

**THE IMACT OF ONLINE PLATFORMS ON HEALTHCARE ADVOCACY
EFFORTS FOR PATIENTS WITH POSTURAL ORTHOSTATIC
TACHYCARDIA SYNDROME (POTS)**

by

Alexa Chronister

A thesis submitted to the Faculty of the University of Delaware in partial fulfillment of the requirements for the degree of Honors Bachelor of Arts in Public Policy with Distinction

2019 - 2020

© 2020 Alexa Chronister
All Rights Reserved

**THE IMACT OF ONLINE PLATFORMS ON HEALTHCARE
ADVOCACY EFFORTS FOR PATIENTS WITH
POSTURAL ORTHOSTATIC TACHYCARDIA SYNDROME (POTS)**

by

Alexa Chronister

Approved: _____
Steven Eidelman, MBA, MSW
Professor in charge of thesis on behalf of the Advisory Committee

Approved: _____
Eric Jacobson, MPA
Committee member from the Department of Public Policy and
Administration

Approved: _____
Barbara Settles, Ph.D
Committee member from the Board of Senior Thesis Readers

Approved: _____
Michael Chajes, Ph.D
Faculty Director, University Honors Program

TABLE OF CONTENTS

LIST OF TABLES	ii
LIST OF FIGURES	iii
ABSTRACT	iv
1 INTRODUCTION	1
2 METHODS	4
3 LITERATURE REVIEW	6
Patient Organization Website Platforms	6
Social Media	11
4 RESULTS	16
Case Study of Dysautonomia International	16
Issue Crawler Software Analysis	18
<i>Redirection to External Sources</i>	18
<i>Internal Pages</i>	22
5 DISCUSSION AND CONCLUSION	28
REFERENCES	34

LIST OF TABLES

Table 1	Redirection to External Sources.....	18
Table 2	Internal Pages.....	23

LIST OF FIGURES

Figure 1	Number of Academic Journal Articles Published on PubMed with Postural Orthostatic Tachycardia Syndrome in the Title or Abstract from 1993 to 2019.....	8
Figure 2	Redirection to External Sources.....	19
Figure 3	Internal Pages.....	24

ABSTRACT

The creation of the internet has significantly changed traditional disease advocacy efforts. This technology has led to the creation of online website and social media platforms with a greater ability to advocate for their communities than previously possible. For rare and lesser-known conditions, these platforms have a more significant impact as they allow those impacted across the world to unite around the cause. Postural Orthostatic Tachycardia Syndrome (POTS), a form of dysautonomia, is not considered a rare disease. However, it is not well-known amongst the public or medical community and has experienced similar advancements to conditions classified as rare.

For POTS patients, social media and online organizational platforms, the most prominent being Dysautonomia International, play a crucial role in advocacy efforts. This study examines how online platforms have increased the effectiveness of POTS advocacy and conducts an in-depth analysis of the most prominent advocacy organization, Dysautonomia International, to investigate which digital elements have allowed for the most significant advances, as well as where the platform externally directs its audience in comparison to the advocacy occurring on the platform itself.

This area of research is just beginning to be explored, but the significance of online platforms is recognized by patients and physicians alike. Social media in particular is a newer advancement and future research may further examine its contributions to patient advocacy efforts.

Chapter 1

INTRODUCTION

Advances in digital technology and social platforms have given rise to a new wave of healthcare advocacy. This new wave is characterized by disease-specific advocacy communities that have emerged over the past two decades (Vigo, 2019). Technological advances and growth in the presence of online platforms have had a particularly influential impact on more uncommon and rare disease advocacy groups.

The lack of information about these conditions and feelings of isolation felt by patients, families, and caregivers have significantly contributed to the growth of patient-led online communities who work to advocate for those fighting the disease. In addition, the majority of these diseases lack sufficient research efforts which means they often have little to no treatments specifically for the condition. While the rate of rare disease therapeutic development has been increasing, ninety-four percent of rare diseases still lack an approved treatment (Austin et al., 2017).

Clearly frustrating for patients and caregivers, many turn to creating or joining online platforms to promote research studies, awareness efforts, and governmental action. While many engage with at least one advocacy platform or create their own, social media platforms also allow individual patients to engage in advocacy efforts. Social media and its “influencers” or those who have built a reputation as being a credible source of information online, are newer concepts that are continuing to change and further develop. The impact of patient leaders utilizing social media

platforms for healthcare related advocacy is now beginning to be recognized and more fully understood (Cornejo, 2017).

The use of technology has helped to transform traditional advocacy work by allowing for the formation of international patient communities which serve a variety of functions including to gather information, contribute to research studies, provide resources to patients, spread disease awareness, and impact legislation. These online groups allow for patients across the globe to come together giving advocacy groups increased influence in their efforts, which without the ability to easily reach individuals across the country and abroad, may have never actualized.

This paper explores the impact of online platforms on advocacy efforts for patients with Postural Orthostatic Tachycardia Syndrome (POTS). POTS is a disorder of the autonomic nervous system which regulates the bodily functions humans do not consciously control such as digestion, body temperature, and heart rate. Symptoms of the condition can include fatigue, lightheadedness and/or fainting upon standing, heart palpitations, nausea, vomiting, shakiness, and exercise intolerance, amongst others (“Postural Orthostatic Tachycardia Syndrome”, n.d.).

Though not widely understood, POTS is not considered a rare disease. In the United States, a condition must impact fewer than 200,000 people to be considered a rare disease. Congress created this definition in the Orphan Drug Act of 1983, P. L. 97-414. Whether or not a disease is considered rare differs by country. For example, in the European Union, a condition is deemed to be rare when it affects fewer than 1 in 2,000 people (“FAQs About Rare Diseases, n.d.). Current estimates put the number of Americans affected by POTS at between 1,000,000 and 3,000,000 (“Postural Orthostatic Tachycardia Syndrome”, 2017). These estimates put the number affected

above 1 in 2,000 people. The condition is also not condition is therefore also not considered rare by the EU. This condition is often under-recognized and misdiagnosed (Pandian, Dalton, Henderson, & McCombe, 2007), unfamiliar to many medical professions (Kavi, Gammage, Grubb, & Karabin, 2012), and has no FDA approved medications to treat the condition (Miller & Raj, 2018).

In this study, online platforms are defined as organizational websites and social media sites such as Twitter and Facebook. Social media use is analyzed within the context of dysautonomia online platforms, as well as through the lens of patient leader utilization of social media platforms. For the purpose of this study, advocacy is defined as any activity carried out either by an individual or group that aims to influence structures, attitudes, and/or decisions within political and social systems and institutions, within the context of the condition.

Chapter 2

METHODS

There were two major methods used in this study. First, a literature review was conducted, and second, a case study of the most prominent online platform for POTS patients, Dysautonomia International, was developed. The literature review was divided into two parts. First, literature related to online platforms in the traditional sense of organizations' website platforms was analyzed, including these organizations' use of social media. As part of this analysis, a review of the number of POTS-related articles published per year was studied to determine any existing correlation between the efforts of POTS advocacy platforms and the amount of disease-related research produced. Second, the review was expanded to study the use of social media by individuals, respecting the use of social media platforms themselves as online advocacy platforms.

To further study the impact of online platforms on advocacy efforts for patients with POTS in particular, Dysautonomia International, was studied in depth. First, the information pathways were examined by analyzing the hyperlinking structures employed by the platform. This analysis was conducted to study if platform visitors are being directed to external pages and if so, what content these pages contain. This was done using a software called Issue Crawler (<https://www.issuecrawler.net/>), which collects a list of every page that the platform redirects its visitors. Each link was then coded by the type of content the page contained (Chart 1). Next, the number of pages in each category were tallied. Categories with under 10 pages of content were

excluded because they made up less than 1 percent of the platform's overall content. The remaining data was used to create a pie chart to display the percentage of total links each content category contained (Figure 2).

Second, an internal page analysis was conducted on every platform page. This was done similarly to the hyperlinking analysis by coding each page by the type of content it contained (Chart 2). Just as in the hyperlinking analysis, the number of pages in each category were tallied and categories with under 10 pages of content were excluded. The remaining data was also used to create a pie chart displaying the percentage of the platform's internal pages each content category contained (Figure 3).

The second method used to study Dysautonomia International's platform investigated and analyzed the digital elements utilized by the platform to engage and inform their audience. The elements were grouped into 3 categories depending on which type of informational mechanism, one-way, two-way, or collective, was used. One-way mechanisms were defined as elements where information flows from the organization to the public, such as an educational video or blog post. Two-way mechanisms were defined as elements which allow for an information exchange between the organization and its audience, such as conferences or the opportunity to host a fundraiser. Collective mechanisms were defined as elements that allow for collaboration between multiple individuals with many individual voices sharing information, such as support groups or live chats.

Chapter 3

LITERATURE REVIEW

Patient Organization Website Platforms

Previous research pertaining to the impact of online platforms on healthcare advocacy for disease is limited. A 2016 study centered around studying rare disease patient organizations, media, and health advocacy concluded that, “the relationship between digital media and health activism, despite the importance of the impact of health activism on public health services and scientific research, has so far remained unexplored” (Vicarri & Cappai, 2016, p. 1653). Because previous research pertaining to the impact of online platforms on disease advocacy efforts is already limited and there is no current research on this impact specifically for Postural Orthostatic Tachycardia Syndrome, this literature review will examine the research that does exist and apply its major findings to the narrower lens of my research.

There are currently 6 established organizations dedicated to Dysautonomia and/or POTS. These include: Dysautonomia Youth Network of America, founded in 1991; Standing Up To POTS, 2014; Dysautonomia Information Network, 2003; Dysautonomia Support Network, 2012; and Dysautonomia International, 2012. Dysautonomia International, as the most prominent and active organization, will be studied more in depth in this paper. Dysautonomia International is the organization with the largest online engagement from the public on their social media accounts and support group pages. The organization also provides the most dysautonomia research grants compared to any other organization and it has the largest network of volunteers.

The first of these advocacy organizations was created in 1991, after the creation of the internet and during the time when the internet was becoming mainstream and more widely used by the public. Before 1991, there is no record of other POTS advocacy organizations. This may suggest that before the internet was widely used by the public, there were no POTS advocacy organizations in existence or that organizations were very locally based and faded out with the development of the internet. The nonexistence of these organizations before 1991 is also likely attributed to the fact that at this time there was significantly less knowledge about the autonomic nervous system and therefore, there were lower diagnostic rates and levels of awareness. The condition name, POTS, wasn't actually coined until 1993 when researchers from Mayo Clinic officially titled the condition. In the last twenty years, researchers have gained significantly more insight into the autonomic nervous system and its dysfunction seen in POTS patients ("Postural Orthostatic Tachycardia Syndrome", n.d.).

A review of the number of academic journal articles published with postural orthostatic tachycardia syndrome in its title or abstract was charted over time (Figure 1). The PubMed database was used as a representative sample of the overall number of medical journal articles published. PubMed is a free resource from the National Center for Biotechnology Information, at the U.S. National Library of Medicine, located at the National Institutes of Health (NIH) and comprises over 30 million citations for biomedical literature ("PubMed Help", n.d.). There were only 2 articles published in 1993, the year the name POTS was coined, but that number grew to 43 articles in 2019.



Figure 1 Number of Academic Journal Articles Published on PubMed with Postural Orthostatic Tachycardia Syndrome in the Title or Abstract from 1993 to 2019

This graph shows a steady increase in the number of articles published since 1993 until the 2010's when there was a significant increase in research publications. While there are many external factors to consider in analyzing these results, including a general increase in awareness of the condition overtime, the data suggests a correlation between the emergence of POTS advocacy organizations online and a greater number of POTS-related academic publications. There are already 6 articles published in the first month of 2020. If this trend continues, 2020 will be the year with the most articles published by far. Future research may consider an exploration of the number of patients diagnosed with the condition each year over this time period to examine the impact of the internet on the recognition and diagnosis of the condition.

Specifically, in the case of POTS, the rise of the internet is directly correlated with the emergence of these online platforms and non-profit organizations that gained support through their reach online. The platforms that developed increased

information sharing through formal medical journals and academic articles or through patient and caregiver informal communication using mediums such as forums. This information sharing and contact between those affected by the condition began to form followings around these platforms, creating patient communities within these organizations. Patients began to participate in research studies, attend events, speak to one another over live chats and webinars, and engage in a variety of other activities that did not exist at all or to this extent before these online platforms existed.

The internet, serving as a method of communication and connection, increased effective advocacy efforts, including for patients with POTS. Medical professionals, researchers, patients, and caregivers began to have access to a variety of research and other information about the condition with the click of a button. Additionally, patients and researchers are now more easily connected with one another for clinical trials (“Online Patient Communities Changing the Nature of Clinical Trials”, 2015). The internet has also allowed activists to communicate with supporters more quickly, coordinate their activities more effectively, and fundraise from a wider pool of supporters (Hestres, 2017).

The rise of the internet and the development of online communities has greatly increased the effectiveness of patient advocacy groups for rare diseases (Black & Baker, 2011). While POTS is actually not considered a rare disease, it is often misdiagnosed and not well-known amongst the general public and even within the medical community (Moon et. al., 2016). As a result, advocacy efforts for the condition have benefited POTS organizations in much the same way as rare disease organizations.

A big change has occurred for patients in their ability to raise awareness and seek support. Those with these less-known and rare conditions are prevalent users of the internet in their search for answers and information that will help them manage their condition. In a Pew Research Center survey, a greater proportion of internet users living with less common chronic health issues reported using the internet to find others who have similar health problems than other respondents. Rare and more uncommon conditions seem to increase an individual's need to connect with similar patients through online networks ("Peer-to-Peer Health Care", 2011). In addition, the isolation so commonly felt by these patients and their families, along with lack of information about these conditions has increased the use of the internet for health-related information. A large and ever emerging facet of this new generation of advocacy is the growth of online patient platforms that are brought together around their goal of advocating for their group (Costello, 2013).

The way these diseases are diagnosed, researched, and treated has also changed, in addition to changes in legislation and policy (Black & Baker, 2011). A 2016 analysis of online patient group advocacy-related campaigns showed that 35 percent of the campaigns were related to increasing access to experimental drugs. Some of these went on to be approved by the FDA (Hawkins, DeLaO, & Hung, 2016). Access to effective medication is a primary advocacy initiative for many of these patient platforms, including Dysautonomia International which is still working to get even one medication approved to treat POTS.

With regard to research and diagnosis, Dysautonomia International has found great success in raising money to provide grants to researchers, providing 1.7 million dollars in grants since the organization was founded in 2012 ("About the POTS

Research Fund”, n.d.). The use of an online platform and the success the organization has found in building its audience as a result has greatly contributed to raising these funds. In addition to their typical research grants, they have also helped expedite research projects by connecting patients to research studies and clinical trials through their website.

In 2014, Dysautonomia International gave two research grants to the POTS Antibodies Research Project. The organization invited Dr. Satish Raj from Vanderbilt University to collect patient samples over two days at their annual conference. This collection would have taken over a year if the project occurred in a research lab setting. The research they have supported provides new advancements that change the way POTS is diagnosed and treated. In addition, aspects of their platform, such as physician education courses, increase understanding and awareness of the condition amongst the medical community and help contribute to more effective outcomes for future patients (“Research Grants”, n.d.).

Social Media

Social media sites have become platforms for healthcare advocacy in their own right. While online platforms for condition-specific advocacy are relatively established and recognized as tools for advocacy work, in recent years the power of social media, especially with regard to use by patients, is being recognized by the healthcare community. Similar to traditional online platforms, social media is greatly improving patient access to healthcare information and other educational resources. Improving information access is healthcare advocacy in itself as it enables patients to speak for themselves and provides the tools necessary for patients to be informed consumers of care (“Paving Pathways for Justice & Accountability”, 2014).

Social media is unique in the way it fosters a sense of community, as well as in the way it allows users to interact and start conversations with one another. These online communities allow patients to seek second opinions on their diagnosis information, treatment options, and health care providers. Patients also use social media to share their own stories, reach out to others, and engage with both peers and providers. Social media is also very conversational, relaxed, and interactive, which may be driving the increases in using these platforms to share and seek health information (Dalmer, 2017).

In addition, these platforms are low-cost, fast, and simple to use tools that enable individuals to spread information and gather support for their advocacy efforts. Notably, this form of activism has allowed marginalized individuals to share their voices and contribute to the national and international discourse (Steinberg, 2016). This contribution has the power to change policy and law, as well as the structure of the healthcare system through patient empowerment as a result of connection with others and access to information.

It is not just the dysautonomia community utilizing social media. The autism community also utilizes social media platforms to spread awareness and to get the public involved with their advocacy work. One of their most prominent advocacy organizations is Autism Speaks. The organization encourages the public to pledge to light it up blue using the hashtag #LightItUpBlue across platforms to increase understanding and acceptance of those with autism (“World Autism Month”, n.d.) They also have a specific Facebook page dedicated to their advocacy work where the public can get involved by participating in call-in days to congress, signing petitions, and providing comments on draft policies (“Grassroots Advocacy Network”, n.d.).

Apart from formal organizational efforts, the autism community uses social media on a daily basis to connect with others. Individuals use their social platforms to share information, seek support, and raise awareness. A significant portion of this community's social media use is by parents and caregivers who are able to connect with other parents, share resources, and provide encouragement to one another (Thomas, 2012).

In a survey of patient influencers, nine out of ten said that online communities on social media play an important role in their health decisions ("Patient Influencer Perspectives on Social Media", 2019). It's not just patient influencers who are using social media, but healthcare consumers at large. In a survey of consumers, forty-two percent reported using social media to access health-related consumer reviews such as reviews of medications, doctors, hospitals, and insurers. In addition, twenty-nine percent reported seeking out information about other patients' experiences with their disease using social media. The information found through these platforms is influencing individuals' decisions surrounding their health. For example, forty-five percent of healthcare consumers said that information found on social media would affect their decision to seek a second opinion ("Social Media "Likes" Healthcare", 2012). Social media is changing the traditional structure of our healthcare system by empowering patients through information access to take control of their health care by questioning their physicians, choosing and changing providers, and seeking desired treatments.

These platforms, such as Instagram, Facebook, and Twitter, allow patients an opportunity to join virtual communities operating only on social media, exchange and increase their access to health information, and participate in research opportunities. In

particular, Facebook has become a large platform for patients to engage in advocacy efforts. The platform remains the social network of choice for patient influencers and advocates with 98% of patient influencers using Facebook and 94% of influencers belonging to a health-related Facebook group (“Patient Influencer Perspectives on Social Media”, 2019).

The power of social media is now beginning to be acknowledged by professionals in the healthcare community. In a 2017 report in the New England Journal of Medicine (NEJM) Catalyst Insight Council Patient Engagement Survey, ninety-nine percent of respondents acknowledged that social networks are potentially useful in healthcare delivery, and eighty-five percent of respondents noted this was especially true for chronic disease management. Additionally, nearly all respondents think social networks will have a major to moderate impact on patient engagement. A large majority think mature social networks will have a significant impact on quality of care and provider engagement. Furthermore, just over half of respondents reported the belief that mature social networks will influence the cost of care. Those surveyed were members of the Catalyst Insights Council, which is composed of healthcare executives, clinical leaders, and clinicians (Volpp & Mohta, 2017).

These responses indicate that many of those working within the system believe that social networks will impact the cost and quality of care – two areas of Triple Aim. Triple Aim is a concept stating that improving the healthcare system requires the simultaneous pursuit of three aims: Improving the experience or quality of care, reducing the costs of care, and improving the overall health of populations (“Triple Aim for Populations, n.d.). Social media is already impacting our healthcare system and the ways consumers interact with providers. These platforms will continue to

shape the patient experience and have the potential to play a large role in our work to improve the healthcare system.

To put these findings in the context of POTS, it is important to have an idea of the social media analytics of the condition. A tool called Symplur Healthcare Social Media Analytics was used to gain insight into the use of Twitter for posting dysautonomia-related content. Symplur generated a report from October 6th to November 4th 2019 of Twitter data using the Hashtag: #Dysautonomia. The report showed that 2.523M impressions were generated during this time period. Impressions are defined as the sum of the total number of tweets multiplied by each individual's number of followers (Symplur, 2011).

These impressions show that content related to dysautonomia reached millions of people in just one month. This is a much larger amount of outreach and visibility than online patient platforms are able to conduct on their own. Dysautonomia International has about 8,000 Twitter followers. This means that even if they tweeted every day for 31 days, a month, they would still only reach about 248,000 impressions. Social media platforms like Twitter allow patients to get engaged and increase visibility, awareness, information sharing, and other advocacy efforts.

It is clear that social media has already had a significant impact on healthcare advocacy efforts. Future research should continue to investigate patient use of social media as new platforms are constantly emerging and the way individuals engage with these platforms is changing as platforms advance. Social media is also still relatively new and we are only beginning to understand its impact.

Chapter 4

RESULTS

Case Study of Dysautonomia International

Dysautonomia International is arguably the most prominent and effective online advocacy platform for patients with POTS and other forms of dysautonomia. The organization was founded in 2012 and began as a group of patients and caregivers who wanted to improve the lives of other patients and families battling dysautonomia. Their mission is to, “identify the causes and cures for all forms of dysautonomia and to enhance the quality-of-life of people currently living with these illnesses” (“Mission/Goals”, n.d.). The organization’s goals include raising funds for research, raising awareness of dysautonomia within the medical profession, and providing information to practitioners on diagnostic methods and treatments in order to improve patient care. Dysautonomia International also works to empower patients and caregivers through tools, resources, and information, as well as to increase awareness and recognition of dysautonomia among the general public (“Mission/Goals”, n.d.).

To date, the organization has provided 1.7 million dollars in research grants to further scientific understanding of the condition and find effective treatments for patients. They have funded 28 studies, currently help recruit patients for 40 studies, and support 30 institutions involved in research (“About the POTS Research Fund”, n.d.). These advancements in research have great potential to make incredible strides in managing POTS, especially given that POTS does not have any specific FDA approved medications to treat the condition (Miller & Raj, 2018). Moreover, the

organization engages in recruiting patients to participate in clinical trials and other research opportunities, which also furthers medical discoveries in the field.

In addition, Dysautonomia International directly reaches over 50,000 individuals and their messages regularly reach over 500,000 individuals. They have 35,000 donors in their database and a substantial social media following including over 60,000 Facebook followers, nearly 8,000 Twitter followers, and almost 12,000 Instagram followers. Additionally, they serve 60,000 individuals through their support groups. (K. Morrissey, personal communication, Nov. 4, 2019). They also engage their audience with dozens of webinars and blog posts and they also have an annual Education and Advocacy Conference which attracts hundreds of patients, caregivers, medical professionals, and advocates.

Dysautonomia International also releases action alerts on policies that affect POTS patients and engage their audience in contacting their congressmen to make their voices heard (“Advocating for Dysautonomia Patients”, n.d.). They have also helped draft language in 2 pieces of appropriations bills passed into law by Congress to further NIH POTS research (“Congressional Victory for POTS Research”, 2018). In addition, the organization holds awareness events in cities across the United States, where they have active city chapters supporting the organization’s mission. They have held over 500 Dysautonomia Awareness Month events and have 300 volunteers helping push the organization’s work forward. Dysautonomia International also holds lobbying events to get those affected by the condition to capitol hill and writes policy letters regarding pressing policy issues (“Mission/Goals”, n.d.). The organization can be contacted at info@DysautonomiaInternational.org.

Issue Crawler Software Analysis

Redirection to External Sources

Online platforms utilize hyperlinking to ease connection between different stakeholders and foster the development of health information pathways. Issuecrawler software allows for the tracking of website links to outside pages (Vicari & Cappai, 2016). When analyzing Dysautonomia International’s website, 216 external links were found redirecting users to a variety of outside content. Grouping these links into categories based on content type (Table 1) a pie chart was generated to show the percentage of links directing to different categories of content (Figure 2).

Table 1 Redirection to External Sources

Content Category	Description	Examples
Academic Article	Research article from an established academic journal	The American Heart Association Journals, European Heart Journal - Oxford Academic, European Journal of Pain
News Article	Articles from news sources featuring patient stories	Huffington Post, New York Post, CBS Philly
Other	Online Platform (10.7%), Blog Post (7.1%), Informational Page (6.7%)	Amyloidosis Foundation, Dysautonomia Dispatch Blog, American Diabetes Association autonomic neuropathy informational page

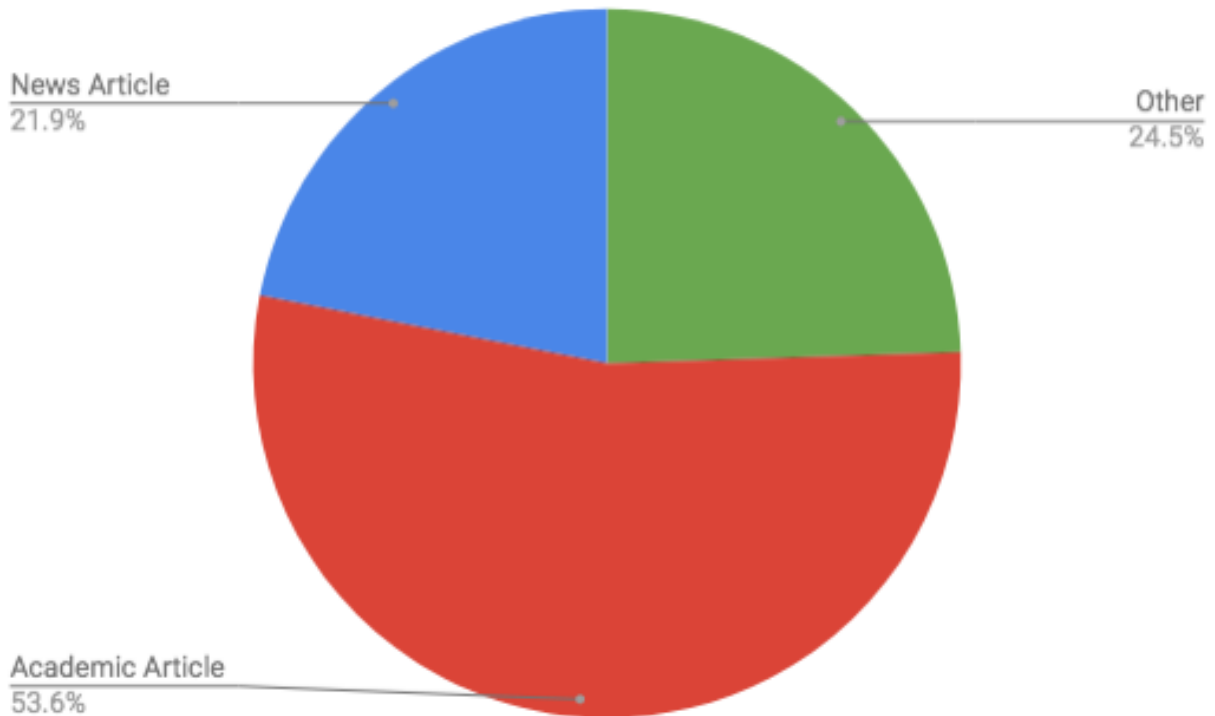


Figure 2 Redirection to External Sources

Categories with under ten pages were removed because they comprised less than 1% of the organization’s overall content. Academic articles and news articles make up the vast majority of redirects to external sites from Dysautonomia International’s website. Informational pages, other organizations or online platforms, and blog posts make up the remaining content areas and are recorded within the other category.

Notably, over 50 percent of these redirects were to academic articles and over 20 percent of these redirects were to news articles. Oftentimes, academic articles are

inaccessible to advocates and the general public because many journals charge users for access to their content. For example, while universities may pay for a subscription to a journal such as the New England Journal of Medicine allowing students and faculty to access articles free of charge, an individual subscription is a minimum of \$159 (“Choose how you Want to Experience NEJM”, n.d.).

Additionally, many of these articles are not easily understood by the general public because they are not written with the public in mind and may use medical terminology that researchers and physicians may use. Dysautonomia International combats both of these issues. They partner with a company called patientINFORM to provide free access to the majority of the articles on their site (“PatientINFORM Journal Access”, n.d.). The organization also encourages their audience to conduct their own review of medical literature using PubMed.gov, which is offered by the National Institutes of Health (NIH) for free. Furthermore, the organization has written article summaries that break down the dense academic literature into easily understandable content (“Medical Journal Articles on POTS”, n.d.).

While informational sources and articles are not what comes to mind when thinking about traditional advocacy efforts such as lobbying or research advancements, access to information is itself a significant form of advocacy (“Paving Pathways for Justice & Accountability”, 2014). The rise in access to information associated with advancements in the internet is arguably changing the healthcare system as it functioned for many decades. Physicians are more often challenged in their thinking and they are also no longer the sole source of information for many patients. Patients and caregivers alike are empowered to gain a greater understanding of their condition through online sources, review emerging research, and from this

have gained the ability to choose and change their physicians, as well as to request specific treatments or medications (Tan & Nadee, 2017).

While this empowerment and access to information online has proven beneficial, there are some notable concerns to consider. Online health information ranges from peer reviewed journals to patient anecdotes. Moreover, the quality of this information can vary significantly from source to source and not all patients have the skills necessary to comprehend the information provided and relate it back to their own circumstances. The varying quality of online information, as well as the challenge for an average patient to fully understand the information they are consuming leads misinformation, distress, and it can increase self-diagnosis and self-treatment (Tan & Nadee, 2017). Patient access to information also adds an additional physician responsibility to interpret and explain the information a patient has found. Additionally, if a patient's online findings do not align with their physician's findings, they may leave dissatisfied and with less trust in their physician (Tan & Nadee, 2017).

Still, patients report using the internet as a tool to be involved in making decisions with regard to their health care. Patient trust in physicians has remained high and they still value consultations with their physicians. The patients of today are able to use the information they found to ask questions, prepare for their visit, and better understand the information their physician presents to them. Internet-informed patients are more empowered to take a more active role in managing their health. These patients are also more comfortable and confident in their physicians' advice (Tan & Nadee, 2017).

It is important to continue to study the impacts of online information access on the patient experience and the patient-physician relationship to better equip providers

to effectively treat patients. The previous “physician-centric paternalistic models of care” are now being pushed out in favor of a “deliberative or participatory model” (Tan & Nadee, 2017, p. 28). This model is recommended for working with patients who use the internet for health information as it allows for more dialogue and patient engagement. Allowing patients to communicate their research with their physician is key to improving physician-patient relationships and ensuring patients’ opinions are valued (Tan & Nadee, 2017). Future research should continue to examine online health information and misinformation to more fully understand its impact and to prepare providers for patients in an age of increased information access.

Internal Pages

The Issuercrawler software was run a second time, but this time it analyzed the website’s internal pages. The results of the internal analysis differed from the external analysis. The content categories differed (Table 2) and the percentage of these categories were different than the percentages when analyzing the websites links to outside pages (Figure 3). Again, categories with less than ten pages of content were removed to show the most significant content categories.

Table 2 Internal Pages

Content Category	Description	Examples
Informational Pages/Resources	Facts, data, statistics, and other information on POTS and other relevant medical conditions	Fact sheet about Dysautonomia, Basic information page on the autonomic nervous system
Advocacy	Promoting actions to directly influence policies, regulations, standards, and/or public opinion	Participation in lobbying days, Encouraging audience to contact their congressmen, Signing a petition, Policy letters
Research Participation/Grant Opportunity	Opportunities for patients to participate in research studies or for researchers to receive grants	POTS Research Fund, POTS Research Registry
Fundraise/Donate	Promoting audience to raise funds for the organization or directly donate	Host a fundraiser, Donate
Academic Article	Research article from an established academic journal	American Heart Association Journals, Journal of Pediatrics, The Journal of Maternal-Fetal & Neonatal Medicine
Other	Events (7.6%), General Organization Information (6.0%), Opportunities to Spread Awareness (5.2%), Physician Education (4.8%), Connect/Contact (4.4%)	Annual conference, About us page, Holding a “cupcakes for a cure” awareness and education bake sale, Educational courses for medical students, Contact page

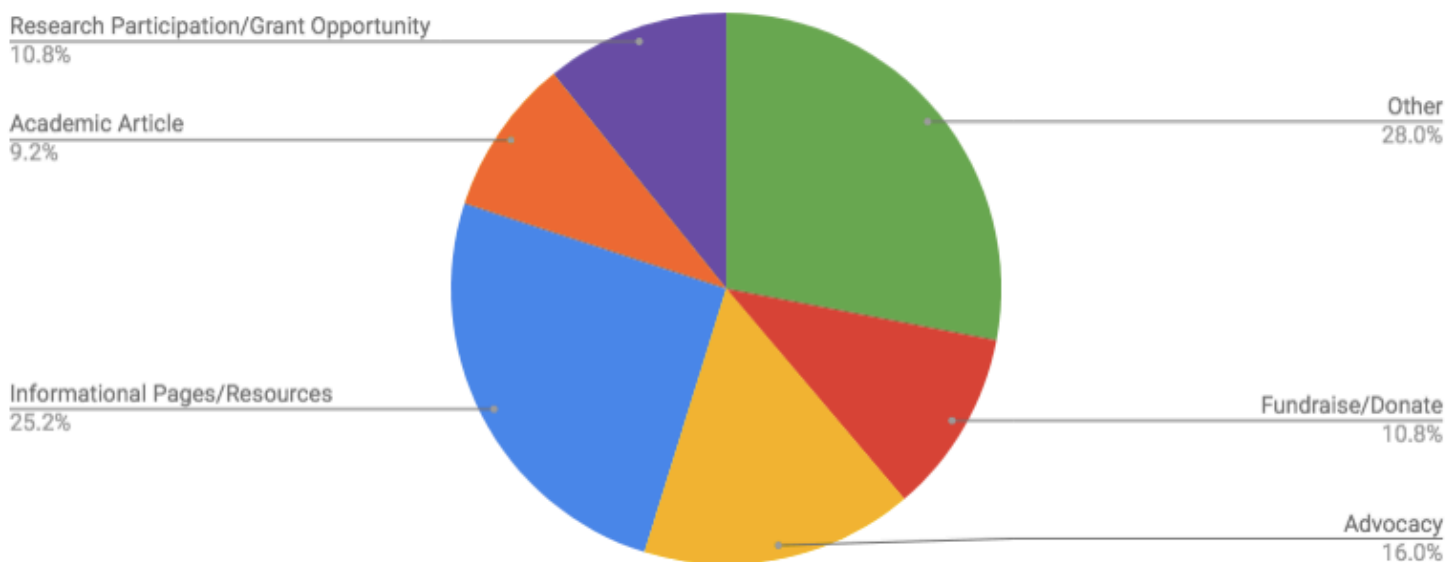


Figure 3 Internal Pages

Whereas research articles are a large percentage of the website’s links to external pages, its internal pages do not have one extremely prominent category of content. Informational pages are the highest percentage of all other categories of website content at around a quarter of content followed by direct advocacy efforts, research participation and fundraising content, and finally academic articles. Events, general organizational information, opportunities to spread awareness, physician education, and information to connect and/or contact others and the organization itself make up the remaining content and are included in the other category.

While almost a quarter of the platform’s content is informational in nature, over 15 percent of the content is direct advocacy-based content such as signing a petition or engaging in lobbying activities. In addition, another 14 percent of the content engaged patients in research studied and/or offered grant opportunities for

researchers. While information access is advocacy in its own right, nearly all of the traditional more direct advocacy efforts Dysautonomia International organizes are internal. This may be a result of more limited external advocacy efforts for POTS patients, but given the power of the internet in easing collaboration efforts, it is notable that the organization conducts the vast majority of its efforts independently and internally.

Digital Mechanism Analysis

A platform's digital mechanisms play a large role in their engagement with the public. Digital mechanisms mainly come into play when discussing website platforms, such as Dysautonomia International, whose use of these mechanisms was examined during this analysis. These sites utilize a wide range of mechanisms to inform and engage with their audience. They can be divided into three major categories: Information access channels or one-way mechanisms, response to organization or two-way mechanisms, and access/contribution to wider audience content or collective mechanisms. The intensity and engagement levels across mechanisms vary by individual. Different channels elicit different types of engagement from the audience and the strength of that engagement can also vary by platform. One-way mechanisms are the most basic digital tools, followed by two-way mechanisms, and finally collective mechanisms engaging multiple voices (Vicari & Cappai, 2016).

Information access channels are digital elements a website audience uses to explore information and acquire relevant knowledge. These one-way mechanisms allow information to flow from the organization to the general public. The audience does not directly engage with the platform when using these elements, but simply

gains access to informational content through the website (Vicari & Cappai, 2016). For Dysautonomia International, examples of these elements include social media feeds, educational materials, and blog posts. Like the majority of platforms, the majority of digital elements used by the organization are one-way mechanisms. These elements increase public information access, allow patients to be better self-advocates, and improve physician effectiveness. They also allow for the multitude of existing research and information to be analyzed together contributing to a greater overall understanding of the condition (Vicari & Cappai, 2016).

The second group of mechanisms, response to organization, are two-way opportunities for engagement where an exchange begins between the organization and its audience. These elements allow for more collaboration between the organization and the individual (Vicari & Cappai, 2016). Mechanisms in this category for Dysautonomia International include contact information, donations, online shops, awareness month events, physical education courses, monthly conferences, and the opportunity to host a fundraiser. These elements take information access to the next level by allowing the public to have a direct connection to the organization. The organization benefits by gaining access to public input and knowledge, as well as public support through donations, online shop purchases, and fundraising efforts (Vicari & Cappai, 2016).

The third group, access/contribution to wider audience content, is more collaborative in nature and encourages collective engagement. In the use of these mechanisms, the organization often moves away from the center of information sharing. They may be the source of information, but they may not be. These mechanisms involve many individual voices sharing information (Vicari & Cappai,

2016). For Dysautonomia International, examples include Facebook support groups, engagement on social media feeds, the opportunity to participate in research, and webinars, as well as live chats. Collective mechanisms allow for the most engagement and interaction from an audience, as compared with one-way mechanisms where the organization is simply disseminating information to a voice-less audience. Yet, these collective mechanisms come with added challenges such as the spread of inaccurate or misleading information as a result of the public freely engaging without an organizational approval or review (Vicari & Cappai, 2016).

Dysautonomia International utilizes a variety of mechanisms across the three categories, which has potentially contributed to the success they have found in maintaining their audience. While they utilize one-way mechanisms most and collective mechanisms least, the organization has made use of all of these mechanisms offering different ways for their audience to interact with their platform whether passively, through contact with the organization itself, or through engagement with the community's broader audience.

Chapter 5

DISCUSSION AND CONCLUSION

Healthcare advocacy organizations today are taking forms that are much different from the more localized, in-person groups we saw even a decade ago. Dysautonomia International has been instrumental in advocacy efforts for POTS patients. The organization has been central to research funding, connecting patients to trials and studies, lobbying members of congress, raising public awareness, advocating for effective prescription drugs, and providing both patients and physicians valuable information to improve the treatment of patients. The organization has reached and connected patients with POTS across the world and it is clear their online platform has had a tremendous impact on their success as an advocacy organization.

Traditional methods such as sending physical mail to organization members, gaining support through word of mouth, connecting patients in-person and even many common fundraising events have been pushed aside in favor of email, social media, online support groups, and virtual methods of fundraising. Current literature has not yet fully understood how social media and the internet have fundamentally changed organizational communication, including the ability to make grassroots social movements more feasible (Murthy, 2018). These tools have allowed the organization to reach thousands of patients, families, and physicians and connect them with a multitude of online resources.

The structure and impact of disease advocacy organizations will continue to look different as we continue to make use of new technology. One change we have

seen thus far is due to the increased reach of these organizations as they utilize online platforms. As a result, patients and their families are beginning to join not just one group, but many (Terry, 2013). This changes the traditional dynamic of disease advocacy and fosters collaboration between advocacy organizations and patient advocates.

While Dysautonomia International is an incredible force for patients with POTS, there are a multitude of organizations working on similar advocacy efforts and these groups have only grown in number over the years. As the external hyperlinking and internal page analyses demonstrated, the organization's advocacy efforts are mainly internal. There was no connection identified between Dysautonomia International and fellow advocacy platforms for POTS patients. The value and impact of collaboration should not be underestimated, especially considering the under-recognition of POTS both within the medical community and society at large. Organizations are now realizing that even the best individual efforts aren't able to measure up to the complex political and social issues we face today. More individuals and organizations are starting to collaborate with one another in order to advance their vision with others who share their objectives (Hecht, 2013).

For example, one of the other six POTS advocacy organizations, Standing Up To POTS, has funded over \$80,000 in POTS research and works on very similar initiatives and events as Dysautonomia International. The organization displays their collaborative efforts clearly on their site and have partnered with another online health community called The Mighty ("Our Initiatives", n.d.). When considering how under-recognized the condition is and how much work still needs to be done to improve

patient lives, collaboration may be a tool that Dysautonomia International considers utilizing within the POTS advocacy community to further and amplify current efforts.

While Dysautonomia International has yet to partner with a fellow POTS advocacy platform or other online health community, they have joined various coalitions to advocate for an overall increase in National Institutes of Health (NIH) funding. NIH-funded research leads to medical breakthroughs and new treatment options. Research supported by the NIH has contributed to the discovery of more than 150 new FDA-approved drugs and vaccines over the past 40 years (“National Institutes of Health”, n.d.). Dysautonomia International participates in the Rally for Medical Research each fall. This rally is a disease neutral coalition of thousands of other non-profit and academic leaders who advocate for increased NIH funding (“For Researchers”, n.d.). They are also part of the Ad Hoc group for Medical Research working with similar groups including universities, hospitals, and disease advocacy organizations to push for more government funding for disease research (“The Ad Hoc Group for Medical Research”, 2019).

Still, the vast majority of the organization’s activities are conducted internally, as well as all POTS-specific advocacy which also appears to always be carried out internally. An exception to this pertains to international dysautonomia advocacy groups, which the organization partners with to advocate for increased funding abroad (“For Researchers”, n.d.). For example, one of the organization’s greatest achievements came after their first ever Congressional Briefing on POTS in 2017. As a result, Congress directed the NIH to begin to stimulate POTS research, which was a major victory for the organization and POTS patients (“Congressional Victory for POTS Research”, 2018). While Dysautonomia International is making a large impact

for POTS patients on its own and is collaborating with researchers, universities, physicians, and in general disease-advocacy spaces, partnerships with fellow dysautonomia advocacy organizations may allow the organization to greatly further their efforts.

The Twitter report generated from Symplur Healthcare Social Media Analytics demonstrates the incredible power and influence generated when many come together around one cause. Dysautonomia International might consider not only collaborating with like-minded organizations, but also elevating the voices of the patients in their community. The internet has provided an incredible platform for their organization to find success, but as the structure of healthcare advocacy continues to change with technological developments, the organization may miss out on opportunities to amplify their impact and achieve their mission if they continue to conduct nearly all of their efforts internally.

Additionally, the use of social media platforms in particular is even newer than the use of traditional organizational websites and has allowed for healthcare advocacy to take place at the individual level. The impact of this is just beginning to be recognized and studied, but these advocates are already having an impact and there is great potential for them to amplify their efforts by collaborating with fellow advocates and like-minded organizations. The advocacy efforts of patients, families, and advocates are no longer constrained to a local organization, but are essentially limitless and have great potential. Evidenced by the existence of online patient leaders, individuals are capable of creating their own initiatives and making an impact in the advocacy space.

Despite the many benefits of online communities, some remained concerned about the potential negative effects of these platforms. Providers' concerns center around patients finding misinformation or trying to diagnosis themselves (Wicks et. al., 2010). It is not common for a public forum, let alone a social media post, to be censored or reviewed based on the accuracy of the information presented. The concern over misinformation is well-intentioned and an aspect of online patient communities that should continue to be monitored. However, chronic disease patients have proven to be well-informed about the limitations of using the internet for a source of information (Wicks et. al., 2010). A survey from the Pew Internet Project found that e-patients, meaning patients who utilize the internet in any capacity for their health, were more likely than other internet users to go to trusted sites versus depending on a search engine (Fox & Purcell, 2010).

Patients are viewing the internet as an added resource that is able to support their existing relationships with their medical providers. For example, a respondent in the Pew Internet Project survey stated that because of her internet research she is more equipped to provide intelligent answers to health questions from her doctor (Fox & Purcell, 2010). Doctors should see patients' online research as an attempt to work with their doctor (Stevenson, Kerr, Murray, & Nazareth, 2007). By promoting physician awareness of the increasing use of the internet among patients and considering initiatives to help better prepare physicians to handle the informed, and sometimes misinformed, patients of this new age, internet-based health information can promote better doctor-patient communication and patient outcomes (Ahmad, Hudak, Bercovitz, Hollenber, & Levinson, 2006).

Patient communities, such as Dysautonomia International, have been able to flourish on online platforms and patients are no longer forced to experience the isolation often felt years ago when connecting with fellow patients was not always feasible. Whereas years ago individuals' networks were limited to those they were lucky enough to form relationships with in-person, the internet has allowed for POTS patients around the world to connect with others also battling their disease. Most importantly, the internet has allowed for these online platforms to develop, rally the support of those affected by POTS around the world, and unite to further their advocacy efforts in an attempt to create a better future for those diagnosed with the condition.

REFERENCES

- About the POTS research fund. (n.d.). *Dysautonomia International*. Retrieved from: <http://www.dysautonomiainternational.org/page.php?ID=178>
- About us. (n.d.). *Dysautonomia International*. Retrieved from: <http://www.dysautonomiainternational.org/page.php?ID=2>
- Advocating for dysautonomia patients. (n.d.). *Dysautonomia International*. Retrieved from: <http://www.dysautonomiainternational.org/page.php?ID=187>
- Ahmad, F. Hudak, P.L., Bercovitz, K. Hollenber, E., & Levinson, W. (2006, September 29). Are physicians ready for patients with internet-based health information?. *Journal of Medical Internet Research*, 8(3). doi: 10.2196/jmir.1549
- Austin, C.P., Cutillo, C.M., Lau, L. O.L., Jonker, A.H., Rath, A., Julkowska, D., ... Dawkins, H.J.S. (2018). Future of rare disease research 2017 – 2027: An IRDiRC perspective. *Clinical and Translational Science*, 11(1), 21-27. doi: 10.1111/cts.12500
- Black, A.P., & Baker, M. (2011, April 4). The impact of parent advocacy groups, the Internet, and social networking on rare diseases: The IDEA League and IDEA League United Kingdom example. *Epilepsia*, 52(2), 102-104. doi: 10.1111/j.1528-1167.2011.03013.x
- Choose how you want to experience NEJM. (n.d.). *New England Journal of Medicine*. Retrieved from <https://www.nejm.org/about-nejm/individual-subscriptions>
- Congressional victory for POTS research. (2018, April 7). *Dysautonomia International*. Retrieved from <https://www.dysautonomiainternational.org/blog/wordpress/congressional-victory-for-pots-research/>
- Cornejo, C. (2017). Social media influencers in healthcare and pharma: What's their role?. *WEGO Health*. Retrieved from <https://www.wegohealth.com/2017/12/04/social-media-influencers/>

- Costello, D. (2013, July 29). Next generation patient advocacy in the rare disease community. *Pharamphorum*. Retrieved from <https://pharmaphorum.com/views-and-analysis/next-generation-patient-advocacy-in-the-rare-disease-community/>
- Dalmer, N.K. (2017, January). *Journal of the Medical Library Association*. 105(5), 61-68. doi: 10.5195/jmla.2017.108
- FAQs about rare diseases. (n.d.). *Genetic and Rare Diseases Information Center*. Retrieved from <https://rarediseases.info.nih.gov/diseases/pages/31/faqs-about-rare-diseases>
- For researchers. (n.d.). *Dysautonomia International*. Retrieved from <http://www.dysautonomiainternational.org/page.php?ID=37>
- Fox, S., & Purcell, K. (2010, March 24). Health information. *Pew Research Center*. Retrieved from <https://www.pewresearch.org/internet/2010/03/24/health-information/>
- Grassroots advocacy network. (n.d.). *Autism Speaks*. Retrieved from <https://www.autismspeaks.org/grassroots-advocacy-network>
- Hawkins, M.C., DeLaO, A.J., & Hung, C. (2016, December). Social media and the patient experience. *Journal of the American College of Radiology*, 13(12), 1615-1621. doi: 10.1016/j.jacr.2016.09.006
- Hect, B. (2013). Collaboration is the new competition. *Harvard Business Review*. Retrieved from <https://hbr.org/2013/01/collaboration-is-the-new-compe>
- Hestres, L.E. (2017). Tools beyond control: Social media and the work of advocacy organizations. *Sage Journals*, 3(2). doi: 10.1177/2056305117714237
- Issue Crawler [Network mapping software]. (n.d.) Retrieved from <https://www.issuecrawler.net/>
- Kavi, L., Gammage, M.D., Grubb, B.P., & Karabin, B.L. (2012, June). Postural tachycardia syndrome: multiple symptoms, but easily missed. *British Journal of General Practice*, 62(599), 286-287. doi: 10.3399/bjgp12X648963
- Medical journal articles on POTS. (n.d.). *Dysautonomia International*. Retrieved from <http://www.dysautonomiainternational.org/page.php?ID=49>

- Miller, A.J., Raj, S.R. (2018, December). Pharmacotherapy for postural tachycardia syndrome. *Autonomic Neuroscience*, 215, 28-36. doi: 10.1016/j.autneu.2018.04.008
- Mission/goals. (n.d.). *Dysautonomia International*. Retrieved from <http://www.dysautonomiainternational.org/page.php?ID=16>
- Moon J., Kim D.Y., Byun J.I., Sunwoo J.S., Lim J.A., Kim T.J., ... Lee, S.K. (2016, October). Orthostatic intolerance symptoms are associated with depression and diminished quality of life in patients with postural tachycardia syndrome. *Health Qual Life Outcomes*, 14(1), 144. doi: 10.1186/s12955-016-0548-x
- Murthy, D. (2018). Introduction to social media, activism, and organizations. *SAGE Journals*, 4(1). doi: 10.1177/2056305117750716
- National institutes of health. (n.d.). *Research America*. Retrieved from: <https://www.researchamerica.org/advocacy-action/research/federal-funding-research/national-institutes-health>
- Online patient communities changing the nature of clinical trials. (2015). *Patient Research Exchange*. Retrieved from <https://www.patientresearchexchange.org/stories/detail/online-patient-communities-changing-the-nature-of-clinical-trials>
- Our initiatives. (n.d.) *Standing Up To POTS*. Retrieved from <http://standinguptopots.org/welcome/our-initiatives>
- PubMed help. (n.d.). *National Institutes of Health*. Retrieved from <https://www.ncbi.nlm.nih.gov/books/NBK3827/#pubmedhelp.FAQs>
- Pandian, J.D., Dalton, K. Henderson, R.D., & McCombe, P.A. (2007, August). Postural orthostatic tachycardia syndrome: an underrecognized disorder. *Internal Medicine Journal*, 37(8), 529 – 35. doi: 10.1111/j.1445-5994.2007.01356.x
- Patient influencer perspectives on social media. (2019). *WEGO Health*, 1-19. Retrieved from https://www.wegohealth.com/wp-content/uploads/2019/04/WEGO_Health_QLS_Q1_Final_4.16.pdf
- PatientINFORM journal access. (n.d.). *Dysautonomia International*. Retrieved from <http://www.dysautonomiainternational.org/page.php?ID=232>

- Paving pathways for justice & accountability: Human rights tools for diaspora communities (2014). *The Advocates for Human Rights*, 97. Retrieved from https://www.theadvocatesforhumanrights.org/uploads/paving_pathways_2014_3.pdf
- Peer-to-peer health care. (2011). *Pew Research Center*. Retrieved from <http://pewinternet.org/Reports/2011/P2PHealthcare.aspx>
- Postural orthostatic tachycardia syndrome (2017). *National Institutes of Health*. Retrieved from <https://rarediseases.info.nih.gov/diseases/9597/postural-orthostatic-tachycardia-syndrome>
- Postural orthostatic tachycardia syndrome (n.d.). *Dysautonomia International*. Retrieved from <http://dysautonomiainternational.org/conditions.php?ID=1>
- Postural orthostatic tachycardia syndrome (pots). (n.d.). *Johns Hopkins Medicine*. Retrieved from <https://www.hopkinsmedicine.org/health/conditions-and-diseases/postural-orthostatic-tachycardia-syndrome-pots>
- Research grants. (n.d.). *Dysautonomia International*. Retrieved from <https://www.dysautonomiainternational.org/page.php?ID=181>
- Salisbury, M. (2016, July 28). Social media is helping to treat and cure rare diseases. Here's how. *World Economic Forum*. Retrieved from <https://www.weforum.org/agenda/2016/07/tweeting-blogging-and-facebooking-our-way-to-better-health>
- Social media “likes” healthcare. From marketing to social business. (2012, April). *Health Research Institute*. Retrieved from <https://www.pwc.com/us/en/health-industries/health-research-institute/publications/pdf/health-care-social-media-report.pdf>
- Steinberg, S. B. (2016). #Advocacy: Social media activism's power to transform law. *Kentucky Law Journal*, 105(3), 413 - 433. Retrieved from <https://uknowledge.uky.edu/klj/vol105/iss3/2/>
- Stevenson, F. A., Kerr, C. Murray, E., & Nazareth, I. (2007, August 16). Information from the internet and the doctor-patient relationship: The patient perspective – a qualitative study. *BMC Family Practice*. 8(47), 1471-2296. doi: 10.1186/1471-2296-8-47.
- Symplur [Healthcare social media analytic software]. (2011) Retrieved from <https://www.symplur.com/healthcare-social-media-analytics/>

- Tan, S.S. & Goonawardene, N. (2017). Internet health information seeking and the patient-physician relationship: A systematic review. *Journal of Medical Internet research*, 19(1), e9. doi:10.2196/jmir.5729
- Terry, S. F. (2013, June 4). Disease advocacy organizations catalyze translational research. *Frontiers in Genetics*, 4, 101. doi: 10.3389/fgene.2013.00101
- The ad hoc group for medical research. (2019, October 24). *Ad Hoc Group*. Retrieved from http://www.dysautonomiainternational.org/pdf/FY2020_NIH_Funding.pdf
- Thomas, D.G. (2012). Three benefits of online social networks for ASD support groups. *Kentucky Autism Training Center*. Retrieved from <https://louisville.edu/education/kyautismtraining/news/three-benefits-of-online-social-networks-for-asd-support-groups>
- Triple aim for populations (n.d.). *Institute for Healthcare Improvement*. Retrieved from <http://www.ihl.org/Topics/TripleAim/Pages/default.aspx>
- Vicari, S. & Cappai, F. (2016). Health activism and the logic of connective action. A case study of rare disease patient organisations. *Information, communication and society*, 19(11), 1653–1671. doi:10.1080/1369118X.2016.1154587
- Vigo, J. (2019, July 31). The patient as customer: How biotech and medicine are being driven by advocacy groups. *Forbes*. Retrieved from <https://www.forbes.com/sites/julianvigo/2019/07/31/the-patient-as-customer-how-biotech-and-medicine-are-being-driven-by-advocacy-groups/#474662c27161>
- Volpp, K.G., & Mohta, N.S. (2017, November). Patient engagement survey: Social networks to improve patient health. *New England Journal of Medicine Catalyst*, 1-15. Retrieved from <https://catalyst.nejm.org/survey-social-networks-patient-health/>
- Wicks P., Massagli M., Frost J., Brownstein C., Okun S., Vaughan T., ... Heywood J. (2010, June 14). Sharing health data for better outcomes on patientslikeme. *Journal of Medical Internet Research*, 12(2). doi: 10.2196/jmir.1549
- World autism month. (n.d.) *Autism Speaks*. Retrieved from <https://www.autismspeaks.org/world-autism-month>