

Lichen Sclerosus (LS)

Disease Experience Survey Results

*LS survey results collected from
October 21- 30, 2018.*



GLOBALESKIN.ORG

International Alliance of
Dermatology Patient
Organizations

The [International Alliance of Dermatology Patient Organizations](#) – a not-for-profit organization working to improve the lives of those affected by dermatological disorders throughout the world – conducted a unique survey on the experience of patients living with Lichen Sclerosus (LS). The survey was designed in collaboration with several leaders of online support groups and was open to public participation, October 21-30, 2018.

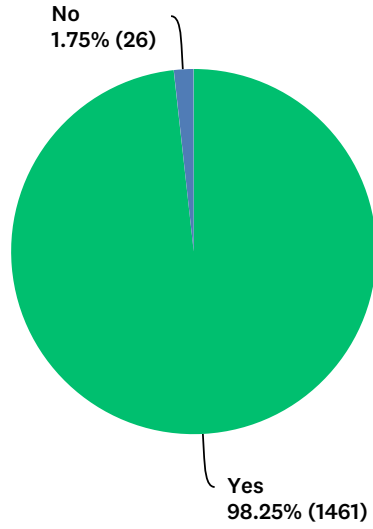
As part of its [RareDERM](#) community building initiative, IADPO is working to determine the impact of LS on those living with it and if the patient is a child, the effect on them and on their families. The objective of the survey was to also determine whether currently available treatments are or are not effective in treating LS from the patient perspective.

The survey was anonymous and was completed by 1492 participants. Patients were invited to participate in the survey via online discussion forums and groups dedicated to supporting LS patients as well as social media posts.

Inquiries related to this research may be directed to info@globalskin.org.

Q1 Have you (or the person for whom you are completing the survey) been diagnosed with Lichen Sclerosus?

Answered: 1,487 Skipped: 5



Q2 In answering this questionnaire, please share with us which perspective you represent:

Answered: 1,487 Skipped: 5

ANSWER CHOICES	RESPONSES	
I am a parent/caregiver to a female child under 18 years of age with LS	1.95%	29
I am a parent/caregiver to a male child under 18 years of age with LS	0.13%	2
I am biologically female	95.56%	1,421
I am biologically male	2.02%	30
I am transgender male	0.07%	1
I am transgender female	0.00%	0
I am intersex	0.27%	4
TOTAL		1,487

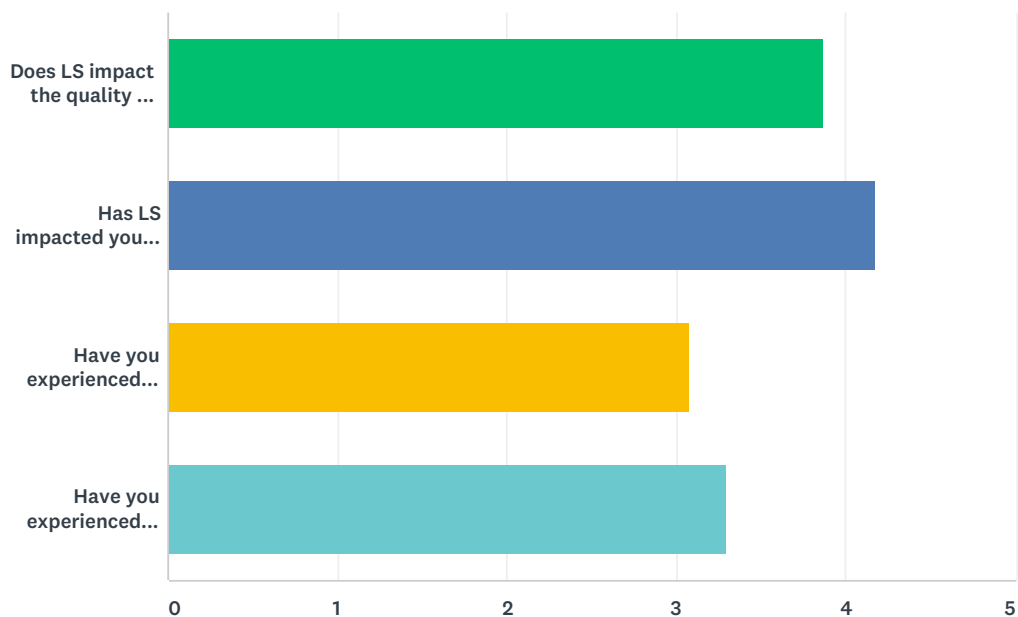
Q3 (Q3-10 Biologically Females) In what country do you live?

Answered: 1,374 Skipped: 118

ANSWER CHOICES	RESPONSES	
United States of America	47.60%	654
United Kingdom of Great Britain and Northern Ireland	21.69%	298
Denmark	7.13%	98
Canada	6.99%	96
Australia	5.46%	75
Netherlands	4.22%	58
Italy	1.46%	20
Germany	1.31%	18
New Zealand	0.80%	11
Ireland	0.51%	7
Norway	0.51%	7
Sweden	0.51%	7
South Africa	0.36%	5
Switzerland	0.29%	4
Argentina	0.15%	2
Austria	0.15%	2
Greece	0.15%	2
Bulgaria	0.07%	1
Cuba	0.07%	1
Finland	0.07%	1
France	0.07%	1
Hungary	0.07%	1
Iceland	0.07%	1
Portugal	0.07%	1
Qatar	0.07%	1
Spain	0.07%	1
United Arab Emirates	0.07%	1
TOTAL		1,374

Q4 (Female) In the questions below, please use the scale of Never to Always to show any impact of Lichen Sclerosus :

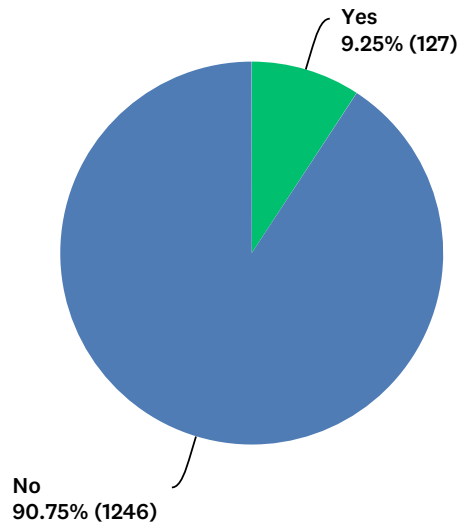
Answered: 1,379 Skipped: 113



	NEVER	RARELY	SOMETIMES	FREQUENTLY	ALWAYS	TOTAL	WEIGHTED AVERAGE
Does LS impact the quality of your life?	0.58% 8	4.58% 63	29.48% 406	37.84% 521	27.52% 379	1,377	3.87
Has LS impacted your sexual activities?	2.51% 34	4.35% 59	16.29% 221	27.78% 377	49.08% 666	1,357	4.17
Have you experienced depression because of LS?	12.68% 174	12.90% 177	38.85% 533	25.36% 348	10.20% 140	1,372	3.08
Have you experienced anxiety because of LS?	8.24% 113	12.17% 167	36.15% 496	29.30% 402	14.14% 194	1,372	3.29

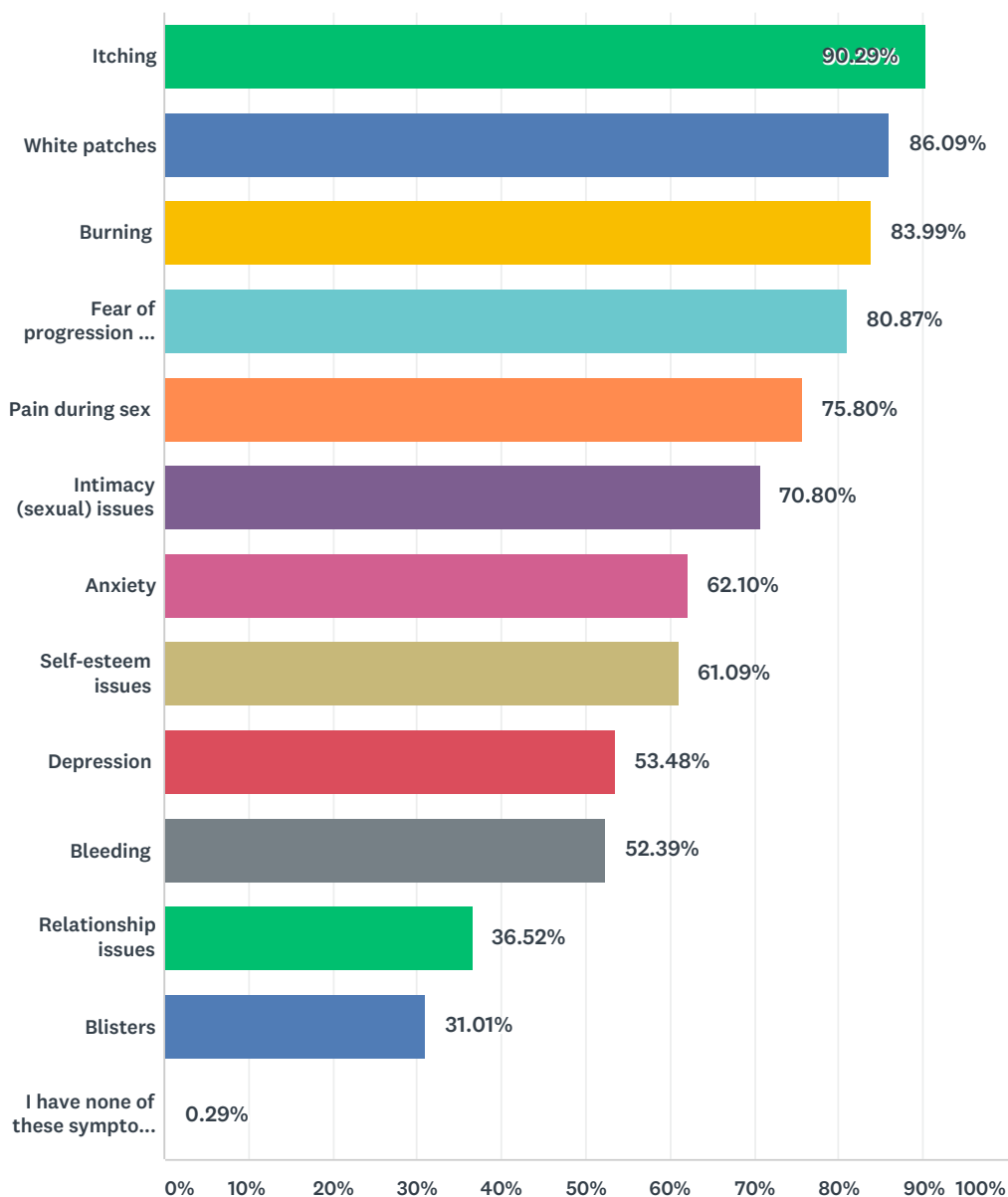
Q5 (Females) Have you considered suicide because of LS?

Answered: 1,373 Skipped: 119



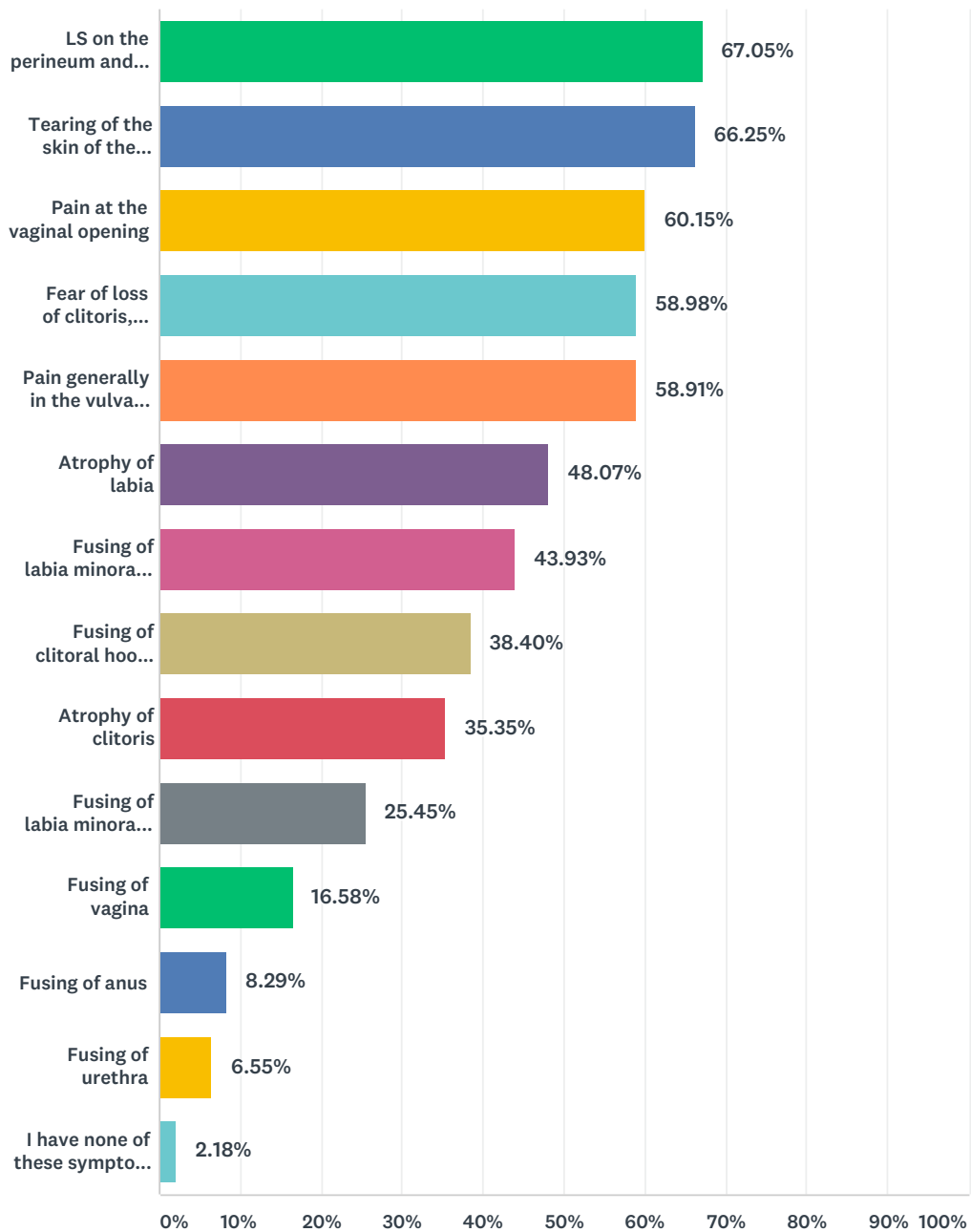
Q6 (Females) What are the issues and/or symptoms that you have experienced with, or as a result of, your LS? (Check all that apply.)

Answered: 1,380 Skipped: 112



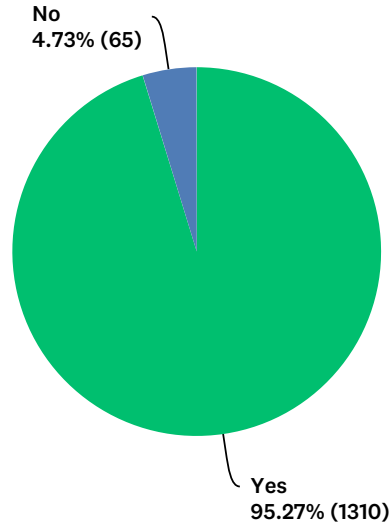
Q7 (Females) Have you had any of the following issues and/or symptoms as a result of your LS? (Check all that apply and tell us "others".)

Answered: 1,375 Skipped: 117



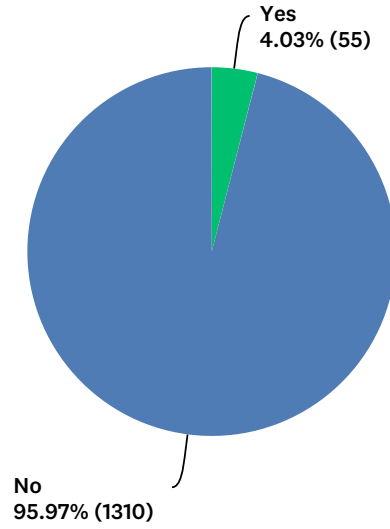
Q8 (Females) Are you aware that if LS is not treated there is an increased risk of developing cancer of the vulva?

Answered: 1,375 Skipped: 117



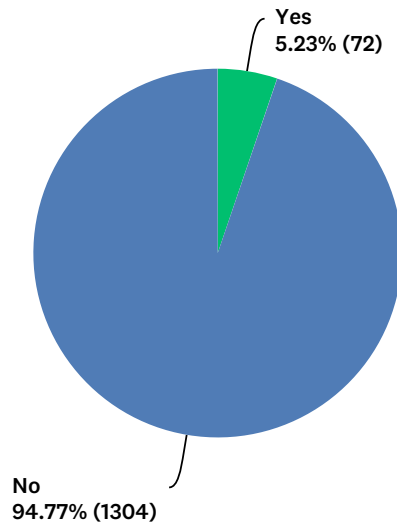
Q9 (Females) Have you been diagnosed with vulvar intraepithelial neoplasia (VIN)?

Answered: 1,365 Skipped: 127



Q10 (Females) Have you been diagnosed with cancer of the vulva?

Answered: 1,376 Skipped: 116



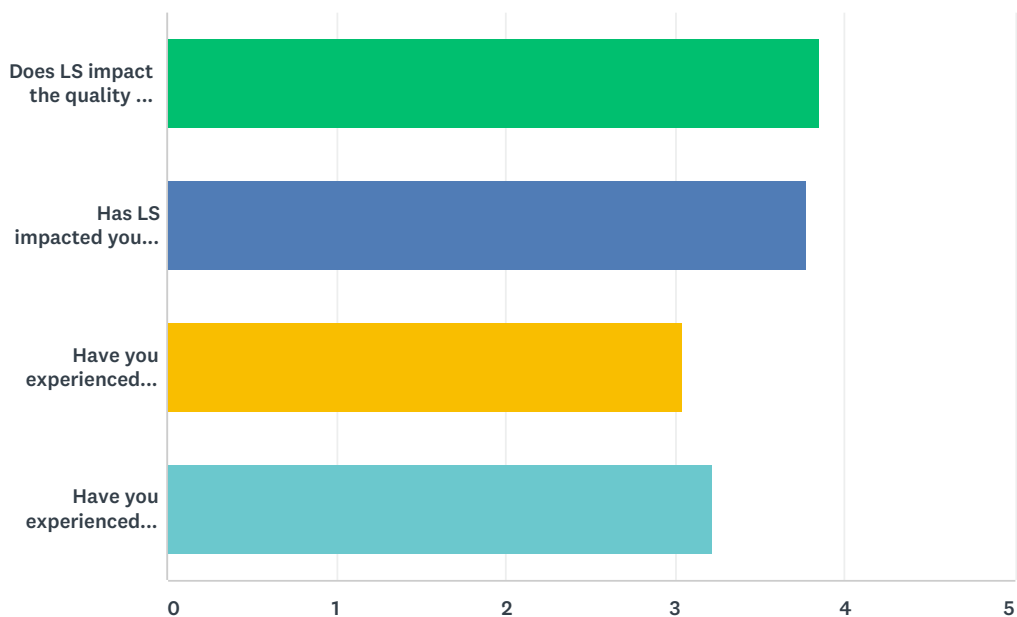
Q11 (Q11-18 Biologically Males) In what country do you live?

Answered: 27 Skipped: 1,465

ANSWER CHOICES	RESPONSES	
United States of America	25.93%	7
Italy	18.52%	5
United Kingdom of Great Britain and Northern Ireland	18.52%	5
Netherlands	14.81%	4
Croatia	3.70%	1
Denmark	3.70%	1
Finland	3.70%	1
New Zealand	3.70%	1
Romania	3.70%	1
Sweden	3.70%	1
TOTAL		27

Q12 (Males) In the questions below, please use the scale of Never to Always to show any impact of Lichen Sclerosus :

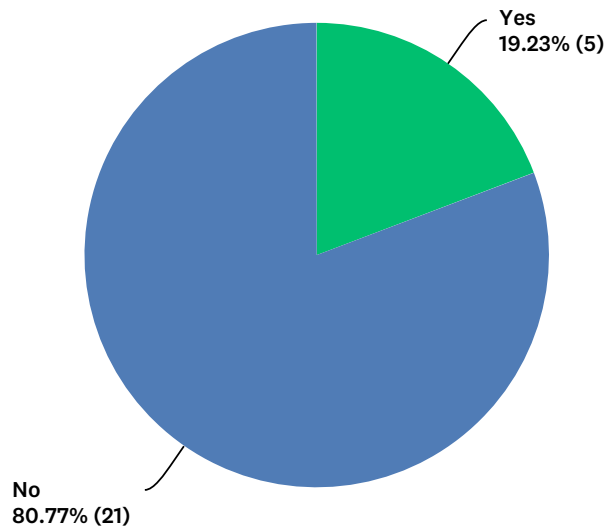
Answered: 27 Skipped: 1,465



	NEVER	RARELY	SOMETIMES	FREQUENTLY	ALWAYS	TOTAL	WEIGHTED AVERAGE
Does LS impact the quality of your life?	0.00% 0	0.00% 0	48.15% 13	18.52% 5	33.33% 9	27	3.85
Has LS impacted your sexual activities?	0.00% 0	11.11% 3	33.33% 9	22.22% 6	33.33% 9	27	3.78
Have you experienced depression because of LS?	18.52% 5	11.11% 3	33.33% 9	22.22% 6	14.81% 4	27	3.04
Have you experienced anxiety because of LS?	11.11% 3	7.41% 2	44.44% 12	22.22% 6	14.81% 4	27	3.22

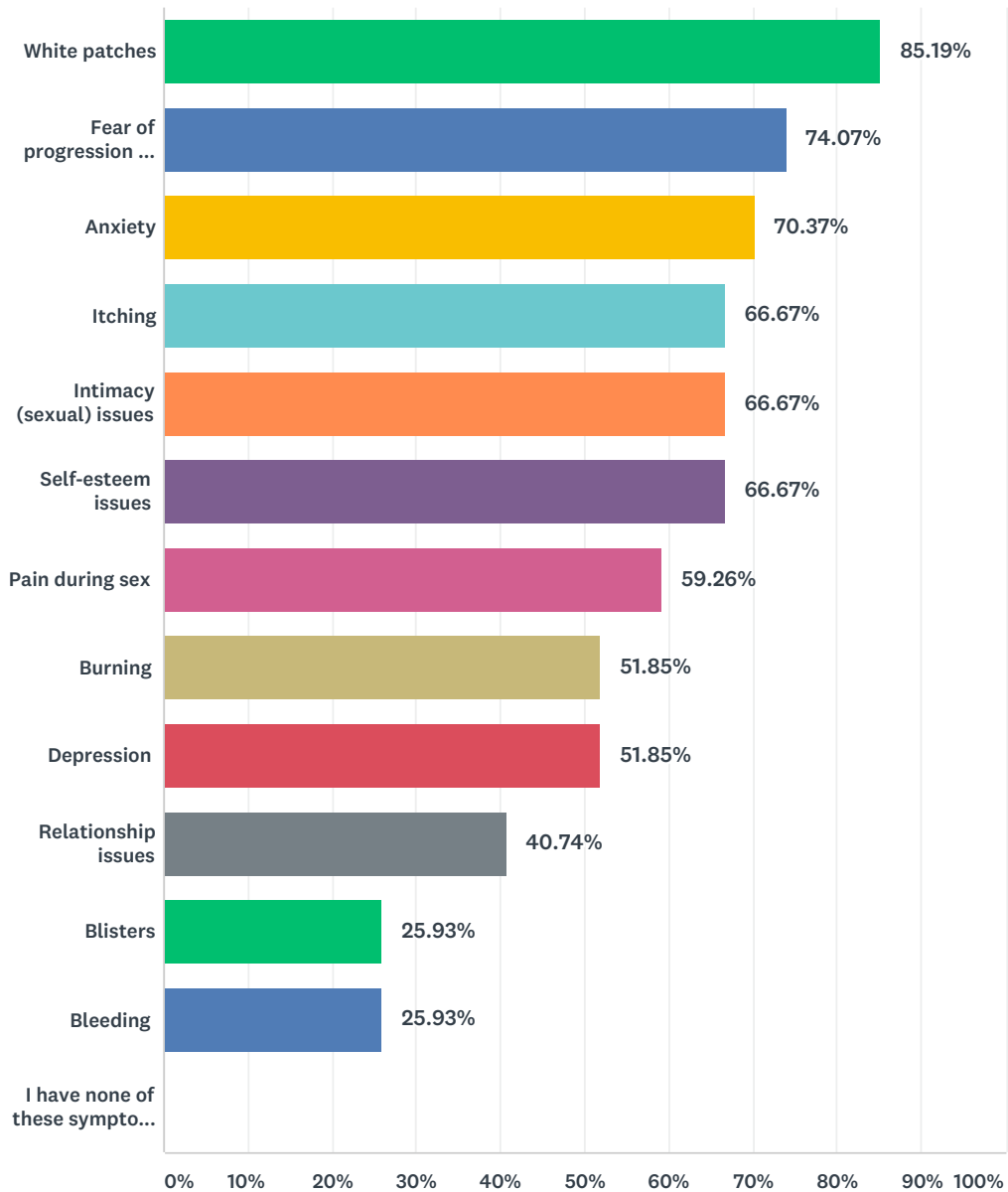
Q13 (Males) Have you considered suicide because of LS?

Answered: 26 Skipped: 1,466



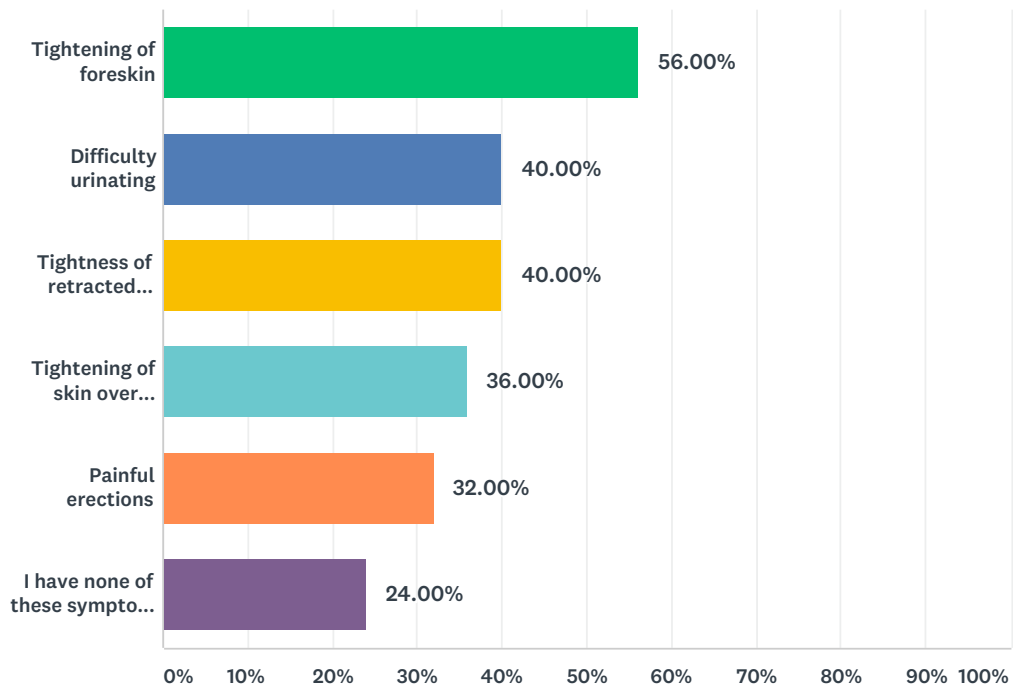
Q14 (Males) What are the issues and/or symptoms that you have experienced with, or as a result of, your LS? (Check all that apply.)

Answered: 27 Skipped: 1,465



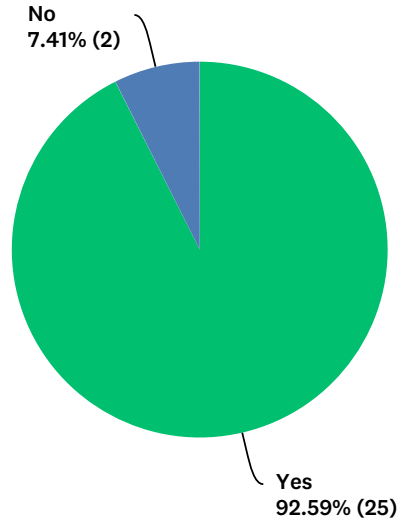
Q15 (Males) Have you had any of the following issues and/or symptoms as a result of your LS? (Check all that apply and tell us "others".)

Answered: 25 Skipped: 1,467



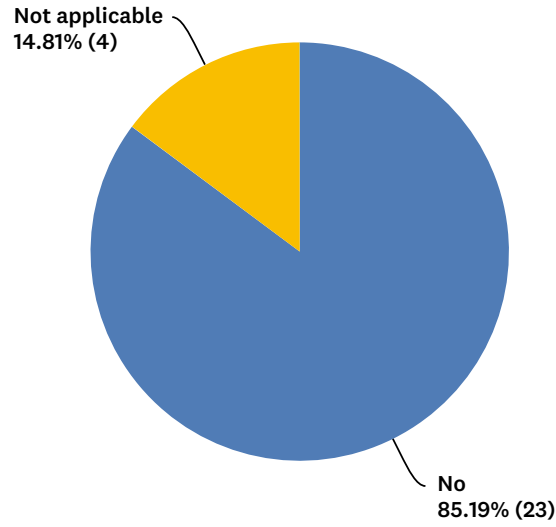
Q16 (Males) Are you aware that if LS is not treated there is an increased risk of developing cancer on the penis?

Answered: 27 Skipped: 1,465



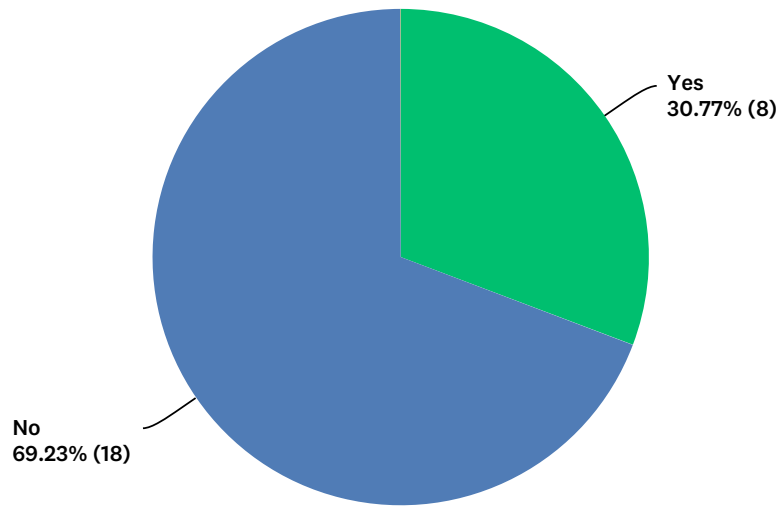
Q17 (Males) Have you been diagnosed with any cancerous cells on your penis?

Answered: 27 Skipped: 1,465



Q18 (Males) Have you been circumcised?

Answered: 26 Skipped: 1,466



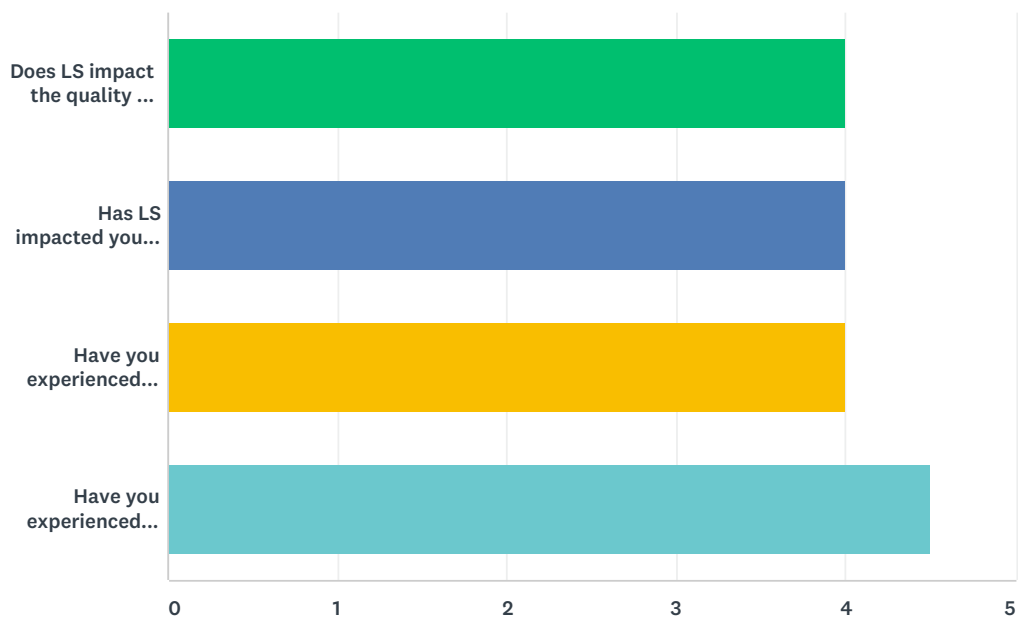
Q19 (Q19-30, Intersex; N=2) In what country do you live?

Answered: 2 Skipped: 1,490

ANSWER CHOICES	RESPONSES	
United States of America	100.00%	2
TOTAL		2

Q20 (Intersex, N=2) In the questions below, please use the scale of Never to Always to show any impact of Lichen Sclerosus :

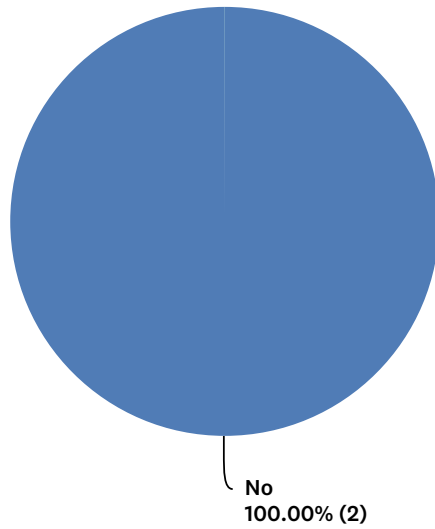
Answered: 2 Skipped: 1,490



	NEVER	RARELY	SOMETIMES	FREQUENTLY	ALWAYS	TOTAL	WEIGHTED AVERAGE
Does LS impact the quality of your life?	0.00% 0	0.00% 0	0.00% 0	100.00% 2	0.00% 0	2	4.00
Has LS impacted your sexual activities?	0.00% 0	0.00% 0	0.00% 0	100.00% 1	0.00% 0	1	4.00
Have you experienced depression because of LS?	0.00% 0	0.00% 0	0.00% 0	100.00% 2	0.00% 0	2	4.00
Have you experienced anxiety because of LS?	0.00% 0	0.00% 0	0.00% 0	50.00% 1	50.00% 1	2	4.50

Q21 (Intersex, N=2) Have you considered suicide because of LS?

Answered: 2 Skipped: 1,490



Q22 (Intersex, N=2) What are the issues and/or symptoms that you have experienced with, or as a result of, your LS? (Check all that apply.)

Answered: 2 Skipped: 1,490

ANSWER CHOICES	RESPONSES	
Itching	100.00%	2
Burning	100.00%	2
Self-esteem issues	100.00%	2
Depression	100.00%	2
Anxiety	100.00%	2
Blisters	50.00%	1
White patches	50.00%	1
Bleeding	50.00%	1
Fear of progression of disease	50.00%	1
Pain during sex	50.00%	1
Relationship issues	50.00%	1
Intimacy (sexual) issues	50.00%	1
I have none of these symptoms or issues	0.00%	0
Not applicable to me	0.00%	0
Total Respondents: 2		

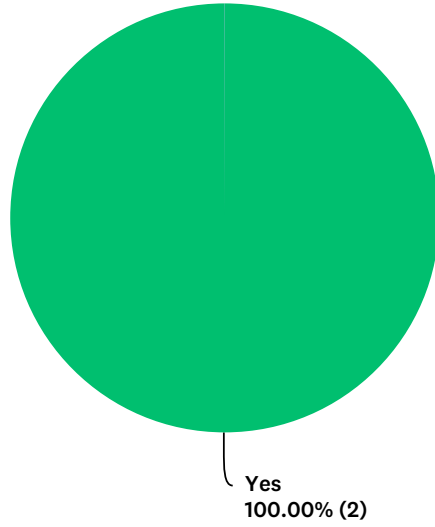
Q23 (Intersex, N=2) Have you had any of the following issues and/or symptoms as a result of your LS? (Check all that apply and tell us "others".)

Answered: 2 Skipped: 1,490

ANSWER CHOICES	RESPONSES	
Pain generally in the vulva area	100.00%	2
Pain at the vaginal opening	100.00%	2
Tearing of the skin of the vulva	100.00%	2
LS on the perineum and/or anus	100.00%	2
Fear of loss of clitoris, full fusion	50.00%	1
Atrophy of labia	50.00%	1
Atrophy of clitoris	50.00%	1
Fusing of labia minora to labia majora	50.00%	1
Fusing of labia minora together	50.00%	1
Fusing of vagina	50.00%	1
Fusing of clitoral hood to clitoris	50.00%	1
Fusing of urethra	0.00%	0
Fusing of anus	0.00%	0
I have none of these symptoms or issues	0.00%	0
Total Respondents: 2		

Q24 (Intersex, N=2) Are you aware that if LS is not treated there is an increased risk of developing cancer of the vulva?

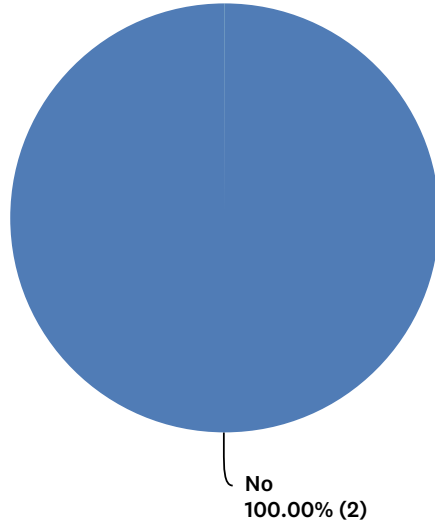
Answered: 2 Skipped: 1,490



Yes
100.00% (2)

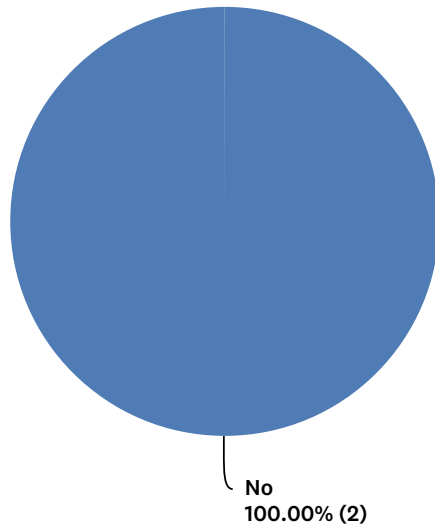
Q25 (Intersex, N=2) Have you been diagnosed with vulvar intraepithelial neoplasia (VIN)?

Answered: 2 Skipped: 1,490



Q26 (Intersex, N=2) Have you been diagnosed with cancer of the vulva?

Answered: 2 Skipped: 1,490



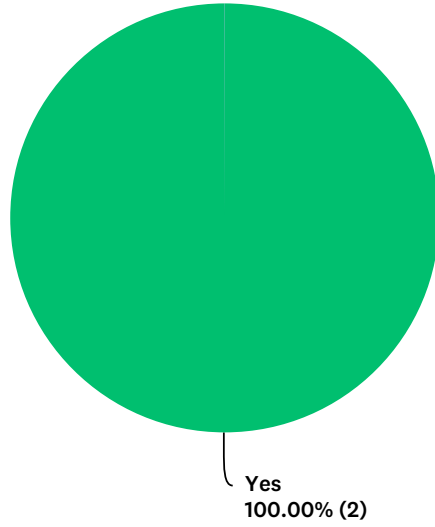
Q27 (Intersex, N=2) Have you had any of the following issues and/or symptoms as a result of your LS? (Check all that apply and tell us "others".)

Answered: 2 Skipped: 1,490

ANSWER CHOICES	RESPONSES	
Not applicable to me	100.00%	2
Difficulty urinating	50.00%	1
Tightening of foreskin	0.00%	0
Painful erections	0.00%	0
Tightening of skin over opening to penis	0.00%	0
Tightness of retracted foreskin over shaft of penis (wasting)	0.00%	0
I have none of these symptoms or issues	0.00%	0
Total Respondents: 2		

Q28 (Intersex, N=2) Are you aware that if LS is not treated there is an increased risk of developing cancer on the penis?

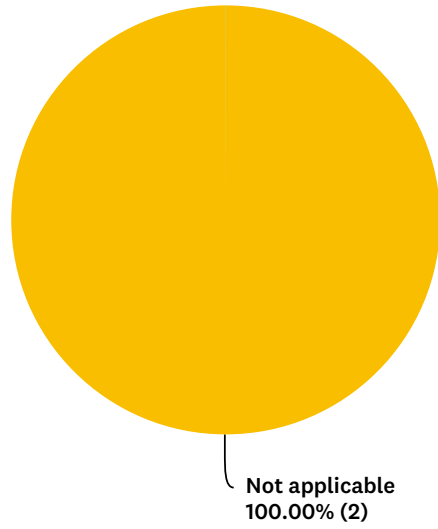
Answered: 2 Skipped: 1,490



Yes
100.00% (2)

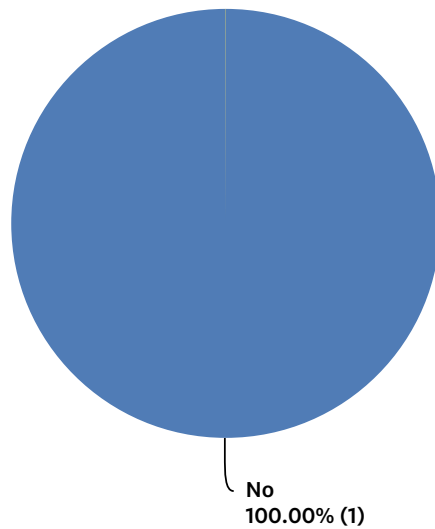
Q29 (Intersex, N=2) Have you been diagnosed with any cancerous cells on your penis?

Answered: 2 Skipped: 1,490



Q30 (Intersex, N=2) Have you been circumcised?

Answered: 1 Skipped: 1,491



Q31 (Males, Intersex) Were you circumcised before or after your LS diagnosis?

Answered: 8 Skipped: 1,484

ANSWER CHOICES	RESPONSES	
Before	75.00%	6
After	25.00%	2
TOTAL		8

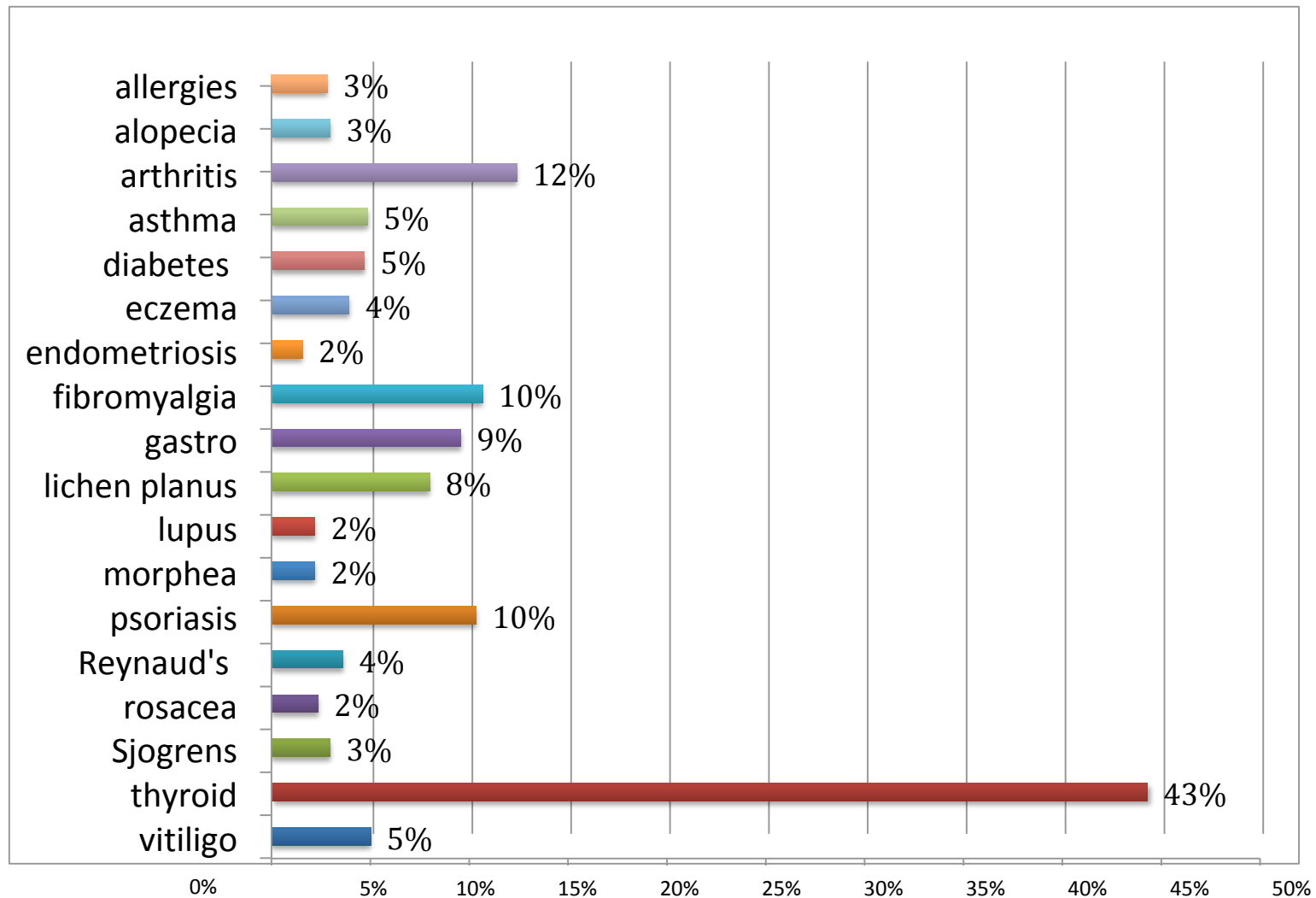
Q32 (Males, Intersex) If after diagnosis, has circumcision helped relieve the LS symptoms?

Answered: 2 Skipped: 1,490

ANSWER CHOICES	RESPONSES	
Yes	50.00%	1
No	50.00%	1
TOTAL		2

Q33 Do you have any other auto-immune diseases? (Please list below.)

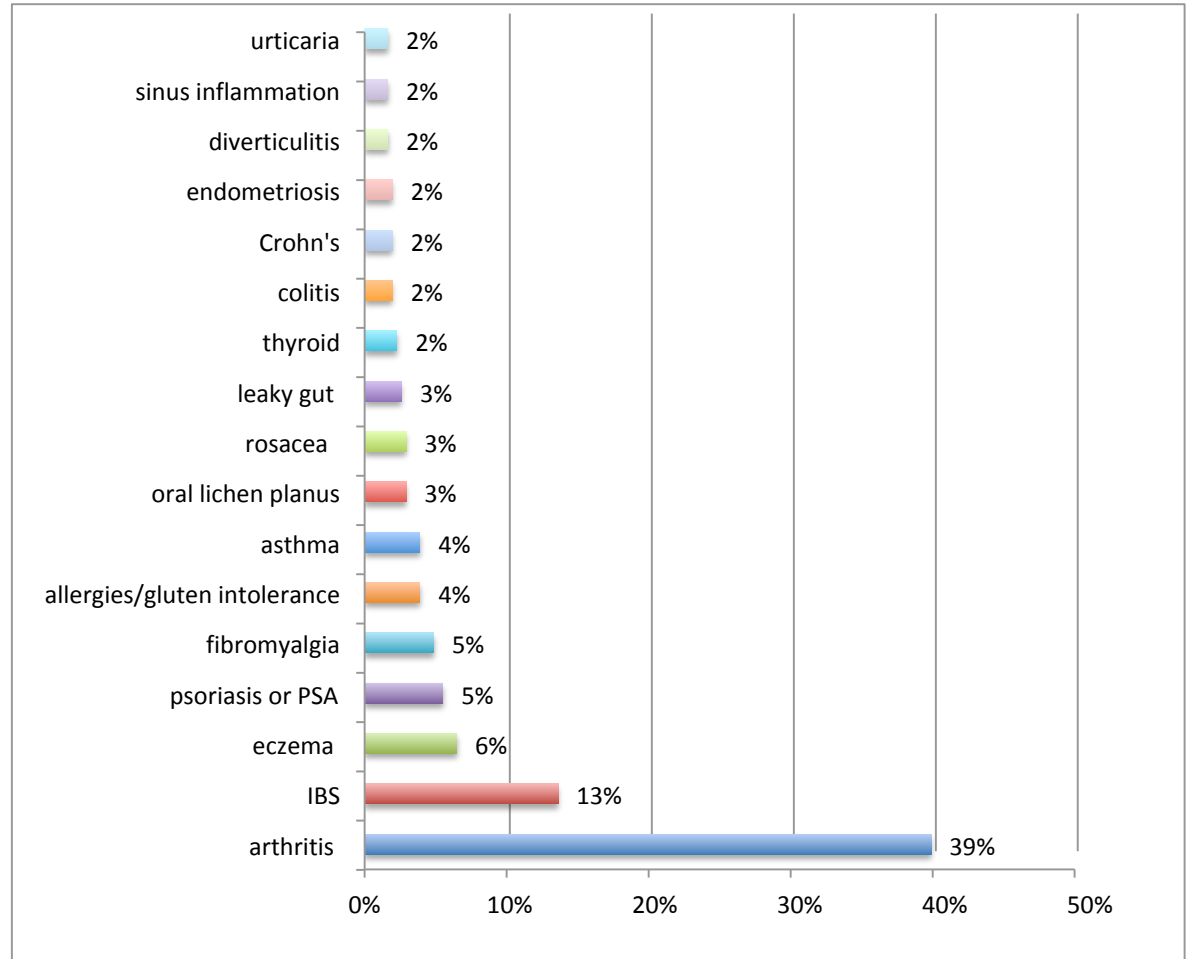
Answered: 1,048 Skipped: 444 N=657



Q34 Do you have any other inflammatory diseases? (Please list below.)

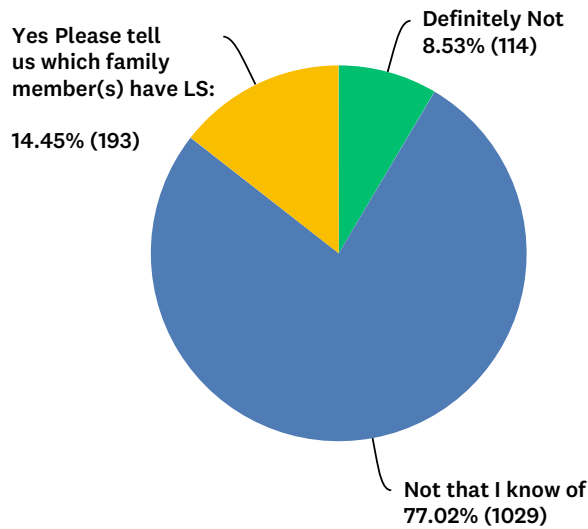
Answered: 871 Skipped: 621, assumed No, 556 no responses
 Yes: 315

Raw	Has Other Inflammatory Diseases:	Incidence
123	arthritis	39%
42	IBS	13%
20	eczema	6%
17	psoriasis or PSA	5%
15	fibromyalgia	5%
12	allergies/gluten intolerance	4%
12	asthma	4%
9	oral lichen planus	3%
9	rosacea	3%
8	leaky gut	3%
7	thyroid	2%
6	colitis	2%
6	Crohn's	2%
6	endometriosis	2%
5	diverticulitis	2%
5	sinus inflammation	2%
5	urticaria	2%
4	celiac	1%
4	diabetes	1%
3	cystitis	1%
3	GERD	1%
3	morphea	1%
3	Sjogren's	1%
3	vulvodynia	1%
2	adrenal issues	1%
2	breast cancer	1%
2	burning mouth syndrome	1%
2	cfs	1%
2	folliculitis	1%
2	lupus	1%
2	Reynaud's	1%



Q35 Does anyone else in your family have LS?

Answered: 1,336 Skipped: 156



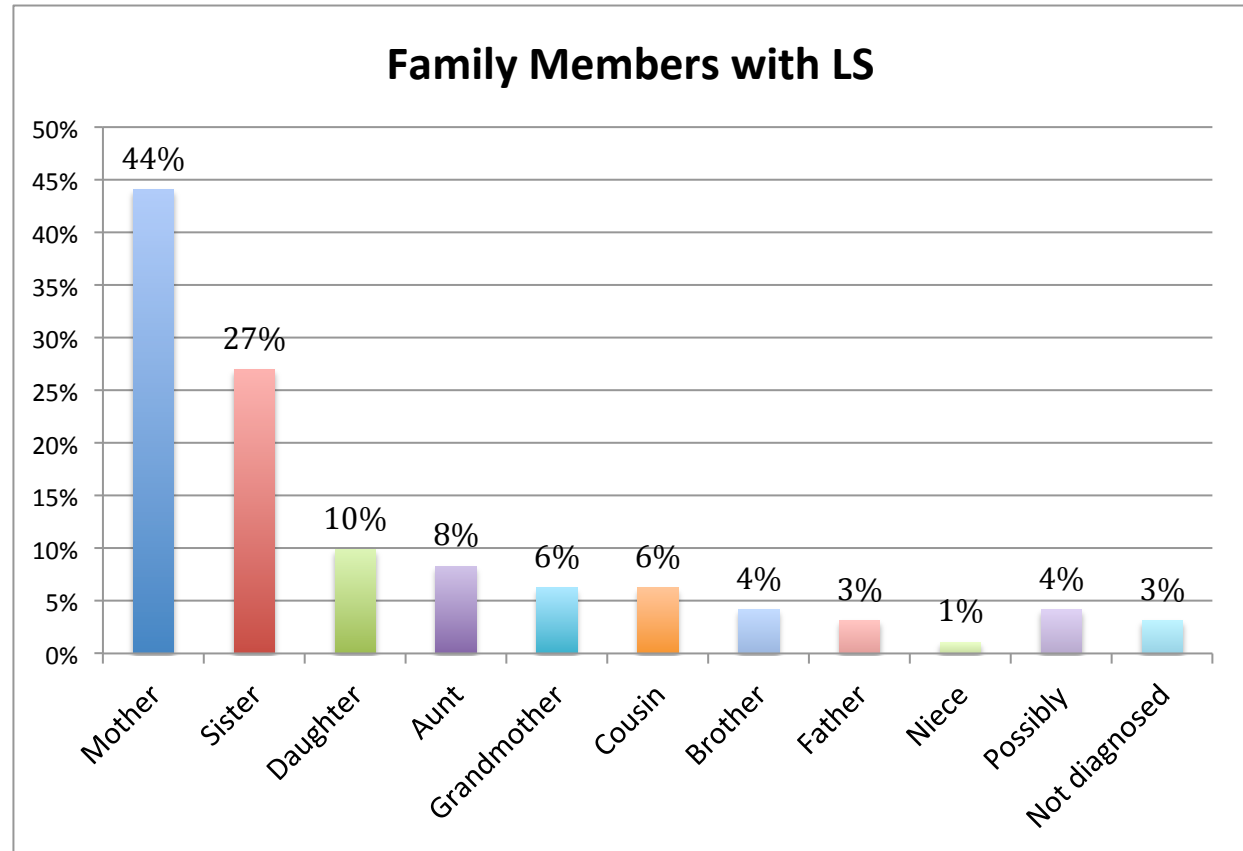
ANSWER CHOICES	RESPONSES	
Definitely Not	8.53%	114
Not that I know of	77.02%	1,029
Yes Please tell us which family member(s) have LS:	14.45%	193
TOTAL		1,336

Q35 Does anyone else in your family have LS? If yes, who?

14.45% Said Yes (N=193)

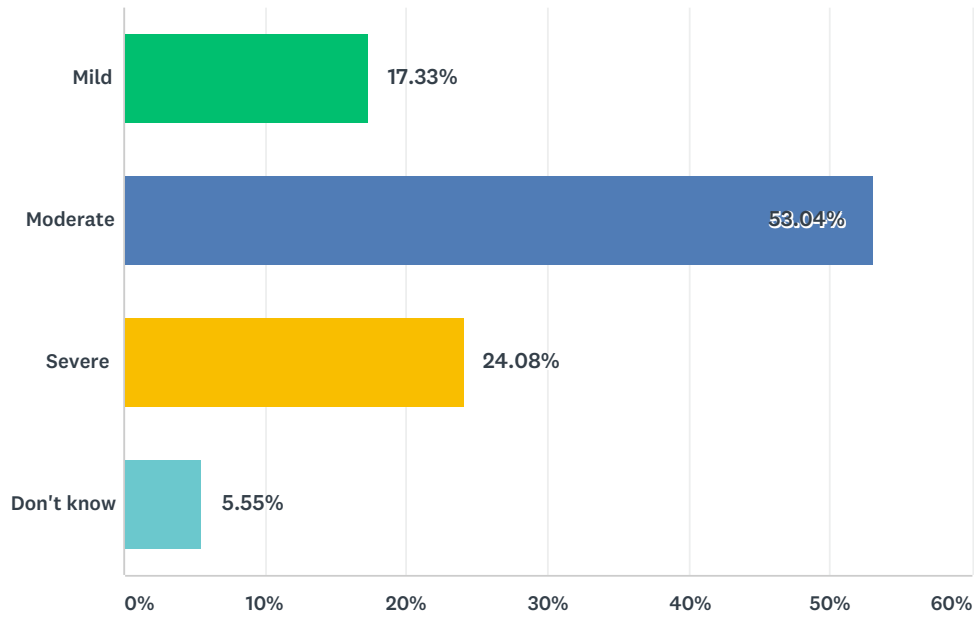
Family member

<u>with LS:</u>	<u>Incidence</u>	<u>Raw</u>
Mother	44%	85
Sister	27%	52
Daughter	10%	19
Aunt	8%	16
Grandmother	6%	12
Cousin	6%	12
Brother	4%	8
Father	3%	6
Niece	1%	2
Possibly	4%	8
Not diagnosed	3%	6



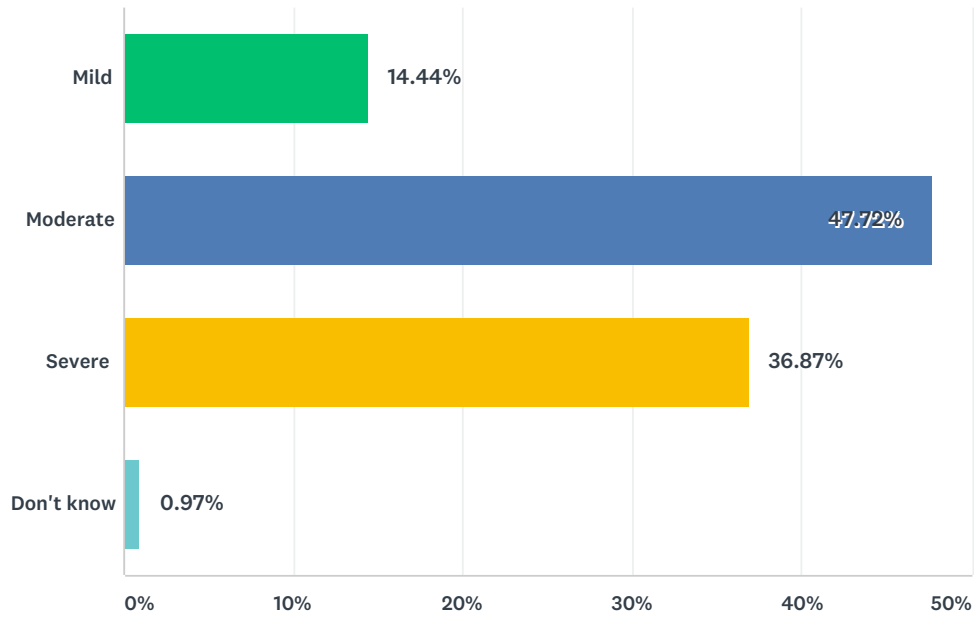
Q36 How would you categorize the severity of your LS condition, based on physical symptoms and progression?

Answered: 1,333 Skipped: 159



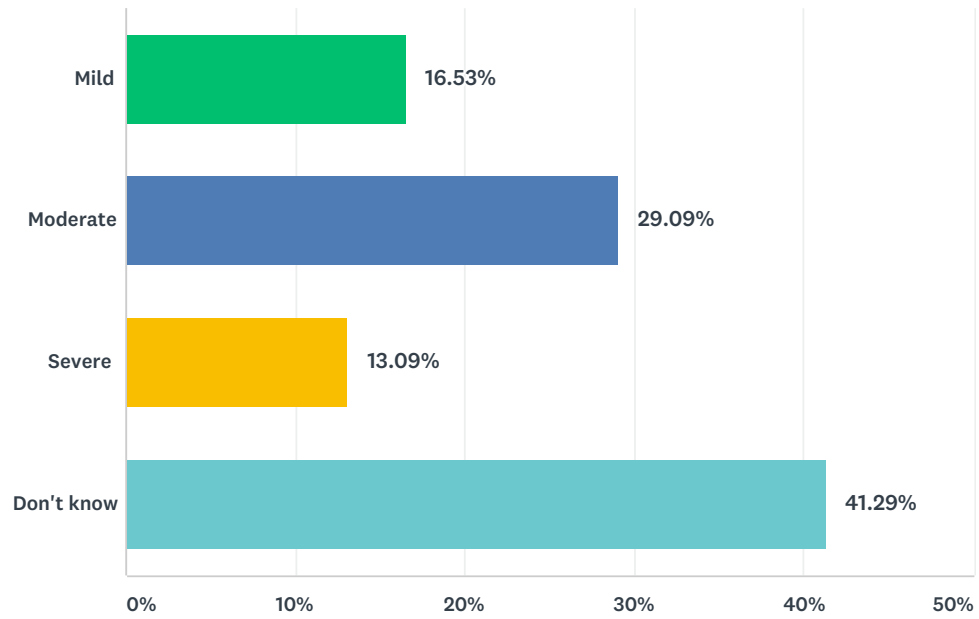
Q37 How would you categorize the severity of your LS condition, based on how it affects your life – the whole you?

Answered: 1,337 Skipped: 155



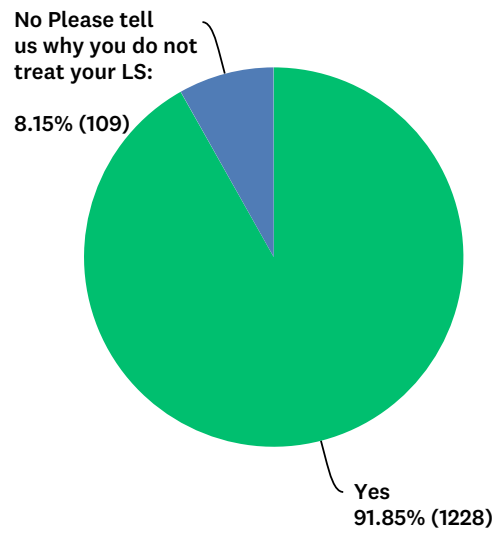
Q38 How does your doctor score your severity of LS?

Answered: 1,337 Skipped: 155



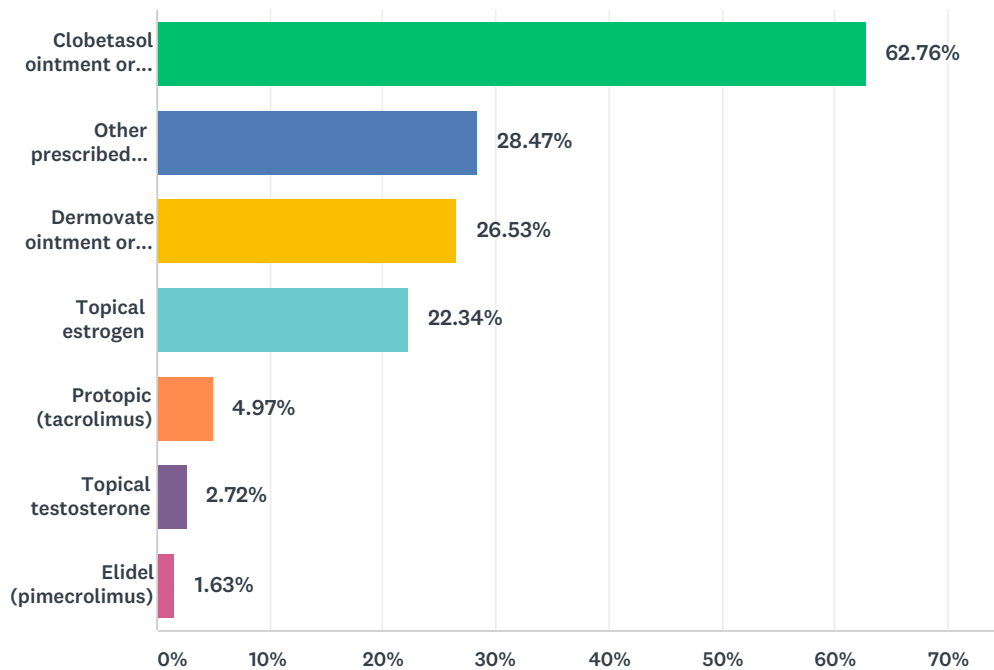
Q39 Do you use any prescriptions and/or therapies treat your LS?

Answered: 1,337 Skipped: 155



Q40 What, if any, topical treatments do you currently use to treat your LS? (Please check all that apply.)

Answered: 1,289 Skipped: 203

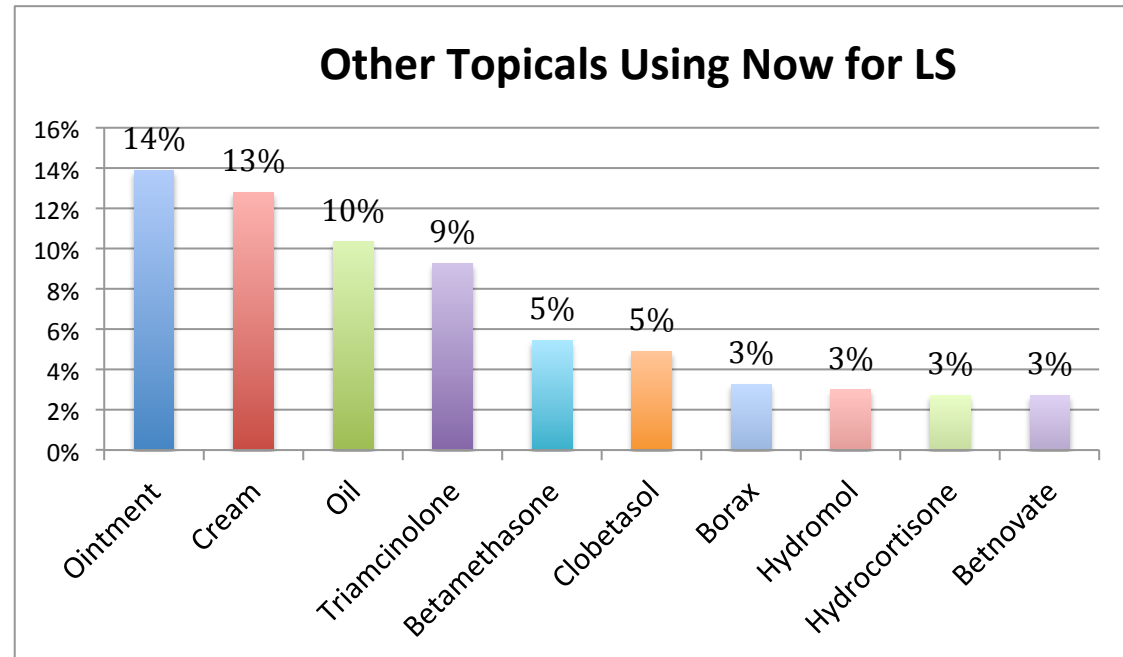


ANSWER CHOICES	RESPONSES	
Clobetasol ointment or cream	62.76%	809
Other prescribed topicals (please list):	28.47%	367
Dermovate ointment or cream	26.53%	342
Topical estrogen	22.34%	288
Protopic (tacrolimus)	4.97%	64
Topical testosterone	2.72%	35
Elidel (pimecrolimus)	1.63%	21
Total Respondents: 1,289		

Q40 What, if any, topical treatments do you currently use to treat your LS? Others:

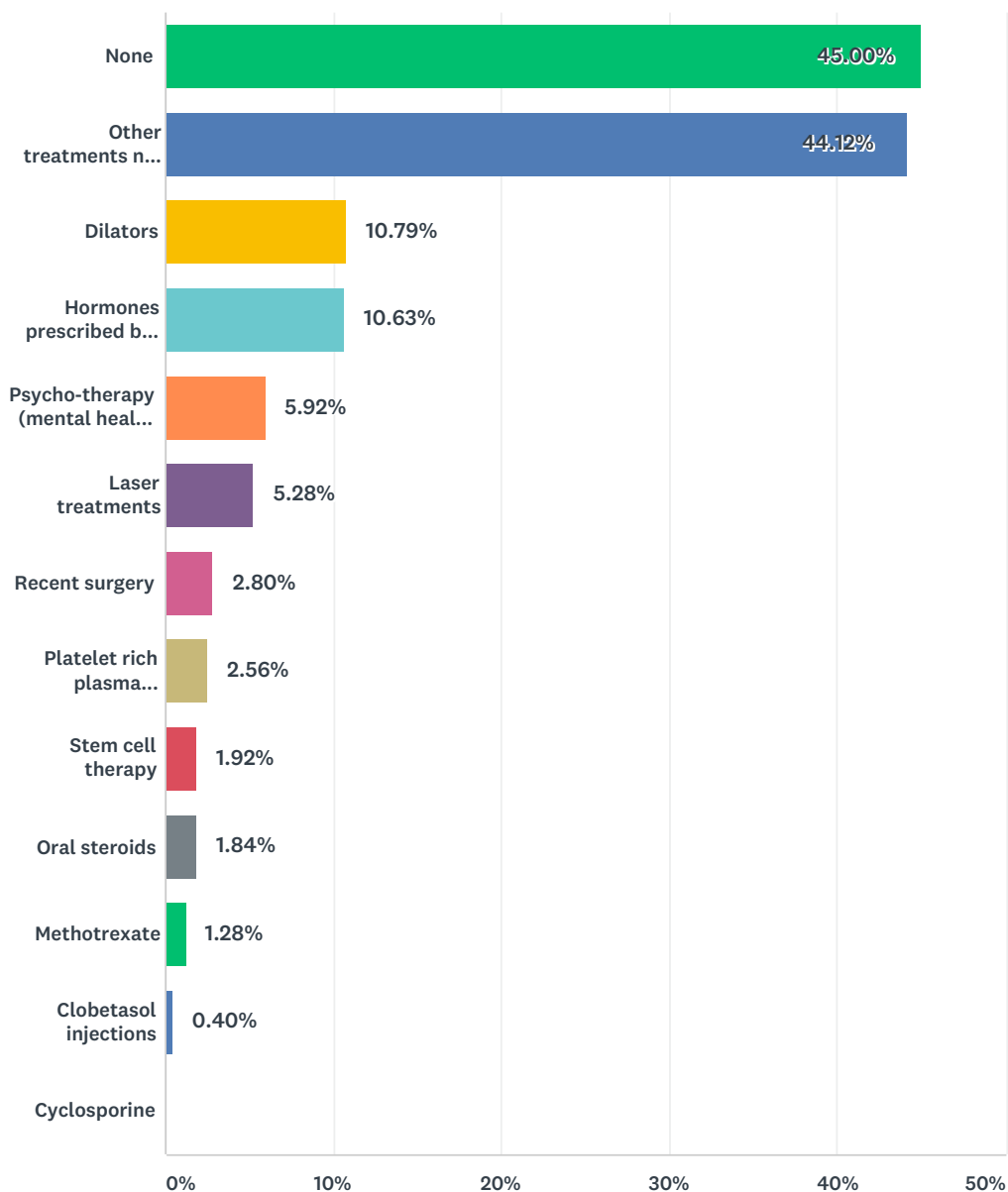
Answered: 1,289 Skipped: 203

Topicals	Incidence	Raw
Ointment	14%	51
Cream	13%	47
Oil	10%	38
Triamcinolone	9%	34
Betamethasone	5%	20
Clobetasol Borax	5%	18
Hydromol	3%	12
Hydrocortisone	3%	11
Betnovate	3%	10



Q41 Do you use any of the following to treat your LS and its affects on your life? (Please check all that apply.)

Answered: 1,251 Skipped: 241



Q42 If you are currently treating your LS, do you follow your doctor's recommended treatment directions exactly?

Answered: 1,306 Skipped: 186

	NEVER	RARELY	SOMETIMES	USUALLY	ALWAYS	TOTAL	WEIGHTED AVERAGE
How often follow doctor directions exactly:	3.14% 41	4.90% 64	14.70% 192	41.81% 546	35.45% 463	1,306	4.02

Q43 How would you rate the efficacy of your current LS treatment?

Answered: 1,313 Skipped: 179

	VERY LOW EFFICACY	LOW EFFICACY	NEITHER HIGH NOR LOW EFFICACY	HIGH EFFICACY	VERY HIGH EFFICACY	TOTAL	WEIGHTED AVERAGE
Efficacy Rating 1-5	7.54% 99	18.13% 238	43.34% 569	27.19% 357	3.81% 50	1,313	3.02

Q44 How confident are you that your current treatment works?

Answered: 1,325 Skipped: 167

	NOT AT ALL CONFIDENT	NOT SO CONFIDENT	SOMEWHAT CONFIDENT	VERY CONFIDENT	EXTREMELY CONFIDENT	TOTAL	WEIGHTED AVERAGE
Confidence in Treatment 1-5	10.57% 140	25.13% 333	45.81% 607	15.70% 208	2.79% 37	1,325	2.75

Q45 What, if any, topical treatments have you tried in the past that you feel did NOT work well (may include those currently used)? (Please check all that apply.)

Answered: 1,000 Skipped: 492

ANSWER CHOICES	RESPONSES	
Clobetasol ointment or cream	34.60%	346
None. I have never tried topical treatments.	25.40%	254
Other prescribed topicals prescribed in the past (please list):	22.90%	229
Dermovate ointment or cream	17.50%	175
Topical estrogen	13.90%	139
Protopic (tacrolimus)	7.60%	76
Elidel (pimecrolimus)	4.20%	42
Topical testosterone	4.00%	40
Total Respondents: 1,000		

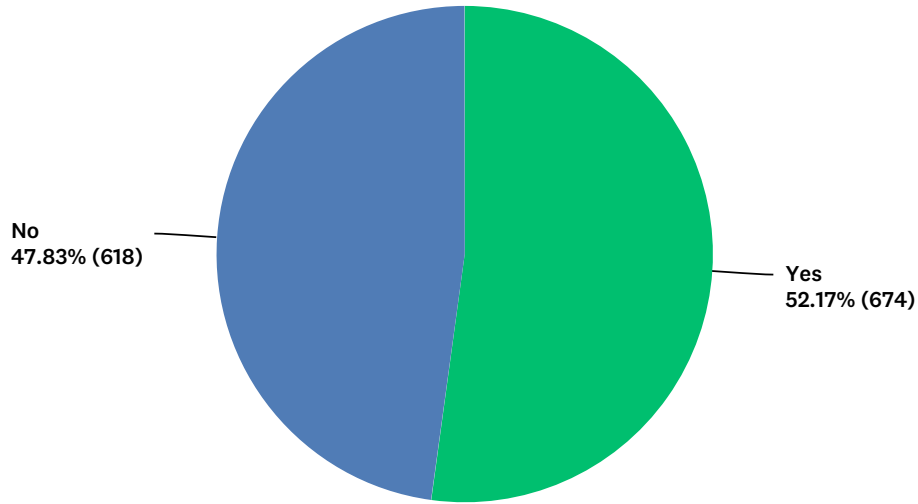
Q46 Which if any of the following have you tried in the past that you feel did NOT work well to treat your LS and it affects on your life (may include those currently used)? (Please check all that apply.)

Answered: 1,007 Skipped: 485

ANSWER CHOICES	RESPONSES	
None. I have never tried any non-topical treatments for LS.	71.50%	720
Other treatments tried in the past, not prescribed by a doctor such as diet, special moisturizers, sitz bath additives (please list all here):	17.68%	178
Hormones prescribed by your doctor	4.87%	49
Dilators	3.87%	39
Oral steroids	2.78%	28
Laser treatments	2.09%	21
Psycho-therapy (mental health) support	1.99%	20
Methotrexate	1.69%	17
Platelet rich plasma injections	1.09%	11
Recent surgery	1.09%	11
Stem cell therapy	0.79%	8
Clobetasol injections	0.40%	4
Cyclosporine	0.40%	4
Total Respondents: 1,007		

Q47 When you were prescribed your treatment(s), did you feel you were given good and thorough instructions on how to use your medication?

Answered: 1,292 Skipped: 200



Q48 How well do you feel you are managing your LS condition?

Answered: 1,175 Skipped: 317

	NOT WELL AT ALL	NOT VERY WELL	OKAY	WELL	VERY WELL	TOTAL	WEIGHTED AVERAGE
How well managing 1-5	5.87% 69	21.87% 257	51.40% 604	15.23% 179	5.62% 66	1,175	2.93

Q49 Have you ever achieved remission, and if so for how long?

Answered: 738 Skipped: 754

ANSWER CHOICES	AVERAGE NUMBER	TOTAL NUMBER	RESPONSES
# of months?	7	5,306	738
Total Respondents: 738			

Q50 To what extent are you satisfied with the information about your condition that you received from your doctor?

Answered: 1,136 Skipped: 356

	VERY DISSATISFIED	DISSATISFIED	NEITHER SATISFIED NOR DISSATISFIED	SATISFIED	VERY SATISFIED	TOTAL	WEIGHTED AVERAGE
Extend satisfied 1-5	15.05% 171	31.25% 355	28.35% 322	21.04% 239	4.31% 49	1,136	2.68

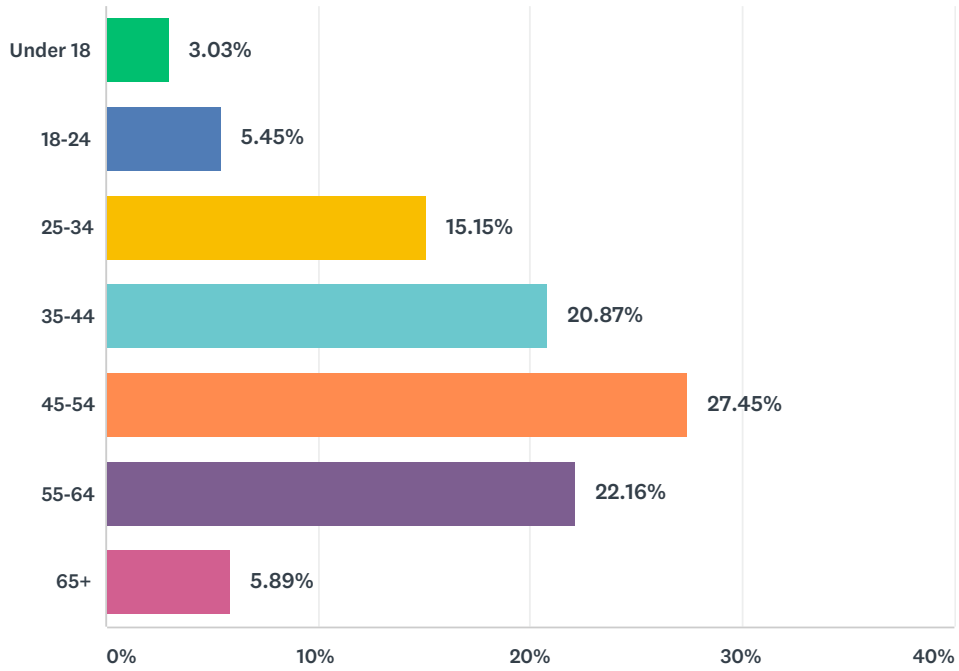
Q51 How long did it take you to get diagnosed with LS?

Answered: 1,100 Skipped: 392

ANSWER CHOICES	AVERAGE NUMBER	TOTAL NUMBER	RESPONSES
# of months?	56	61,057	1,100
Total Respondents: 1,100			

Q52 At what age were you diagnosed with LS?

Answered: 1,155 Skipped: 337



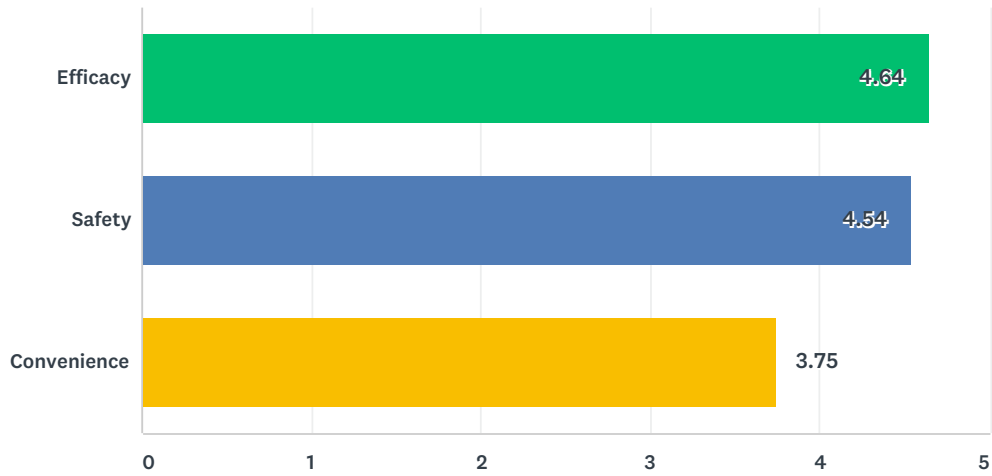
Q53 If you could wave a magic wand and create a great treatment for LS, what are the top three things a new LS treatment would address?

Answered: 1,076 Skipped: 416

ANSWER CHOICES	RESPONSES	
#1:	100.00%	1,076
#2:	95.26%	1,025
#3:	86.52%	931

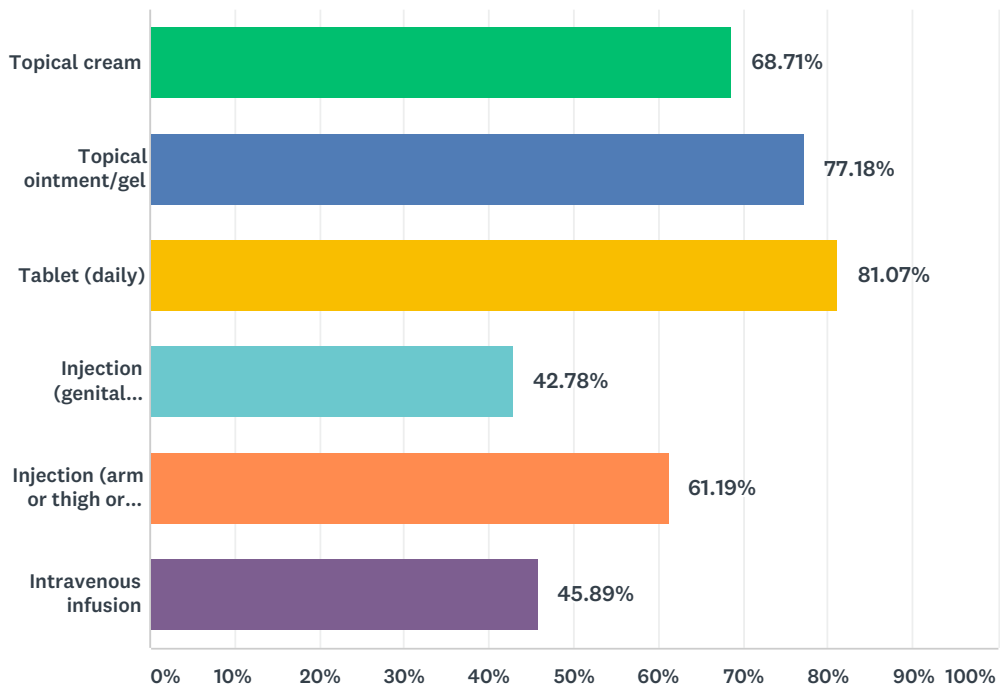
Q54 When thinking about a new medication to treat LS, please rate these three factors:

Answered: 1,167 Skipped: 325



Q55 Using your magic wand again, what delivery form would you be willing to use for a future LS treatment? (Please check all that apply.)

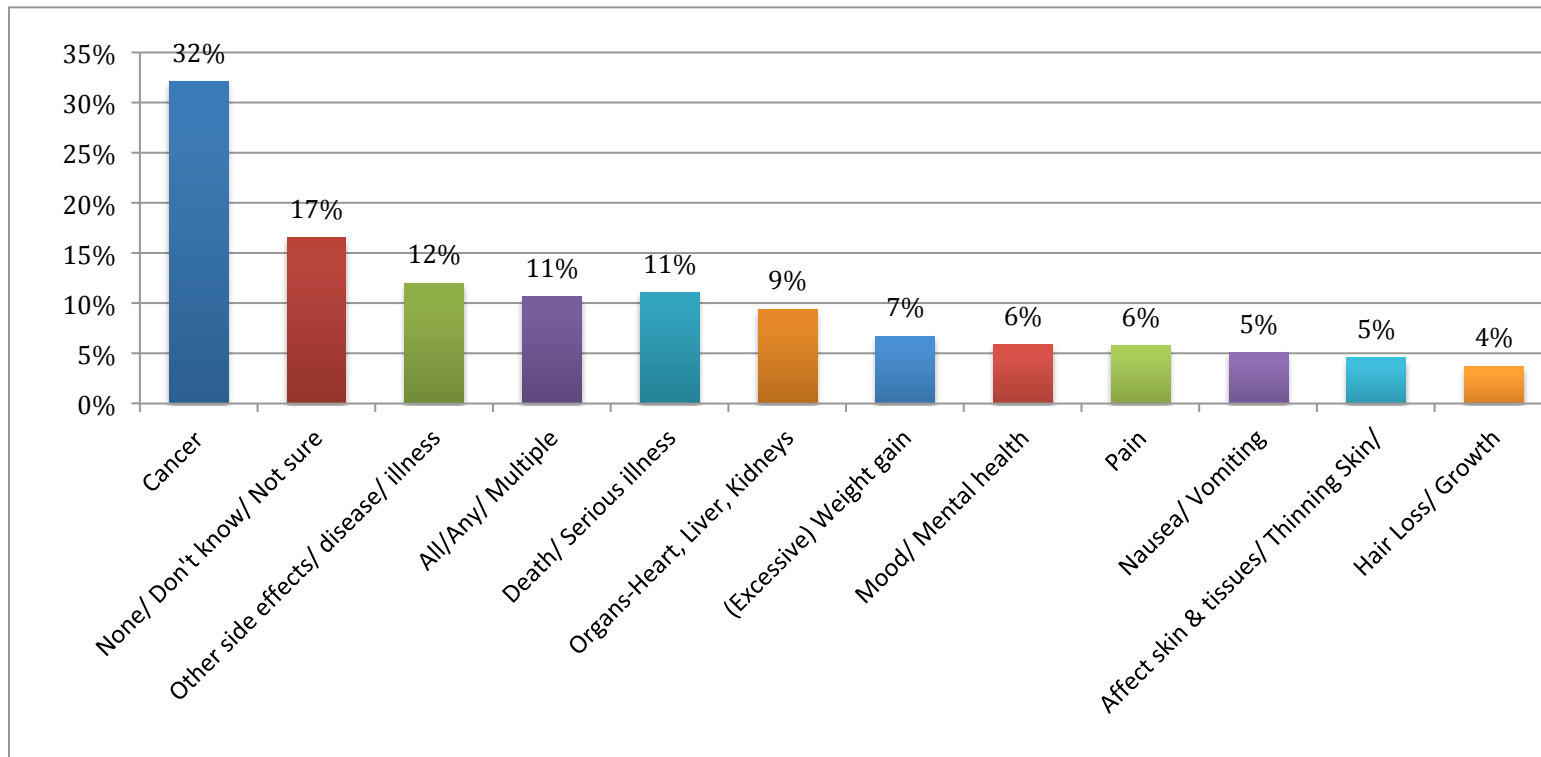
Answered: 1,157 Skipped: 335



Q56 What risks and/or side-effects would stop you from taking a medication that could have your LS stopped in its tracks?

Answered: 979 Skipped: 513

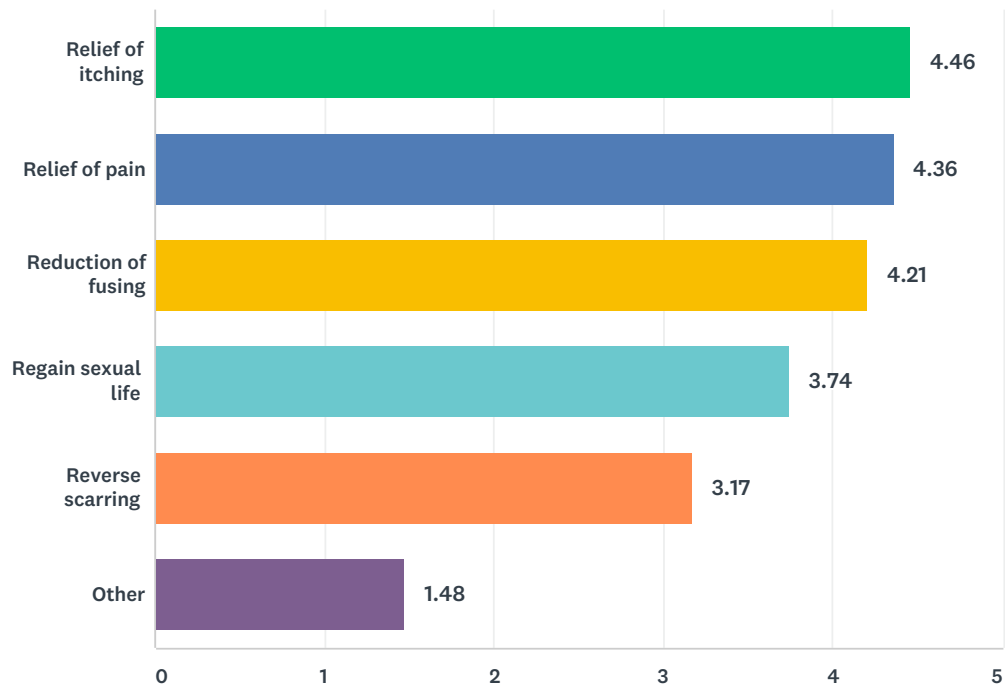
Top Responses over 3%:	Cancer	None/ Don't know/ Not sure	Other side effects/ disease/ illness	All/Any/ Multiple	Death/ Serious illness	Organs- Heart, Liver, Kidneys	(Excessive) Weight gain	Mood/ Mental health	Pain	Nausea/ Vomiting	Affect skin & tissues/ Thinning Skin/ Damage to skin	Hair Loss/ Growth
	32%	17%	12%	11%	11%	9%	7%	6%	6%	5%	5%	4%



3% or less: Maternal/ fetal/fertility; Migraine/headaches; Affect sex life; Burning/ Blistering; Quality of Life; Gastro/ Stomach; Itch, Neuro/ Nerve damage; Risks/ Safety; Bleeding or clotting; Cost

Q57 What would be the most important efficacy parameters in a future treatment? (Rank in order of importance, with 1=top importance.)

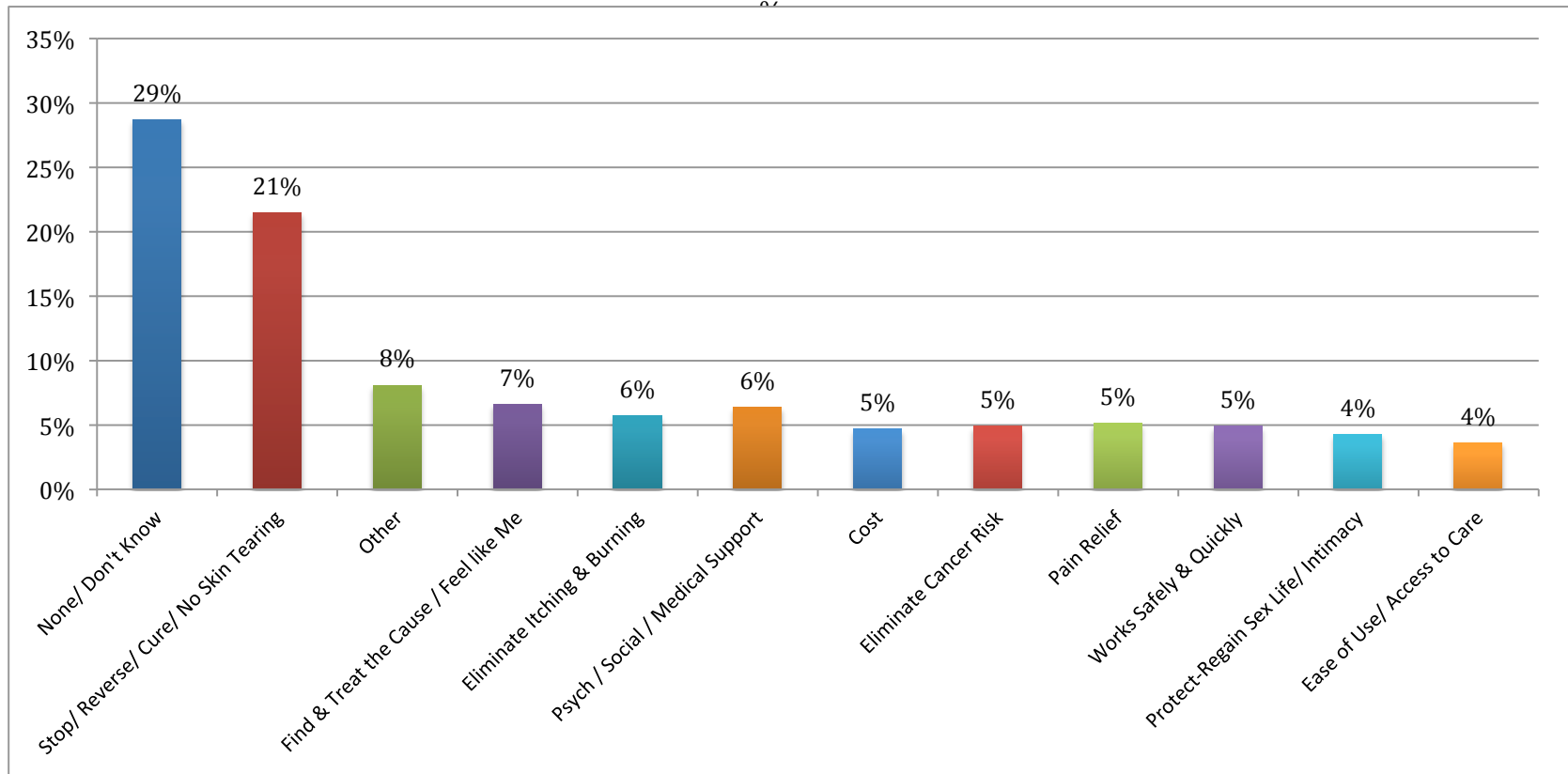
Answered: 1,170 Skipped: 322



Q58 Please share any other most important efficacy parameters in a future treatment; please list all:

N: 461

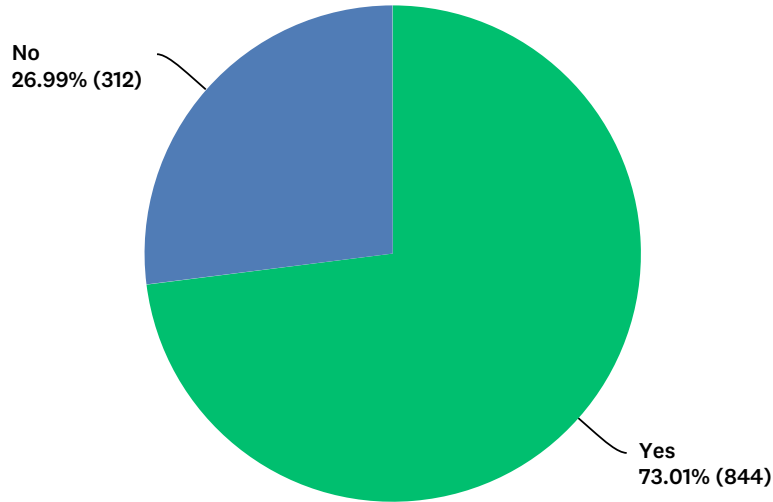
Top Responses :	None/ Don't Know	Stop/ Reverse/ Cure/ No Skin Tearing	Other	Find & Treat the Cause / Feel like Me	Eliminate Itching & Burning	Psych / Social / Medical Support	Cost	Eliminate Cancer Risk	Pain Relief	Works Safely & Quickly	Protect-Regain Sex Life/ Intimacy	Ease of Use/ Access to Care
Incidence:	29%	21%	8%	7%	6%	6%	5%	5%	5%	5%	4%	4%



Two per cent said they would not use anything. Another 1% or less mentioned ease of application (i.e., not fingers, help from mirror on stick); being able to wear any clothing and resume activities; no worsening side effects.

Q59 Would you be willing to have your doctor send small biopsy tissue samples for use in early research?

Answered: 1,156 Skipped: 336



Q60 Finally, is there anything you think we should know about the impact or care of your LS? We recognize that here are so many questions left unasked in this survey.

Answered: 671 Skipped: 821

Replies are being compiled. More to follow.

Q61 Do you have anything to share from your personal experience that will help with our understanding of the true impact of LS? (If we can quote your exact words in advocating for this disease – please include your first name and last initial only, or simply your two initials, and we will take that as permission to use your exact words from this question only.)

Answered: 630 Skipped: 862

Replies are being compiled. More to follow.

Q62 If you are interested in being on our organization's confidential mailing list to stay up-to-date on our research advocacy efforts for LS patients, please share your email address with us:

Answered: 795 Skipped: 697

This mailing list data is confidential. To join our mailing list, contact Shona.Fleming@globalskin.org with the subject: **Join LS Mailing List.**