



# RESEARCH REPORT

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PREPARED FOR:

**LUPUS**<sup>TM</sup>

FOUNDATION OF AMERICA  
UTAH CHAPTER

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## EXECUTIVE SUMMARY

### **Research Prepared for:** The Lupus Foundation of America—Utah Chapter

**Description:** The Utah Chapter and its dedicated staff are focused on providing for the overall needs of its patients/members. As part of their ongoing determination to provide for and better facilitate its patients/members needs, they have asked the Capstone Group to conduct research on their behalf. The Chapter is aware that each patient/member has a unique set of needs and circumstances. They would like to clarify what those needs are and which ones are not being represented. The Chapter has noticed a rise in its membership. However, this number is in no way proportioned to the estimated 17,000 individuals with Lupus in Utah. This report will focus on discovering why this is such a disproportionate number and what can be done to increase participation within the Utah Chapter.

**Problem:** Determine what the Utah Lupus Chapter is not providing patients/members.

**Objective:** Discovery

**Relevance:** What are the patients/members needs and wants and are they being represented?



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## RESEARCH QUESTION

Why aren't more people utilizing the services offered by the Utah Lupus Foundation?

## HYPOTHESIS

- Hypothesis 1)** Those with Lupus in Utah have a low awareness of the Utah Lupus Chapter and this may be causing a low utilization of services.
- Hypothesis 2)** The Utah Chapter is not providing what its patients/members are looking for.
- Hypothesis 3)** The Utah Chapter is providing for member needs but members are not utilizing the services.
- Need 1)** Patients/members need to be aware of the services offered by the Utah Chapter.
- Need 2)** The Chapter needs to know what patients/members expect from their services.

## RESEARCH DESIGN

In order to obtain the information necessary for a “*discovery oriented*” research question, our Research Design weighed heavily on conducting new research. Although secondary research was utilized, the majority of our data was collected through primary research. This included surveys, focus groups, and interviews.



Research was focused on representative users of the Utah Lupus Foundation. Our team identified the research participants, or representative users, as:

- Lupus patients - Those who have Lupus
- Caregivers and Supporters - Those who care for or support someone with Lupus
- Volunteers and Staff - Those that volunteer for or staff the Utah Chapter

The following is the criteria used to determine the representative users as persons who:

- Support the Utah Lupus Foundation but do not have Lupus
- Currently utilize the Utah Lupus Foundation services
- Have utilized the Utah Lupus Foundation services in the past
- May utilize the Utah Lupus Foundation services in the future

In designing the research we kept the initial research question at the heart of every survey question, interview, and focus group.

### **Research Question**

Why aren't more people utilizing the services offered by the Utah Lupus Foundation?



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## METHOD

The method of research revolved around the objective of discovering why more people aren't utilizing the services offered by the Utah Chapter of the Lupus Foundation. We started by interviewing the management of the organization to confirm our direction and to learn about the Utah Chapters needs. This led us to our research question and set the direction that this research took.

To investigate the overall awareness level of Lupus and the Utah Lupus Chapter we prepared a survey that was given to a random sampling of individuals in Utah. This helped us gauge the awareness levels of the organization and this disease in Utah. Then we prepared a survey that was targeted directly at members of the Utah Chapter of the Lupus Foundation. The survey was emailed to their entire email list and was designed to separate members into categories which were patients, supporters and caregivers, and volunteers or staff.

Focus groups were conducted with members the chapter, these groups were aimed at determining what members currently thought of the services being offered and what they would like to see improved. To further answer this question one on one interviews were conducted to also answer this question. Additional interviews were completed with a physician and someone who is not a member of the foundation to see if they could offer insight on the things that people expect from these organizations.



To supplement and complete our research we completed secondary research to gather any additional information that would help prove results. This information was pulled from variety of Lupus specific, competitors, and charity publications. Because our research was discovery oriented the majority of our results came from primary research conducted.

### **SWOT Analysis**

An analysis of the organizations strengths, weaknesses, opportunities and threats was conducted to determine where the organization has room to grow. We found that the the organization has an overwhelming number of strengths, and that there were a number of opportunities for the organization. We also discovered that there were additional items that we had not considered or needed to be changed from a weakness to a strength after conducting our research.

### **Limitations**

To accurately evaluate our research it is important to identify and share the limitations of each method to gathering data. Below is each research method and their limitation.

#### **Interviews**

Limitation - Limited knowledge, ideas of respondents may not represent everyone

#### **Survey #1 - General Survey**

Limitation - Sample was random, so result may vary within a different sample



### **Survey #2 - Targeted Survey**

Limitation - Survey was distributed mainly online and may not represent users that are not online.

### **Focus Group #1**

Limitation - Only one respondent attended, results were evaluated as an interview

### **Focus Group #2**

Limitation - Respondents were in an environment where staff were around so they may not have been as candid as they would in another environment.

### **Secondary Sources**

The following resources were used to gather additional information as secondary research.

- Lupus Resource Doc & Results
- Alliance for Lupus Snap Shot
- Vision Page
- Article: UF researchers see progress on new Lupus treatment
- Lupus News Letter
- The role of an online community for people with a rare disease
- Lupus Now, Fall Edition
- The use of the internet in data assimilation in rare diseases
- BBB, Charity Report
- Daily Strength Snap Shot
- Gentle Hugs Snap Shot





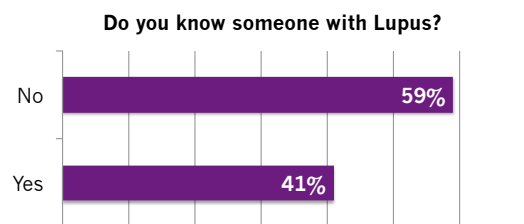
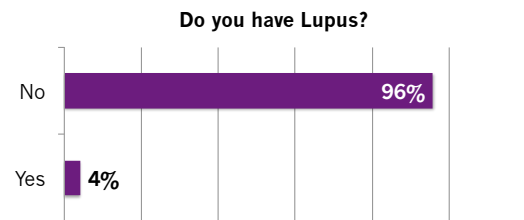
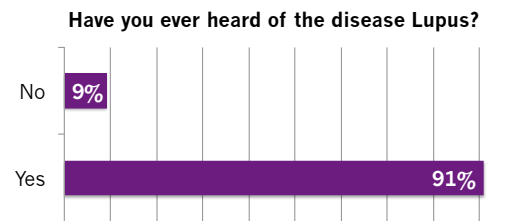
## ANALYSIS AND RESULTS

### Survey #1 - General Survey

The general survey was administered to a random sample of individuals in Utah. The purpose of this survey was to see what the awareness level of both the foundation and the disease are in Utah. The three main questions were:

- Have you ever heard of the disease Lupus?
- Do you have Lupus?
- Do you know someone with Lupus

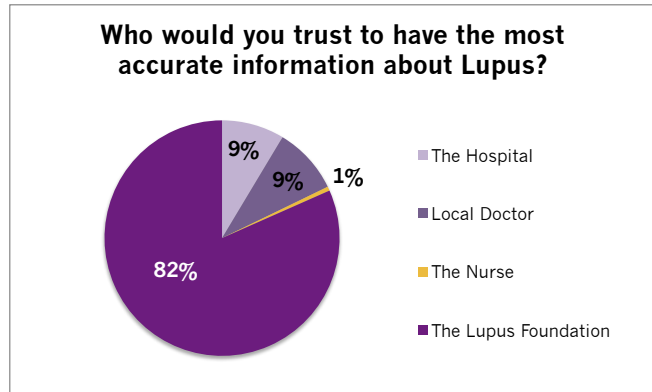
The random sample for this survey was 60% female and 40% male with 60% of respondents selecting the age range or 25 to 44. The diversity of the survey in line with Utah census information, with 89% of respondents selecting “White/Caucasian” as their race.



The main results from this survey was the information about awareness, when respondents were asked “Have you heard of the Lupus Foundation?” 34% of respondents selected “Yes”. This is high considering 96% of respondents said “No” when asked “Do you have Lupus?” so 34% of those who have heard of the disease have heard of the Foundation as well.



The last result to consider from the first survey was that when respondents were asked who they would trust to have the most information about the disease 82% said they would trust The Lupus Foundation. This lead us to rule out our



first hypothesis that low awareness may be leading to low utilization (page 4). Although awareness is still important this is not the main factor causing low utilization.

### **Focus Group #1**

To gather more insight a focus group was put together to evaluate members of the Lupus Foundation of America Utah Chapter. This was intended to give us a better picture of what was being offered to evaluate if there was anything that was not being provided. One challenge of this initial focus group was participation. Because only one respondent attended this was evaluated as an interview and another Focus group was planned.

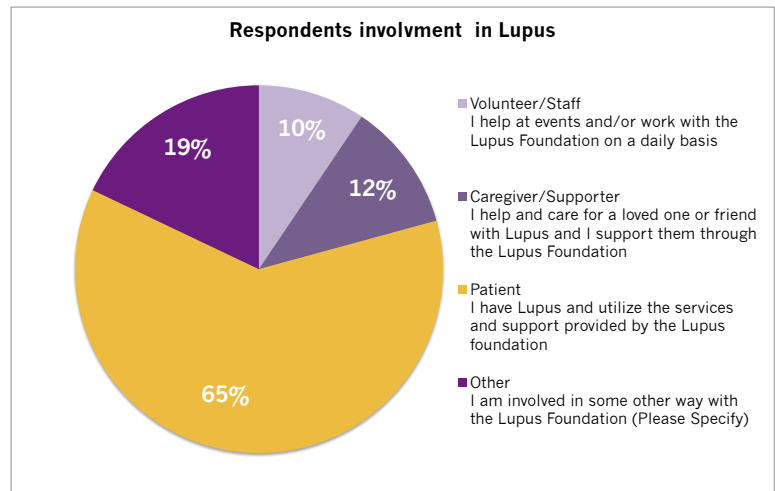
### **Survey #2 - Target Survey**

The second survey that was prepared was emailed out to the email list provided by the Utah Chapter of the Lupus Foundation. This survey was intentionally distributed to members of the foundation so that we could further evaluate what members felt was being done well and how



services could be improved. This was also helpful to ask about their needs and preferences in communication. This survey broke members into three groups:

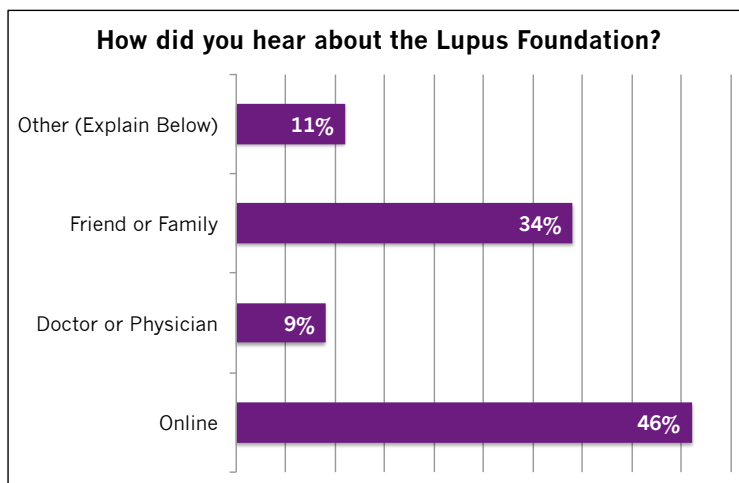
- Lupus Patients
- Supporter and Caregivers
- Volunteers and Staff
- Other



Respondents to the survey were mainly Lupus patients with 65% of total respondents classifying

themselves as someone who has Lupus. This result was great for our research question because we were able to learn specifically what the people with Lupus needed from the foundation.

One of the first questions asked was how respondents heard about the foundation. This showed



that 46% of respondents heard about the foundation online, which may be higher as a result of the fact that the survey was conducted online. This makes the 34% that heard of the Foundation from



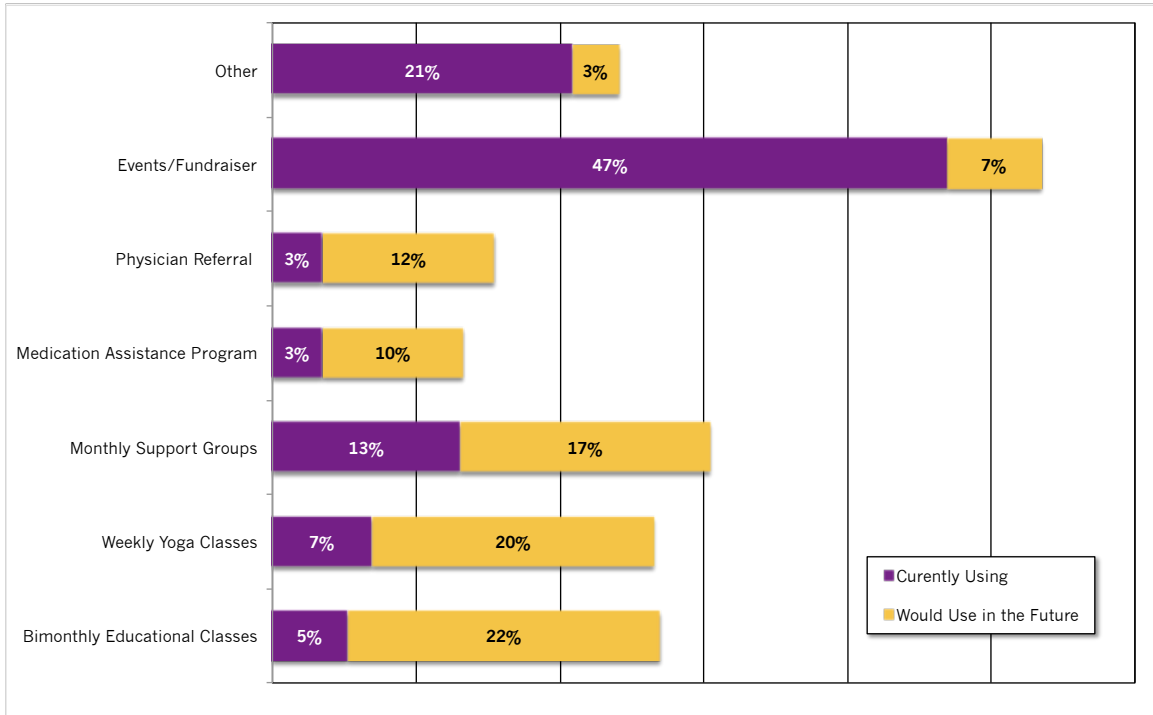
family and friends much more

notable. This indicated that word of mouth and outreach from members along with online services are the most common way that members heard of the Utah Chapter of the Lupus Foundation. While Doctors and Physicians may present an opportunity for the Foundation to help other Lupus patients in the future.

	Very Dissatisfied	Dissatisfied	Somewhat Dissatisfied	Neutral	Somewhat Satisfied	Satisfied	Very Satisfied
Follow through	4	2	2	12	5	22	38
Customer Service	4	3	0	12	3	20	43
Accessibility	4	3	0	13	4	22	39
Accommodating	4	2	0	13	1	24	41
Overall Satisfaction	4	2	0	12	2	22	43

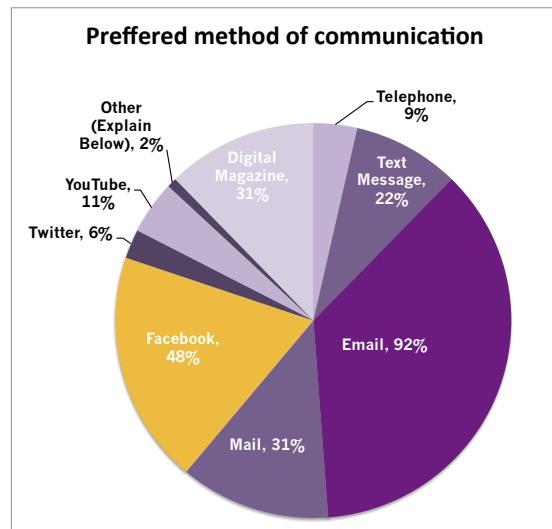
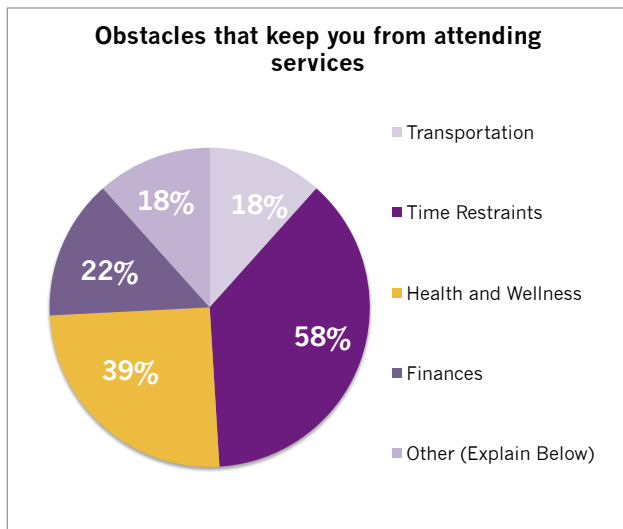
Respondents were asked to rate the foundation on follow through, customer service, accessibility, accommodating, overall satisfaction. Most respondents chose “Very Satisfied” when rating these areas. This indicated that individuals within the organization were very happy with what was going on and the services offered. All though the majority of respondents were “Very Satisfied” there was still room for growth.

Along with how respondents had heard of the organization and how they would rate it, we asked them what services they use and which they would like to use in the future. The results show that 47% of respondents take part in events and fundraisers with 13% taking part in the monthly support groups. When respondents were asked what they would like to utilize in the future most respondents choose between monthly support groups, weekly yoga classes, and bimonthly



educational classes as can be seen in the trap on the next page. This shows that there could be something keep people from attending these services or they are not known to them.

When asked what obstacles keep them from attending 58% of respondents selected “Time Restraints” and 39% selected”Health and Wellness” making these the two biggest obstacles to







## **Focus Group #2**

A focus group was held with respondents selected from members attending a monthly meeting. Respondents were asked a number of questions to help confirm results from Survey #2 (page 10). The first question they were asked was to rate the Chapter on Accessibility which they rated at a 7, Outreach received a 3 average, Programs were rated 8, and overall they gave the chapter an 8. When asked about the low score for Outreach they said that the foundation could do a better job at reaching out to possible members.

The group was also asked what their preferred method of communication was and 4 out of 5 said email was the preferred method with the other saying Facebook and everyone saying they are good with text messages. When the group was asked about social media 3 out of 5 wanted more to be going on on Facebook while the other 2 said they were not interested in social media right now.

It was very important for the group to see members of the board and management at the events. When asked what they would do differently if they were in charge they said they would try to find better ways to reach out, do more on social media, send out reminders for events earlier and multiple times to be sure people know about the event. They also mentioned that the biggest assets were the staff, their friendliness, and their understanding. When asked what keeps people from attending the meetings the answers included, social anxiety, busy on Wednesdays, they dealt with it this long why go now.



## **Interviews**

We conducted interviews to help reinforce the ideas and opinions that were expressed in the focus groups, and surveys. This was also an opportunity to talk to people that were not directly involved with the Utah Chapter. Were able to conduct an interview with a Rheumatologist, individuals that were not part of the Lupus Foundation, and individuals with Lupus that were involved.

In the interview conducted with a rheumatologist the doctor indicated that he diagnoses about 75 patients a year with Lupus. This is a large number for a single doctor to be diagnosing in a year, and represents the growing need for organizations like the Lupus Foundation and it's services. When asked if he ever recommends individuals to any organizations he said "I always advocate that they seek out sources that can help them cope with the disease. I never recommend any one group." he continues to say that he does not keep stacks of literature in the office but encourages people to go online to seek information about the disease.

When we interviewed an active member of the Lupus Foundation they gave the organization overwhelming praise for the organization and it's staff. Things that they felt could be improved was more notice and reminders about events, and improved contact through social media. They also indicated that they would prefer to receive contact through email and text. The service that they found the most helpful is the Social Butterflies because it is a place for them to find reassurance and advice from those that are going through the same thing as they are. They did





mention that they would like to see staff and board members at the socials on a regular basis, and said that this has been an area where the foundation has improved a lot.

The final interview was conducted with an individual that is not a part of the organization and has had Lupus for 13 years. They said that they wished the organization had advertised more because that may have helped them hear about it more. This interviewee did not complete the question outline and simply stated that they did not feel they could answer the questions because they were not a part of the organization.

## CONCLUSIONS

Returning now to our original research design and question we were able to draw the following conclusion. First, we looked at our 3 hypotheses and ruled out 1 and 2 and felt the 3, which states that “The Utah Chapter is providing for member needs but members are not utilizing the services.” most accurately summed up our results.

To answer the question further we investigated why they may not be utilizing the services that are offered since they have indicated that these are services that they would like to use. After analyzing the data we concluded that individuals are not all getting the same sense of community when they attend meetings, or they are not aware of this benefit to attending. Further we felt that increased notification and reminders of services, offering varying times and events to



accommodate to changing schedules, and addressing the social anxiety individuals face when attending services for the first time would help increase attendance at these meetings.

What individuals wanted above all was a place where they could come and be understood, where people wouldn't try to give them a new home remedy that would "heal Lupus", a place where they could unite with like minded individuals in a common cause and support one another through the ups and the downs of this mysterious disease. This sense of community and camaraderie was the thing that people were most interested in receiving from the Lupus foundation.

## RECOMMENDATIONS

After analyzing the information we would make the following three recommendations to the Utah Chapter of the Lupus Foundation of America:

1. Provide a community, where-in you members will find a sense of camaraderie, acceptance, and trust via communication knowledge and representation.
2. Increase communication with frequent notices of chapter programs and events.
3. Provide an incentive that may provide a higher value than time.



THE CAPSTONE GROUP WOULD LIKE TO THANK  
THE UTAH LUPUS FOUNDATION  
FOR GIVING US THE OPPORTUNITY TO HELP,  
IN A SMALL WAY,  
WITH ITS WORTHY CAUSE.

### **Acknowledgements**

- Noelle Raymond - President and CEO of the Utah Lupus Foundation of America  
Annette Lee - Development Director of the Utah Lupus Foundation of America  
Ahmad Kareh - Professor of the MKTG 2100 Research Class at SLCC  
Participants - Patients and Members of the Utah Lupus Foundation of America

—THANK YOU FOR YOUR TIME AND INSIGHT.



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## APPENDICES

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Appendix 1    Research Request & Proposal  
                  Competition Analysis  
                  SWOT Analysis

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Appendix 2    Interviews  
                  Focus Groups

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Appendix 3    Survey Results