



XTRAORDINARY Joy!

Situation Analysis

Prepared for Amy & Tony Meacham, Founders

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by Lauren Yockey & Blakeley Kilgore



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Introduction

Xtraordinary Joy is a young foundation founded in June 2016 that is passionately committed to finding a cure for a genetic disorder so rare that it only affects nine other girls in the world, according to founder Amy Meacham.. As a new foundation, Mrs. Meacham has made clear that the number one objective for the coming year is growth, primarily concerning fundraising efforts. Additionally, she implied the necessity of providing a virtual resource for parents who may have questions about such an obscure and unknown disorder.

As we seek to create this online space that will provide a solution to both of these needs, it is critical that we look deeper into the following: the foundation's purpose; target audience; performance within its industry and among industry competitors; and current communications strategy. Then we will use these insights to perform an analysis of the organization's strengths, weaknesses, opportunities and threats. It should be noted that this assessment will have a focus on Xtraordinary Joy's digital footprint, meaning that while the long term goal is to set the non-profit apart as a premier research foundation for gene deletion and other genetic disorders, our agency's niche has a digital marketing and web focus.

Once the analysis is complete, our agency will be equipped to begin our branding and IMC campaign, which will not only provide you with a website more optimized to the foundation's needs, but also with a strategic approach to boost your overall online presence.

Organization Overview

HISTORY

The organization was founded only recently in June of 2016, but its roots go further back with the adoption of Amy and Tony Meacham's daughter, Moriah Joy. Realizing a few months into Moriah's life that she was having some developmental and health issues, the Meacham's were faced with an ambiguous diagnosis of an unnamed gene deletion disorder, known as Xq27.3-q28 Deletion. The disorder has a wide array of possible symptoms, from low muscle tone, to gagging and seizures. Along with these frightening symptoms, there exists potential for other underlying disorders including Fragile X Syndrome, Autism and Parkinson's Disease.

Despite the various symptoms and disorders that fall under the category of this gene deletion, there is surprisingly little known about the disorder. Mrs. Meacham, a leukemia research scientist at the University of Florida, as well as Mr. Meacham, an academic advisor also at the University of Florida, sought to change this. The couple dreamed of starting a foundation with the sole purpose of funding research at the University of Florida College of Medicine to find answers about this and other rare genetic disorders. As a result, Xtraordinary Joy, Inc was born.



Organization Overview

TODAY

Mission Statement:

Xtraordinary Joy is a 501(c)(3) non-profit foundation providing advocacy and funding for X chromosome deletion research that advances lifelong health, behavior and learning.

Quick Facts

Number of Staff: **2**
Board Members: **12**
Volunteers: **~50**
Total Event Partners: **18**

The organization seems to be performing quite well from a local standpoint. Despite being run by two people, they have hosted two successful events: a human foosball tournament and the Unmask Joy masquerade ball. Both of these events as well as some sporadic online donations led to a total \$36,000 for the first year. The donations are contributed to the scientific research plan created by the foundation, which is currently pending approval. Donations and contributions are sourced from both private donors as well as corporate partners. For its second year running, the founders of Xtraordinary Joy have set a goal of raising \$60,000.

Apart from fundraising research, the foundation offers information and resources about Xq27.3-q28 Deletion within its site. The site includes a brief bulleted list while more detailed resources are linked away from the website.



Target Audience

Donors &
Participants

Based on the foundation's purpose of raising funds for researching the genetic disorder, the first target audience is philanthropists and donors within the Gainesville, Florida medical community. Since most Xtraordinary Joy's funds are generated from annual events, the first target audience can be further segmented into event and fundraising participants.

These individuals likely have an affiliation with the University of Florida and its College of Medicine given the chosen research institute, as well as the professions of its founders, Amy, a leukemia research scientist at the University of Florida, and Tony Meacham, an academic advisor at the University of Florida. Because the university is the economic driving force of the Gainesville community, this target audience is likely college educated with at least a Bachelor's degree.

Target Audience

Due to the diverse demographics of a university town, these audience members are likely to span a wide age range; however, they are likely between the ages of 21 and 60. On the younger side of the age spectrum, these donors are likely undergraduate or graduate students who participate in local fundraisers at restaurants such as The Blaze. Rather than seeking out a fundraiser to participate in or donate to, these students would prefer the fundraiser come to them. In other words, the fundraiser should also be convenient and benefit these donors (like receiving a discounted meal at the fundraising restaurant). This convenience also comes into play with the Internet, as members of Generation Y as well as Millennials are more apt to crowd-funding, according to Amy Butcher of Nonprofit Quarterly (Butcher, 2015). These donations are smaller in size due to their generally lower income bracket. These early adopters are digital natives and constant media users. Aside from academic purposes, most of their media use is recreational or social and takes place on social media.

Members of the target audience above the college age range are most likely in working in a job related to the medical field, and are active within the medical community. They are probably employed by either the University of Florida College of Medicine, but may also work for UF Health hospital or North Florida Regional Medical Center. These professionals value community participation and are more likely than the college-aged demographic to attend more formal fundraising events such as the UnMask Joy event. While not necessarily less technology savvy, these working professionals' have a more utilitarian approach to their media use. Given their interest in community events, they might look to the organization's website for event schedules and updates.

Target Audience



(Credit: Xtraordinary Joy Client Presentation)

Parents

The desire to create an informative resource with advice and post-diagnosis guides gives rise to a second target audience: Parents searching for answers about rare genetic disorders. With little to no information available from doctors, these couples will turn to the Internet for help. Because the disorder is typically diagnosed at a very young age and is unfortunately lethal to males, these parents are fairly young and have a daughter between infancy and ten years old. The ambiguity of the disorder and uncertain outlook means these parents are not only looking for answers and advice, but for comfort and empathy. Connecting with parents across the world who also have a child suffering from a genetic disorder would help provide this comfort. While these disorders can affect any child regardless of circumstances, families within this target audience have access to a computer and the Internet for support.

Volunteers

Target Audience

With the Meacham's both working full-time jobs while managing a foundation on the side, volunteers are essential to keeping the nonprofit running smoothly. Currently Xtraordinary Joy features a 12-chair voluntary board of directors and approximately 50 event volunteers, according to Tony Meacham. While this is a fairly substantial number of volunteers, it would be beneficial for the organization to target a more specialized volunteer audience to fill more technical roles such as digital marketing and web administration. Given the proximity to the University of Florida, the Meachams can easily reach out to students in the College of Journalism and Communications for unpaid or paid internship opportunities. These local

students are between the ages of 18 and 21, majoring in either Public Relations, Advertising, Journalism, and Telecommunications. Given their chosen academic path, the majority of these students are fluent in social media and basic digital marketing skills. Outside of the classroom, they pursue memberships with professional organizations on campus. Because volunteer hours are a great way to build a resume, and in fact are sometimes required as part of the program, these young professionals-in-training are actively seeking opportunities to hone their skills in a real-world environment. They will often connect with these organizations via volunteer fairs on campus, academic advisors, or student organizations that have established a group-volunteer relationship with the nonprofit.



Trends

There are many national and local trends involving nonprofit organizations and the philanthropic habits of individuals that Xtraordinary Joy should be aware of.

Donations

With the exception of the recession around 2008, the United States as a whole has witnessed a consistent increase in charitable donations each year, with individual donors accounting for about 71% of those donations in 2015. (“Charitable Giving Statistics”, 2017) This can be seen in examples such as Giving Tuesday in 2016, a day designated for raising money for charitable efforts, during which donations were up 44% from the previous year. However, the election year could affect these numbers, as individuals may wish to protect their charitable interest during a new presidency. (Fessler, 2016) Gainesville specifically has also seen a spike in volunteering and

donations in 2016. This is beneficial because much of the fundraising thus far has been local events, so an increase in philanthropic actions is a promising sign for events in 2017. (Cobb, 2016) However, Xtraordinary Joy should also be wary of advertising towards solely local donors, as the medium income is \$31,818 with 35.6% of the population in poverty in its hometown of Gainesville. (“Population estimates”, 2015) It would benefit the organization to look to additional regional, national, or online donors to reach a larger population with more available funds to donate. Optimizing the website to make donating more easily accessible and improving its social media presence will help achieve this goal.

Trends

Logistical Obstacles

There are some logistical obstacles that a young nonprofit such as Xtraordinary Joy may have to face as they grow. The first of which is registering with Florida's Department of Agriculture and Consumer Services. While it is registered with the IRS as an organization eligible to receive charitable donations on a federal level, it must register and annually renew with this department after total revenues, not just donations, reaches \$25,000. It is not currently listed in the department's charity search. ("Statutes & Constitution", 2017) As stated in correspondence with Mrs. Meacham, there are also logistical obstacles as far as getting the funding to the department in the UF College of Medicine for research. The Internal Review Board must "approve the human pediatric study so that blood draw can be performed to initiate personalized research." (Meacham, 2017)

Marketing

One trend in marketing with which Xtraordinary Joy is already excelling is to "humanize your marketing." (Council, 2016) Photographs of Amy Meacham's family along with photos of Joy give the organization a soft, friendly, and relatable face. The touching story behind Joy Meacham's adoption and her X chromosome deletion give the organization a strong emotional element. Mrs. Meacham explained that she wants the organization to be perceived as genuine and as "small time, regular parents with big dreams." (Meacham 2017) This not only allows the organization to stay true to its roots, but it follows the trend of harnessing community and putting a face on marketing efforts.

Competitors

Donors may prefer to support highly visible, more established medical institutions in the Gainesville area such as the following:

UF Health

UF Health dominates the Google results page for any questions concerning medical issues when targeted with Gainesville, Fla in the search query. Given their .edu web suffix and its extensive library of medical information, UF Health's SEO ranking will likely continue to tower above the rest of the pack. As the leading hospital in the Gainesville area that is both a research and teaching institution, they are apt to receive large gifts from philanthropic donors. However, despite its outstanding SEO rankings, its actual website is a bit overwhelming and cramped. There is an excessive amount of information on the homepage, leaving visitors lost and unsure of how to continue. The "Make a Gift" link is very small and does not stand out from the navigation or other links.

At A Glance

SEO: Very good, consistently first with "Gainesville" & "medical" keywords.

Brand Positioning:
Premier healthcare and online health resource in the Gainesville, Fla., area.

Website:
ufhealth.org
Overwhelming, cramped and dated.

Social Media:
Daily activity;
Stable presence on Facebook, Twitter and YouTube.

Followers:
Facebook: 14,205
Twitter: 5,541
YouTube: 1,694

Competitors

Donors may prefer to support highly visible, more established medical institutions in the Gainesville area such as the following:

University of Florida Genetics Institute

This graduate-level academic institute is a hub for genetics research. Its mission features a similar community oriented goal of “building community, facilitating collaboration and creating opportunities for intellectual exchanges....” (Mission and Goals, n.a.). The institute has a broader focus on furthering overall knowledge of genomics rather than narrowly focusing on human genetic disorders. The institute funds research by competing for “multidisciplinary grants,” and hosts several events geared mostly towards professionals within the study of genomics. Its website is designed well with content arranged in an aesthetically pleasing and organized manner. Information is presented clutter-free and there is a decent flow throughout the homepage. This homepage features a slider, recent news, social media feed, a “learn more” banner, an about blurb, and an excerpt of the most recent e-newsletter. Its social media accounts, however, lack a significant following. SEO rankings are decent when containing keyword phrases such as “genetics research Gainesville FL”

At A Glance

SEO: Good with long-tail keyword phrases like “Gainesville genetics research”.

Brand Positioning:
UF’s center for advancing genomics research at a graduate level.

Website:
ufgi.ufl.edu
Clean, organized, updated, simple.

Social Media:
Frequent posts to Twitter and Facebook accounts despite few followers.

Followers:
Facebook: 188
Twitter: 508
YouTube: 1

Competitors

At A Glance

Donors may prefer to support highly visible, more established medical institutions in the Gainesville area such as the following:

**University of Florida
College of Medicine**

Even though the UF College of Medicine is responsible for carrying out the foundation's research, donations to the college directly could mean those funds might not have an impact on Xtraordinary Joy's cause. Generally, a Google search for genetic disorders or foundations will return UF Health rather than the College of Medicine. Much like UF Health, the College's website is fairly cramped and has a generally outdated design. The message communicated is generally student- and college-centric, providing updates from within the college. The homepage includes recent news, an event schedule, and a content slider with recent blog posts.

SEO: Poor; Must include keywords “College of Medicine” with other keywords like “Gainesville medical research”

Brand Positioning:
UF's medical school

Website:
med.ufl.edu
Outdated, organized, text-heavy.

Social Media: Daily posts to Twitter and Facebook accounts, average following.

Followers:
Facebook: 1918
Twitter: 2,394
YouTube: 1,694
(shared account with UF Health)

Competitors

In addition to the well known regional medical centers, other medical foundations might compete for funding and participation. While there are countless research-oriented nonprofit organizations in the surrounding Gainesville area, the following are strategic examples of medical foundations that might compete directly with Xtraordinary Joy for success:

Epilepsy Foundation Florida

The Epilepsy Foundation Florida is a genetic disorder foundation that has very similar goals as Xtraordinary Joy: to support research and discover therapies to improve the quality of life for those who suffer from the disorder. The nonprofit has established itself as the leading organization for research and information about epilepsy in the state of Florida, much like the client wishes to become of Xtraordinary Joy. EFF also boasts a strong community presence, hosting a number of events such as their Walk the Talk for Epilepsy fundraiser. These events are promoted on their Facebook page. In addition, the website is well constructed and presents a strong brand image with consistent colors, images and messages. The homepage of the website makes it very clear to visitors where to find information, whether they are newly diagnosed or want to get involved with the organization. It demonstrates a strong sense of community, featuring a “Faces of Epilepsy” section as well as a prominent image slider with a photograph of their Walk the Talk for Epilepsy event. While this foundation is located in Miami, its establishment as a statewide resource makes it a considerable competitor. However, it could also be used as a model for success, as many of the organization’s features are in line with the client’s desires for their own web presence.

At A Glance

SEO: Poor to Decent; Can use short-tail keyword phrases but must include highly specific keywords like “epilepsy,” “Gainesville,” or “Florida.”

Brand Positioning:
Leading Epilepsy resource & community

Website:
efof.org
Attractive, consistent, sophisticated,

Social Media: Daily posts to Twitter and Facebook accounts, fairly substantial following.

Followers:
Facebook: 9,453
Twitter: 4,412
YouTube: 86
Instagram: 1,858

Competitors

In addition to the well known regional medical centers, other medical foundations might compete for funding and participation. While there are countless research-oriented nonprofit organizations in the surrounding Gainesville area, the following are strategic examples of medical foundations that might compete directly with Xtraordinary Joy for success:

Relay For Life Gainesville

Relay for Life, a branch of the American Cancer Society, is an extremely community oriented nonprofit organization that hosts events held in towns throughout the country. It is a highly regarded event and usually experiences a high participation rate, likely because it attracts participants from varying walks of life. As a national organization, ACS clearly has more resources at its disposal, including a very professional web presence and existing national website. The Relay for Life Gainesville website is very professional in appearance, with consistent use of the brand's purple color. It is clearly organized by section and features two main calls-to-action: donate and find an event. The site features a Get Involved page detailing ways to participate, whether as an attendee, volunteer, or sponsor. There are high quality photographs from events sprinkled throughout the site that show off the organization's community emphasis. One weakness, however, is that the social media icons lead you to share a post rather than simply direct you to the account's page. There are two different branches within the community that could lead to confusion among participants: one for the city of Gainesville, and one for the University of Florida. This could potentially point to its minute following on social media.

At A Glance

SEO: Poor; did not appear for generic phrases like "Gainesville nonprofit events" or "Gainesville walkathons"

Brand Positioning: A well-known and time-honored community event.

Website:
relayforlife.org/gainesvillefl
Attractive, consistent, easy to read, direct.

Social Media: Poor following, sporadic posting

Followers:
Facebook: 49
Twitter: Unknown
YouTube: None

Competitors

At A Glance

In addition to the well known regional medical centers, other medical foundations might compete for funding and participation. While there are countless research-oriented nonprofit organizations in the surrounding Gainesville area, the following are strategic examples of medical foundations that might compete directly with Xtraordinary Joy for success:

National Organization For Rare Disorders

NORD is a national level nonprofit organization dedicated to “the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services” (Our Mission, n.a). As a multipurpose organization, its website is smartly divided based on its target audience. Upon hover, a secondary menu will appear with appropriate menu options. For instance, their is a menu tab designated for patients and families, for clinicians and researchers, and for patient organizations, among other categories. The website capitalizes on organization and structure to optimize user experience and usability. A donation button stands out at the top right of the page, and a fixed banner at the bottom features another donation button adjacent to the organization’s slogan. It is quite active on social media and boasts a strong following, with followers frequently engaging via comments, reviews, and post reactions. It hosts virtual events like free webinars, or allows online registration for in-person events like their Rare Impact Awards benefit. They promote their own hash tag, #TogetherweAreStrong, which is taken from the slogan.

SEO: Poor; did not appear for generic phrases like “Gainesville nonprofit events” or “Gainesville walkathons”

Brand Positioning: A well-known and time-honored community event.

Website:
rarediseases.org
Visually engaging, bright, welcoming, extensive

Social Media: Large following, daily posts and frequent engagement with followers

Followers:
Facebook: 41,084
Twitter: ~20,200
YouTube: 0

General Communication Strategy

Social media

Word-of-mouth

Community engagement through events

Overall Goals

Research

Fundraising

Joy

Awareness through Community

Research Goals

Xtraordinary Joy's main goal is to support and fund scientific research of Xq27.3-28. It hopes to gain more understanding of this specific X chromosome deletion and discover treatments or therapies to help those affected. The organization aims to give the disorder a name, and it hopes to expand in the future to support research of other rare disorders characterized by "autism, speech apraxia, intellectual disability and epilepsy." The goal is to spread this mission through their online outlets and sense of community. (Meacham 2017)

Fundraising Goals

Xtraordinary Joy aims to continue to fundraise through local events and other fundraising efforts such as T-shirt sales and restaurant fundraisers. The Meacham's hope the website will attract event sponsors or participants. (Meacham 2017)

Awareness Goals

Xtraordinary Joy hopes to encourage a community through their website, beginning with Xq27.3-28 and linking to directories to help connect children with other X chromosome deletions. By becoming the official organization and website for Xq27.3-28 it will create an environment in which a community and awareness surrounding this specific deletion could thrive. It also aims to further engage this community through social media by allowing for participation and sharing. (Meacham 2017)

Communication Methods

Xtraordinary Joy does not currently have a marketing budget or plan in place. Its efforts have been limited to volunteered time and resources, but it does have people willing to help. It had a volunteer designer last year, and they spent approximately \$500 on marketing materials. It has a website in place along with a Facebook, Twitter, and GoFundMe page that has been successful. It plans to further reach the local community through a Human Foosball Tournament and Masquerade ball, both of which were successful in 2016. (Meacham 2017)

Positioning & Branding

Xtraordinary Joy is focused on funding research for and spreading awareness of the X chromosome deletion Xq27.3-28 that affects the Meacham's daughter, Joy. It hopes to expand to help fund research of other rare disorders once its current research concept proves true. Based on a usability test conducted with five participants, the organization's website does not clearly communicate the goal of funding research, and 4 out of five participants thought the organization helped directly support children affected by the disorder. However, the organization is not set up, nor prepared, to financially help others affected by these disorders. The organization has had people reach out to it for assistance in the past, and they gladly help them get in touch with organizations that are set up for financial support. It is important that the organization

reach potential donors that want to support the research at the University of Florida, people seeking information about Xq27.3-28, and a welcoming community. (Meacham 2017) According to Mrs. Meacham, it is important to keep the brand's colors, turquoise and magenta, as the brand has become recognizable throughout their area. Mrs. Meacham emphasized that these colors create an atmosphere of community and joy. The goal is to not only spread awareness of the disorder but to also spread awareness of the brand: a warm and welcoming family that hopes to spread joy through community. (Meacham 2017) The brand is also characterized by photographs of the Meacham family and community events, sticking true to this welcoming, family-operated feel. However, the logo is not as fitting for the brand or its mission, and a revision will be suggested.

Current SEO

Xtraordinary Joy does not have a Google Analytics account set up for its website. (Meacham, 2017) Without an analytics platform, the organization can have no real way of knowing how their visitors are coming across the website. It is also hard to track how successful the website is at funneling visitors through the site to important areas after their arrival to the site. However, keywords can still be researched for organic SEO rankings by using search queries in Google based on keywords relevant to Xtraordinary Joy's purpose and mission.

Search Queries & Page Results

First Page Listing:

x chromosome research
florida (6th)
chromosome deletion
research florida (10th)
chromosome deletion
research Gainesville (1st)
x chromosome research
Gainesville (5th)
joy gainesville florida (6th)
Xq27.3-q28 deletion
research (3rd)
Xq27.3-q28 deletion
community (3rd)

Did not show up on first three (3) pages:

Donate
donate gainesville florida
donate research
gainesville florida
x chromosome research
Xq27.3-q28 deletion
Xq27.3q28 deletion
research
Xq27.3q28 deletion
community
volunteer
volunteer gainesville
florida
spreading joy florida
spreading joy Gainesville
(Gofundme page listed in
page 2)
joy florida
gene disorder gainesville
florida

Current SEO, cont'd.

It is beneficial that search queries locate Xtraordinary Joy through Google using keywords relevant to research of the X chromosome deletion research in the Gainesville community. However, it is a missed opportunity that it does not rank for queries involving the keyword “donate,” as acquiring donations is one of the organization’s main goals.

Although some search queries do successfully rank Xtraordinary Joy’s web page on the first page of results, it is nearly impossible to know which search queries are most likely to result in a donation after the search engine result listing has been clicked without an analytics tool, such as Google Analytics. It is also noted that adding or removing the hyphen in the deletion name changes the search results. Using a hyphen gives them an advantage in rankings.

Social Media & Online Presence

Xtraordinary Joy utilizes two social media accounts: Facebook and Twitter. The Facebook account has approximately 530 likes as of January 2017, and its Twitter has about 21 followers. The organization does not have a Pinterest, Google+ or Instagram account, but it has been found tagged on Instagram using the hash tag “#xtraordinaryjoy.” An Instagram account is an untapped opportunity given Mrs. Meacham’s desire to prominently share images from events.

Improving Integrated Marketing

Step 1: The Website

Usability

Usability tests performed by five users show that the intent of the website is not clear. It is somewhat easy to find that the organization is about an X chromosome deletion, but the wording gets confusing on the website and visitors are unsure of what exactly the organization aims to do. ("Usability Test on Xtraordinaryjoy.com", 2017) The website's content should be revised on the homepage in particular in order to better explain the organization's purpose: fund research and spread awareness through community and joy.

Call to Action

The website should consider a better placed and updated donate button, as the current one is small, generic and uninviting. It is also unclear where donations go, so a description of the University of Florida's Medical Research Center should be included. Visitors were also confused that the "Learn More" button under the "Our Story" section lead to the blog, and they hoped for a more static page to explain what the organization is and does. Another frustration for users was when new pages opened in a new tab, even when they were still within the website. It is a simple fix to remove the "target = _blank" attribute from each link tag in the HTML pages of the website, and this will prevent the link from opening a new tab. ("Usability Test on Xtraordinaryjoy.com", 2017)

Website Design

The design of the website should be modernized, and it is important to make the website responsive, so that it is easy to use on mobile devices. According to Gloria Horsley's Forbes online article, there is a trend to simplify donating, and mobile devices can help (Horsley 2016). Almost every new smartphone has a mobile wallet, allowing visitors to the Xtraordinary Joy website to make a donation quickly and easily. It is also important to find a content management system, such as WordPress, that can handle the amount of photos from events that Xtraordinary Joy would like to include. Wordpress has many plugins for image galleries that will allow for customization and improved site performance. However, Xtraordinary Joy should take into consideration the price of some higher quality plugins (Editorial Staff, 2016).

Improving Integrated Marketing

Step 2: Marketing

Have A Plan

Even without a budget, an organization should have a marketing plan in place to optimize its outreach. One simple way to market on a budget is to turn to the web. Social media is a great platform to engage with potential donors and help create a community. Xtraordinary Joy currently posts to Facebook and Twitter, but the posts are sporadic and not daily. Xtraordinary Joy would benefit from posting at least one post per day to Facebook, but no more than two, and three times per day to Twitter. (Roy, 2016) Both of these social media platforms have analytics tools built in. This means the organization can monitor its social media posts and determine the best topic to post about at the most advantageous times. Once this is determined, the organization can create a social media-posting calendar and utilize tools such as Hootsuite to consistently post without spending too much time or effort. Hootsuite will allow the organization to schedule posts for up to three social media accounts for free and monitor their feeds. (“Social Media Marketing & Management Dashboard”, n.a.) It would also be beneficial for Xtraordinary Joy to utilize other social media platforms such as Instagram, Google+, and Pinterest. Instagram is an important outlet for Xtraordinary Joy since the organization hosts events and likes to share the photos with the community. Pinterest could also be a good way to help build up a community by connecting with people based on similar experiences and needs.

Reach Volunteers

Because many of its donations come from event sponsors, it would be beneficial for the fundraising of the organization to host and participate in as many events as possible. Although they do not currently have much manpower to orchestrate events, it can begin to reach out to more volunteers. For example, the website could feature a volunteer information section, or opportunities can be better promoted through social media.

Although it has attained 20 dedicated volunteers this year, including student athletes through Tony Meacham’s advising position at the University of Florida, it could also look to direct marketing to other schools, churches, and groups that often participate in volunteer opportunities. (Meacham, 2017) As awareness and donations grow, the organization should also look to hire a small staff to see that events are handled professionally.

Improving Integrated Marketing

Step 3: SEO

Google Analytics

As previously mentioned, Xtraordinary Joy does not have a Google Analytics account set up for their website. We suggest that the first step in optimizing SEO is to input a Google Analytics tracking code into the website to enable the collection of analytics. This will allow the organization to see where most of their visitors are coming from, how long they are visiting the page, and what they are doing once they arrive on the page. (“Analytics Solutions”, n.a.) It will also allow the organization to track traffic to their website from specific social media posts, giving them insight to the best types of traffic-driving social posts. To do so, Xtraordinary Joy can visit the Google URL Campaign builder in order to create a UTM parameter. This parameter can be attached to social media posts, and tracking can begin. (“URL builder”, n.a.)

Google Grant

An option to help Xtraordinary Joy in their online rankings is to register and apply for a Google Grant. This grant offers non-profit organizations \$10,000 each month in Google AdWords dollars, and there are options for a hands-on AdWords campaign or a campaign that the organization manages itself. (“Ad Grants”, n.a.) By having Google Ads, Xtraordinary Joy can greatly improve their Google rankings, expand their online reach, and hopefully obtain more donations.

Improving Integrated Marketing

Step 3: SEO (cont'd)

Inbound Links

Aside from paid and organic rankings, there are other steps that can be taken to make the website itself more search-engine friendly. One step is to create a network of inbound links that is consistent, relevant, and makes sense. To do so, the organization should aim to create shareable content that is also relevant to their targeted keywords and landing pages. (“SEO: The Beginner’s Guide to Search Engine Optimization from Moz”, 2014) A great approach should focus on emphasizing the blog aspect of the organization’s website and promote the shareable content from the blog on social media. The organization should also aim to recruit links from relevant websites, such as those focused on similar medical research or that are affiliated with the University of Florida.

HTML Structure and Page Content

Another aspect of the website that can help SEO is the structure of the content. According to the HTML5 outliner, the HTML structure of the organization’s current website homepage has one big section that is “untitled”, yet there are many sections of content on the page. (“HTML5 Outliner”, n.a.) Moz’s SEO guide tells us that search engines index content that is in the page’s HTML structure, so by making sure the HTML matches the content of the page and dividing up the sections in a logical way, Xtraordinary Joy will allow Google and other search engines to more easily understand the page’s important content. (“SEO: The Beginner’s Guide to Search Engine Optimization from Moz”, 2014)

Improving Integrated Marketing

Step 3: SEO (cont'd)

Meta Tags

A final aspect of the web page that can be improved for SEO purposes is the metadata. Metadata describes the content of the page, but it is usually not seen. For example, images in the HTML of a page have metadata. This data includes the source of the image, the title, and the alternate tag in case the image does not appear. Because search engines are unable to see the image itself, it reads this meta data in order to discover its relevance and context on the page. (“SEO: The Beginner’s Guide to Search Engine Optimization from Moz”, 2014) Xtraordinary Joy has many images on its website, but these images currently do not have any meta tags. The organization should consider updating this meta data in order to increase its chances of higher organic search engine rankings. The website would also benefit from utilizing a meta description tag, which is hidden in the “head” tag of the HTML, but appears as the description in search engine rankings. It can be useful in not only helping Google understand the content, but it can also persuade visitors to click on the web page link. (“SEO: The Beginner’s Guide to Search Engine Optimization from Moz”, 2014)

SWOT Analysis

Strengths

1. Authority in the research field

Because she works in scientific research already, it gives her more credibility and trustworthiness in the organization's donation solicitations. Given the Meacham's professional connection with the University of Florida, they already have an extensive network in the community.

Having a daughter with the same X chromosome deletion as the research that the organization funds gives the brand another level of trustworthiness.

2. Passion for the cause

The background and passion of the family not only connects them directly to the cause and adds a face to the efforts, but it also allows audiences to connect on an emotional level and allows for a great platform for social media and other marketing efforts.

1. Limited Budget

As a young nonprofit with limited manpower, the organization faces economic obstacles in funding their events and outreach.

2. Rare disorder means not as much initial awareness

This could lead to a potential lack of interest, as not as many people have heard of the disorder that is yet to be named. The rarity of the disorder means donors may pass over it for better known, more common disorders.

Weaknesses

1. No marketing plan in place

Even a small organization can benefit from a marketing plan to have a consistent presence in the community and online.

2. The website is not as user-friendly as it could be

The website is not responsive, and a usability test shows that the purpose of the website is not easily evident.

1. Volunteers to help with online presence and marketing

Having friends that can help limit the costs of marketing is immensely beneficial to a nonprofit with a limited budget.

2. Successful events that can be marketed in the future

Having a photo album of successful past events gives potential participants and donors insight into what to expect and could influence their commitment.

3. Free online resources for growing nonprofits

One example is Google AdWords Grant. It is simple to apply, and can offer a non-profit organization \$10,000 a month in Google

Threats

Opportunities

Conclusion



With a national trend that sees an increase in individual donations, and a local trend that sees an increase in philanthropic endeavors, there is a lot of promise for a young nonprofit in the Gainesville, Florida area such as Xtraordinary Joy. The organization's current online marketing goals are to solicit donations to help fund the research of Xq27.3-28, and to spread awareness of this disorder and its effects

through community. Currently, the organization stays true to its brand: a normal family with big dreams that hopes to spread joy to others affected by this disorder. However, the website does not clearly state its goals, and the content can be optimized for a better user experience and better SEO. The organization can also look to online tools to help it expand its online reach including a Google Grant for free monthly AdWords and platforms such as Hootsuite to help it manage multiple social media platforms with limited manpower. With its authority, passion, and potential untapped resources, Xtraordinary Joy should feel optimistic about reaching its goals.

Appendices

WEBSITE

HOME



is a 501(c)(3) non-profit foundation providing advocacy and funding for X chromosome deletion research that advances lifelong health, behavior and learning.

UnMask Joy! MASQUERADE BALL & AUCTION



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[RESOURCES FOR RARE DISORDERS](#)

In 2014 we adopted Moriah Joy. Our story is one of patience, joy and unexpected discovery of a rare X chromosome deletion that has led to the formation of Xtraordinary Joy, Inc. Click the link below to follow our journey.

[LEARN MORE](#)

Established in 2016, our vision for Xtraordinary Joy, Inc. is to raise funds that will promote clinical interventions, therapies and care opportunities for children afflicted by X chromosome deletions. Click the link below to find out about partnership opportunities.

[XQ27.3-Q28 DELETION](#)

[POST DIAGNOSIS](#)

[SCIENTIFIC RESEARCH PLAN](#)



Enjoy yourself and support our cause at a special fundraising event for:

Organization name: Xtraordinary Joy
Date: 7/16/2016
Time: 4:00 pm-8:00 pm
Location: Blaze Pizza – 3617 SW Archer Road
Gainesville, FL 32608

Bring in this flyer or show it on your phone before paying. Blaze Pizza will donate 20% of proceeds from your meal back to our organization.



FAST-FIRED.

Support Xtraordinary Joy.

When you shop at [smile.amazon.com](#), Amazon donates.

[Go to smile.amazon.com](#)

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XTRAORDINARY NEWS!



Click on the link below to see our story on WCJB TV20:
<http://www.wcjb.com/local-news/2016/07/gainesville-two-year-old-fighting-rare-genetic-disorder>



We are excited to invite you to partner with Xtraordinary Joy, Inc. Below you can read about our last fundraising event for 2016.

[PARTNER](#)[SPONSORSHIP COMMITMENT FORM](#)

E-mail completed form to: info@xtraordinaryjoy.org

Masquerade Ball & Auction to Unmask JOY

November 5, 2016

Harrell Medial Education Building

6:30-10:00pm

Expected turnout of 300+ guests

Xclusive Sponsor - \$5000

- All benefits for marketing and involvement for all events (including Human Foosball Tournament) for the year
- Your business logo, link and personal message prominently displayed on our Website for the year

X Caliber Sponsor - \$3000

- Custom Event Table/Booth to represent your business and interact with participants (ideas: photo booth, sample demonstrations, Auction Basket). Opportunity to provide special offers, branded items. Volunteer Leadership Opportunity
- Half Page Advertisement in Event Program
- Logo on Event Media Presentation
- Logo on pre-event advertising
- Table of 8 to dine, dance and shop live auction

Xcellence Sponsor - \$1500

- Logo on event day signs and program
- Logo on pre-event advertising
- Four tickets to dine, dance and shop live auction

Xtreme Sponsor - \$500

- Recognition in Event Program
- Two tickets to dine, dance and shop live auction

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XQ27.3-Q28 DELETION POST DIAGNOSIS

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Joy!

Xq27.3-q28 DELETION

Possible symptoms:

- Low muscle tone resulting in delayed crawling, walking
- Sensory Processing Disorder
- Gag reflex, swallow difficulty, sucking difficulty, oral aversion, teeth grinding
- Drooling
- Chronic sinus and ear infections
- Autism; non-verbal
- Seizures
- Intellectual disability
- Constipation
- Some families have reported breathing issues, organ anomalies, growth problems

Underlying disorders within deletion:

- Fragile X Syndrome due to FMR1 gene deletion:

FRAGILEX.ORG

- Hunter Syndrome (Mucopolysaccharidosis II) due to IDS gene deletion:

HUNTER SYNDROME



POST DIAGNOSIS

These sites below provide many resources and are a great start to understanding the new diagnosis. You can also register your child's exact deletion, duplication or mutation so you can contact other families with similarities.

National Organization for Rare Disorders NORD
<http://rarediseases.org>

Unique
<http://www.rarechromo.org>

Chromosome Disorder Outreach
<http://chromodisorder.org>

Facebook support groups! (Apraxia, hypotonia, feeding tube...look for local special needs groups too)

Federal Early Intervention (each state has their own program) for physical, occupational and speech therapies

X-inactivation
<https://en.wikipedia.org/wiki/X-inactivation>
Because this chromosome is on the X chromosome, and girls have X-inactivation, geneticists typically test to see how much of the X with deletion is present and how much the intact X is present. This test is done with a blood draw. This could affect the severity of symptoms.

SCIENTIFIC RESEARCH PLAN

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SCIENTIFIC RESEARCH PLAN

University of Florida scientists are teaming up to examine the effects of gene deletion on biochemical pathways and attempt to rescue brain circuitry with targeted therapies.

University of Florida College of Medicine

-Center for Cellular Reprogramming
<http://ccr.med.ufl.edu>

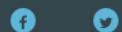
Your donation will go directly to fund this research

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-Department of Neuroscience
<http://neuroscience.ufl.edu>

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If you have any questions about our website or our Privacy Promise, please contact us at
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XTRAORDINARY *Joys!* Photo Album

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XQ27.3-Q28 DELETION - Xtraordinary Joy

www.xtraordinaryjoy.org/xq27.3-q28-deletion.html ▾

-Fragile X Syndrome due to FMR1 gene deletion: ... Xq27.3-q28 DELETION · POST DIAGNOSIS · SCIENTIFIC RESEARCH PLAN · PRIVACY POLICY · Photo ...

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https://www.researchgate.net/.../236601267_Deletion_Xq273q28_in_female_patient_wit...

Official Full-Text Publication: Deletion Xq27.3q28 in female patient with global ... observed in previous studies suggested a primary role of the Xq27-28 region in ...

Schematic of X chromosome and genes in the Xq27.3-q28 region ...

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[Home - Chromosome Disorder Outreach Inc | chromodisorder.org](#)

chromodisorder.org/ ▾

Jan 4, 2017 - Chromosome Disorder Outreach, Inc. (CDO) is a non-profit organization for families affected by any type of rare chromosome disorder: ...

[Chromosome 12q deletion | Genetic and Rare Diseases Information ...](#)

<https://rarediseases.info.nih.gov/diseases/10847/chromosome-12q-deletion> ▾

Oct 7, 2015 - Features that often occur in people with chromosome 12q deletion include developmental delay , intellectual ... Many are the driving force behind research for better treatments and possible cures. ... Boca Raton, FL 33429

[Chromosome 3q deletion | Genetic and Rare Diseases Information ...](#)

<https://rarediseases.info.nih.gov/diseases/10838/chromosome-3q-deletion> ▾

Features that often occur in people with chromosome 3q deletion include developmental delay , intellectual disability , behavioral ... Many are the driving force behind research for better treatments and possible cures. ... Boca Raton, FL 33429

[Chromosome 10q deletion | Genetic and Rare Diseases Information ...](#)

<https://rarediseases.info.nih.gov/diseases/3711/chromosome-10q-deletion> ▾

Features that often occur in people with chromosome 10q deletion include developmental delay , intellectual disability ... Many are the driving force behind research for better treatments and possible cures. They can ... Boca Raton, FL 33429

[Chromosome 22q11.2 Deletion Syndrome - NORD \(National ...](#)

<https://rarediseases.org> › For Patients and Families › Rare Disease Information ▾

Chromosome 22q11.2 deletion syndrome is associated with a range of problems including: congenital NIH/National Institute of Dental and Craniofacial Research ... 4208 Chateau Rd. Orlando, FL 32808 USA; Phone: (407) 617-4111; Email: ...

[Chromosome 18q- Syndrome - NORD \(National Organization for Rare ...](#)

<https://rarediseases.org> › For Patients and Families › Rare Disease Information ▾

18q Deletion Syndrome; 18q- Syndrome; Chromosome 18 Long Arm Deletion Syndrome Chromosome 18, Monosomy 18p is a rare chromosomal disorder in which all or part of the short Chromosome 18 Registry & Research Society ... P.O. Box 724; Boca Raton, FL 33429-0724 USA; Phone: (561) 395-4252; Email: ...

[Cri du Chat Syndrome - NORD \(National Organization for Rare ...](#)

<https://rarediseases.org> › For Patients and Families › Rare Disease Information ▾

Cri du chat syndrome is a chromosomal disorder caused by a partial deletion (monosomy) of a Research and studies of cri du chat syndrome are ongoing. ... P.O. Box 724; Boca Raton, FL 33429-0724 USA; Phone: (561) 395-4252; Email: ...

[Smith Magenis Syndrome - NORD \(National Organization for Rare ...](#)

<https://rarediseases.org> › For Patients and Families › Rare Disease Information ▾

This deleted portion within chromosome 17p11.2 includes the RAI1 gene, which National Institutes of Health (NIH) SMS Research Registry and Tissue Bank ... 800 Florida Avenue NE; 2047; Washington, DC 20002-3695; Phone: (866) 895- ...

[8th Biennial International 22q11.2 Deletion Syndrome Meeting ...](#)

www.floridahospitalhearing.com/8th-biennial-international-22q11-2 ▾

May 31, 2012 - The Florida Hospital Hearing Centers provide a variety of hearing healthcare ... Anne Bassett, Director, Clinical Genetics Research Program, Centre for ... extra piece section (microdeletion or micro duplication) of chromosome ...

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Chromosome 6 Project - Chromosome 6 Research Project

<https://www.chromosome6.org/> ▾

Chromosomal anomalies, such as chromosome 6 deletions (too little chromosomal material) or duplications (too much chromosomal material), are a cause of ...

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Latest Research & Studies - Chromosome Disorder Outreach Inc ...

chromodisorder.org/latest-research-and-studies ▾

Jan 4, 2017 - Each month CDO will select a few recently published genetic journal articles which we believe present the most interesting and important new ...

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Cytogenetics - Sunflower Health Foods - Gainesville

www.sunflowerhealthfoods.com/ns/DisplayMonograph.asp?StoreID...DocID... ▾

Jump to **Research** - When researchers study all of the chromosomes in a cell, it is ... Deletions within one chromosome can now be more specifically ...

Human foosball to raise money for rare-disorder research | Local ...

www.alligator.org/news/local/article_5e014568-7a2c-11e6-b12d-93c16cb1ba03.html ▾

Sep 13, 2016 - To help fund research for X-chromosome deletion, a disorder that can cause autism-like symptoms in young girls, Gainesville Human Foosball ...

Familial segregation of an imprinting centre deletion. : Angelman ...

www.nature.com/nrneurol/journal/v12/n10/fig_tab/nrneurol.2016.133_F4.html

Sep 12, 2016 - The figure shows segregation of a chromosome 15q11.2-q13 imprinting centre deletion in a large five-generation family. Females are ...



x chromosome research Gainesville



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X-citing X chromosome discovery could aid research on many sex ...

www.uofmhealth.org/.../x-citing-x-chromosome-discovery-could-aid-research-many-... ▾

Oct 19, 2015 - A new genetic discovery could help scientists understand exactly how one X chromosome in each cell of a female's body gets "silenced" – and ...

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Chromosome X News, Research - News Medical

www.news-medical.net/?tag=/Chromosome-X ▾

The X chromosome is one of the two sex chromosomes in humans (the other is the Y chromosome).

The sex chromosomes form one of the 23 pairs of human ...

Missing: gainesville

X chromosome - Genetics Home Reference

<https://ghr.nlm.nih.gov/chromosome/X> ▾

Females have two X chromosomes, while males have one X and one Y ... Identifying genes on each chromosome is an active area of genetic research. Because ...

Missing: gainesville

Genetics | UF Health, University of Florida Health

<https://ufhealth.org/genetics> ▾

Jan 25, 2016 - DefinitionGenetics is the study of heredity, the process of a parent passing ... In females, the presence of one normal X chromosome masks the ...

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is a 501(c)(3) non-profit foundation providing advocacy and funding for. X chromosome deletion research that advances lifelong health, behavior and learning.

UF scientists awarded \$4.7M for hemophilia research - Gainesville Sun

www.gainesville.com/news/.../uf-scientists-awarded-47m-for-hemophilia-research ▾

Jan 13, 2011 - Boys get the disease, which is linked to the X chromosome, while girl "carriers" rarely show symptoms. Patients with hemophilia B risk death ...



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The JOY FM

www.thejoyfm.com/ ▾

The Joy FM, Christian radio station in Sarasota features of format of family and Bible teaching programs, Contemporary Christian music, and an Internet audio ...

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Gainesville FL 32605 MAP external link. Office Phone: 352.373.9553. Fax: 352.373.9888. 91.5 FM Studio 6214 Springer Dr Port Richey FL 34668 MAP external ...

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bmcmedgenet.biomedcentral.com/articles/10.1186/1471-2350-14-49 ▾

by LS Marshall - 2013 - Cited by 2 - Related articles

May 1, 2013 - Gene deletions of the Xq27-28 region are less frequently found in either BAC array showed a ~10.6 megabase deletion at Xq27.3q28 ...

Missing: community

OMIM Entry - # 300869 - CHROMOSOME Xq27.3-q28 DUPLICATION ...

www.omim.org/entry/300869 ▾

Chromosome Xq27.3-q28 duplication syndrome is an X-linked recessive neurodevelopmental disorder characterized by mild mental retardation, mild facial ...

Missing: community

XQ27.3-Q28 DELETION - Xtraordinary Joy

www.xtraordinaryjoy.org/xq27.3-q28-deletion.html ▾

Possible symptoms: -Low muscle tone resulting in delayed crawling, walking -Sensory Processing Disorder -Gag reflex, swallow difficulty, sucking difficulty, oral ...

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Molecular cytogenetic characterization of Xp22.32→pter deletion and ...

www.sciencedirect.com/science/article/pii/S1028455916301346

by CP Chen - 2016

Oct 15, 2016 - The present case had a 19.22-Mb duplication of Xq26.3–q28 ... Hickey et al [23] reported a duplication of Xq27.3–q28 including FMR1 in ...

Chromosome 1p32-p31 deletion syndrome: Prenatal diagnosis by ...

www.sciencedirect.com/science/article/pii/S1028455911001379 ▾

by CP Chen - 2011 - Cited by 17 - Related articles

Oct 23, 2011 - To present prenatal diagnosis of chromosome 1p32-p31 deletion ... 21q22.2-q22.3 deletion, Xp22.3 deletion, and Xq27.3-q28 duplication [18].

European Journal of Human Genetics - De novo microduplication of ...

www.nature.com/journal-home-archive/short-reports ▾

by J Vengoechea - 2012 - Cited by 9 - Related articles

May 2, 2012 - A large 5.1-Mb interstitial duplication in the Xq27.3q28 region containing 28 ... to share this case report with the medical genetics community.



Xq27.3-q28 deletion research



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[Deletion Xq27.3q28 in female patient with global ... - ResearchGate](#)

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from publication 'Deletion Xq27.3q28 in female patient with global ... Chromosome and DNA studies found an abnormal karyotype with a deletion on the X ...

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Joy!

