

## 2019 Global Survey of People with LupusTop Line Results

What is your connection to lupus?			
I have lupus.*	4,710	92.8%	
I might have lupus, but I have not sought medical treatment.	16	0.3%	
I might have lupus, but I have not yet received a diagnosis.	107	2.1%	
I have a family member with lupus.	196	3.9%	
I am a health professional.	24	0.5%	
I have no connection to lupus.	20	0.4%	
Submitted surveys	5,073	100.0%	0.0%      25.0%      50.0%      75.0%      100.0%
<p><i>* Of the 4,710 surveys submitted by people with lupus, 151 of those respondents only answered the first question, leaving a net of 4,559 valid surveys. Not every respondent answered every question.</i></p>			
How long has it been since you first started having symptoms of lupus?			
Less than a year	194	4.3%	
1 - 3 years	447	9.9%	
3 - 5 years	796	17.6%	
6 or more years	3,084	68.2%	
Total Answering	4,521	100.0%	0.0%      17.5%      35.0%      52.5%      70.0%      87.5%
Total Not Answering	38		
Total*	4,559		

<b>How long has it been since you received a diagnosis of lupus?</b>				
Less than a year	522	11.5%		
1 - 3 years	685	15.2%		
3 - 5 years	840	18.6%		
6 or more years	2,474	54.7%		
Total Answering	4,521	100.0%	0.0% 15.0% 30.0% 45.0% 60.0%	
Total Not Answering	38			
Total	4,559			
<b>Have you ever participated in a lupus clinical trial?</b>				
Yes	1,197	26.3%		
No	2,996	65.9%		
Unsure/Don't remember	353	7.8%		
Total Answering	4,546	100.0%	0.0% 17.5% 35.0% 52.5% 70.0%	
Total Not Answering	13			
Total	4,559			

<b>What is your level of interest in learning about new opportunities to participate in a clinical trial for a potential new lupus treatment?</b>					
Extremely interested	2,281	50.2%			
Moderately interested	1,120	24.7%			
Neutral	854	18.8%			
Not very interested	201	4.4%			
Not at all interested	87	1.9%			
Total Answering	4,543	100.0%	0.0%	15.0%	30.0%
Total Not Answering	16				
Total	4,559				

<b>Has the doctor who treats your lupus ever asked you about your interest in participating in a lupus clinical trial?</b>					
Yes	675	14.8%			
No	3,624	79.7%			
Unsure/Don't remember	247	5.4%			
Total Answering	4,546	100.0%	0.0%	20.0%	40.0%
Total Not Answering	13				
Total	4,559				

How much has lupus affected your emotional or mental well-being?							
A lot	2,799	61.6%					
Some	1,331	29.3%					
Very little	289	6.4%					
Not at all	82	1.8%					
Unsure/Can't decide	45	1.0%					
Total Answering	4,546	100.0%	0.0%	17.5%	35.0%	52.5%	70.0%
Total Not Answering	13						
Total	4,559						

How well does the doctor who treats your lupus understand the emotional impact lupus has on you?								
Good understanding	1,743	38.3%						
Moderate understanding	1,429	31.4%						
Poor understanding	767	16.9%						
Does not understand at all	279	6.1%						
Unsure/Can't decide	331	7.3%						
Total Answering	4,549	100.0%	0.0%	10.0%	20.0%	30.0%	40.0%	50.0%
Total Not Answering	10							
Total	4,559							

<b>If offered, what level of interest would you have in participating in a lupus support group that focuses on helping improve your emotional or mental well-being?</b>			
Extremely interested	2,271	49.9%	
Moderately interested	1,366	30.0%	
Neutral	625	13.7%	
Not very interested	220	4.8%	
Not at all interested	70	1.5%	
Total Answering	4,552	100.0%	0.0% 12.5% 25.0% 37.5% 50.0% 62.5%
Total Not Answering	7		
Total	4,559		
<b>What is your age?</b>			
Under 18	40	0.9%	
18 – 24	290	6.5%	
25 – 34	989	22.2%	
35 – 44	1,328	29.8%	
45 – 64	1,664	37.3%	
65+	145	3.3%	
Total Answering	4,456	100.0%	0.0% 10.0% 20.0% 30.0% 40.0%
Total Not Answering	103		
Total	4,559		

<b>What is your gender?</b>								
Female	4,285	96.2%						
Male	171	3.8%						
Total Answering	4,456	100.0%	0.0%	25.0%	50.0%	75.0%	100.0%	125.0%
Total Not Answering	103							
Total	4,559							
<b>Total Countries Represented</b>								
Countries represented by 100 or more valid surveys	10							
United States	682	15.0%						
United Kingdom	464	10.2%						
Portugal	352	7.7%						
Italy	280	6.1%						
France	271	5.9%						
Spain	254	5.6%						
Argentina	244	5.4%						
The Netherlands	159	3.5%						
Canada	145	3.2%						
Australia	132	2.9%						
Total valid surveys	4,559	100.0%	0.0%	4.0%	8.0%	12.0%	16.0%	

<b>Subgroup 1. Have never participated in a clinical trial.</b>					
What is your level of interest in learning about new opportunities to participate in a clinical trial for a potential new lupus treatment?					
Extremely interested	1,345	45.0%			
Moderately interested	789	26.4%			
Neutral	643	21.5%			
Not very interested	141	4.7%			
Not at all interested	71	2.4%			
Total Answering	2,989	100.0%	0.0%	12.5%	25.0%
Total Not Answering	7				
Total	2,996				
Has the doctor who treats your lupus ever asked you about your interest in participating in a lupus clinical trial?					
Yes	214	7.2%			
No	2,680	89.6%			
Unsure/Don't remember	97	3.2%			
Total Answering	2,991	100.0%	0.0%	22.5%	45.0%
Total Not Answering	5				
Total	2,996				

<b>Subgroup 2. Have participated in a clinical trial.</b>					
What is your level of interest in learning about new opportunities to participate in a clinical trial for a potential new lupus treatment?					
Extremely interested	753	62.9%			
Moderately interested	245	20.5%			
Neutral	145	12.1%			
Not very interested	45	3.8%			
Not at all interested	10	0.8%			
Total Answering	1,198	100.0%	0.0%	17.5%	35.0%
Total Not Answering	0				
<b>Total</b>	<b>1,198</b>				
<b>Subgroup 3. Lupus has affected emotional or mental well-being a lot.</b>					
How well does the doctor who treats your lupus understand the emotional impact lupus has on you?					
Good understanding	1,006	36.0%			
Moderate understanding	867	31.0%			
Poor understanding	539	19.3%			
Does not understand at all	215	7.7%			
Unsure/Can't decide	168	6.0%			
Total Answering	2,795	100.0%	0.0%	10.0%	20.0%
Total Not Answering	4				
<b>Total</b>	<b>2,799</b>				



If offered, what level of interest would you have in participating in a lupus support group that focuses on helping improve your emotional or mental well-being?								
Extremely interested	1,678	60%						
Moderately interested	758	27%						
Neutral	269	10%						
Not very interested	65	2%						
Not at all interested	27	1%						
Total Answering	2,797	100%	0%	15%	30%	45%	60%	75%
Total Not Answering	2							
Total	2,799							

The 12-question online survey was developed by the World Lupus Federation as part of the 2019 observance of World Lupus Day. The survey ran April 15-29, 2019 and was available in nine languages: Bengali, Chinese, Dutch, English, French, German, Italian, Portuguese and Spanish. Links to the survey were posted on the World Lupus Federation’s website and social media channels and shared with Federation members who were encouraged to share the

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