

# Mission Statement Oriented Changes to FRAXA.org

An Interactive Qualifying Project to be submitted to the faculty of Worcester Polytechnic Institute in partial fulfillment of the requirements for the Degree of Bachelor of Science

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## **Chapter 1: Introduction**

The Fragile X Research Foundation (FRAXA) is a non-profit organization run by the parents of children with Fragile X Syndrome who are working to increase awareness and find a cure. The mission of FRAXA as stated by the website is “to accelerate progress toward effective treatments and ultimately a cure for Fragile X, by directly funding the most promising research” (FRAXA, 2014). The website is one method of acquiring funding for FRAXA in order to continue this research. Resources on the website include information about the disease, clinical trials, and information for researchers.

The founders of FRAXA believe that their website is not being utilized to its full potential. The website contains various important pieces of information, but in some cases the information an individual is searching for may be in an unrelated location and difficult to find. If a user cannot find facts and details for which they are searching within a short period of time, they may become disillusioned with the website and move on, searching for a different source of information.

The current organization of the webpage does not necessarily highlight the priorities stated in FRAXA’s mission statement. For example, clinical trials are a critical part of researching a cure for Fragile X Syndrome, but an individual may visit the website without grasping the concept of how significant the trials truly are. With an increase in understanding of the importance of clinical trials, more Fragile X families may become involved with them, which will ultimately move the organization closer to finding a cure.

Another important resource that seems to be missing from the website is information for parents with newly diagnosed Fragile X children. The internet is a common source of quick information, and it is likely that the parents of a recently diagnosed child will search the internet

for helpful tips on raising a child with Fragile X. Unfortunately, if a parent visits FRAXA's website looking for this information, they might find the website to be not easily navigable, and will not be able to find the desired information.

While there are several different changes that could be implemented in the website to improve these points, it is important to find out which ones will be worthwhile in terms of highlighting FRAXA's mission. The goal of increasing traffic to the certain parts of the FRAXA website can be achieved by the following improvements: moving informational tabs around; creating guides for parents; simplifying and dividing up current research and clinical trials for families and scientists; streamlining the donation process; and adding options for content sharing in social networks.

In order to successfully help FRAXA to highlight its main goals, a comprehensive analysis of the website and data collection was performed to provide information as to why the crucial parts of FRAXA's website are underutilized. The goal was to determine why the parts of the website related to the mission statement are less frequented than areas of lesser significance to the FRAXA organization. While not in the immediate scope of this project, the societal dimension of this project is spreading a greater awareness and involvement in key parts of FRAXA that may result from final suggestions made to better highlight its goals. Thus, this project was completed with the goal of benefiting both FRAXA and individuals whose lives are affected by Fragile X Syndrome.

## **Chapter 2: Background**

Although the FRAXA website contains resources for parents and researchers, the organization still wishes to increase web traffic so that more users can find these resources with ease and use them as needed. The website is a way for FRAXA to provide resources and information to families and researchers, while ultimately supporting research for Fragile X treatment. Because many factors influence the web traffic a website receives, it is important to take a closer look at the design, user statistics, type of organization and resources offered to see if there are any base indicators as to what may be improved to increase the effectiveness of a website.

### ***2.1: Fragile X Syndrome***

Fragile X Syndrome is the most common inherited cause of mental retardation and autism, and is caused by a single mutation on the FMR1 gene located on the X chromosome (Hagerman, 2005). The mutation contains an expanded set of cytosine, guanine, guanine nucleotides in repetition (Hagerman, 2005, p. 195). Those with a normal copy of the gene will have this sequence repeated as many as 45 times, a carrier may have 55-200 repeats, and an individual with a full mutation will have the sequence greater than 200 times in repetition. (Hagerman, 2005).

Parents of children with Fragile X Syndrome will notice developmental setbacks and symptoms in their children (Hagerman, 2005). Signs may appear early on in the child's life, especially if the child is male since this is a sex-linked disease (Hagerman, 2005). Hypotonia (decreased muscle tone), otitis media (ear infections), delayed language capabilities, prominent ears, flat feet, and double jointed thumbs are common symptoms for male children. ("Hypotonia," "Ear Infections," Hagerman, 2005, p. 195-196). Behavioral problems emerge

when young and can continue into adulthood (Hagerman, 2005). After puberty, the jaw and forehead are often observed to be long and prominent, and macroorchidism, abnormally large testes, is also seen in males (Hagerman, 2005). The majority of females with the full mutation are mentally impaired, often tested to have a borderline or retarded IQ (Hagerman, 2005). Those who fall into the normal IQ range are often challenged with learning disabilities, such as difficulty with math, focusing, and language (Hagerman, 2005). Both males and females may be autistic or autistic-like, due to deficiencies in range of social skills (Hagerman, 2005).

There is no cure or specific drug that targets all the symptoms of Fragile X, but there are medications that target select symptoms. The FRAXA website recommends early intervention. At school age, “most children benefit from an Individualized Education Plan (IEP)”, which uses various forms of therapy to help (FRAXA, 2014).

## ***2.2: FRAXA Research Foundation***

The FRAXA Research Foundation was founded by a group of parents of children with Fragile X Syndrome in 1994. Since then, they have strived to achieve their mission statement, “to accelerate progress toward effective treatments and ultimately a cure for Fragile X, by directly funding the most promising research” (FRAXA, 2014). When the nonprofit research foundation began, less than \$2 million in research for Fragile X Syndrome was funded by the government, and of that approximately \$30,000 was used for clinical trials (FRAXA, 2014). Progress has since been made, with FRAXA funding research through grants and fellowships internationally with over \$24 million during the past twenty years (FRAXA, 2014).

FRAXA has also worked hard to educate people about Fragile X. Resources for families are provided on their website and include educational materials, referrals, guidance, and a community of support that spans nations. The organization is proud to say it “runs scientific



meetings, advises pharmaceutical companies large and small, provides education on college campuses, community settings, and international conferences” (FRAXA, 2014). The FRAXA Research Foundation understands that they will better be able to fund research as knowledge and awareness grow.

### **Chapter 3: Literature Review**

This project touched upon several different knowledge bases. Sources included: Fragile X information such as symptoms, diagnosis, and current research news; website development and editing data, including suggestions for improvement advice on the layout and presentation of content as well as basic programming and formatting; and feedback gathered from users in the form of surveys and statistical analysis. Sources regarding effective website design techniques were referenced with the intention of improving the website. Statistical information from FRAXA's website provided data that has been analyzed to see which aspects of the website are used the least, illustrating whether FRAXA's goal is important to the web visitors.

#### ***3.1: Web Design***

The scope of this project is to improve upon the website with changes that are based on analysis of current website traffic and the reported needs of the Fragile X Syndrome community. Any redesign of the website involving changes to the program through which the website is currently maintained is beyond the scope of this project. The design of the website aspect of this project relates more to effective placement and organization. Utilizing hierarchy charts and the method of grouping in order to analyze where the central focus of the website currently is helped the group to establish a new design for FRAXA's page to assist in emphasizing that focus (England, 2006).

Plumley (2010) recommends considering if the design aids in helping to find information or pages in which the user may be interested. The author also suggests giving subjects a task to complete when testing a design. Having a task that relates to the test material, such as finding causes behind Fragile X Syndrome and how they work, enables the subjects to give better feedback on aspects of the web design that are the focus.

Plumley's book, "Website Design and Development: 100 Questions to Ask Before Building a Website," continues into more detail about verifying that the site has content that serves the intended purpose, construction and maintenance, layout and design of the site, and strategies for marketing and promotion. Included in the strategies mentioned is social media. The author includes a table to help the reader to decide which form of social media would serve them best in garnering attention. It is advised to engage others in conversation on social media sites and to maintain a regular schedule for updates, whether daily, weekly, monthly, etc. so that users will know and look forward to when updates are released (Plumley, 2010).

### ***3.2: Website Metrics***

In order to fully utilize the data gathered through the FRAXA website, an understanding of the constantly collected website data was necessary. Specific and unknown terms were researched so that the analysis of data was correct and relevant. The FRAXA website metrics were provided by Google's webmaster feature. A series of web pages provided by Google defined and explained the several components that make up the collected website data. These pages were helpful to understand the data collected about the FRAXA website, as the explanations provided by Google were entirely related to the specific metrics analyzed (Google Support). The webmaster forum, which is also provided through Google, was useful in providing knowledge as real-life experiences and suggestions could be referenced during data analysis.

### ***3.3: Non-Profit Sources***

A nonprofit organization is a corporation that uses surplus money, or money beyond its self-sustaining needs, to achieve the goals of the mission statement rather than use them as profit. Nonprofit organizations tend to function in areas that society believes will not be adequately funded by the government or by the business sector (Hart, Greenfield & Johnston, 2005). A

nonprofit organization which focuses on medical research uses these funds to encourage and support the research on and pharmaceutical development for a specific medical issue. Possible methods for nonprofit organizations to achieve these goals are:

- Increasing awareness
- Connecting with families of those affected by the disease
- Fundraising
- Funding research aimed at their target medical condition
- Promoting clinical trials
- Holding conferences

The economy can significantly affect nonprofits, as government funding as well as private donations may decrease in times of financial crisis. Private investments, donations from individuals, and money from goods, events, and services also contribute to an organization's revenue (Joseph, 2012). As a nonprofit, FRAXA uses its donations to continue working on clinical trials and funded research, which are the organization's route to finding a cure (FRAXA, 2014).

The book *Nonprofit Internet Strategies* combines both the theory behind running a successful nonprofit organization and designing a website, and gives many ideas on how to organize a nonprofit website, build a community within the supporters, and reach as many people as possible with the message of the organization (Hart, Greenfield & Johnston, 2005). This source provided possible website improvements to highlight FRAXA's main goals, as its nonprofit focus was in line with the scope of this project.

### ***3.4: Parent Resources***

When a child is first diagnosed with any form of disease, a parent often wants to know

more information and begins to look for resources that may contain professional advice, support groups, information about planning for the future, possible treatments, and current research. A blind study conducted in 2014 based in Canada analyzed the needs of parents with children diagnosed with autism spectrum disorder (ASD). Questions asked in the survey fell under categories such as finances, child care, family and social support, professional support, explanations to other people, and information about ASD (Hodgetts, Zwaigenbaum, & Nicholas, 2014). Besides these categories researchers included an open ended question, and responses were grouped based upon the themes of the answers (Hodgetts, Zwaigenbaum, & Nicholas, 2014).

Worst met needs, defined as needs where more than 50% of respondents replied that the need was still unmet, included the categories of child care, family and social support, explanations to other people, and information, such as current and future services (Hodgetts, Zwaigenbaum, & Nicholas, 2014). The majority of the needs about explaining were not fulfilled, indicating that parents do not know how to properly answer questions and educate others. One may conclude this might be due to not being fully knowledgeable and properly educated about ASD. According to the survey, families need help discussing issues and finding solutions (Hodgetts, Zwaigenbaum, & Nicholas, 2014). Parents also wanted to feel supported when tasks become difficult (Hodgetts, Zwaigenbaum, & Nicholas, 2014). The most unmet need was information about current services (Hodgetts, Zwaigenbaum, & Nicholas, 2014).

Since Fragile X is the most common known cause of autism, and even some patients without autism display autism-like symptoms, the needs of the families that responded to this survey are relevant to the project (Hodgetts, Zwaigenbaum, & Nicholas, 2014). Needs, especially those unmet according to the survey, should be reviewed on the FRAXA website before changes are made to determine whether they are actually necessary. A survey, much like the one

described in the paper mentioned above, would be utilized to analyze the effectiveness of the FRAXA website before and after suggestions are made or used.

In a different study that analyzed the answers of over one thousand participants who were contacted with the help of the National Fragile X Foundation, Conquer Fragile X Foundation, and FRAXA Research Foundation, the relationships between family and child characteristics, possible mediating variables, and family outcomes were studied (Raspa, 2014). Generally, when high levels of positive adaptation were reported, the families also had high levels of parenting knowledge, including knowing the biological mechanisms of Fragile X Syndrome (Raspa, 2014). Yet there still were difficult areas, including “knowing how to help their child behave, knowing where to find needed services for their child, and knowing their rights” (Raspa, 2014). While social support was reported to be high, there were still approximately 25% of families that were not in contact with another family. Social support and knowledge of Fragile X Syndrome help to increase the quality of life of families with one or more children affected (Raspa, 2014). Creating a social forum on the FRAXA website, such as a blog, forum, or chat room, could better connections between families, support, and quality of life, as there is currently room for improvement.

## **Chapter 4: Methodology**

The analysis of the FRAXA website consisted of the following tasks: reviewing website analytics, surveying users, and making suggestions to the FRAXA Foundation to increase traffic, improve organization, and highlight available resources.

### ***4.1: Reviewing Website Analytics***

Website analytics were provided through the owners of the website, primarily Katie Clapp. Search queries, which show what a user searched in order to find the FRAXA website; impressions, which show how many times a link to the FRAXA website shows up on a person's computer; click through rates, which show how many times a link to the FRAXA website was clicked on; and average position in search results for different search terms are all attainable, and lead to the creation of a priority list for what to optimize and improve for the FRAXA website (Google Support).

Of the information provided by the website analytics, the frequency of impressions and clicks were provided in a graph with respect to date. For further clarification, an impression is made when a respective search term or webpage relating to FRAXA appears on an individual's computer screen. An impression results in a click when an individual clicks on the link resulting from the search query. The graphs of impression and click frequency correspond to the three month period of November 12, 2014 to February 12, 2015 and can be found in Section 5.1 of the results.

The pages most viewed after one click were documented and used to determine what pages need search optimization as well as improved formatting of their layouts. The data that was available through the web metrics tools clearly illustrated what individuals searched for and what pages were viewed during different visits to the FRAXA website. Once the information

from the web metrics was collected, it was determined which pages on the FRAXA website need to be improved in order to bring more traffic to them.

The metrics also provided information as to which website brought the individual to the FRAXA page. The various types of websites the FRAXA visitors came from somewhat reflects the interests of the individuals. For example, an individual leaving a search engine to visit the FRAXA webpage may likely be an individual searching for answers to more simple questions as opposed to someone leaving a complicated Fragile X research website. Observing the various types of websites also illustrated what the visitor saw immediately before viewing the FRAXA page. Knowledge of where the website visitors were coming from was a possible method to gauge whether they were aware of the mission statement and goals.

## ***4.2: Organic Search Terms***

### *4.2.1: External Search Engine*

In order to better learn how popular certain parts of FRAXA's website are, an exploration into Google search queries of multiple terms was performed. The search terms included:

- FRAXA
- Fragile X Diagnosis
- Fragile X
- Fragile X Prognosis
- Fragile X Syndrome
- Fragile X Cure
- Fragile X Clinical Trials
- Fragile X Research
- Fragile X Symptoms



- Fragile X Fundraising
- Fragile X Donate

By looking at the results provided during these searches and through the Webmaster Tools for the FRAXA website, the parts of FRAXA's website that are being used most appeared. In addition, seeing the ranking of websites on the search results page illustrated what people were searching for, and how likely the FRAXA website was to capture attention from the list of websites to visit. Links to the FRAXA website that appeared for the search terms listed as well as other terms that appeared during the Google search query analysis were analyzed to determine if the traffic FRAXA is receiving is consistent with their mission goals.

#### *4.2.2: FRAXA Website Search Bar*

In order to determine the efficacy of the internal search bar within the FRAXA website, a list of organic search terms was created using the some questions from the first-time user survey (see section 4.2.2) and some other terms. These terms included:

- Clinical Trial Location
- David Nelson
- Fall X Ball
- Donate
- Listserv
- Parent Resources

Some of these terms are relevant to goals outlined by the FRAXA foundation, and some came from suggestions obtained from the current user survey on what information users had trouble finding on the website. The resulting pages from each search were recorded and analyzed to evaluate the efficacy of the search function within the FRAXA website itself.

### ***4.3: Surveying Users***

#### *4.3.1: Surveying First Time Users*

In addition to an online survey, a survey was conducted in person to gauge the experience of a first time user of the FRAXA website. The volunteer selected which part of the website caught his or her immediate attention as well as what link appeared to be the most helpful. Timed tasks were given to the volunteer with a time limit of two minutes. The search bar was not allowed to be used during these tasks. The tasks were designed to have varied levels of difficulty in order to better gauge differences in usability between different parts of the website.

Before tasks were given, each person was asked two questions using Qualtrics, a survey software available to WPI students. For the first trial, the question read: “Which part of the website first catches your eye?” with a picture of the home page for the FRAXA website. Those being surveyed were able to click on the appropriate location. The second question was presented two different ways between the two survey trials. For the first trial, the second question was “Which part of the website seems to you like it would be the most helpful?” For the second trial, the second question was "Which part of the website seems to you like it would be the most helpful as a first-time user?" This change was added because of some confusion with the survey subjects as to what kind of help they would be looking for from the website. Again, a picture of the home page for the FRAXA website was displayed, and the volunteer was able to click on the appropriate location.

The first task was to find a clinical trial location, since clinical trials are crucial to FRAXA and finding a location may be difficult for individuals. Another task was to find a researcher’s information page, as research is also important in the FRAXA community. However, it was already known that many of the research pages were difficult to find, so this

task was added as an intentionally difficult task against which to compare some of the easier tasks. For the first trial, there was some discrepancy between how this question was presented. Some facilitators told the subjects that the person they were looking for was a FRAXA researcher, and some did not. For the second trial, all subjects were told that the person they were looking for was a FRAXA researcher.

Finding information on the Fall X Ball was the third task, since hosting events and attending events are both methods of spreading awareness and learning more about Fragile X Syndrome. An easier task was to find out how to donate, since there is a donate button located in the top corner of the FRAXA website that is fairly noticeable. This was expected to take a very short amount of time, and to be as shorter task against which to compare the other tasks. Donations are also crucial to FRAXA, therefore ease in the process of donating is beneficial to the organization. The last task was to find the signup page for the FRAXA listserv, which is a harder question that may even be difficult for common website visitors to find without use of the search bar, as it is simply a few lines of text within the "Get Involved" page. This question was also changed for the second trial, from "Find information about the FRAXA listserv, please," to "Find information about the FRAXA listserv, please. The listserv is an e-mail group that facilitates discussion between the members of the FRAXA community. It is NOT the same as the e-mail newsletter." The question was changed because most first-time users were found to have never heard the term "listserv" before, and it required some explanation. This task was assigned as the listserv is also a beneficial aspect of the FRAXA website which may enhance a user's experience.

The audience consisted of students and faculty of Worcester Polytechnic Institute with no previous knowledge of the FRAXA website. The responses from this survey were used in order

to examine the first time user's response to the website. Given this information, consideration was taken for moving or enhancing certain parts of the website. A script of the interactions with the students and faculty is available in Appendix B.

The time to complete each task was recorded and all results were compiled together. Statistical analysis was performed on the data and analyzed.

#### *4.3.2: Surveying Past and Current Users*

Surveys were used to obtain user information of those who explore and utilize the website in order to find patterns of use, as well as needs that are unmet. The survey questions are in Appendix A. The survey included topics such as:

- Relationship to FRAXA
- Frequency of visitation
- How website is utilized
- Opinion on the current layout of the FRAXA website
- Opinion of content to be added
- Opinion of content to be simplified or formatted

A question of association to FRAXA was asked with the intention to determine what role Fragile X has in the lives of those who frequent the FRAXA website. Given that common users were found to have a specific relationship to Fragile X (parent of, carrier, researcher, etc.), suggestions were made with the aim of highlighting FRAXA's goals and providing relevant resources to those users. Information about the connection between Fragile X Syndrome and the web user, such as a researcher or a parent, was useful to gauge reasons behind visiting the website and level of knowledge regarding Fragile X Syndrome.

The frequency of visitation topic was included to discover how often users are using the

FRAXA website and their resources. Knowledge of how respondents are utilizing the website helped to determine if pages were sufficient, and also helped to determine which pages were the most helpful to the respondents. The questions regarding how often the individual frequents the website aimed to determine how resourceful the website is and to see if information was frequently sought after through the website.

Understanding how the FRAXA website is currently utilized provided a general idea of suggestions to be made. Knowing the strengths of the site in terms of audience interest indicated areas of weakness, highlighting potential areas where positive changes can be made. The areas that are commonly frequented can be reinforced to illustrate FRAXA's main goals, and the areas that are not frequented can be evaluated regarding emphasis of goals and overall usefulness.

The survey was conducted using mainly closed questions. Closed questions allow for concise answers that are also quantifiable. Open ended opinion questions were limited due to a potential time commitment issue with those otherwise occupied not having time to answer them. Answering questions to advance through the survey was not made mandatory in case respondents did not wish to answer or did not have time to answer every question. Qualtrics, an online survey software, was used to create the survey.

Respondents were obtained by including the survey in FRAXA newsletters, sending e-mails to members of FRAXA's e-mail database, posting on FRAXA's Facebook and Twitter accounts, as well as posting links in visible areas on the FRAXA website. The URL to the survey was included in the newsletters and emails, and the posts and links lead directly to the survey. Telephone or in-person interviews were not conducted due to the interest of time and considering they would not reach as wide an audience as electronic surveys. Mailed questionnaires were not used due to cost and the potential long response time.

When the survey was sent out, a notice was sent to all potential participants informing them of the survey and its importance to FRAXA. The initial date to send out the survey was December 15<sup>th</sup> 2014, and the survey was resent on January 20<sup>th</sup> 2015. Two weeks later, on February 3<sup>rd</sup> 2015, a notice was sent to the FRAXA community that the survey was closed. Based on the results of the survey, suggestions were determined on certain aspects of the website design, in order to fit with the wants and needs of the community targeted.

The targeted audience of this voluntary survey was primarily the people who have self-subscribed to the FRAXA newsletter; therefore the people receiving the survey were most likely to be fairly close with the organization, and likely frequent the website more often than the average passerby. However, the survey still provided a fairly clear picture of what parts of the website need improvement. The target audience was primarily composed of parents of children with Fragile X and researchers. As such, they likely had a vested interest in the improvement of the site. The survey participants were asked to specify their relation to FRAXA, so the responses were separated by these relations. This survey provided a clear picture of what parts of the website need improvement as indicated by its users.

## Chapter 5: Results

### 5.1: Web Analytics

The data provided by Google Analytics delivers the number of impressions and clicks when FRAXA appears in results of search engine inquiries. The following Figures 5.1, 5.2, and 5.3 illustrate these numbers of search impressions and clicks from November 12, 2014 through February 12, 2015. It can be observed that the frequency of impressions is much greater than the frequency of clicks, which is expected as impressions lead to clicks.

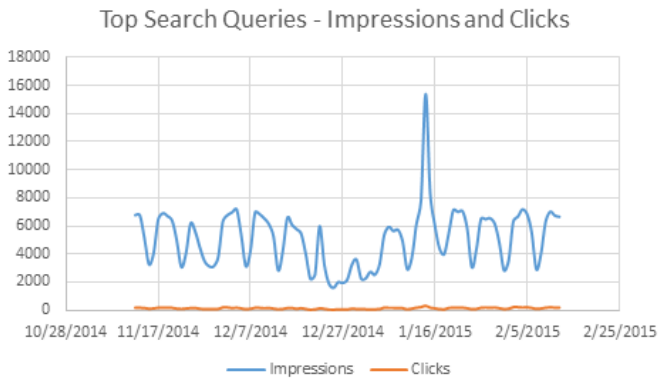


Figure 5.1: Top Search Queries - Impressions and Clicks

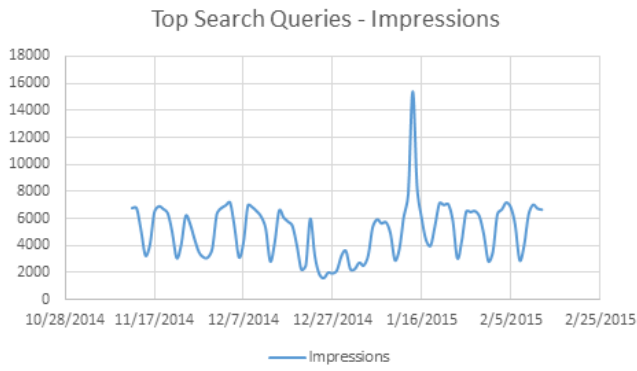


Figure 5.2: Top Search Queries - Impressions

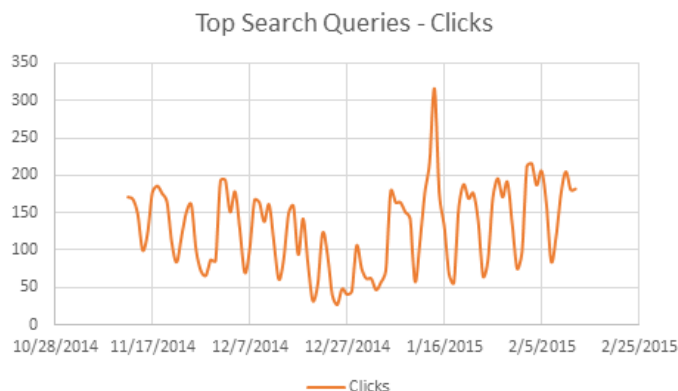


Figure 5.3: Top Search Queries - Clicks

As seen in the data, a common trend is a decrease in activity over the weekend. The charts depict the data recorded from Wednesday, November 12, 2014 through Thursday, February 12, 2015. Noting this mid-week difference, the frequency increases during the weekday and decreases during the weekend. Activity during the winter holidays is significantly lower than that of the previous and following months. There is also a notable decrease around Thanksgiving as well. Without further data, it is difficult to gauge the source of this trend. One may speculate the cause to be related to an increased amount of computer time during the week, in which individuals both in the office and at home are actively online as opposed to spending time with family.

There is a notable increase in activity on January 14, 2015 where the number of impressions and clicks reached 15400 and 316, respectively. A possible reason for this significant increase is that the deadline for Letters of Intent for FRAXA Grants and Fellowships was January 15, 2015 at 11:59 PM.

In general, the fluctuations in the web analytics were observed to remain fairly unchanging over the period of time for which they were analyzed. Impressions and clicks were high on weekdays and low on the weekends, and most irrational spikes or dips in the data were explained by a major holiday or FRAXA event. While some helpful information can be gleaned



from the data available, without detailed information such as duration of visit, sequence of pages accessed and nature of visit, it is difficult to ascertain the true purpose of certain fluctuations.

## ***5.2: Organic Search Terms***

### *5.2.1: External Search Engine*

If the FRAXA Foundation wants to optimize their viewer potential, they should do everything in their power to make sure their website appears under as many organic search terms as possible. There are many generic, or "organic", search terms a user might employ when looking for information about FRAXA or Fragile X in general. Eleven terms were chosen as organic terms for FRAXA and Fragile X searches, and were entered into the Google search bar. Google was chosen since it is used in 65% of searches, according to a 2011 Rosetta study (Allen, 2011). These results can also be found in a table in Appendix E. The search terms used were chosen based on relevance to FRAXA's mission statement and website resources.

The first term entered was "FRAXA," and a link to the homepage of FRAXA was the first link. Next "Fragile X" was entered. This time the FRAXA associated link was listed seventh, and the link brought the user to the "About Fragile X" web page. Two of the links that appeared before the FRAXA associated link were from the National Fragile X Foundation. Other links that appeared before the FRAXA associated link were pages from Wikipedia, the National Institute of Health (NIH), news for Fragile X and images for Fragile X. However when "Fragile X Syndrome" was searched, FRAXA's homepage was the fourth result. This time the NIH, Wikipedia, and the National Fragile X Foundation had results ahead of FRAXA.

The following search terms can then be grouped into different categories, such as medical information, research, and fundraising. Terms related to medical information include symptoms, diagnosis, and prognosis. "Fragile X Symptoms" was chosen because it was assumed to be a

common search term for parents trying to diagnose their children. If the FRAXA website ranked highly with this search term, they could attract new parents to the FRAXA community right at the beginning of their Fragile X journey. The search of "Fragile X Symptoms" did bring up the symptoms web page of FRAXA, but it was the ninth result. Websites that appeared before FRAXA included the NIH, medicinenet.com, healthline.com, Wikipedia, Images for symptoms, childrenshospital.org, and two different pages for the National Fragile X Foundation. The term "Fragile X Diagnosis" was chosen for similar reasons, as a parent trying to get ideas on a possible diagnosis for their child might use this term. When "Fragile X Diagnosis" was searched, no FRAXA link was seen on the first page. Instead, FRAXA was the twelfth result and the link was for the Fragile X Testing web page of FRAXA. Websites that appeared before the link from FRAXA included two different links for genome.gov, NIH, National Fragile X Foundation, healthline.com, American Academy of Family Physicians, childrenshospital.com, medicinenet.com, Wikipedia, Journal of Clinical Investigation, and a New York Times article. All pages contained information on Fragile X or were more specific and focused on Fragile X symptoms. The last search term used in the medical information category was "Fragile X Prognosis." Parents who have recently found out that they have a child with Fragile X would probably want to know what the future holds for their child, which is why "Fragile X Prognosis" would most likely be a common search term among parents. There were many different links that were returned, but none of the first five pages of results contained a link to a FRAXA web page.

Research was the next category, which included clinical trials, cure, and research. Since furthering clinical trials is a huge part of FRAXA's mission, it would be good for the FRAXA website to show up when the term "Fragile X Clinical Trials" is searched. When "Fragile X Clinical Trials" was searched, the FRAXA Clinical Trials page was the fourth link. The three

results ahead of FRAXA's page were from the Genetic Disease Foundation, Fragile X Clinic, and the National Fragile X Foundation. The first two of the three were ads. FRAXA's "slogan" on their webpage is "Finding a cure for Fragile X," indicating that this is one of their core values. For this reason, "Fragile X Cure" was tested as a search term. FRAXA was the third result when "Fragile X Cure" was entered, with an ad from kennedykreiger.org and a link to the National Fragile X Foundation appearing first. The link associated with FRAXA leads to the home page. Both clinical trials and finding a cure for fragile X highly depend on fragile X research, so "Fragile X Research" was chosen as a search term. Searching for "Fragile X Research" returned a link to the FRAXA home page as well, but with this search term FRAXA was the first result.

The third category was fundraising. In order to fund research projects to work towards a cure, fundraising needs to be an important part of the FRAXA organization. "Fragile X Fundraising" did not show any results that included a link to FRAXA until the second page, as the link to the FRAXA homepage was the twelfth result. Links returned before FRAXA included six from the National Fragile X Foundation, two from crowdrise.com, livingwithfragilex.com, Fragile X Association of Australia, and two from basicallyfx.com. The main method by which FRAXA fundraises is by encouraging donations. The last search term used in the external search engine was "Fragile X Donate." FRAXA was featured as the fourth result, which linked to the FRAXA homepage. All three results returned before FRAXA were from the National Fragile X Foundation.

Given that the National Fragile X Foundation appeared before FRAXA in each of the three categories, it is clear that both websites have similar content and can be accessed in the same way. If FRAXA's website were to appear as a direct fit for the user's exact search terms in these categories, then there would likely be an increase in FRAXA's overall web traffic (Jerath,

485). In the circumstance where FRAXA's goals are insufficiently illustrated by the search terms above, work can be done to title webpages accordingly so that they show up when these terms are searched.

#### *5.2.2: FRAXA Website Search Bar*

In order to determine the scope of search results within the FRAXA website, six terms were entered into the FRAXA website search bar, and the resulting pages were recorded. The six terms chosen were:

- Clinical Trial Location
- David Nelson
- Fall X Ball
- Donate
- Listserv
- Parent Resources

These terms were chosen with the intention to encompass the variety of material and resources offered by the FRAXA website. By and large, the search results returned by the chosen terms were appropriate. The first term entered was "Clinical Trial Location." Three results were obtained from this search. The first was the main page for Clinical Trials on the website, the second was a list of all the Clinical Trial Centers that FRAXA has on file, and the third was the researcher page for Patricia Cogram. While the third page is not particularly helpful for finding a clinical trial location, the first two absolutely are. These two pages would most likely be exactly what a user would be looking for when entering that search term.

FRAXA likes to highlight many of their researchers on their website, to show users what their donations are funding and the progress that is being made. It was important to the study to

find out how easy it is to use the website to find a specific researcher and what he/she has worked on. A researcher (David Nelson, a researcher and Scientific Advisor for the FRAXA foundation) was selected at random, and his name was entered into the search bar. The first page on the list was his personal research page, which is what would give a user the most information about his FRAXA research. The other results the search came up with were "Resources for Scientific and Pharma Partners," "List of Scientific Advisors," and the page describing the cause of Fragile X. While none of these pages are exactly what a user would be looking for when researching David Nelson in order to find his research, each page references him or a piece of his research.

Next, "Fall X Ball" was entered into the search bar. Six links were displayed from this search. The first was the link to the page containing information about the 2014 Fall X Ball (which has already taken place). Next was a link to a video of a speech from the 2013 Fall X Ball. After that was a link to the 2013 Fall X Ball, and the last few results were links to various general events pages. In general, all of these links are helpful to have included on the search bar, as all would give a user some sort of information about the Fall X Ball. There is not yet any information about the 2015 Ball, but it can be safely assumed that as the date gets closer, there will be a similar page to the 2014 and 2013 pages.

Although donating to FRAXA was assumed to be fairly simple, given the many links on the homepage, "Donate" was still included as a term in the internal organic search, since donations are such an integral part of the FRAXA organization. The search returned forty results, many of which were not links to how to donate, but just FRAXA events that took place which allowed the opportunity for donation. The very first result returned was a page about how to donate stocks to FRAXA, with the second being the link to regular donation page.

A big part of the FRAXA community is the FRAXA Listserv. A listserv is an electronic mailing list that users can sign up for to get updates about FRAXA and communicate within the community. The first link that pops up is the page that appears after signing up for the FRAXA e-newsletter. Underneath the "thank you" blurb, there is a paragraph explaining how to get more involved, which includes instructions on how to join the listserv. The second result links to FRAXA's "Get Involved" page, which also displays instructions for how to join the listserv. The last two links that appear mention the FRAXA listserv, but do not directly link to the instructions to sign up.

One improvement to the website that was suggested by many participants in the current user survey (see section 5.4.7) was that FRAXA should provide more resources for parents. For this reason, "Parent Resources" was included as a search term for the internal search bar. Only three results were returned, and they were perhaps the least helpful of all the terms that were tested. The first result was a link to resources for scientists and pharma partners, which would most likely provide little or no help to a parent. The second result was exponentially more helpful, though still not exactly what a parent would be looking for. It was a link to a page called "Where to learn more about Fragile X," and provides links to outside sources that could be helpful to Fragile X parents. The last result was the About FRAXA Page, which doesn't really provide parents with any resources to care for their child.

### ***5.3: First Time User Survey***

A total of 113 first time users of the FRAXA website participated in the survey. Times, in seconds, were recorded and imported into Excel. The average time to complete each task was calculated, and the number of volunteers who did not complete tasks was tallied. The latter included both those who could not complete the task in less than 2 minutes and those who quit in

trying to complete the task. A separate histogram for each task was created where volunteers were sorted by time brackets for task completion. Single factor analysis of variance was also performed on the data collected to compare the average times and variance for different tasks.

Some results were gleaned from the first time user survey as a whole. First, many users were unaware that the main tabs (About Fragile X, About FRAXA, etc.) could be clicked on, and would bring them to a different page than the links underneath each tab would. This suggests that the tabs on the website may be confusing to users, and that another system might be more straightforward. Another observed behavior was that there were multiple pieces of information that volunteers were asked to find that they simply scrolled right past and did not see, which would suggest that some pages on the website contain too much text and important links are not flashy or highlighted enough to catch the attention of users.

### *5.3.1: Heat Maps*

A heat map is a great tool for website optimization. Survey participants can click on any part of the website and the survey tool records the frequency of clicks on each portion of the site. Parts of the site that are clicked on most frequently will show up in the red part of the color spectrum, and parts that are clicked on the least will show up blue. For the heat map portion of the survey, volunteers were first asked to click on the piece of the FRAXA homepage that first caught their eye when looking at it. Below is the heat map generated from the seventy volunteers who took the heat map portion of the survey for Trial 1. During Trial 2, the Qualtrics data was recorded incorrectly, therefore the data has been removed. A picture of the homepage of the website without the heat map can be found in Appendix C.

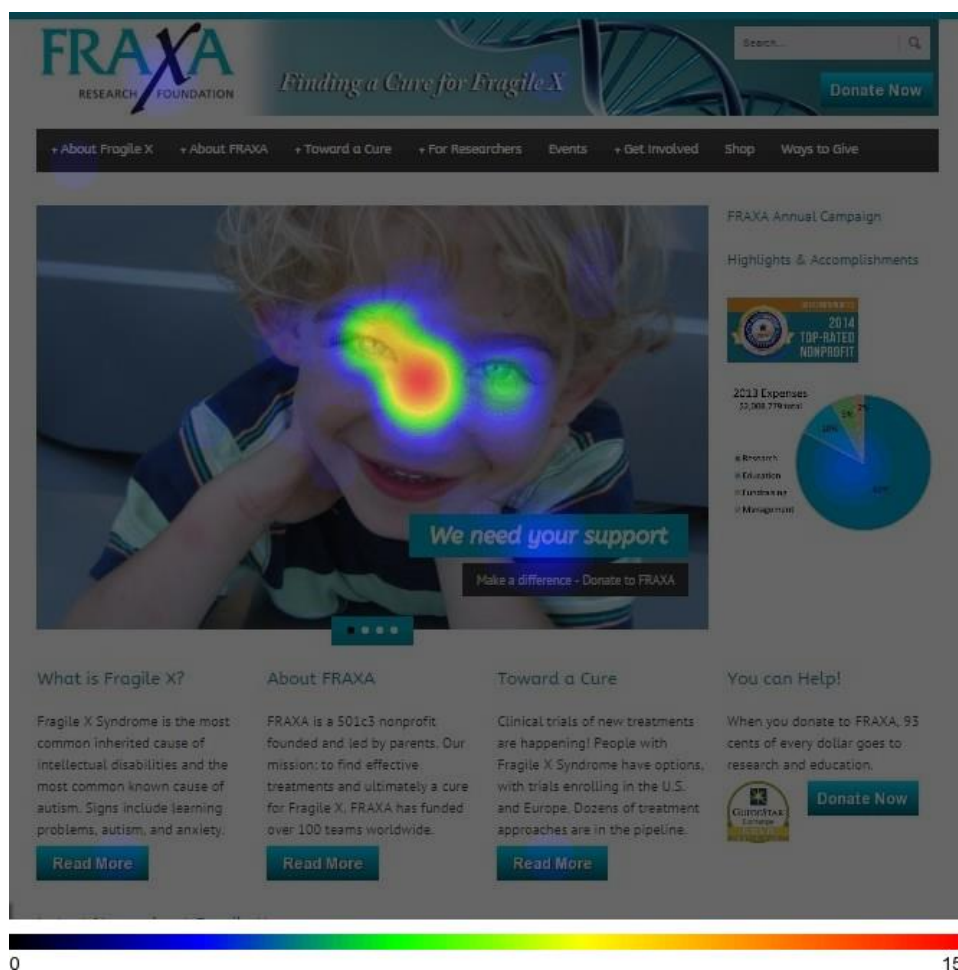


Figure 5.4: Heat map for the question: "Which part of the website first catches your eye?"

As can be clearly seen in the picture, the vast majority of people were first drawn to the picture of the boy on the homepage. Considering that clicking on that picture would bring the user to a donation page that is definitely a positive outcome. However, this also shows that most other parts of the website are simply not as noticeable as the huge picture that takes up most of the page. Anything that FRAXA wants to highlight besides donating is not immediately noticed by the viewer, such as increasing awareness of Fragile X Syndrome.

In the heat map below the same picture of the FRAXA homepage was utilized, but at this time volunteers were taking a second glance. After taking a moment to consider, volunteers clicked on the area that they believed would lead to helpful information.



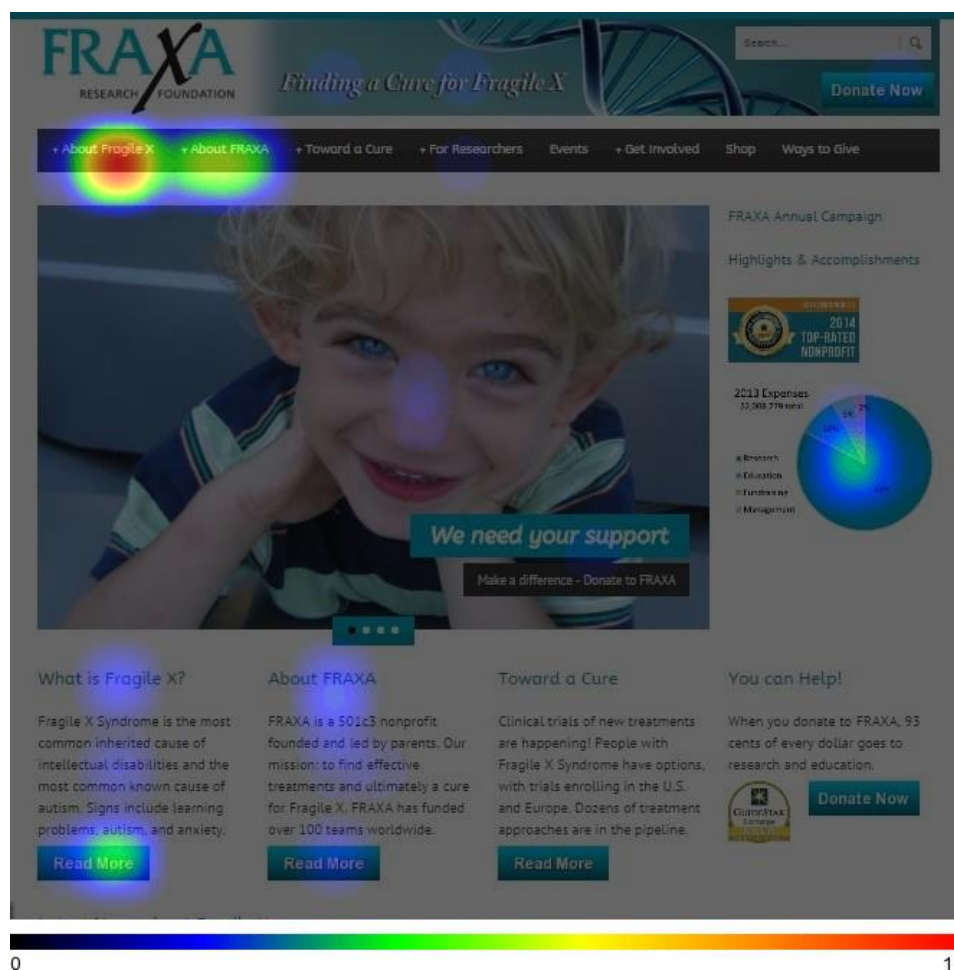


Figure 5.5: Heat map for the question: “Which part of the website seems to you like it would be the most helpful?”

Here the data supports the idea that being first time users, they would want to seek more basic information about Fragile X and FRAXA. The majority of users chose to click on the “About Fragile X” or the “About FRAXA” links on the navigation bar. Other users noticed the short introductions to “What is Fragile X?” or “About FRAXA,” whether it was the blue title, the introduction, or the “Read More” button. The “About Fragile X” and “What is Fragile X?” link to the same page; similarly both the “About FRAXA” on the navigation bar and the link in the blue title also lead to the same page.

Some users clicked on the pie chart shown to the right of the picture of the boy. The pie chart displays distribution of expenses in 2013 between research, education, fundraising and

management. This simple infographic also leads to the “About FRAXA” page. It can be concluded that most users are seeking basic information about what FRAXA is and what Fragile X is as well.

### 5.3.2: Clinical Trial Location Task

For the Clinical Trial Location task, the volunteers were asked to find a location for a Clinical Trial on the website. This task seemed to not pose a problem to many first-time users. Two users ran out of time to complete the task, which accounts for the two occurrences of "more," but the majority of volunteers hovered around thirty seconds to find the page. However, it did take many users multiple clicks to find the page. Almost no users were able to find it immediately. From this task, we believe that the Clinical Trials portion of the website, for being such a central part of FRAXA’s mission statement, could be presented in a more noticeable location or manner.

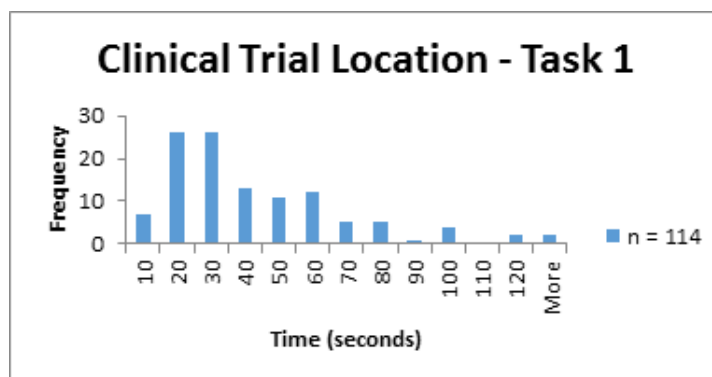


Figure 5.6: Histogram showing the amount of time taken to complete the Clinical Trial Location task

### 5.3.3: Researcher Task

While surveying volunteers, a name was given to them with the task to find more information about that person. The name given belongs to a randomly chosen Fragile X researcher. This was designed to be a more difficult task to assess the difficulty of finding a less noticeable page on the FRAXA website. Many people took about 50 seconds or less to find

information about the researcher.



Figure 5.7: Histogram showing the amount of time taken to complete the Researcher Task

In the first trial of surveys, some volunteers were told that the name they were given belonged to a researcher and other volunteers were not. The differences can be seen in the following graphs.

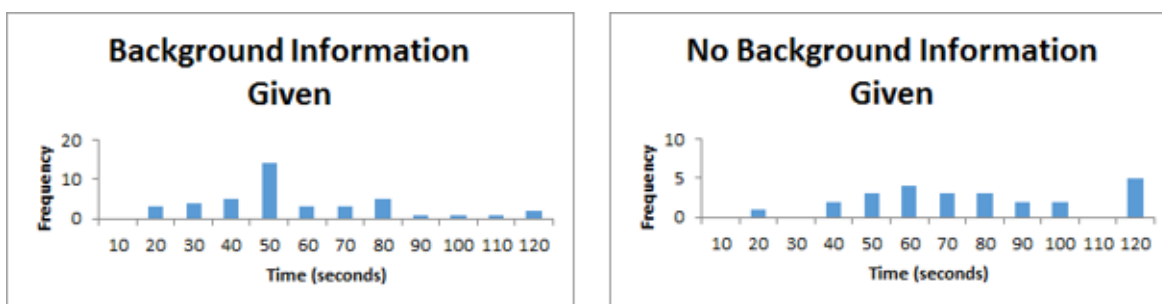


Figure 5.8: Histograms showing the difference between first-time users who were given background information for the Researcher Task and those who were not during Trial 1 (n=69)

A general behavior that was observed in volunteers who were not given background information about the researcher was searching through the various tabs under “About FRAXA,” which are “Board of Directors,” “Honorary Board,” “Our Staff,” “Scientific Advisors,” and “Regional Contacts.” Volunteers would scroll down on a page looking for the name given and if it was not found move on to one of the other tabs listed above. As shown in the graphs, those who given background information were able to find the researcher faster overall than those who were not.

For the second trial of surveys, the fact that the individual is a researcher was given. Even with the extra information given to them, volunteers were hard pressed to find the page of the specific researcher. Several survey takers immediately looked under the "For Researchers" tab when given the background information, which lead them in the wrong direction. Even though one of FRAXA's main goals is to highlight the research that they fund, that information is very difficult to find on their website.

#### 5.3.4: Fall X Ball Task

Volunteers were then asked to find information regarding the Fall X Ball to determine how easily one could learn more about Fragile X events. The "Events" tab in the navigation bar was a common route students took to find such information. When hovering over the link, no additional links are provided below, therefore it was clear to volunteers that the navigation tab would bring them to event information. Since the events page is ordered by date and both survey trials were done in the winter months after the 2014 Fall X Ball, the 2015 ball was not the first event listed. Volunteers had to scroll through the page until the October events were shown.

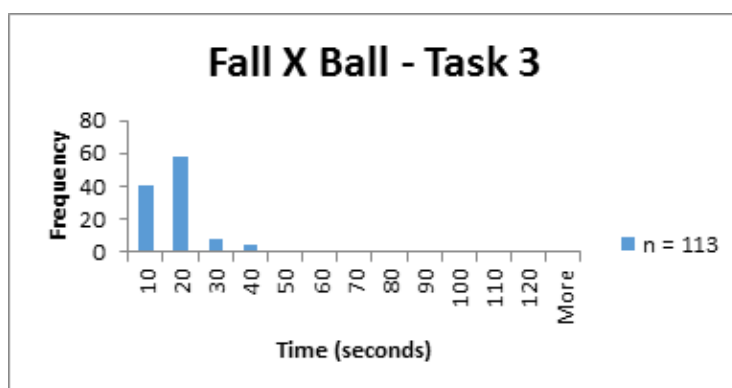


Figure 5.9: Histogram showing the amount of time taken to complete the Fall X Ball task

#### 5.3.5: How to Donate Task

The fourth task students were asked to complete was to find a way to donate to FRAXA. On the top banner there is a button captioned "Donate Now," as well as a link in the navigation

bar titled “Ways to Give.” The “Donate Now” button is positioned above and slightly to the left of “Ways to Give” and is underneath the search bar. The vast majority of volunteers first noticed the “Ways to Give” and followed that link to find information pertinent to the task given. This indicates that even though there is a separate button used specifically to donate, it is clearly not very noticeable to a first-time user.

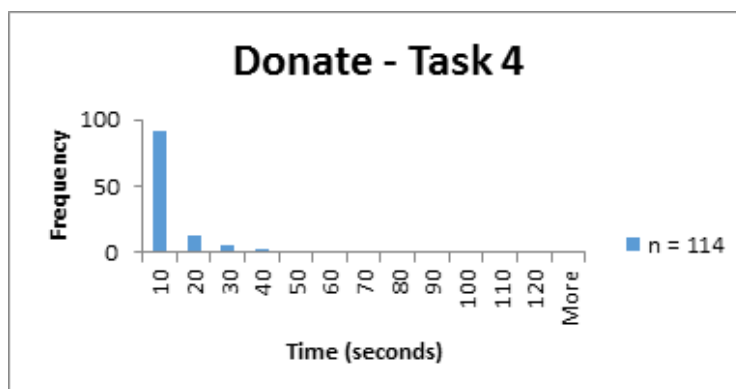


Figure 5.10: Histogram showing the amount of time taken to complete the Donate task

### 5.3.6: FRAXA Listserv Task

When asking volunteers to find information about the FRAXA Listserv, seldom did individuals know what a listserv was, or even understood what word was being said. Surveyors had to explain what a listserv is (a form of automatic email management where the sender can send one message and all electronic addresses listed on the listserv will receive the message). Once explained, volunteers overall had a quick understanding of where to look, often going to the “Get Involved” tab on the navigation bar or clicking on the “Learn More” option that appears in the drop down menu under “About FRAXA.” Other volunteers found the link to sign up for the FRAXA E-newsletter, and believed that to be the same as the FRAXA Listserv, even though they are two different things. While the idea behind the creation of the FRAXA Listserv is wonderful, the difficulty first-time users had in finding the correct web page or understanding what a listerv is illustrates that potential new members of the FRAXA community may have

similar difficulties as well. If the FRAXA Listserv was better highlighted on their website, more new members may be obtained.



Figure 5.11: Histogram showing the amount of time taken to complete the Listserv task

### 5.3.7: Task Comparison

As expected, the below Figure 5.12 illustrates that the average time varies between tasks. Each task was chosen specifically to provide variety in level of difficulty. The “Donate” button and “Events” tab are very straightforward for their purpose, and for this reason the two relevant tasks were expected to be simple. Those two have the lowest medians and smallest variances. The first task, clinical trial location, fell directly in the middle for average time. The longest average times were for finding a specific researcher’s information page and finding out how to get involved with the FRAXA community through the listserv. As stated previously, the increased time required for finding the listserv could be a result of volunteers not understanding the term. Finding information on researchers required more sifting through the website, and one volunteer noted that in most instances, a new user would probably use the search bar.

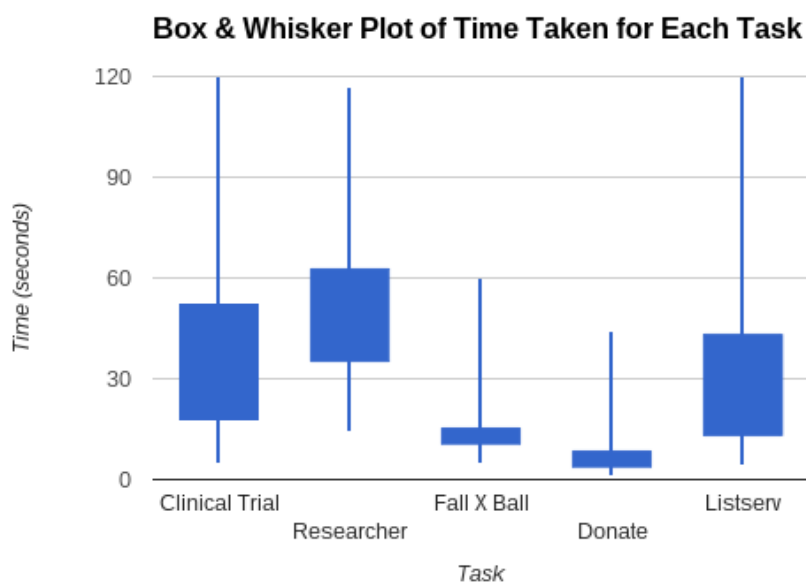


Figure 5.12: Box & Whisker Plot representing the amount of time taken for each task ( $n = 114$ )

Students who did not complete tasks given either timed out after two minutes or quit looking for information. It was expected that the Researcher Page task would be one of the more difficult tasks to complete but the difficulty of the listserv task was unexpected. This could be due to a younger target audience who has not grown up with "listserv" in their vocabulary, but is more comfortable with the terms "email alias" or "newsletter signup." No subjects were unable to find information about how to donate. Only one volunteer did not find information about the Fall X Ball. Figure 5.13 below, along with the previous figures, helps to illustrate what types of information may need to be made more accessible for current and potential members of the FRAXA community depending on how important FRAXA deems that information to be.

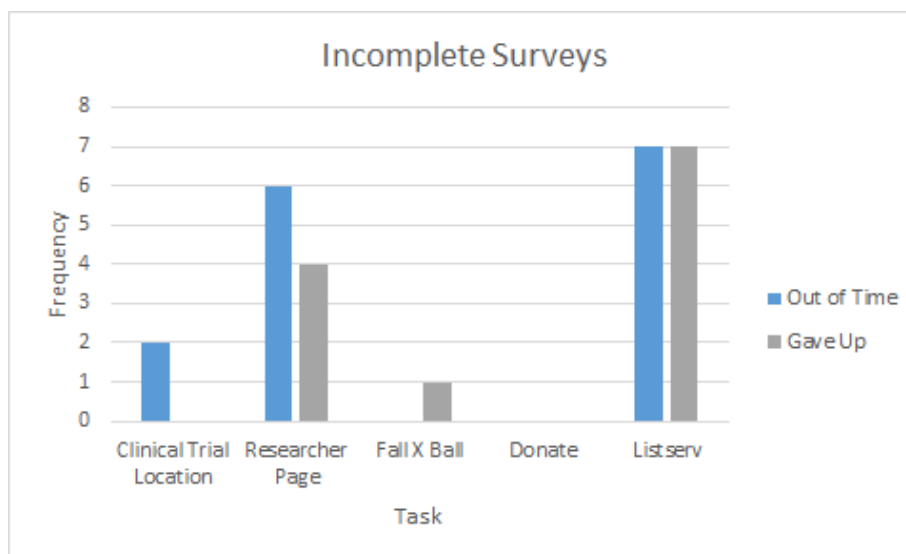


Figure 5.13: Bar graph showing the number of volunteers who did not finish each task (n = 114)

## 5.4 FRAXA User Survey

### 5.4.1 General Overview

At the time that the survey was closed, 217 people had responded with 62% of them having fully completed the survey. The clear majority of respondents were parents of someone with Fragile X, and many others were family members or caregivers. Discussion on results from the FRAXA User Survey will focus primarily on questions that are relevant to our focus of inquiry, so not all questions that appear in Appendix A will be reviewed here.

### 5.4.2 FRAXA Audience

As shown in Figure 5.14 below, the largest group of respondents were parents, and many other users identified themselves as a relative, such as a grandparent, aunt, uncle, cousin, or sibling of someone with Fragile X. The main audience that FRAXA is reaching at this time is comprised of family members. This trend is also reflected by the membership of the FRAXA listserv, which contains about 700 members with the majority being parents. It can be concluded that the following questions will focus on parents and caregivers due to the demographics discovered by this first question.



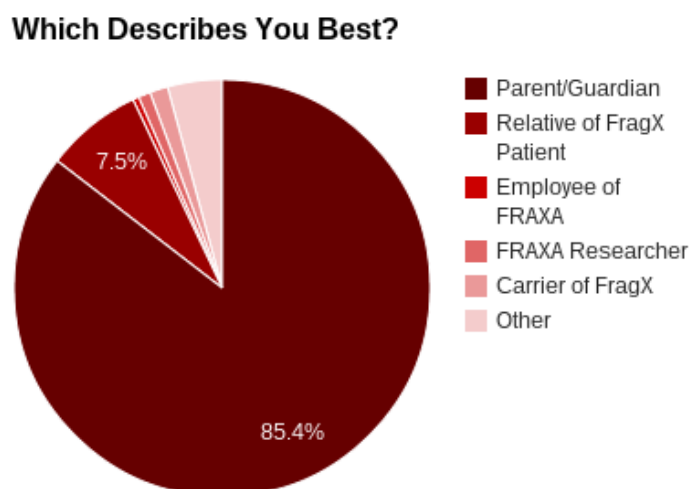


Figure 5.14: Pie chart showing the different groups of people answering the survey, and how they are related to the FRAXA foundation (n = 214)

### 5.4.3 Frequency of Website Usage

Those who took the survey are invested enough in the FRAXA community to spend time providing this feedback. As shown in Figure 5.15, 80% of survey takers visit the FRAXA website once a month or less. As the number of website visits increases, the number of users decreases. With about 700 participants on the newsletter mailing list, about 3000 followers of the Facebook page, and 217 survey takers, the data suggests that of the active users of the website, 80% of these users do not find it necessary to visit the FRAXA website more frequently than once a month or less.

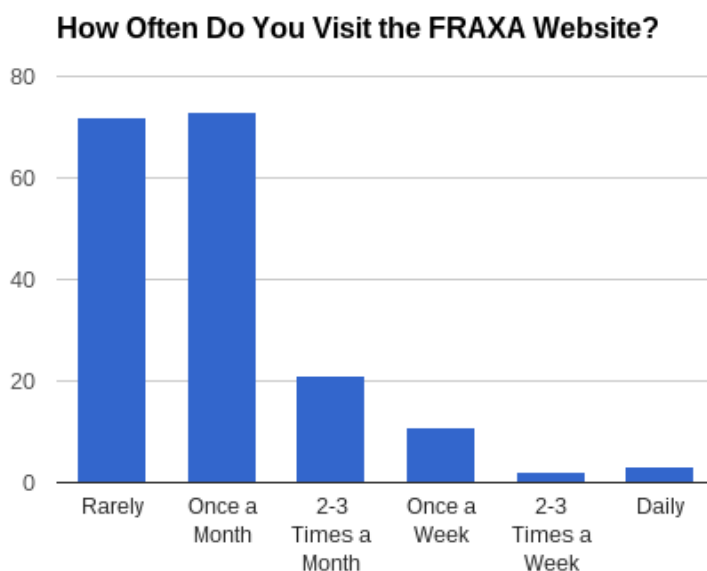


Figure 5.15: Bar Graph showing how often survey takers use the FRAXA website ( $n = 182$ )

Given these results, it may be that participants get all of the information they need from other sources, such as the email newsletter or Facebook updates, and do not feel the need to visit the website for additional information. Another possibility is that the website does not have what the user is looking for, in which case other sources would be used. Noting that the majority of the email list consists of caregivers and carriers of FRAXA, it is possible the users see the website as a knowledgebase to receive updates on research and not as a resource for caregivers.

#### 5.4.4 User Suggested Changes to Website Layout and Design

Only 21 respondents chose to answer the open question "What about the layout/design of the website would you like to see changed?" Of those, 11 gave an answer that they did not think any changes would be needed or that the FRAXA website is nice the way it is. Three responses indicated that navigation is an issue and that they have trouble finding items such as resources, old articles, and videos. Another response indicated that pages are text rich and another said that the formatting needs to be cleaner. A similar response said that the pages look nice but are

boring, that the format seems to be focused on mobile users, and that there is too much space on the sides. One user asked for an audio feature so that material can be read for users. It is thought that there was a lower answer count to this question as it was open ended. The question was created in this way to gauge overall thoughts on the FRAXA website without putting forth suggestions for the users to choose that could influence their responses.

#### 5.4.5 Most Frequented FRAXA Web Page

Of the survey participants, 40% visit the "Toward a Cure" web page most frequently. This section consists of information on FRAXA research teams and their findings, clinical trial information, and news on Fragile X advances. 24% of survey participants visit the "Clinical Trial" page most frequently, which is located underneath the general "Toward a Cure" tab. Specific clinical trial information is provided on this webpage, such as trial sites, sponsors, and medicines. 20% of survey participants visit the FRAXA homepage most frequently, which contains recent news and links to the donation page.

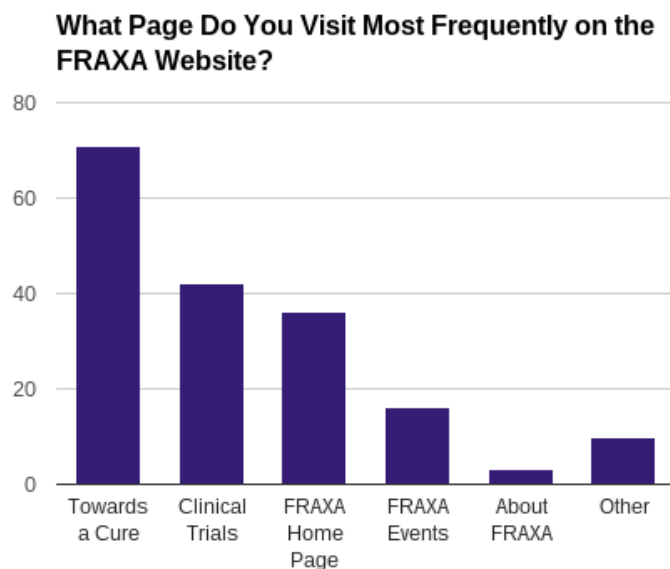


Figure 5.16: Bar Graph of which page survey takers visit most frequently on the FRAXA website (n = 178)

It can be noted that the Toward a Cure and Clinical Trial pages have the most frequent

visitors of the active survey responders. Given this data, it can be considered that users may be looking for new clinical trials or for any new research. Considering these pages are reportedly the most frequented on the FRAXA website, the data suggests that FRAXA provides beneficial resources for its audience in regard to clinical trials and research.

#### 5.4.6 Most Helpful FRAXA Webpage

With a clear leading percentage of 50%, the "Towards a Cure" web page was chosen to be the most helpful to users, which was also seen to be the most frequented FRAXA web page. "Clinical Trials" had the second highest percentage, which is closely linked to the "Towards a Cure" page. Responses under "Other" include all web pages, "Meet our Kids" Fragile X information, "Learn More," and the "Shop" tab.

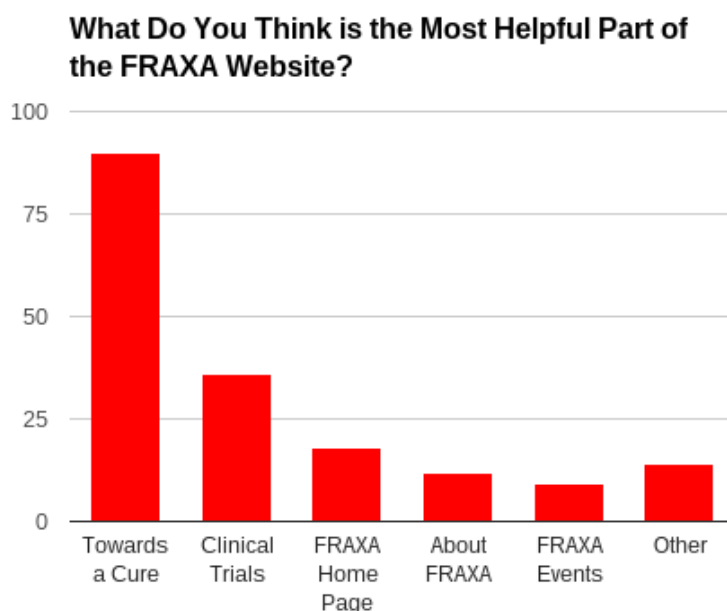


Figure 5.17: Bar Graph of what survey takers find to be the most helpful page on the FRAXA website (n= 179)

One user stated that s/he does not visit the website often, but is subscribed to email updates. With the majority of the responses focusing on research and clinical trials, it can be inferred that users are looking to follow updates on research and potentially sign up for any trials

if locations are nearby.

#### 5.4.7 User Suggested Content Addition to Website

As can be seen below, 81 of 163 respondents who answered would like to see more resources for parents and families on the website. Some respondents who chose to answer "Other" did so in order to give specific suggestions that were also resources, such as sibling resources, getting help with state services, parent support groups, a handout to give to those interacting with Fragile X children, other diagnoses with the same symptoms as Fragile X, and layperson language.

**Is There Any Information You Would Like to See Added to the Website?**

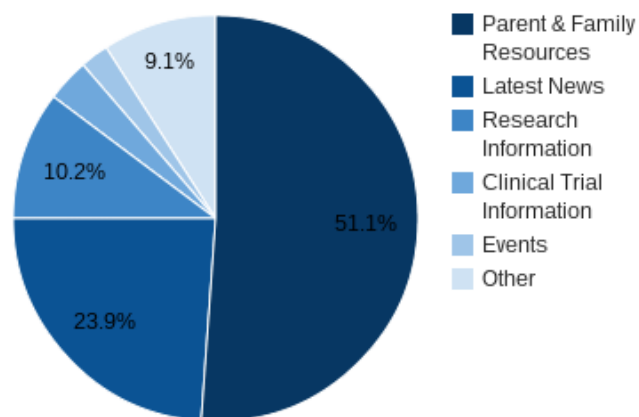


Figure 5.18: Pie Chart showing what information survey takers would like to see added to the website (n = 163)

Other answers included personal stories and family success stories, suggesting that some users are not aware of the "Meet Our Kids" web page. The suggestion asking for tips on making a Fragile X child's life easier indicates that the resource "Fragile X - A to Z; A Guide For Families By Families" is not easily seen or that it may not contain enough information. Another example of a suggestion that asks for a resource that is currently on the website is for a link to Dr. Mike's Blog, which can be found after clicking on the "Learn More" option under "About Fragile X." A few answers indicated that those users were satisfied with the current amount of

information on the FRAXA website.

There are a few important details that can be inferred from the results of this question. First, that the users would like there to be more parent & family resources. Second, that while some parent & family resources as well as other web pages do exist, the users may not be able to successfully find this information. Third, that those who are able to find these resources and pages on the FRAXA website may have deemed that these resources and pages do not contain sufficient information.

#### 5.4.8 User Ratings of Current Website Components

Based on the responses illustrated in the above bar graph, the highest rated components of the FRAXA website are the quality of information, home page, and "About Fragile X" page. This is ideal in that the FRAXA survey responders find the information to be of high quality, which is an important matter when appealing to potential donors. Lowest rated components of the website were the events page, images and videos, and patient stories. These aspects of the website likely to be more important to a carrier of or a caregiver to an individual with Fragile X. Improvement on these sections could increase the sense of connection between the web user and the FRAXA website.

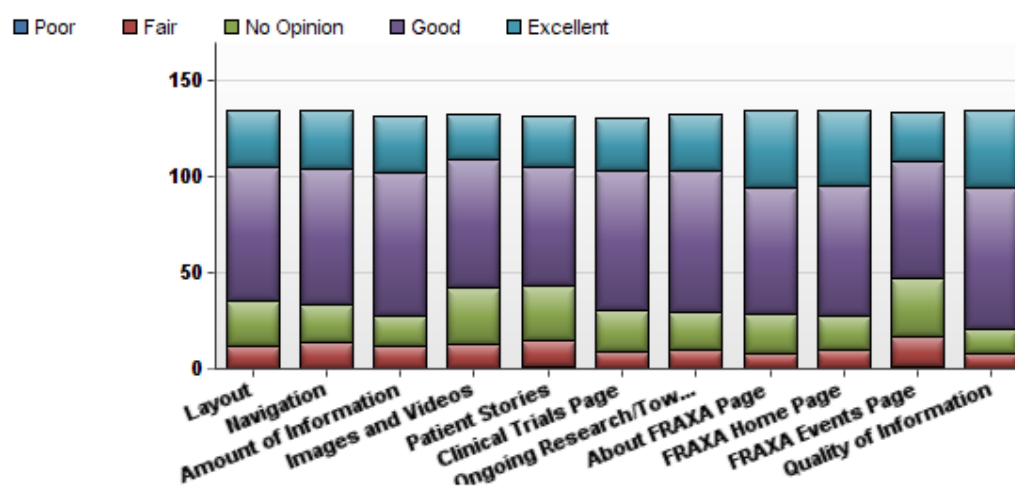


Figure 5.19: Bar Graph of website component ratings (from n=130 to n=134)

#### 5.4.9 User Awareness of Clinical Trials

Overwhelmingly, almost 99% of users are aware that there are clinical trials. This is wonderful for FRAXA since their mission is to find a cure for Fragile X Syndrome, and clinical trials are an integral part of research for the cure (FRAXA(2)).

#### Are You Aware That There are Clinical Trials for the Treatment of Fragile X Syndrome?

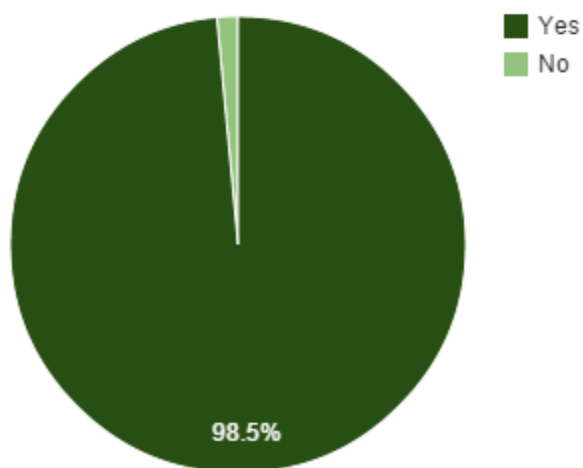


Figure 5.20: Pie Chart showing awareness of clinical trials (n = 135)

#### 5.4.10 Summary of Survey Results

Most of the 217 respondents that answered identified themselves as either a family member or a caregiver. Katie Clapp, co-founder and president of FRAXA, has identified that the target audience at this time is parents and other family members (personal communication, January 26, 2015). Since the major demographics of this survey and the target demographics of FRAXA align, results and suggestions from this survey are highly relevant. Overall, those who responded with comments about overall potential changes to the website focused on different format changes and ease of navigation. Currently, "Towards a Cure" and "Clinical Trials" are the two pages that are most likely to be visited or used as a resource. However, most of those who

responded visit the FRAXA webpage less than once a month. When asked what type of information users would like to see added to the website, most asked for parent and family resources. Some respondents even chose "Other" in order to give specific suggestions, such as parent support groups or handouts to give to those interacting with Fragile X children.

The general response provided a high rating for quality of information, which is a positive reflection of FRAXA's overall delivery of news to the website users. In remaining consistent with this quality of information, providing caregiver resources with quality as a priority will be beneficial to the audience of FRAXA.



## Chapter 6: Conclusions and Recommendations

### 6.1: Design

#### 6.1.1: Website Homepage

As shown in Figure 6.1, a conceptual design for the website homepage would feature three main categories, "For Parents and Family Members," "Get Involved with FRAXA," and "For Researchers." This is a simple yet very informative layout and would help direct users to areas of the website that would be most useful. Websites are more practical when organized by a hierarchy based on themes, which allows users to follow menus and links as they travel to the depth needed to find information (Djonov). By following themes and corresponding specifications as a user navigates a website to find information, the task is made easier due to an increased sense of direction. Additionally, themes create cohesion between topics and allow for related information to also be more easily found (Djonov). Due to these reasons, the conceptual rework of the homepage has three themes indicating where certain types of information can be found relatively quickly.



Figure 6.1: Possible concept for the "FRAXA.org" homepage

In terms of implementation of this suggestion, users of the website should be notified of this change, considering it is significant and would affect each individual user of the FRAXA website. This notification could be via social media, such as Twitter, Facebook, newsletter, and other means of communication. Notifying users of the website before making drastic changes would help avoid confusion and would communicate the motives for such changes to the users.

### 6.1.2: Donate Button

There is little contrast between the "Donate Now" button and the home page header. As stated in the results section, many first time users did not click the button in order to donate to FRAXA and instead clicked "Get Involved" in the navigation bar directly beneath it. By providing contrast between the donate button and the header, the user's attention will likely be caught by the difference in color (Plumley, 2010). In order to make the button stand out more, a soft yellow (#FFE96B) has been chosen to stand against the current teal of the banner. The result is shown in Figure 6.2.



Figure 6.2: Proposed color change

As seen in above Figure 6.2, the yellow provides a change in color on the banner. As suggested by the literature, the images were changed to black and white in order to gauge the level of contrast between the button color and the header color (Figure 6.3).



Figure 6.3: Contrast check

The soft yellow has significantly more contrast against the background than the previous light blue. The soft yellow was chosen as it is a warm color as opposed to a cool color. It is not the exact complementary color of the teal, as the contrast would be beyond the point of providing button emphasis and would become a visual distraction (Plumley, 2010). The yellow is highly visible against the darker teal background without becoming a distraction to the user.

### 6.1.3: Photo to Text Ratio

When viewing the FRAXA homepage, there are different types of photos shown. The photographs, graphics, and elements all contribute to the aesthetics of the page; however they may be distracting from the overall goal of the website (Plumley, 2010). During the first-time user survey, for the second heat map question "What seems most helpful to you," respondents often took a period of time to glance over all of what the homepage has to offer. There are many photos and graphics that direct the user's attention, which may distract them from their original goal when using the website.

With further scrolling through the website, one comes across several photos, which are of various sizes. They are surrounded by significant white space which contributes to the somewhat unorganized appearance. After observing the photos more closely, one can see that the photos

and graphics are in rows and columns. With the addition of lines or modules, more structure in the form of shaded boxes may be provided to better organize content (Plumley, 2010). This can be incorporated in the FRAXA news on the homepage. When considering the background graphic of the homepage in addition to the white space behind the content, it may seem that the page is too compact (Plumley, 2010). There is more space available that could be utilized to spread the page out and better display the given information.

While it is clear from the heat maps in the first time user survey that the photos and graphics are what capture the immediate attention of visitors, it is important that the actual web content is displayed as well (Plumley, 2010). In terms of immediately loading the FRAXA homepage, the content that loads predominantly consists of photos. This photo to text ratio may be initially overwhelming for users, as there are many more visual graphics to take in than there are explanations. In comparing the homepage to a newspaper, ideally the information over the centerfold should catch the reader's attention with graphics and explanatory text to encourage further reading (Plumley, 2010). By increasing the amount of explanatory text or reducing the number of photos on the homepage, the FRAXA homepage visitor may be more inclined to read on about certain articles as opposed to not acquiring enough information to become intrigued about the photograph.

## ***6.2: Organization***

### ***6.2.1 Clinical Trial Map***

Currently on the FRAXA website there is a text and information rich page about clinical trials. At the top there is a short section encouraging participation, thanking families, and explaining the clinical trial process. Clinical trials are listed below, and information about locations can be seen once a button is clicked. A way to improve the clinical trial page would

be to incorporate an alphabetical list of clinical locations by state, similar to the way that the "Regional Contacts" under "About FRAXA" is laid out. There could be a clickable link under the initial text but before information about specific clinical trials is seen. The link could bring the user to a new page.

Another possibility to make clinical trial locations easier to find would be to use a map. ZeeMaps, is one tool FRAXA could utilize to create interactive maps with clinical trial locations. ZeeMaps allows the user to create locations on a Google Map <sup>TM</sup> by inputting information manually, or uploading information using Google Spreadsheets <sup>TM</sup>, Microsoft Excel <sup>R</sup>, or a csv file (ZeeMaps). Locations can be color coordinated, and in FRAXA's case this could be used to organize locations by clinical trial using the same color. Additionally, color regions can also be added. The final map product can be imbedded into a website as an interactive map or published as a picture or pdf (ZeeMaps). Cost for ZeeMaps is relatively low. As a basic user, FRAXA would be allowed to create 5 maps, and there is no monthly or yearly fee. The highest amount of locations allowed on a map with the free basic account is 100, but that should be no issue for FRAXA since the number of clinical trial locations listed currently on the website is less than twenty. The only costs FRAXA would have to potentially pay for would be removing ads from their published maps (\$49.95), removing ads and the ZeeMaps logo from their published maps (\$99.95), or if they chose to publish the maps as a pdf or image (varies, likely \$9.95 at most) (ZeeMaps). Below, a sample map has been created using the ZeeMaps tool, containing all the Clinical Trial locations listed on the FRAXA website that are within the continental United States.



Figure 6.4: Map created using ZeeMaps, containing all Clinical Trial Locations listed on the FRAXA website that are within the United States

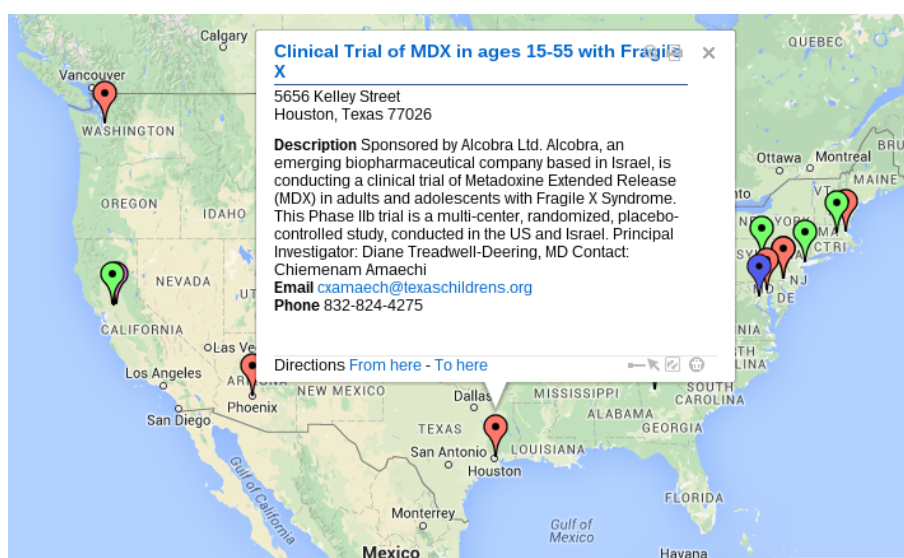


Figure 6.5: Display that would appear when a location is clicked on in the ZeeMaps tool

Another possibility would be to incorporate a map of clinical trial locations into the potential app that is being proposed by another team working with FRAXA. If a map were used in the potential app it could still be interactive for users. The app could also link to the website for more clinical trial information based on which clinical trial site was chosen.

### 6.2.2 Internal Search Bar

When searching for information on the FRAXA website using the internal search bar, the display of results can be confusing. The following image is a screen shot of what appears when

an individual searches the term “Parent Resources.”

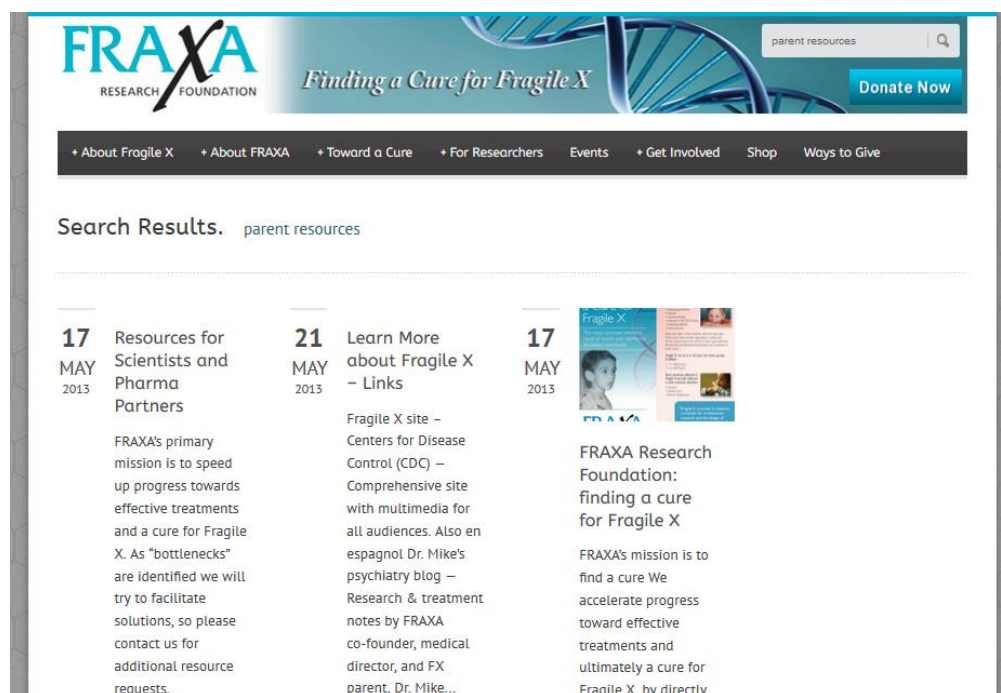


Figure 6.6: Screen shot of the search results page after searching the term “Parent Resources”

When results appear, they are sorted by date so that the most recently posted web page is seen first. The date's font is large and immediately to the left of each result, which appears with a picture at the top if there is one, a short title or lead in, and then some further text. This layout for each result is contained within an upright rectangle. The appearance of the search results is very similar to the way FRAXA displays news on their home page, "Latest News about Fragile X." This may be somewhat disorienting to a user and turn them away from following a link, believing it to be news and not a resource. An alternative would be to display results in a horizontal style, with the most relevant results appearing first and less pertinent sources below. Also, the part of the result that should be immediately noticeable is the title or first phrase of the web page instead of the date. An applicable image could be retained for each image, as pictures do help to draw a reader's attention. This sort of formatting when search results are returned can easily be seen if one uses a major search engine, such as Google™ or Bing™. By using a

similar formatting, results will appear in a more familiar way to users and the use of the returned results will be more intuitive for the users.

When phrases were searched for within the FRAXA website, most results were appropriate to the search terms used. However, some initial pages were not helpful information, and the returned web pages that could have better served a user were listed later in the list of pages. Many people do not read very far into returned search results, so it would be best to have the more relevant pages appear at the top of the list. Better search optimization for within the site should be employed to enable easier searches for users.

### *6.2.3 Display of Events*

When the website user clicks the "Calendar of Events" shown at the bottom of the homepage, the following webpage does not include a visible calendar. Instead, there are several rows of text that state the dates of each event with minimal descriptions. If a visual calendar were added to the "Calendar of Events" webpage, the page layout would be more consistent and more organized for viewers. Events on the calendar could be linked to dedicated webpages, highlighting information for the most recent or upcoming event. There are websites available that allow users to create interactive online calendars for free or for a monthly fee.

One platform that is available for FRAXA to utilize is UpTo, Inc. UpTo allows customers to share and sync their calendars. As a free user, one can embed a calendar in the web page and allow other customers and users to find the calendar on UpTo. However, only one calendar is allowed to be embedded, though they are allowed to create unlimited calendars (*Choose A Plan*, 2015). Custom photos are able to be used for events and different layouts. Additional features come at a cost. at \$9.00 a month, a user is able to further customize with colors, fonts, links to registration and tickets, as well as embed up to two calendars in their webpage (*Choose A Plan*,



2015). When a customer pays \$29.00 a month, they receive the benefits of the previous plan, but can now embed an unlimited amount of calendars as well as remove the UpTo logo from their creations (*Choose A Plan*, 2015). Different formats that are available are list view, a month view, a week and list view, or a month and list view (*Add New Embed*, 2015). Considering that FRAXA already has a simple list view and few events listed over the course of the year, only the list view would be feasible. Changing the format or the program used to create the calendar list would only create more work for FRAXA.

### **6.3: Content**

#### *6.3.1: Parent & Family Resources*

In the survey for FRAXA users, many participants gave feedback asking for resources, whether it was specific in naming a type of resource or indicating that they were interested in resources. As mentioned earlier, some of those resources need to be better organized or featured more prominently than they are already on the website; existing resources and links to external web pages do contain viable information regarding interactions with kids who have Fragile X, carriers, and parent support information.

There is a link to a website owned by Marcia Braden, an expert on Fragile X development, seeded under "For Fragile X Families" in "About Fragile X." Her website contains resources and guides for parents and those who interact with children who have Fragile X, and they focus on behavior modification. Two of her articles from 2013 are titled "Behavior Modification in the Classroom" and "Behavior Modification in the Community." They are the first two parts of a four part series, yet the remainder of the series is not up on the website. Additionally, Braden takes readers through a story as she explains her topics, and does not hone in on quick tips or charts immediately. The articles are lengthy, especially for a parent who may

not have much free time while taking care of a child with Fragile X. Also available on her website are Fragile X Lecture Series on DVD, but these are for sale and most often people will look for free resources first. Perhaps to add to the resources on the website, FRAXA could create a short video that highlights key points when interacting with a child who has Fragile X. Underneath or nearby the video could be direct links to Marcia Braden's articles for further reading.

Another resource that is also underneath "For Fragile X Families" is "Fragile X - A to Z; A Guide For Families By Families." This is a document that was originally created back in 1998 and was updated in 2006. At this time, this resource may need to be revised and updated but it is still a high quality resource for parents looking for ways to make their child's life easier. Topics are ordered alphabetically with some having family stories, links to external websites for more information, outlines and charts for quick tips, and cited resources for further reading. A wide range of topics are covered from bike riding to toilet training to education to medication. This document does not appear when using the internal search engine using phrases such as "Guide" or "A to Z." Thus, this valuable resource is not very visible.

Sibling resources are available on the FRAXA website, but they are difficult to find. If one reads the "Fragile X- A to Z" document, there is a section titled "Sibling Support." After a short story describing how a sister interacts with her Fragile X brother, there is a description of The Arc, a national community organization for those with and families of developmental and intellectual disabilities (The Arc, 2015). The Arc has a program for sibling support, and this falls into the category of sibling resources that was asked for on the survey. Instead of taking the information that The Arc provides and turning it into a FRAXA resource, a simple solution would be to provide the link under "For Fragile X Families" in the "Learn More" tab of "About

Fragile X." Providing links to other websites and pages would be a quick and easy solution for FRAXA, and this can be done for multiple resources and websites.

There are also some resources for carriers of Fragile X in "Fragile X - A to Z." Topics there focus on medication and genetic testing. Additionally, carriers are also mentioned in the "Fragile X-associated Disorders (FXD) Handbook," which contains information on reproductive options, tremor / ataxia syndrome, primary ovarian insufficiency, and treatment options. This information may be what the carriers who took the survey were looking for but could not find it. A better labeling or a separate webpage or form may be helpful for carriers of Fragile X.

Another resource for parents and family that was directly asked for was support groups. FRAXA currently offers the opportunity to join their listserv, which is over 800 members strong. According to the website, the purpose of the listserv is to be a virtual support group where all different members of the FRAXA community can share questions and tips about living with Fragile X (FRAXA(3)). Additionally, "Fragile X - A to Z" was written in part by parents. Here they contributed stories, ideas, tips, and tricks that had help their children in some way. Another form of support group that may be available for the FRAXA community in the future is a FRAXA app. Currently there is another group which is looking into the feasibility of an app for FRAXA, and one of the features that could be worked into that is a discussion board. This would make discussion easier among parents and would be extremely mobile.

One FRAXA user response mentioned that resources that aid in getting help from state services, such as placements and jobs, would be useful. Again, some information can be found in "Fragile X - A to Z." Under the topic "Life Planning," there are website links and descriptions. Some involve planning for a child after the caregiver's death, but there are other links that pertain to obtaining help from the state and jobs. The Arc is one such resource which is mentioned in

multiple places in "Fragile X - A to Z," and on their website they do have articles and webpages containing information about government benefits and jobs.

Another resource that was asked for in the FRAXA user survey was other diagnoses with the same symptoms. Under "About FRAXA" on the "Symptoms" page FRAXA does well in explaining and identifying the symptoms of Fragile X and the other conditions individuals with Fragile X have. However, no resource could be currently found on the website specifically mentioning other conditions that could be mistaken for Fragile X. Perhaps a simple web page that could link from the "Symptoms" page containing this information would be a useful resource.

### *6.3.2: Electronic Communication Tools*

Throughout the First-Time User Surveys, it was noted that participants initially had a difficult time finding the correct information and location to sign up for the FRAXA listserv. The majority of participants believed that the "Email News - Sign Up" button located at the bottom of each web page was what was being asked for. It may be beneficial to FRAXA to have a portion of their side bar highlighting the different forms of electronic communication that primarily family users can utilize for their benefit, such as the email newsletter and listserv. This information could be a sidebar feature in sections such as "About Fragile X," "Learn More," and "Parent Resources." Since there are many ways to get involved, the sidebar feature could be a graphic or button similar to what is at the bottom of the FRAXA website currently. This link would lead to a webpage dedicated to descriptions of these methods of involvement with their respective submission forms.

### *6.3.3: Sidebar Content*

On most pages of the FRAXA website, content is displayed within a sidebar to the right

of the main area. Material displayed in that sidebar is not always needed or may be seen as repetitive. For example, on many pages a graph showing the breakdown of FRAXA expenses for 2013 is seen. When clicked, the link takes one to a pdf of a report done by an auditor. This information does not fall into any category that users asked for when surveyed, and the graph appears frequently. Material on the side of the main area can draw away attention, which is what sidebars are meant to do. However, this is detrimental if the information being put on display is not pertinent. Following the idea of organizing web pages by theme, sidebar content value could be enhanced if other topics within that theme were featured, or featured more prominently than information outside of that theme (Djonov).

Another potential use of that space would be to highlight ways that parents and families can connect with each other, since they appear to be the majority of the population FRAXA is reaching. Such resources could include the FRAXA listserv, the FRAXA Facebook page, and the potential FRAXA app if it is created in the future. If the FRAXA Twitter tweets frequently, another use of the sidebar space could be to embed the FRAXA Twitter feed. This could promote the FRAXA Twitter page or use of hashtags involving FRAXA and Fragile X. This may provide interesting material for visitors on the FRAXA website on webpages which do not have relevant or updated sidebar material.

#### *6.3.4: Drop-Down Menus*

The FRAXA website currently has a feature in the navigational bar where the tabs change color when hovered over. This is ideal in showing users that the link is active and that it can be clicked on. In addition, the FRAXA website navigational bar has plus signs on the specific tabs which drop down to provide more webpages. In order to increase consistency, one suggestion is to remove the plus sign and have each navigational bar link drop down to provide more

information. Consistency is ideal in the navigational bar in order to provide a better sense of direction and ease of access for website users (Plumley, 2010).

In addition to the three-tiered home page, it follows that each respective page would provide more useful information to that specific user. In the following Figures 6.5 through 6.7, the drop down options are catered towards the category of user which is selected after entering the home page.



The image shows a screenshot of the FRAXA website's navigation menu. At the top, there is a header with the FRAXA logo (Research Foundation) and the tagline 'Finding a Cure for Fragile X'. A search bar and a 'Donate Now' button are also visible. Below the header is a dark navigation bar with five main tabs: 'About Fragile X', 'About FRAXA', 'Resources', 'Get Involved', and 'Ways to Give'. Underneath these tabs is a grid of sub-tabs. The 'About Fragile X' tab has sub-tabs for 'Symptoms', 'Causes', 'Diagnosis', and 'Treatment'. The 'About FRAXA' tab has sub-tabs for 'Board of Directors', 'Honorary Board', 'Our Staff', and 'Scientific Advisors'. The 'Resources' tab has sub-tabs for 'Kids' Pages', 'About Clinical Trials', 'For Parents/Caregivers', and 'For Fragile X Carriers'. The 'Get Involved' tab has sub-tabs for 'Upcoming Events', 'Run Your Own Event', 'Join Clinical Trials', and 'Regional Contacts'. The 'Ways to Give' tab has sub-tabs for 'Donate' and 'Shop'. A 'FRAXA Community' link is also visible at the bottom right of the sub-tab grid.

About Fragile X	About FRAXA	Resources	Get Involved	Ways to Give
Symptoms	Board of Directors	Kids' Pages	Upcoming Events	Donate
Causes	Honorary Board	About Clinical Trials	Run Your Own Event	Shop
Diagnosis	Our Staff	For Parents/Caregivers	Join Clinical Trials	
Treatment	Scientific Advisors	For Fragile X Carriers	Regional Contacts	
			FRAXA Community	

Figure 6.7: Tabs and sub-tabs that would be present under the "For Parents and Family Members" portion of the website

The above Figure 6.5 shows the options for one entering the website as a parent or family member of an individual with Fragile X Syndrome. The resources and involvement options that are provided in this figure were chosen based on the results of the FRAXA User Survey and based on how the FRAXA website currently labels each resource. The Kids' Pages are more likely to be a family resource, as reading other stories may provide advice or comfort for those in similar situations. Family members may find that information about clinical trials is a key resource, considering the family may be interested and just need more information to make a decision.

The two drop down tabs "For Parents/Caregivers" and "For Fragile X Carriers" were created to provide a clear section dedicated to resources for individuals who fall into these categories. The FRAXA User Survey provided results which heavily leaned towards resources

for its participants.



The screenshot shows the FRAXA Research Foundation website header with the slogan "Finding a Cure for Fragile X". Below the header is a navigation menu with five main tabs: "About Fragile X", "About FRAXA", "Resources", "Get Involved", and "Ways to Give". A search bar and a "Donate Now" button are also visible in the header.

About Fragile X	About FRAXA	Resources	Get Involved	Ways to Give
Symptoms	Board of Directors	Grants	Scientific Meetings	Donate
Causes	Honorary Board	Research Teams	Be a Speaker	Shop
Diagnosis	Our Staff	News		
Treatment	Scientific Advisors			

Figure 6.8: Tabs and sub-tabs that would be present under the "For Researchers" portion of the website

When identifying as a researcher, the navigational bar shown in Figure 6.6 would be utilized. The aspects of the FRAXA website which are tailored towards researchers are compiled into the drop down links. Considering the spike in activity seen in the website metrics around the grant deadline, it was determined that grant information is crucial for researchers. Research teams and scientific news are also likely resources for researchers. The methods in which researchers get involved are different than those of general family members; therefore scientific meetings are located under the involvement tab. There is also the option for a researcher to be a speaker, in which case information can be provided under that tab as well.



The screenshot shows the FRAXA Research Foundation website header with the slogan "Finding a Cure for Fragile X". Below the header is a navigation menu with five main tabs: "About Fragile X", "About FRAXA", "Events", "Online Resources", and "Ways to Give". A search bar and a "Donate Now" button are also visible in the header.

About Fragile X	About FRAXA	Events	Online Resources	Ways to Give
Symptoms	Board of Directors	Upcoming Events	Listserv	Donate
Causes	Honorary Board	Plan Your Own Event	e-Fundraising	Shop
Diagnosis	Our Staff		News	
Treatment	Scientific Advisors			

Figure 6.9: Tabs and sub-tabs that would be present under the "Get Involved" portion of the website

Entering the website through the "Get Involved" section would result in the navigational options shown in Figure 6.7. Since the option to get to this navigational pane is titled "Get Involved," it would be illogical to also have a tab titled the same; therefore this navigation bar is modified to account for that. It is instead used to emphasize the many ways for an individual to

get involved, highlighting several different methods. The suggested methods are also independent of whether or not the user has a direct connection to Fragile X Syndrome, considering any individual can put on an event or e-Fundraise.

#### ***6.4 Conclusions:***

The scope of this project included significant analysis on the current state of the FRAXA website in terms of design, content, and organization in order to determine what improvements could be made to provide users with a deeper understanding of FRAXA's mission statement by simply using the website. The surveys implemented were used to examine initial reactions to the website, as well as to determine what components of the website are important to previous and current users.

In many instances, the suggestions provided are minor changes which make information easier to find or the website slightly easier to use. The FRAXA website has a plethora of resources which are useful and informative, and these suggestions are intended to provide more organization and a greater awareness of them.



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## Appendix

### A. Survey Questions for FRAXA community

1. Which describes you best?
  - a. I am a parent or guardian of a child with Fragile X
  - b. I am a Fragile X researcher
  - c. I am an employee of the FRAXA Foundation
  - d. Other (please specify) \_\_\_\_\_
2. How frequently do you visit the FRAXA website?
  - a. Rarely
  - b. Once a month
  - c. 2-3 times a month
  - d. Once a week
  - e. 2-3 times a week
  - f. Daily
3. What page do you visit most frequently on the FRAXA website?
  - a. Clinical Trials
  - b. Ongoing Research/Towards a Cure
  - c. About FRAXA
  - d. FRAXA home page
  - e. FRAXA events
  - f. Other (please specify) \_\_\_\_\_
4. What do you think is the most helpful part of the FRAXA website?
  - a. Clinical Trials
  - b. Ongoing Research/Towards a Cure
  - c. About FRAXA
  - d. FRAXA home page
  - e. FRAXA events
  - f. Other (please specify) \_\_\_\_\_
5. Is there any information you would like to see added to the website?
  - a. Clinical Trials
  - b. Research Information
  - c. Parent & Family Resources
  - d. Events
  - e. Latest News
  - f. Other (please specify) \_\_\_\_\_
6. Please rate the following aspects of the FRAXA website

	Poor	Fair	No Opinion	Good	Excellent
Layout					
Navigation					
Amount of Information					
Images and Videos					
Patient Stories					
Clinical Trials Page					

Ongoing Research/Towards a Cure Page	Poor	Fair	No Opinion	Good	Excellent
About FRAXA Page					
FRAXA Home Page					
FRAXA Events Page					
Quality of Information					

7. What about the layout/design of the website would you like to see changed?
  - a. \_\_\_\_\_
8. Do you own a smart phone or tablet?
  - a. Yes, an Apple device
  - b. Yes, an Android device
  - c. Yes, other (please specify) \_\_\_\_\_
  - d. No
9. Are you aware that there are clinical trials for the treatment of Fragile-X syndrome?
  - a. Yes
  - b. No
10. Has your child participated in a Fragile-X clinical trial?
  - a. Yes
  - b. No
  - c. I was not aware of clinical trials
11. Would you be interested in a Fragile-X related app that uses GPS services to locate nearby clinical trials or events?
  - a. Yes
  - b. No
  - c. Maybe
12. How likely are you to participate in a discussion board / forum with other parents of children with Fragile X?
  - a. Very Unlikely
  - b. Unlikely
  - c. Somewhat Unlikely
  - d. Undecided
  - e. Somewhat Likely
  - f. Likely
  - g. Very Likely
13. Would interacting with other parents who have undergone the clinical trial process be helpful for making a decision to participate in a clinical trial?
  - a. Yes
  - b. No
14. How many hours per week do you spend using apps?
  - a. Less than 1
  - b. 1-3
  - c. 3-5

- d. 5-7
  - e. More than 7
15. Are any of the apps you use health related?

- a. Yes
- b. No
- c. Unsure (please specify name of the app) \_\_\_\_\_

Those who answered *a* to question 1 had questions 10, 12, and 13 shown to them.

Those who answered *a*, *b*, or *c* to question 8 had questions 14 and 15 shown to them.

## B. Script for Survey of First-Time Users

“Hi! Are you interested in helping us with an IQP project? It won’t take long. We’re looking to collect data from interactions between you and a website. No personal information will be recorded.”

*If the student responds yes, they will be directed to look at the laptop screen, which will have the [www.fraxa.org](http://www.fraxa.org) website and Qualtrics survey loaded.*

“Thank you for voluntarily participating. Can you tell me what part of this website you notice first?”

*Student will click on a spot in the Qualtrics survey in order to record their answer in a heat map.*

Trial 1: “What link looks to be the most helpful to you?”

Trial 2: “What link looks to be the most helpful to you as a first-time user?”

*Student will click on a spot in the Qualtrics survey in order to record their answer in a heat map.*

“Now I’m going to ask you to complete some tasks. You will have a time limit of 2 minutes per task or you may quit if what is requested is too difficult. You are not allowed to use the website’s search bar to complete your task.”

“Your first task is to find a clinical trial location”

*Record the links the student follows to try to find information relevant to the task given. Note time until information is found or until the student quits.*

Trial 1: “Now please find David Nelson’s Page.”

Trial 2: “Now please find David Nelson's Page. He is a FRAXA researcher.”

*Record the links the student follows to try to find information relevant to the task given. Note time until information is found or until the student quits.*

“Find information about the Fall X Ball, please.”

*Record the links the student follows to try to find information relevant to the task given. Note time until information is found or until the student quits.*

“Can you find out how to donate to FRAXA?”

*Record the links the student follows to try to find information relevant to the task given. Note time until information is found or until the student quits.*

Trial 1: “Find information about the FRAXA listserv, please.”

Trial 2: “Find information about the FRAXA listserv, please. The listserv is an e-mail group that facilitates discussion between the members of the FRAXA community. It is NOT the same as the e-mail newsletter.”

*Record the links the student follows to try to find information relevant to the task given. Note time until information is found or until the student quits.*

“You have gone through the tasks. Thank you for your time and contributing to our research. Please, take a cookie and have a wonderful day.”

## C. Front Page of FRAXA Picture

*Finding a Cure for Fragile X*

[Donate Now](#)

[+ About Fragile X](#)
[+ About FRAXA](#)
[+ Toward a Cure](#)
[+ For Researchers](#)
[Events](#)
[+ Get Involved](#)
[Shop](#)
[Ways to Give](#)

**We need your support**

Make a difference - Donate to FRAXA

FRAXA Annual Campaign

Highlights & Accomplishments

2013 Expenses  
\$2,008,279 total

Category	Percentage
Research	55%
Education	10%
Fundraising	27%
Management	8%

- Research
- Education
- Fundraising
- Management

What is Fragile X?

Fragile X Syndrome is the most common inherited cause of intellectual disabilities and the most common known cause of autism. Signs include learning problems, autism, and anxiety.

[Read More](#)

About FRAXA

FRAXA is a 501c3 nonprofit founded and led by parents. Our mission: to find effective treatments and ultimately a cure for Fragile X. FRAXA has funded over 100 teams worldwide.

[Read More](#)

Toward a Cure

Clinical trials of new treatments are happening! People with Fragile X Syndrome have options, with trials enrolling in the U.S. and Europe. Dozens of treatment approaches are in the pipeline.

[Read More](#)

You can Help!

When you donate to FRAXA, 93 cents of every dollar goes to research and education.

[Donate Now](#)

## D. Organic Search Results

<b>Search Terms</b>	<b>Result #</b>	<b>Specific Page</b>	<b>Sites Ahead of FRAXA</b>
FRAXA	1	Home Page	None
Fragile X	7	About Fragile X Page	<ul style="list-style-type: none"> <li>• National Fragile X Foundation (x2)</li> <li>• Fragile X Syndrome Wikipedia Page</li> <li>• NIH Fragile X Page</li> <li>• News for Fragile X</li> <li>• Images for Fragile X</li> </ul>
Fragile X Syndrome	4	Home Page	<ul style="list-style-type: none"> <li>• NIH Fragile X Page</li> <li>• Fragile X Syndrome Wikipedia Page</li> <li>• National Fragile X Foundation</li> </ul>
Fragile X Clinical Trails	4	Clinical Trials Page	<ul style="list-style-type: none"> <li>• Genetic disease Foundation (Ad)</li> <li>• Fragile X Clinic (Ad)</li> <li>• National Fragile X Foundation</li> </ul>
Fragile X Symptoms	9	Symptoms Page	<ul style="list-style-type: none"> <li>• NIH Fragile X Page</li> <li>• Medicinenet.com</li> <li>• Healthline.com</li> <li>• Fragile X Wikipedia Page</li> <li>• Images for Fragile X Symptoms</li> <li>• Childrenshospital.org</li> <li>• National Fragile X Foundation (x2)</li> </ul>
Fragile X Diagnosis	12 (On second page of search)	Testing page	<ul style="list-style-type: none"> <li>• Genome.gov (x2)</li> <li>• NIH Fragile X Page</li> <li>• National Fragile X Foundation</li> <li>• Healthline.com</li> <li>• American Academy of Family Physicians Fragile X Page</li> <li>• Childrenshospital.org</li> <li>• Medicinenet.com</li> <li>• Fragile X Syndrome Wikipedia Page</li> <li>• Journal of Clinical Investigation</li> </ul>



			<ul style="list-style-type: none"> <li>• New York Times article on Fragile X</li> </ul>
Fragile X Prognosis	Couldn't even find it on the first 5 pages of search	N/A	N/A
Fragile X Cure	3	Home Page	<ul style="list-style-type: none"> <li>• Kennedykrieger.org (Ad)</li> <li>• National Fragile X Foundation</li> </ul>
Fragile X Research	1	Home Page	None
Fragile X Fundraising	12	Home Page	<ul style="list-style-type: none"> <li>• National Fragile X Foundation (x6)</li> <li>• Crowdrise.com (x2)</li> <li>• Livingwithfragilex.com</li> <li>• Fragile X Association of Australia</li> <li>• Basicallyfx.com</li> <li>• Basicallyfx.com</li> </ul>
Fragile X Donate	4	Home Page	<ul style="list-style-type: none"> <li>• National Fragile X Foundation (x3)</li> </ul>