

Seeking Relevance in a Social Media Age: A Guide for the FRAXA Research Foundation



An Interactive Qualifying Project Report
Submitted to the Faculty of the
WORCESTER POLYTECHNIC INSTITUTE

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Abstract

To remain relevant in an age where digital marketing is the norm, nonprofit organizations are challenged to develop innovative methods of self-promotion to encourage the public to support their cause. We analyzed and provided recommendations to improve the FRAXA Research Foundation's social media strategies in order to increase public outreach, thus raising awareness and advancing FRAXA's cause of finding a cure for Fragile X Syndrome, a genetic neurodevelopmental disorder. We performed in-depth research into three focus areas: business models, social media strategies employed by nonprofit organizations, and the psychology behind gift-giving. We further analyzed data on user demographics and engagement from FRAXA's Facebook, Twitter, and YouTube accounts. Our research culminated in an experiment in which we created two videos that were used to track user engagement across all three platforms in order to support future recommendations. Our recommendations include both general suggestions about post timing and content that can be applied to all social media platforms, and more specific suggestions that apply to Twitter, Facebook, and YouTube separately. We observed that posting more frequently and cross-posting helped improve FRAXA's social media presence. With these updated social media strategies – and support from the professionals, volunteers, families, and followers dedicated to raising awareness of Fragile X Syndrome – we believe that the FRAXA Research Foundation can advance its goal of finding a cure for Fragile X Syndrome.

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Acknowledgements

We would like to thank our sponsor liaison, Ms. Katie Clapp, for her assistance in obtaining data from FRAXA's Facebook, Twitter, and YouTube accounts for analysis, as well as FRAXA staff member Ms. Melissa Budek, for her cooperation in performing a SWOT analysis. The results from our analyses allowed us to provide recommendations that we believe will benefit FRAXA. Furthermore, we'd like to thank our advisors, Prof. Natalie Farny and Prof. Patricia Stapleton. Their advice and support for the duration of this project was vital to its success.

Executive Summary

With the growing popularity of social media platforms, nonprofit organizations are provided with new opportunities to promote themselves to a wider audience. The FRAXA Research Foundation (FRAXA) is a nonprofit organization created by parents of children who are affected with Fragile X Syndrome (FXS). FXS is an inherited form of mental retardation that presents similar symptoms to those associated with autism and is, in fact, the most common known cause of autism (fraxa.org). FRAXA provides helpful resources and information regarding Fragile X Syndrome on its website, however, its social media pages lack much of those resources, dividing the information among various platforms and making it difficult for parents to get involved. The goal of this project is to assist FRAXA in the improvement of its social media strategies to obtain better outreach and a higher likelihood of donors and volunteers dedicated to advancing FRAXA's mission. Grounded in research of social media usage by nonprofit organizations, we offer means to help the FRAXA Research Foundation achieve their mission of "accelerat[ing] progress toward effective treatments and ultimately a cure for Fragile X, by directly funding the most promising research" (fraxa.org).

The methods used to achieve the goal of the project included assisting FRAXA in performing a self-analysis to assess the current direction of the organization and assessing FRAXA's current social media use by obtaining metrics from its various social media accounts. We first assessed various aspects of the organization as a whole. Background research on specific analytical tools led us to perform a SWOT analysis (strengths, weaknesses, opportunities, and threats), which provided a structured system for reviewing strategies and directions of an organization. This tool is helpful for identifying and

understanding areas where an organization is performing well and areas that need improvement to see more success. Using this tool, we created a set of questions for the FRAXA team as well as a template to illustrate the answers to those questions in a concise manner.

We next assessed FRAXA's social media use, including obtaining metrics from its Twitter, Facebook, and YouTube accounts. By observing FRAXA's Twitter account, we took note of how many tweets FRAXA posted in 2015, categorized those tweets, and measured the audience engagement with respect to tweet content and the time at which tweets were posted. On Facebook, we took note of the number of page likes over the span of three months and, as we did on Twitter, measured audience engagement with respect to post content to determine which types of posts are more popular with FRAXA's audience. On YouTube, we categorized the videos and analyzed the content of the videos and how those factors related to the traffic to both the FRAXA channel and individual videos. Across all three platforms, we also analyzed the demographics (when data was available) to determine the general profile of an average FRAXA supporter.

In addition to the analysis that we performed on FRAXA's various social media accounts, we also created a two-part experiment that tracked the activity of three videos on all of FRAXA's social media platforms. The first part of the experiment focused on two videos created by the project team with differing content categories. These videos were posted to YouTube, Facebook, and Twitter simultaneously and were tracked for ten days to determine what kind of video content FRAXA's audience prefers. The second part of the experiment involved using a video created by FRAXA and embedding the video to both

Facebook and Twitter. This video was also tracked for ten days to determine audience engagement with embedded videos versus videos posted as a YouTube link.

The results of this project are presented in four sections, focusing on FRAXA's Twitter, Facebook, and YouTube pages, as well as the results from an interview conducted with a member of the FRAXA team. Specifically, the Twitter section categorizes the FRAXA account's various tweets into categories and comparing the user activity each tweet generated to determine the most popular content with FRAXA's Twitter followers. While the tweets that were marked as informational and community-based received more engagements overall, action-based posts received more average engagements, at approximately 35 engagements per tweet compared to informational and community's 18 and 10 engagements per tweet, respectively. Additionally, we found that a higher number of engagements occur on Mondays and Thursdays, between midday and late evening. On Facebook, we found that the majority of engagements received by the page were due to posts that were informational and community-based, and that FRAXA's audience tended to engage more with posts that used more specific language rather than more general language.

On YouTube, videos that were classified as being emotional or community-based received more engagements than informational videos. Furthermore, we found that FRAXA's audience retention of any given video was 38% of the length, and most of the traffic sources for YouTube were external (from Facebook or Twitter). Across all three platforms, we found that FRAXA's audience was composed overwhelmingly of females between the ages of 18 to 45, suggesting that the majority of FRAXA's online supporters are likely mothers of children with FXS. In regards to the YouTube experiment, we found that

videos that are embedded to Facebook gain fewer engagements when compared to posting a YouTube link to the video. However, on Twitter, the opposite is true; embedded videos receive significantly more engagements than a link.

The last section of our results focuses specifically on the answers provided to us by Ms. Melissa Budek, a member of the FRAXA team, to the questions outlined in our methodology section. During this interview, we determined that FRAXA is able to keep expenses low, partly due to the fact that they only have two full-time and two part-time employees. With such a small staff, however, the organization struggles with grant-writing and social media outreach, as there is a significant shortage of both time and experience between the four employees. During the interview, Ms. Budek identified opportunities for FRAXA, including creating a stronger link between Fragile X Syndrome and Autism Spectrum Disorder that could help increase fundraising.

The deliverables for this project include recommendations based upon the results of our research phase of the project, as well as the related guides located in the appendices. Our recommendations include both general suggestions that can be applied to all social media platforms, as well as more specific suggestions for each platform. General suggestions include increasing the frequency of posts and posting the same content on all platforms when possible to increase the reach of each post. Additionally, we suggest that FRAXA post mostly original content and use more descriptive language in post titles and text to maintain audience interest. More specific suggestions include: posting on Mondays and Thursdays on Facebook and Twitter, embedding videos on Twitter while posting video links on Facebook, posting more action-based posts on Twitter while posting more

informational posts on Facebook, and posting more emotional videos on YouTube. A more complete list of our recommendations can be found in Table 6.1.

Beyond the scope of this project, we also recommend that FRAXA continue to emphasize the connection between Fragile X Syndrome and Autism Spectrum Disorders, as this connection could offer FRAXA opportunities for collaboration with other nonprofit organizations as well as raise awareness of the disease among a larger audience. We recommend that FRAXA offer volunteer opportunities to students pursuing secondary and postsecondary education looking to fulfill community service requirements or gain relevant work experiences. Lastly, we recommend that FRAXA use the deliverables presented in the appendices of this project as training tools and guides for future employees and volunteers. With these resources, and with the professionals, volunteers, families, and followers dedicated to raising awareness of Fragile X Syndrome, we believe that the FRAXA Research Foundation can accelerate towards its goal of finding a cure for Fragile X Syndrome.

1. Introduction

Since the first decade of the 21st century, the adoption of social media as a primary means of communication has opened up a new realm of opportunities for individuals and organizations alike. The shattering of geographic boundaries has led to the decentralization of communication, allowing for a greater capacity of interaction and networking. Thus, it is becoming increasingly important for businesses and nonprofit organizations to take advantage of the benefits that these platforms have to offer. To remain relevant in an age where digital marketing is becoming the norm, nonprofit organizations are challenged to develop innovative methods of promoting themselves in order to engage and encourage the public to support their cause. The FRAXA Research Foundation (FRAXA) is one such organization looking to improve upon the ways in which it promotes its cause online.

FRAXA is a nonprofit organization created by parents of children who are affected with Fragile X Syndrome (FXS), a neurodevelopmental and autism-spectrum disorder. FRAXA seeks to “accelerate progress toward effective treatments and ultimately a cure for Fragile X, by directly funding the most promising research” (fraxa.org). On its website, FRAXA provides information regarding Fragile X Syndrome for parents of an individual with FXS, other family members, and researchers, as well as information about current clinical trials, support, and FRAXA-sponsored events occurring across the nation. These resources are crucial for raising awareness of FXS and promoting further research into treatments and cures for the condition. Like many nonprofit organizations, FRAXA relies heavily on monetary and time contributions from supporters across the country who set up fundraising events, volunteer, donate, and spread the word of their mission to friends and family.

Websites are just one medium through which an organization like FRAXA can raise awareness for its cause and receive donations to help fund research. Although FRAXA does maintain social media accounts on Facebook, Twitter, and YouTube, there is room for improvement in the way that they are utilized and integrated with the website. This report presents plans and guidelines for optimizing social media platforms (like Facebook, Twitter, and YouTube) for FRAXA to engage its audience and increase the likelihood of volunteer work, donations, and participation in clinical trials. The team has separated research topics into three primary categories, namely: business models, social media use, and the psychology behind gift-giving to aid in research and strategy development. Through background research and working with FRAXA President and Co-Founder Katie Clapp, the team developed a comprehensive plan of action to improve FRAXA's online presence and, ultimately, bring it one step closer to completing its mission.

2. Background

The FRAXA Research Foundation provides helpful resources and information on its website. However, its social media pages lack much of those resources, essentially dividing the information among various platforms and making it difficult for parents to get involved because of inconsistencies between the website and social media. Due to the large number of factors associated with marketing through online social platforms, it was necessary to determine first the most important information that the organization wants to communicate to its followers, volunteers, supporters, and donors. Once the most important information was determined, we integrated that information into social media strategies in order to increase FRAXA's outreach and influence in the community.

2.1. Fragile X Syndrome

Fragile X Syndrome (FXS) is an inherited form of mental retardation that presents similar symptoms to those associated with autism and is, in fact, the most common known cause of autism (fraxa.org). The severity of FXS can range from slight learning disabilities to full-scale mental retardation. In most cases, symptoms include intellectual and emotional disabilities, attention disorders, mild to severe anxiety, sensory issues, speech problems, and epileptic episodes (fraxa.org). The physical features that this syndrome exhibits are not always obvious, varying from person to person and between sexes as well, however physical features of FXS individuals can include "long face, large prominent ears, flat feet, hyperextensible joints, [and] low muscle tone" (fraxa.org).

Fragile X Syndrome is most commonly caused by a mutation in the nucleotide sequence of the Fragile X Mental Retardation-1 (FMR1) gene located on the X chromosome

(Garber, Visootsak, and Warren, 2008). Because males have only one X chromosome, males who have a mutation on the FMR1 gene will be affected by FXS. Females, however, are more likely to be carriers for the condition because of the presence of a second, unaffected X chromosome that can “take over” for the affected chromosome (Garber, Visootsak, and Warren, 2008). Statistics support this, providing evidence that more males are affected by this disease than females, with 1 in 4000 males in the United States affected and 1 in 6000 females affected (fraxa.org). The average age of FXS diagnosis is about 26 months, with parents expressing developmental concerns typically around one year and receiving diagnosis within the following year (CDC, 2015). About 96% of males that are diagnosed with FXS exhibit developmental delay or intellectual disability, while 64% of cases display autistic phenotypes. Unfortunately, there is currently no approved cure for this disease (CDC, 2015). However, early diagnosis and interventions, such as education and behavioral conditioning, can reduce the severity of the patient’s symptoms.

2.2. FRAXA Research Foundation

FRAXA is an organization dedicated to raising money for research into a cure for Fragile X Syndrome. Founded in 1994 by parents of children affected with Fragile X, FRAXA educates, guides, and supports parents just like them. FRAXA also provides information for medical professionals and researchers, as well as information on clinical trials conducted throughout the United States, all while running “scientific meetings, advis[ing] pharmaceutical companies large and small, provid[ing] education on college campuses, community settings, and international conferences” (fraxa.org). With only one full-time employee (organization President and Co-Founder Katie Clapp), FRAXA’s efforts are almost entirely based upon the volunteer work of parents of children affected by

Fragile X Syndrome (fraxa.org). Aside from federal research grants, FRAXA raises most of its research funds through direct donations and donations at charity events such as galas, balls, bike races, and sports tournaments. As stated previously, FRAXA's mission is "to accelerate progress toward effective treatments and ultimately a cure for Fragile X", and with the help of grants and small donations, FRAXA has been able to raise over \$24 million since its inception (fraxa.org). Because Fragile X Syndrome affects the neurological systems of individuals in various ways, scientists and researchers are still working toward a cure; as a result, FRAXA continues to raise funds in order to support these research efforts.

FRAXA recognizes that in order to not only sustain its audience but also engage them, the Foundation must transition much of its content into a digital format. This digital format includes both web content and social media platforms. In addition to its website, FRAXA currently has accounts on Facebook, Twitter, and YouTube. This project's goal is to improve the organization's social media strategies on one or more of these platforms in order to increase public outreach, thus raising awareness for Fragile X Syndrome and advancing FRAXA's cause. Understanding how information spreads through social media and how nonprofit organizations can benefit from employing marketing techniques online are key factors in raising awareness for FRAXA, which will in turn help the Foundation to gain the volunteers and donations needed to complete its mission.

3. Literature Review

The research conducted throughout this project involved various spheres of knowledge including: the disease state of Fragile X Syndrome; business models employed by both for-profit and not-for-profit organizations; integration of social media into non-profit organization campaigns; and the likelihood of donation through social media as compared to traditional, offline gifting. The goal throughout this research was to determine the likelihood that assisting FRAXA in the optimization of its various social media platforms would generate increased recognition and donations to the organization.

3.1. Business Models Employed by Nonprofit Organizations

When beginning a business of any kind – profit-driven or not, selling products or promoting a cause – it is important to know the market. Knowing the wants and needs of all stakeholders involved and how they pertain to the mission of the business or organization are the first steps in analyzing the direction in which the business or organization needs to proceed. There are many different methods that can be used to help determine the wants and needs of both the organization and the stakeholders. One such method of analysis is the SWOT approach.

3.1.1. *SWOT Analysis*

One of the best ways to study any nonprofit organization is to perform a case study that focuses on as many aspects of that organization as possible. According to Blery, Katseli, & Tsara (2010), one method that can be employed during a case study to effectively analyze the strengths and weaknesses of an organization is a SWOT analysis. The term “SWOT” refers to the “strengths, weaknesses, opportunities and threats” of a business or

organization (Blery, Katseli, & Tsara, 2010). Broken down into four focus areas, this type of analysis begins by listing all of the strongest aspects of the organization and the factors that make that organization unique in its industry. The next step involves performing an opposite but equally important analysis of the shortcomings of the organization, including improvements to be made and further ways to prevent additional weaknesses from forming. The third and fourth steps, labeled “opportunities” and “threats”, encompass brainstorming actions that can be taken in the future to provide more opportunities for the organization to grow, and listing all of the threats or risks that the organization has encountered in the past or expects to encounter during the opportunities phase. The final step (not listed in the acronym) involves stepping back and looking at the outcomes of the previous steps comprehensively to find a way to bring them together into a plan of action that will help better accomplish the goals of the organization.

3.2. Social Media use by Nonprofit Organizations

Transitioning an organization from an offline to an online platform is generally an easy task to accomplish, as social media networks like Twitter, Facebook, and YouTube now have step-by-step tutorials that teach first-time users how to establish a presence on their respective platform. However, difficulty emerges when an organization seeks to grow and maintain support for its cause. Maintaining continuous donations and support is challenging without certain investments like time, funds, and manpower. Daniels and Narayanswamy (2014) note that “for [an organization’s] digital approaches to be compelling to donors, the efforts have to be integrated into the organization’s overall fundraising strategy”. Engaging the audience and piquing their interests, rather than

passively supplying them information, are key factors in increasing the online presence and success of an organization.

3.2.1. Twitter

One of the biggest problems nonprofit organizations face in the growing technological era is lack of resources, including both time and the necessary know-how to take advantage of the benefits that social network advertising provides (Lovejoy & Saxton, 2012). Over the last decade, social networking sites like Facebook and Twitter have become popular avenues for people to express their ideas and for organizations to share their cause, completely free of charge. However, the difficulty becomes the question of not just where an audience is, but what kinds of information people are interested in receiving that will hold their attention and give them a reason to support the cause.

In their study, Lovejoy and Saxton (2012) attempt to determine a common marketing strategy employed by various nonprofit organizations in the United States, finding their answer in “microblogging”, a form of communication involving short, frequent updates by a particular party. Twitter, a popular microblogging site, gives the user the ability to update their status through tweets: short messages, limited by character, that compel the user to get their point across in a concise manner. This approach to communication, Lovejoy and Saxton (2012) assert, is the best way to grasp the attention of the organization’s “stakeholders” and the public at large.

Throughout their study, Lovejoy and Saxton (2012) categorize the specific goals of different tweets based on their involvement in either “information”, “community”, or “action”. Tweets with an informational goal serve to familiarize the public with the organization through the distribution of data and factual information related to the cause.

As the most common, these types of tweets are posted by the organization and remain generally one-sided and free from standard advertising techniques (Lovejoy and Saxton, 2012). According to the study, these types of tweets largely help the connection between other organizations rather than with potential donors.

Tweets with a community-oriented goal serve to connect more personally to stakeholders and potential donors, filling the gaps between the organization and the public. This manner of communication is multifaceted, involving the organization and any number of stakeholders at one particular time. These kinds of tweets encourage stakeholders to hold conversations, not just with the organization, but with other supporters of the cause to build a community. Lovejoy and Saxton (2012) found that over a fourth of all tweets had community-oriented goals. Finally, tweets with goals involving action include references to donating, events, products, and volunteering. Comprising over 15% of all tweets, action-based tweets serve to turn followers into activists (Lovejoy and Saxton, 2012).

This project postulated that in order for an organization to be successful in its social network push (specifically in regards to Twitter), it must employ and balance all three of the techniques listed above. FRAXA, though involved with Twitter, does not receive a great deal of attention through that social network platform, as compared to high-profile organizations like The American Cancer Society (ACS), as shown in Figure 3.1 below.



Figure 3.1 - Side-by-Side Comparison of ACS and FRAXA Twitter Pages, retrieved October 4, 2015 from twitter.com

As depicted in Figure 3.1, the American Cancer Society’s Twitter page has 12 times the number of tweets, follows 590 times the number of pages, is followed by 802 times the number of pages, and has 48 times the number of favorites than FRAXA’s Twitter page has. Lovejoy and Saxton’s (2012) study proved useful when we analyzed FRAXA’s Twitter use, as it distinguishes between various types of tweets and how to balance their use to maximize outreach.

3.2.2. Facebook & Viral Marketing

The rise of social media networks among all age groups has brought new opportunities for organizations to advertise and promote their cause through viral marketing. In the study written in “Viral Advertising in Social Media”, Chu (2011) studied the potential links between Facebook group participation and viral advertising responses. This study was conducted in an attempt to determine the outcome of viral advertising on Facebook users – both those who are members of at least one group on the site and those who are unaffiliated with groups – and to determine whether the Facebook users’ actions

after receiving viral advertisements can be predicted in order to tailor future advertisements towards those users (Chu, 2011).

Facebook offers users many opportunities to connect with the world around them. In addition to creating a personal profile, users can join groups of other users (that may or may not be for a particular cause), 'like' and receive updates from business, celebrity, or organization pages, and create and attend events. Due to the large volume of groups, pages, and events, as well as the large number of users on the site, one can assume that the average user is active in 80 or more groups, pages, or events (Chu, 2011). Thus, these Facebook activities are great ways to advertise to many people at once.

Viral marketing uses the idea that people feel more comfortable taking advice from a friend than from a stranger (group security) to its advantage. Chu (2011) asserts that those who are in a group on Facebook are more likely to trust the other members of that group with certain information than they would strangers, especially if that group is linked by a common cause, belief, or passion. Thus, if an organization is successful in advertising its cause to a user who is a member of at least one group, it is easier to spread its message via Facebook than it is if the organization is successful with just one individual who is not affiliated with any groups. Taking advantage of "peer pressure", an organization can improve their social media outreach by verifying that members of their target audience are affiliated with at least one group on Facebook.

Chu (2011) does note, however, that users sometimes "hesitate to forward viral advertising to their Facebook friends", suggesting that Facebook groups alone are not enough to achieve the desired outreach in some scenarios. Users who are comfortable with revealing parts of their personal life online are more likely to pass on viral advertisements

than users who are not comfortable with personal information available to others on Facebook. Chu (2011) suggests that a way to approach this is to create more personal advertisements tailored to these types of users, give the users a reason to pass on the message, or provide a way for users who are uncomfortable sharing personal information online a way to pass on the message without disclosing any of their sensitive information publicly.

3.2.3. Video Marketing

In *YouTube and Video Marketing: An Hour a Day*, Greg Jarboe (2011) notes that “video is an integration of text, image and music towards a unified goal, functioning effectively when these elements are symbiotic rather than disintegrated”. There are many factors that make video marketing one of the most successful methods for advertising an organization or business in order to reach out to a wide variety of people across the globe. One of these factors is the increasing popularity of video-based sites such as YouTube, as they increase the scope of the audience and the rate at which an audience is able to view and share videos. Many people have started to watch online videos as a source of entertainment, and organizations can take advantage of this, “[benefitting] from a creative idea, [and executing it] in an entertaining fashion” (Miller, 2011).

A successful video possesses many features that make it so: it must look professional, it must be a reliable source to extract information from, and it must be interesting to the audience. However, Jarboe (2011) notes that regardless of the purpose and content of the video, generally the quality of the resolution and audio of the video can in, many cases, determine the success of a video. The use of engaging videos “allows you to generate instant emotional connection with an audience helping you to build influences

quickly and efficiently from agnostic parties” (Jarboe, 2011). This point illustrates our goal of implementing video as a form of advertising in an effort to help FRAXA raise awareness for individuals with Fragile X Syndrome. FRAXA has the capability of generating instant emotional connections with the audience by showing them stories of the children and families affected by this condition. This will allow FRAXA to directly influence the audience in an engaging way to promote interest in this syndrome, as well as invite them to contribute and play a part in helping this community. Through video, FRAXA would be able to bring people closer together by creating a virtual face-to-face experience.

3.3. Psychology behind Gift Giving

When attempting to increase the number and size of donations that a nonprofit organization receives, it is important to understand your audience and what factors influence a person’s decision to donate. Saxton and Wang (2014) suggest that “understanding what drives the ‘Facebook generation’ to connect and work with an organization is critical for those organizations seeking to be relevant in the social media age”. Saxton and Wang’s study, “The Social Network Effect: The Determinants of Giving Through Social Media”, provides an analysis of the outcomes of the traditional model of giving as compared to outcome determined from metrics pulled from the Facebook pages of sixty-six of the United States’ biggest nonprofit organizations.

Saxton and Wang (2014) posit five hypotheses throughout their study, all linking the rise in online donations to the employment of various techniques by nonprofit organizations who choose to integrate social media into the promotion of their cause. Their study confirmed that three out of their five hypotheses accurately reflect the current trends

in online gifting. These determining factors include the amount of fans, followers, and members that an organization has, its ability to successfully integrate the organization to an online platform, and the industry that they represent, be it related to health, art, religion, preservation, or various other topics (Saxton and Wang, 2014). The better an organization can identify and improve its current presence on the web, the easier it is to integrate its cause onto a social media platform, gaining supporters and potential donors who will further the cause.

The information garnered in this study allowed us to offer recommendations to FRAXA in order to increase crowd-sourced funding efforts and awareness for Fragile X Syndrome. FRAXA has already begun integrating themselves into the world of social media, however we posited that the organization lacks both the resources (time) and the technical knowledge to optimize social media platforms. Saxton and Wang (2014) suggest that “having the appropriate level of ‘tech savvy’ is just as important as adequate financial resources”. The information in the study presented above was useful in identifying some of the determining factors (listed previously) that could help increase the amount of online and offline donations that FRAXA receives.

4. Methodology

The goal of this project was to assist the FRAXA Research Foundation in the improvement of its social media strategies in order to obtain better outreach and a higher likelihood of donors and volunteers dedicated to advancing FRAXA’s mission.

This project aimed to:

- assist FRAXA in performing SWOT analysis
- assess FRAXA’s current social media use
- provide new strategies and plans for implementation to improve FRAXA’s social media presence

Presented below is the methodology this project used to meet these goals. For reference, a schedule of tasks is included below in Figure 4.1, detailing the time between the preparation period in September 2015 to the conclusion of the project in May 2016.

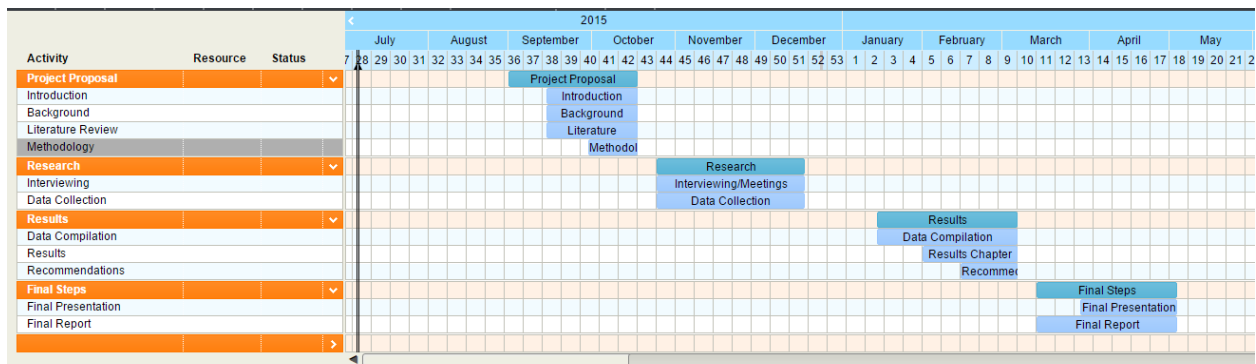


Figure 4.1 - Preliminary schedule for the project during the 2015-2016 academic year. Gantt chart created using Tom's Planner (2015).

4.1. Objective I

Assist FRAXA in performing SWOT Analysis

The central focus of this project, and the previous projects completed by Worcester Polytechnic Institute students (Bora, Lavoie, & Prescott, 2015 and Gillis & Nazareth, 2015), was the promotion of the FRAXA Research Foundation's mission. In order to help FRAXA promote its mission, this project involved first assessing various aspects of the organization as a whole. To do this, some background research on specific analytical tools was needed. In this regard, this project's research into commonly used analytical tools guided the approach both we and FRAXA took to assess the current direction of the organization.

Our research, highlighted in the previous chapter, led us to a helpful analytical tool, known as SWOT analysis, which we used as a guide for assessing FRAXA as an organization. Tools such as this are extremely helpful for identifying and understanding key areas where an organization is performing well and areas that need improvement in order to see more success. They provide a structured system for reviewing strategies and directions of an organization. The first step that we took was to create a SWOT template to aid us and Katie Clapp (President and Co-Founder of FRAXA) in performing this analysis as part of the project. The template is shown below, in Figure 4.2.

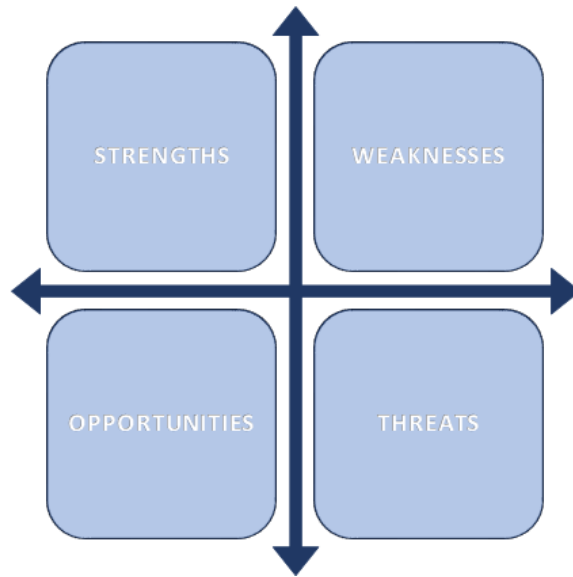


Figure 4.2 - SWOT Analysis Template for use by the IQP team and Katie Clapp in assessing FRAXA's strengths, weaknesses, opportunities, and threats.

The SWOT template, shown in Figure 4.2, is divided up into four sections, one for each step of the analysis (strengths, weaknesses, opportunities, threats). The inclusion of axes in the diagram helps to show the relationships between the four steps. The steps to the left of the vertical axis, strengths and opportunities, list items that are helpful for the organization's objective. Alternatively, the steps to the right of the vertical axis, weaknesses and threats, list items that are harmful for the objective. Furthermore, the steps above the horizontal axis, strengths and weaknesses, represent items that are internal to the organization, while the steps located below the horizontal axis represent items that are external to the organization.

This template provides a helpful way of visualizing many of the factors that can affect an organization. We used this template to perform our own SWOT analysis of FRAXA, and then guided Katie Clapp and FRAXA team member Melissa Budek in performing their

own analysis for comparison. Included with this template is a set of questions for each factor (strengths, weaknesses, opportunities, threats) that helped both us and FRAXA complete the analysis process (Appendix A). When performing a SWOT analysis, there are additional steps that one could take with the information obtained from the answers to those questions to help push the analysis further. For example, prioritizing the factors within each section can help to determine what the first step for the organization will be in terms of improvements. To help prioritize factors, it may be worthwhile to determine which factors are more likely to affect the organization than others, and to also understand which factors are outside of the organization's control. Information that we gained from this analysis was applied to FRAXA's current and future social media techniques in an attempt to turn strengths and weaknesses into opportunities. This project provided the organization with a guide to improve its social media outreach whilst taking into consideration its expectations and capabilities.

4.2. Objective II

Assess FRAXA's current social media use

4.2.1. Twitter Strategies

Twitter is a news feed as much as it is a social network. While users can connect with friends, they can also stay up to date on local, regional, and global news headlines. Twitter presents an instantaneous platform to deliver information to and communicate with a wide audience, which is one of the reasons why it is so attractive to businesses and organizations (Lovejoy and Saxton, 2012). There are various reasons why someone who supports a nonprofit organization would be interested in Twitter as well. Organizations can

tweet anything that they would put on their website, whether it be news headlines about their cause, event details, or polls, which users have access to and can interact with instantaneously. The instantaneous availability of information is attractive, and thus has the potential to drive many audiences towards Twitter.

As discussed in the previous chapter, the FRAXA Research Foundation has its own Twitter account, however it is comparatively less active when measured against those of higher profile nonprofit organizations, like the American Cancer Society (Figure 1). It is safe to assume that should supporters of FRAXA have their own Twitter account, they would be following FRAXA on Twitter. Thus, the comparatively low number of followers led us to believe that many of FRAXA's supporters are not users on Twitter, and that Twitter itself presents a largely untapped audience of potential supporters. This project, in part, seeks to improve FRAXA's social media strategies on Twitter in order to increase outreach and likelihood of donors and volunteers.

As discussed in the previous chapter, Lovejoy and Saxton (2012) categorized tweets into three distinct categories based on the intended outcome of each tweet: community-based, informational, and action-based. This project seeks to integrate this categorization system into a strategy to analyze FRAXA's current activity on Twitter. By observing FRAXA's Twitter account, we first took note of how many tweets FRAXA posts per week, month, and year, and categorized each tweet based upon Lovejoy and Saxton's model of community-information-action. With this information, we determined the total number of tweets in each category to ascertain which type of tweet FRAXA uses the most.

In the next step, we obtained Twitter analytics from Katie Clapp, President and Co-Founder of FRAXA. This data helped us determine when each tweet was posted, how many

people interacted with each tweet, how many profile clicks FRAXA received from each tweet. Shown below in Figure 4.4 is an example of the data one can obtain by exporting the tweet activity metrics for an account through a particular time period.

| | A | B | C | D | E | F | G | H | I | J | K | L | M | N |
|----|----------|---------------------|----------------|-----------|-------------|-------------|-----------------|----------|---------|-----------|---------------------|------------|----------------|----------------|
| | Tweet ID | Tweet Permalink | Tweet Text | Time | Impressions | Engagements | Engagement Rate | Retweets | Replies | Favorites | User Profile Clicks | URL Clicks | hashtag clicks | Detail Expands |
| 1 | 5.3E+17 | https://twitter.coi | 19 years old | 2014-11-0 | 222 | 9 | 0.040540541 | 0 | 2 | 1 | 1 | 0 | 4 | 1 |
| 2 | 5.3E+17 | https://twitter.coi | "Can you do | 2014-11-0 | 260 | 6 | 0.023076923 | 0 | 0 | 3 | 1 | 0 | 0 | 2 |
| 3 | 5.3E+17 | https://twitter.coi | That momen | 2014-10-3 | 238 | 6 | 0.025210084 | 0 | 0 | 2 | 1 | 0 | 1 | 2 |
| 4 | 5.2E+17 | https://twitter.coi | Prof. Dave Ai | 2014-10-1 | 457 | 11 | 0.024070022 | 1 | 0 | 3 | 1 | 0 | 0 | 5 |
| 5 | 5.2E+17 | https://twitter.coi | Tried to do le | 2014-10-0 | 266 | 13 | 0.04887218 | 0 | 0 | 4 | 2 | 0 | 0 | 7 |
| 6 | 5.2E+17 | https://twitter.coi | @Hi_lmliz te | 2014-10-0 | 76 | 2 | 0.026315789 | 0 | 1 | 0 | 0 | 0 | 0 | 1 |
| 7 | 5.2E+17 | https://twitter.coi | Bryan asks oi | 2014-10-0 | 261 | 6 | 0.022988506 | 0 | 0 | 3 | 0 | 0 | 0 | 3 |
| 8 | 5.2E+17 | https://twitter.coi | @sarahsurah | 2014-09-2 | 77 | 4 | 0.051948052 | 0 | 1 | 0 | 0 | 0 | 0 | 3 |
| 9 | 5.2E+17 | https://twitter.coi | Prof. Cullon t | 2014-09-2 | 310 | 11 | 0.035483871 | 2 | 0 | 3 | 1 | 0 | 0 | 5 |
| 10 | 5.1E+17 | https://twitter.coi | @themagicw | 2014-09-1 | 68 | 7 | 0.102941176 | 0 | 0 | 1 | 3 | 0 | 0 | 3 |
| 11 | 5.1E+17 | https://twitter.coi | @themagicw | 2014-09-1 | 62 | 3 | 0.048387097 | 0 | 1 | 0 | 0 | 0 | 0 | 2 |
| 12 | 5.1E+17 | https://twitter.coi | @themagicw | 2014-09-1 | 81 | 5 | 0.061728395 | 0 | 0 | 1 | 1 | 0 | 1 | 2 |

Figure 4.3 - Tweet activity metrics for Kate Rielly's Twitter account (Rielly802) from September 1, 2014 to November 30, 2014. Data obtained from Twitter Analytics, October 4, 2015.

The columns highlighted in red depict the most important information that we used to help FRAXA improve its social media outreach through Twitter. The first red column shows exactly what was tweeted. This was helpful, as it allowed us to categorize the content of the tweet. Moving across the table, the next two red columns show the “Impressions” and “Engagements” – the number of people who saw that particular tweet and the number of times users interacted with that particular tweet, respectively (Twitter Analytics, 2015). These pieces of information are helpful because they give a quantitative value to each tweet: a tweet with a higher number of impressions and engagements can be considered more successful than a tweet with less impressions and engagements, as it has reached more people.

The last six red columns break down the types of engagements that users had with a particular tweet. On Twitter, there is one main, quick and easy way to engage with the content of a particular tweet: favorite the tweet. Favoriting a tweet sends a notification to

your friends and followers that you found a particular tweet to be valuable or informative. Though “favorites” represent a helpful tool for measuring user engagement, they cannot necessarily tell an analyst how the user feels about the content of the organization’s tweets. Other ways to interact with tweets include “retweeting” and replying. Retweeting a tweet essentially tweets that same message through your Twitter account and linking that message back to the account that originally posted it. Users have the option to not only tweet that message but quote it and add their own commentary to it, which can allow an organization to gauge the user’s reaction to the content of specific tweets.

Another way to interact with a tweet is to reply to it. Users can send messages to other users’ accounts privately (through Direct Messaging) or publicly, through replies. When a user replies to a tweet, their reply is shown underneath that tweet for all to see. Replies can be negative, positive, or neutral, depending on how the user feels about that particular tweet. Because of this, when analyzing the replies that a tweet receives, it is important to take note of the content of those replies as well as the quantity to determine the relative impact that tweet may have had on those who saw and interacted with it. These are all good ways to measure how many people have engaged with the contents of your tweets, and thus can be used to determine which of FRAXA’s tweets receive the most attention and favorability.

The last three columns, User Profile Clicks, URL Clicks, and Detail Expands, quantify the number of times users wanted to know more about another user from that particular tweet. User Profile Clicks show the number of times users clicked on the original poster’s profile from a particular tweet. From there, users can see information about the poster, called “Details”, including their location, pictures, a short description of who they are, and

other ways to contact them (Twitter Analytics, 2015). Usually, when a user first visits the profile of another user, these details are hidden in a dropdown box, forcing the user to click on it in order to see more details or “expand” them (Twitter Analytics, 2015). The last red column in the table in Figure 4.4 shows the number of detail expands each tweet generated. Once all details are shown, a user can see the other user’s information, which sometimes includes a URL if they are affiliated with a website external to Twitter. The number of times users click on a URL when directed to the profile from a particular tweet is shown in Figure 4.4 under the “URL Clicks” column. We used these three pieces of information – User Profile Clicks, Detail Expands, and URL Clicks – to determine how many people were interested in learning more about FRAXA after reading a particular tweet.

These metrics helped us determining which types of tweets – community-based, informational, or action-based – FRAXA’s audience prefers to receive in order to help FRAXA tailor future tweets to its audience while still getting the Foundation’s message out.

4.2.2. Facebook Strategies

When analyzing FRAXA’s Facebook strategies, we utilized similar techniques as described in the previous section, 4.2.1. Because FRAXA’s Facebook page is visibly more active than its Twitter page, it would be beyond the scope of this project to read through and categorize every post since the page’s inception. Thus, to start, we needed to contact Katie Clapp, President and Co-Founder of The FRAXA Research Foundation, in order to get the metrics for the FRAXA Facebook account. From this data, we obtained not only post history and popularity, but also demographic information about who sees and interacts with the posts. Using this information, we determined the interests of FRAXA’s audience and gave recommendations on how to create posts that have a greater likelihood of user

views and interactions. An example of the metrics “homepage” for a Facebook page is shown below in Figure 4.4.

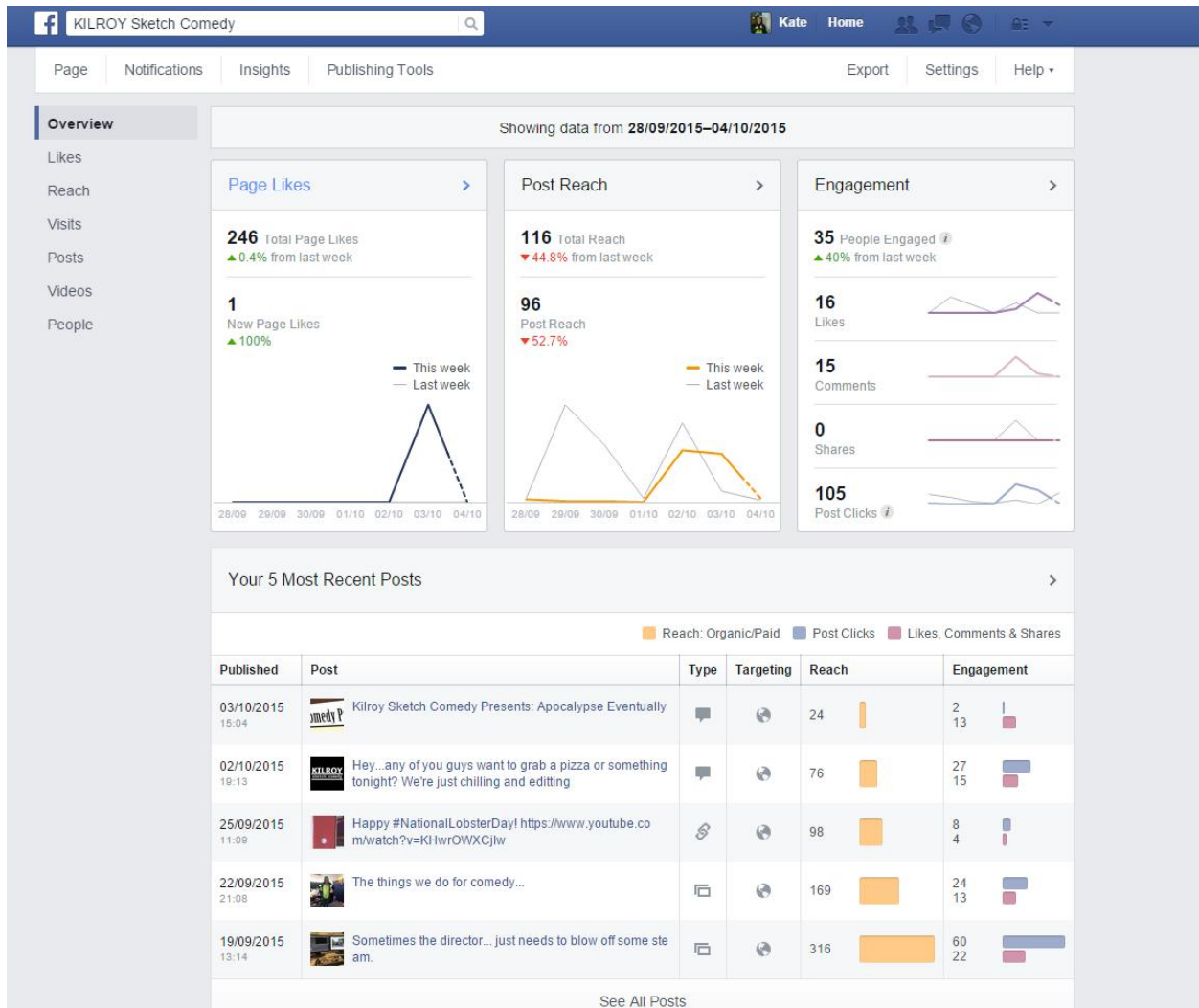


Figure 4.4 - Facebook Metrics Homepage using WPI's Kilroy Sketch Comedy club as an example, retrieved on 4 October, 2015 from facebook.com.

Facebook metrics or “insights” are helpful because they show comprehensive data about a page from any specified date range and include graphs to help visualize all of the information provided. The homepage, shown in Figure 4.4, includes an overview of page

'likes', post reach, and user engagement for the specified time period. These overviews include not just values of 'likes' or people reached, but compares it to previous time periods as a positive or negative percentage (shown in green if positive, red if negative). This is helpful in gauging the relative success per time period that the page is active to determine what more can be done to keep the percentages positive for coming weeks.

Beyond the homepage are tabs for 'Likes', Reach, Visits, Posts, Videos, and People. Under the 'Likes' page, the analyst can view the total number of people who 'like' the page and the net 'likes' over a certain specified period of time. Additionally, the analyst can also determine how many 'likes' were obtained organically (users liking the page) or through advertisements to determine the relative success of the organization's advertisements. The insights also give data for 'likes' obtained through web browsers and mobile applications to show the organization through which interface its audience prefers to interact. This data is shown below in Figure 4.5.

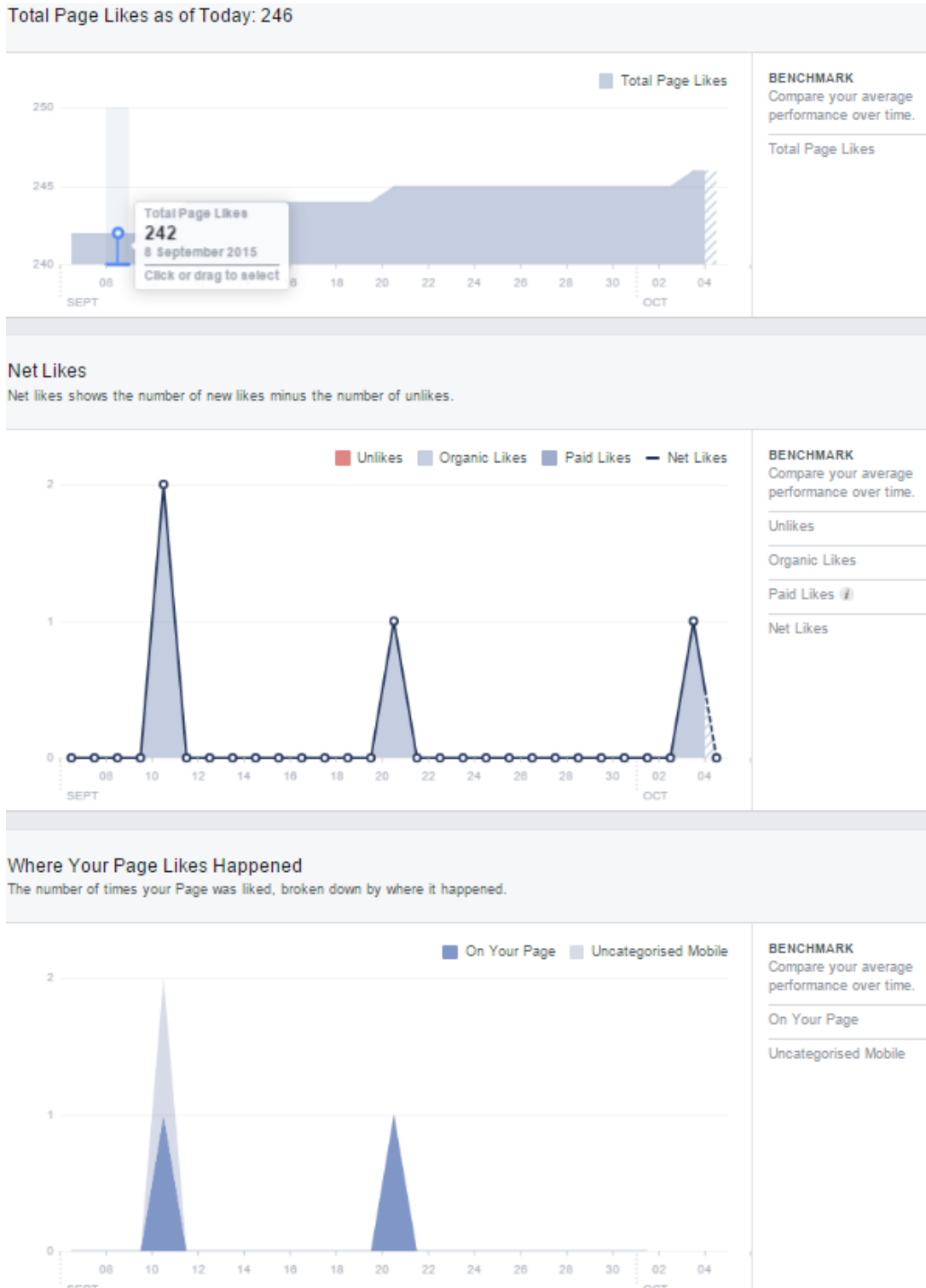


Figure 4.5 - Facebook Metrics 'Likes' Page using WPI's Kilroy Sketch Comedy club as an example, retrieved on 4 October, 2015 from facebook.com.

Visiting the Reach, Visits, Posts, and Videos pages provides information about the success of the page in the same ways that the 'Likes' page does. Information gained from these pages of the FRAXA Facebook account helped us to determine the types of Facebook posts that its audience prefers. The last tab, labeled People, gives demographic information about the page's audience rather than their activity and interactions. Shown in Figure 4.6, the People page breaks down the page's audience by fans (people who 'like' the page) and people reached (people who may not 'like' the page but see it because they are friends with a fan). Beyond this, the information is broken down by specified gender, country, city, and preferred language.

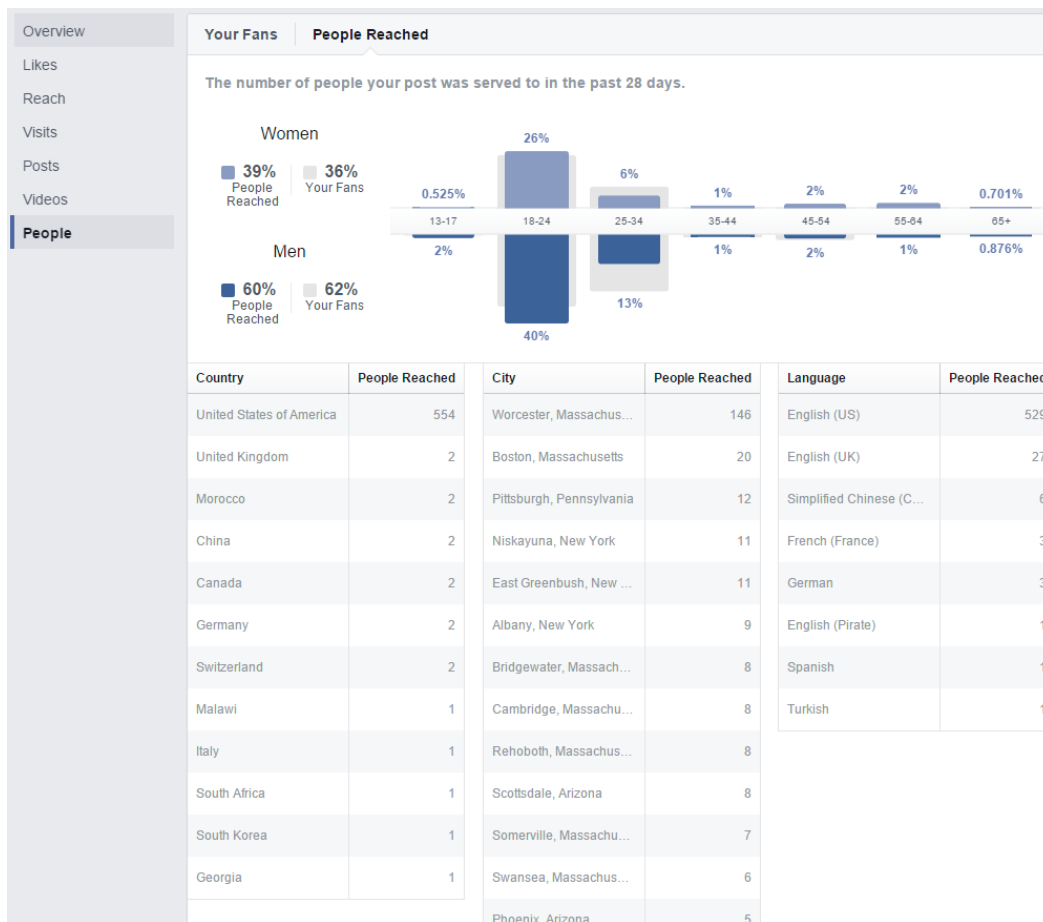


Figure 4.6 - Facebook Metrics People Page using WPI's Kilroy Sketch Comedy club as an example, retrieved on 4 October, 2015 from facebook.com.

Much like Twitter, Facebook allows an analyst to export all of this information for offline viewing. Obtaining exported data from Katie was integral to our goal of improving FRAXA's Facebook outreach. In addition to studying FRAXA's Facebook data, we visually analyzed posts and pages of high-profile nonprofit organizations to draw inspiration from them. We determined the relative success of implementing these strategies by observing the number of user interactions with FRAXA's accounts compared to those of previous time periods.

4.2.3. YouTube Strategies

Though YouTube is a platform primarily used to share video content, similar methods of analysis to those presented in the previous sections can be utilized to assess the success of FRAXA's YouTube channel. We analyzed the content of the videos, quality of the videos, and traffic data to determine which strategies might work best for FRAXA. Video content can be analyzed much in the same way that the content of a tweet is analyzed; that is to say, videos can be categorized based on their intended outcome. Videos can be informational, community-based, calls to action, or a combination of these categories. Our first step in analyzing FRAXA's YouTube strategies was to watch clips or short sections of each of the 37 videos available on FRAXA's channel and categorize them, so that we had an understanding of the types of videos that FRAXA is able to produce.

Second, we analyzed video quality. As discussed in Chapter 3, much of a video's success can be attributed to its quality, not its content. The lower production quality a video has, the more frustrated viewers will become, eventually skipping over parts of the video or stopping the video entirely and moving on to something else. Factors that affect the quality of a video as a whole include sound quality and picture quality, which each can

be further broken down into more specific attributes. Sound quality can include: volume of music, volume of narration or dialogue, clarity of sound, and background noise. If the volume of crucial parts of a videos is too low, or background noise is too loud, the quality of the video depreciates. Picture quality can include lighting, movement, focus, and zoom. If a video is too dark, too bright, shaky, unfocused, or zoomed too far in or out, video quality once again depreciates. Though many of these factors are qualitative and subjective rather than quantitative, these are all important factors to keep in mind when analyzing videos on FRAXA's YouTube channel.

The third and most important step in analyzing FRAXA's YouTube strategies was to examine the channel and videos using metrics obtained from YouTube. Out of the three social media sites discussed in this project, YouTube has the most comprehensive analytics report available for a channel owner. Figure 4.7, located below, shows the Analytics menu located on the Overview Page of a YouTube Channel.

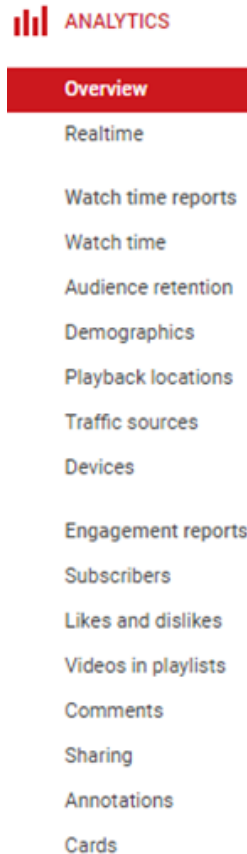


Figure 4.7 - YouTube analytics menu of krielly00's account, retrieved 4 October, 2015 from YouTube.com

The Overview page shows the channel's general performance over a specified time period. On this page, one can see a list of information that YouTube provides for analysts. YouTube breaks these reports down into three main sections: Earnings reports, View reports, and Engagement reports. Earnings reports show the income received from advertisements on videos and is helpful in determining which ads work best, as well as which videos should be paired with ads based on viewership. However, as FRAXA does not show advertisements on their videos, we did not further explore further this section. View reports gives information about all of the channel and video views, breaking down the category into subcategories that include demographic information, playback locations,

traffic sources, playback devices, and audience retention. Engagement reports shows how many people follow the particular YouTube page as well as the likes and dislikes for each video.

4.2.3.1. YouTube Experiment

In addition to analyzing the raw data acquired from the YouTube channel, we conducted an experiment in order to answer two questions:

1. Which types of videos get more views, emotional or informational?
2. How do videos of each type perform on various social media platforms (Facebook vs. YouTube vs. Twitter)?

We conducted this experiment because there is not enough current data from the FRAXA YouTube channel in order to accurately answer these questions.

In preparation for the experiment, we searched FRAXA's YouTube Channel and determined which types of videos already existed on their page. Previously, we had communicated with Katie Clapp regarding video content and determined that FRAXA did not have any new content that we could use for the experiment. With Ms. Clapp's permission, we isolated short clips from various videos already on the FRAXA YouTube page for use in the experiment. Using Adobe Premiere Pro CC 2015 video editing software, we created the two videos from these isolated clips, as well as inserted informational slides that we created ourselves into the videos. All music that was used was obtained from a royalty-free, online source (freesound.org).

By compiling these videos ourselves, we were able to lay out a set of controls that we would use to monitor the consistency of our experiment. Our controls included many of the video qualities listed above in YouTube Strategies, such as: similar picture and audio

quality as well as similar lengths. We were additionally able to control the novelty and consistency of the videos by compiling the videos ourselves. Though the clips that were isolated and used in the creation of the videos had been presented as part of longer videos on the FRAXA YouTube channel, they had not been seen in the same context as our created videos. We also created our own title cards and text slides, keeping the design consistent across both videos, and included controls that would ensure that the descriptions and titles for each video were similar in tone, length, and detail. Finally, we ensured that we published the videos simultaneously to YouTube, Facebook, and Twitter. Once the videos were released, we tracked activity on the YouTube channel and Facebook posts, as well as Twitter tweets, related to the videos for the following ten days (February 17 - February 27).

Furthermore, the team noticed that after the initial planned experiment, FRAXA had embedded a video to Facebook regarding an upcoming fundraising event. Embedding a video to Facebook means that the video was directly uploaded to Facebook and exists on Facebook independently of any other website. This is a different technique than what the FRAXA Facebook page has used previously, as many of the previous video posts included links that directed a user to the video hosted on YouTube. After noticing this new embedded video, the team decided to conduct a secondary experiment to determine the engagement levels that videos get when they are embedded to Twitter and Facebook rather than posted to those sites using a YouTube link.

During the secondary experiment, we obtained permission from Ms. Clapp to download the video that had been embedded on the FRAXA Facebook page so that we could embed the video on FRAXA's Twitter page as well. In contrast to embedding a video

on Facebook, Twitter only allows for 30 seconds of the video to be embedded on the page. However, for videos longer than 30 seconds, Twitter permits the account manager to choose which 30 second clip they would like to embed, allowing for some degree of control over the embedded content. Because of the length limitation, we could no longer use video length as a control in the secondary experiment as we did with the first, however we were able to keep post title and text consistent across both platforms. The video was released on Twitter and we tracked activity on the YouTube channel, Facebook page, and Twitter page as well as the individual posts on each platform for a week after the release date (March 28 - April 4). The results of these experiments are recorded and discussed in Chapter 5.

4.2.4. If This Then That

One issue that arose during conversations with Ms. Clapp regarding social media use by FRAXA was the organization's time constraints. Because Ms. Clapp is one of two full-time employees, and the other employees are part-time or volunteers, the organization does not have a lot of time to devote to implementing proposed strategies on various social media networks. Thus, the use of an additional, third-party service could be helpful in managing the organization's social media accounts while accounting for time constraints. If This Then That (IFTTT) is a service that allows its users to create connections between mobile apps, web apps, websites, and services. As such, IFTTT can link multiple social media accounts together in order to minimize the amount of work needed to post to each platform (Figure 4.8).

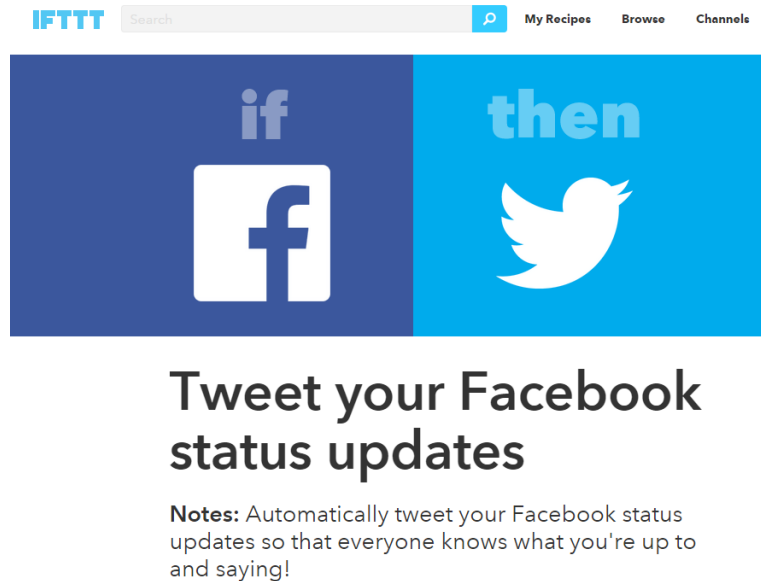


Figure 4.8 - IFTTT Connection, retrieved 4 October, 2015 from ifttt.com

When two or more social media accounts are connected, the user can determine specifically what actions they wish to take regarding those accounts. For example, if Twitter and Facebook accounts are connected, a user can specify the action shown in Figure 4.8 above; a status posted to Facebook will automatically get tweeted on the connected Twitter page. This spreads messages quickly and efficiently. During our data collection phase, we explored IFTTT so that we could create a guide for FRAXA to use IFTTT to link its social media accounts. During this phase, we built sample “recipes” or connections between social media accounts to determine with which social media platforms the service is compatible and which types of connections would be most useful to FRAXA. A guide detailing how to create an IFTTT account and link social media accounts to each other, as well as a list of useful “recipes” are located in Appendix B.

5. Results

This section details the results developed in this project, based upon the objectives defined in the previous section. Sections 5.1, 5.2, 5.3, and 5.4 detail the results obtained from the FRAXA Twitter, Facebook, YouTube, and SWOT Analysis data, respectively. The Twitter section focuses on organizing FRAXA's various tweets into categories and on comparing the user activity each tweet generated to determine the most popular content and context that FRAXA's followers prefer to see. Additionally, we analyzed tweets based upon time and day of the week to determine when FRAXA's followers are most active. Finally, the Twitter section details the demographics of FRAXA's Twitter followers to determine the general interests of both FRAXA's followers and the average Twitter user.

The Facebook section looks at the activity on FRAXA's Facebook page. We studied the various posts to see which ones had the most activity and determined which types of posts were most popular on Facebook. We determined the popularity of a post by looking at how many likes, comments, and shares the various posts received.

The first three subsections (5.3.1 – 5.3.3) of the YouTube results focus on analyzing the types of videos published on the FRAXA YouTube channel, the user demographics, and the users' interactions with each video and the page overall. We obtained all information for these analysis from the public YouTube page and also from the analytics tool built into YouTube. The last subsection (5.3.4) focuses on analyzing data collected during the YouTube experiment from the FRAXA YouTube page.

The SWOT analysis section focuses on the answers provided to us by Ms. Budek, one of FRAXA's employees, to the questions outlined in our methodology. A full transcript of the conversation can be found in Appendix C.

5.1. Twitter

The integration of Twitter into FRAXA’s social media repertoire could provide an excellent resource for FRAXA to move forward in pursuit of its overarching goal: to find a cure for Fragile X by funding research directly through donations. However, FRAXA does not currently have all of the resources necessary for continual maintenance of a Twitter account. As such, the findings presented in this report will guide further recommendations on how FRAXA can efficiently and successfully integrate Twitter into its outreach strategies.

5.1.1. Tweet Categories

The tweets obtained from the Twitter Analytics Tools represent FRAXA’s Twitter use for the entire year of 2015. We categorized all of the 2015 tweets from the FRAXA account in two different ways. First, we categorized them by origin, and then identified them as Organic, Replies, or relating to Social Media Activity (Figure 5.1).

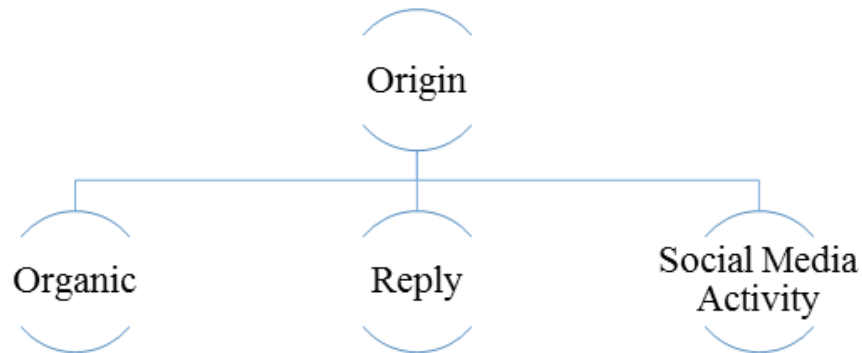


Figure 5.1 - Categorizing tweets based on origin. Categories include original compositions by the account holder (Organic), replies to others’ tweets (Reply) or alerts about activity on other social media platforms (Social Media Activity).

As described in Chapter 3, organic tweets are those that are originally posted by the FRAXA Twitter account; they do not include retweets. Replies are tweets that are posted by the FRAXA account in response to another account. Like organic tweets, replies can be seen by a general audience, however, the general audience is not notified that a reply has been posted, and has to specifically click on the original tweet in order to see any replies made by the FRAXA account. Tweets categorized as Social Media Activity are tweets that alert FRAXA's followers that the FRAXA account has performed an activity on another social media site, such as liking a video on YouTube. These tweets are almost always automatically posted by the account when the social media activity occurs.

The second way that we categorized the tweets was based on their Type. As described in Chapter 3, there are three types of tweets: Informational, Action-based, and Community-based tweets (Figure 5.2).

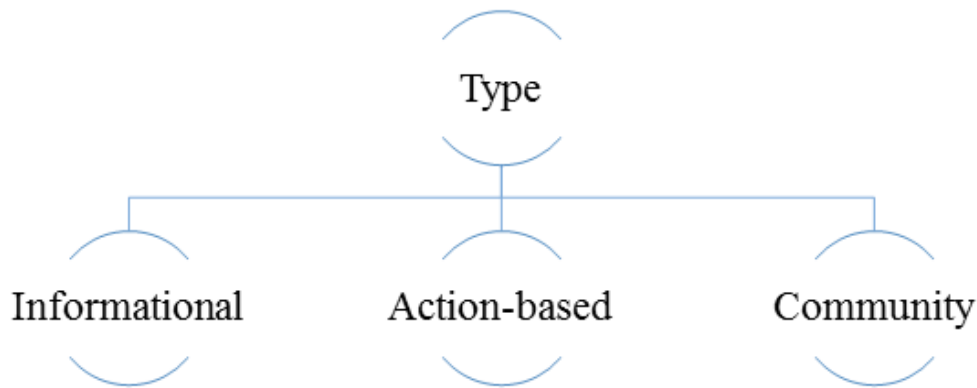


Figure 5.2 - Categorizing tweets based on type. Categories include tweets that deliver factual content (Informational), tweets that serve as a call to action (Action-based), or tweets that serve to connect more personally to followers (Community).

Informational tweets are those that deliver data and factual content related to the Twitter account's purpose in order to familiarize the public with the organization that owns the account. Action-based tweets serve as a call to action for followers of the account

and generally include references to donating and volunteering to further the organization’s cause. Community-based tweets allow the organization to connect with its followers on a more personal level, and usually contain pictures and personal anecdotes as well as conversational language.

Figure 5.3 below shows all of FRAXA’s tweets in 2015 categorized by their origin. Of 69 tweets posted by the FRAXA Twitter account in 2015, 51 tweets were organic, 14 tweets were replies, and four tweets were related to social media activity. Organic tweets made up 74% of all of FRAXA’s tweets in 2015. Replies contributed to 20% of all of FRAXA’s 2015 tweets, while the remaining 6% of tweets were related to social media activity. This data shows that organic tweets contribute to the majority of FRAXA’s tweets from 2015, suggesting that FRAXA is producing mostly original content through its Twitter account.

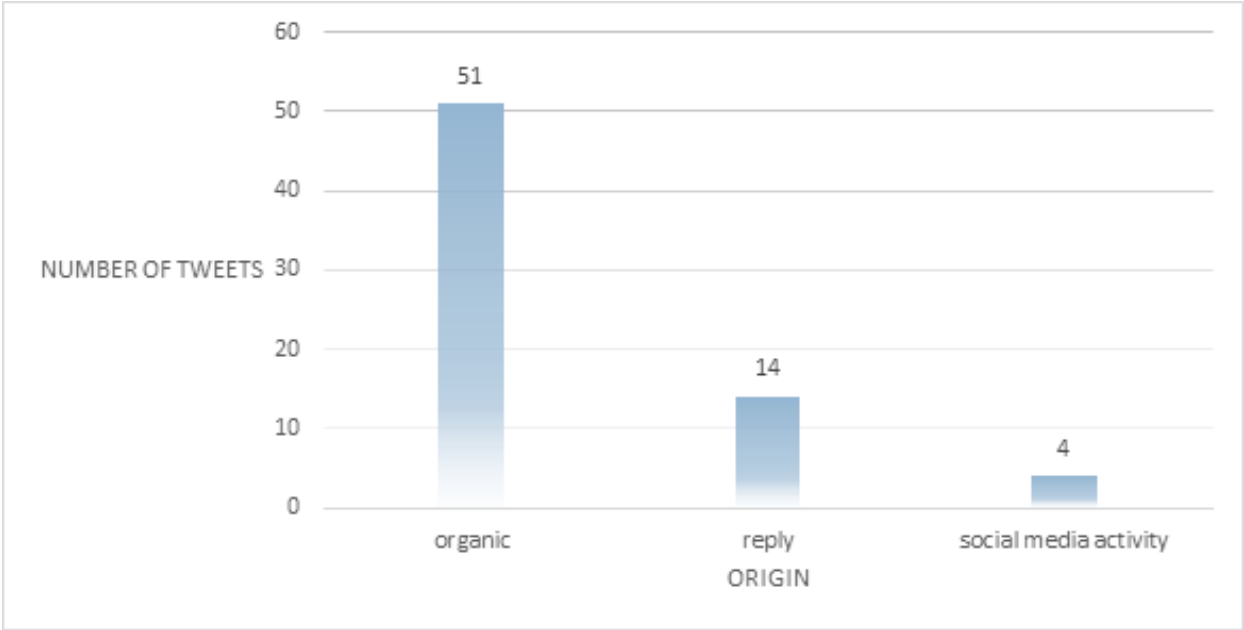


Figure 5.3 - Sum of FRAXA’s Tweets by Origin in 2015. A breakdown of the amount of tweets in each origin category posted by the FRAXA Twitter account in 2015.

Figure 5.4 below shows all of FRAXA’s tweets in 2015 categorized by type of tweet. Of the 69 tweets posted by FRAXA in 2015, 30 (43%) were informational, two (3%) were action-based, and 37 (54%) were community tweets. This data suggest that the vast majority (97%) of FRAXA’s tweets deliver information about the organization and Fragile X Syndrome, as well as share personal anecdotes and use more community-oriented language.

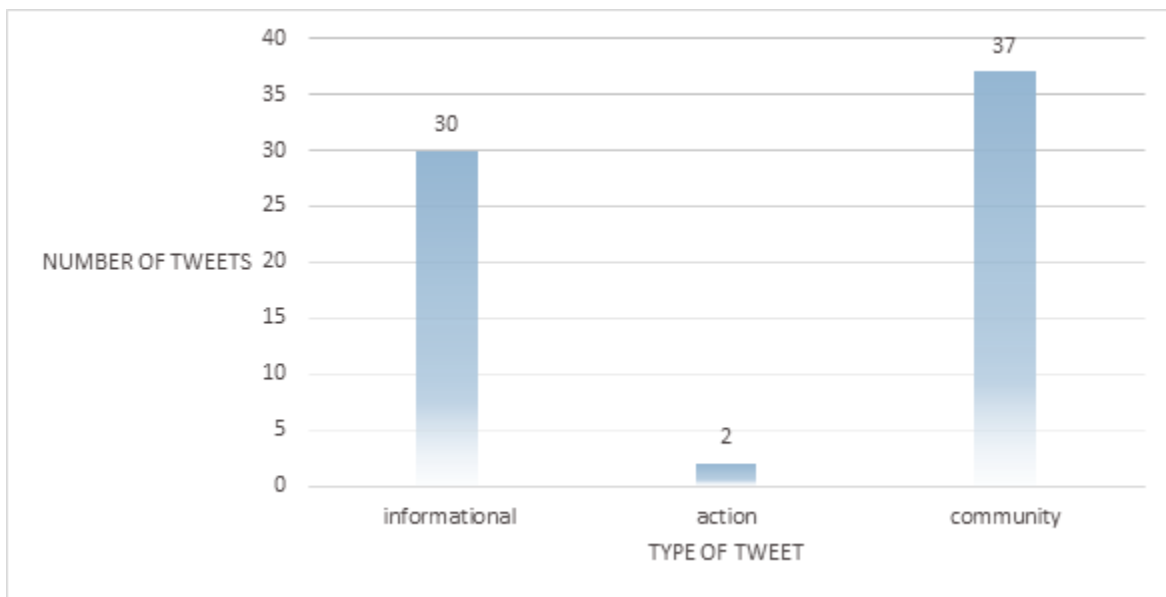


Figure 5.4 - Sum of FRAXA’s Tweets by Type in 2015. A breakdown of the amount of tweets in each Type category posted by the FRAXA Twitter account in 2015.

5.1.2. Tweet Engagements

After determining the sum of tweet types and origins, we determined the sum of all engagements gained by tweets of each origin and type over 2015. Figure 5.5 shows the sum of FRAXA’s tweet engagements by type and origin in 2015. It is important to note that data in blue represents the total number of engagements with the FRAXA Twitter account broken down into engagements based on type of tweet, while the data in orange represents

the total number of engagements with the FRAXA account broken down into engagements based on origin of tweet. Of 953 engagements gained by all of FRAXA’s tweets in 2015, organic tweets had 890 engagements (93% of total engagements), replies received 36 engagements (4%), and tweets involving social media activity had 27 engagements (3%).

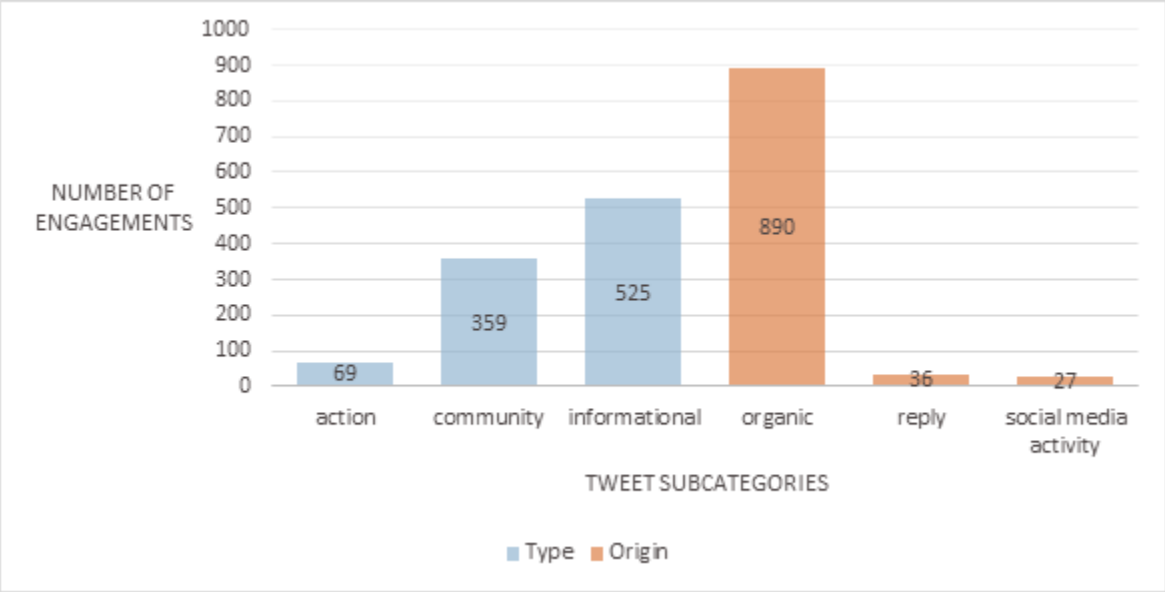


Figure 5.5 - Sum of FRAXA’s Tweet Engagements by Type and Origin in 2015. A breakdown of the amount of engagements of each tweet within in each Type category and Origin category.

Moreover, of all 953 engagements with FRAXA’s tweets in 2015, informational tweets received 525 engagements (55%), community-based tweets received 359 engagements (38%), and action-based tweets received 69 (7%) engagements. FRAXA’s informational and community-based posts received the majority of all engagements in the tweet type category, which at first glance suggests that FRAXA’s Twitter followers are more interested in informational and community-based posts than action-based posts. However, when the engagement data is scaled with the number of tweets in each subcategory, the opposite is true. Table 5.1 shows the total number of tweets in each Type or Origin

category, as well as the total number of engagements tweets in each category received, and the approximate (rounded to the nearest whole number) average number of engagements per tweet. We determined the approximate average number of engagements per tweet by dividing the total number of engagements for each category by the total number of tweets in that category, and then rounded that number to the nearest whole number.

| Tweet Type/Origin | Total Number of Tweets | Total Number of Engagements | Approx. Average Engagements per Tweet |
|------------------------------|-------------------------------|------------------------------------|--|
| Action-based | 2 | 69 | 35 |
| Community | 37 | 359 | 10 |
| Informational | 30 | 525 | 18 |
| | | | |
| Organic | 51 | 890 | 17 |
| Reply | 14 | 36 | 3 |
| Social Media Activity | 4 | 27 | 7 |

Table 5.1 - Normalized Engagement Data. A breakdown of the amount of tweets in each subcategory, the amount of engagements each tweet subcategory received, and the average number of engagements per tweet in each subcategory.

Table 5.1 also shows that Action-based tweets receive more engagements per tweet (35) than both Community (10) and Informational (18) combined. Thus, the higher number of engagements for informational and community-based tweets can be attributed to the higher frequency of those posts. Because the FRAXA account posted far less action-based tweets, it is not surprising that the action-based tweets received fewer engagements.

It is also not surprising that reply tweets and tweets involving social media activity received fewer engagements per tweet than organic tweets. Because replies are made in response to a tweet from another account, they specifically target that one account, rather than a general audience. That targeted account receives a notification any time that the FRAXA account (or any other Twitter account) has replied to a tweet of theirs. As described previously, replies can be seen by a general audience, but the general audience is not notified that a reply has been posted, and has to specifically click on the original tweet in order to see any replies made by the FRAXA account. Thus, the low number of engagements can be attributed to the fact that replies only reach those who specifically look for them, which constitutes a smaller fraction of FRAXA's Twitter followers.

Tweets involving social media activity tell an organization's followers when that organization has performed an activity on another social media platform. These tweets are automatically posted when FRAXA performs an activity on another social media site because FRAXA's Twitter account has been previously linked with the particular site in question. These tweets are generic in that they do not contain any language selected by those using the FRAXA Twitter account, but contain a blanket statement describing the activity performed on the external social media site using an automated program within Twitter. Figure 5.6 below shows an example of a Social Media Activity tweet posted by the FRAXA account.



Figure 5.6 - Example of a Social Media Activity tweet posted by the FRAXA Twitter account on August 21, 2015, retrieved April 12, 2016 from twitter.com

These tweets can serve to show FRAXA’s Twitter followers what types of media and content the organization is interested in and where FRAXA goes to find that content. These tweets highlight the external social media site involved in the activity, rather than the content of the tweet itself, thus urging the audience to follow FRAXA’s activity elsewhere. This can prevent direct engagement, as it shifts the focus away from the tweet itself and onto the external social media site. Additionally, though Social Media Activity tweets received fewer engagements per tweet than Organic tweets in 2015, the amount of engagements per tweet was surprising for the apparent value that they serve. Thus, it can be concluded that FRAXA’s Twitter followers are willing to interact with Social Media Activity tweets despite their more generic form.

Next, we plotted tweet engagements gained in 2015 over time to determine when FRAXA’s audience was most active on Twitter. Figure 5.7 shows FRAXA’s tweet engagements for 2015 plotted against the time of day each tweet was posted. With the

exception of one outlier, the majority of FRAXA’s tweet activity begins during business hours and continues into the late evening. The seven tweets with the highest number of engagements (30 or more engagements per tweet) occurred between 12:00 PM and 6:00 PM EST, while 61 other tweets with fewer engagements (less than 30 engagements per tweet) were more spread out throughout the day.

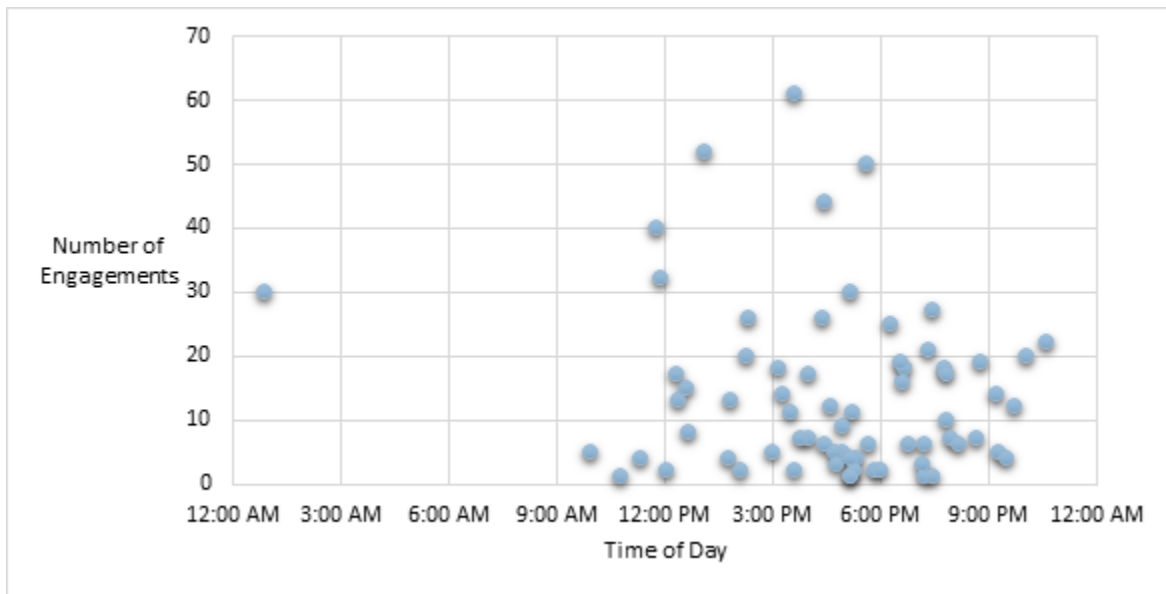


Figure 5.7 - FRAXA’s Tweet Engagements against Time of Day in 2015. Each tweet posted by the FRAXA Twitter account in 2015 plotted based upon the number of engagements and the time of day (EST) at which it was posted.

Furthermore, we plotted tweet engagements gained in 2015 over the days of the week to determine when FRAXA’s audience was most active on Twitter during the week. Figure 5.8 below shows the sum of all engagements gained on each weekday. The data in Figure 5.8 shows that the FRAXA Twitter account received 254 engagements (27%) on Mondays, 157 engagements (16%) on Tuesdays, 124 engagements (13%) on Wednesdays, 191 engagements (20%) on Thursdays, 149 engagements (16%) on Fridays, and 78 engagements (8%) on Saturdays. Sunday was excluded because there were no recorded

engagements with the FRAXA Twitter account on Sundays. According to the data presented in Figure 5.8, FRAXA’s Twitter audience is most active on Mondays, as indicated by the number of engagements. The number of engagements undergoes a gradual decrease in activity during the middle of the business week, but then becomes more active again towards the end. Saturday exhibits the lowest amount of activity, suggesting that FRAXA’s audience does not spend as much time on Twitter over the weekend.

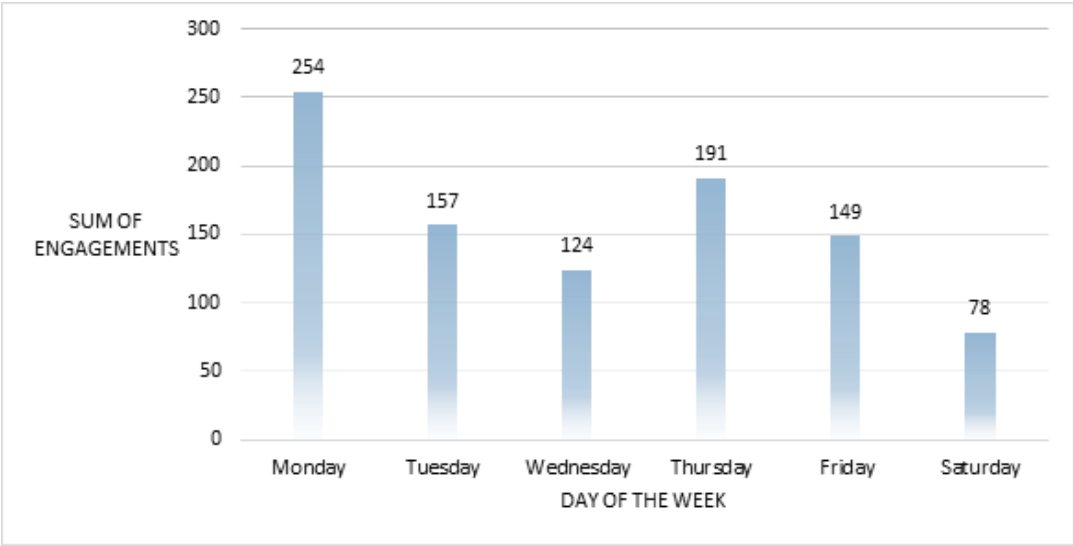


Figure 5.8 - Sum of FRAXA’s Tweet Engagements by Day of the Week in 2015. Each tweet posted by the FRAXA Twitter account in 2015 plotted based upon the number of engagements and the day of the week on which it was posted.

In addition to the engagements based on tweet type, tweet origin, and tweet time, we determined the breakdown of the type of engagements that FRAXA’s account received in 2015 (Figure 5.9). The majority of the engagements that FRAXA received on its tweets in 2015 were URL clicks (35.36%), detail expands (24.03%), retweets (15.63%), and likes (11.23%). The frequency of these types of engagements, as discussed in the previous section, can be used to determine the general response rate of FRAXA’s audience in regards

to its tweets and Twitter activity. User profile clicks, replies, and hashtag clicks were less common reactions to FRAXA’s tweets in 2015, only making up 6.72%, 0.94%, and 0.94%, respectively. Using this information, it is apparent that FRAXA’s followers are engaging more with tweets that include links or URLs to other sites, articles, or information sources. Additionally, almost one quarter of all engagements were detail expands, suggesting that FRAXA’s followers are interested in learning more about the particular tweet and the other users that have interacted with it. Similarly, approximately 15% of all engagements were retweets, which indicates that FRAXA’s followers are passing along information to additional users.

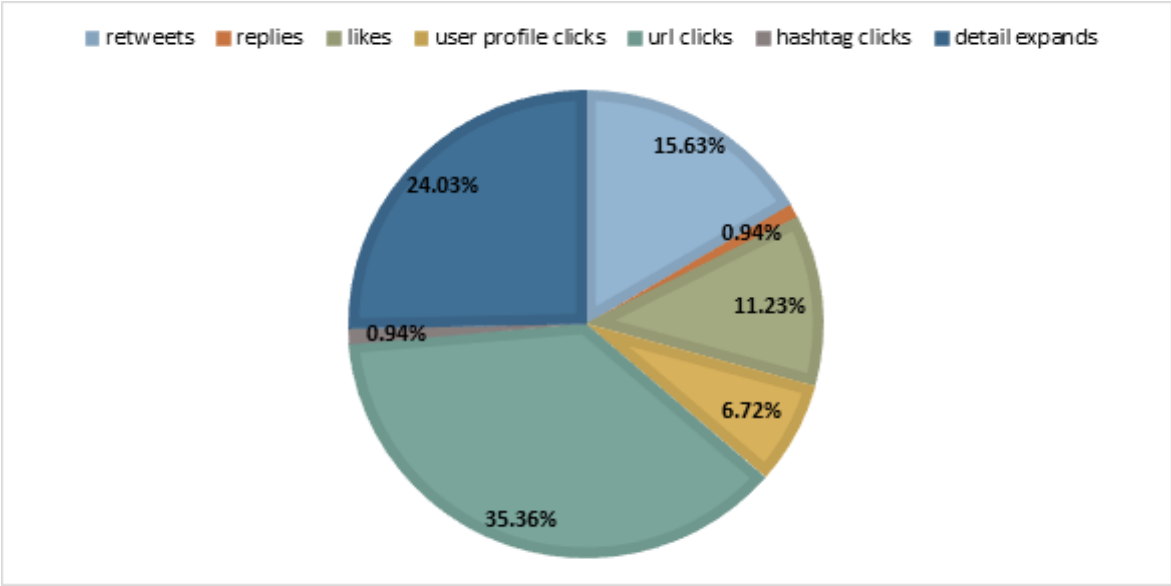


Figure 5.9 - Types of Engagements FRAXA’s Tweets Received in 2015. A percentage breakdown of each type of engagement that FRAXA’s tweets received in 2015.

5.1.3. Tweet Impressions

After determining the sum of FRAXA’s tweet engagements, we determined the sum of all impressions gained by tweets of each origin and type over the whole year of 2015.

Tweet impressions, unlike engagements, do not measure user interaction with the FRAXA account, rather, it measures the number of users who have seen the tweet appear on their Twitter feed or homepage. Thus, these sums will be significantly larger than the sums from the previous section, Twitter Engagements, as not every Twitter user who sees a post will interact with it.

FRAXA's informational and community-based posts received the majority of all impressions in the tweet type category, quite similarly to results found in the engagement section previously. Moreover, when the tweet impressions were scaled in the same way that the engagements were in the previous section, we found that the action-based tweets received more average impressions per tweet than Community and Informational tweets (Table 5.2). Thus, the higher number of impressions for informational and community-based tweets can be attributed to the higher frequency of those posts. Because the FRAXA account posted far less action-based tweets, it is not surprising that the action-based tweets received fewer impressions. All other data collected on FRAXA's Twitter impressions, including impressions per day of the week and time of day, presented similar results to the engagement data, and thus was not reproduced in this report.

| Tweet Type/Origin | Total Number of Tweets | Total Number of Impressions | Approx. Average Impressions per Tweet |
|------------------------------|-------------------------------|------------------------------------|--|
| Action | 2 | 1,888 | 944 |
| Community | 37 | 19,445 | 526 |
| Informational | 30 | 22,941 | 765 |
| | | | |
| Organic | 51 | 39,128 | 767 |
| Reply | 14 | 2,858 | 204 |
| Social Media Activity | 4 | 2,288 | 572 |

Table 5.2 - Normalized Impression Data. A breakdown of the amount of tweets in each subcategory, the amount of impressions each tweet subcategory received, and the average number of impressions per tweet in each subcategory.

5.1.4. Twitter Demographics

According to FRAXA’s Twitter page, the FRAXA account has 815 Twitter followers. Using the Twitter Analytics Tools, we determined that 65% of these followers are female, while 35% of these followers are male. Additionally, we found that 64% of FRAXA’s followers are located in the United States, 20% of followers are located in other English-speaking countries such as Canada, the United Kingdom, and Australia, while the remaining 16% of followers are located in mainly European countries, such as Spain, France, Italy, Netherlands, and Belgium.

Using the Twitter Analytics Tools, we determined the top 10 interest areas for FRAXA’s followers. Those interest areas include (from most popular with the FRAXA

audience to least popular): business and news, movie news and general info, comedy, politics and current events, music, business news and general info, tech news, science news, technology, and health, mind, and body. For the purposes of this project, we will exclude all data related to music, comedy, and movie news and general info because they are not relevant to the goal of this project.

Specifically, we compared five particular “interest groups” or audiences to FRAXA’s audience on these particular interest areas using a built-in tool within Twitter Analytics. The five interest groups include only United States (US) users, as the majority of FRAXA’s Twitter following is located inside the US. The five interest groups that we focused on were: all US Twitter users, US Twitter users who self-identified as parents, US Twitter users interested in nonprofits, US Twitter users interested in special education, and US Twitter users interested in parenting of special needs children. For clarity’s sake, these groups will be referred in the text as: all users/average user, parents, those interested in nonprofits, those interested in special education, and parents of special needs children. We chose these interest groups for comparison because we believe that they most accurately describe the types of Twitter users who might be interested in FRAXA and their mission.

Figures 5.10, 5.11, and 5.12 show the interests of FRAXA’s Twitter followers in comparison with interests of all Twitter users, parents on Twitter, and those interested in special education, respectively. In general, FRAXA’s followers are more interested in health, mind, & body, technology, science news, tech news, business news and info, politics and current events, and business news than all US Twitter users, all parents on Twitter, and all those interested in special education.

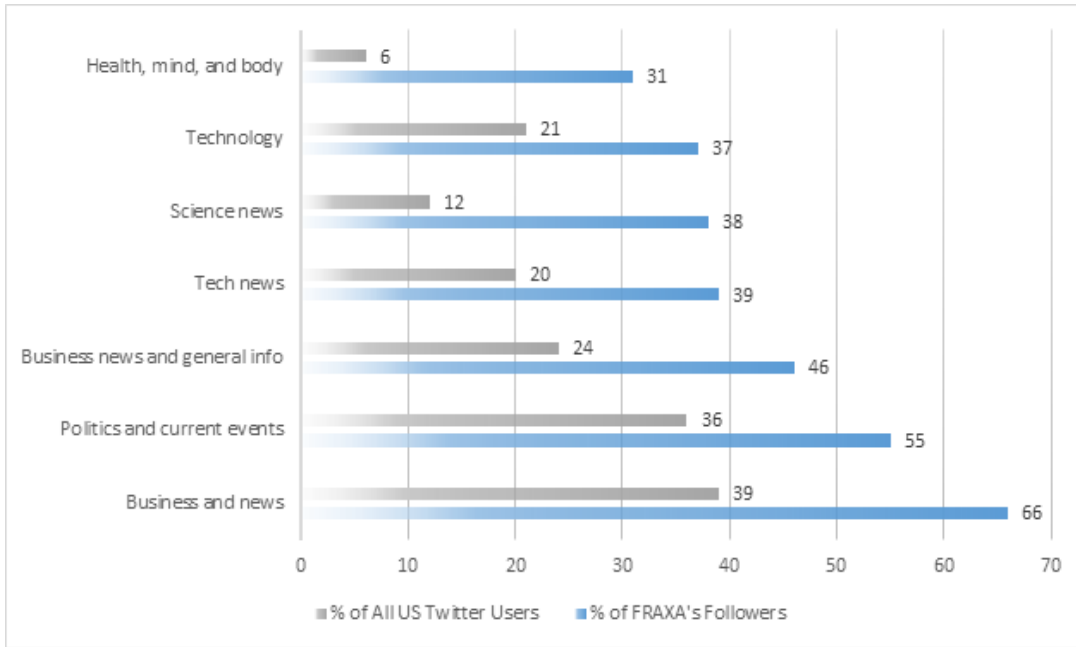


Figure 5.10 - Interests of FRAXA's Twitter Followers versus All US Twitter Users. Percent of FRAXA's followers who indicated that they were interested in each topic versus the percent of all Twitter users who indicated their interest in each topic.

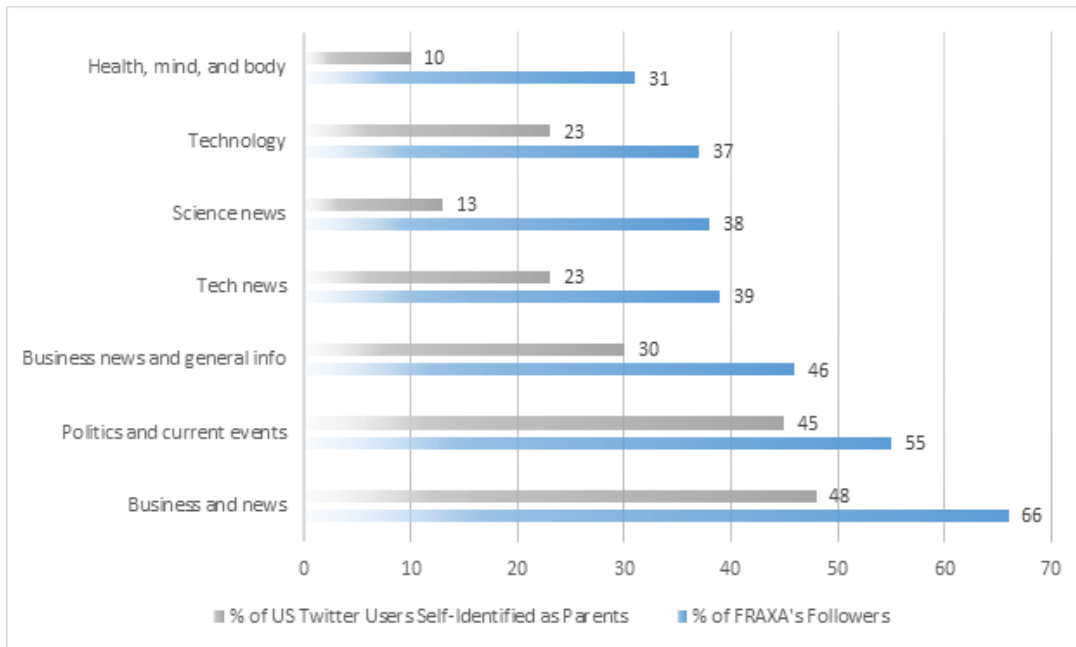


Figure 5.11 - Interests of FRAXA's Followers versus all US Twitter Users Self-Identified as Parents. Percent of FRAXA's followers who indicated that they were interested in each topic versus the percent of parents on Twitter who indicated their interest in each topic.

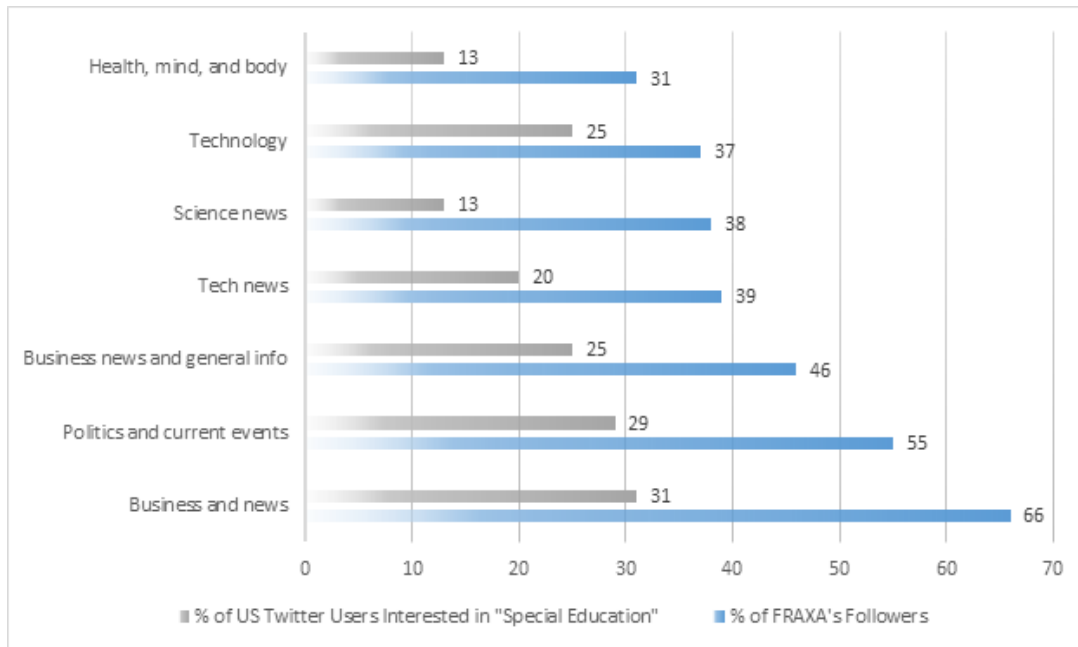


Figure 5.12 - Interests of FRAXA's Twitter Followers versus all US Twitter Users Interested in "Special Education". Percent of FRAXA's followers who indicated that they were interested in each topic versus the percent of Twitter users interested in special education who indicated their interest in each topic.

Figure 5.13 shows the interests of FRAXA's followers in comparison with the interests of all users interested in nonprofits. Figure 5.14 shows the interests of FRAXA's Twitter followers in comparison to interests of those on Twitter who are parents of special needs children. In general, FRAXA's Twitter followers are more interested in technology, science news, tech news, business news and general info, politics and current events, and business news compared to Twitter users interested in nonprofits and parenting of special needs children. FRAXA's Twitter followers are less interested in health, mind, and body than Twitter users who listed themselves as being interested in nonprofit organizations and parenting of special needs children.

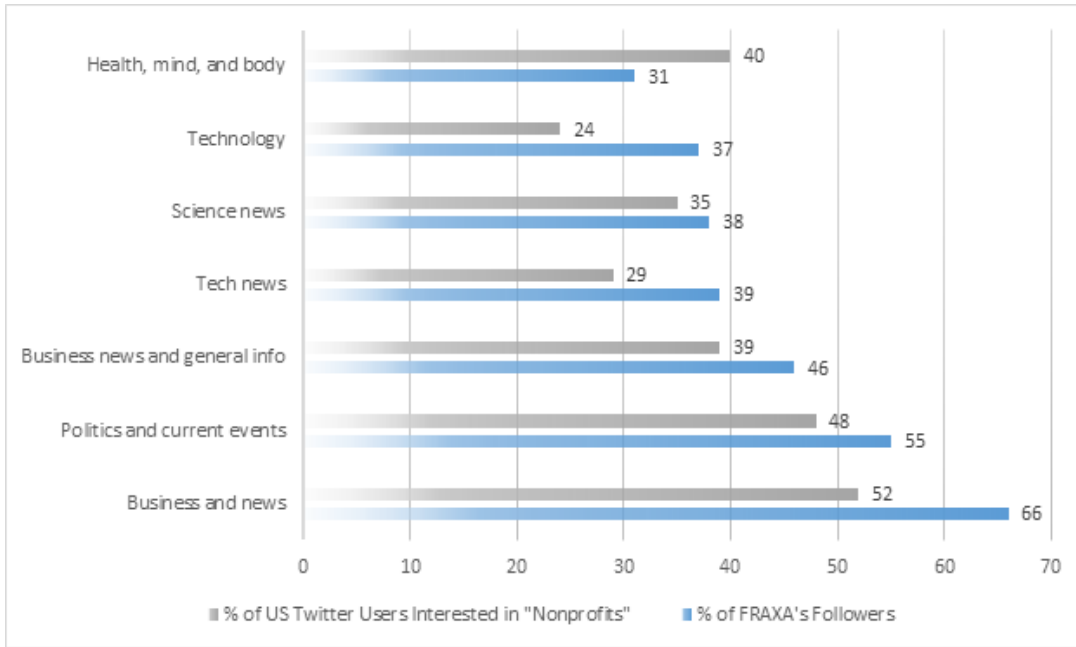


Figure 5.13 - Interests of FRAXA's Followers versus all US Twitter Users Interested in "Nonprofits". Percent of FRAXA's followers who indicated that they were interested in each topic versus the percent of Twitter users interested in nonprofits who indicated their interest in each topic.

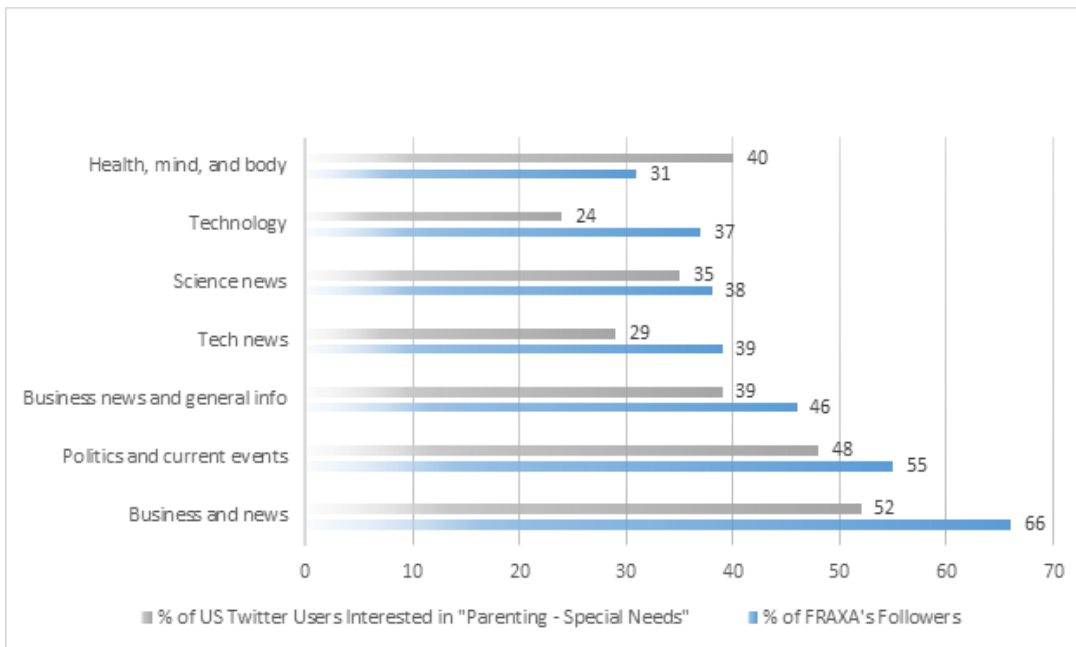


Figure 5.14 - Interests of FRAXA's Followers versus all US Twitter Users Interested in "Parenting - Special Needs". Percent of FRAXA's followers who indicated that they were interested in each topic versus the percent of Twitter users interested in parenting - special needs who indicated their interest in each topic.

It seems that, in general, FRAXA's followers are more interested in health, technology, science, business, current events, and general news topics than those who fall into the general categories of parents and all US users. This data suggests that FRAXA's followers are paying more attention to news sources and informational posts than the average Twitter user.

5.2. Facebook

The metrics of FRAXA's Facebook page show that Facebook users' awareness of FRAXA is growing. However, this growth is relatively slow, with an increase at a rate of about 1.5 new users liking the page per day, or about three people liking FRAXA's Facebook Page every two days. This rate was determined by calculating the trendline of the lifetime total likes for the Facebook page over three months, as shown in Figure 5.15. On February 5, 2016, this page had 2,002 page likes, which is low compared to other organizations with similar missions and goals. For instance, Autism Speaks has 1.5 million likes on their Facebook page and The National Fragile X Foundation Facebook Page has about 9,000 page likes.

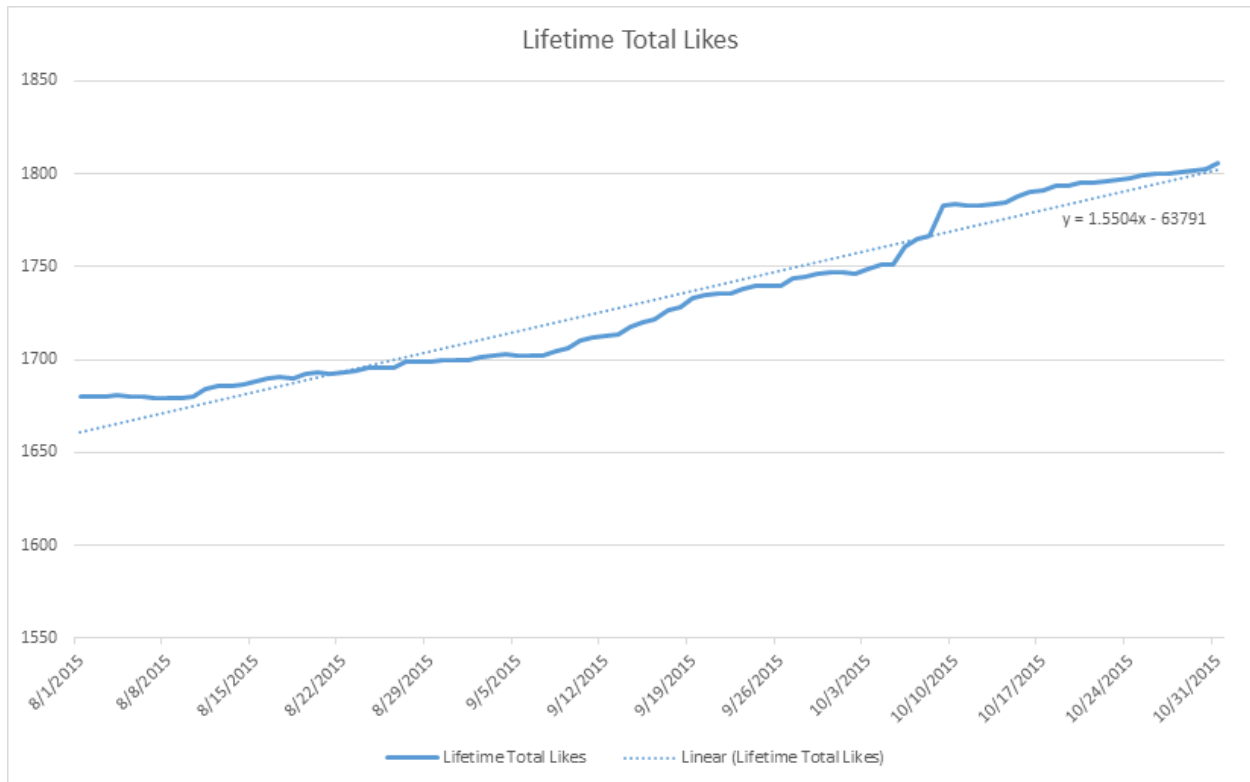


Figure 5.15 - Demonstration of the total number of people who liked the page from August 1 through October 31, 2015, including the trendline, which shows the average rate of growth of the number of page likes.

Figure 5.16 shows the daily likes and unlikes for the page from August 1 through October 31, 2015. In general, more people are liking the page rather than unliking the page. Around October 10, there were two spikes in this graph, meaning that an unusual number of people liked the page around that time. There are two posts that could possibly have contributed to this occurrence. The first post was about CRISPR, which is a biotechnology process that allows scientists to “edit” genes. The second post is about job opportunities for adults with Fragile X Syndrome. While these two posts are unrelated in terms of content, they are both important pieces of information to families with somebody who has Fragile X Syndrome. For Facebook users interested in helping people with Fragile

X Syndrome and who were not previously following FRAXA on Facebook, these two articles could have helped draw them towards FRAXA's Facebook page.

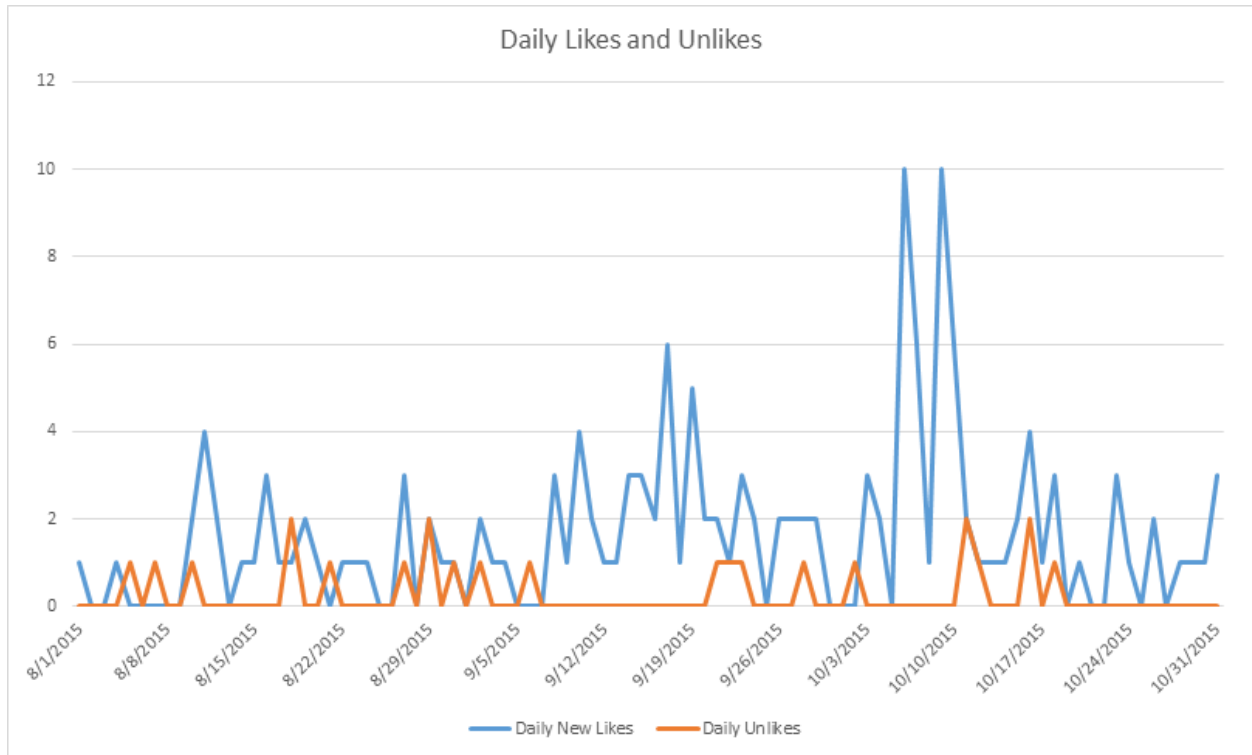


Figure 5.16 - The daily number of people who liked and unliked the FRAXA Facebook page from August 1 through October 31, 2015.

Taking a closer look at the page likes, we see in Figure 5.17 where these page likes are originating. Over the three month period of August 1 through October 31, 2015, the majority of the page likes came from the categories of mobile or page profile. The page profile category consists of people who liked the page by looking at the profile of another Facebook user, or in other words, liking a page that his/her friend has liked. Forty-four of the page likes came from this category, which is about 33% of all of the page likes over this time period. The mobile category is the number of likes that came from a mobile

device. Thirty-one of the page likes came from this category, which is about 23%. In total, over half of the page likes come from these sources.

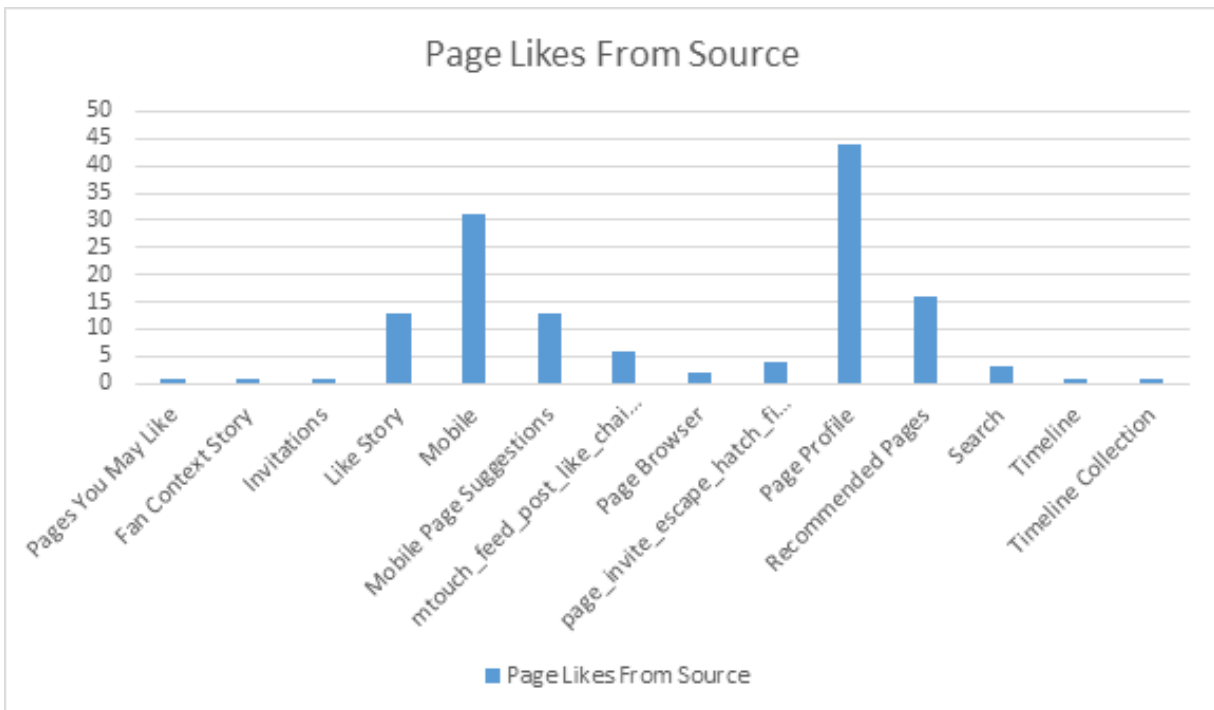


Figure 5.17 - The number of page likes from August 1 through October 31, 2015 broken down by the source of each page like.

Overall, the most Facebook activity is associated with the informational posts and emotional posts, unlike what we see with Twitter activity which is mostly action-based posts. In terms of emotional posts, these are the posts that are about specific cases in families or posts concerning the lives specifically of those with Fragile X Syndrome. As for informational posts, these posts are about progress made in research related to Fragile X Syndrome.

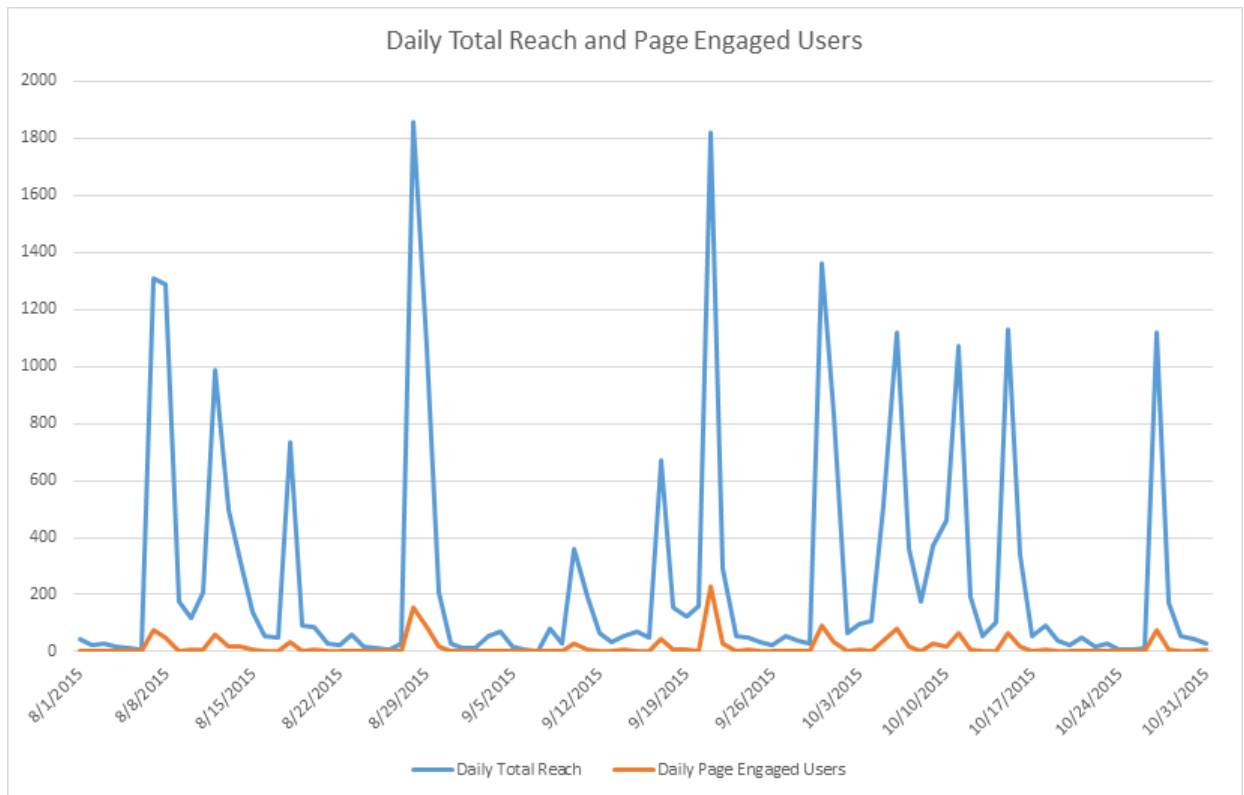


Figure 5.18 - This figure demonstrates the daily number of users who engaged with any of the posts on FRAXA's Facebook page and the daily number of users who saw one of FRAXA's Facebook posts.

Over the timeline of this graph, only a small percentage of the users that FRAXA's Facebook posts reached actually engaged with the posts, as seen in Figure 5.19. On average, 270 users per day were reached by FRAXA's post, while an average of 17 users per day interacted with any of the posts (clicked on a link, "liked", commented, or shared). In total for these three months, 24,266 users were reached and 1,574 users engaged with the posts. This results in an average engagement of just 7% of the users reached per day, with an observed maximum level of engagement of about 30%. This is similar to the trend in Twitter where the average engagement was 2% when compared to how many users saw a post from FRAXA.

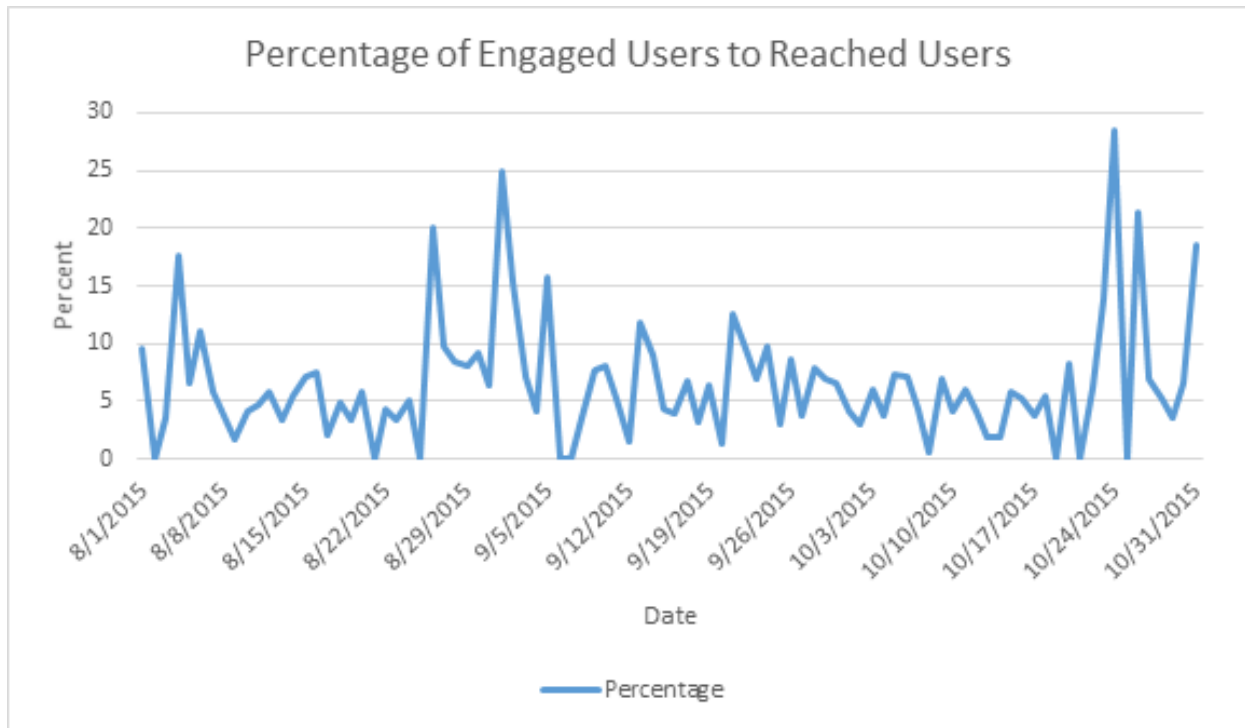


Figure 5.19 - The daily percentage of reached users who engaged with a post. Demonstrates the level of interaction with FRAXA's Facebook posts when compared to the number of users who have seen the posts.

The first of the two largest spikes in Figure 5.18 occurred around August 29-31, 2015, and was most likely caused by the news story posted by FRAXA on August 29 entitled, John and David: The Ultimate Tag Team. This story was about two brothers with Fragile X Syndrome. This post got 26 “likes” on Facebook, 4 shares, and 1 comment. Another post, posted the day before, may have also contributed to this spike. This post was titled, Who Decides Where Autistic Adults Live?, and got 24 “likes,” 19 shares, and 1 comment on Facebook. The second of the two largest spikes occurred around September 21-23, 2015. This is most likely caused by the post on September 21, which was the only post at the time of this spike with a significant level of engagement. This post included

information about FRAXADev, a project formed in France that aimed to develop a new drug for Fragile X Syndrome. The post got 35 “likes,” 15 shares, and 2 comments on Facebook.

There were a number of other popular posts on FRAXA’s Facebook page that were associated with the other spikes in the graph. We defined a “popular” post to be a post that received more than ten likes and shares, respectively. One post included a link titled, Fragile X and Alzheimer’s Research, which got 35 “likes” and 24 shares. Another popular post was about a study concerned with a type of drug and how it affected brain development and got 35 “likes” and 12 shares. A third post, this one concerned with developing treatments for Fragile X Syndrome, got 48 “likes,” 15 shares, and 2 comments. Similar to the posts mentioned above, these posts provide information for the FRAXA community.

Some posts did not receive a high level of engagement and are considered unpopular, meaning that the number of likes and shares of these posts were significantly lower than the number of likes and shares of popular posts. Many of these posts were more general posts; for example, one post included updates on the status of current research, as well as a reference to resources for families. This post received 13 “likes” and no shares or comments. Another post was a reminder about the Fall Event and received 8 “likes.” Both of these posts were uploaded during the time between August 31 and September 21, when the Facebook page was receiving a low level of engagements. Similar trends can be seen on the FRAXA Twitter page, as more general posts, such as those that

include links with no descriptive text, also did not receive a high level of engagement compared to posts that were more descriptive.

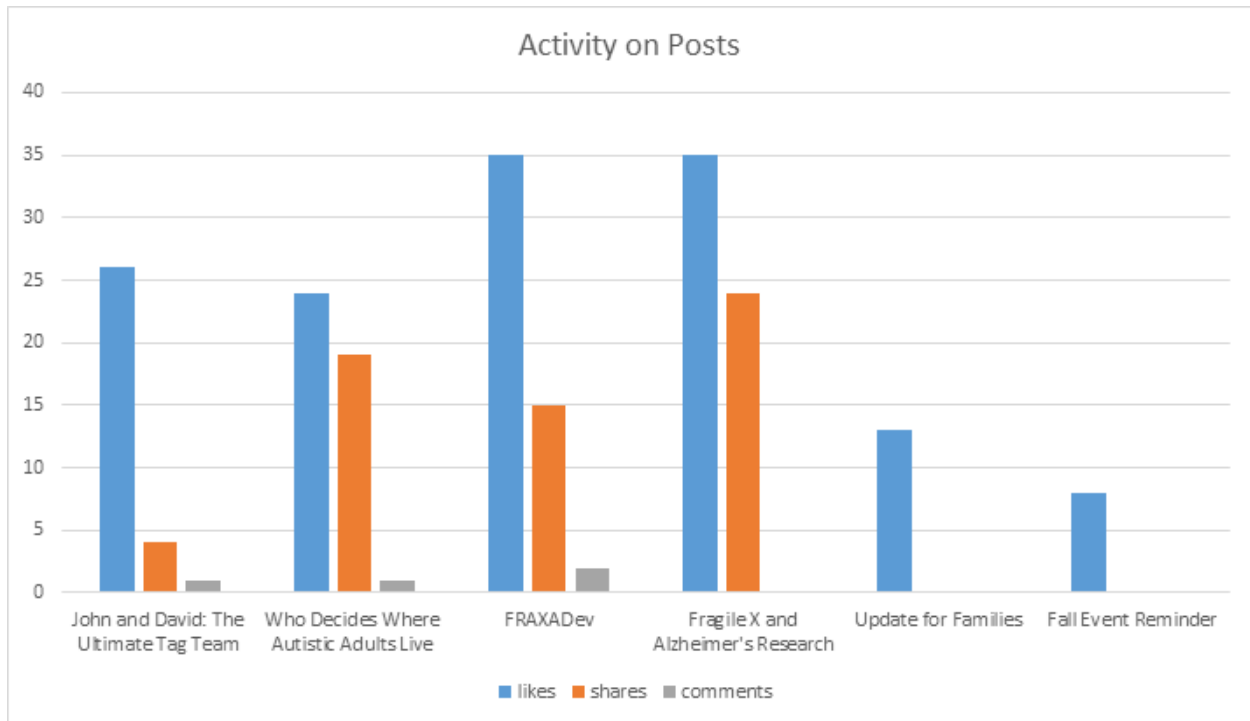


Figure 5.20 - Demonstrates the activity, broken down by likes, shares and comments, on some of the FRAXA Facebook posts.

Figure 5.20 shows the difference in activity between various posts on the Facebook page. For post likes, the “popular” posts have more than double the amount when compared to the number of likes on the “unpopular” posts. The number of shares for the “popular” posts are also generally more than the number of shares that the “unpopular” posts received. As for the comments, all of the posts received close to zero comments.

Looking at the demographics of the Facebook users (Figure 5.21) who have liked FRAXA’s Facebook page, we see that 78% of the users are female and 21% are male. In terms of location, 1,484 users are from the United States. There is a correlation with the Twitter demographics, which had 65% of the followers as female and 35% of the followers

as male. This indicates that the gender of Facebook users and Twitter followers is mainly female. It was determined that 60% of the total page likes come from females of the age group of 25 to 54 years old.

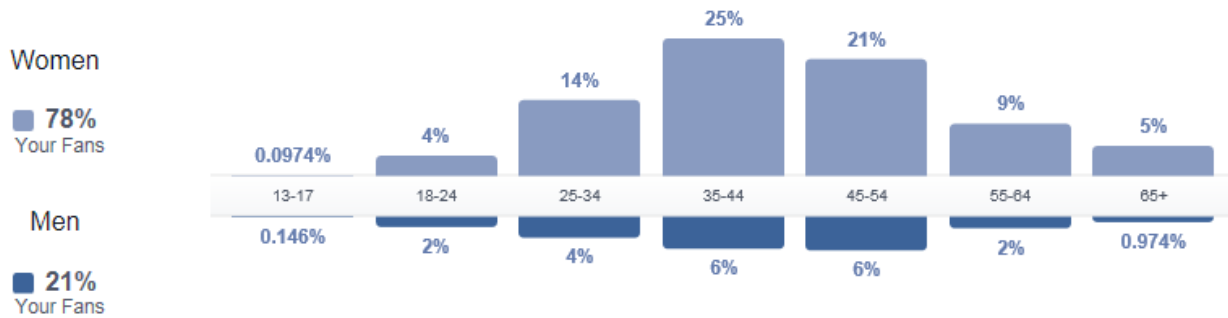


Figure 5.21 - The total number of users who have liked FRAXA's Facebook page, broken down by age and gender.

5.3 YouTube

5.3.1. External Analysis

We performed preliminary analysis on FRAXA's YouTube channel by observing the channel's activities as an external user. We found that FRAXA's page contains 37 videos total. The popularity of videos was based on the total number of views a video has generated. The first video was published on 2007 and the last video was posted on 2013. Table 5.3 demonstrates the exact number of videos posted each year. On average, FRAXA has published two videos per year. Twenty-two of these videos (~60%) were an introduction to FRAXA's team members. Table 5.4 demonstrates the number of videos published from each category. The videos that included stories of people living with Fragile X syndrome were the ones that have generated the highest number of views, likes, and comments. In fact, seven out of the nine most popular videos belong to the "people stories"

category. The most popular video was a ten minute film, “Fragile X- Hitting the Mark”, that describes the situation of living with people with Fragile X Syndrome. The least popular seven videos belong to the “FRAXA’s team” category. Since 2013, FRAXA has not published any new videos.

| Number of Videos | Year |
|-------------------------|--------------|
| 2 | 2007 |
| 2 | 2008 |
| 1 | 2009 |
| 24 | 2010 |
| 2 | 2011 |
| 5 | 2012 |
| 1 | 2013 |
| 37 videos | TOTAL |

Table 5.3 - Demonstration of the number of videos posted each year. In 2010 FRAXA has posted twenty two short videos introducing their team members as well as the doctors that FRAXA work with.

| Number of Videos | Type of Video |
|-------------------------|----------------------|
| 2 | Educational |
| 8 | People Stories |
| 2 | Events |
| 3 | News & Results |
| 22 | FRAXA Team |
| 37 videos | TOTAL |

Table 5.4 - Demonstration of the number of videos posted of each type. Aside from the “FRAXA Team” video category, the number of “People Stories” videos is significantly higher than the other categories.

5.3.2. Demographic Analysis

We analyzed the demographics of FRAXA’s YouTube channel viewers to determine the distribution of views over geographical locations, age, and gender. Figure 5.22 demonstrates the views generated by both genders. We noted that about 62.7% of these views were from females, which is consistent with the gender distribution of FRAXA’s Twitter and Facebook followers.

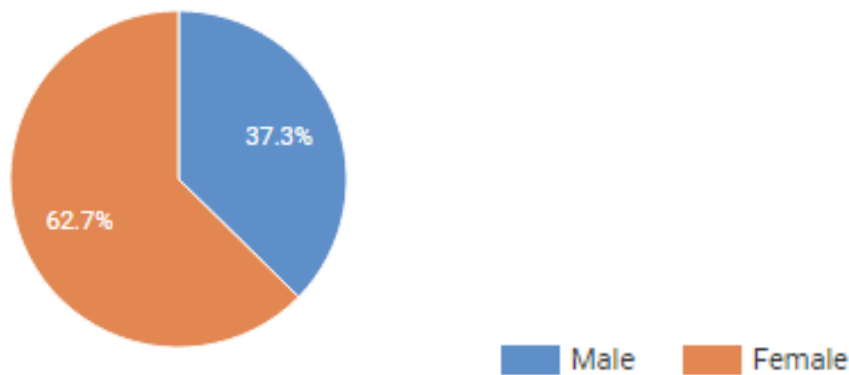


Figure 5.22 - Demonstration of the views percentage generated by each gender. Most of the FRAXA Channel views (62.7%) are generated by females.

As demonstrated in Figure 5.23, the percentage of views generated by each age group from each gender in 2015. Comparing the Facebook number of page likes with the YouTube views in terms of age and gender distribution, we found that there is a strong correlation between the two, as 43% of the YouTube views and 43% of the Facebook page likes are generated by females in the age group between 18 and 44 years. We assume that the females in these age groups are parents with or siblings of children who are affected by Fragile X Syndrome. However, there are more YouTube views generated by females in the

18 to 24 age group than Facebook page likes, while there are more Facebook page likes generated by females in the 45 to 54 age group than YouTube views.

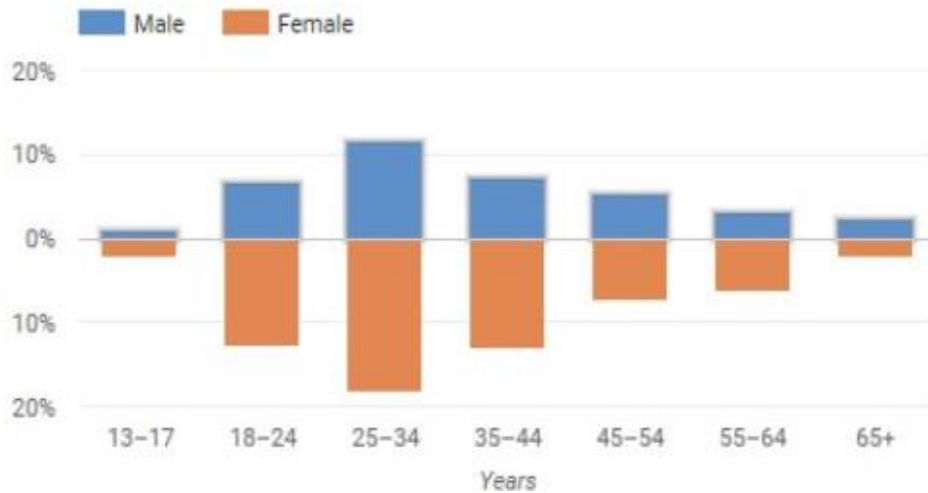


Figure 5.23 - The percentage of the total channel views generated by each age group from each gender, in 2015. 43 % of the views are generated by females between the age of 18 and 44.

Figure 5.24 shows the top ten countries where the FRAXA channel has generated its views. As shown below, the vast majority of these views are from within the United States with a total of 6778 views, which is consistent with Facebook and Twitter.

| < Top locations | Views ↓ | 13-17 | 18-24 | 25-34 | 35-44 | 45-54 | 55-64 | 65+ | Gender | > |
|-----------------|---------|-------|-------|-------|-------|-------|-------|------|--------|---|
| United States | 6,798 | 3.5% | 19% | 30% | 17% | 14% | 10% | 5.5% | | |
| United Kingdom | 770 | 1.4% | 20% | 23% | 29% | 9.5% | 14% | 2.7% | | |
| Canada | 634 | 3.9% | 15% | 27% | 28% | 15% | 5.2% | 6.4% | | |
| Australia | 524 | 3.0% | 16% | 24% | 29% | 12% | 13% | 4.0% | | |
| Netherlands | 275 | 0.0% | 20% | 29% | 18% | 10% | 20% | 2.0% | | |
| France | 170 | 2.1% | 4.2% | 29% | 52% | 6.3% | 6.3% | 0.0% | | |
| Sweden | 147 | 3.6% | 11% | 29% | 32% | 11% | 11% | 3.6% | | |
| India | 136 | 0.0% | 19% | 46% | 27% | 7.6% | 0.0% | 0.0% | | |
| Israel | 132 | 4.5% | 41% | 32% | 14% | 0.0% | 9.1% | 0.0% | | |
| New Zealand | 123 | 0.0% | 27% | 23% | 27% | 0.0% | 23% | 0.0% | | |

Figure 5.24 - The top ten countries from which FRAXA has generated its views. The United States comes in the first place with 6793 views.

5.3.3. Channel Viewership and Traffic Analysis

The FRAXA team was able to grant administrative privileges to the FRAXA YouTube Channel to one of our team members, which gave us the opportunity to conduct further, detailed analysis. The team was able to identify a few important findings that helped us provide more precise recommendations for FRAXA. Some of these findings include the Channel's traffic sources, audience retention, and the number of user engagement (likes, comments, and shares).

The audience retention analysis is an extremely helpful tool that allowed us to determine the ideal video length in order to maximize the number of views. Audience retention refers to average duration of each view and of the channel as a whole. In other words, it is the average number of minutes watched by the users at any given video in the FRAXA Channel. The average view duration of the channel in 2015 was found to be two minutes and thirteen seconds (2:13). This is about 38% of the length of the videos viewed in that year. This means that on average, users only watched 38% of the total length of the video they selected.

Furthermore, it was found that the FRAXA channel has generated twenty shares in total during 2015, as shown in Figure 5.25. The first two shares occurred on March 13, meaning that no shares occurred during the first two and a half months of the year, while the maximum number of shares (three shares) occurred on November 3. This allowed us determine the best times of the year to publish videos.

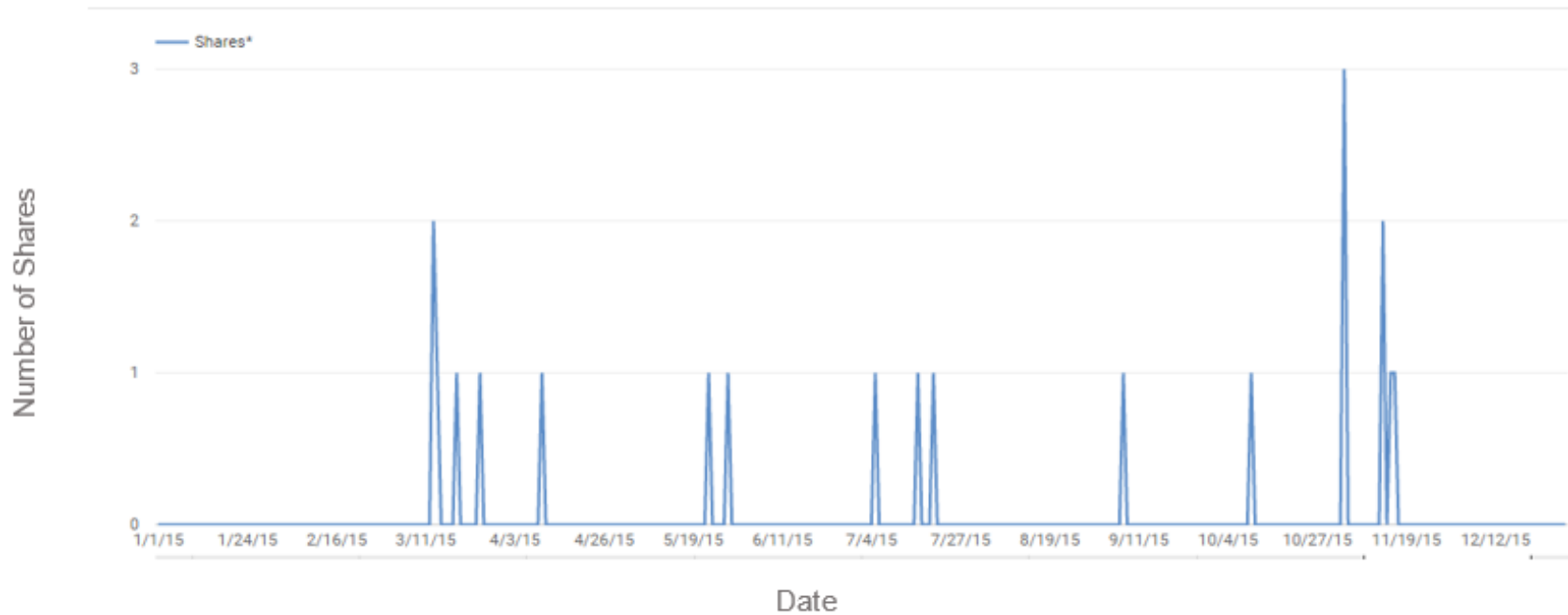


Figure 5.25 - This figures illustrates the number of shares obtained during 2015. The first shares did not happen until three months after the beginning of the New Year.

The Watch Time term refers to the number of minutes that the channel has been viewed in one day. As shown in Figure 5.26, the first two shares generated the highest number of Watch Time in 2015. The spike shown in the figure below, which is 721 minutes, occurred the day after the two shared. However, the three shares that occurred on November 3 did not have any effect of the Watch Time minutes. This might indicate that the website or page to which the videos have been shared have a significant impact on the channel Watch Time.

Traffic Source is another significantly important analysis tool that can enable us to optimize delivering the videos to the right audience using the right tool (e.g., Facebook, Twitter, Instagram). As Figure 5.27 shows, there are a few sources from which the FRAXA Channel obtain its views. Some of these sources are external or unknown, referring to any website that is not YouTube. The majority (over five hours) of the Watch Time minutes corresponding to the spike are from external sources, which as mentioned earlier can refer to any external website such as Facebook or Twitter.

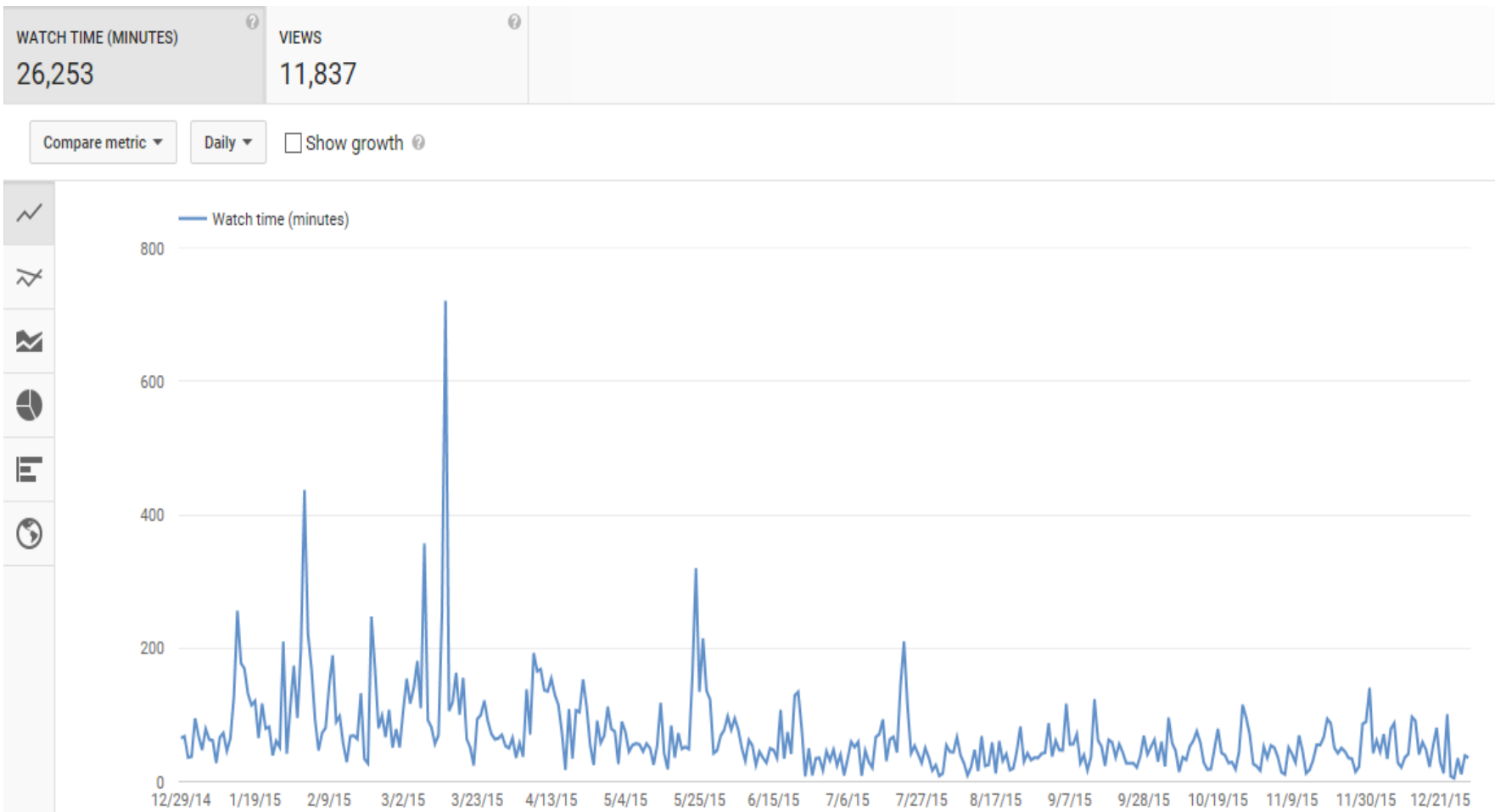


Figure 5.26 - This figure demonstrates the total watch time in minutes during 2015. The spike occurred the next day that the shared happened

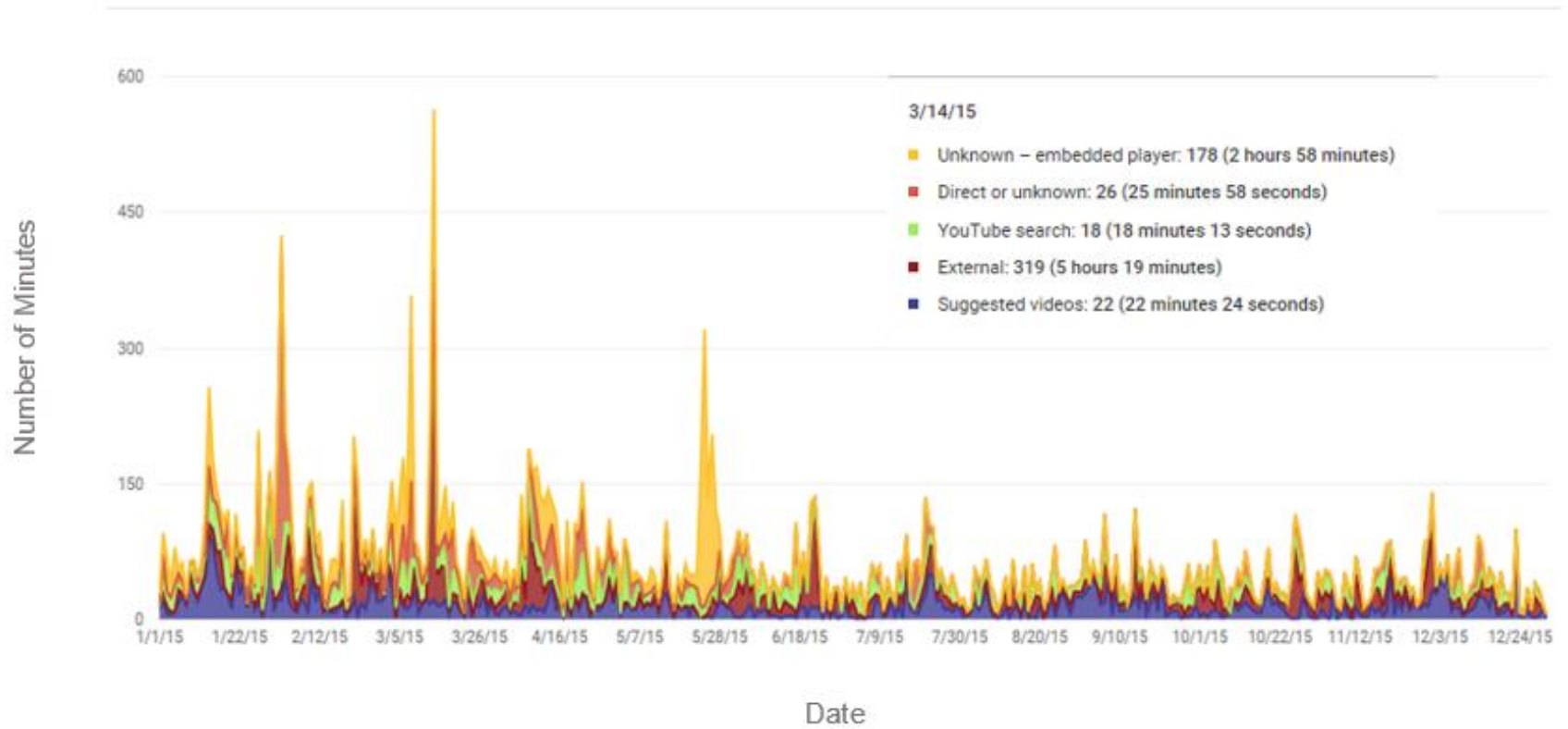


Figure 5.27 - This figure demonstrates the traffic source during 2015. The legend summarizes the sources that correspond to the spike generated due to the first two shares in 2015.

5.3.4. YouTube Experiment

We created a YouTube experiment to test the popularity of informational and community/emotional videos to see which videos were more popular. This experiment used two videos, one of each type: Community and Informational. We titled the videos: “What is Fragile X Syndrome? A short history with Dr. Mark Bear – FRAXA” and “Journey Through Fragile X Syndrome – FRAXA”. The informational video, “What is Fragile X Syndrome?” was a description of a short history of Fragile X Syndrome and its pathology as described by Dr. Mark Bear at his address to the Congressional Biomedical Research Caucus. The video was two minutes and two seconds long with tags for Fragile, Fragile X, Fragile X Syndrome, and Autism. The emotional/community video, “Journey Through Fragile X Syndrome” was a compilation of photographs and home videos featuring families of children affected by Fragile X Syndrome. This video was two minutes and 45 seconds long with tags for Fragile, Fragile X, Fragile X Syndrome, and Autism. Both the videos have similar hyperlinking to other social media sites for more information, as well as the tagline “Learn more”, which appeared after every 30 seconds of the video, totaling to five taglines per video. Both the emotional and the informational videos were published on YouTube on February 17, 2016 at noon. We also shared the videos on FRAXA’s Twitter and Facebook pages. After ten days, the team obtained the metrics from YouTube and performed analysis using these metrics to determine the results of the experiment. The team compared the metrics obtained for ten days after the video was posted to the metrics obtained for ten days before the video was posted. The data can be seen in Tables 5.5 through 5.7 and in Figures 5.28 through 5.33.

In Tables 5.5 and 5.6, we see that overall, most of the attention and the interaction for both videos occurred from Facebook. The reach on Facebook of the informational video was 5,960 views, while the reach on the Twitter page was significantly lower at 139 views. Views on Twitter represented only 2.28% of the total amount of views on both platforms, while Facebook views represented the other 97.72%. The reach of the emotional video on Facebook was 5,222 views, which contributed to 96.33% of its total views across both platforms; views from Twitter only represented 3.67% of its total.

Due to the nature of YouTube views and engagements, a view on YouTube is not synonymous with a view on Twitter or Facebook, and cannot be compared in the same way. In order to view a video on YouTube, the video must be physically clicked by the user. Thus, the user must engage with the video, making YouTube views synonymous to the definition of engagements on Twitter and Facebook. In terms of engagements, the informational video gained 398 engagements (65%) on Facebook, 5 engagements (0.80%) on Twitter, and 209 engagements (34.2%) on YouTube, for a total of 612 engagements across all three platforms. For the community/emotional video, a total of 768 engagements were recorded for the duration of the experiment. The community/emotional video gained 474 engagements (61.7%) on Facebook, 20 engagements (2.6%) on Twitter, and 274 engagements (35.7%) on YouTube.

On Facebook, the informational video had a greater reach than the community/emotional video. At the same time, the community/emotional video had a greater level of engagement than the informational video. Though the community/emotional video had a lower reach than the informational video, more users who saw the community/emotional video interacted with it, contributing to its higher level

of engagement. Conversely, more users saw the informational video than the community/emotional video; however, fewer users directly interacted with the informational video than with the community/emotional video.

We know from the Facebook Analytics that 67 unique users shared the informational video on Facebook, while 55 unique users shared the community/emotional video. When a Facebook user shares a post, that post becomes visible to all those who are friends with that particular user on Facebook, regardless if those friends follow the FRAXA page. Because the informational video was shared more times than the community/emotional video, the reach potential for that video was higher. However, we cannot definitively say that this is the reason for the higher reach than that of the community/emotional video because not every Facebook user has the same number of friends. On both Twitter and YouTube, the community/emotional video had a greater reach and level of engagement than the informational video.

It is interesting to note that across all three social media platforms, followers of the FRAXA Twitter, Facebook, and YouTube pages interacted with the community/emotional video more than the informational video. It is also interesting to note that the majority of all followers across FRAXA's three social media pages are female. While we cannot definitively say that there is causation between the two data points (the popularity of community/emotional videos across all sites is due to the fact that the majority of FRAXA's followers are female), we can note that there is a correlation between the popularity of community/emotional videos and the higher percentage of female followers on FRAXA's social media pages.

| Informational Video | | |
|-----------------------|---------------------|-------------|
| Social Media Platform | Reach & Impressions | Engagements |
| Facebook | 5,960 | 398 |
| Twitter | 139 | 5 |
| YouTube | 209 | 209 |

Table 5.5 - Results from experiment regarding the informational video, showing the reach and impressions as well as the engagements gained on each social media platform.

| Community/Emotional Video | | |
|---------------------------|---------------------|-------------|
| Social Media Platform | Reach & Impressions | Engagements |
| Facebook | 5,222 | 474 |
| Twitter | 199 | 20 |
| YouTube | 274 | 274 |

Table 5.6 - Results from the experiment regarding the community/emotional video, showing the reach and impressions as well as the engagements gained on each social media platform.

| | | | |
|---|-----|------|-----|
| Journey Through Fragile X Syndrome - FRAXA | 506 | 1:50 | 79% |
| What is Fragile X Syndrome? A short history wi... | 432 | 2:04 | 75% |

Figure 5.28 - YouTube results showing the total number of views and average watch time for each video.

| <input type="checkbox"/> Traffic source ? | Watch time (minutes) ? ↓ | Views ? |
|--|--------------------------|-----------|
| <input type="checkbox"/> External ? | 1,216 (66%) | 637 (64%) |
| <input type="checkbox"/> Suggested videos ? | 372 (20%) | 185 (19%) |
| <input type="checkbox"/> YouTube search | 131 (7.0%) | 76 (7.7%) |
| <input type="checkbox"/> Direct or unknown ? | 77 (4.1%) | 53 (5.3%) |

Figure 5.29 - YouTube results broken down by where the views came from.

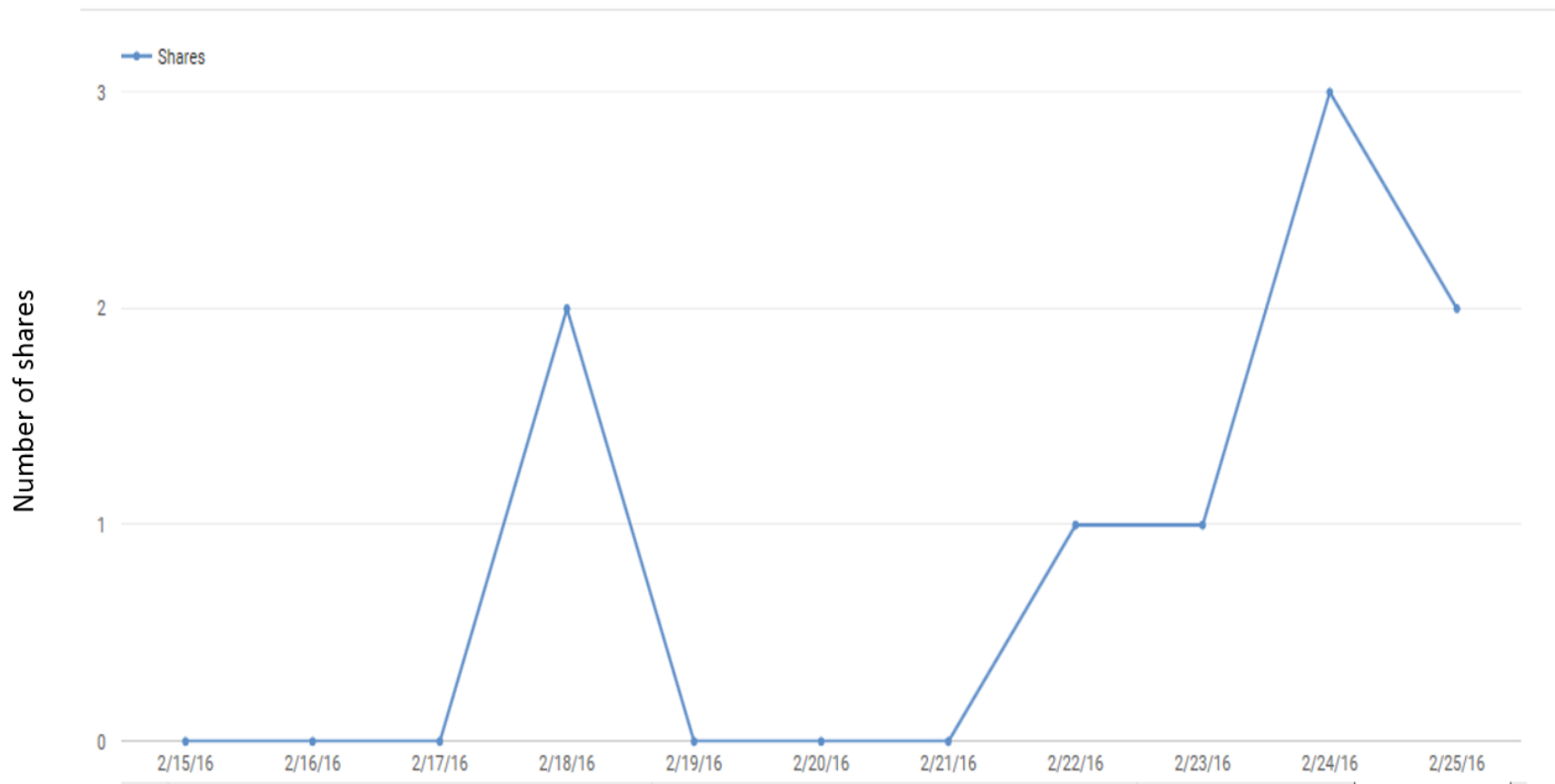


Figure 5.30 - The number of videos shared on the FRAXA YouTube page after the videos were posted.

There were no videos shared ten days before the video was posted, and we found that the number of shares increased with time, which can be seen from the graph above. There were significant shares from the February 21-25, 2016. We observed that the videos already on the FRAXA YouTube page received a maximum of 55 views ten days prior to when the videos were posted, while the new videos received a maximum of 350 views after they were made public.

Figure 5.32 shows that people watched an average of 562 minutes of videos within the time span of ten days before the videos were posted. It was also noted that a maximum of 84 minutes were watched on February 10, 2016. Similarly, we observed from Figure 5.33 that the average watch time increased significantly, with data from the YouTube analytics tool giving the specific values of 89 average minutes watched previously to 1859 average minutes watched by people after the videos were posted.

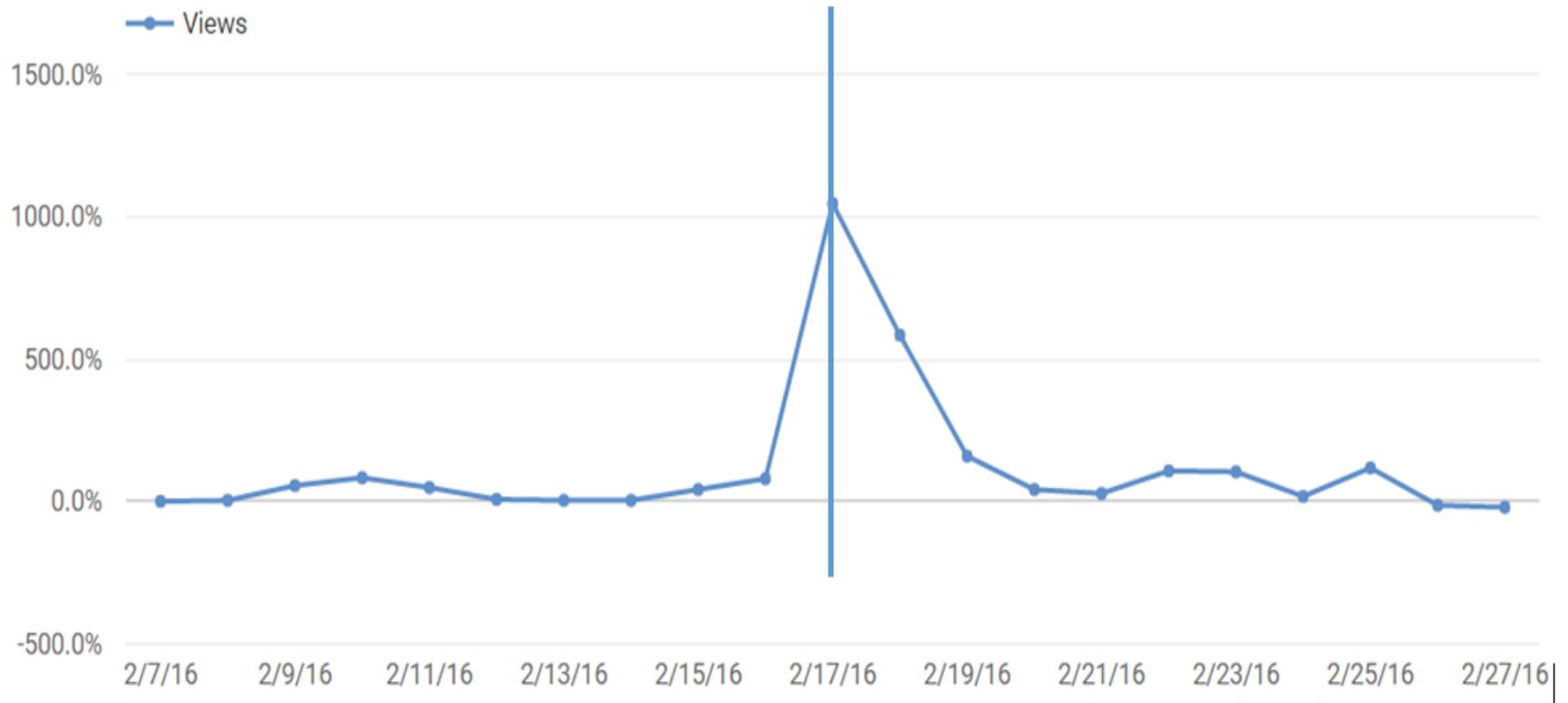


Figure 5.31 - The graph represents the percent change in the number of views FRAXA's YouTube channel received for the duration of ten days before and after the video was posted



Figure 5.32 - Percent change in watch time in minutes of the channel ten days before and after the experimental videos were uploaded.

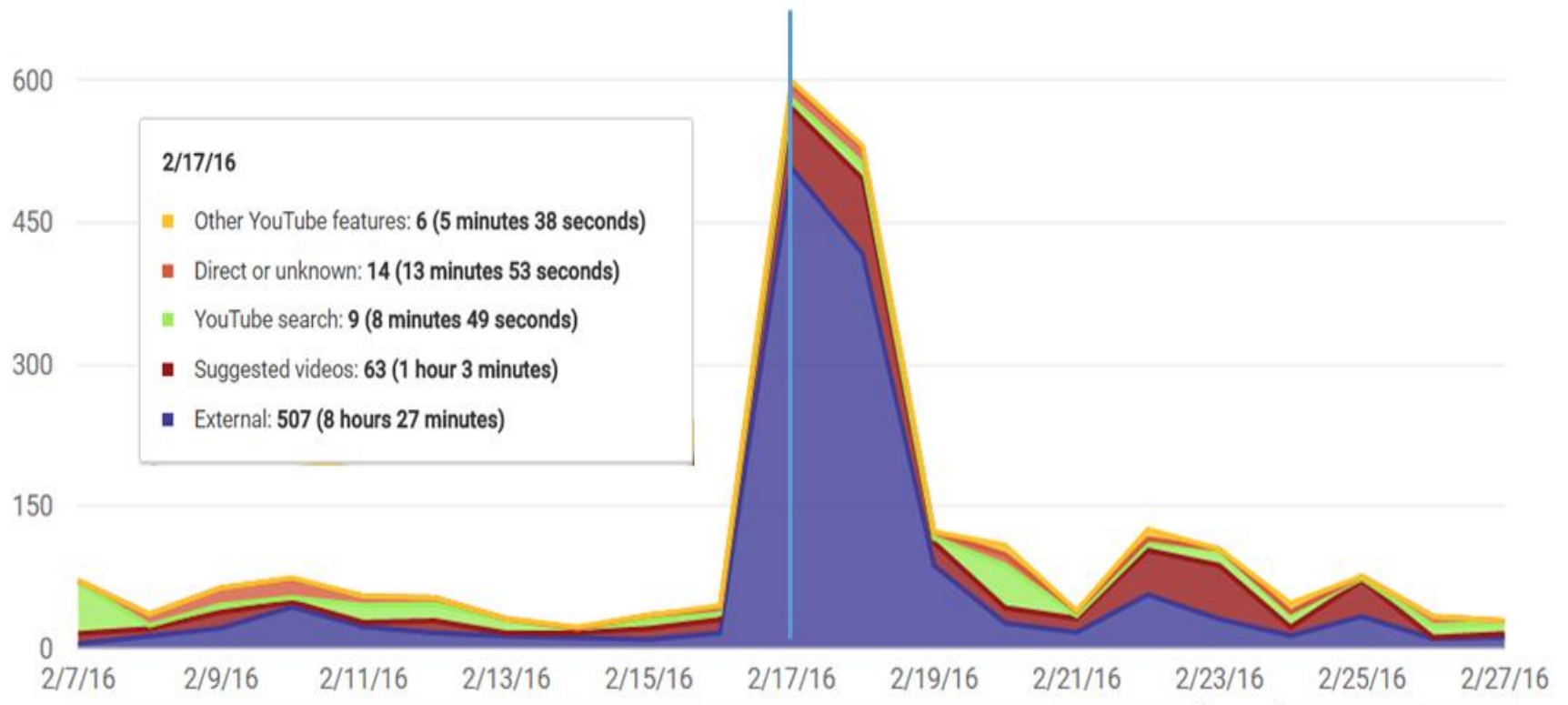


Figure 5.33 - Traffic source graph for ten days before and after posting videos.

Traffic sources indicate how many minutes of FRAXA’s videos were watched on various sources. In the key, “Suggested videos” measures the number of minutes watched when a user was directed to one of FRAXA’s videos via automatic suggestion by YouTube itself. External Sources include any non-YouTube source, such as Facebook and Twitter. We found that before posting the videos, a maximum number of 44 minutes were watched on the external sources. After the videos were posted, the team observed a dramatic increase in the total number of minutes watched on external sources, from 44 minutes to 508 minutes.

In addition to the YouTube experiment above, the team performed a secondary experiment that investigated the differences in engagement between videos that were posted using a YouTube link versus videos that were posted directly to social media, without a link. A video was uploaded directly to Facebook and Twitter, in a process called embedding, explained previously in Chapter 4. The engagement and reach data collected for the duration of this secondary experiment are shown in Table 5.7 below.

| | Reach/Impressions | Engagements |
|----------------------------|--------------------------|--------------------|
| Embedded - Facebook | 1,887 | 137 |
| Embedded - Twitter | 414 | 24 |
| YouTube | 168 | 168 |

Table 5.7 - Results from the second part of the experiment regarding the embedded video, showing the reach and impressions as well as the engagements gained on each social media platform.

The embedded video on Facebook reached 1,887 users and received 137 engagements, while the same video embedded to Twitter reached 414 users and received

24 engagements. On YouTube, the video was clicked on and viewed 168 separate times. Based on this experiment, we find that embedding videos on Facebook generates more activity and reaches more users than embedding videos on Twitter and solely uploading videos to YouTube.

Meanwhile, in comparison to the videos posted to the FRAXA YouTube, Twitter, and Facebook pages during the first part of the experiment, the embedded video received far fewer impressions and engagements on Facebook, but a higher number of impressions and engagements on Twitter, which can be seen in Tables 5.5 and 5.6. However, when a link is posted to both Facebook and Twitter, the engagement data acquired through the YouTube page are higher than for videos that were solely embedded on social media. This is most likely due to the nature of embedded videos, whose metrics on Twitter, Facebook, and YouTube are independent of one another. When a video is posted to Facebook or Twitter using a link, it directs the user to the FRAXA YouTube page, where the video is located, which generates activity for the YouTube page. However, when a video is embedded to Facebook or Twitter, the user is not redirected to YouTube, as the video is located on Facebook or Twitter as well.

5.4 SWOT Analysis

The team analyzed FRAXA's operations and strategies by crafting a SWOT analysis for the organization. The analysis consisted of questions regarding the strengths, weaknesses, opportunities, and threats for FRAXA. The purpose of these questions was to help understand FRAXA in more depth. Based on the telephone conversation with Ms. Melissa Budek, one of FRAXA's staff members, the team summarized the information into a SWOT chart consisting of FRAXA's strengths, weaknesses, opportunities, and threats

(Figure 5.34). In addition, we have created a graphical representation that highlights the most important points of this conversation (Figure 5.34).

In order for an organization to grow, it is essential to recognize and evaluate its internal strengths. FRAXA, a twenty-year-old organization, was started by FRAXA's strongest assets Katie Clapp and Dr. Michael Tranfaglia. Ms. Budek explained that Dr. Tranfaglia is the backbone of FRAXA, and he communicates between the researchers and the organization about on-going drug trials to find a cure for Fragile X. According to Ms. Budek, to date FRAXA has funded twenty five million dollars dedicated to research for finding cure for Fragile X Syndrome. FRAXA also has thousands of families who actively take part in fundraising and Fragile X clinical drug trials. Ms. Budek also added to the strengths by mentioning that, "We have one single focus – to find a cure for Fragile X – that's our mission". Ms. Budek also added to FRAXA's strengths by mentioning, "Katie was on a few boards with other nonprofits and she worked with developmental disabilities in that aspect, but as far as running a nonprofit, we just started from scratch". Ms. Budek concluded the introductory portion of the interview by stating: "We have a small base here but we try to keep it that way so that we can get as much of our income right into research expenses". The team also established that FRAXA is goal-oriented and does its best to avoid unnecessary spending.

Despite these strengths, FRAXA has its shortcomings too. One of the biggest weaknesses of FRAXA is grant writing. Ms. Budek mentioned, "I've done a little bit of grant writing but I never really got any experience on that". She also added that FRAXA does not have enough time, experience, or resources, which, as discussed in Chapter 2, are some of the factors that the organization lacks. Though grant-writing is an issue for FRAXA in

regards to funding more research, it falls outside of the scope of this project. As indicated in Figure 5.34, Ms. Budek had also identified social media as a potential weakness of the organization.

Ms. Budek further explained by saying, “All of us here are older, so all these newer media and changes going on in the world have been a challenge for us since we are a small group and we have our job to do, so that’s definitely something that we need”. Ms. Budek expressed concern that with the growing popularity of social media, FRAXA is facing difficulties keeping up with social media trends, as FRAXA does not intend to increase their staff in the near future. Currently FRAXA’s staff includes two full time and two part time employees, limiting the amount of experience and the amount of time they can put into improving their social media presence. However, Ms. Budek noted that, though FRAXA has been responsible with its spending thus far, the FRAXA team worries that the addition of new employees may lead to unnecessary spending, particularly in the form of training. Thus, balancing the number of employees with spending is an area that Ms. Budek believes FRAXA must monitor in order to prevent diversion from its mission.

During the conversation, Ms. Budek also pointed out a few opportunities for FRAXA, including fundraising. She explained by saying:

Every year on February 1, we have all these grants that come in, and we fund as many as we can, but there are some that we just can't fund because we don't have the income...So I think that definitely if we had more fundraising, we could meet our goal by being able to support more of those grants.

Another opportunity Ms. Budek listed was that FRAXA could further increase its audience by including families affected by Autism Spectrum Disorders. Though Ms. Budek did not explicitly say what her reasoning was behind her claim, we believe that she was referring

to the biological connection that exists between Fragile X Syndrome and autism, as Fragile X is the most common known cause of Autism. Ms. Budek noted that FRAXA does have families in its community that are not related to Fragile X Syndrome but are related to Autism Spectrum Disorders, and that FRAXA works to solidify “that interrelation with Autism and Fragile X”.

Furthermore, Ms. Budek suggested FRAXA could possibly benefit by getting in touch with other organizations like National Fragile X Foundation. This would help FRAXA improve its interactions with its audience by providing them with the information about doctors in different states. Ms. Budek also stated one of the ways FRAXA can provide this missing link between the organization and its audience is by reaching out to the National Fragile X Foundation. During the conversation, Ms. Budek also stated that, “There’s one other foundation, the National Fragile X Foundation – they do more of helping families find locations for doctors in their state, while we’ve been working mostly on the research part of it, so mostly all our funds go straight towards research”.

As a part of the SWOT analysis, it is important to acknowledge threats an organization may face. When asked about potential threats to FRAXA, Ms. Budek replied by saying:

For a nonprofit, I don’t know if competitors is the right word – even with the National Fragile X Foundation...we don’t really call them competitors, because any information that we have we share because we’re all working on a team to find a cure for Fragile X and help Fragile X families. However, she believes that the income from the donors gets divided between FRAXA and the National Fragile X Foundation since people get confused about where to donate between the two. Ms Budek added by saying, “So I would say that our obstacles include raising more money, getting fundraising, and getting more companies to invest in us”.

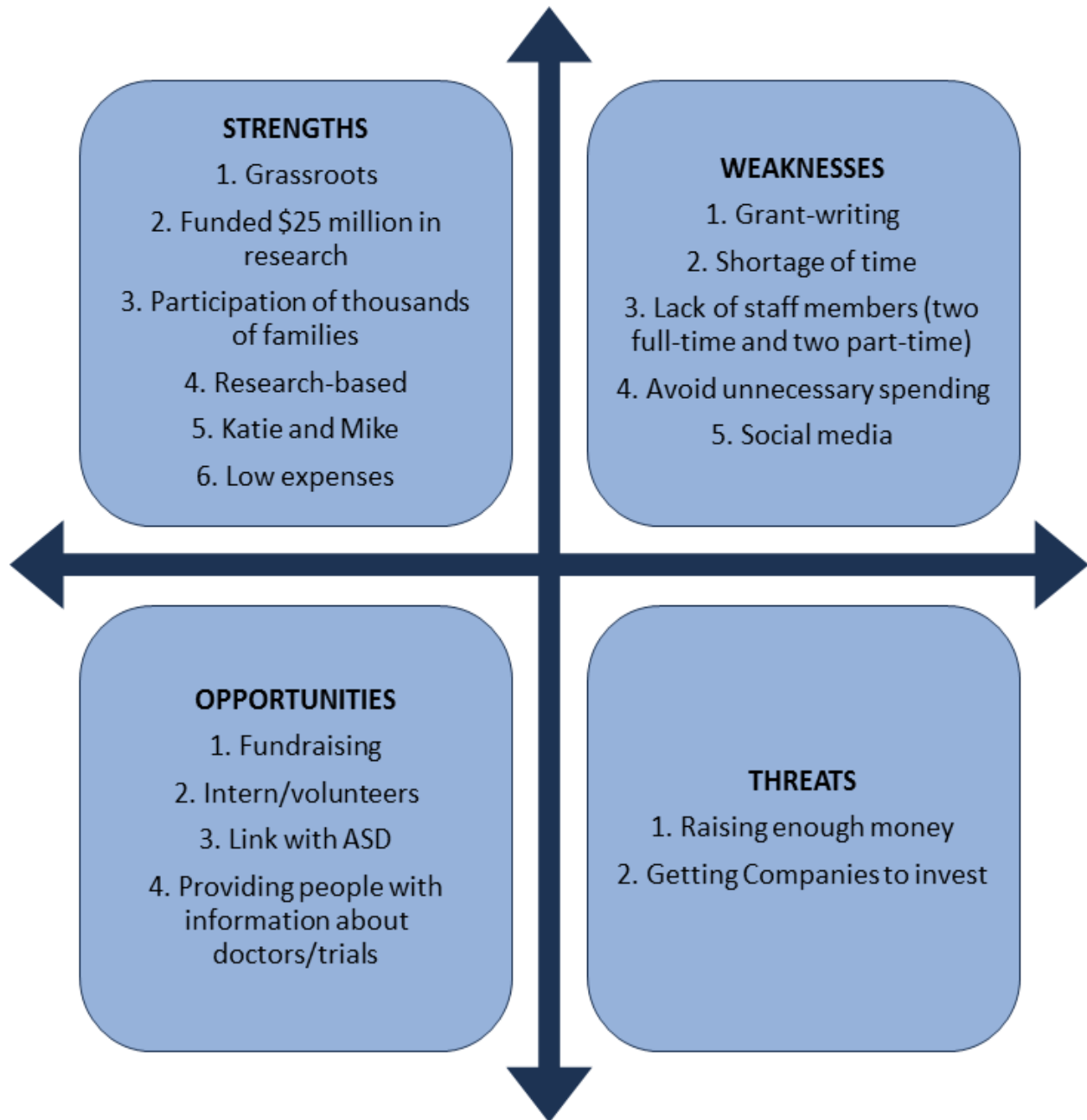


Figure 5.34 - This figure is a summary of FRAXA's SWOT analysis. It depicts FRAXA's potential strengths, weaknesses, opportunities and threats.

6. Recommendations

During the course of this project, our team researched business models and social media use employed by nonprofit organizations in order to develop a system of methods to assess FRAXA's current social media use. Through the process of working with the FRAXA Research Foundation and employing these methods, we were able to obtain results that allowed us to provide recommendations to assist FRAXA in the future expansion of its social media outreach. Our recommendations include suggestions to assist in time management, post content, and post management to help keep FRAXA's current followers engaged, as well as ideas on how FRAXA can expand its social media presence in the future.

Due to the small size of FRAXA's staff, the organization is at a disadvantage in terms of promotion through social media, as it does not have the capacity to have an employee dedicated to social media outreach. However, social media plays an important role in the distribution of information and raising awareness for a cause in today's society (as discussed in Chapter 3), and therefore cannot be ignored despite the challenges that successful integration may pose. Thus, in the interest of pursuing a more robust social media presence, we strongly recommend the use of cross-posting using tools built into social media sites, as well as third party applications like If This Then That (IFTTT), explained in the methodology section in Chapter 4. Cross-posting is a term that refers to posting the same or similar messages across all social media platforms at the same time. By cross-posting information, FRAXA can ensure that all of its followers are receiving the same information, regardless of whether those social media users follow them on just Facebook or Twitter. Additionally, by employing the use of built-in tools and third party applications, FRAXA can reduce the amount of time that its employees need to spend on social media

strategies in order to meet their social media goals. On Facebook, a manager or admin of a particular page can effectively “link” that page with a specified Twitter account and control which posts are cross-posted on both platforms. A step-by-step guide for linking Facebook and Twitter accounts is provided in Appendix D.

In addition to the built in tools that allow a user to link their Facebook and Twitter accounts, the use of third-party applications makes it easy to link other social media accounts to one another and manage the interactions between them. IFTTT is one such application. Explained in detail in Chapter 4, IFTTT is a web and mobile application that allows the user to create “recipes” that link multiple social media accounts together to perform specific tasks. IFTTT works with over 100 different applications and sites, including Facebook, Twitter, and YouTube, which are the main focus points of this project. IFTTT will significantly cut the time required to update FRAXA’s various social media accounts without hindering the rate at which information is spread about FRAXA through social media platforms. The steps in Appendix B demonstrate how to create an account and begin creating recipes on IFTTT using Facebook and YouTube.


Based on the results gathered from both parts of the YouTube experiment, we have found that the total number of likes on FRAXA’s Facebook page and the total number of followers on FRAXA’s Twitter page increase every time a post is published. Therefore, in addition to cross-posting, we recommend that FRAXA post more frequently on Facebook and Twitter in general. Keeping in mind FRAXA’s time constraints, the team recommends the use of scheduled posts on Facebook in order to help increase the frequency of posts while managing time effectively. We recommend that a member of FRAXA’s team, whether s/he be an employee or a volunteer with administrative access to the Facebook page,

allocates an hour of his/her time each week to schedule upcoming posts. This will provide Facebook users who follow the FRAXA Facebook page with new posts periodically, without the need for the FRAXA team to find time to create multiple posts throughout the week. Additionally, FRAXA can use this publishing tool to schedule posts on days and at times when engagements are highest. Figure 6.1 below outlines the instructions for scheduling posts on Facebook.

How do I schedule a post for my Page?

You can create a post and schedule it to publish on your Page in the future. Keep in mind that all times correspond to the current time zone you're in.

To schedule a post:

1. Start creating your post at the top of your Page's Timeline
2. Click  next to **Publish** and select **Schedule**
3. Below **Publication**, select the date and time when you want the post to publish
4. Click **Schedule**

Note: You can't schedule a post from your personal Timeline.

Figure 6.1 - Facebook's instructions for creating scheduled posts on a Facebook Page.

The Facebook page is arguably the most important social media platform for FRAXA to maintain, as more people are connected to FRAXA through Facebook than through Twitter or YouTube. Compared to the 2,070 people who follow FRAXA on Facebook, the FRAXA Twitter page only has 837 followers and the YouTube page has only 119 subscribers.

Other general recommendations across the various social media platforms include employing the use of hashtags where appropriate, using more descriptive language in posts, and posting original content. Hashtags on Twitter allow a user to easily find and

follow posts that relate to a specific topic of interest, as a hashtag marks a post as being about a certain topic. Hashtags generally follow the main text of a tweet and always begin with the pound sign (#). Employing the use of hashtags can help FRAXA expand their follower-base on Twitter by making their tweets visible to those who are not currently following them but are interested in topics similar to Fragile X Syndrome. Shown in Figure 6.2 below is a tweet that the FRAXA account posted that represents model hashtag use. Not only was the relevant phrase #FragileX used, but #BostonBruins was also used, which can help link those who search for the Boston Bruins on Twitter to this tweet, generating a greater reach for this post.

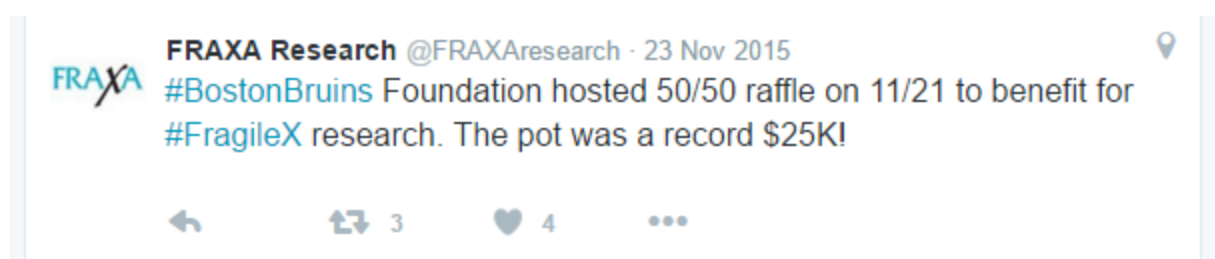


Figure 6.2 - Example of a tweet that represents model hashtag use posted by the FRAXA Twitter account on November 23, 2015, accessed April 12, 2016 from twitter.com

In 2015, FRAXA used hashtags on 18 different tweets, out of the total 69 tweets that were posted. Tweets using hashtags received an average of 17 engagements and 786 impressions per tweet, while tweets that did not use hashtags received an average of 13 engagements and 591 impressions per tweet. Thus we recommend using hashtags more frequently in order to increase the amount of impressions that each tweet receives, which can increase the size of FRAXA's audience and reach. A list of relevant hashtags and guidelines for hashtag use can be found in Appendix E.

Moreover, all posts on Facebook, Twitter, and YouTube can benefit from descriptive titles and language. Posting more descriptive titles and summaries on YouTube videos can help a subscriber determine whether they would be interested in the video. Similarly, posting descriptive but brief summaries on Facebook and Twitter posts that include links to articles help the followers determine what the link is referring to (article, blog, video) and can also help them determine whether they would be interested in the content. Specific to YouTube, we recommend including the word “FRAXA” at the end of the title when publishing a video (for example, “Journey through Fragile X Syndrome - FRAXA”), as this would allow users to find the video simply by searching for the name of the organization. Furthermore, original content is more likely to receive a higher amount of average engagements per post, as shown by our data in Chapter 5. Thus, we suggest that FRAXA focuses on producing mostly original content with descriptive language that helps connect the content to their followers more directly.

Furthermore, this project also focused on FRAXA’s audience and their relationship to post content. On Twitter, we observed a trend in which both informational and community-driven posts received a majority of the users’ engagements. As discussed in Chapter 5, on Twitter, informational and community posts gained nearly 93% of all engagements in 2015. Similarly, when comparing the data from the YouTube experiment, the informational video gained 398 engagements and the community video gained 474 engagements, while the newly posted, action-based video regarding the upcoming fundraiser received 137 engagements. However, when we determined the average engagement per post type on Twitter, our data showed that action-based tweets actually received more engagements and reached more users than did informational and

community-based tweets. Using this information, we recommend that, in addition to cross-posting and posting more frequently, FRAXA posts more action-based posts in general, so that when those posts are cross-posted to Twitter, the Twitter page is receiving maximum engagement, keeping their audience engaged. Examples of all three post types can be found in Appendix F.

On Facebook, most of FRAXA's followers are interested in gaining new information. While on average 270 users saw one of FRAXA's posts per day, only 17 users actually engaged with the post. None of the posts have more than a few comments, and most of those comments are very general, such as someone thanking FRAXA for posting the content. Thus, we conclude that FRAXA's Facebook followers treat the FRAXA Facebook page as a source of information rather than a forum, and FRAXA should continue to post more informational and community-based content on Facebook.

Furthermore, we found that across all three social media platforms, the majority of FRAXA's followers are female. On Facebook, 78% of FRAXA's followers are female, compared to 65% on Twitter and 63% on YouTube. Though there was no age data for Twitter, the majority of FRAXA's followers on Facebook were between the ages of 25 to 50 years old and the followers on YouTube were between the ages of 18 to 44 years old. This, combined with the predominantly female audience, suggests that most of FRAXA's followers are mothers of children with Fragile X Syndrome. The data regarding post type popularity combined with the demographic data suggests that FRAXA's female followers are more interested in posts and videos with informational or community-driven goals. While we cannot definitively say that women are more likely to enjoy these types of posts, we can say that there is a correlation between the high percentage of engagements on these

types of posts and the high percentage of women that make up FRAXA's fan base. This correlation further supports our recommendation that FRAXA post more informational and community driven posts on Facebook, where the majority of their fan base is located, whilst ensuring that there is enough variety in post type to attract a potential new audience.

In addition to focusing on the type of posts originating from the various social media pages, it is also important to keep in mind the time when the pages' followers are active. On Twitter, the data collected and displayed in the Results in Chapter 5 show that the majority of FRAXA's Twitter followers are minimally active on the weekends and are more active on Mondays and Thursdays during the day. Additionally, through analysis of the other two social media platforms, we have found that user engagement and number of views for any given post drops significantly during the weekend. Although it would be ideal for FRAXA to publish posts throughout the week, members of FRAXA's team are concerned that FRAXA does not have enough content to achieve this goal. Therefore, we strongly recommend that FRAXA publish the majority of its posts biweekly, on Mondays and Thursdays in order to maximize the number of user engagements and total post reach.

Specifically regarding YouTube, we found previously in Chapter 5 that FRAXA's YouTube audience watches only between two to three minutes of any given video, on average. Therefore, we recommend that FRAXA avoid publishing videos longer than three minutes and focus more on producing shorter, high-quality videos, ideally between two and three minutes. Shorter videos should be less time-consuming for FRAXA to create, as less content is necessary. In turn, they are less time-consuming for FRAXA's audience, which makes short videos a more effective method to convey information than longer

videos. The team suggests using the videos created for the first part of the YouTube experiment as models for future videos. Furthermore, a guide detailing best practices in regards to uploading videos on YouTube is included in Appendix G.

Should FRAXA have issues generating content for YouTube, the team recommends reaching out to families and those who host events on FRAXA's behalf for videos and pictures that FRAXA could use to put together short slideshows for the YouTube channel. We suggest that the best way to collect these videos is for FRAXA to create a Dropbox account that allows for anyone with access to the link to upload content that FRAXA can then access. A Dropbox is a site that offers free virtual storage to a user, who can then download or share that content with others. Should FRAXA choose to make a Dropbox for this purpose, we suggest that FRAXA post a link to that Dropbox on its website. This way, those who have videos they would like to share can follow that link and upload those videos on FRAXA's Dropbox account. However, if FRAXA is concerned with multiple users having access to this Dropbox account, FRAXA could make the link available only to event organizers to ensure that appropriate content is uploaded. Furthermore, this link could be posted routinely on social media using scheduled posts.

In terms of video content, data from the YouTube experiments show that across all three platforms, community-based or emotional videos receive more activity from FRAXA's followers than do informational videos, and thus we suggest that FRAXA, if possible, should focus on posting videos with content that is more likely to elicit an emotional response, such as home videos. Additionally, results from the YouTube experiment show that videos that are embedded to Facebook gain fewer engagements when compared to posting a YouTube link to the video. However, on Twitter, the opposite is true; embedded videos

receive more engagements than a simple link to the video on YouTube. Because of this, we cannot conclusively say whether embedding videos is better or worse than posting YouTube links to the videos on Facebook and Twitter, but we can make recommendations that may help increase the reach and engagement of videos on each platform.

While embedded videos did not receive as much attention on Facebook, they do offer the advantage of accessibility. When FRAXA embeds a video to its Facebook page, that video is permanently tied to that page and can be accessed by anyone who follows the page, simply by clicking on the “videos” tab. However, posting links does not offer the same accessibility. Should FRAXA post all of its videos to Facebook using links, followers who would like to access a particular video would have to know when the video was posted and would then have to scroll through FRAXA’s timeline to that particular point in time to find the video link; or, if using the search function, followers would need to know the name of the video or the relevant text associated with the post to find it. This also applies to accessibility on Twitter; however, the difference is that Twitter only accepts uploads up to 30 seconds of embedded video. Should FRAXA have a video it would like to share that is longer than 30 seconds, a link to an external site hosting the video, like YouTube, would be necessary. Thus, we offer FRAXA a few recommendations in regards to embedded and linked videos:

1. Upload videos to YouTube. Embed full-length videos on Facebook and embed the best or most pertinent 30 seconds of the video on Twitter. In the text portion of the post, include the link to the video on YouTube and encourage followers to navigate to YouTube for more full-length videos or information. This option allows for the video to be accessible at any point in the future on all three platforms, while also

including a link should followers want to watch on YouTube rather than on Facebook or Twitter.

2. If lack of time is too large of a factor, upload videos to YouTube. As in option 1, embed the best 30 seconds of the video on Twitter while posting the YouTube link to Facebook. This option ensures that FRAXA is still getting benefits from the link popularity on Facebook and the embedded video popularity on Twitter while saving some time.
3. If time availability and expertise are obstacles, continue to post YouTube links to Facebook and Twitter as was done previously.

In summary, data collected during the research phase of this project allowed our team to provide FRAXA with multiple recommendations in order to help improve its social media strategy. Below, in Table 6.1, is a summarized list of these recommendations and their respective social media platforms:

| Recommendation | Social Media Platform |
|--|------------------------------|
| More frequent posting | All |
| Cross-post between platforms (IFTTT) | All |
| Descriptive titles and language in posts | All |
| Post organic content as often as possible | All |
| More informational/community-based posts | Facebook |
| More action-based posts | Twitter |
| Post on Mondays and Thursdays | All |
| Increase hashtag use | Twitter |
| Schedule multiple posts in advance | Facebook |
| Embed videos and post links in description | Facebook, Twitter |
| Create a Dropbox to store user-generated content | YouTube |

Table 6.1 - List of recommendations provided in this section and the relevant social media platform.

Beyond the scope of this project, we strongly recommend that FRAXA continue to connect Fragile X Syndrome with autism research. As discussed in Chapter 5, emphasizing the connection between Fragile X Syndrome and Autism Spectrum Disorders could offer FRAXA opportunities for collaboration with other nonprofit organizations as well as raise awareness of the disease among a larger audience. If FRAXA were able to connect their mission of finding a cure for Fragile X more concretely with other organizations whose goals are similar – though more focused on Autism Spectrum Disorders – by strategic use of relevant hashtags and articles, FRAXA would be able to raise more awareness about the connection between Fragile X Syndrome and autism, and thus gain more support for FRAXA’s efforts.

Finally, we suggest that FRAXA offers volunteer opportunities to students pursuing secondary and postsecondary education looking to fulfill community service requirements, or as summer internships. Because younger people are more familiar with social media than older generations, FRAXA can save time training volunteers and continue to keep expenses low by offering volunteer positions that can fulfill educational institutions' community service requirements or provide relevant work experience to students. FRAXA can use the deliverables we have created for this project as a social media guide for potential future employees and volunteers. With these resources, and with the professionals, volunteers, families, and followers dedicated to raising awareness of Fragile X Syndrome, we believe that the FRAXA Research Foundation can accelerate towards their goal of finding a cure for Fragile X Syndrome.

7. Appendices

7.1. Appendix A – Questions to Guide SWOT Analysis

The analysis questions are broken down into four sections: strengths, weaknesses, opportunities, and threats. These questions serve to guide both the project team and Katie Clapp, President and Co-Founder of FRAXA, in completing a SWOT analysis of the FRAXA Research Foundation.

Strengths

1. What aspects of FRAXA are you most proud of? What makes FRAXA unique?
2. What are FRAXA's assets and which assets are the strongest?
3. What advantages does FRAXA have over other, similar nonprofit organizations?
4. Does any member of the FRAXA Team have previous experience working with nonprofit organizations?

Weaknesses

1. In which areas do you wish FRAXA could do more?
2. What are some things that FRAXA needs to avoid?
3. In which areas do other nonprofit organizations have advantages over FRAXA?
4. What kinds of experience or knowledge are you, volunteers, and FRAXA lacking?

Opportunities

1. What external changes could bring opportunities to FRAXA and help meet its goals?
2. How large is FRAXA's audience? Can FRAXA take advantage of other audiences?
3. Can FRAXA provide any missing links between the Foundation and its audience?
4. How can funding and grants affect FRAXA's mission?

Threats

1. Does FRAXA have any potential competitors?
2. What are the current obstacles FRAXA faces in completing its mission?

7.2. IFTTT Guide

The following is a guide created to help FRAXA connect its social media accounts using the third party service, If This Then That (IFTTT).

1. Open Facebook and YouTube in two separate tabs on the same window and log into each site.
2. Open a third tab and navigate to ifttt.com. The screen should look like the image in Figure 7.1.
3. Click on the “Sign Up” button in the top right corner.

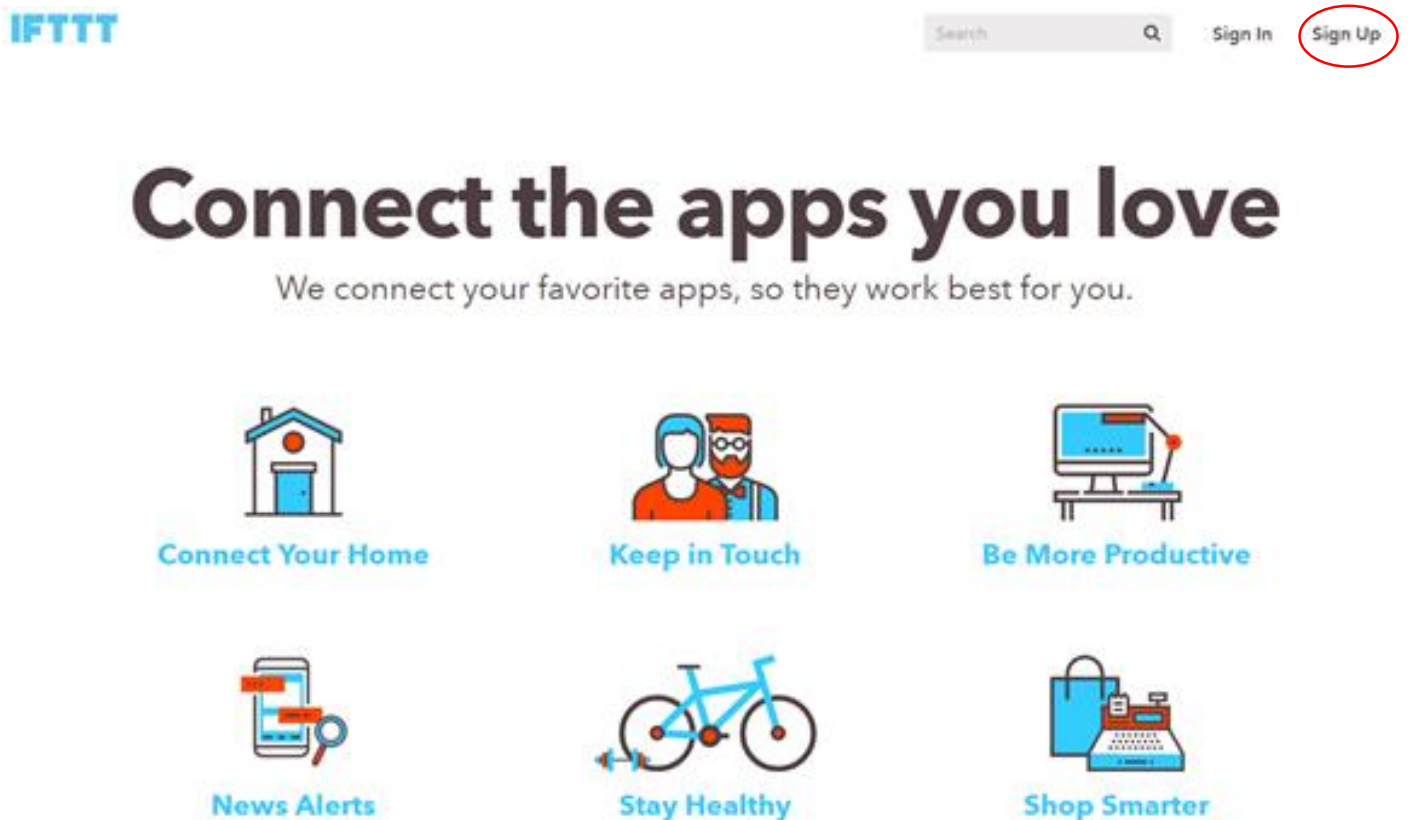


Figure 7.1 - IFTTT homepage, retrieved March 28, 2016 from ifttt.com

4. Follow the on-screen instructions to create an account with a username and password of your choice. When you are satisfied, click the blue “Create account” button.
5. The next screen should look like the image in Figure 7.2. This begins the tutorial. Follow the on-screen instructions through the short tutorial.

IFTTT

Make powerful connections with a simple phrase:



Figure 7.2 - Start of the tutorial detailing how to create recipes on IFTTT, retrieved March 28, 2016 from ifttt.com

6. Once the tutorial is complete, you should be redirected to the IFTTT home page. Click on “My Recipes” at the top of the screen next to the search bar. You should be redirected to your Recipe page.

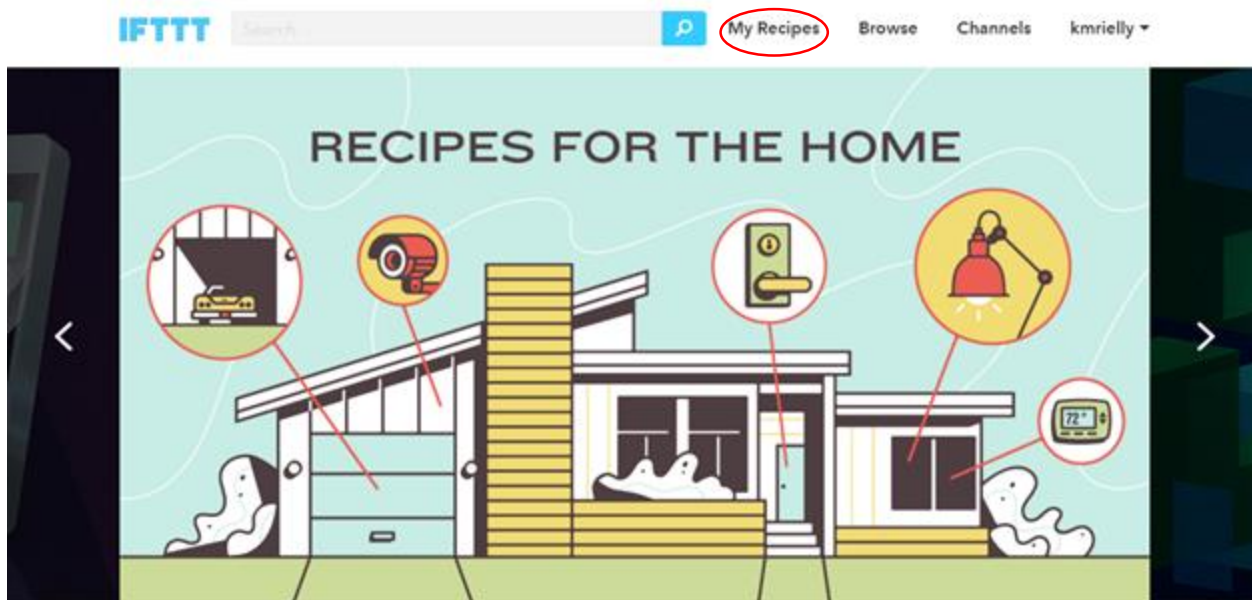


Figure 7.3 - Home page of IFTTT after account creation, retrieved March 28, 2016 from ifttt.com

7. On your Recipe page, click the blue “Create a Recipe” button on the right side of the screen.

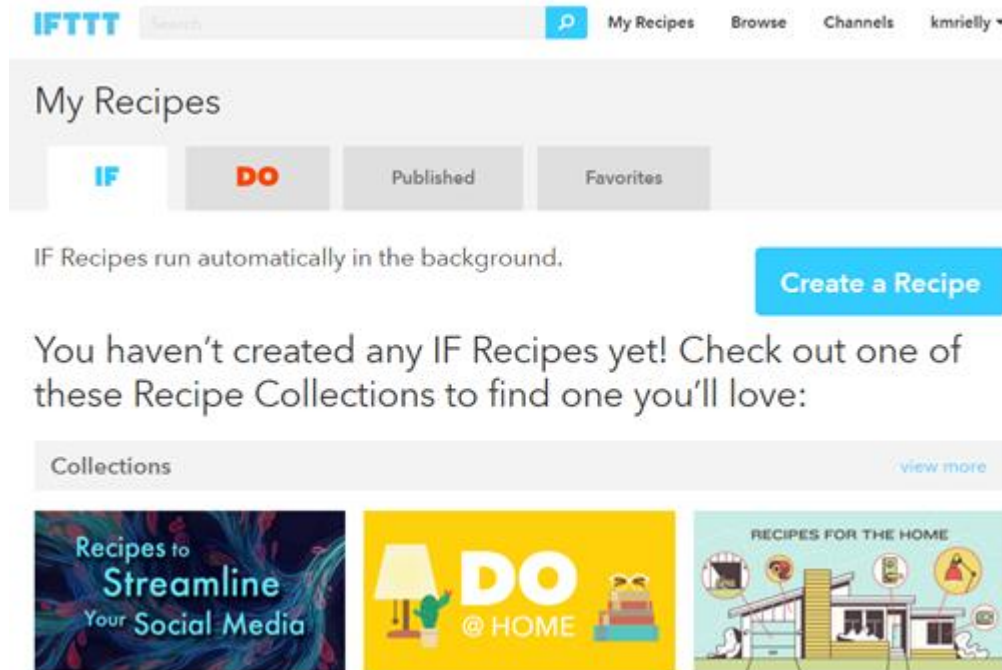


Figure 7.4 - "My Recipes" page on IFTTT, retrieved March 28, 2016 from ifttt.com

8. Once redirected to the recipe creation page, shown in Figure 7.5, click on the blue, underlined "this" button. The "this" button opens a list of Trigger Channels that you can choose from. Channels represent your social media platforms, and Trigger Channels are those that begin an "If-this" statement. An example of this list is shown in Figure 7.6.

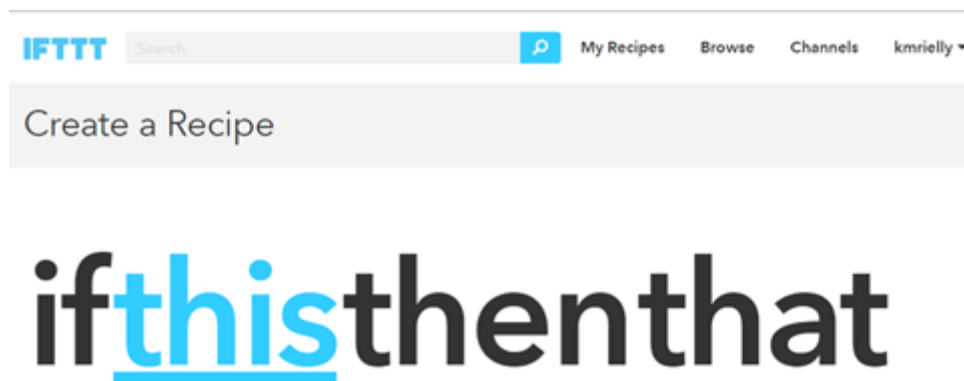


Figure 7.5 - Recipe creation page of IFTTT, retrieved March 28, 2016 from ifttt.com

Choose Trigger Channel step 1 of 7

Showing Channels that provide at least one Trigger. [View all Channels](#)

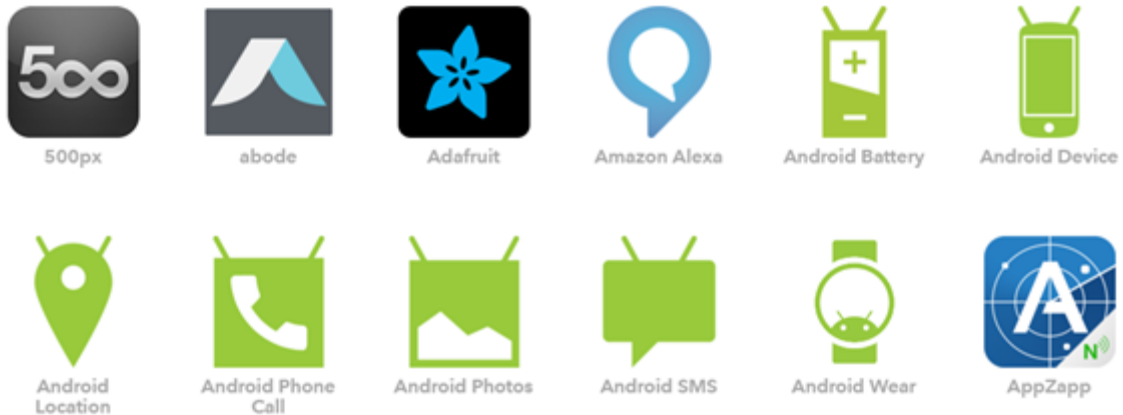


Figure 7.6 - Trigger Channel page of IFTTT, retrieved March 28, 2016 from ifttt.com

9. Type “YouTube” into the search bar and click on the YouTube icon, shown in Figure 7.7.

Choose Trigger Channel step 1 of 7

Showing Channels that provide at least one Trigger. [View all Channels](#)



Figure 7.7 - Example of searching for a Trigger Channel on IFTTT, retrieved March 28, 2016 from ifttt.com

10. You will be prompted to connect your YouTube account. Click on the blue “Connect” button. A window will pop up asking if you would like to give IFTTT permission to post on behalf of your YouTube account. Click the blue “Allow” button. Another window should pop up alerting you that your YouTube Channel was successfully connected. Click the blue “Done” button. The window should close.
11. On the next page, click the blue “Continue to the next step” button. You should be redirected to a page that asks you to choose a Trigger, which is an event that occurs on that particular account that begins the “If-this-then-that” sequence. Click on the “New public video uploaded by you” button and click the blue “Create Trigger” button.

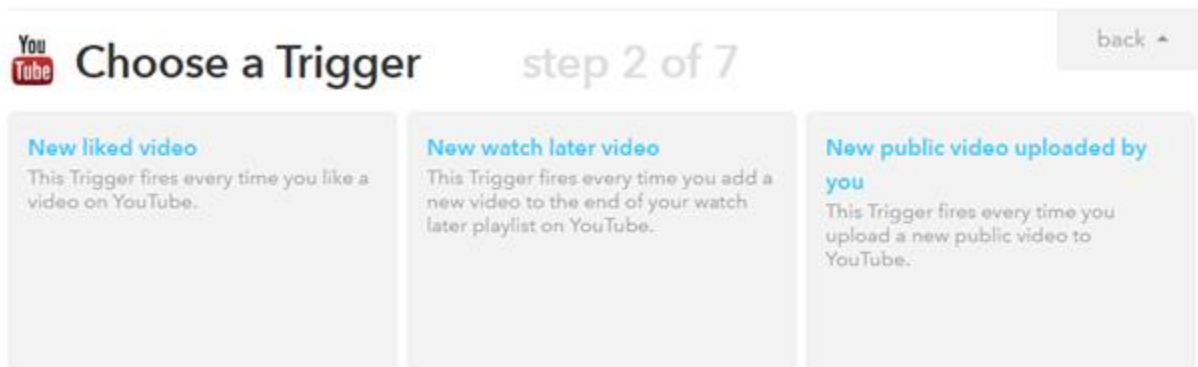


Figure 7.8 - Choose a Trigger page on IFTTT, retrieved March 28, 2016 from ifttt.com

12. The next page should look like the image in Figure 7.9. Click on the blue, underlined “that” button. You will be prompted to choose an “Action Channel”. This channel represents the action that the recipe will take on a specified social media site after the “If-this” statement has been initiated. Type “Facebook” into the search bar and click on the Facebook Pages icon, shown in Figure 7.10.



Figure 7.9 - Example of a half-completed If This Then That statement, retrieved March 28, 2016 from ifttt.com

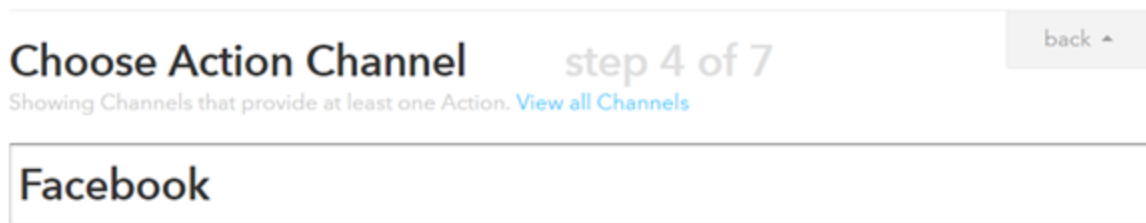


Figure 7.10 - Example of an Action Channel search on IFTTT, retrieved March 28, 2016 from ifttt.com

13. The next page will prompt you to connect the Facebook Pages Channel. Click the blue “Connect” button. A window will pop up asking you which Facebook Page you would like to connect (the pages that are available are only those that you have editing or ownership rights to). Click the dropdown menu and choose the Facebook Page you would like to use and click the blue “Update” button as shown in Figure 7.11. Another window should pop up alerting you that the Facebook Page has been connected.

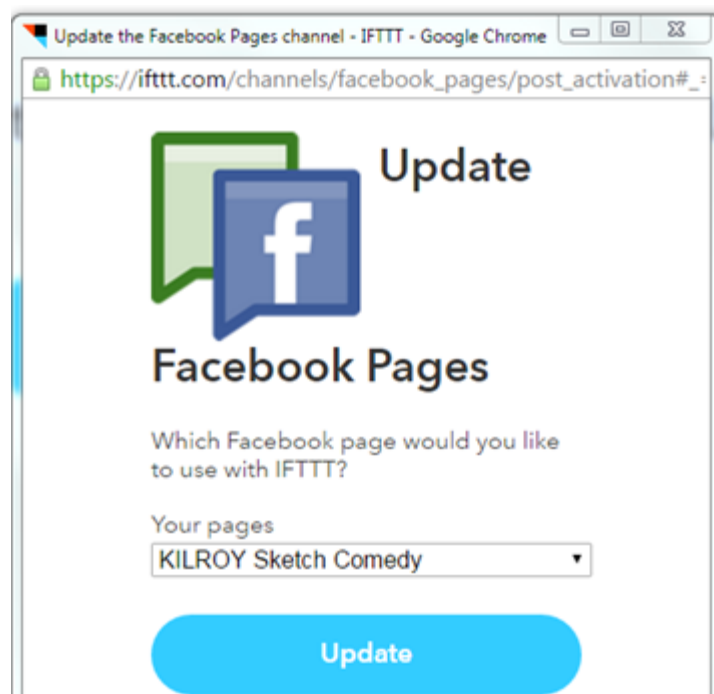


Figure 7.11 - Example of updating the Facebook Pages channel on IFTTT, retrieved March 28, 2016 from ifttt.com

14. Follow the on-screen prompt to continue to the next step as in step 11 above. You will then be prompted to choose an action that you want the recipe to perform on behalf of the Facebook Page you have chosen. Click on the button that reads, “Create a link post”.



Figure 7.12 - Choose an Action page on IFTTT, retrieved March 28, 2016 from ifttt.com

15. You will then be directed to a page that looks similar to that in Figure 7.13. Here, you will tell the recipe to post a specific message each time the “If-this-then-that” statement is initiated. In this example, we have chosen to include the URL of the video that initiated the recipe (the “If-this” statement) and a message that reads, “Check out this video on our YouTube page!”. You may also choose to include the title of the video, among other details, by clicking the blue beaker button on the right-hand side of the Link URL and Message elements and choosing the desired items from the drop-down menu. Once you are satisfied, click the blue “Create Action” button.

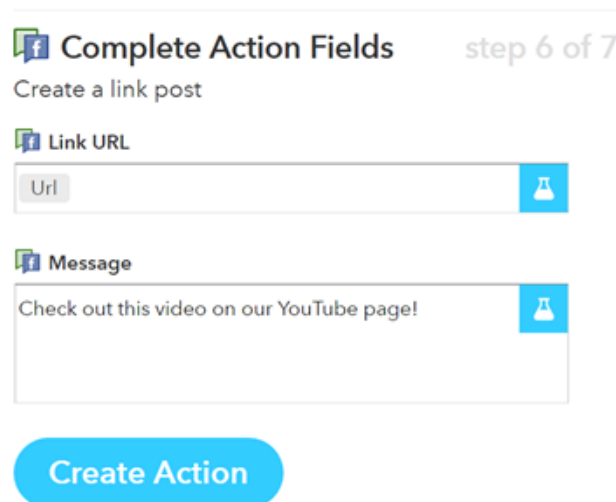


Figure 7.13 - Complete Action Fields page on IFTTT, retrieved March 28, 2016 from ifttt.com

16. You will be directed to the final step in the recipe creation process, shown in Figure 7.14, where you can name your recipe (only visible to you) and create it, by clicking on the blue “Create Recipe” button. At this point, your recipe is successfully created and active. With this particular recipe, every new video uploaded on YouTube will automatically get posted to Facebook with your specified message.

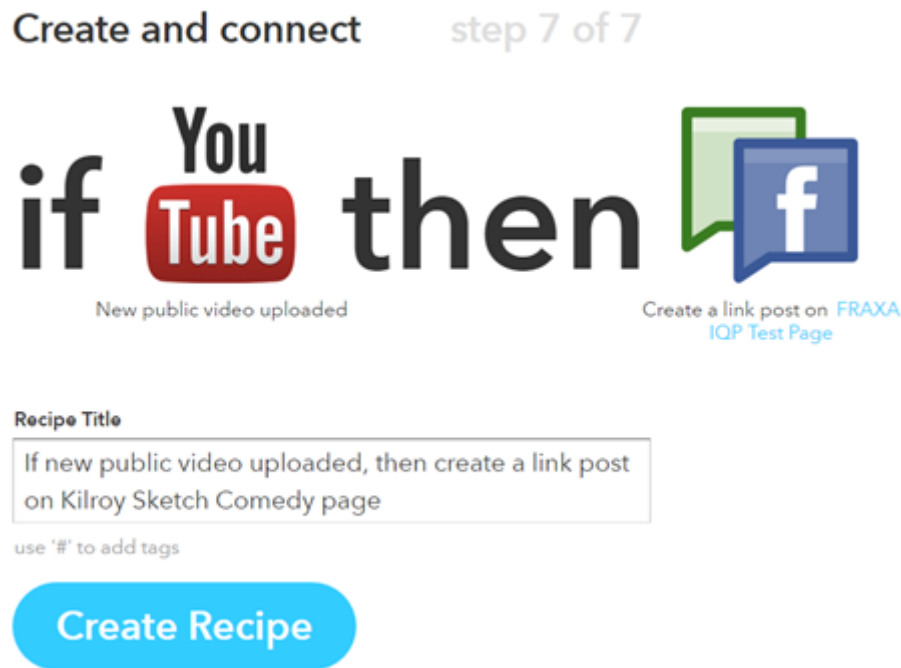


Figure 7.14 - Example of a completed If This Then That statement and sample recipe title, retrieved March 28, 2016 from ifttt.com

17. To create a similar link between YouTube and Twitter, you can follow the above steps but replace Facebook Pages with Twitter, or you can browse for a recipe that another user has already created that accomplishes the same task. Figure 7.15 shows the results of typing “YouTube” into the search bar on the home page.

2,926 Recipes found



Figure 7.15 - Search results for recipes using YouTube, retrieved March 28, 2016 from ifttt.com

- Click on the recipe to the right, labeled "Share new YouTube uploads on Twitter". You will be redirected to a page similar to that shown in Figure 7.16. There, you can modify the message that will be included in the Action Channel and click the blue "Add" button, which will add this recipe to your Recipe page. At this point, YouTube and Twitter are now successfully connected, and all new videos uploaded to your YouTube page will be posted to Twitter.

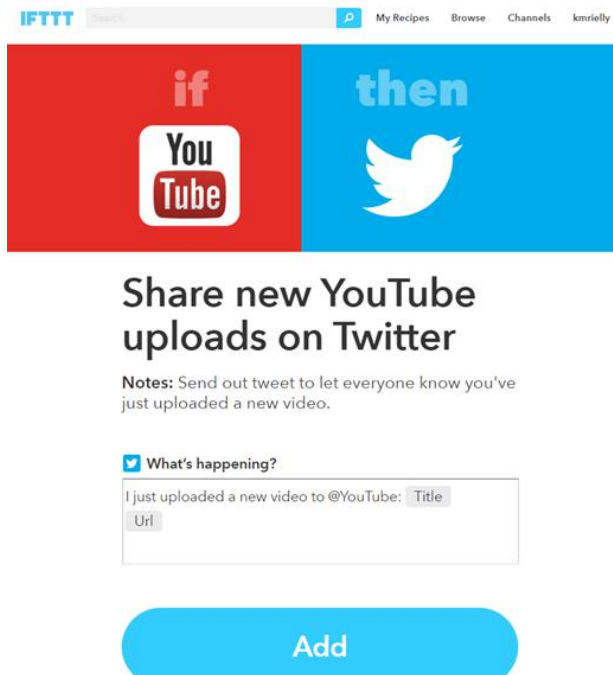


Figure 7.16 - Sample pre-created recipe connecting YouTube and Twitter accounts, retrieved March 28, 2016 from ifttt.com

7.3. Appendix C – Phone Conversation with Ms. Melissa Budek

The following is a transcript of answers provided to us during our phone conversation with Ms. Melissa Budek, a member of the FRAXA team. The questions asked by the team are included in the transcript for reference. Ms. Budek's responses are bolded, while the team's questions are italicized.

Ms Budek's introduction: **“Well I've been at FRAXA since FRAXA started; I've been here for about 20 years, started from the grassroots with Katie, the President, and Mike. They've had children with Fragile X, I'm sure you know that, and I took care of their children. I worked with handicapped children and adults in my work-related job, and I went to school for accounting, so I just couldn't think of any other place I'd want to be, besides working at a nonprofit for handicapped children plus doing financial work. I love my job, FRAXA's doing great, and I'm happy to put what I can into it.”**

Strengths

1. *What aspects of FRAXA are you most proud of? What makes FRAXA unique?*

“We started from grassroots scratch, and I think that we're really proud of everything that FRAXA has been able to do. We've funded 25 million dollars in research since the beginning and we give a personal touch to Fragile X families. We've got quite an extensive list of over thousands of families that participate in Fragile X trials, fundraising, and all kinds of things, so I think that's a strength right there. That, and we're unique in how we're working with just Fragile X Syndrome and helping the community. There's one other foundation, the National Fragile X Foundation – they do more of helping families find locations for doctors in their state, while we've been working mostly on the research part of it, so mostly all our funds go straight towards research. We have a small base here but we try to keep it that way so that we can get as much of our income right into research expenses.”

2. *What are FRAXA's assets and which assets are the strongest?*

“I would say some of our strongest assets are just the people that we have – Katie has her Masters in science, Mike is a doctor. He speaks with all the researchers and is able to communicate with them on all different levels with all the drug trials going on and he's been traveling to different research facilities to discuss details. I just think that that is the greatest thing and really pulls FRAXA together and gets us towards our mission, which is to find a cure for Fragile X and, on the way, also find treatments.”

3. *What advantages does FRAXA have over other, similar nonprofit organizations?*

“We have one single focus - to find a cure for Fragile X - that’s our mission. The National Fragile X Foundation looks up to us. They’ve wanted to connect with us all together and be one big foundation, but we find that our strategies are a little bit different and that they spend more money on management. They have more staff, and more staff means more cost, and we just try not to do that. We try to use what we have and the people that we have to facilitate everything that way.”

4. *Does any member of the FRAXA Team have previous experience working with nonprofit organizations?*

“Katie was on a few boards with other nonprofits and she worked with developmental disabilities in that aspect, but as far as running a nonprofit, we just started from scratch. All of us here are older, so all these newer media and changes going on in the world have been a challenge for us since we are a small group and we have our job to do, so that’s definitely something that we need.”

Weaknesses

1. *In which areas do you wish FRAXA could do more?*

“I would say the grant-writing. I’ve done a little bit of grantwriting but I never really got any experience on that. I just go for what we have for information and try and put that into a nice letter for some people. We have parents that want to do fundraisers that are, say, in Pennsylvania, and a lot of their donors want to hear what we’ve done in their state. So I write these letters for them, and it works out - they give them these donations from companies, but if I could do that with everybody that’s running a fundraiser, that would be just great, because we’d get a lot more income, but I just can’t do that myself, so that’s definitely a weakness; just writing the grants in general and we don’t have the time or the experience, so that’s something we really need help on.”

2. *What are some things that FRAXA needs to avoid?*

“We’ve done pretty good at it, but I think we need to avoid spending - we’ve done fundraisers and sometimes there’s a new person that comes into FRAXA that says, ‘we want to help!’, and we talk about it and we discuss that we have to make sure that the money that they’re going to bring in is going to be a higher percentage than the money that we’re going to give them for expenses, and most of the time we don’t even need to discuss it - they find donors who want to donate a hall or food and they have their own little fundraiser and bring in the donations which is great. But definitely avoid spending and diverting from our mission, which is to find a cure for Fragile X.”

3. *In which areas do other nonprofit organizations have advantages over FRAXA?*

“The National [Fragile X Foundation] has a larger staff and they’re able to get out there in the media more. We aren’t able to do that because we just don’t have the staffing for it and we just don’t want to bring ourselves to that level, where making us bigger means bringing in more people which increases spending, because we pride ourselves on the low management and low expenses, so it would take a hit. Right now we have two part time and two full time employees and that’s all we have. Sometimes we have parents come in and help when we do our annual appeal letter, during which we send out a massive amount of letters. Some of them are done specifically for different families that we have – they make their own letter – and we have it printed up for them and they personalize it, so some of those letters we do here. So we have parents that come in and just give their time and that’s great too, but that’s all we have is really just four people, so it definitely gets tough to find the time to do the things that we need to do to expand.”

4. *What kinds of experience or knowledge are you, volunteers, and FRAXA lacking?*

“I would say that because we’re all older, that the new changes in media is pretty tough. With our database, we used to send letters to everybody, every single person. But now we, say, in our gift envelopes, we put a little letter in there that says if you would like updates, give us your email address. So now, I would say that 60% of our database we have emails for, so we’re able to send out those annual appeal letters through email and that’s part of the new changes that we’ve done, but that’s nothing compared to what we can be doing through media at this point. Because we’re all not really up to that, I’d say it’s definitely something we’re all lacking.”

Opportunities

1. *What external changes could bring opportunities to FRAXA and help meet its goals?*

“More fundraising to support more grants – we have, every year on February 1, we have all these grants that come in, and we fund as many as we can, but there are some that we just can’t fund because we don’t have the income, but we would if we had more fundraising. So I think that definitely if we had more fundraising, we could meet our goal by being able to support more of those grants.”

2. *How large is FRAXA’s audience? Can FRAXA take advantage of other audiences?*

“Well, we have about 100,000 Fragile X patients and families right now – they’re all related to, well some of them, are related to the listserv, and when they call up, they talk about their child having autism. So in the autism spectrum, with how close Fragile X is, we do have other people in our community that aren’t Fragile X related but are related to autism, and we do that interrelation with autism and Fragile X.”

3. *Can FRAXA provide any missing links between the Foundation and its audience?*

“On our website, we have so many links on it – I know over the past two years we worked on getting more information out to Fragile X families through our website just by having chapters. We have chapters in some states where all they are is parents, so they can go to them for help. But a lot of people call and ask about doctors, and we don’t really know about doctors in different states, and so that could be a missing link where we can’t really help them. But we’ve been filling our website as much as we can with new information that comes in and putting in all those links so people can click and search on their own.”

4. *How can funding and grants affect FRAXA’s mission?*

“We funded 18 new grants last year and we had a few that carried over from two year grants, so about 22 total. But we do get about 30 to 40 applicants, and some of them we pass off, but there are a couple that we really want to fund. We work hard during the season right now, and when we do see potential, we start notifying some of the higher donors to ask if they would like to help out. For example, we have the Boston Bruins Foundation that just gave us \$90,000 to fund research. It’s just those connections.”

Threats

1. *Does FRAXA have any potential competitors?*

“For a nonprofit, I don’t know if competitors is the right word - even with the National Fragile X Foundation, which works right here too, we collaborate – we don’t really call them competitors, because any information that we have we share because we’re all working on a team to find a cure for Fragile X and help Fragile X families. Yes, some of our income could be taken away by the National, because some people decide that they’d rather help families with their children and spend money that way rather than research. I do tell people when they call, and sometimes they’re confused – they don’t know who to donate to - so I explain to them the difference between us and the National and they choose – a lot of people just want to put their money straight towards the research.”

2. *What are the current obstacles FRAXA faces in completing its mission?*

“Raising money - it's slow paced science right now – it’s a challenge. We’ve been doing a lot of trials, and we’ve got three trials going right now and that’s a big deal, so we’ve kind of turned the way FRAXA is spending our money on basic research, but also other treatment targets, drug trials, and preclinical research projects, which is pretty exciting. So I would say that our obstacles include raising more money, getting fundraising, and getting more companies to invest in us.”

7.4. Appendix D – Guide to link Facebook and Twitter Accounts

The following steps outline the procedure for linking a Facebook page with a Twitter account.

1. Open Facebook and Twitter in two separate tabs of the same window and log in to each.
2. Navigate to www.facebook.com/twitter

Link your Facebook Profile to Twitter

Update your friends and followers at the same time.

Link my Profile to Twitter

Link a page to Twitter

Post to Twitter from Facebook

Share specific types of updates

When you post a public update to Facebook, it'll be posted to Twitter, too. Only posts with a privacy setting of "Public" are eligible.

Choose which public updates you share, such as only photos or links and events.

Figure 7.17 - Example of what the facebook.com/twitter page looks like, retrieved March 28, 2016 from facebook.com

3. Click "Link a page to Twitter" underneath the green button.
4. Find the Page you would like to link to Twitter in the list of Pages and click the grey "Link to Twitter" button.



Figure 7.18 - Example of the "Link To Twitter" page, retrieved March 28, 2016 from facebook.com

5. On the next page, Facebook will ask if you would like to authorize Facebook to use your Twitter account. Click the blue "Authorize app" button.

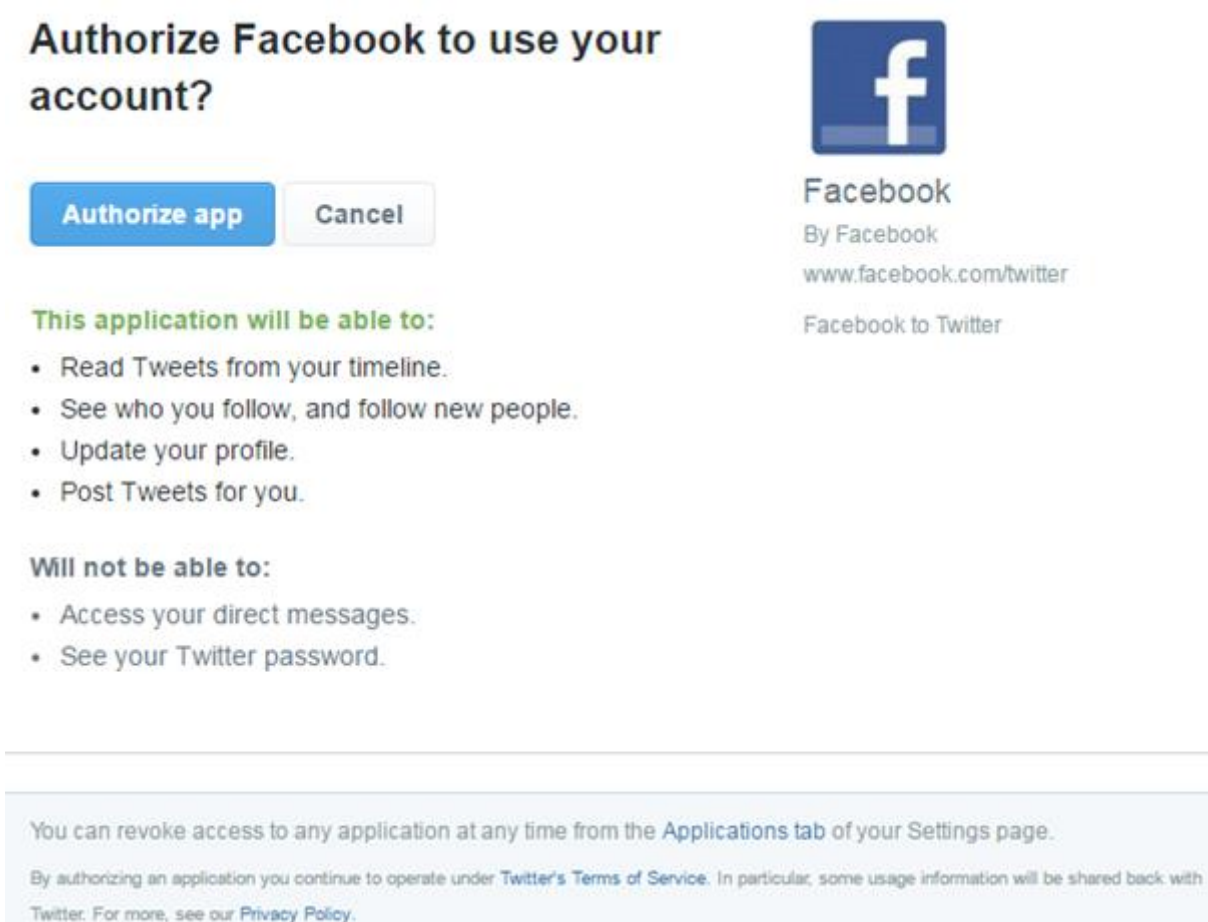


Figure 7.19 - Example of the authorization popup, retrieved March 28, 2016 from facebook.com

- Once the app has been authorized, you should see a message on the screen notifying you that your Facebook Profile or Page is linked to your Twitter. From here, you can modify which types of posts you would like Facebook to share on Twitter. Your choices include status updates, photos, links, video, notes, and events. Check the boxes next to the types of posts you would like Facebook to share with Twitter and click the blue “Save Changes” button.

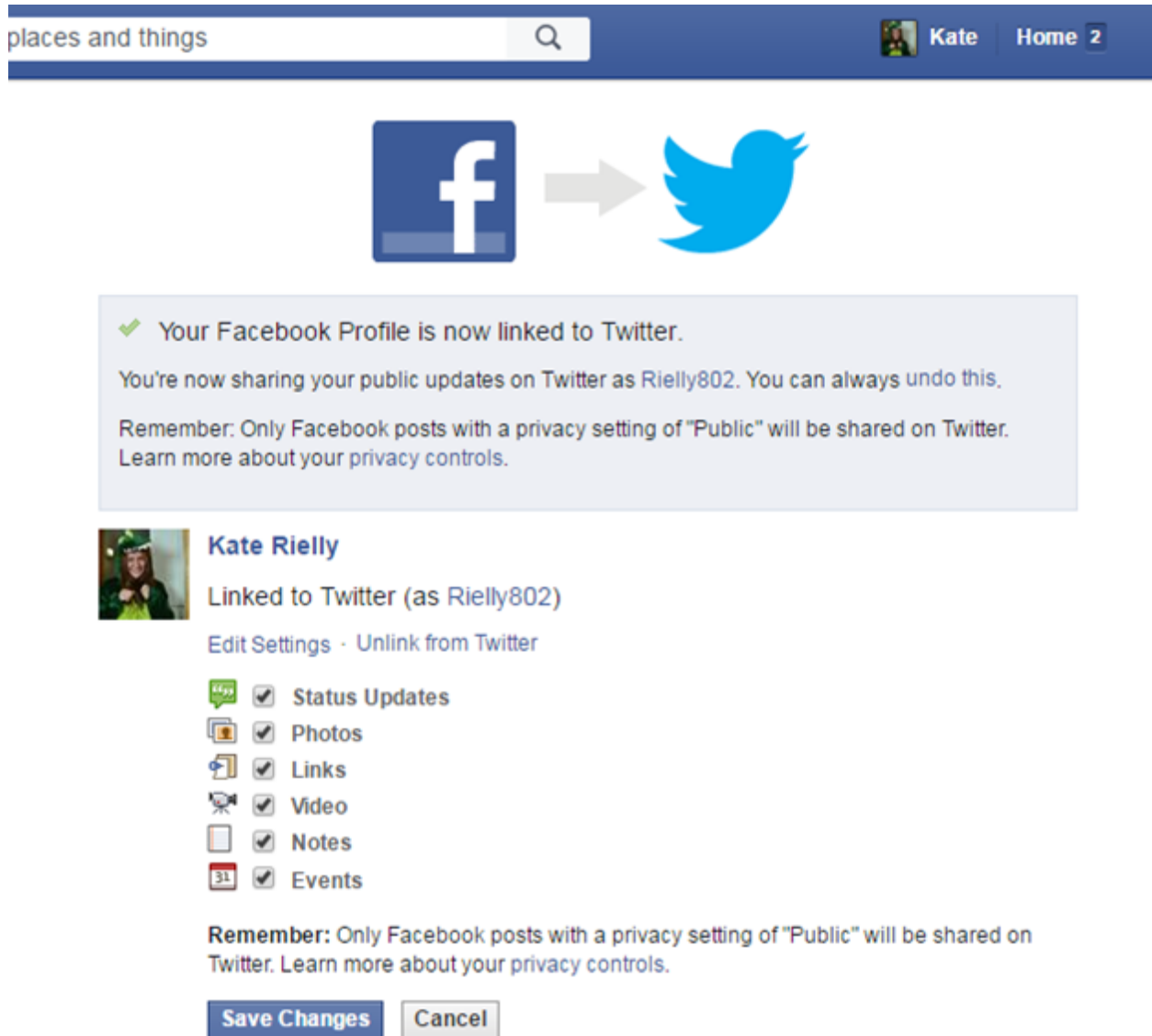


Figure 7.20 - Example of the Settings page for linking Facebook to Twitter, retrieved March 28, 2016 from facebook.com

- Clicking cancel will bring you to a page that alerts you that your changes have been saved. At this point, your Facebook and Twitter accounts are linked, and you may edit your desired post type by clicking the “Edit Settings” link or delete the link between Facebook and Twitter by clicking the “Unlink from Twitter” link.



Your changes have been saved.



Kate Rielly

Linked to Twitter (as Rielly802)

[Edit Settings](#) · [Unlink from Twitter](#)

Figure 7.21 - Example of a completed link between Facebook and Twitter, with the option to unlink, retrieved March 28, 2016 from facebook.com

7.5. Appendix E – Examples of Relevant Hashtags

The following table shows a list of hashtags that could help FRAXA link their posts to other relevant posts on Twitter. Hashtags that are bolded are ones that have been used by the FRAXA Twitter account and received a higher number of engagements.

| Hashtag |
|------------------------|
| #FragileXSyndrome |
| #FragileX |
| #FRAXA |
| #NPO |
| #NonProfitOrganization |
| #Research |
| #FindACure |
| #Autism |
| #ASD |
| #MakeADifference |
| #FXS |
| #KnowFragileX |
| #ResearchFoundation |
| #Advocacy |
| #FragileXNews |
| #PatrickPals |

Table 7.1 - Table of relevant hashtags for use by the FRAXA Twitter account.

7.6. Appendix F – Examples of Post Types

The following table shows a list of tweets posted by the FRAXA Twitter account in 2015 and the category that each tweet was assigned while completing our analysis. These tweets act as examples for creating future posts on both Facebook and Twitter with a specific goal (informational, community, action-based).

| Tweet | Category |
|--|---------------|
| FRAXA Scientific Advisor Mark Bear @MIT has shown mGluR5 blockers correct memory problems in a new autism mouse. | Informational |
| great Fragile X story with the Silver family by @katiecouric http://t.co/17cZdBxBNO | Community |
| Rare case uncovers missing clue to Fragile X discovered by FRAXA-funded team at Washington University at St. Louis - http://t.co/fOgkmuE7jy | Informational |
| Hope you enjoy this article by FRAXA Board member and fx parent, Leslie Eddy! http://t.co/ERV8NT1NuL | Informational |
| Jim Cantore's as passionate about Fragile X as he is about Thundersnow @JimCantore https://t.co/US6vknjBsZ | Community |
| India Prime Minister visits FRAXA investigator Dr. Sumantra Chattarji's new brain center in Bangalore http://t.co/fEOzOrQWBf | Informational |
| fascinating article ... first treat fragile X flies, then mice ... http://t.co/dNVHI1ISmH | Informational |
| Updates: Bryostatins, trofinetide, and new Fragile X research http://t.co/fpI2B9L8Hv #vr4smallbiz | Informational |
| http://t.co/z6mlBUwK3n New Fragile X research grants and fellowships awarded. Biomarker studies and studies of available medicines & more. | Informational |
| Talks will be recorded and posted a few weeks after the #FragileX symposium at http://t.co/cwrCERLce9 | Community |
| New #fragilex study @pwcentre looking at barriers to clinical trials. Take part now! https://t.co/1g60ZfLMCb | Action |
| #FragileX Research & Intervention today, noon ET or 9am PT online @StanfordMed @PWCentre #FXS http://t.co/I3xEoLleC1 http://t.co/ogqGH9GHsp | Informational |
| Survey for Parents of Children with Fragile X Syndrome - http://t.co/DbkunOr3LC by researchers at USC Genetic Counseling | Action |
| At a crossroads of Fragile X and Alzheimers Research - http://t.co/wWhptipL68X From Bagni lab in Leuven, Belgium, published in Neuron. | Informational |
| This applies so well to adults with Fragile X syndrome too: Who Decides Where Autistic Adults Live? http://t.co/mRHidljhJ3 | Community |
| Looking forward to going to this great meeting! Fragile X Quebec https://t.co/b8qfgTogPv | Community |

7.7. Appendix G – Manual for Uploading Videos to YouTube

This manual provides step-by-step instructions for new users to upload videos to the FRAXA YouTube Channel. Additionally, it provides a few tips that can potentially allow the videos to reach a larger audience by providing accessible ways to search for the video, and to allow users to interact and learn more about FRAXA by linking the official page, Facebook page, and Twitter page to the video.

1. When on the FRAXA channel, click on Upload on the top right corner, click on the “select files to upload”, and then double click on the intended file.

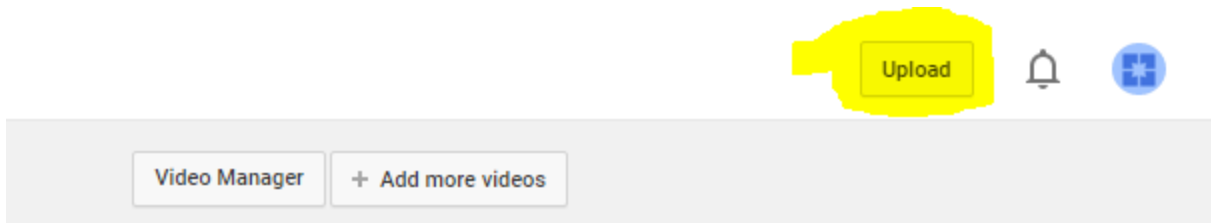


Figure 7.22 - Example of a YouTube channel, showing the upload button, retrieved March 28, 2016 from youtube.com



Select files to upload

Or drag and drop video files

Public ▼

Figure 7.23 - Example of the "Select files to upload" page on YouTube, retrieved March 28, 2016 from youtube.com

2. Once the video is being uploaded, under “basic info”, insert a descriptive title in the “title” box and make sure to include the word “FRAXA” at the end of the title to provide the users with an easy and accessible way to search for video simply by searching for the word “FRAXA”. On the description box, provide more in depth description of what is the video about (Figure 7.24).
3. On the box below the description, insert a few tags that are relevant to what the video is about. We have included four words that we thought are very closely related to any video that FRAXA might publish. You can add any word that you think is related to the video. For example, if you are publishing a video about the Patrick’s Pal basketball tournament, you can include the words “basketball”, “fundraising events”, etc. These tags are very important

because they identify the nature of the video and broaden the search options for the users, which allow it to be reached by more people. For instance, when a YouTube user searches for the work “Fragile”, there is a potential that this video comes up as one of the first few options because the word that is being searched is listed in the tags.

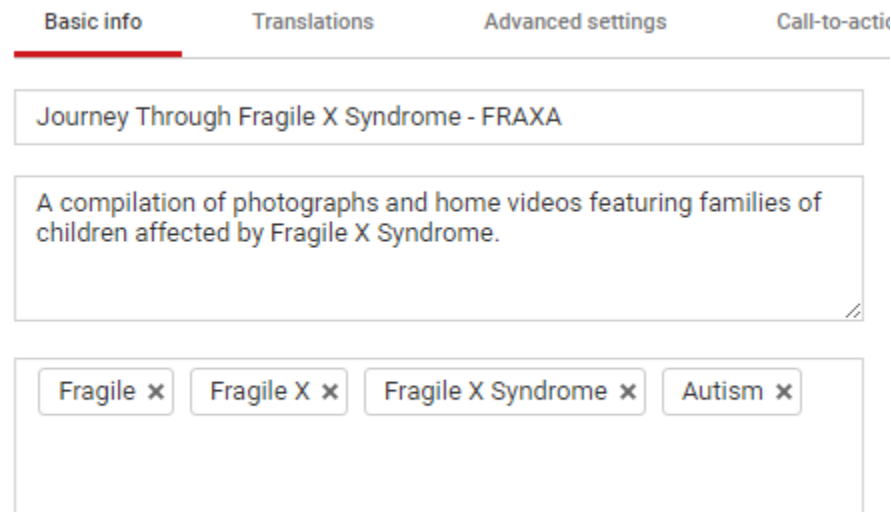


Figure 7.24 - Example of the Basic Info page and potential titles, descriptions, and tags, retrieved March 28, 2016 from youtube.com

4. Under “Advanced Settings”, select the category of the video. In this case all videos will be of the category “Nonprofit & Activism”.

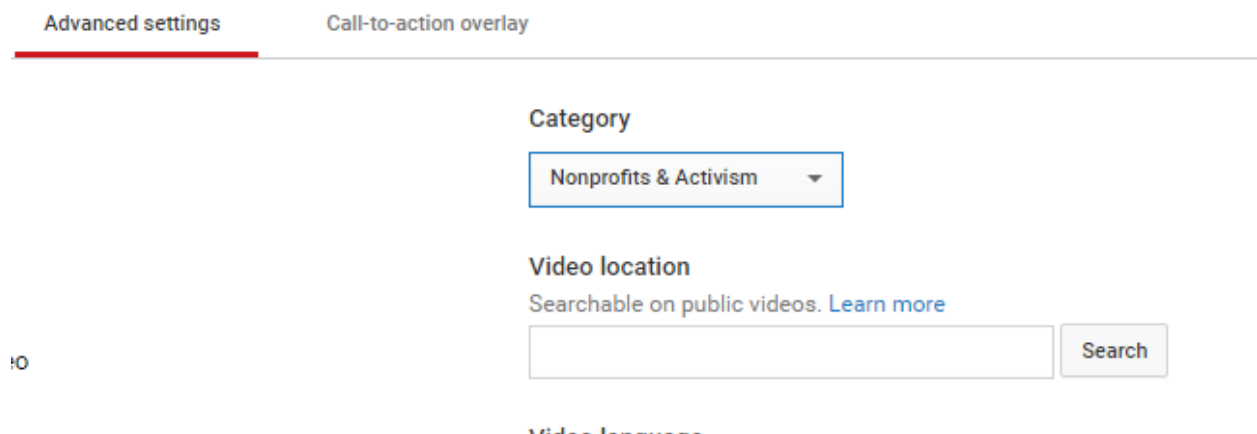


Figure 7.25 - Example of the Advanced Settings page, retrieved March 28, 2016 from youtube.com

- On the top of the page, under cards, click on “Add cards” to link the FRAXA official page, Facebook page and Twitter page to the video. Once you click on “add cards”, copy and paste the link of the FRAXA official page to the “link URL” box. Then insert an appropriate title for the card. This title will be seen by the viewer, so make sure it refers to FRAXA. The title shown below is a great example. “Call to action” is the word that is going to show up on the video, so make sure it is descriptive and concise. The “teaser text” is just the name of the site that the user will be taken to if they click on the card. This process must be done for each of the following (official page, Facebook and Twitter). Each card will only show up on the video for 10 seconds, therefore feel free to create multiple cards for each.

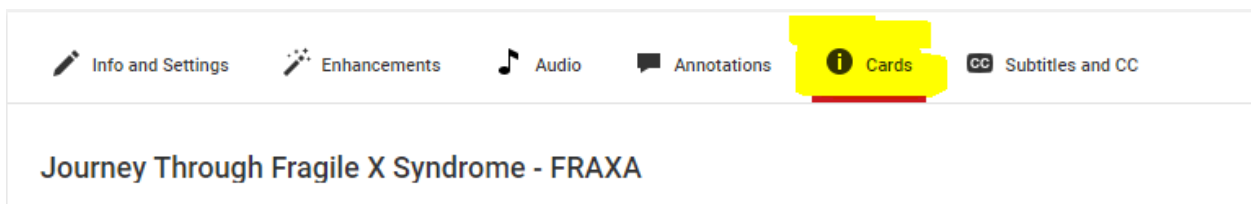


Figure 7.26 - Cards page, retrieved March 28, 2016 from youtube.com

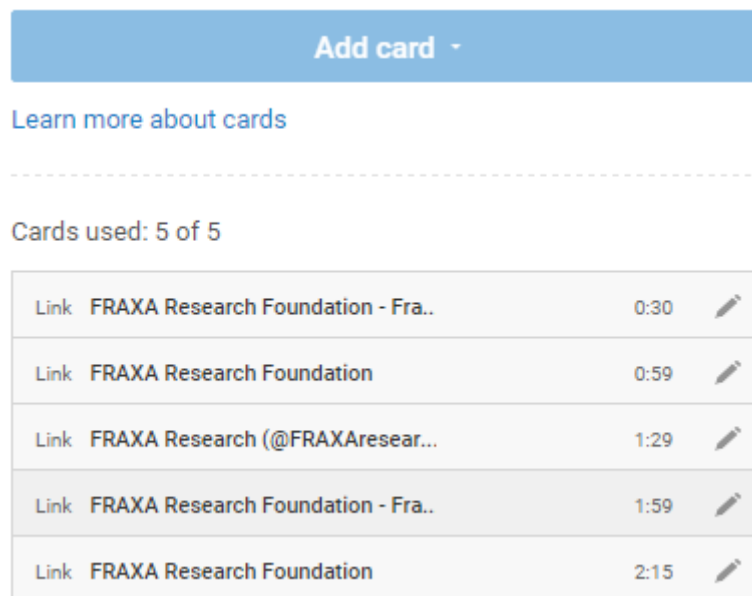



Figure 7.27 - Example of adding cards to a video, retrieved March 28, 2016 from youtube.com

Link

LINK URL

CARD TITLE

CALL TO ACTION

DISPLAY DOMAIN

TEASER TEXT

Figure 7.28 - Examples of Call to Action text, Display domain use, and Teaser Text, retrieved March 28, 2016 from youtube.com

6. Once all the cards are done, distribute the cards along the length of the video. In this example, we created 5 cards, where the Facebook and Twitter cards were duplicated. These cards were then evenly distributed, 30 seconds apart from one another. This way, every 30 seconds, a card will show on the top right corner of the video and ask the user to click on it to be directed to the official website, Facebook, or Twitter (shown in the example below).

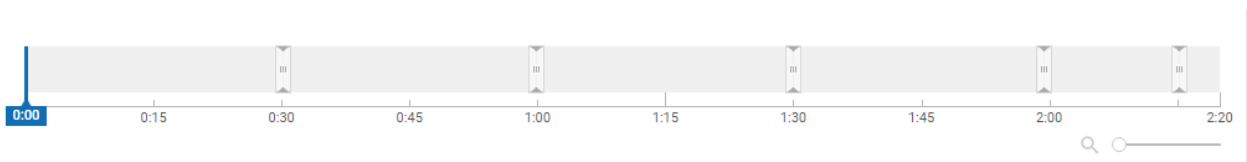


Figure 7.29 - Example of cards spread out through the length of a video, retrieved March 28, 2016 from youtube.com



Figure 7.30 - Example of a video with a card displayed in the upper right hand corner, retrieved March 28, 2016 from youtube.com

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