examine the effectiveness of lobbying for disease-specific interest groups because it addresses the unique challenges and advantages faced by disease-specific interest groups. One method of coalition building is for a single-disease interest group to find a representative who already has a personal stake in the disease. The next section examines the effectiveness of this strategy.

Models of Collaborative Success:

Single-disease interest groups in the United States must find ways to make their agenda relevant to elected officials who may or may not be affected by the issues with which the groups are concerned. In order to convince elected officials of their agenda, these groups spend a significant amount of time and effort lobbying. One lobbying method is to pursue the support of those elected officials who already have a pre-existing interest in the goals or agenda of the single-disease interest groups (Hall, Deardorff, 2006). This theory of lobbying may be formulated as:

A single-disease interest group seeks representatives with complimentary agendas

Hypothesis:

Through collaboration with these elected officials the single-disease interest group gains access and is more likely to succeed.

The more a single-disease interest group is able to link its agenda to the existing goals and interests of elected representatives, the greater its access, and thus it is able to accomplish more of its agenda.

Examining if a single-disease interest group can gain access to legislators by courting representatives with a personal tie to the disease in question tests this hypothesis.

A Comparative Case Study of the Connection between Personal Interest and

Access: The MS Society and ME Action Network:

Comparing the advocacy efforts of the MS Society and ME Action Network demonstrates that single-disease advocacy groups gain access to representatives when they target those Congressional representatives with a personal interest in the disease. The MS Society and ME Action Network are both single-disease interest groups with the stated interest of improving the lives of patients living with each society's respective diseases through research and advocacy. Since this is not a medical paper, but a political science one, I will follow the recommendation of Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome; Board on the Health of Select Populations; Institute of Medicine and refer to ME/CFS as a disease throughout the rest of this paper in order to convey the severity of this illness to the layperson (Clayton 2015).

The two advocacy organizations were chosen because each disease effects primarily women and have a close, although not identical disability weight but very different levels of funding (Dimmock 2017). Gender is an important variable to control because the role gender plays in the perception and funding of diseases is contentious and poorly understood (Dresser 1992). Both politics and medicine have been and, in many ways, continue to be male-dominated fields. This gender imbalance leads to skewed research funding. Controlling gender as a variable avoids the issue. Disability weight attempts to quantify the burden of a disease on patients. Dimmock calculates that ME/CFS has a disability weight of 0.44 (Dimmock 2017). The closest disability weight she found was the 0.27 to 0.28 disability weight of MS (this disagreement between

researchers about the disability weight of MS is within a reasonable margin) (Dimmock 2017).

The comparison between the two groups is not perfect because MS has been recognized by the medical community and the government for longer than ME/CFS has been. However, I account for this discrepancy by also examining early efforts of the MS Society when MS did not have the public profile it does today. Additionally, the MS Society has a larger budget than the ME Action Network but the comparison is still worthwhile because both groups have the same mission of advocacy to improve the lives of patients living with the respective illnesses. The similarity of goals between the two groups acts as the control. The cases vary because the ME Action Network has not been able to identify a congressional representative with a personal connection to ME/CFS while the MS Society has a long history of using this tactic.

The first independent variable is identification of representatives with a personal experience with the disease or other comparable illness that may create empathy for other illnesses. Identification of these representatives is gauged by public mentions of lobbying specific representatives whose biographies or public remarks reveal personal experience with illness. This variable is valid because it agrees with both previous research on the importance of lobbying representatives with a pre-existing interest in the topic at hand and it follows the method that many single-disease interest groups use (Hall, Deardorff 2006).

The dependent variable is access to specific representatives. Access is measured by public remarks drawing attention to the single-disease interest group's mission or legislation sponsored by the targeted representative. This variable is valid because it is a

concrete, public way to understand access. Operationalizing access in this manner uses a public, repeatable benchmark to calculate access.

This comparative case study illuminates the impact of a representative's personal connection on access by examining how the variables operate in practice through the study of two, similar single-disease interest groups. It is important research because, while identification of similar goals is a well-respected and well-researched lobbying strategy, more research is needed to understand the success of this strategy when single-disease interest groups that have identified a representative's personal connection to their disease use it.

A Representative's Personal Connection to a Disease Can Lead to Access

Comparing the MS Society and ME Action Network:

The MS Society and the ME Action Network have pursued similar strategies in order to gain access to congressional representatives. They have both conducted letter writing campaigns, asked constituents to contact their representatives, and made emotional appeals (<http://www.nationalmssociety.org>, <http://www.meaction.net>).

However there is one key difference in their strategies: from the MS Society's inception, it has identified and focused on accessing members with a personal connection to MS. Meanwhile, there is no public record that shows that the ME Action Network has been able to identify any representatives with a personal connection to ME/CFS that would encourage them to grant access to the ME Action Network.

Similar Goals, Similar Strategies:

Both the MS Society and ME Action Network employ strategies common to interest groups generally and disease specific interest groups in particular. These

similarities allow an appropriate comparison to be made about the key difference found in this analysis: identification of a representative’s personal connection to the disease.

A comparison of the websites and newsletters for each group reveals that each targets a similar constellation of patients with each condition, caregivers, friends and relatives of patients, medical professionals, and activists for the condition. It is expected that these categories will often, but not always, overlap.

Both groups send out petitions, ask members to share personal stories with representatives, and hold fundraising events (“Get Involved,” “Take Action”). Both group also stress public and government awareness of the disease with which they are concerned.

Table 1: Comparison of Lobbying Techniques

Action recommended by disease-specific interest group:	MS Society	ME Action Network
Petitions	✓	✓
Contact members of government to share personal stories	✓	✓
Fundraising events	✓	✓
Raising awareness	✓	✓
Identification of representatives who have a personal connection to disease	✓	

MS Society: Identification, Access, and Outcomes:

The MS Society has identified representatives with a personal, pre-existing interest in the MS Society’s mission from the society’s inception. This strategy allows the society to build stronger coalitions with legislators who are already predisposed to agree with the society’s aims and allows the society to focus its resources. When Sylvia Lawry began to advocate for those with MS on behalf of her brother Bernard, she worked with Senator Charles Tobey (R-NH) whose daughter suffered from the same disease

(“Founder Sylvia Lawry”). This partnership succeeded since Senator Tobey was motivated to grant access to Sylvia Lawry and her newly formed MS Society because of his personal interest in improving the lives of MS sufferers that was motivated by his daughter’s illness. Sylvia Lawry expanded that personal interest by giving Senator Tobey the information and direction needed to transform personal interest into political action. This follows the basic pattern of lobbying in which interest groups are a source of information for representatives too busy or without the resources to gather or have their staffs gather information on every topic of concern. It is the personal experience of illness as the point of access that is noteworthy with disease-specific interest groups like the MS Society. The MS Society and Sylvia Lawry were able to gain access (in the form of attention) to Senator Tobey by identifying that MS was likely to be of concern to Senator Tobey because of his daughter’s disease. The access the MS Society gained through partnership with Senator Tobey resulted in the creation of the National Institute of Neurological Disorders and Stroke in 1950 (“Founder Sylvia Lawry”). This center, part of the National Institute of Health (NIH), aided people with MS as well as other neurological disorders because it created a place to study their diseases and a formal channel for research funding.

The MS Society has also employed personal interest as an access point more recently. Representative Barbara Lee (D-CA) and Senator Mike Johanns (R-NE) were named MS Society representative and senator of the year respectively in 2011 (National Multiple Sclerosis Society, 2012.). The society awards this honor to “elected officials who work to improve the lives of people affected by MS and continue to support the Society and its policy priorities” (National Multiple Sclerosis Society, 2012). The

designation suggests the society's confidence in their ongoing access to both congresspersons.

Representative Barbara Lee has a personal connection to MS because her sister has been disabled by the disease since 1974 (Lee, 2012). She has spoken on the House floor about her connection to patient advocacy saying, "I personally know the many challenges faced by people with disabilities. Therefore, I honor and salute the Center for Independent Living for its vision and steadfast hard work in meeting these challenges in magnificent ways" (Lee, 2012). This statement shows a clear link in Representative Lee's own mind between her sister's disease and Representative Lee's agenda in Congress.

Representative Lee has also taken on other issues that accord with MS Society positions and would benefit those living with MS. She referenced MS in a speech on the House floor in support of an amendment to the Commerce, Justice, Science, and Related Agencies Appropriations Act, 2013 intended to protect patients using legal prescriptions for medical marijuana from Drug Enforcement Agency (DEA) action (U.S. Congress, May 09, 2012). Representative Lee said in her statement in support of the amendment, "these raids are shutting down legally operating businesses and are putting the health and the well-being of patients with cancer, HIV and AIDS, multiple sclerosis, and other serious illnesses in jeopardy" (U.S. Congress, H. Amdt. 1089 to H.R. 5326).

Representative Lee was clearly mindful of the legislation's impact on people with MS in her comments. Although it is impossible to draw a direct link between these comments on medical marijuana and the MS Society's ability to access Representative Lee without interviews, these comments do echo the MS Society's explicitly stated position of supporting access to the legal use of medical marijuana on a state-by-state basis

(“Marijuana”). Representative Lee’s specific mention of MS in a more general amendment and Representative Lee and the MS Society’s identical positions on medical marijuana support the hypothesis that a representative’s personal connection to a disease can be an access point for disease-specific interest groups.

Representative Lee has also sponsored H.R.138 and H.R. 560 to express support for the goals and ideals of Multiple Sclerosis Awareness Week and H.R.883 - Adult Day Achievement Center Enhancement Act that would benefit people with MS and their caregivers (U.S. Congress). These resolutions demonstrate MS Society access to Representative Lee as the variable was operationalized in the research design.

At the same time Representative Lee was named MS Society representative of the year, Senator Johanns was named MS Society senator of the year. He also has a personal connection to chronic illness generally and MS specifically: his mother has Parkinson’s disease and his former sister-in-law has MS (“Family Caregivers, MS Research and MS Champions”). This personal connection to MS and to another, similar disease, Parkinson’s, is the independent variable used by the MS Society to find representatives who are potentially sympathetic to their cause. MS Society access to Senator Johannes is demonstrated through his commitment to creating a national registry of neurological diseases, a priority for the MS Society (“A World Free of MS.”). In 2011 he co-sponsored a bill to create such a registry with four other senators (U.S. Congress, S. 425). This registry would help researchers study these diseases by collecting and collating incidence rates, ages of onset, any geographical clusters of outbreaks, and other relevant information (“Casey, Udall, Isakson, Johanns, and Stabenow Introduce Bipartisan Bill to Create National Registry for Neurological Diseases”).

Although the bill failed, it is worth noting that the original sponsor of the bill, Senator Mark Udall (D-CO), also has a personal connection to chronic illness because his father died of Parkinson's disease ("Casey, Udall, Isakson, Johanns and Stabenow Introduce Bipartisan Bill to Create National Registry for Neurological Diseases.>"). Another co-sponsor, Senator Bob Casey (D-PA), has a father, Gov. Robert P. Casey, who suffered from familial amyloidosis and required a heart-liver transplant while Governor of Pennsylvania (Rensberger 1993). Senator Casey also circulated a dear colleague letter on behalf of the bill, which the MS Society used when asking members to contact their senators (FY18 MS Research Senate Dear Colleagues). These efforts suggest that the MS Society has also successfully accessed representatives through their personal connections to diseases other than MS.

This bill also demonstrates that the MS Society has pursued access through a representative's personal connection to MS while also forming coalitions with other disease-specific interest groups. Creating a national registry for neurological diseases was a priority for many single-disease interest groups representing neurological disease and so the MS Society was able to collaborate with other groups such as Parkinson's Action Network (PAN). PAN had a relationship with Congressman Udall through his father's death from Parkinson's disease ("Casey, Udall, Isakson, Johanns and Stabenow Introduce Bipartisan Bill to Create National Registry for Neurological Diseases.>"). By forming a coalition with other single-disease interest groups, the MS Society was able to gain access to more members of Congress who had personal connections to diseases other than MS. This type of coalition-building expands the reach of the access through personal connection to a disease strategy and offers an approach for single-interest disease that are

unable to find representatives with first-hand experience of the disease with which they are concerned.

Table 2: MS Society Case Study

Hypothesis: The more a single-disease interest group is able to link its agenda to the existing goals and interests of elected representatives, the greater its access, and thus it is able to accomplish more of its agenda, with existing goals and interests of elected representatives defined as a personal connection to disease.		
	Independent Variable: Identification of representatives with a personal experience of the disease in question	Dependent variable: Access to Representatives
<i>Case Study 1: MS Society</i>	Senator Charles Tobey (R-NH) – daughter had MS	Helped to pass bill that created a research institute for MS and other neurological diseases (now known as National Institute of Neurological Disorders and Stroke (NINDS))
	Senator Mike Johanns (R-NE) – mother has Parkinson’s disease and former sister-in-law has MS	co-sponsored the National MS and Parkinson’s Disease Registry Act
	Representative Barbara Lee (D-CA) – sister has been disabled by MS since 1974	Sponsored: H.R.138 – 112th Congress –Expresses support for the goals and ideals of Multiple Sclerosis Awareness Week H.R.883 –112th Congress – Adult Day Achievement Center Enhancement Act (benefits people with MS) https://www.congress.gov/bill/112th-congress/house-bill/883 Introduced H. Res. 560. A resolution supporting the goals and ideals of Multiple Sclerosis Awareness Week Spoke on House Floor in support of Rohrabacher-Hinchey- McClintock-Farr amendment to Commerce, Justice, Science, and Related Agencies Appropriations Act, 2013
	Senator Mark Udall (D-CO) –father had Parkinson’s disease	Sponsored bill to create national registry of neurological diseases
	Senator Bob Casey (D-PA) – father, Gov. Robert P. Casey, suffered from familial amyloidosis	Circulated dear colleague letter on behalf of bill to create national registry of neurological diseases

Close analysis of the MS Society strategy suggests a link between identification of representatives with a personal connection to MS or other similar illness and access to those members. This finding would support the hypothesis that the more a single-disease interest group is able to link its agenda to the existing goals and interests of elected representatives, the greater its access, and thus it is able to accomplish more of its agenda. In the research design, existing interest was narrowly defined as a personal connection to the disease. The next case study, the ME Action Network, examines what happens when that link does not exist or cannot be discovered.

ME Action Network: Who Will Listen?

An unrestricted search for chronic fatigue syndrome in the congressional database (congress.gov) returns 310 results. An unrestricted search without quotation marks was important because at times the disease has been referred to as chronic fatigue and immune dysfunction syndrome, a restricted search without quotations eliminates these results. Many of the results are actually concerned with Gulf War Syndrome, a different disease, represented by other constellations of advocacy groups. By contrast, a restricted search for “multiple sclerosis” returns 1,384 results. This disparity comes despite the NIH’s 2014 finding that MS affects 400,000 Americans while ME/CFS affects 1,060,000 Americans (Dimmock 2016). By this measure, the ME Action Network has a problem accessing the members of Congress upon whom the organization’s advocacy goals depend. Thus far they have been unable to identify the same kind of personal connection to ME/CFS that the MS Society has found in representatives whose family members have suffered from MS. Examining the impact of this absence on the degree of access afforded

to the ME Action Network implies that a representative's personal connection to a disease can lead to greater access for an advocacy organization.

Instead of developing long-term relationships with a few representatives who have a personal interest in the disease, the ME Action Network has encouraged its members to contact their congressional delegations in support of particular resolutions or bills and to share their personal stories (<http://www.meaction.net>). One of the greatest successes of this approach has been Senator Ed Markey's (D-MA) February 23, 2017 public commitment to become an advocate for those with ME/CFS

(<http://www.meaction.net/2017/02/26/thank-senator-markey-for-promising-to-help-me-patients/>). Rivka Solomon, a Massachusetts resident and patient living with ME/CFS, asked Senator Markey for his commitment to ME/CFS at a public town hall meeting. There is not a publically discoverable effort to focus on Senator Markey because of any personal connection on his part to chronic illness.

(<http://www.meaction.net/2017/02/26/thank-senator-markey-for-promising-to-help-me-patients/>). However, Ms. Solomon does mention that she asked Senator Markey for his commitment to more research funding after he celebrated the state's commitment to research and stated how proud he was to have three Ph.Ds. on his staff ("Thank Senator Markey for promising to help ME patients"). These remarks suggest a pre-existing interest in the economic benefit of NIH funding for research that may happen in the state of Massachusetts, which receives more NIH grants per capita than any other state (video 0:20) (SolveCFS, 2017). Additionally, Senator Markey's wife, Susan J. Blumenthal, M.D., M.P.A, is a noted physician with an interest in women's health from her days as a U.S. Assistant Surgeon General and First Deputy Assistant Secretary for Women's

Health (Blumenthal). She links her decision to pursue medicine to the “fear and powerlessness” she experienced as a child while watching her mother undergo radiation treatment for thyroid cancer (“Changing the Face of Medicine | Susan J. Blumenthal”). This finding suggests that illness is so pervasive that even when the single-disease interest group does not identify a personal connection before approaching the representative, unknown personal interests in medical research may aid the interest group in gaining access to the representative.

In absence of representatives with a direct link to ME/CFS, the ME Action Network recommends that its members create and sign petitions, approach representatives at town halls and in state and municipal government, and promote any activism they engage in through the ME Action Network (“How-to Guides”). In the how-to guide for encouraging state resolutions the ME Action Network recommends finding representatives “with an already-established connection” to ME/CFS (“State Resolution for ME: How-to Guide and Case Study”). This technique is distinct from the one under investigation in this paper of identifying representatives with a personal connection to either the disease of the interest group or another illness that might form a bridge to that disease. However, it relies on the same the strategy of building upon connections that the representative already has to expand his or her legislative interests.

The ME Action Network has used strategies such as outside lobbying to increase public awareness of ME/CFS in the hope that greater general knowledge about ME/CFS will then lead to increased government funding and advances in medical research. Outside lobbying efforts include sponsoring internet campaigns such as #Bedfest, a virtual concert of artists with ME/CFS and #BelieveME, an internet protest designed to

show that anyone may become ill from ME/CFS (“Contact Your Local Journalist about #Bedfest,” “Show Your Face to the World: #BelieveME”). ME Action has also promoted and encouraged members to support Jen Brea’s award-winning documentary, “Unrest,” about ME/CFS (“Three Ways to Help Unrest Change the Story”). These efforts are designed to raise public awareness in order to gain attention within Washington. They have had some success with this strategy but it has not led to the same kind of long-term access to representatives that the MS Society has been able to develop by focusing on representatives who have a personal connection to MS.

Table 3: The ME Action Network Case Study

Hypothesis: The more a single-disease interest group is able to link its agenda to the existing goals and interests of elected representatives, the greater its access, and thus it is able to accomplish more of its agenda, with existing goals and interests of elected representatives defined as a personal connection to disease.		
	Independent Variable: Identification of representatives with a personal experience of the disease in question	Dependent variable: Access to Representatives
Case Study 2: ME Action Network	Senator Ed Markey (D-MA) lacks personal experience with ME/CFS but his wife has a long-standing interest in women’s health & watched her mother die of thyroid cancer	Held congressional briefing on ME/CFS on May 26, 2017
	Unable to identify representatives with personal connection to ME/CFS	Website makes few references to ongoing relationships with particular representatives and instead encourages general petitions based on state of residence

Examining the different levels of access to representatives that the MS Society and the ME Action Network have achieved supports the hypothesis under consideration, that the more a single-disease interest group is able to link its agenda to the existing goals and interests of elected representatives, the greater its access, and thus it is able to

accomplish more of its agenda, with existing goals and interests of elected representatives defined as a personal connection to disease.

When Disease Becomes Identity:

Identity group politics is major and lasting trend. In many ways, a single-disease interest group that finds legislators who have a personal connection to a disease is helping to create a shift in which suffering or observing a family member suffer from a disease changes from an unfortunate occurrence to an identity analogous to gender, race, religion, or any number of other characteristics that help shape one's political identity.

The qualitative examination of the comparative success of the MS Society in gaining access to representatives by focusing on those who have a personal connection to the disease suggests that finding a personal connection to the disease under consideration can be a successful strategy for a single-disease interest group. The ME Action Network's lack of success and difficulty in creating sustained relationship with legislators who lack a personal connection to ME/CFS further supports the personal connection-access hypothesis. While the research in this paper indicates that this strategy would be successful for any single-disease interest group, a large-scale quantitative survey comparing levels of access between single-disease interest groups that have found representatives with a personal connection to the represented disease and those that have not would add weight to this conclusion.

Limiting the data sources to publically available information means that each case contains assumptions about the process the MS Society and the ME Action Network went through to decide on which legislators to focus their attention. In-depth interviews with strategists at each single-disease interest group would shed more light on the process and

thus be a valuable addition to the literature on single-disease interest groups and their lobbying process; however, the publically gathered data is still sufficient to support the personal connection-access hypothesis for single-disease interest groups because it includes both congressional records and newsletters and other media the MS Society and the ME Action Network created to explain their lobbying process to members.

Conducting interviews with strategists at the interest group would also shed light on if and how a single-disease interest group that is unable to find a representative with a personal connection to the disease at stake might instead pursue a coalition with other single-disease interest groups that have sustained access to a legislator or legislators through personal connections, name recognition of the disease, or other strategies.

Isolating a particular strategy with which single-disease interest groups can succeed in gaining access to legislators provides practical assistance to these groups. It also begins to test a common theory of lobbying on a particular subset of interest groups, adding to the literature on both the role of a personal connection to a topic in lobbying and how single-disease interest groups can lobby effectively.

References

- Abdelal, Rawi, Yoshiko M. Herrera, Alastair Iain Johnston, and Rose McDermott. 2006. "Identity as a Variable." *Perspectives on Politics* 4(04): 695–711.
- Best, Rachel Kahn. 2012. "Disease Politics and Medical Research Funding." *American Sociological Review* 77(5): 780–803.
- Blumenthal, Susan J. <http://susan-blumenthal.org> (July 18, 2017).
- Boehmke, Frederick J., and Daniel C. Bowen. 2010. "Direct Democracy and Individual Interest Group Membership." *The Journal of Politics* 72 (July): 659–71.
- "Casey, Udall, Isakson, Johanns and Stabenow Introduce Bipartisan Bill to Create National Registry for Neurological Diseases." 2011. Sen. Bob Casey. <https://www.casey.senate.gov/newsroom/releases/casey-udall-isakson-johanns-and-stabenow-introduce-bipartisan-bill-to-create-national-registry-for-neurological-diseases> (July 18, 2017).
- "Changing the Face of Medicine | Susan J. Blumenthal." 2015. U.S. National Library of Medicine. https://cfmedicine.nlm.nih.gov/physicians/biography_39.html (July 18, 2017).
- Clayton, E. W. 2015. "Beyond myalgic encephalomyelitis/chronic fatigue syndrome: an IOM report on redefining an illness". *Jama*, 313 (11), 1101-1102.
- "Congressional MS Caucus." I'm an MS Activist. http://msactivist.blogspot.com/p/congressional-ms-caucus_15.html (July 18, 2017).

“Contact your local journalist about #BedFest.” ME Action.

<http://www.meaction.net/2017/05/03/contact-your-local-journalist-about-bedfest/>

(July 20, 2017).

Denzau, Arthur T., and Michael C. Munger. 1986. “Legislators and Interest Groups: How Unorganized Interests Get Represented.” *American Political Science Review* 80 (March): 89–106.

Dimmock, Mary. E., Arthur A. Mirin, and Leonard A. Jason. 2016. “Estimating the disease burden of ME/CFS in the United States and its relation to research funding.” *Journal of Medicine and Therapeutics* 1(1).

Dresser, Rebecca. 1992. “Wanted Single, White Male for Medical Research.” *The Hastings Center Report* 22(1): 24–29.

Epstein, Steven. 2016. “The politics of health mobilization in the United States: The Promise and Pitfalls of “Disease Constituencies”.” *Social Science & Medicine* 165 (September): 246–54.

“Founder Sylvia Lawry.” National Multiple Sclerosis Society.

<http://www.nationalmssociety.org/About-the-Society/Leadership/Founder-Sylvia>

Lawry (July 18, 2017).

“FY18 MS Research Senate Dear Colleagues.” National Multiple Sclerosis Society.

<https://secure.nationalmssociety.org/site/Advocacy?cmd=display&page=UserAction&id=3509> (July 18, 2017).

“Get Involved.” National Multiple Sclerosis Society.

- <http://www.nationalmssociety.org/Get-Involved> (July 18, 2017).
- Hall, Richard L., and Alan V. Deardorff. 2006. "Lobbying as Legislative Subsidy." *American Political Science Review* 100 (February): 69–84.
- Hojnacki, M. 1998. "Organized Interests' Advocacy Behavior in Alliances." *Political Research Quarterly* 51(June): 437–59.
- "How-to Guides." ME Action. <http://www.meaction.net/how-to-guides/> (July 18, 2017).
- Keiser, L. R., and S. M. Miller. 2009. "The Impact of Organized Interests on Eligibility Determination: The Case of Veterans' Disability Compensation." *Journal of Public Administration Research and Theory* 20 (April): 505–31.
- Lee, Barbara. 2012. "Honoring the Center for Independent Living" *Congressional Record — Extensions of Remarks*, September, E1516.
- Lowery, David et al. 2005. "Reconsidering The Counter-Mobilization Hypothesis: Health Policy Lobbying In The American States." *Political Behavior* 27 (June): 99–132.
- Lowery, David. 2007. "Why Do Organized Interests Lobby? A Multi-Goal, Multi-Context Theory of Lobbying." *Polity* 39 (January): 29–54.
- "Marijuana." National Multiple Sclerosis Society.
<http://www.nationalmssociety.org/Treating-MS/Complementary-Alternative-Medicines/Marijuana> (July 18, 2017).
- Martin Gilens, and Benjamin I. Page. 2014. "Testing Theories of American Politics: Elites, Interest Groups, and Average Citizens." *Perspectives on Politics* 12 (3) (September): 564-581.

Mathew, M., and A. O. Goldstein, K. Hampton. 2008. "Advocacy in Action: Survivors of Tobacco-Related Diseases and Advocacy for Tobacco Control." *Tobacco Control* 17 (February): 6-11.

National Multiple Sclerosis Society. 2012. "Family Caregivers, MS Research and MS Champions." MSConnection.org Blog.

<https://www.msconnection.org/Blog/March-2012/Family-Caregivers,-MS>

Research-and-MS-Champions?feed=BlogFeed (July 18, 2017).

"The Power of Prevention: Chronic disease . . . the public health challenge of the 21st century" National Center for Chronic Disease Prevention and Health Promotion.

<https://www.cdc.gov/chronicdisease/pdf/2009-Power-of-Prevention.pdf> (2009).

Rensberger, Boyce, "Pensylvania's Gov. Casey Has Heart-Liver Transplant," *The Washington Post*, 15 June, 1993.

Salisbury, Robert H. 1969. "An Exchange Theory of Interest Groups." *Midwest Journal of Political Science* 13 (February): 1-32.

"Show your Face to the World: #BelieveME." ME Action.

<https://www.meaction.net/2017/04/19/be-part-of-believeme/> (July 20, 2017).

SolveCFS. 2017. "Senator Markey Stands Up for ME/CFS disease!" YouTube.

<https://www.youtube.com/watch?v=IT1gLfiFkjs> (July 18, 2017).

"State Resolution for ME: How-to Guide and Case Study." ME Action.

<http://www.meaction.net/2017/05/24/state-resolution-for-me-how-to-guide-and>

-case-study/ (July 18, 2017).

"Take action." ME Action. <http://www.meaction.net/take-action/> (July 18, 2017).

“Thank Senator Markey for promising to help ME patients.” ME Action.

<http://www.meaction.net/2017/02/26/thank-senator-markey-for-promising-to-help-me-patients/> (July 18, 2017).

“Three ways to help Unrest change the story.” ME Action.

<https://www.meaction.net/2017/03/31/three-ways-to-help-unrest-change-the-story/> (July 20, 2017).

Truman, David B. 1960. The governmental process: political interests and public opinion. New York, NY: Alfred A. Knopf.

U.S. Congress. House. Energy and Commerce. 2011. Supporting the Goals and Ideals of Multiple Sclerosis Awareness Week. 112th Cong., 1st sess., H.R. 138.

U.S. Congress. House. Energy and Commerce. 2011. Adult Day Achievement Center Enhancement Act. 112th Cong., 1st sess., H.R. 883.

U.S. Congress. Senate. Health, Education, Labor, and Pensions. 2011. National Neurological Diseases Surveillance System Act of 2011. 112th Cong., 1st sess., S. 425.

U.S. Congress. House. Energy and Commerce. 2011. Commerce, Justice, Science, and Related Agencies Appropriation Act, 2013. 112th Cong., 2nd sess., May 09, 2012.

U.S. Congress. House. Energy and Commerce. 2012. Supporting the Goals and Ideals of Multiple Sclerosis Awareness Week. 112th Cong., 2nd sess., H.R. 560.

“A World Free of MS.” National Multiple Sclerosis Society.

https://secure.nationalmssociety.org/site/SPageServer/%3Bjsessionid=6BC322DB085552A76009F87239BDBD6.app321a?pagename=FLS_advocacy_homepage (July 18, 2017).

Yaghoubi, Roxanne. 2015. "Disease on the Hill: Patient Advocacy Groups and Their Lobbying Efforts." Master's thesis. Johns Hopkins University.