DOI: 10.1111/1467-9566.13655

Patient-activist or ally? Assessing the effectiveness of conscience and beneficiary constituents in disease advocacy fundraising

Edward T. Walker¹
 | Michel L. Ehrenhard⁴
 |

Tijs van den Broek² 💿 | Anna Priante³ 💿 |

¹University of California, Los Angeles, Los Angeles, California, USA

²Vrije Universiteit Amsterdam, Amsterdam, The Netherlands

³Rotterdam School of Management, Erasmus University, Rotterdam, The Netherlands

⁴University of Twente, Enschede, The Netherlands

Correspondence Edward T. Walker. Email: walker@soc.ucla.edu

Funding information Twitter DataGrant

Abstract

Disease advocacy organisations (DAOs) are critical for raising awareness about illnesses and supporting research. While most studies of DAOs focus on personally affected patient-activists, an underappreciated constituency are external allies. Building from social movement theory, we distinguish between beneficiary constituents (disease patients and their loved ones) and conscience constituents (allies) and investigate their relative fundraising effectiveness. While the former have credibility due to illness experience that should increase fundraising, the latter are more numerous. Our study is also the first to investigate where DAO supporters fundraise-through friendship- versus workplace-based networks-and how this interacts with constituent types. Our large-scale dataset includes 9372 groups (nearly 90,000 participants) active in the 'Movember' campaign, a men's health movement around testicular and prostate cancer. We find robust evidence that groups with more beneficiary constituents raise significantly greater funds per participant. Yet because conscience constituents are more numerous,

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

^{© 2023} The Authors. Sociology of Health & Illness published by John Wiley & Sons Ltd on behalf of Foundation for the Sociology of Health & Illness.

they raise the majority of total aggregate funds. We also find an interaction effect: beneficiary constituents do better in friendship networks, conscience constituents in workplaces. Our findings bear implications for DAOs, indicating they may benefit by encouraging disease patient families to fundraise through friends, and for external allies to focus requests on workplace networks.

KEYWORDS

fundraising, men's health, prostate cancer, resource mobilisation, social movements

INTRODUCTION

Disease advocacy organisations (DAOs) represent a powerful force in society, raising funds for, and awareness of, a vast range of diseases (Best, 2012, 2019; Ganchoff, 2004; Gunnarsson Payne & Korolczuk, 2016; Hess, 2004; Kurhila et al., 2020; Lindén, 2021; Nahuis & Boon, 2011; Ozieranski et al., 2022; Rose, 2013; Strach, 2016). Such organised efforts influence patient access to drugs (Lindén, 2021), allocations of public research budgets (Best, 2012), provide rare condition patients with empowerment and ability to influence science (Hess, 2004; Panofsky, 2011), offer partnership between patients and care providers (Kurhila et al., 2020; Wong-Rieger, 2017) and foment broader public engagement (ibid). DAOs often also play key roles in health social movements, drawing attention to conditions overlooked by mainstream medicine (e.g. Kempner, 2006; Zavestoski et al., 2004).

Most research on DAOs focuses on activism by those who suffer from the disease personally (patient-activists) and their family members or close friends; this is logical, of course, given that DAOs rely most heavily upon those personally affected (see e.g. Vicari & Cappai, 2016; Zavestoski et al., 2004). Such individuals have a deeply personal investment in finding treatments for the condition (Lindén, 2021). For Panofsky (2011, p. 32), for instance, the very definition of a DAO is rooted in the activism of families of 'disease sufferers... [who] connect with each other, serve as a source of information and support, and promote research into their particular diseases'. As we explain below, we borrow from the Resource Mobilization Theory (RMT) of social movements (McCarthy & Zald, 1977; Owen, 2019; Wahlström et al., 2018) and refer to such participants in DAOs as *beneficiary constituents*, as they would personally benefit from the amelioration of the condition.

Yet we also know that DAO supporters extend well beyond personally affected beneficiary constituents—whether through the many coloured-ribbon campaigns (King, 2006) or corporate cause-marketing promotions (Strach, 2016). Such 'ally' participants are *conscience constituents* (McCarthy & Zald, 1977; Owen, 2019) who instead take part due to altruistic or community interests. Although they may lack personal narratives of disease experience, conscience constituents may have better potential for outreach due to their greater number and, accompanying their number, more extensive social networks. Ally constituent support was important not only in the 'pink ribbon' campaigns and the massive 'Race for the Cure' events hosted by the Komen Foundation (Strach, 2016), but there are deep historical precedents in earlier social advocacy campaigns (Oshinsky, 2005). While conscience constituents are important for DAOs as they might raise

considerable funding, the bulk of research on the sources and impacts of DAO campaigns has only seldom taken them substantially into account (but see e.g., Phing & Yazdanifard, 2014).

Hence, our purpose is to carry out the first systematic study of the relative effectiveness of both patient-activists and allies-that is, beneficiary and conscience constituents-in DAO fundraising. We study fundraising as a critical indicator of the effectiveness of activism as it is a central goal of DAOs to support medical research (Best, 2012, 2019).¹ In particular, we focus on fundraising as a group-based strategy, which is common in campaigns to generate friendly competition and accountability (Priante et al., 2021) both in workplace and non-workplace settings (see Sargeant & Shang, 2016). That is, fundraising groups in disease advocacy also vary in where supporters fundraise—through friendship- versus workplace-based networks—and we investigate how this interacts with constituent types. Building upon RMT (McCarthy & Zald, 1977) and studies at the intersection of health advocacy and social movement research (e.g. Best, 2012), we expect that, although beneficiary constituents with a direct connection to the disease should have more credibility that confers greater success in fundraising than for conscience constituents, the latter group should be more effective in workplace-based groups with more indirect connections to the illness. In some ways, our expectations are analogous to findings in research on charity sport fundraising (e.g., Filo et al., 2020; Wood et al., 2010). Thus, for DAO campaigns that wish to expand beyond their core base, workplace-based fundraising efforts may be more successful. As we discuss later, this bears implications for DAO fundraising strategies.

Our empirical context is one of the most prominent DAOs in recent years: The Movember campaign to raise funds for prostate and testicular cancer research (Van den Broek et al., 2019). Through a data access agreement, we obtained rich micro-data on all participants in the Movember US campaign during one of their most active campaign years (2014).² We distinguished between beneficiary and conscience constituents using information from participants' biographical statements about whether they attribute their participation to a personal connection (they and/or a loved one were affected) or due to another reason (e.g. they appreciate the community, want to have fun, a co-worker asked, etc.). In addition, we use information about how participants are nested within fundraising groups to distinguish between groups based on *friendship* networks versus *workplaces*.

Importantly, our study is unique in providing insights into DAO engagement on a men's health social movement, building on existing studies (e.g., Baker, 2001; Leone & Rovito, 2013; Richardson & Carroll, 2009). Without necessarily endorsing this perspective, the Movember campaign argues that cancers affecting men such as prostate and testicular cancer have gained less attention and funding relative to campaigns surrounding, for instance, breast cancer (Strach, 2016). As we illustrate below, given the campaign's normative encouragement to grow a moustache for the month of November, our data source shows that campaign participants are overwhelmingly (91.5%) male. While this may be seen as limitation in terms of generalisability, we note that there is almost always some uniqueness to any disease advocacy campaign, whether on a rare or common condition (Panofsky, 2011) or affecting some subset of the population. We take this as an opportunity to examine advocacy fundraising surrounding conditions that affect large populations; for prostate cancer in particular, this refers to roughly one in eight men in the UK,³ roughly the same level in the US,⁴ and it is the second most common cancer in men globally.⁵ As such, it is critically important to understand both this condition and the role of advocacy organisations in raising funds for research. We also take account of the critical role of gender in shaping engagement.

In the next section, we review prior research on the roles of beneficiary and conscience constituents in disease advocacy and introduce the distinction between workplace and friendship-based

venues for advocacy. Accordingly, we also develop our main hypotheses about the relative effectiveness of beneficiary and conscience constituents in fundraising campaigns and how such effectiveness might depend upon whether the fundraising takes place through workplace- or friendship-based networks. After reviewing our data sources and methods, we illustrate our findings and discuss their implications for research on DAOs and social movements. We conclude with practical insights about how constituent types and fundraising networks intersect in generating effective disease advocacy.

THEORETICAL BACKGROUND AND RESEARCH EXPECTATIONS

Beneficiary and conscience constituents in disease advocacy

Scholarship has long distinguished between those who take part in a social or political cause for reasons connected directly to their personal experience versus those who join based on their general values and preferences (e.g., Edwards & McCarthy, 2004; Owen, 2019; Wahlström et al., 2018). This distinction goes back to McCarthy and Zald's (1977) RMT of social movements, which defines beneficiary constituents as people who stand to benefit directly from a movement achieving its goal, while conscience constituents are those who take part despite not benefitting directly. One important historical point is that since the 1970s many social causes have granted a larger role for conscience constituents (McCarthy & Zald, 1977; Skocpol, 2003). The growing interest in funding and supporting social change causes has expanded the pool of resources for activism, alongside the growth of professional classes with time and resources. In response, a wave of advocacy groups-many focused on diseases (Best, 2019)-were founded since the closing decades of the 20th century, and many of them emphasised converting conscience constituent resources into institutional change (Skocpol, 2003). While the advocacy group expansion has levelled off or declined somewhat in more recent years, such groups continue to play an important role in creating social change. In fact, the distinction between beneficiary and conscience constituents has been at the core of considerable bodies of work about allyship (Owen, 2019), insider/ outsider roles in social advocacy (Levitsky, 2007) and ally motivations (Wahlström et al., 2018). While allies may feel more psychological distance from the disease (Kim, 2019), despite these weaker connections they may still play a considerable role in fundraising.

DAOs, in particular, rely upon the fundraising efforts of conscience constituents to supplement and support the efforts of beneficiary constituents. This is particularly true for rare diseases, which, by definition, affect only a small population (Panofsky, 2011). Beyond rare diseases, the notion that conscience constituents play a critical role remains important for other conditions, as outside support can reach vastly larger resource pools (Strach, 2016).

Consider, for instance, the wildly successful 'ice bucket challenge' in 2014, which raised an estimated \$115M for research on Amyotrophic Lateral Sclerosis (ALS), which also leveraged additional funding from the U.S. NIH.⁶ Similarly, a vast range of 'ribbon' campaigns invite engagement from members of the general public to support disease awareness (e.g. King, 2006), not to mention the various bracelet campaigns that followed after Lance Armstrong's 'LIVESTRONG' campaign. Critically, as in the case we are investigating, both of these analogous campaigns had strong recruitment through both workplaces—recall the trend, for instance, of many university presidents and CEOs taking part in the 'ice bucket challenge'—and also through interpersonal networks.

While prior studies have at times recognised the importance of allies, as we review now, they often overlook the broader implications that follow from distinguishing constituent types. Best (2019, Ch. 2), for example, describes how disease advocacy itself shifted over the course of

the 20th century from universalistic principles to constituency-based organising around particular illnesses. These patients, in turn, found a 'prominent place... in congressional hearings', and 'their unapologetic claims on behalf of affected subpopulations demonstrate[d] the new political legitimacy of disease constituencies' (ibid, p. 64). In their survey of DAOs involved in genetic research, Landy et al. (2012) find that their primary leadership were predominantly patients and their families, but allies also played important roles. In addition, medical providers might be directly involved as conscience constituents (what Morantz [2021] calls 'advocacy allies'). Research also finds that other DAO funders, such as pharmaceutical firms, can also play a key role as conscience constituents, although their participation might be not entirely altruistic, as they derive benefits from advocates' lobbying (Rose, 2013).

While the distinction between beneficiary and conscience constituents is undeniably important in these practical findings, we need to know more about their effectiveness. We expect that there will be differences in fundraising success depending on their representation of each type. Primarily, we argue that this is because beneficiary constituents are typically taken as more credible given their direct personal experience, whereas conscience constituents, as allies, are more likely to have secondhand experience (Owen, 2019). At the same time, however, for most diseases, only a minority of the broader public is personally affected, and so there will be a much larger group of potential conscience constituents, with access to much larger pools of resources; while they may be less credible as spokespeople, allies' greater numbers and extensive networks may give them considerable fundraising capacity (McCarthy & Zald, 1977). We expect, then, that groups including a higher share of beneficiary constituents are likely to be the most credible spokespeople given their personal disease experiences and are likely to be more successful at fundraising. More formally, we hypothesise

Hypothesis 1. Fundraising groups with a higher share of beneficiary constituents will be more effective in fundraising than groups with a higher share of conscience constituents.

Where fundraising happens: Friendship- versus workplace-based groups

Overview of fundraising groups

As mentioned above, one of the key assets of conscience constituents is that, for most issues, they are theoretically a much larger group, and they also have access to significant resource pools. We also know that for many causes, activism often takes part through groups rather than through isolated individual-level efforts (Priante et al., 2021). A notable body of scholarship, primarily in non-profit studies, has pointed out the wisdom of fundraising through groups, given that group membership generates friendly competition, accountability and monitoring. Coordinated groups—as a type of 'team' supporting collective action—are critical for increasing the accountability and monitoring of individual contributions (Sargeant & Shang, 2016) and helping to overcome free rider problems (Marwell & Oliver, 1993). In addition, the group-fundraising strategy has been found to collect higher donation amounts than relying upon individuals, because they can count on their social capital (Priante et al., 2021). Ad hoc coordinating groups are critical serving as a vehicle for voluntary programmes (Plewa et al., 2015; Priante et al., 2021). Segmentation of a campaign into subgroups makes apparent where contributions are more (or less) substantial, implicitly pressuring laggards (Dixon & Roscigno, 2003). Yet, groups of participants

in disease advocacy come in different forms: some are rooted in workplaces and others are organised informally through friendship networks. As we elaborate below, these varying contexts have significant implications for how DAOs engage with participants.

Workplace-based groups

Workplace-based groups have a distinct advantage in terms of tapping into otherwise inaccessible resource pools (Barman, 2006), as employees' commitments to their coworkers and employers can be converted into a pro-social asset (Plewa et al., 2015). When considering campaigns to change society or support attention to an illness, research on the benefits of organisation-based recruitment and mobilisation strategies often points to the advantages of workplace-based engagement strategies. When building on top of preexisting organisational structures, campaigns tend to enjoy greater ease of recruitment *en masse* (Oberschall, 1973), and they also borrow from the cultural legitimacy of their constituent organisations and may benefit from dense preexisting ties (Swarts, 2008). For fundraising in particular, workplace campaigns often connect to positive pro-social sentiments, reinforcing warm feelings about one's coworkers and employer (Plewa et al., 2015).

These factors may be converted into significant reservoirs of resources that can be deployed by DAOs. This is part of the reason, for instance, why workplace fundraising campaigns such as the United Way in the US are often so effective (Barman, 2006), similar to payroll-based giving in the UK (Romney-Alexander, 2002). Those requesting donations for such campaigns can be enlisted into self-selected fundraising groups (Sargeant & Shang, 2016) within workplaces that can support friendly competition against peers, while tapping into contributions from coworkers' networks. Thus, for DAOs, this offers those who have little or no experience with the illness an avenue for making contributions, thereby dramatically broadening resource pools.

Friendship-based groups

Friendship-based groups, on the other hand, are more likely to involve strong ties which tend to close off and provide less expansive access to resources (Granovetter, 1973). Although they should be more likely to feature those who are beneficiary constituents with direct experience of the disease—who, as we hypothesised above, should be more effective fundraisers—friendship-based groups do not necessarily allow access to the more expansive workplace networks. Friendship-based fundraising groups may also be more flexible and informal, which may make for weaker commitments and less accountability. In contrast to workplaces, they also lack access to the considerable preexisting organisational structure provided by a workplace. We therefore expect that

Hypothesis 2. Workplace-based fundraising groups will be more effective in fundraising than friend-based groups.

Interaction of constituent types and fundraising group type

Building from the expectations above, we also anticipate that the efforts of each constituent type will generate differential returns within each setting. More specifically, because one's credibility as a beneficiary spokesperson for a DAO should matter less to one's coworkers than it would to one's (presumably closer) friends and family, beneficiary-heavy workplace groups should be less effective. Similarly, without the tie of a workplace nor a close connection to the disease, the

efforts of conscience constituents in a friendship-based group should also be relatively weaker. Therefore, we expect a negative interaction effect between a group's share of beneficiary constituents and being located in a workplace:

Hypothesis 3. Fundraising groups with a higher share of beneficiary constituents will be less effective when found in workplace-based fundraising groups than when found in friendship-based groups.

EMPIRICAL SETTING

The setting of our study is the 2014 fundraising campaign organised by the Movember Foundation, a global DAO that aims, as they see it, to help men live happier, healthier and longer lives, and to raise awareness of prostate and testicular cancer. The Foundation organises a campaign primarily in the month of November and uses the symbol of the moustache to facilitate identification with the cause and foster participation in campaign activities, such as collecting donations for medical research. Since 2003, Movember has mobilised 5.2M fundraisers who raised a total of \$710M US dollars to fund health projects related to prostate cancer, testicular cancer and mental health. We focus on the year 2014 as it was one of the very highest fundraising years in the campaign as a whole. In 2014, Movember participants raised a total amount of \$13.6 million dollars in the US, while \$89M were raised globally during the course of that year.⁷ Movember-related advocacy also generated a higher number of patient referrals for prostate cancer screening, although this may not be an unquestionable benefit (see Aronowitz, 2014). While the Movember campaign is global in nature, based on data availability we focus on the United States during the year of observation.

The fundraising system used by the Movember Foundation is peer to peer (Van den Broek et al., 2019; Priante et al., 2021): Fundraisers reach out to their social networks—including family, friends and coworkers—to donate to the organisation's cause (Priante et al., 2021). Fundraisers use both social media (mainly Twitter) and offline events to collect donations (Movember, 2014). In addition, the Movember Foundation largely encourages a group-based strategy: Most Movember fundraisers join the campaign as part of a group, led by a Movember captain. Groups self-organise through either friendship networks or their workplace (Priante et al., 2021). A Movember fundraising group has its own webpage (a 'MoSpace'), hosted on the foundation's website, where the group registers all the donations. The Movember Foundation uses the collected donations to rank groups on competitive leaderboards.

We consider the Movember fundraising campaign as an ideal setting to study beneficiary and conscience constituent participation in both workplace- and friendship-based settings. The Movember campaign takes place in both friendship- and workplace-based environments, recruiting participants both through organisations (such as workplaces) and through individual membership organising (via informal networks of friends/family). As such, the Movember campaign offers a unique opportunity to examine whether fundraising in workplace-based versus friendship-based settings is likely to be more effective within the same campaign, as well as to assess our hypotheses about beneficiary and conscience constituents.

DATA AND METHODS

Our observations consist of 9372 Movember fundraising groups of at least two members based in the United States in 2014. These data are not shareable due to privacy restrictions and the data agreement with the project's funder. These groups contain a total of 87,897 individual

participants.⁸ The dataset includes groups with members that have a publicly available Movember profile.

Dependent variable

Our dependent variable is the average donation amount in USD raised by group members during the Movember campaign. The selected time span of the campaign is from 2 weeks before the cycle's beginning (15 October 2014) to 2 weeks after the end (15 December 2014). Average donation amount was calculated by summing all individual donations raised by group members and dividing this by group size; we estimate the measure in this way (rather than using a total), given the variable size. The average donation amount ranges between 0 and \$4762 and is log-transformed to reduce skewness.

Independent variables

Share of beneficiary (vs. conscience) constituents

We measured a fundraising group's share of beneficiary constituents with the presence of a personal connection to the cause among groups' members (all other participants, by definition, are conscience constituents acting as allies). At the start of the campaign, members can describe their personal motivation to join the campaign (e.g., 'Honouring my Grandfather') in their Movember profile description (the 'MoSpace'). We used an automatic text classifier developed by Nguyen et al. (2015) to measure members' stated reasons for participating. Nguyen et al. (2015) built a supervised motivation classifier by combining human annotation with natural language processing to automatically detect motivations. The classifier was built with profiles from the 2014 US Movember campaign. Building on Van Zomeren et al. (2008), the machine learning algorithm measured whether a personal connection with the campaign was expressed by a group member in their profile, such as 'I had testicular cancer myself' or 'My dad'.⁹ Evaluation of the classifier on a separate validation dataset showed a very high classification performance for identifying beneficiary (and, by implication, conscience) constituents (F1 = 0.816).¹⁰ We aggregated the data at the group level by calculating the share of members with a stated personal connection (ranging from zero to one).

Workplace-based versus friendship-based groups

To distinguish between workplace- versus friendship-based groups, we started by identifying the former using three data sources: group name (e.g., 'Hairy Business'), common membership of an organisation (e.g., Google) and common organisational domain names of group members' e-mail addresses (e.g., @google.com). We used the Google search engine API to check whether e-mail address domains were affiliated with an organisation. We coded a group as workplace-based when there was a clear organisation name or abbreviation in the group name (e.g., 'The IBM moustaches'); or when the most common membership of the organisational domain of e-mail addresses among group members represented at least half of the group members. We were able to identify 5259 workplace-based groups (e.g., companies, nonprofits, universities), which

represent 56.1% of fundraising groups. We considered the remaining 4113 groups (43.9%) to be friend-based, that is, organised through individual participation (e.g., friends, family members). All of our classifications were manually checked on face validity. We created a dichotomous variable (workplace-based group = 1) to distinguish workplace- versus friendship-based groups.

Control variables

Group composition

Following research on group composition and performance (Bell et al., 2011), we included gender composition, fundraising experience with Movember and geographical dispersion as controls. First, gender composition was measured as a share of female participants in a group, ranging from zero (all men) to one (all women). Gender data come from the Movember Foundation.¹¹ Second, we added the average years of experience as a control variable, on the grounds that prior experience with Movember should also generate higher fundraising (see e.g., Li et al., 2020). Third, geographical dispersion in a group was included as a control, given that those who are less dispersed might fundraise more effectively (e.g., Kiesler & Cummings, 2002). This measure was calculated by the average distance between the centroid of the group members' US zipcode and the centroid of the most common zipcode among group members (mode) or the group leader's zipcode if no single mode existed. This variable was measured in miles with Stata's GEODIST package and log-transformed.

Group resources

Previous research has shown that income is an important predictor of charitable giving and peer-to-peer fundraising (Priante et al., 2021). Similarly, social movement scholars find that the availability of material resources increases the likelihood of mobilisation (Edwards & McCarthy, 2004). As individual income data was not available, we included a proxy of group resources using income data from the US Census, calculated as the average median income of group members based on their home zipcodes.

Volume of Twitter activity about Movember (by group)

Social media usage may boost fundraising (Di Lauro et al., 2019; Priante et al., 2021). Among all social media, Twitter has been a prominent platform for supporters of Movember, especially in the year under consideration (Jacobson & Mascaro, 2016; Movember, 2014; Priante et al., 2021). We therefore counted the number of Twitter messages that contained 'Movember' sent by group members. For this purpose, we linked participants to their Twitter accounts based on tweets with a link to a Movember profile (removed for anonymity). The proportion of groups that used Twitter for the Movember campaign is 16.8%. The variable was log-transformed due to skewness.

RESULTS

Descriptive results

Table 1 presents the means, standard deviations and ranges of the dependent variable, independent variables and control variables. Given that we expect some differences in these characteristics

TABLE 1 Descriptive statistics.

	Mean	SD	Range	Mean	SD	Range
Variable	Friends $(n = 41)$	Friendship-based groups (n = 4113)		Workplace-based groups $(n = 5259)$		ed groups
Avg. donation amount in US \$ raised by group	107.54	230.30	0-3788.38	85.96	192.30	0-4761.50
Share of beneficiary constituents in group	0.253	0.350	0-1	0.198	0.286	0-1
Gender composition in group (proportion female group members)	0.072	0.164	0-1	0.096	0.169	0-1
Avg. fundraising experience in group (in years)	1.52	1.09	0–11	1.28	0.921	0-10
Distance in miles between group members (ln)	2.12	2.39	0-8.48	2.33	2.15	0-8.28
Median income of group members (in 1000 US dollars, by zip code)	70.61	21.35	15.54-250	71.81	21.12	11.23– 209.35
Volume of Twitter activity about Movember sent by group (ln)	0.266	0.742	0-5.22	0.312	0.744	0-5.15
Group size (members)	5.73	18.27	2-817	12.23	19.24	2–531

between friendship- and workplace-based groups, we separate these by group type (although in our write-up below we also provide overall averages across both types).

First, descriptive evidence highlights that, as expected, there is considerable variation across groups in their fundraising. While the mean fundraising amount for each group is quite modest (at only \$95.43 per participant across both types), groups range widely in the funds they collect. And we also see initial evidence that there is variation across group types: Absent any controls, we see evidence that would initially appear to be *against* Hypothesis 2: friendship-based groups have higher *average* fundraising amounts (\$107.54) than workplace-based groups (\$85.96). However, these measures are highly skewed and the *median* fundraising level for friendship-based groups is, in fact, lower (at \$34.38) than the median for workplace-based groups (\$36.67); this supports our initial expectation, and we return to this in the full analysis below.

In addition, we see a few important takeaways. First, groups overall tend to have at least 1 year (on average) of prior experience in the Movember campaign; this is relatively similar across types although friendship-based groups have slightly greater experience (1.52 years, compared to 1.28 years for workplace groups). They also generally lack gender diversity: As a men's health social movement that encourages moustache-growing, participants are overwhelmingly male; only 9.6% of participants are female in workplace-based groups and 7.2% in friendship-based ones; a significant (p < 0.001) difference. Additionally, most participants live in relatively higher-income areas (with median income of \$71,283 overall, compared to the U.S. 2014 median of \$53,657; Table 1 shows that this figure is slightly higher in workplace-based groups than friendship-based ones).

As noted earlier, short of half of the groups in our study are friendship-based (43.9%), and the remainder are workplace-based. Also, friend-based groups have a significantly (p < 0.001) higher share of beneficiary constituents (25.3%) than workplace-based groups (19.8%); it is important to recall, as noted earlier, that beneficiary constituents in most advocacy causes tend to be a relative minority (McCarthy & Zald, 1977), just as we find here. Still, beneficiary constituents raised one-third (\$2.8 million USD) of the total campaign funds in the cycle, while conscience constituents, with their larger number, raised two-thirds (\$5.6 million USD).

TABLE 2 Tobit regression coefficients explaining donations to the 2014 Movember campaign.

	Model 0 (null model)	Model 1 (H1)	Model 2 (H2)	Model 3 (H3)
	<i>b</i> (s.e.)	b (s.e.)	b (s.e.)	b (s.e.)
Share of beneficiary constituents		0.920***		1.190***
		(0.07)		(0.10)
Workplace-based groups			0.188***	0.353***
			(0.05)	(0.06)
Workplace-based groups \times share of beneficiary constituents				-0.517***
				(0.14)
Gender composition	-0.450***	-0.525***	-0.485***	-0.574***
	(0.14)	(0.13)	(0.14)	(0.13)
Avg. fundraising experience	0.327***	0.297***	0.337***	0.308***
	(0.02)	(0.02)	(0.02)	(0.02)
Distance between group members	0.229***	0.234***	0.228***	0.231***
	(0.01)	(0.01)	(0.01)	(0.01)
Median income of group members (by zip code)	0.014***	0.014***	0.014***	0.014***
	(0.00)	(0.00)	(0.00)	(0.00)
Volume of Twitter activity about Movember sent by group	0.470***	0.446***	0.468***	0.442***
	(0.03)	(0.03)	(0.03)	(0.03)
Constant	0.949***	0.782***	0.846***	0.587***
	(0.09)	(0.09)	(0.09)	(0.09)
Ν	9372	9372	9372	9372
Pseudo R squared	0.03	0.04	0.03	0.04

Note: The dependent variable is average donation amount (log-transformed), with a lower censoring level of 0. *p < 0.05, **p < 0.01, ***p < 0.001.

Hypothesis testing

To test our hypotheses, we estimate a series of Tobit regression models. The exclusively non-negative values of the dependent variable (i.e., no negative donations) justify a Tobit model left-censored at zero (Lankford & Wyckoff, 1991), which provides more accurate estimates than Ordinary Least Squares regression. The model parameters were estimated using Stata/IC 16. Table 2 presents the results for four different models. There is no significant concern of multicol-linearity since correlations remain below 0.7. In addition, our models produced VIF scores that never exceed 1.7.

In Model 0, we estimate our null model. In this model, importantly, we see important findings independent of our hypothesis testing. First, and notably, we find that groups active in Movember—as a men's health movement—tend to have higher fundraising with a higher composition of male participants; an all-female group is estimated to fundraise approximately 36% less than an all-male group. Second, Model 0 shows that fundraising levels are higher among groups that have more experience with Movember (perhaps due to reactivation of prior years' networks); this corresponds to a 39% increase for each additional year of average fundraising



FIGURE 1 Interaction plot.

experience. Third, other control measures also have significant effects: although one would expect that groups in closer geographic proximity would be less effective, we see that they instead raise significantly *more* (perhaps because coordinating across greater distance reflects a higher threshold of engagement); groups from places with higher median incomes fundraise at higher levels (each \$1000 increase corresponds to a 1.4% fundraising increase); and groups that send tweets about Movember more often raise significantly if modestly higher funds (a 10% increase in volume of Twitter activity about Movember corresponds to a 6.6% fundraising increase).

Moving to our analytic results, in Model 1 we test Hypothesis 1, on the influence of group's share of beneficiary constituents on the average donation amount collected by a group. We find a positive relationship for having a higher share of beneficiary constituents (b = 0.92, p < 0.001), supporting Hypothesis 1. This corresponds to a roughly 151% increase in donations, net of controls, for groups comprised entirely of beneficiary constituents relative to those that have none.

In Model 2, we test Hypothesis 2 regarding the influence of being a workplace-based group on fundraising performance. In contrast to the basic averages without controls as found in Table 1 described above (but consistent with the median fundraising levels by type), we find a positive relationship for workplace-based groups (b = 0.19, p < 0.001). This finding suggests that group members embedded in an organisation raise greater donations during the Movember campaign, thus supporting Hypothesis 2. This coefficient shows that, net of controls, workplace-based groups tend to raise around 21% more than friendship-based groups.

Lastly, in Model 3 we test Hypothesis 3 about the potential interaction effect between the share of a group's beneficiary constituents with whether the group is workplace-based. We find a significant negative interaction effect (b = -0.52, p < 0.001) for workplace-based groups with higher shares of beneficiary constituents. Figure 1 visualises this interaction effect. This finding suggests that the site of engagement offsets the negative relationship between higher shares of conscience constituents and average amount of donations raised by group members and thus supporting Hypothesis 3. The coefficients in Model 3 illustrate that although being

a group comprised exclusively of beneficiary constituents increases fundraising by 229% (relative to groups with exclusively conscience constituents) and that being a workplace-based group increases fundraising by 42% (relative to a friendship-based groups), having both of these characteristics together *decreases* fundraising by 40%. Thus, consistent with Hypothesis 3, beneficiary constituents are more effective in friendship-based networks and conscience constituents do better in workplace contexts; mismatches between these constituents and network types decrease effectiveness.

DISCUSSION

We sought to understand how distinct types of advocates are differentially effective in DAOs. We expected that beneficiary constituents, with their greater credibility as spokespeople, would be more effective, *on average*, at fundraising (Hypothesis 1). We found that having a higher share of self-identified beneficiary constituents in one's fundraising group had a considerable impact: Results from Model 1 make clear that a group composed entirely of beneficiary constituents will, on average, raise 151% more than one without any, holding other factors constant. Although one might worry that the effect for beneficiary constituents is potentially driven by a stronger willingness to devote effort to fundraising (rather than their credibility given disease experiences), we note that our model controls for prior fundraising effort through our measure of years of experience with the campaign.

Related to this, we expected that there would be important differences in how beneficiary and conscience constituents harness their networks. While the former would be more likely to recruit others into DAO activism through interpersonal networks of friends and family members, conscience constituents would be more likely to become involved through other networks, namely workplaces. Following from this expectation and given that workplaces provide considerable resources, we further posited that workplace-based groups would, *on average*, be more effective fundraisers than friendship-based groups (Hypothesis 2). And indeed, we found that workplace-based groups—with their considerable resource pools—collect higher average donations. Model 2 illustrates that members of workplace-based fundraising groups raise 21% more than those that are based around friendship ties, when holding other measures at their means, thus supporting Hypothesis 2. While there are likely multiple mechanisms at work—and a limitation of our study is that we do not have evidence to clearly demarcate how much of this effect is due to the greater resource capacities of workplaces versus the greater 'peer pressure' among coworkers (Dixon & Roscigno, 2003)—we take this as confirming that workplaces are effective fundraising venues (Barman, 2006).

Lastly, given that beneficiary constituents are more likely to be found in friendship-based groups and conscience constituents more in workplace-based ones, we expected an interaction effect such that in the 'off-diagonal' scenarios where this is less common—workplace groups with a high proportion of beneficiary constituents (and, by implication, friendship groups with a high proportion of conscience constituents)—fundraising would be less effective (Hypothesis 3). We argued that one's credibility as a beneficiary spokesperson for a DAO should matter less to one's coworkers than to one's (presumably closer) friends and family; similarly, without the tie of a workplace nor a close connection to illness, being a conscience-based supporter in a friendship-based group should also weaken fundraising.

Model 3 makes clear that there is a significant negative interaction between a fundraising group's share of beneficiary constituents and being a workplace-based group. Thus, although the

credibility benefit of being a prostate/testicular cancer patient and/or their close tie is considerable, this effect is weakened in workplaces. And, in additional models not shown, we find it is strengthened through a positive interaction when beneficiary constituents raise funds in friendship-based groups.

IMPLICATIONS

Our findings bear at least four important implications for DAOs as they consider the most effective strategies. First, although most DAO research overlooks outside supporters, when they are recognised, analysts point to their limitations. Nonetheless, for the simple goal of fundraising, these broader supporters are often highly effective in aggregate, and the work of both beneficiary and conscience constituents can help in a way that does not detract from public policymaking in fact, these private funds can leverage increased public funding through public agencies (Best, 2012, 2019). Such was true, for instance, in the 'ice bucket challenge' supporting ALS research, as noted earlier, although we are not aware of comparable evidence yet for Movember and prostate cancer; this is an important avenue for future research.

Second, our findings make clear that venues of activism matter for mobilising distinct kinds of constituents: those closely connected to the illness appear to get better results when mobilising through friendship networks, and those without such connections (allies) tend to be effective in tapping into workplace networks. Hence, DAO campaigns may find benefit through amplifying further support of conscience constituents within workplaces, as well as encouraging those affected by the illness to conduct additional outreach in their interpersonal networks. Employer fundraising matching campaigns may also benefit by accounting for this.

Third, a more general implication for DAOs is that there is benefit in engaging in cause-marketing that gives outside supporters a way to become involved and show their support beyond making financial contributions. While perhaps somewhat 'kitschy', the Movember campaign's moustache campaign gave (male-identifying) supporters a public way to show their support and made it important that they 'walk the talk' by engaging in active fundraising. Importantly, the campaign's focus on the month of November meant an intense focus during a constrained period, perhaps reducing burn-out.

Fourth and finally, our study contributes to understanding DAOs by focusing in on engagement in a key men's health movement, following other important studies (e.g., Baker, 2001; Leone & Rovito, 2013; Richardson & Carroll, 2009). Our analyses show that, regardless of constituent and fundraising network types, those most likely to face this disease (men) are, of course, far more heavily involved than women. More importantly, our models also show that men yield higher fundraising totals when they engage in fundraising for this DAO, and this holds true across model specifications. Thus, there is an additional implication in that DAOs may wish to focus their outreach efforts on allies who, while they may not have direct experience with illness, still share key socio-demographic characteristics with disease patients.

CONCLUSION

While prior research has made clear DAO campaigns' importance in generating awareness and raising funds for illnesses and emphasised the central role of those suffering from the disease (and their loved ones) as advocates (Best, 2012, 2019; Ganchoff, 2004; Gunnarsson Payne &

Korolczuk, 2016; Hess, 2004; Kurhila et al., 2020; Lindén, 2021; Nahuis & Boon, 2011; Ozieranski et al., 2022; Panofsky, 2011; Rose, 2013; Strach, 2016; Wong-Rieger, 2017), little attention has been paid to the important role of outside supporters. Our study illustrates that in one major DAO active in the domain of prostate and testicular cancer—the widely prominent Movember campaign—outside supporters, or conscience constituents, played a very important role. Even though prostate and testicular cancer patients (and their close ties) tend to be more effective at fundraising than allied supporters, we find that the latter are more numerous and able to tap into considerable resources. Those resources are often derived from where fundraising happens, given that conscience constituents are more likely to fundraise in workplaces. Our study is also one of the first to examine how patient-activists and allies' characteristics intersect with *where* they fundraise—through friendship—versus workplace-based networks—as prior studies have lacked the rich data needed to carry this out.

Limitations

Beyond its contributions, it is important to note the limitations of our study. First, despite our rich data, we were limited by the specific empirical context. We have only 1 year of data on the campaign. We expect that patterns may have looked slightly different in the peak year of 2012, as well as in the post-2014 period when engagement waned. That said, there are reasons to expect that the 2014 and 2012 campaigns may have looked relatively similar, if at a different scale. There might have been higher levels of beneficiary constituent participation during 2012 relative to 2014, as the US Centers for Disease Control reported that incidence rates of prostate cancer were slightly higher in 2012 relative to 2014 (119 relative to 100 per 100,000, respectively).¹² At the same time, we expect that conscience constituent participation was likely also higher in 2012 given that peak years of disease advocacy fundraising in other campaigns—such as the aforementioned 'ice bucket challenge' for ALS (Phing & Yazdanifard, 2014)—tend to draw in high numbers of conscience constituents. In later, non-peak years, however, we expect that conscience constituent fundraising likely dropped off considerably, leaving more of the responsibility with core beneficiaries. Fundraising fatigue may also have been an issue in later years.

We also acknowledge the limitation that demographic factors may be partially shaping the finding that beneficiary constituents are more effective at fundraising via friendship networks; prostate cancer is much more common among older men who are more likely to have departed the labour force and who may have less access to workplaces. That being said, it is important to recall that the Movember campaign covers both prostate and testicular cancers, the latter of which tend to affect younger men aged 15–45, who are therefore closer to conventional working ages.¹³ It is also important to note that beneficiary constituents include not only those affected by disease but also (the more numerous group of) their close ties; there is much less of an a priori reason to expect that their loved ones should have less access to workplaces, save for some smaller proportion caring for their ill family member.

There are also limitations resulting from our focus on the US Previous research has found significant variation in fundraising approaches internationally (Breeze & Scaife, 2015; Van Leeuwen & Wiepking, 2013). The US has a well-organised and less regulated non-profit sector with high participation (Brown et al., 2015). As a result, we would expect a higher rate of participation in groups in the US than in other countries. Supplementary analyses from other portions of our data source reveal that the US Movember campaign indeed has the highest percentage (73.0%) of participation in fundraising groups, but this number is close to Sweden's percentage (72.3%) and Canada's percentage (70.8%). We encourage future research to take a cross-national approach.

Additionally, although we see it as a value that our data identifies beneficiary and conscience constituents, we were limited to participants' biographical statements. Certain participants failed to report this and/or may have omitted critical information. The data available also only allowed to create a binary classification of workplace-based and friendship-based fundraising groups, while there might be the possibility of groups that combine both colleagues and friends. Future research would benefit from asking DAO participants directly (e.g., by surveys) about the extent of their personal ties to illness and analysing how that affected their participation. This would allow for a more fine-grained measure of team type.

Lastly, as noted earlier, we were not able to identify whether workplace groups have, on net, higher fundraising levels because they have access to more considerable resource pools or whether instead it is because of the greater fundraising 'peer pressure' linked to workplace groups (see Peloza & Hassay, 2006). We expect that both of these mechanisms are at work and encourage future studies to unpack this further. We also could not assess the extent to which workplace-based groups were driven by having top-level corporate leaders as participants in groups (Walker, 2002).

Directions for future research

We believe that our study suggests a variety of productive directions for future research. We identify four such potentials.

First, our findings raise potentials for future research around how fundraising appeals are communicated by each constituent type. For example, qualitative (or computational text-analysis) studies could carry out investigations into how requests for donations vary between them, and whether certain messaging is more effective for each, extending beyond prior studies that have examined health advocacy communications and their reception (e.g., Bail, 2016). As other scholars have done, it might be possible for researchers to develop partnerships with advocacy organisations, who then have the capacity to track their constituents' fundraising appeals and have an incentive to systematically understand which messages resonate. Both scholars and DAOs also benefit by knowing more about how messaging connects differentially with friends versus coworkers.

Second, a strong expectation of RMT was that in settings where conscience and beneficiary constituents need to work together in close contact, they are likely to have some degree of animosity (McCarthy & Zald, 1977, p. 1231). This is because beneficiary constituents may at times resent feeling dependent on 'outside' allies with less of a shared experience with the problem (disease) they seek to address, and conscience constituents may feel underappreciated as less authentic supporters (see also Owen, 2019). Future studies could do more to investigate these dynamics by surveying both conscience and beneficiary constituent fundraisers in DAO campaigns to assess constituent feelings towards one another and willingness to collaborate. To the extent that such sentiments are indeed negative, campaigns might benefit from taking a differentiated strategy when engaging with each.

Third, future research could provide greater depth on DAO fundraising within workplaces. Prior studies have shown, for example, that elite endorsements—such as a CEO taking part in a campaign directly (Walker, 2002)—can boost participation. At the same time, we are not aware of prior studies that have systematically tested how the full range of features of workplaces may shape fundraising effectiveness and how this may interact with constituent types. For DAOs such as Movember that focus on conditions affecting men, for instance, the gender composition of workplaces may (naturally) be a powerful factor as well.

Fourth and finally, future research should gather data on the trajectory of fundraising campaigns over time, ideally with rich micro-data on participation in each year's campaign. As noted above, a limitation of our study is that we were only granted access to 1 year of data. Being able to follow the trajectories of individuals over time, and how they dynamically interact with fundraising contexts, would be an enormous benefit.

Summary

Our study makes clear that both beneficiary and constituents are important in advocacy by DAOs, particularly in their ability to raise funds for research about the illness in question. Additionally, the returns to such efforts are different for those constituents depending on the types of social networks they engage. We encourage future research to continue to look beyond the narrow focus on beneficiary constituents when seeking to understand DAOs and their impacts and to also consider how these diverse parties can work together more effectively to coordinate.

AUTHOR CONTRIBUTIONS

Edward T. Walker: Conceptualisation (lead); Investigation (equal); Writing – original draft (lead); Writing – review & editing (equal). **Tijs van den Broek**: Data curation (lead); Formal analysis (lead); Funding acquisition (lead); Investigation (equal); Writing – review & editing (equal). **Anna Priante**: Conceptualisation (supporting); Funding acquisition (supporting); Investigation (equal); Writing – review & editing (equal). **Michel L. Ehrenhard**: Conceptualisation (supporting); Funding acquisition (supporting); Investigation (equal); Writing – review & editing (equal).

ACKNOWLEDGEMENTS

We thank Twitter and the Movember Foundation for data access, through a Twitter DataGrant. In addition, we thank conference audiences at the European Group for Organisational Studies (EGOS) and the Academy of Management for feedback on portions of this project.

DATA AVAILABILITY STATEMENT

These data are not shareable due to privacy restrictions and the data agreement with the project's funder. Results from alternative specifications of the models are available by request to the authors.

CONFLICT OF INTEREST STATEMENT

The authors acknowledge funding from a Twitter Datagrant provided with the support of Twitter and the Movember Foundation. Neither of these sponsoring organisations were involved in the research other than providing data on participant engagement in the Movember campaign and their associated Twitter postings (tweets). The authors have no other conflicts of interest to disclose.

ETHICS STATEMENT

The authors affirm that this research was conducted in an ethical and responsible manner and complies with all relevant legislation, in addition to providing results transparently, describing methods clearly, and that this work is original to this publication and does not appear elsewhere. We take collective responsibility for the submitted and published work.

14679566, 2023. 8, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/1467-9566.13655 by University Of Twente FEZ, Wiley Online Library on (08/02/2024). See the Terms and Conditions (https://onlinelibrary.wiley com/terms-and-conditions) on Wiley Online Library for rules of use; O Aarticles are governed by the applicable Creative Commons License

PATIENT CONSENT STATEMENT

Not applicable.

PERMISSION TO REPRODUCE MATERIALS

Not applicable.

ORCID

Edward T. Walker D https://orcid.org/0000-0001-9633-4723 Tijs van den Broek D https://orcid.org/0000-0002-8686-7312 Anna Priante https://orcid.org/0000-0003-1536-3755 Michel L. Ehrenhard D https://orcid.org/0000-0002-5608-9628

ENDNOTES

- ¹ Although outside our scope, DAOs are also important for raising awareness and generating policy changes (Strach, 2016), in addition to providing education (Kurhila et al., 2020).
- ² We return later to consider how our findings might have differed had we used a different year. For the 2014 Annual Report, see: https://cdn.movember.com/uploads/files/Annual%20Reports/Movember%20Foundation%20US%20AR%202014%20final.pdf.
- ³ See: https://prostatecanceruk.org/prostate-information/about-prostate-cancer.
- ⁴ See: https://www.cancer.org/cancer/prostate-cancer/about/key-statistics.html.
- ⁵ See: https://www.wcrf.org/cancer-trends/prostate-cancer-statistics/.
- ⁶ See: https://www.als.org/stories-news/ice-bucket-challenge-dramatically-accelerated-fight-against-als.
- ⁷ The estimates in our analyses sum to lower totals because they only represent the U.S. portion for a segment of the year (albeit the dominant period surrounding November). The peak fundraising year between 2007 and 2018 was 2012 (\$148M), followed by 2011 and 2013 (each at \$124M). Unfortunately the highly detailed fundraising data we employ was not made available for scholarly use for years other than 2014. See: https://www.statista.com/chart/2906/movember-donations-since-2007/.
- ⁸ Only 11 participants (0.01% of total participants) did not have a motivation in their Movember profile. Since they were part of very large fundraising groups, we excluded them from the calculation of the share of beneficiary constituents. Seven hundred and twenty-five groups were excluded due to missing zip code data.
- ⁹ The top terms classified as being part of such a personal connection include: 'cancer', 'friend', 'lost', 'father', 'had', 'survivor', 'prostate', 'for my', 'my', 'every', 'this', 'who', 'my father', 'think', 'my dad', 'suffered', 'illness', 'men will', 'men to', 'so', 'affected', 'diagnosed', 'is for', and 'dad'.
- ¹⁰ In Van Zomeren et al. (2008), the authors referred to beneficiary constituents as having an 'injustice motivation', as participants often connected their personal (beneficiary) ties to illness to a motivation to address grievances related to illness. The other motivations, which Van Zomeren et al. (2008) referred to as 'social identity' and 'collective efficacy', both relate to non-beneficiary (conscience) ties.
- ¹¹ Although the Movember database did allow participants to omit gender, all observations indicated either male or female. To our knowledge, non-binary or other genders were not listed as options.

¹² See: https://seer.cancer.gov/statfacts/html/prost.html.

¹³ Source: https://www.mayoclinic.org/diseases-conditions/testicular-cancer-care/symptoms-causes/syc-20352986.

WALKER ET AL.

REFERENCES

- Aronowitz, R. (2014). "Screening" for prostate cancer in New York's skid row: History and implications. American Journal of Public Health, 104(1), 70–76. https://doi.org/10.2105/ajph.2013.301446
- Bail, C. (2016). Cultural carrying capacity: Organ donation advocacy, discursive framing, and social media engagement. Social Science & Medicine, 165, 280–288. https://doi.org/10.1016/j.socscimed.2016.01.049
- Baker, P. (2001). The international men's health movement. *BMJ*, *323*(7320), 1014–1015. https://doi.org/10.1136/ bmj.323.7320.1014
- Barman, E. (2006). Contesting communities. Stanford University Press.
- Bell, S. T., Villado, A. J., Lukasik, M. A., Belau, L., & Briggs, A. L. (2011). Getting specific about demographic diversity variable and team performance relationships: A meta-analysis. *Journal of Management*, 37(3), 709–743. https://doi.org/10.1177/0149206310365001
- Best, R. K. (2012). Disease politics and medical research funding: Three ways advocacy shapes policy. American Sociological Review, 77(5), 780–803. https://doi.org/10.1177/0003122412458509
- Best, R. K. (2019). Common enemies. Oxford University Press.
- Breeze, B., & Scaife, W. (2015). Encouraging generosity: The practice and organization of fund-raising across nations. In P. Wiepking & F. Handy (Eds.), *Palgrave handbook of global philanthropy* (pp. 570–596). Palgrave.
- Brown, E., Einolf, C. J., & Ottoni-Wilhelm, M. (2015). Giving in the United States. In P. Wiepking & F. Handy (Eds.), Palgrave handbook of global philanthropy (pp. 44–63). Palgrave.
- Di Lauro, S., Tursunbayeva, A., & Antonelli, G. (2019). How nonprofit organisations use social media for fundraising: A systematic literature review. *International Journal of Business and Management*, 14(7), 1. https://doi. org/10.5539/ijbm.v14n7p1
- Dixon, M., & Roscigno, V. J. (2003). Status, networks, and social movement participation: The case of striking workers. American Journal of Sociology, 108(6), 1292–1327. https://doi.org/10.1086/375198
- Edwards, B., & McCarthy, J. D. (2004). Resources and social movement mobilization. In D. A. Snow, S. A. Soule, & H. Kriesi (Eds.), *Blackwell companion to social movements* (pp. 116–152). Blackwell.
- Filo, K., Fechner, D., & Inoue, Y. (2020). Charity sport event participants and fundraising: An examination of constraints and negotiation strategies. *Sport Management Review*, 23(3), 387–400. https://doi.org/10.1016/j. smr.2019.02.005
- Ganchoff, C. (2004). Regenerating movements: Embryonic stem cells and the politics of potentiality. *Sociology of Health & Illness*, 26(6), 757–774. https://doi.org/10.1111/j.0141-9889.2004.00417.x
- Granovetter, M. S. (1973). The strength of weak ties. *American Journal of Sociology*, 78(6), 1360–1380. https://doi. org/10.1086/225469
- Gunnarsson Payne, J., & Korolczuk, E. (2016). Reproducing politics: The politicisation of patients' identities and assisted reproduction in Poland and Sweden. Sociology of Health & Illness, 38(7), 1074–1091. https://doi. org/10.1111/1467-9566.12433
- Hess, D. J. (2004). Medical modernisation, scientific research fields and the epistemic politics of health social movements. Sociology of Health & Illness, 26(6), 695–709. https://doi.org/10.1111/j.0141-9889.2004.00414.x
- Jacobson, J., & Mascaro, C. (2016). Movember: Twitter conversations of a hairy social movement. Social Media + Society, 2(2), 2056305116637103. https://doi.org/10.1177/2056305116637103
- Kempner, J. (2006). Gendering the migraine market: Do representations of illness matter? Social Science & Medicine, 63(8), 1986–1997. https://doi.org/10.1016/j.socscimed.2006.05.001
- Kiesler, S., & Cummings, J. N. (2002). What do we know about proximity and distance in work groups? A legacy of research. In P. J. Hinds & S. Kielser (Eds.), *Distributed work* (pp. 57–82). MIT Press.
- Kim, D. H. (2019). 'How do you feel about a disease?' The effect of psychological distance towards a disease on health communication. *International Journal of Advertising*, 38(1), 139–153. https://doi.org/10.1080/026504 87.2018.1438031
- King, S. (2006). Pink Ribbons, Inc. University of Minnesota Press.
- Kurhila, S., Lehtimaja, I., & Drew, P. (2020). Correcting medical decisions: A study in nurses' patient advocacy in (Finnish) hospital ward rounds. Sociology of Health & Illness, 42(7), 1709–1726. https://doi. org/10.1111/1467-9566.13159
- Landy, D. C., Brinich, M. A., Colten, M. E., Horn, E. J., Terry, S. F., & Sharp, R. R. (2012). How disease advocacy organisations participate in clinical research: A survey of genetic organisations. *Genetics in Medicine*, 14(2), 223–228. https://doi.org/10.1038/gim.0b013e3182310ba0

- Lankford, R. H., & Wyckoff, J. H. (1991). Modeling charitable giving using a Box-Cox standard Tobit model. The Review of Economics and Statistics, 73(3), 460–470. https://doi.org/10.2307/2109570
- Leone, J. E., & Rovito, M. J. (2013). "Normative content" and health inequity enculturation: A logic model of men's
- health advocacy. *American Journal of Men's Health*, 7(3), 243–254. https://doi.org/10.1177/1557988312469659 Levitsky, S. (2007). Niche activism: Constructing a unified movement identity in a heterogeneous organisational
- field. Mobilization, 12(3), 271-286. https://doi.org/10.17813/maiq.12.3.3v020m3751v1k642
- Li, Y. M., Wu, J. D., Hsieh, C. Y., & Liou, J. H. (2020). A social fundraising mechanism for charity crowdfunding. Decision Support Systems, 129, 113170. https://doi.org/10.1016/j.dss.2019.113170
- Lindén, L. (2021). Running out of time: The case of patient advocacy for ovarian cancer patients' access to PARP inhibitors. *Sociology of Health & Illness*, 43(9), 2141–2155. https://doi.org/10.1111/1467-9566.13385
- Marwell, G., & Oliver, P. (1993). The critical mass in collective action.
- McCarthy, J. D., & Zald, M. N. (1977). Resource mobilization and social movements: A partial theory. American Journal of Sociology, 82(6), 1212–1241. https://doi.org/10.1086/226464
- Morantz, A. (2021). Clinicians as advocacy allies for people with ASD. In F. R. Volkmar, et al. (Eds.), Handbook of autism spectrum disorder and the law (pp. 417–437). Springer.
- Movember. (2014). Movember 2014 global annual report. https://cdn.movember.com/uploads/files/Annual%20 Reports/Movember%20Foundation%20US%20AR%202014%20final.pdf
- Nahuis, R., & Boon, W. P. C. (2011). The impact of patient advocacy: The case of innovative breast cancer drug reimbursement. Sociology of Health & Illness, 33(1), 1–15. https://doi.org/10.1111/j.1467-9566.2010.01271.x
- Nguyen, D., Van den Broek, T. A., Hauff, C., Hiemstra, D., & Ehrenhard, M. (2015). #SupportTheCause: Identifying motivations to participate in online health campaigns. EMNLP 2015.
- Oberschall, A. (1973). Social conflict and social movements. Prentice-Hall.
- Oshinsky, D. M. (2005). Polio. Oxford University Press.
- Owen, N. (2019). Other people's struggles. Oxford University Press.
- Ozieranski, P., Pitter, J. G., Rickard, E., Mulinari, S., & Csanadi, M. (2022). A 'patient–industry complex'? Investigating the financial dependency of UK patient organisations on drug company funding. *Sociology of Health* & *Illness*, 44(1), 188–210. https://doi.org/10.1111/1467-9566.13409
- Panofsky, A. (2011). Generating sociability to drive science: Patient advocacy organisations and genetics research. Social Studies of Science, 41(1), 31–57. https://doi.org/10.1177/0306312710385852
- Peloza, J., & Hassay, D. N. (2006). Intra-organisational volunteerism. Journal of Business Ethics, 64(4), 357–379. https://doi.org/10.1007/s10551-005-5496-z
- Phing, A. N. M., & Yazdanifard, R. (2014). How does ALS ice bucket challenge achieve its viral outcome through marketing via social media? *Global Journal of Management and Business Research*, 14(E7), 57–64.
- Plewa, C., Conduit, J., Quester, P. G., & Johnson, C. (2015). The impact of corporate volunteering on CSR image: A consumer perspective. *Journal of Business Ethics*, 127(3), 643–659. https://doi.org/10.1007/s10551-014-2066-2
- Priante, A., Ehrenhard, M. L., Van den Broek, T. A., Need, A., & Hiemstra, D. (2021). "Mo" together or alone? Investigating the role of fundraisers' networks in online peer-to-peer fundraising. *Nonprofit and Voluntary Sector Quarterly*, 51(5), 986–1009. https://doi.org/10.1177/08997640211057456
- Richardson, N., & Carroll, P. C. (2009). Getting men's health onto a policy agenda. *Journal of Men's Health*, 6(2), 105–113. https://doi.org/10.1016/j.jomh.2009.03.004
- Romney-Alexander, D. (2002). Payroll giving in the UK: Donor incentives and influences on giving behaviour. Journal of Philanthropy and Marketing, 7(1), 84–92. https://doi.org/10.1002/nvsm.169
- Rose, S. L. (2013). Patient advocacy organisations: Institutional conflicts of interest, trust, and trustworthiness. Journal of Law Medicine & Ethics, 41(3), 680–687. https://doi.org/10.1111/jlme.12078
- Sargeant, A., & Shang, J. (2016). Outstanding fundraising practice. International Journal of Nonprofit and Voluntary Sector Marketing, 21(1), 43–56. https://doi.org/10.1002/nvsm.1546
- Skocpol, T. (2003). *Diminished democracy*. University of Oklahoma Press.
- Strach, P. (2016). Hiding politics in plain sight. Oxford University Press.
- Swarts, H. J. (2008). Organizing urban America. University of Minnesota Press.
- Van den Broek, T. A., Need, A., Ehrenhard, M. L., Priante, A., & Hiemstra, D. (2019). The influence of network structure and prosocial cultural norms on charitable giving: A multilevel analysis of Movember's fundraising campaigns in 24 countries. *Social Networks*, 58, 128–135. https://doi.org/10.1016/j.socnet.2019.04.001

SOCIOLOGY OF HEALTH & ILLNES

- Van Leeuwen, M. H., & Wiepking, P. (2013). National campaigns for charitable causes: A literature review. Nonprofit and Voluntary Sector Quarterly, 42(2), 219–240. https://doi.org/10.1177/0899764012467084
- Van Zomeren, M., Postmes, T., & Spears, R. (2008). Toward an integrative social identity model of collective action: A quantitative research synthesis of three socio-psychological perspectives. *Psychological Bulletin*, 134(4), 504–535. https://doi.org/10.1037/0033-2909.134.4.504
- Vicari, S., & Cappai, F. (2016). Health activism and the logic of connective action. A case study of rare disease patient organisations. *Information, Communication & Society*, 19(11), 1653–1671. https://doi.org/10.1080/13 69118x.2016.1154587
- Wahlström, M., Peterson, A., & Wennerhag, M. (2018). "Conscience adherents" revisited: Non-LGBT pride parade participants. *Mobilization*, 23(1), 83–100. https://doi.org/10.17813/1086-671x-23-1-83
- Walker, C. (2002). Philanthropy, social capital or strategic alliance? The involvement of senior UK business executives with the voluntary sector and implications for corporate fundraising. *International Journal of Nonprofit* and Voluntary Sector Marketing, 7(3), 219–228. https://doi.org/10.1002/nvsm.181
- Wong-Rieger, D. (2017). Moving from patient advocacy to partnership: A long and bumpy road. *The Patient*, *10*(3), 271–276. https://doi.org/10.1007/s40271-017-0216-1
- Wood, L., Snelgrove, R., & Danylchuk, K. (2010). Segmenting volunteer fundraisers at a charity sport event. Journal of Nonprofit & Public Sector Marketing, 1, 38–54. https://doi.org/10.1080/10495140903190408
- Zavestoski, S., McCormick, S., & Brown, P. (2004). Gender, embodiment, and disease: Environmental breast cancer activists' challenges to science, the biomedical model, and policy. *Science as Culture*, 13(4), 563–586. https://doi.org/10.1080/0950543042000311869

How to cite this article: Walker, E. T., Van den Broek, T. A., Priante, A., & Ehrenhard, M. L. (2023). Patient-activist or ally? Assessing the effectiveness of conscience and beneficiary constituents in disease advocacy fundraising. *Sociology of Health & Illness*, *45*(8), 1652–1672. https://doi.org/10.1111/1467-9566.13655