

# APPENDIX #1

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## Research Documents & Forms

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**Research Request & Proposal Research Request from :**

The Lupus Foundation of America Utah Chapter

**Interview with:**

Noelle Reymond & Annette Lee

**Summary:** Main Focus - Support the people of Utah suffering from/impacted by Lupus. The Utah Lupus Chapter and its dedicated staff are focused on providing for the overall needs of its patients/members. In an attempt to fulfill these needs, they have implemented and focused on three main programs.

- Support group-SocialButterflies
- Educational Programs-Different focuses
- Financial assistance-Medication and future cash assistance

The Utah Lupus Chapter has noticed a rise in the number of people taking advantage of its three main programs. This number, in relation to the estimated 17,000 suffering from Lupus, is in no way proportioned. The Utah Lupus Chapter is well aware that each patient/member has a unique set of needs and or circumstances. However, they want to clarify what these needs are and which ones are not being represented.

**Your Research Question** - “What do people want?”

- “What”are the needs of our Utah patients? → “What”do people in Utah want?
- “What”are we not providing?

**Research Proposal from :** The Capstone Group

**Decision Problem/Question :**

- Why aren't more people utilizing the services of theUtahLupusChapter?

**Description:** You have presented us with a *Discovery-Oriented Decision Problem* v. a Strategic one. The Lupus foundation is not asking us “how to” do anything;; they are asking us “what” questions. We will try and find basic information. We are not solving a problem, we are providing insight.

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

**Objective:** Discovery:

**Relevance:** Patient/member wants, needs, awareness, representation etc...

**Time Frame:** This Project will be complete by April 20, 2015.

**Research Design:** We will conduct *Primary* Research in the form of - interviews, surveys and focus groups. *Secondary* research will need to be utilized as well.

**RESEARCH DATA REQUEST:** Please consider this a formal request for any and all data related to the research question posed above. We are also requesting any mailing list you are able to provide to us regarding patients, members, staff and volunteers.

**Agree X** \_\_\_\_\_

\* If you agree to and accept our Research & Proposal please accept our sincere thanks for your cooperation and time. We will look forward to receiving your prior data and mailing list.

Thank you for this opportunity ~ The Capstone Group, SLCC ~ Rep, Morgan Nelson  
435-592-4477

## Competition & Competitive Advantage

**Direct:** The Alliance for Lupus Research

Falls under—Resource, area of influence

**Indirect:** Daily Strength

Falls under—Resource & Support, immediately contiguous

**Indirect:** Cancer, Fibromyalgia, Rheumatoid Arthritis, Kidney disease, Leukemia.

Falls under Resource, area of interest.

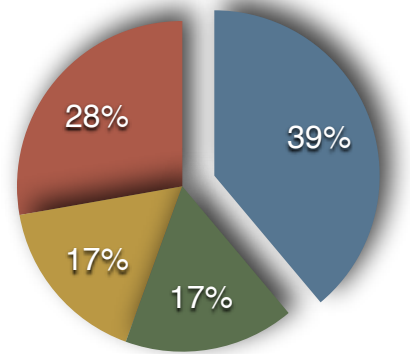
### **Advantages:**

The only national force devoted to solving the mystery of lupus

Reputable and Reliable source for research/information.

knowledgeable and adaptable volunteers.

Strong foundation to build upon.



● Lupus Utah Chapter ● Alliance for Lupus ● Daily Strength ● Other Diseases

## SWOT Analysis

STRENGTHS	WEEKNESSES
<ul style="list-style-type: none"> <li>• Wide spread outreach from Salt Lake to St. George</li> <li>• Bi-monthly educational program</li> <li>• Financial assistance</li> <li>• Medication assistance</li> <li>• Temporary assistance program</li> <li>• National awareness of their programs</li> <li>• Great facilities</li> <li>• Very knowledgable staff</li> <li>• Excellent programming</li> <li>• Good relationships with many doctors in their outreach area</li> <li>• Doctors seeking out Utah Lupus chapter</li> <li>• Supportive donor and caregiver networks</li> <li>• Grant reception</li> <li>• 75% return on participant donor-ship</li> <li>• Gala and Walk fundraiser and awareness events</li> <li>• Broad range of supporters</li> <li>• Expansion in the future</li> <li>• Locked in Utah geo-demographic</li> </ul>	<ul style="list-style-type: none"> <li>• They have broken relationships with the doctors from the previous organizers.</li> <li>• Lupus medications are not covered by insurance.</li> <li>• Frustrated patients who have not had a straight answer.</li> <li>• Late diagnosis.</li> <li>• No lupus doctor.</li> <li>• Too many primary care doctors to reach.</li> <li>• Its up to the patient to contact organization.</li> <li>• Associate lupus with cancer.</li> <li>• People just don't know What Lupus is. They compare with Fibre Malaysia etc...</li> <li>• They try to support the people in need, the best they can.</li> <li>• Research on minorities/ current statistics</li> </ul>
OPORTUNITIES	THREATS
<ul style="list-style-type: none"> <li>• Do the Doctors know who you are?</li> <li>• Lupus information Prescription pad</li> <li>• Educating Nurses</li> <li>• Learn where your target market is? (If they are women where can you find them)</li> </ul>	<ul style="list-style-type: none"> <li>• Time redeveloping and rebuilding the bridges that were broken</li> <li>• Not enough drugs to treat</li> <li>• Education/people really don't know much about lupus</li> <li>• Accurate epidemiology study challenge</li> <li>• Removal of literature from Doctors offices</li> <li>• How to diagnose Lupus/follow a criteria</li> <li>• They try to support the people in need, the best they can</li> </ul>

## APPENDIX #2

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### Interviews and Focus Groups

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## INTERVIEW #1

**Interviewee:** Noelle Reymond

**Interviewee:** Annette Lee

### **Discussion Topic: Lupus Utah Chapter**

30 years, last 7... Redevelopment and relationship repair

Serves Utah - primarily. Serves surrounding states - accidentally

90% of board members have Lupus. This can be a challenge, along with volunteers who have

Lupus, the disease can be disabling therefore hindering efforts

Utah Chapter is its own chapter, 1 of 25, bound by its own 501 C3 and bylaws.

Money stays in Utah, 10% going to research

Nationally rebranding—Cruel Mystery—web enforced—Push uniform Programs

Main Focus - Support the estimated 17,000 people of Utah suffering from Lupus

Larger—Donors are Lupus care givers or people who support/friends with someone who has

Lupus. People who are most directly affected by someone with Lupus; less patients

CAREGIVERS ARE UNDERREPRESENTED, THEY NEED HELP AS WELL

### 3 Main areas of focus

1.Support group - Social Butterflies

2.Educational Programs - Different focuses

3.Financial assistance - Main, medication

EVERYONE NEEDS SOMETHING DIFFERENT

SUPPORT GROUP HAS SHOWN THE MOST GROWTH

Lupus walk is the largest fundraiser (Reaches people)

People usually choose one event (where they fit)

1 ½ to 2 million suffer from Lupus. (Study is 10 years old)

More than MS, Cystic Fibrosis, cerebral palsy, and Cancer combined.

(People know more about these?) We can ask for national study results\*\*

Efforts to build relationships with medical community.

Mix of specialist. Lack of Rheumatologist There are no Lupus Doctors.

Different types of Lupus. Hard to correlate. Removal of literature

Need to break barriers (focus on CNA or nurse) Physician / patient time is only 6 min.

Lupus is a unique illness. It is often not visible

Doctors tend to only discuss visible symptoms

80% of patents have an ANA diagnosis

Up to the patient to contact us

People tend to find Lupus Chapter while in the diagnosis stage.

(6yrs from 1st symptom to diagnosis)

They tend to be frustrated (no answers, never heard of or known anyone with the disease)

Lupus is more common in African Americans, hispanics and asians. (No representation)

Majority of Lupus patients have insurance. (will not pay for Lupus medications)

Cash assistance program will soon be in effect.

3 yr. ago the FDA approved the first Lupus drug.

(Profitable to the pharmaceutical ind. does not help most Lupus patients)

Personal, greatest impact/get the most out of—financial help

“Support groups change lives, but financial support is qualified—you see the results—Powerful

No one wants to talk about Lupus

It is often times associated with cancer or other diseases.

Utah presents its own issues—unique state

Minorities are 2-3 times more likely to be affected and Lupus Utah Chapter has

NO MINORITY REPRESENTATION; how can we reach them in order to meet their needs?

We do have national studies on how to bridge the gap\*\*\*

A past member conducted a research project/study epidemiology\*\*\*

**Questions:** What do people in Utah want? What are the needs of Utah patients? What are we not providing



## INTERVIEW #2

Interviewee: Patient/Member-

Q. Share how you first heard about the lupus foundation.

— I learned on line

Q. Rate the lupus foundation on a scale of 1-10 on the following:

-Accessibility

-Outreach=8

-Programing=8

-Education=8

-Overall Quality=8

— It has gotten better. The walk, the Gala, and the social butterflies.. I think they still need push everything.

Q. Do you believe that time constraints are a big issue for people involved with the lupus foundation in regards to event participation? -What could help solve this problem?

— Time is Accommodating...for the illness. Location is fine...for the illness, shade and parking etc...

Q. Do you think there is a problem with accessibility surrounding the lupus events? -How can the Lupus Foundation help solve this problem?

— No

Q. Which programs do you find most valuable?

— Social Butterflies...needs more outreach. Health and Education. Its good place to find reassurance, learn about medications and its unmediated. However, its not appreciated when their is no representation; a board member or Noelle or someone who is an advocate for the chapter.

Q. Which programs do you think most others find most valuable?

— Support group, medication, and soon to be, cash assistance.

Q. How often do you use the services provided by the foundation.

— Once a month Social Butterflies. Gala and MAP.

Q. How often would you like to use the services provided?

— Facebook seems to be rare, maybe once a month...Social media the same. They could do more. More social media...When asked about the message board she replied, I forgot it existed. I used it a few times when it came out, it was a downer, a place for people to whine. When asked about a blog... She said she would definitely use it.

Q. Would you find social media or blogs helpful in regard to accessibility of information?

— Under-diagnosed?

Q. What ways would be best for you to learn what is happening with the lupus foundation?

—

Q. By which method would you like to be contacted? -By which method(s) would **not** like to be contacted?

— Texting and e-mail

Q. Do you think that the Lupus foundation could benefit from social media?

— YES more advanced notice, invites, reminders, “IN MY FACE”. Yes, but there needs to be a personal level

Q. Have you had a good response rate from staff members in regards to care and answering questions?

— For the most part

Q. How can the lupus foundation overcome patient time restraints and health problems which keep them from attending or participating?

— Support, I don't want to hear motivate yourself. Offer more frequent times for services or the groups?

Q. Is 1 on 1 interaction important in respect to your level of involvement with the Lupus Foundation?

— Resource of people to do one-on-one...Private advocate, organized group.

Q. If you were the head of the Lupus Foundation, what would you do differently?

— Less conflict more participation. Maybe people were hurt from previous actions of board members. Show appreciation, board support, participation.

Q. Could you suggest some reasons why you think the majority of Lupus Foundation participants might not be taking full advantage of what the foundation has to offer?

— Walk was a paid event, it would bring in more people...Discount for the Gala if you attend the butterflies...They are scared, They are un-sure of what to expect or what goes on there. Intimidated and alone. If you could them to g once they will be more likely to again, after realizing what happens. Personal connection.

Q. Would you recommend the Lupus Foundation to a friend or family member? -Why or why not?

— Yes...Personal Connection

Q. In your opinion, what would you consider the Lupus Foundation's biggest asset? -Biggest obstacle or liability?

— Butterfly Group. THEY ARE ALWAYS TRYING..Growth is always a goal. Give more value;

Q. MS foundation gives t-shirts or has a t-shirt contest.Learn from other organizations?

Would you mind describing the best experience you've had at the Foundation? -The worst?

— Lupus Gala; Alein Walker—key note speaker.

NOTES— Would like to see support from Physicians. She might have been in shock upon diagnosis but she doesn't feel like she received any link to a support network or any information on support group. She had to research and look into finding the Utah Chapter. She had to motivate herself, talk herself into going to events and groups to find a connection. AND THE BUTTERFLY DOES REPRESENT LUPUS PATIENTS. WHY would you change that now? I am upset and I am the one being represented? I was not asked...Keep the butterfly.

Interview #3      4-09-2015

Dr. B is a Rheumatologist in Ogden, Utah. Dr. B requested that his information and answers remain anonymous to any person outside of the group. He didn't want his information disclosed to the Lupus Foundation.

-What is your experience with diagnosing Lupus?

“Quite a bit actually. I diagnose approximately 75 people a year with Lupus.”

-Even mix of men and women? “Overwhelmingly female.”

-Do your patients understand what lupus is upon being diagnosed?

“Most of them do not unless they do preliminary research in an attempt to diagnose themselves before seeking professional diagnoses.”

-After diagnosing your patients, do you refer them to anyone specifically? “Not unless I cannot treat them in my office or if they request a second opinion.”

-Do you refer them to any groups or foundations who specializing in assisting these types of patients?

“I always advocate that they seek out sources that can help them cope with the disease. I never recommend any one group.”

-Have you ever referred any of your patients to the Lupus Foundation or Utah Lupus Chapter?

“Not directly.”

-Are you aware of the Lupus Foundation?

“Yes. I'm aware of them but do not have an intimate knowledge of how they run their organization or which programs are offered there.”

-Would you say that is the same case with your colleagues?

“That's difficult to say. I know that a few of my colleagues are aware of the Foundation but can't say that it is an active prescription for treatment or resources.”

-Do you offer your patients literature on the subject after a diagnoses?

“Not usually. I recommend that they do their own research. Of course I will answer any of their questions and give them information at my disposal but we don't keep a stack of literature in every cabinet if that's what you're asking.”

-Would you say that is a commonality in other Rheumatologists offices? “For the most part.”

-Do you feel that there are adequate resources for your patients to find their own way to coping with the disease?

“Absolutely. Like I said I am aware of the Lupus Foundation and other groups that assist people with the disease as well as mounds of online resources.”

-Do you feel that you and your colleagues are helping them cope with this disease and the symptoms?

“Yes.”

-In what way, other than the initial diagnosis?

“...We answer their questions and concerns as well as hold meetings in our offices to assist them with any concerns.”

-Are these consultation sessions free of cost? “We bill the appropriate insurance companies.”

## INTERVIEW #4

Q1. Share how you first heard about the lupus foundation.

Q2. Rate the lupus foundation on a scale of 1-10 on the following:  
-Accessibility-Outreach-Programing-Education-Overall Quality

Q3. Do you believe that time constraints are a big issue for people involved with the lupus foundation in regards to event participation?  
-What could help solve this problem?

Q4. Do you think there is a problem with accessibility surrounding the lupus events?  
-How can the Lupus Foundation help solve this problem?

Q5. Which programs do you find most valuable?

Q6. Which programs do you think most others find most valuable?

Q7. How often do you use the services provided by the foundation?

Q8. How often would you like to use the services provided?

Q9. Would you find social media or blogs helpful in regard to accessibility of information?

Q10. What ways would be best for you to learn what is happening with the lupus foundation?

Q11. By which method would you like to be contacted?  
-By which method(s) would **not** like to be contacted?

Q12. Do you think that the Lupus foundation could benefit from social media?

Q13. Have you had a good response rate from staff members in regards to care and answering questions?

Q14. How can the lupus foundation overcome patient time restraints and health problems which keep them from attending or participating?

Q15. Is 1 on 1 interaction important in respect to your level of involvement with the Lupus Foundation?

Q16. If you were the head of the Lupus Foundation, what would you do differently?

Q17. Could you suggest some reasons why you think the majority of Lupus Foundation participants might not be taking full advantage of what the foundation has to offer?

Q18. Would you recommend the Lupus Foundation to a friend or family member?  
-Why or why not?

Q19. In your opinion, what would you consider the Lupus Foundation's biggest asset?  
-Biggest obstacle or liability?

Q20. Would you mind describing the best experience you've had at the Foundation?  
-The worst?

**RESPONSE**—"I guess for me a lot of these questions would be hard to answer because I don't know anything about the foundation I actually just googled it the other day when they were using an ad or something about the lupus walk. So I guess the only thing I can say is that they need to advertise more about support groups and other counties." "Yeah you would think after having lupus for 13 years I would know more about their program but it isn't very well advertised or known about."

## INTERVIEW #5

### Lupus Patient

Q1. Share how you first heard about the lupus foundation.

Q2. Rate the lupus foundation on a scale of 1-10 on the following:  
-Accessibility-Outreach-Programing-Education-Overall Quality

Q3. Do you believe that time constraints are a big issue for people involved with the lupus foundation in regards to event participation?  
-What could help solve this problem?

Q4. Do you think there is a problem with accessibility surrounding the lupus events?  
-How can the Lupus Foundation help solve this problem?

Q5. Which programs do you find most valuable?

Q6. Which programs do you think most others find most valuable?

Q7. How often do you use the services provided by the foundation?

Q8. How often would you like to use the services provided?

Q9. Would you find social media or blogs helpful in regard to accessibility of information?

Q10. What ways would be best for you to learn what is happening with the lupus foundation?

Q11. By which method would you like to be contacted?  
-By which method(s) would **not** like to be contacted?

Q12. Do you think that the Lupus foundation could benefit from social media?

Q13. Have you had a good response rate from staff members in regards to care and answering questions?

Q14. How can the lupus foundation overcome patient time restraints and health problems which keep them from attending or participating?

Q15. Is 1 on 1 interaction important in respect to your level of involvement with the Lupus Foundation?

Q16. If you were the head of the Lupus Foundation, what would you do differently?

Q17. Could you suggest some reasons why you think the majority of Lupus Foundation participants might not be taking full advantage of what the foundation has to offer?

Q18. Would you recommend the Lupus Foundation to a friend or family member?  
-Why or why not?

Q19. In your opinion, what would you consider the Lupus Foundation's biggest asset?  
-Biggest obstacle or liability?

Q20. Would you mind describing the best experience you've had at the Foundation?

-The worst?

**RESPONSE**— Does not use anything the Utah Chapter Offers. Prefers to depend on and trust in her Physician.

## FOCUS GROUP #2

Lupus Patient/Members—Location: Social Butterfly Group—

Rate the following on a scale from 1-10

Accessibility 7, 7, 8

Outreach 2, 4, 3

Programs NA, 8, NA

Overall 8, 8, 8

(would give MS 10)

Outreach -

13 years without knowing about it, couldn't reach out until they knew about them

Events are very accessible

Social Butterflies is the most valuable - Safe place - Understanding - you can speak your mind

How frequently do you attend Lupus events and activities?

Daily...twice a month...once a week

\*\*Email newsletter is really valuable

Want contact via...Facebook...Email...Email or text (everyone is ok with Text messages)

Don't want to contact by...No phone calls...2 No Facebook...NO direct mail

Social Media? Could benefit from more social media

Radio? (This is how one respondent heard about Lupus)

Response Rate when you contact lupus?

None yet

Plenty

They get it and they get in touch and will find someone who will.

What keeps people from participating

- Scared to reach out and find help
- Tired of being judged for having a disease
- Been dealing with it for this long why do I need help now
- Social anxiety
- Busy on Wednesdays and things got really bad
- Community and sense of belonging is huge
- Tired of doing it alone

How do they do at maintaining a community? Really well...They care a lot when you reach out to them, but not when they need to reach you. They need to reach out to people more balance it out.

\*\*Tough times bring people to the social events

If there were more things offered other than Wednesdays would you attend? YES

\*\*Miss once then you miss for two months!

Is there anywhere on line that you can talk to people online if you miss? Not that they know if.

How do you feel about one on one contact?

It is very important but there is a line

They like talking one on one but not forced to talk to someone one on one

Need to keep the group dynamic

If you were the head of the Utah Chapter what would you do differently?

- Try to find ways to reach OUT to people - Doctors office did not tell them about it, reach out to doctors.

- More social media, update more frequently short bursts - be more consistent -

- Remind people about the social butterflies meeting sooner than the afternoon so she can plan - 1 or 2 days before

How would you feel about meeting in a Park?

- food helps with the conversation - outside is hard

- Sunshine is not their friend

- Sun is no guarantees

Utah Lupus foundations—-Biggest Asset

- Staff excellent staff

- friendly

- Staff understand what you are REALLY going through

What do you think about the staff coming to the events?



IT IS HUGE THAT THEY COME TO EVENTS -

Unanimous

Logistics distance

Not very many younger people

Respondents Ages

27

16

62

How did you find out about the Lupus

Foundation?

- Taught someone with Lupus
- Grandma found a news article gave to mother and mother went in to find out more.
- Radio program and co worker told her

that she needed to listen

What are some of the liabilities of the Utah Lupus Foundation?

Community is very small - awareness

UNDERSTANDING - People outside the org don't understand what you are going through and mean well but do not know how to help.

Having a place to go where people understand what you are going through is very helpful.

Guys Perspective

Biggest Assets

- Sense of Community - great people involved
- tight nit community (Walks in the afternoon)

Accessibility

- good time and a good day
- socials are good - walks not as much

(Would like to walk earlier before the sun gets out)

IF meetings were More frequent

-Would attend if they were more frequent

How often do you participate

3 times in 20 years

2-3 time a month

DISTANCE - Keeps them from participating

What keeps people others from participating

Daytime events -

because of the sun

Could be personality issues staying involved

If you were in charge what would you do differently

- Nothing I would keep it the same

Rate outreach

- Really good (Facebook Lupus and Me)

- Staff reaches out and they are very good at communicating

Does the staff need to be at all events?

- It is fine either way

How did you Find the Lupus Foundation

- Online - Found main organization found all the info online

- Doctor recommended getting on line and see what events that were available

What are your thoughts on

Social Media

- Not

big on social media  
- Not huge right now

How would you like to be Contacted

- Emails  
- Emails

\*\*\*Text or phone is ok

Factors contributing to not

participating

-Health and wellness

they are sick and can't come  
-Health

support helps them come

\*\*Hard for people outside to understand what you are going through and you feel alone

How did you feel when you first found out you had Lupus?

-felt screwed no support or outlet

- Wish there was someone there to let him know what the other options were. (When he first discovered he had Lupus)

-Denial you think it will pass - but it is good to have someone to talk to who has done it.

How would you feel about

having a Buddy?

- Felt that it would help to have someone that could support them  
- Someone to let them know that there are options and that things are not as and as you think they are

-Doctors don't have a lot of experience with Lupus

- Interaction is a he thing

Last Thoughts?

\*\*Need to be more proactive about taking a stance in the community

# APPENDIX #3

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## *Survey Results*

*Survey #1 - General Survey*      *Page*

*Survey #2 - Target Survey*      *Page*

