

315

Communications, Inc.

Crohn's & Colitis Foundation of
America- New England Chapter
Education and Awareness Research
Report

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This report was prepared by the members of 315
Communications, Inc., in response to the request of the CCFA.

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Executive Summary:

This is a research client report for the Crohn's and Colitis Foundation of America's New England Chapter. The CCFA wants to increase the target audience's level of awareness regarding the organization and their knowledge of inflammatory bowel disease (IBD). We conducted primary and secondary research with individuals from the New England areas, which includes Massachusetts, New Hampshire, Rhode Island, Vermont, Maine, and Connecticut. Our sampling frame included college students from New England areas who are currently attending Syracuse University. We found that most people do not trust online sources for health-related information, yet the best way to educate them is through a social media campaign.

Problem Statement:

The CCFA New England Chapter would like for the New England region to have an increased awareness of the impact that IBD can have on individuals and their loved ones. Because IBD is not perceived as having as large of an impact as other chronic disorders and can be difficult to talk about, awareness about IBD is currently low. Research will be conducted to better understand how the people of the New England area perceive IBD and to identify the most effective channel to educate them.

Situational Analysis:

The Company:

- CCFA's mission is to cure Crohn's disease and ulcerative colitis, and to improve the lives of children and adults who suffer from these diseases. This organization has a very welcoming and family friendly environment. Due to this, it has a warm and positive image.
- CCFA offers a summer camp called Camp Oasis for children living with IBD and also offers a range of educational and training programs to inform communities nationwide about Crohns and Colitis. CCFA also hosts sporting events to raise money for their cause that are appropriate for the whole family to attend.
- The company is active on social media through Facebook, Twitter, YouTube, Pinterest, and LinkedIn. The goal of these social media sites is to maintain a very inspirational and personable image, with posts consisting of inspirational quotes and stories about people who suffer from IBD. CCFA also provides a website just for teenagers who suffer from IBD.
- CCFA has been extremely profitable and earns more than 55 million dollars annually through fundraising events, memberships, sponsorships, and other programs.

The Service:

- Research programs for seeking cure and treatment for Inflammatory Bowel Diseases (IBD), which include Crohn's and Colitis.
- Education programs to inform and raise awareness regarding Crohn's and Colitis disease for current patients and their friends and families. These programs take forms of:
 1. Awareness campaigns
 2. Webcasts
 3. Magazines published twice annually (*Take Charge* and *Under the Microscope*)
 4. Scientific journal for healthcare professionals, published monthly (*Inflammatory Bowel Diseases*)
 5. Camp Oasis (summer camp for children living with IBD)
 6. Workshops for healthcare professionals
- Support services for patients, friends and families, and health care professionals that include:
 1. Support and treatment information available through CCFA's Information Resource Center (1-888-MY-GUT-PAIN)
 2. Live chat through website
- Fundraising events to gain funding for research on IBD's cure and prevention
- Merchandise in the form of caps, backpacks, and sweatshirts. These products are available at CCFA's online store.
- Books related to Crohn's and Colitis disease that answer questions such as what is the disease, how to live with the disease, etc. These books are available at CCFA's online store.

The Consumer

- Demographics
 - Philanthropic, affluent individuals
 - Membership to CCFA is \$30
 - Most events hold a high entrance fee. Individuals must be able to afford to attend such fundraising events, and therefore have a steady income.
 - Casino For a Cause: \$1,000 package deal
 - Take Steps For Fashion: \$425 package deal
 - Denim & Diamonds Dinner & Auction: Sponsorships range from \$1,000- \$7,5000
 - Families of all ages
 - Events held solely for educational purposes, free of charge
 - Vermont Pediatric IBD Lecture
 - Pediatric IBD Lecture in Worcester, MA
 - Nutrition and IBD Lecture in Providence, RI
 - The New England Chapter covers the following geographical areas: Maine, Massachusetts, New Hampshire, Rhode Island and Vermont
- Psychographics
 - Those impacted by Crohn's/Colitis either personally or who have friends/family who have been affected
 - Those in need of a mentor to deal with Crohn's/ Colitis symptoms
 - Those looking for educational tools in regards to Crohn's/Colitis
 - Those who participate in an active lifestyle or who are seasoned athletes, as well as those interested in professional sports
- Seasonality and Donation Cycle
 - Events are held across the country throughout the year, so CCFA can work to attract new and returning participants in virtually any month
 - New England Chapter in particular is holding quite a few events this upcoming fall (2015)

The Competition:

- There is a lot of competition in New England for charity funds. The Crohn's and Colitis Foundation of America in New England is competing with more well-known and larger corporations such as:
 - Jimmy Fund
 - Ronald McDonald's House
 - Susan G. Komen
- These competitors are more recognizable, and are thus more likely to draw funds from donors. They also offer a way for people to donate to diseases that are more prevalent, and thus more likely to have personally affected them. Those charities also cater to diseases that are easier to talk about publicly.

The Market:

- New England is a smaller market in comparison to other parts of the America. Its largest portion of the population is found in Boston.

- CCFA's New England chapter is situated in Needham, MA, a town right outside of Boston. This CCFA chapter serves a market that is at a higher risk of developing an IBD due to the regional climate (CCFA, 2015).
- Geographic
 - Maine, Massachusetts, New Hampshire, Rhode Island, Vermont
 - Estimated populations as of 7/1/14 of 1,330,089; 6,745,408; 1,326,813; 1,055,173; and 626,562 respectively (Census, 2014)
 - Urban areas such as Boston (IBD development more common in cities) (Crohn's & Colitis Foundation of America, 2014)
 - Most populated areas include Boston; Worcester, MA; Providence, RI; and Springfield, MA. (Census, 2014)
- Demographic
 - 15-35 years old (the age group where affliction is most prevalent)
 - Children under 18 (the fastest growing rate of affliction is in this age group)
 - All genders (all are equally affected by IBD, although ulcerative colitis more common in men) (Crohn's & Colitis Foundation of America, 2014)
 - Maine, Mass., New Hampshire, RI, VT- 95%, 82.6%, 94%, 85.1%, and 95% respectively ID as white. (Census, 2014)
- Market Needs
 - Education: Most of the target market has not been properly informed about how serious IBD is and that it's affecting more people each year, especially in climates like New England
 - Awareness: Most of the target market is unfamiliar with CCFA's mission and its importance.
 - Solutions/cures: There is currently no cure, but if more people are being affected, more people will need a cure soon.
- Market Growth
 - As many as 700,000 new patients are diagnosed with an IBD each year. This is a rate of about 11 per 100,000 people (Crohn's) and 12 per 100,000 people (Colitis).
 - The majority of cases tend to occur in Northern climates, giving people in the New England region a higher likelihood of being diagnosed with an IBD. (Crohn's & Colitis Foundation of America, 2014)
- Market Trends
 - Children under 18 are developing IBD at a faster rate each year (Crohn's & Colitis Foundation of America, 2014). Younger demographics, therefore, need to be educated about potentially developing an IBD sooner. Younger demographics seek information in two distinct ways:
 - Younger demographics tend to multitask and skim rather than sit down for long periods of time.
 - Young people are much more interested in things that immediately affect them.

SWOT Analysis:

Strengths:

- CCFA is a charity that focuses in on a very specific illness, so advances in treatment are able to be made much quicker
- CCFA has a great website that shares peoples personal experiences with the disease and it is very user friendly
- Since CCFA is a smaller company people will be more trusting to donate to them because they are able to track where their money is going
- CCFA is up front with how they spend donation money. 82% of donation money goes to research about the disease and only 18% is going toward employee salaries
- CCFA is very active in holding events to support the disease
- CCFA has chapters all over the country. This helps in educating more people about IBD so that they will donate

Weaknesses:

- Poor access to media outlets
 - Newspapers and magazines do not show interest in posting articles about CCFA events
 - CCFA does not know what media outlets to turn to for support in posting articles on a semi-regular basis
- Lack of public awareness and knowledge about Crohn's/Colitis
- Uncomfortable or difficult topic to talk about in comparison to other chronic diseases
 - Hard for people even with the disease to speak out about their experience
 - Feelings of embarrassment and frustration
- Crohn's/ Colitis affects less people than other, just as serious diseases in the U.S.
 - Crohn's affects about 1.6 million Americans
 - Ulcerative Colitis affects about 700,000 Americans
 - About 14.5 million people in America had cancer in 2014
 - About 60,000 people die of heart disease each year (1 in 4 individuals)

Opportunities:

- Promoting the urgency of IBD to young people, especially those attending Boston universities and colleges, may help educate people faster. (CCFA, 2015)
- CCFA has contributed to cancer research, a disease that is more openly discussed. This could lead to a partnership opportunity with a foundation like Susan G. Komen that could help spread the word.
- Because IBD has become more likely to develop in young people than it was previously, social media will be a great place to raise awareness about IBD.
- New England, especially in heavily populated areas like Boston, is a place where IBD is more likely to occur. Spreading this knowledge could lead to people thinking about IBD as a more urgent matter.

Threats:

- Competition from other bigger and more well-known charities such as the Ronald McDonald's House and Susan G. Komen
- People's reluctance to discuss IBD issues can be an obstacle for the effort to spread awareness about the disease.
- Lack of budget for advertising purposes
- Information overload in social media world can easily make an organization's messages lost in the crowd.

Research Objectives:

1. Determine where people turn to for reliable health related information, specifically media channels.
2. Identify what people know about IBDs.
3. Explore the comfort level in the target audience in discussing IBDs.

Research Methodology:

All listed methods are primary research tactics, based on previously conducted secondary research. The survey methods are quantitative while the focus group is qualitative.

a) Method 1: Intercept Survey

- Sampling frame: New England residents 18 and over who are currently in the Syracuse area
- Rationale: The New England chapter of CCFA focuses on constituents in Massachusetts, Maine, New Hampshire, Rhode Island and Vermont. Because many college students attend Syracuse from these states, it makes sense to use an intercept survey to obtain information from them.
- Execution:
 - Recruiting Method: Use of a non-probability sampling technique by reaching out to friends, classmates and fellow students on campus, asking them to take the survey
 - Location: Syracuse University
 - Length: 12 questions
 - Incentive: None
 - Number of Participants: 100
- Data Analysis Method: SPSS

b) Method 2: Online Survey

- Sampling frame: New England residents 18 and over who are currently living in Syracuse or the New England Area
- Rationale: The Qualtrics survey allows us to collect data from New England residents who are not currently in Syracuse. It does not limit us only to individuals whom we can reach in person, which broadens our scope.
- Execution:
 - Recruiting Method – Use of snowball sampling by first recruiting friends and family members, and asking them to share the survey with friends of their own
 - Location: Internet (Facebook post, email, etc.)
 - Length: 12 questions
 - Incentive: None
 - Number of Participants: 205
- Data Analysis Method: Qualtrics

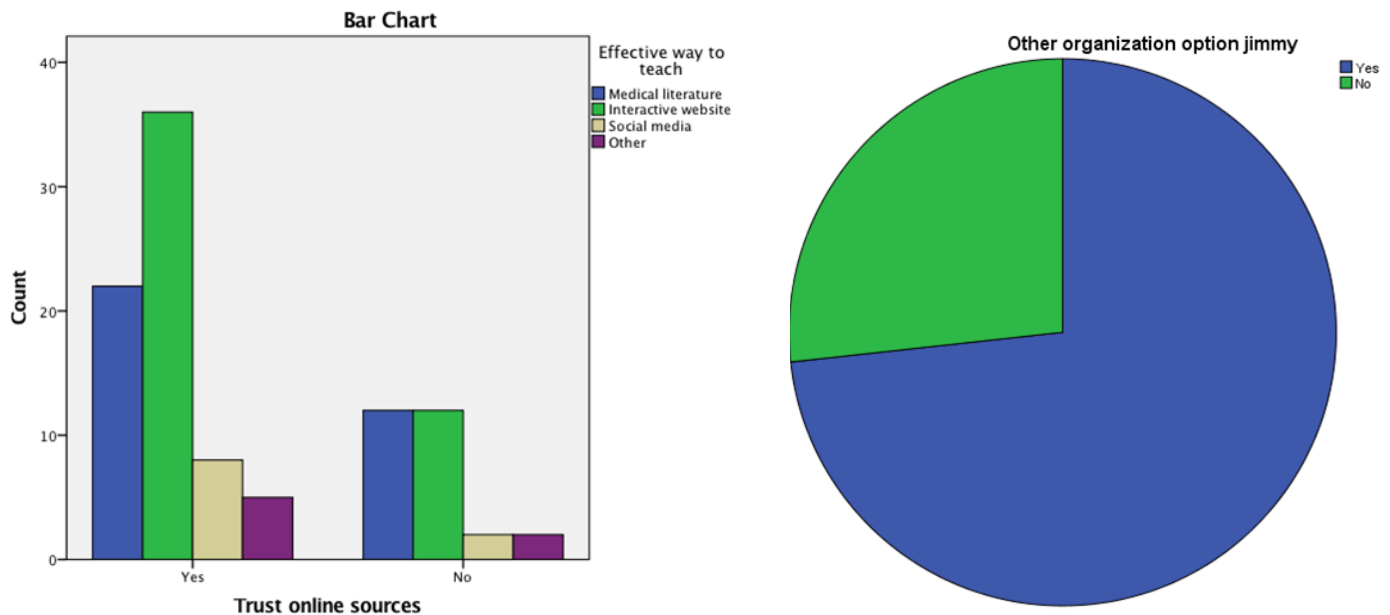
c) Method 3: Focus Group

- Sampling frame: People 18 or older from the New England who are currently in Syracuse
- Rationale: A focus group gives us an opportunity to receive a more in-depth perspective about what people know about IBD and CCFA. We picked our subjects because they are part of the audience that CCFA wants to target.
- Execution:

- Recruiting Method: Convenience sampling, snowball sampling (asking individuals who we know personally)
- Location: Newhouse 2, Room 469
- Length: 6 questions, approx. 10 minutes each (~1 hour total)
- Incentive: Snack foods
- Number of Participants: 8 (two groups of 4)
- Data Analysis Method: Manual coding

Research Results and Analysis:

a.) Intercept Survey:



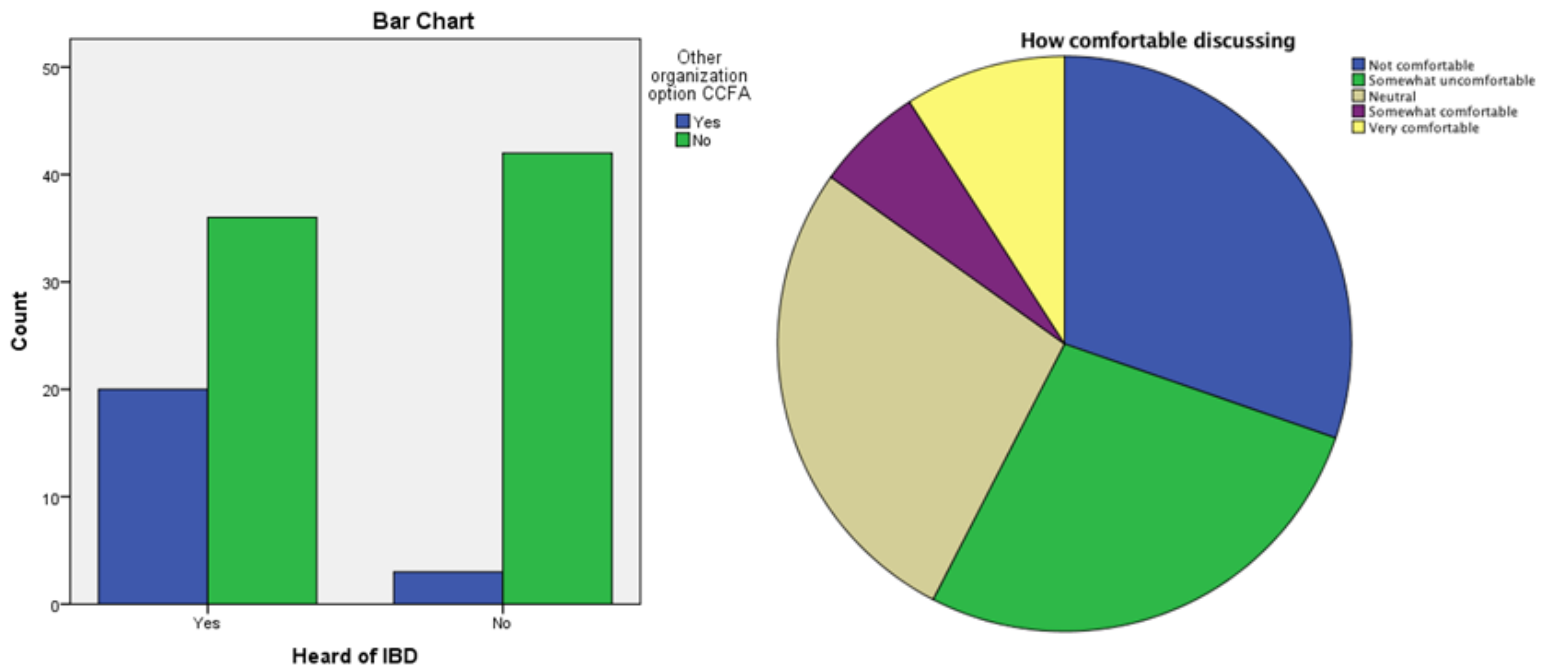
Question asked: “Rank the following sources by how reliable you believe them to be”

People seem to trust information from other people over websites and social media. Most people feel that doctors and family are more trustworthy than Google. People chose other people as either the most reliable or second most reliable overwhelmingly more often than either of the online suggestions. Around 75 percent of respondents knew about the ALS Foundation, the Jimmy Fund and The American Cancer Society. Conversely, only a quarter of our respondents were familiar with the Crohn’s and Colitis Foundation of America. The former three options are all known throughout the region while the latter clearly is not as publicized.

Question asked: “Have you heard of any of the organizations listed below” (CCFA compared with Jimmy Fund is shown)

Nearly 40 percent of people who trust online sources think that the idea of an interactive website would be a good way to teach them about IBD. They chose this option far more often than they chose medical literature (a little more than 20 percent), which was also above social media. People who claim not to trust online sources rejected social media entirely, but approximately 15 percent selected the option of an interactive website. This figure is equivalent to those who do not trust online sources and chose medical literature as an effective teaching tool. People are also much more likely to trust a medical website or social media for health information if they identified as trusting online sources, but

even among those who claimed not to trust online sources, there were a few people (7 and 12 respectively) who claimed they trusted social media and medical websites.



Questions asked: “Have you heard of IBD?” and “Have you heard of the CCFA?”

Even among people who have heard of IBD, the CCFA is not well known. A lot of people who have heard of IBD have not heard of the CCFA. The same is true for those who know someone diagnosed with an IBD. Many of the people who have heard of IBDs or know someone with an IBD have never heard of the CCFA, which means that the CCFA is not promoting itself well even among the people who are closest to the disease.

Question asked: “How comfortable would you be in discussing IBD?”




Most people are very uncomfortable or somewhat uncomfortable talking about IBD. Some people are neutral, but only 15% are somewhat comfortable or very comfortable talking about IBD. This is not even equal to the number of people who are neutral on the topic, 26%. Over 50% are either very or somewhat uncomfortable with the topic. The data also shows that people find their doctors and their families and friends the most reliable sources for this kind of information, which supports our theory that people are more comfortable talking about IBD and health topics in private.

b.) Online Survey:

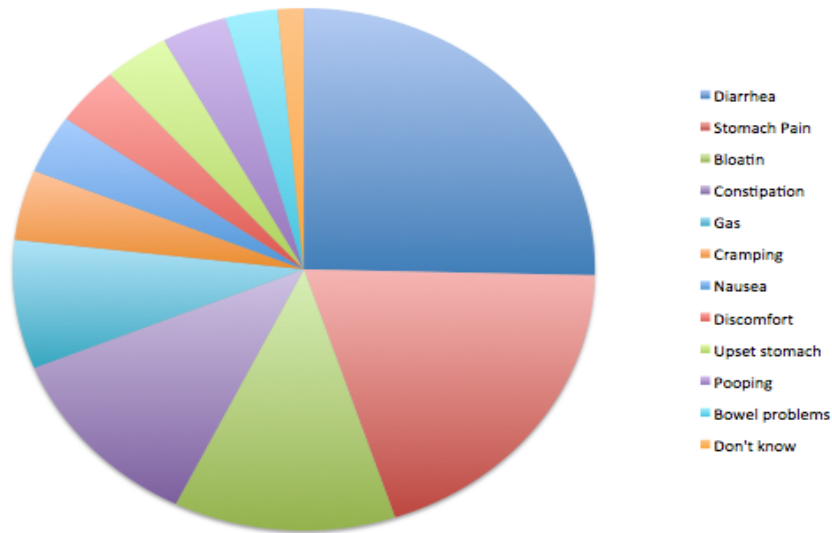
Statistic	Health websites	Social Media	Family or friends	Your doctor
Min Value	1	2	1	1
Max Value	4	5	4	4
Mean	2.40	3.83	2.48	1.24
Variance	0.41	0.28	0.64	0.29
Standard Deviation	0.64	0.53	0.80	0.54
Total Responses	123	122	126	127

Question asked: “Ranking of sources, most reliable (1) to least reliable (5)”

In general, people who took the electronic survey claim to trust social media. However, when asked to rank it among other sources, social media came out with the lowest ranking. This might mean that people do trust social media for health-related information, but not as much as they trust health websites, their doctors, or their family and friends.

#	Answer		Response	%
1	Yes		104	80%
2	No		26	20%
	Total		130	100%

Question asked: “Do you trust social media?”



Question asked: “When you hear the term ‘inflammatory bowel disease,’ what symptoms would you believe to be associated with this?”

Most people know that the disease has to do with the bowels, and symptoms associated with the bowels. They understand that it could include pain such as cramps and stomach aches, as well as discomfort and bloating. They also understand that this can include uncomfortable regurgitation like diarrhea, gas, constipation, pooping, and nausea. Most of the answers were vague, indicating that while people had some idea what an IBD could be, they did not have specific information about the diseases.



Question asked: “Have you or someone you know been diagnosed with IBD?”

We also learned that a little less than half of the people surveyed said they know someone diagnosed with an IBD. This is about equal to the percentage of people who claim they

do not know someone diagnosed. 12% admit to not being certain. The large number of people who were not certain could indicate that these people either do not know enough about the disease, or that they acknowledge that this is not a topic people generally speak about. In other words, they may not be aware if someone they know has been diagnosed because the diagnosed individual would not make it obvious.

Lastly, the data we collected via the online survey told us that people who took the electronic survey claim to be more comfortable discussing IBD than those who took our intercept survey, with the response “somewhat uncomfortable” replacing “very uncomfortable” as the most common response. Regardless, people were generally not comfortable with the topic. The data also tells us that people are more comfortable learning about this topic on their own through medical literature or an interactive website that they could investigate on their own, as opposed to social media, which would be more likely to require some social aspect that would require conversation with other people instead of just a computer or a book.

c.) Focus Groups

We noticed that during the first few questions, people were answering without much hesitation. However, as we progressed to discuss IBD specifically, there seemed to be more hesitation. One of the respondents had a particularly strong aversion to the idea of trusting social media for health-related advice, but was calm throughout the rest of the questions. Another respondent informed us that she did not find this topic uncomfortable, although we noted that her face turned red when talking about the symptoms of IBD. When she said that she did not feel uncomfortable, she was looking straight down at the desk, not making eye contact with anyone.

Other behavior that we noticed was a lot of blushing and stuttering, as well as some exchanging glances with other respondents before answering any questions. Other participants tended to be more vocal after one person had responded. We also noticed a contradiction in the attitudes of people about social media. While they claimed that they did not trust social media for health-related information, preferring physically being able to communicate with family member or doctors, the respondents recommended social media as a way for the CCFA to promote awareness.

Overall, we found that in general, people feel uncomfortable speaking about the topic of IBD, and that people do not trust social media for their medical information.

Recommendation:

After conducting our research, we have come up with several recommendations for the CCFA. To further study, we should recommend expanding on our target audience to people beyond the 18-34 age group. Our current study is based on non-probability and convenience sampling, using the college student population within this given age range. From the results we gathered and analyzed, we came up with several suggestions for future campaigns.

The CCFA should continue to include using personal stories in their efforts to spread awareness of Crohn's and Colitis, giving the public the opportunity to put a face to the disease and feel more connected to it. We would also suggest that the organization take one person with a particularly powerful story and use him/her as a face for the disease. When people feel connected to the given individual they will be more likely to donate or learn more about the issue. Celebrity personalities are extremely valuable in this part of the campaign, as the general public tends to gravitate toward products and causes that celebrities endorse. Well-known public figures, who have a large following on social media and the ability to reach large audiences, can bring the CCFA's campaigns to the public eye easily. Another possibility for promotion would be to utilize sports teams and athletes that people admire, and have them spread the message. The many professional teams in the Boston area are especially good outlets for this.

We also recommend that CCFA conduct a social media campaign similar to the ALS Ice Bucket Challenge, which took off on social media and resulted in a huge increase in awareness of the disease, as well as donations to the ALS Association. As we have found out through our focus groups, many people had not heard of ALS until this challenge, or had a very limited understanding. While the challenge has not expanded their knowledge of the particular symptoms of ALS, it did promote awareness and became a topic of household discussion. The CCFA needs a campaign with a similar goal, getting the names "Crohn's" and "colitis" out to the public and giving them something to associate them with. Once this connection is established, the organization can focus on educating the public about the diseases. It is our belief that a similar challenge will also increase donations.

Our data also suggests that people would be responsive to learning about this kind of disease through an interactive website, as opposed to medical literature, giving the CCFA an opportunity to create an engaging website that educates its users about Crohn's and Colitis. This would be a private but interesting way of learning, that keeps people engaged without forcing them to talk about a topic that we have found something people find uncomfortable. With this type of educational platform, people also do not have to go out of their way to learn, but rather can do it in the comfort of their jargon, because this frustrates people, especially with a topic they know very little about. Instead, the site should be simplified and brought to them on a platform that they already understand.

To promote the CCFA as an organization, and awareness of Crohn's and colitis, the CCFA should institute some sort of challenge, using a celebrity or spokesperson, and then utilize social media to distribute the challenge. After people have heard the name CCFA and begin to associate it with the challenge, the CCFA should put out an interactive website to educate about those specific diseases or IBD in general.

Appendix:

- **Intercept Survey:**

Kim Flatley, Phoebe Sudargo, Tahirah Newkirk, Jessica Steele, Amanda Shea
315 Communications Inc. Final Intercept Survey

We, a group of Syracuse University students, are conducting a survey on health related non-profit organizations. Please help us by completing the survey below. Respondents to this survey will remain anonymous. The survey will take approximately 5 minutes to complete. Thank you.

1. Where do you obtain your health knowledge? Check all that apply.

- Books
- Doctors/ nurses/ other health professionals
- Medical websites
- Social media
- TV
- Other (please specify):

2. Would you trust online sources for health-related information?

- Yes
- No

3. Rank the following sources by how reliable you believe them to be, 1 being the most reliable source and 6 being the least reliable.

Medical websites	_____
Social Media	_____
A medical journal	_____
Family or friends	_____
Your doctor	_____
Other	_____

4. Have you heard of any of the organizations listed below? (Check all that apply)

- Jimmy Fund
- American Cancer Society
- New England Celiac Organization
- The ALS Association
- The Crohn's and Colitis Foundation of America
- I have not heard of any of them

5. Have you heard of Irritable Bowel Disease before?

- Yes
- No

6. Have you or someone you know been diagnosed with Irritable Bowel Disease?

- Yes
- No

7. When you hear the term, “irritable bowel disease,” what symptoms would you believe to be associated with this?

8. How comfortable would you be discussing IBD, where 1 is not comfortable to discuss it and 5 is very comfortable in discussing it?

Not comfortable 1 2 3 4 5 Very comfortable

9. What would be the most effective way to teach you about IBD?

- Medical literature
- Interactive website
- Social media
- Other (please specify): _____

10. What age group do you belong to?

- Under 18
- 18-34
- 35-44
- 45-54
- 55-64
- 65 +

11. In what state is your permanent address?

- Maine
- Massachusetts
- New Hampshire
- Rhode Island
- Vermont
- Other (please specify): _____

- **Electronic Survey:**

We, a group of Syracuse University students, are conducting a survey on health related non-profit organizations. Please help us by completing the survey below. Respondents for this survey will remain anonymous. The survey will take approximately 5 minutes to complete. Thank you.

In which state is your permanent address?

- Massachusetts
- New Hampshire
- Vermont
- Maine
- Rhode Island
- Connecticut
- Other

In which range does your age fall?

- Under 18
- 18 - 34
- 35 - 44
- 45 - 54
- 55 - 64
- 65+

Which of the following sources do use to obtain health-related information?

- Books
- Health professionals
- Medical websites
- Social media
- Other

Do you trust online sources for health-related information?

- Yes
- No

Rank the following sources based on how reliable you believe them to be for providing accurate health related information, with 1 being the most reliable and 4 being the least reliable.

- Health websites _____
- Social Media _____
- Family or friends _____
- Your doctor _____

Have you heard of any of the organizations below? Check all that apply.

- The Jimmy Fund
- The American Cancer Society
- New England Celiac Organization
- The ALS Association
- The Crohn's and Colitis Foundation of America
- I have not heard of any of these

Have you or someone you know have an Inflammatory Bowel Disease (IBD)?

- Yes
- No
- Not sure

When you hear the term "inflammatory bowel disease," what symptoms would you believe to be associated with this?

How comfortable would you be discussing IBD with friends or family?

- Very uncomfortable
- Somewhat uncomfortable
- Neither comfortable nor uncomfortable
- Somewhat comfortable
- Very comfortable

What would be an effective way to teach you about a medical condition? Check all that apply.

- Medical literature
- Interactive website
- Social media
- Other

Thank you for participating in this survey. Your participation is greatly appreciated.