Survey #2 - Target Survey

1. How would you categorize your involvement with the Lupus Foundation?(Select all that apply)

Answer	Bar	Response	%
Volunteer/Staff I help at events and/or work with the Lupus Foundation on a daily basis	0.0989	9	10%
Caregiver/Supporter I help and care for a loved one or friend with Lupus and I support them through the Lupus Foundation	0.12088	11	12%
Patient I have Lupus and utilize the services and support provided by the Lupus foundation	0.64835	59	65%
Other I am involved in some other way with the Lupus Foundation (Please Specify)	0.18681	17	19%

Other I am involved in some other way with the Lupus Foundation (Please Specify)
More of Donator
The Lupus Foundation is a member of Community Health Charities, an umbrella group who provides, amongst other things, workplace giving campaigns wioth local and national business partners.
support of a family member
I volunteer in a unique way
with my health, I can not serve anymore but would like to be involved in the new program you are doing with the college students very much!
Board Chair
I am a friend of someone with Lupus
I volunteer
My Mother died from Lupus. I live in Jacksonville Florida. I come for the walk every year. I'm Wes Dodds daughter.
walker, raise funds with different events family puts on
Fundraising for my team
I help with Social Butterflies
I may have lupus... doctor is still learning
supporter
Donor
Friend
physician supporter

2. How did you hear about the Lupus Foundation?

Answer	Bar	Response	%
Online	0.46154	42	46%
Doctor or Physician	0.08791	8	9%
Friend or Family	0.34066	31	34%
Other (Explain Below)	0.10989	10	11%
Total		91	100%

Other (Explain Below)
My current partner has Lupus
I've been a member so long that I honestly don't remember. It would have been before "online" was even available.
Rheumatologist office
Lupus run 2013 @ Liberty Park
Booth at Farmers Market
found out about it by searching and found a support group meeting at our public library... they fell apart but from the few meetings I went to they gave me information about the foundation
Walk Banner at Park
Mom works at LFAU
self
I helped set up the original Lupus Foundation of Northern Utah in early 1980's. I was an officer, over Patient Education.

3. Please rate the Utah Lupus Chapter on the following:

Question	Very Dissa	Dissatisfie	Somewhat	Neutral	Somewhat S	Satisfied	Very Satisfie	Total Respor	Mean
Follow through	4	2	2	12	5	22	38	85	5.71
Customer Service	4	3	0	12	3	20	43	85	5.81
Accessibility	4	3	0	13	4	22	39	85	5.73
Accommodating	4	2	0	13	1	24	41	85	5.84
Overall Satisfaction	4	2	0	12	2	22	43	85	5.87

4. Browser Meta Info

Browser	Operating	Screen Resolution
Safari	Android 4.4	720x1280
Firefox	Windows N	1920x1080
Safari iPhone	iPhone	320x568
Safari iPhone	iPhone	320x568
Firefox	Windows N	1400x1050
MSIE	Windows N	914x514
Chrome	Linux	360x640
Chrome	Windows N	1366x768
Chrome	Android 4.4	360x640
Chrome	Linux	360x640
MSIE	Windows N	1051x591
Safari iPad	iPad	768x1024
Firefox	Windows N	1280x1024
MSIE	Windows N	1024x768
Chrome	Windows N	1600x1200
Safari iPhone	iPhone	320x568
Chrome	Windows N	1920x1080
Safari iPhone	iPhone	320x568
MSIE	Windows N	1301x731
Chrome	Linux	320x534
Firefox	Windows N	1366x768
Safari iPhone	iPhone	320x568

Chrome	Linux	360x640
Safari iPhone	iPhone	375x667
Chrome	Linux	360x640
Safari iPad	iPad	768x1024
Safari iPhone	iPhone	320x568
MSIE	Windows N	1344x840
MSIE	Windows N	1680x1050
Chrome	Windows N	1280x1024
MSIE	Windows N	1920x1080
MSIE	Windows N	1366x768
Firefox	Windows N	1920x1080
MSIE	Windows N	1400x875
Safari	Android 4.	480x800
Chrome	Linux	360x640
Safari	Android 4.	1080x1920
Chrome	Linux	360x640
Safari iPhone	iPhone	375x667
Firefox	Windows N	1360x765
MSIE	Windows N	1280x720
Safari	Macintosh	1280x800
MSIE	Windows N	1366x768
Chrome	Windows N	1366x768
Chrome	Linux	640x360
Safari	Macintosh	1280x800
Firefox	Windows N	1920x1080
MSIE	Windows N	1366x768
Chrome	Windows N	1680x1050
MSIE	Windows N	1920x1200
Chrome	Windows N	1920x1080
Safari	Macintosh	1280x800
Mozilla	iPhone	320x568
Chrome	Windows N	1366x768
Safari iPhone	iPhone	375x667
Safari iPhone	iPhone	320x568
Safari iPhone	iPhone	320x568
Chrome	Windows N	1680x1050
Chrome	Linux	360x640
Safari iPhone	iPhone	320x480
Chrome	Linux	360x592
Firefox	Windows N	1680x1050
Firefox	Windows N	1366x768
Chrome	Macintosh	2560x1440
Safari iPhone	iPhone	320x568
Chrome	Windows N	1280x1024
Chrome	Android 4.	360x598
Safari	Macintosh	1440x900
Firefox	Windows N	1366x768
Safari iPad	iPad	768x1024
Chrome	Windows N	1280x800
Chrome	Linux	360x640
Chrome	Windows N	1920x1080
Safari	Android 4.	480x800
Chrome	Windows N	1280x1024
Safari	Macintosh	1440x900
Chrome	Linux	360x592
Mozilla	iPad	768x1024
Firefox	Windows N	1280x1024
MSIE	Windows N	1429x804
Chrome	Windows N	1024x768
Safari iPad	iPad	768x1024
Chrome	Linux	600x960
MSIE	Windows N	1280x720
Firefox	Windows N	1366x768

5. What services offered by the Lupus Foundation do you utilize or take part in? (Select all that apply)

Answer	Bar	Response	%
Bimonthly Educational Classes	0.07595	6	8%
Weekly Yoga Classes	0.10127	8	10%
Monthly Support Groups	0.17722	14	18%
Medication Assistance Program	0.03797	3	4%
Physician Referral	0.03797	3	4%
Events/Fundraisers	0.6962	55	70%
Other (Explain Below)	0.29114	23	29%

Other (Explain Below)
Most of these are only avaliable in Salt Lake
None
When are the bimontly classes?
My health and age no longer allow me to participate much at all. I used to attend a monthly support group as well as some events and fundraisers. Once physician referral
discovered the foundation and will start to use all the services and so excited to be apart of the lupus community
I support my sister from north carolina
Getting to hang out with awesome lupus people and the staff are amazing
I used to do things but haven't for a while. I would love to do the weekly yoga and support groups if I get to having enough energy
Newsletters
Online Resources
read the magazine
Lupus Magazine
too far away cause even though they say they also support Idaho, there is no help here from them and the couple of times I went to a functions in SLC UT, we were not recieved very well cause we were not know to anyone so they were not open to us being there
Emails and information online.
My niece is a beneficiary of this foundation. I support her and my other family members with services of their choosing.
None so far, but I am planning on attending some events in the future if I feel well enough.
If yoga was closer I would participate more. I hear that a dinner group in American Fork is now organized so I would be interested in attending.
website, updates of current events, drug trials...
social media support
Walk to end lupus.
Online
message board

I am not involved in any way at this time.

6. Which of these obstacles might keep you from utilizing resources/services from the Lupus Foundation? (Select all that apply)

Answer	Bar	Response	%
Transportation	0.1791	12	18%
Time Restraints	0.58209	39	58%
Health and Wellness	0.38806	26	39%
Finances	0.22388	15	22%
Other (Explain Below)	0.1791	12	18%

Other (Explain Below)
im not sure what I need help for but it's nice to know they are there if I do
Not avaliable in my area
Location.
Not in my town
none
I think professionals need to lead support groups and education classes. I went to an education class and it pulled me down emotionally because it seemed like everyone started talking about their symptoms and it almost felt like people were competing to prove their symptoms were worse. I didn't feel the facilitator kept the group on track and that experience has kept me from going to other groups.
2-3 hour travel to SLC UT... I need a traveling companion and can not find one anymore... health and wellness is another one
Location. It seems like a lot if things are in SLC and if it's at night I'm to tired to drive the distance.
distance from events
I would love to go to a support group just feel nervous to go by myself so never have
Distance
Burn-out.

7.   What services or   resources do you feel people with Lupus need from the Lupus Foundation?

Text Response
Im not sure
Names/Locations of Doctors who specialize in treating Lupus; Suggestions for alternative or homeopathic medicine treatments for patients with Lupus.

I like the services you provide, but they are only in Salt Lake except for support group wich I have not been able to utilize because of the day and time and health issues! I would also love a meditation class for dealing with stress.
More outreach and advertisement
The Utah chapter does a fantastic job of covering services that are offered. From social to medication. I am still learning and finding out what is available.
You all are doing a commendably full job.
Financial assistance
The community needs to know that they are there. They are a big resource if patients and caregivers knew where to turn for help.
Support groups. Medicine options.
I think they're doing a great job!
Education, Support · what they do now.
Easy access to the most current information on Lupus treatments. A comprehensive list of the side effects that are caused by these drugs. Did you know that long term plaquinel use causes a discoloration of the skin on your legs? No told me.
A list of others that have it with phone numbers. All I hear is that everyone is different so I don't know that I get any answers from anyone. The Doctors don't help that much........I feel very alone and am too exhausted from the day to go to the support group in the evening. I wish I knew how to get through this emotionally. I also wish I knew some good counselors who can help people with long term health problems..........
N/A
Education, prescription assistance, resources for caregivers and a social outlet to talk with and visit with other people that understand the complications that lupus can cause.
Support of people in similar situations.
Just keep providing great support and information.

We need help making the community, our family and friends, our bosses and coworkers, everyone in our lives understand this invisible disease. We need help learning how to explain it and ask for help, how to deal with people who aren't open to understanding. I feel we need help learning how to have a new normal. Quality of life help; like babysitting services, free yoga and health and wellness classes, feeling connected to others. Help with eating healthy, both financially and knowing how to do this for lupus.
I would love help with medical trials-knowing where to go for good ones.

It depends on where the person is with her/his disease. Newly diagnosed: physician referrals, emotional support, information about disease and treatment. On going: social networking, breakthroughs in treatment, volunteer opportunities. Elderly: transportation to medical appointments, Foundation meetings and events if needed or desired.

A deeper understanding of the condition, support and alternatives to having better quality of life.

to be honest I didn't even know there was a medication assistants on here until I did this survery.

Just being with others who understand so you don't feel so alone!

I think a cure is what they need!!!

Literature

Outreach to the west side of salt Lake, more cookies, actually the cooking class sounded like fun

Support, information,

I would need to educate myself more about my own lupus before I could answer this! When I attempt to educate myself I get scared- and quit!

Education and awareness in the community

Support Group, Education,

keep the info coming. thank you

Physical therapy

Social support and education particularly when their symptoms are active

Information

Help with meds; support groups; dis.ease education

Support groups with professional facilitators. TOSH has a great one for people with traumatic brain injuries if you need an example. I want resources on how to proactively treat my lupus.
meetings in more places
reach out more to people with Lupus. Make events more affordable for them to attend.
A way to communicate.
support-- physical and mental, materials as in book lists, video support lists, as we do not know all that is out there that may help us to cope, do, learn how to help ourselves
Education to general population; higher visibility
Help in finding a cure.
Understanding of how we can help ourselves cope with the flares and the challenges of living with a disease where there are so many unknowns.
I am mostly seeking information.
I think that you do a great job helping with resources for people who are in need.
I feel as though the lupus community would benefit from the use of essential oils to assist in remedying some of their ailments. It has been proven that the properties of essential oils and other oil blends can help reduce the symptoms of pain, RA, migraines, nausea, and some skin disorders. I personally am able to provide these services and resources to the lupus community. I completely understand the need for Western medications as there are some symptoms that can not be alleviated without the care of a physician but I also understand and fully believe in the power of our natural biology that can prove to be a powerful aide for those suffering with specific, chronic lupus ailments.
More collaboration with other non-profit organizations in the Health and Wellness field.
Retreats.
Everything.
Information about doctors that are well-versed in lupus (not just rheumatologists, but other specialists). I love the idea of face-to-face support groups, but I live in Utah County and just don't have the energy to drive up to SLC.
Support groups

I don't know
What you do already.
physician and healthcare involvement. Clinical trails notifications.
Medication assistance and therapy groups.
I like all the things you have. Support groups, classes, yoga, fundraiser's, etc. I would probably attend more of them if I lived closer to where they were happening. Maybe even a cheeper version of the gala so more people could come that maybe can't afford the usual gala.
Activities scheduled at different times. I would love to participate in the support group, yoga or cooking classes but, I work too late to ever try them. If possible, maybe every 3rd month offering a later class would be nice.
not sure
Support Groups Education Dietary Help
social groups, fun outings, therapy services, and help with cost of medications
At this time I don't think I need any assistance.
family support groups (which they have) funds to assist families with any financial hardships caused by Lupus
Not sure
Education, a place to call to coordinate resources and doctor referrals
References for Mental Health Services
Research!!! Money for research please!!
Here stories from others suffering from the disease.
support, monetary help, education
Getting the word out more on what is ,available
Support
Information
A well moderated message board. Currently we have one that is lorded over by a few very opinionated members that, while there are worthshile messages, decide who should be on the board and humiate and drive off those who do not agree with them. Sorry, I had to say that. I know too many members who have just stopped having any intereset in this board, including myself.

SUPPORT! WE NEED
INFORMATION AND RESOURCES
FOR HELP! RESOURCES FOR
HELP WITH ALL THE THINGS
LUPUS AFFECTS. OUR BODIES,
OUR MINDS, OUR LIVES!
PLEASE PLEASE HELP US!

I think everything is great, there
are plenty of opportunitites, I
really loved the cooking class
earlier this year. I feel that events
aren't as well known about as I
wish they were. I am constantly
letting others know about this
great foundation and what they
have to offer.

8. Have you ever been involved with one of the following comparable services?(Select all that apply)

Answer	Bar	Response	%
Alliance for Lupus	0.07042	5	7%
Lupus Research Institute	0.08451	6	8%
National Fibromyalgia Association	0.04225	3	4%
The Leukemia & Lymphoma Society	0.07042	5	7%
American Cancer Society	0.1831	13	18%
Other (Explain Below)	0.07042	5	7%
I have not used services from any of these	0.59155	42	59%
Arthritis Foundation	0.16901	12	17%

Other (Explain Below)
I don't know anything about any of them.......
none
Epilepsy Foundation
Susan G Komen
get monthly info from Fibromyalgia and use to belong to an RA group but they disbanded as well

9. Please rate the (Alliance for Lupus) services on the following:

Question	Very Dissa	Dissatisfie	Somewhat	Neutral	Somewhat S	Satisfied	Very Satisfie	Total Respor	Mean
Follow through	0	0	0	1	1	1	2	5	5.8
Customer Service	0	0	0	2	0	0	3	5	5.8
Accessibility	0	0	0	2	0	1	2	5	5.6
Accommodating	0	0	0	2	0	0	3	5	5.8
Overall Satisfaction	0	0	0	2	0	0	3	5	5.8

10. Please rate the (Lupus Research Institute) services on the following:

Question	Very Dissa	Dissatisfie	Somewhat	Neutral	Somewhat S	Satisfied	Very Satisfie	Total Respor	Mean
Follow through	0	0	1	1	1	1	1	5	5
Customer Service	0	0	1	1	1	1	1	5	5
Accessibility	0	0	1	1	0	2	1	5	5.2
Accommodating	0	0	1	1	0	2	1	5	5.2
Overall Satisfaction	0	0	1	1	1	1	1	5	5

11. Please rate the (National Fibromyalgia Assoc...) services on the following:

Question	Very Dissa	Dissatisfie	Somewhat	Neutral	Somewhat S	Satisfied	Very Satisfie	Total Respor	Mean

	Very Dissa	Dissatisfie	Somewhat	Neutral	Somewhat S	Satisfied	Very Satisfie	Total Respon	Mean
Follow through	0	0	2	0	0	1	0	3	4
Customer Service	0	0	2	0	0	1	0	3	4
Accessibility	0	0	2	0	0	1	0	3	4
Accommodating	0	0	2	0	0	1	0	3	4
Overall Satisfaction	0	0	2	0	0	1	0	3	4

12. Please rate the (The Leukemia & Lymphoma Soc...) services on the following:

Question	Very Dissa	Dissatisfie	Somewhat	Neutral	Somewhat S	Satisfied	Very Satisfie	Total Respon	Mean
Follow through	1	0	0	1	1	2	0	5	4.4
Customer Service	1	0	0	1	0	3	0	5	4.6
Accessibility	1	0	0	1	0	3	0	5	4.6
Accommodating	1	0	0	1	0	3	0	5	4.6
Overall Satisfaction	1	0	0	1	0	3	0	5	4.6

13. Please rate the (American Cancer Society) services on the following:

Question	Very Dissa	Dissatisfie	Somewhat	Neutral	Somewhat S	Satisfied	Very Satisfie	Total Respon	Mean
Follow through	1	0	1	3	2	4	2	13	4.92
Customer Service	1	0	0	3	2	4	3	13	5.23
Accessibility	1	0	0	4	0	5	3	13	5.23
Accommodating	1	0	0	3	1	5	3	13	5.31
Overall Satisfaction	1	0	0	3	1	5	3	13	5.31

14. Please rate the (Other (Explain Below)) services on the following:

Question	Very Dissa	Dissatisfie	Somewhat	Neutral	Somewhat S	Satisfied	Very Satisfie	Total Respon	Mean
Follow through	0	0	1	1	2	0	1	5	4.8
Customer Service	0	0	1	1	2	0	1	5	4.8
Accessibility	0	0	3	1	0	0	1	5	4
Accommodating	0	0	2	1	1	0	1	5	4.4
Overall Satisfaction	0	0	2	1	1	0	1	5	4.4

15. Please rate the ${lm://Field/1} services on the following: (I have not used services fr...)

Question Not Shown to Respondents

16. Please rate the (Arthritis Foundation) services on the following:

Question	Very Dissa	Dissatisfie	Somewhat	Neutral	Somewhat S	Satisfied	Very Satisfie	Total Respon	Mean
Follow through	1	0	0	3	1	6	1	12	5.08
Customer Service	1	0	2	2	0	6	1	12	4.83
Accessibility	1	1	1	3	0	5	1	12	4.58
Accommodating	1	1	0	3	1	5	1	12	4.75
Overall Satisfaction	1	1	0	4	0	5	1	12	4.67

17. Are there any of these services provided by the Lupus Foundation that you would like to utilize in the future?

Answer	Bar	Response	%
None	0.17778	8	18%
Bimonthly Educational Classes	0.44444	20	44%
Weekly Yoga Classes	0.4	18	40%
Monthly Support Groups	0.37778	17	38%
Medication Assistance Program	0.2	9	20%
Physician Referral	0.26667	12	27%
Events/Fundraisers	0.11111	5	11%
Other (Explain Below)	0.06667	3	7%

Other (Explain Below)
Maybe a camp of some sorts where growth and discussion/2-day workshop or seminar

not sure what the time constraints would be
ANY HELP THEY CAN OFFER ME AND MY FAMILY WITH THIS LIVING NIGHTMARE

18. Are there any services that are not yet provided that you would like to utilize?

Text Response
I don't know
Meditation classes
A lupus support group would be helpful here at Pocatello ID.
No
No
no
No
Phone numbers that I can call so see how others are getting through this...............
They are not provided in Southern Utah.
Help finding the best health care insurance options.
an easy, clear, thorough place for family and friends to go to get info and support.
A support group for children with moms or dads that have lupus.
Currently my health greatly limits my ability to engage in most activities. My personal support system takes care of most of my "needs." Many of my "wants" are no longer a possibility. I cannot think of any new services I would like to utilize. I do wish, however, that I were in a position to be more helpful to the organization itself.
No
I am still getting to know the foundation, and I still have a lot of questions. This is all new to me still.
Yoga class and educational classes here in St George, Utah.
No
Education without feeling like I am going to die next week·
no
unknown
no
Not at this time.
No.
Not that I can think of.
None that I can think of at this time.
No
I think they should provide therapy services
More services on St George.
More things available in South Salt Lake Valley/Utah County
Have events ,closer to the west side of the valley
No

A chapter that covers the eastern Idaho, western Wyoming. But I realze that that will never be. RESOURCES AND INFORMATION. PLEASE PLEASE HELP US IN ANYWAY TO GET THROUGH JUST ONE MORE DAY.

19. In your opinion, what keeps others with Lupus from utilizing the resources and services provided by the Lupus Foundation?

Text Response
For myself im not sure I have truly excepted my lupus so I don't know the answer to this
I don't know, but I would guess the same as me; they are not avaliable in our area.
They may not be aware of everything that is involved or how to get involved with the chapter. They are too scared to reach out.
I have no idea.
Sickness
Not knowing what is provided and not having local community events instead of driving to Salt Lake.
Not being aware of services. My first rheumatologist never once mentioned the Lupus Foundation as a source of support
Not knowing about the Foundation, time and energy constraints.
Health, distance and time.
Not knowing about them, physical health
Health, transportation, location.
Not knowing what is available.
Mainly health and energy constraints. It's so hard when you're so limited already. Then knowledge, people still don't understand lupus and don't hear enough about it yet. Also, just lack of knowibg what's available and not searching it out.
Lack of knowledge about the Foundation and its services. Lack of time, health, transportation, etc. to make use of the services.
Deniel not wanting to acknowledge it is infact a serious condition hoping it will go away.
Not knowing you exist.
They don't know about the Foundation
Energy, time, transportation
Admitting they need it- like me! I have only ever done one 5 k run!

Lack of professional facilitators. I don't want to go to a get together at a restaurant. I want a legitimate support group. I want to feel emotionally uplifted and not dragged down. Have it be more personal.
too sick to go out
lack of information about what is available and when
Some people are just not ready to reach out and get the support needed for this issue. I think it just takes time and education.
Not sure people know about the foundation.
I'm not sure.
Don't really understand what services are offered. Plus I don't really hear about the support groups until it's too late for me to make plans to get there.
Time
Location and not making the time.
Not knowing how to get these services or even knowing they exsist.
Location
I think they are scared to reach out to someone.
I don't know
can't get transportation or not well enough to attend events
Lack of knowing about them, fear of nor knowing someone there, not feeling well
Need more research = more knowledge so many mis diagnosed!
Lack of knowledge.
health
Distance from chapter locations.
THEY DON'T EVEN KNOW ABOUT IT
They don't know about it, and are scared and don't step out of their boundaries.

20. How frequently do you utilize services provided by the Lupus Foundation?

Answer	Bar	Response	%
Daily	0	0	0%
2-3 Times a Week	0.02326	1	2%
Once a Week	0.04651	2	5%
2-3 Times a Month	0.11628	5	12%
Once a Month	0.16279	7	16%
Several Times a Year	0.30233	13	30%
Once a Year or Less	0.2093	9	21%
Never	0.13953	6	14%
Total		43	100%

21. What do you feel would help you and others with Lupus the most?

Text Response
Im not sure
Already told you: offer the same services her in St.George! No one is going to drive 6 hours to participate.
More educational classes on alternative treatments. As a Doterra representative·I would love more attention brought to the use of essential oils and lupus as it has helped me incredibly.
support groups
Help finding employment with employers who understand lupus.
A cure of course! Well, and understanding from others/society.
a cure! :)
One on one support. Each lupus patient experiences are so different.
Exercise and nutrition classes.
Finding help with medical costs.
Helping my son and other kids get support and understanding about what it's like to have a parent with lupus. And just help managing others expectations. Things that help my self esteem. Programs and info that can help me be confident in my current health situation. And just more knowledge in our community. Being more visible
The impossible dream: Research to find a cure. Hope in a real possibility that advancements would provide us with a better quality of life. Learning to appreciate and fully utilize the abilities Lupus has left us. Finding fulfillment and value in a diminished lifestyle.
To understand the symptoms and ways to get through flar ups.
I just do not know who to talk to, to find out more about resources that are out there through the foundation.
Not sure
Visability
I'm Not sure. I think you do a great job.
Not sure yet
Feeling more in control by proactive things we can do to help us feel better.
education
Just information. Knowledge is power.
More exposure in the media.

News on research and new treatment.
Lupus is very isolating. Making it easy to make connections with others who understand or who can help when needed.
Functions that are more accommodating for lupus patients. Not in the middle of an unshaded area.
New research and information that helps educate about how people can deal with symptoms.
More awareness.
On line meetings/forums
A cure! In the meantime, more medications specifically for lupus and more doctors that treat lupus patients.
A cure
An online support group to go to even if you can't get to "regular meetings" , i.e. Skype meetings or "GoTo" meetings in an online fashion, so you can still "attend" and participate in meetings even if you are a 'shut in' like me.
A cure, better treatments
Research and understanding the issues that comes with Lupus!
I also have Type 1 Diabetes. I know others with the disease & a lot of people know about Diabetes. Lupus is another story. I don't really know anyone with the disease & people have heard of Lupus, but don't really know what it is. I just wish more people could somehow here more about it.
email newsletter
Educating the public as to how disabling and exhausting SLE really is.
SUPPORT, RESOURCES, INFORMATION AND MOST OF ALL ACCSESSIBILITY AND AWARNESS OF THE THINGS OFFERED
Getting the information out there to them. Bringing more awareness to a disease not many understand.

22. As a Supporter, how often do you help with, or use services provided by the Lupus Foundation?

Answer	Bar	Response	%
Daily	0	0	0%
2-3 Times a Week	0	0	0%
Once a Week	0.125	1	13%
2-3 Times a Month	0	0	0%
Once a Month	0	0	0%
Several Times a Year	0.5	4	50%
Once a Year or Less	0.25	2	25%
Never	0.125	1	13%
Total		8	100%

23. What services or resources have you found to be the most helpful?

Text Response
I've not used any services, I've only participated in the Walk for Lupus Now event each year, and any emails I receive that I believe may hold interest for my Mom (who has Lupus), I forward the information to her.
the support group interaction has been eye opening for someone that is dealing with a partner with Lupus.
Fundraising
Newsletter, Local Events, Q & A Section , New Research in Drugs
Information
Fundraising.
group get togthers

24. Which of the following best describes why you support Lupus?

Answer	Bar	Response	%
I have a family member with Lupu	0.75	6	75%
I have a friend with Lupus	0	0	0%
I believe in the cause and want to	0.125	1	13%
Other (Explain Below)	0.125	1	13%
I care for someone with Lupus	0.25	2	25%

Other (Explain Below)
I have lupus

25. What do you feel is not being provided to you as a supporter that would be beneficial?

Text Response
Nothing.
Perhaps it is out there already, but I feel that I don't have access to information as a concerned individual that has friend with Lupus as too how to comfort and help when she has a "flare up". Simply: what to do when an attack happens.
More real stories
Local educational events, Yoga (St. George Area)
None
more information on medical issues
No answer
Utah County get togethers, classes

26. Do you feel the Utah Lupus Foundation Chapter has adequate resources to meet members' needs?

Answer	Bar	Response	%
Yes	0.66667	6	67%
No	0.33333	3	33%
Total		9	100%

27. What resources do you feel are needed to better meet members' needs?

Text Response
Local community involvement
I think we need more big donors so that we can expand our financial and education programs.
More money right.

28. Which of the following services would you estimate is utilized the most?

Answer	Bar	Response	%
Bimonthly Educational Classes	0	0	0%
Weekly Yoga Classes	0.11111	1	11%
Monthly Support Groups	0.11111	1	11%
Medication Assistance Program	0.11111	1	11%
Physician Referral	0	0	0%
Events/Fundraisers	0.66667	6	67%
Other (Explain Below)	0	0	0%
Total		9	100%

29. How frequently do you volunteer at events and other services for the Lupus Foundation?

Answer	Bar	Response	%
Daily	0	0	0%
2-3 Times a Week	0	0	0%
Once a Week	0.11111	1	11%
2-3 Times a Month	0.22222	2	22%
Once a Month	0.11111	1	11%
Several Times a Year	0.33333	3	33%
Once a Year or Less	0.22222	2	22%
Never	0	0	0%
Total		9	100%

30. Please tell us how you originally got involved with the Lupus Foundation

Text Response
I have Lupus
The SLC Lupus walk.
Wanted to donate to this cause at work.
Noelle
My niece was diagnosed with lupus at the age of 7. My sister shortly became a part of the foundation after her diagnosis.
Friend
Collaboration with Yoga Classes
Got in contact through Lupus Foundaton of America.
I met Katie Fillnow who then introduced me to Noelle.

31. What do you feel would help the Utah Lupus Foundation Chapter better serve its members?

Text Response
Needs more funding for the programs that help lupus patients directly.
Because there are so many outlying areas in Utah, perhaps some type of mobile visiting service to reach out to those persons that can't travel. The problem with all of these is that they take time, people, and financial resources. The foundation works so hard already...that is why I suggested really going after some bigger donors in Utah so that they can fund more staff and projects.
Give Noelle a raise ;)
Bigger office
To expand its resources in holistic healing and other spiritual practices.
Social hours around meals
More organization and support from community partners.
Nothing I can think of.

32. Would you refer the Lupus Foundation to your friends and family?

Answer	Bar	Response	%
Yes	0.98485	65	98%
No	0.01515	1	2%
Total		66	100%

33. What would keep you from referring friends and family to the Lupus Foundation?

Text Response
I don't know what they do besides meet once a month to talk and eat.

34. What do you feel the Utah Chapter of the Lupus Foundation is doing really well?

Text Response
Consistent information regarding events, health and wellness classes (like Yoga) offered to Lupus patients, etc.
E-mails is really the only contact I have, so I guess e-mails.
Really great with events and are inviting to newcomers.
Consistency in emails and keeping us informed on what's happening with research and other events happening outside of the state.
Their monthly support group activities are great! The fundraisers are well thought out and very well attended. Noelle puts 100% into all she does...
education / personalized advice

Lupus awarness
When we're able we do the lupus walk. We enjoy that.
Communication & updates
I haven't been participating enough lately to know.
I do t know.
Events & the MAP
Nurturing its members. Making each person feel valuable and understood.
Reaching out to the community & offering support to patients & caregivers.
Gala!
They are very easy to approach, talk to, get to know. they are very enthusiastic about the programs and organization. They feel very invested in my health and life experience and my families. I think they are very good at making changes, updating the marketing info, the gala, etc. Helping us be more visible here in Slc and around the state. They are very good at recruiting for the gala and the walk. They find really great fundraising ideas. They are very creative.
I haven't been involved enough in recent years to offer a valid opinion. From what I've read, it seems progress has been made.
Informing and giving support
Salt Lake seems to have more programs.
Support groups and recognition at galas
Lupus Walk
Fundraising events
Communicating
I enjoyed the 5 k
With such a small staff they are involved and care about the mission of Lupus. Very pleasant to work with and they do a good job of advocating the foundation
Support, Educating the public about Lupus
Everything
I enjoy the annual walk.
i don't know
They are trying.
probably alot for people in UT but as they say they are here for us in Idaho, not at all... I am in my doctor's terms "circling the drain" it would be really nice to have some support before it's too late
Walk is most successful, but, again, increased visibility of our work in the community is needed.
I'm not that familiar with it.

Their events and reaching out to those who would like to be involved.
I haven't had a great deal of interaction but what I have had has been good.
They are always very capable of putting together the two main fundraising events. The know how to bring people together and show them a good time, while the underlying purpose is to raise money for research and awareness.
Yes!
Everything!
I've never been able to make it, but it sounds like the walk is always a big success.
The monthly newsletters
Raising money, showing concern and support for others
Yes
Member support, resources for members, individualization of needs for members
Involving the community in their events.
I love the emails and how the web site is set up. I feel like I have had questions answered and have felt validated in what I may be feeling or experiencing. I love all the different classes and groups there is. I wish I made more time to travel to participate in the groups and classes more.
Community involvement\education. Working with local media to bring awareness ot the disease.
getting the word out about Lupus
Sure
The Social Butterflies group is really on point. The walk is great. And they support they give thier patients is really awesome.
Fundraising
the events they've already got in play are consistent
Fundraising. Awareness. Meetings.
not sure.
Medication and Life Assistance, Outreach, Activities in Salt Lake, being a solid source of information.
Everything such upbeat attitudes and answers questions ver well! Love that they are trying to raise funds wish they had more assistance!

We have done the Lupus walk for the last 2 years. It was organized really well & it was really fun. The only thing I would do different is maybe have it on another weekend that's not the same as the Susan Komen walk for breast cancer.
outreach
Communication
I cannot go to Utah, but just having emails pop up says that someone is thinking about me.
THE FACT THAT THE LUPUS FOUNDATION EXISTS IS A BLESSING. ANY AND ALL SERVICES ARE APPRECIATED BEYOND MEASURE.
Offering great quality resources and events.

35. In what ways could the Lupus foundation better share its services with those that need them?

Text Response
N/a
More TV/Cable/Radio advertisements if possible · I don't see many advertisements for Lupus. Breast Cancer Awareness has support from so many different places · food, clothing, etc. Not that breast cancer shouldn't, but I believe Lupus should have more of these same types of advertising · providing more national awareness of Lupus.
By making them accessible in all areas!
Provide material to doctors/rheumatoid doctors and clinics where they can first hear about the foundation upon diagnosis and the doctor can refer the patient to the foundation.
More social media attention to the fact that the Utah chapter is there and can help.
support groups
Financial
I don't know.
I don't think it's the Lupus Foundation that can do this, I think it's Doctors & clinics who need to share that this is an option
Provide more online resources, such as recording the Education seminars and letting us view ones we missed.
I don't know.
N/A

Google and/or Facebook advertising. More frequent FB posts. Perhaps use a tool that you could link instagram, twitter and FB and send out one message that updates all three pages at once?
N/a
n/a
If we had a regular presence somewhere in the community, sponsoring a local radio show for example, talking about lupus and health issues on something like Good for Utah. Just getting the information out there more. Also, the simpler the better, with fundraising and marketing. Making it easy for people to donate. Also, we could have more for kids and families together.
Perhaps by supplying brochures to rheumatologists and other physicians who routinely treat patients with lupus. Of course, this could be something you are already doing.
Not sure
I have triedd to call and leave a message to speak with someone at the foundation to help me but no one ever called me back
I learned about it from a paper on the wall of my Dr's officein St George, Utah! I lived in Cleveland and have had Lupus for 9 years and was never told about the foundation or support services.
Local community involvement
Emphasize to Doctors about what services are available
I don't know
Maybe have a both at some of the trade shows
Unknown
Not sure
Get more information out
education
phone calls follow ups
Offer them more frequently.
don't just promote the magazine and donations to us who live too far to be involved in the walkathons, the classes, the seminars... or help us to get a caravan... share the ride to these functions so that us up here can come down there to get information and interact with others in the same condition we are all in
Visibility in community; more ads and media
I think they are doing great.
I think they already do a pretty good job.

Advertise more.
Possibly partake in more communal fundraisers?
Collaborations in the Health and Wellness arena
Nothing more than they're already doing.
Put flyers at rheumatologist offices.
Just keep doing what you do.
social media advertising, more presence at the Universities and community health fairs.
Maybe more Facebook posts.
I think they do a great job! I wish things were a little closer to me but understand that it makes more sense to have it located to where a grater population would be to attend.
Continue to spread the word about the ULC, the disease and available services.
not sure
More accessible to those not in Salt Lake
I think they need more outreach services.
More advertising
not sure
They are doing it already.
online meetings as stated previously
Find ways to reach out beyond downtown SL City.
More research needed
email newsletter
Very hard question. Every outreach costs money. I just need information to read. Maybe know who the really outlying members are and (I know this sounds different) have the LFA actually give them a phone call. You might be surprised what you might hear. And that personal touch is worth so much. Doesn't have to be any more than one call. But you might find (like 1 in 10) lupus patients that really could use some real help, but did not know where to go.
I DON'T THINK MOST PEOPLE WITH LUPUS EVEN KNOW THE LUPUS FOUNDATION EXESTS. AWARENESS   AWARENESS AWARENESS

36. Through which of the following would you prefer to receive information about the Utah Lupus Chapter? (Select all that apply)

Answer	Bar	Response	%
Telephone	0.09375	6	9%
Text Message	0.21875	14	22%
Email	0.92188	59	92%
Mail	0.3125	20	31%
Facebook	0.48438	31	48%
Twitter	0.0625	4	6%
YouTube	0.10938	7	11%
Other (Explain Below)	0.01563	1	2%
Digital Magazine	0.3125	20	31%

Other (Explain Below)
information that we can buy or borrow to learn how to help ourselves, printed magazines

37. If you would like to be entered into the Giveaway please enter your information below.

First Name	Last Name	Email
Information Intentionally Left out		