

Results of Global Survey of People with Lupus

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Below are results from the global survey of people with lupus conducted by the World Lupus Federation for the 2019 observance of World Lupus Day. **Please to not share this information until May 9.** I will send to you within a few days a media release and additional messages about the survey that you can share on social media and on your website.

Data from the survey can be downloaded using the link provided below.

<https://ws.onehub.com/folders/2bu94jhq>

RELEASE OF SURVEY DATA EMBARGOED UNTIL MAY 9, 2019

2019 Global Survey of People with Lupus

Top Line Results

Purpose:

The World Lupus Federation, a coalition of approximately 200 nonprofit lupus organizations around the world, conducted an online survey to measure community interest in participating in clinical trials of potential new treatments for lupus, and to gain insight into the emotional and mental impact of the disease on people living with lupus and their interest to participating in a lupus support group that addresses with this health issue.

Conduct:

The 12-question survey was conducted using Survey Monkey, an online tool, and was made available in nine languages: Bengali, Chinese, Dutch, English, French, German, Italian, Portuguese and Spanish. The survey was posted on the World Lupus Federation's website from April 15 to April 29, 2019 and its availability was promoted and linked through social media channels managed by the Federation and its global affiliates.

Participation:

The survey received 5,073 submissions representing participants from 96 countries. 4,710 surveys were submitted by people who self-identified that they had lupus. Of these surveys, 4,559 surveys were completed sufficiently to be included in the data analysis. The findings below are based on these completed surveys.

Key Findings:

Clinical Trial Participation

- 2 in 3 (65.9%) of participants with lupus have never participated in a clinical trial of a potential new treatment for lupus.
- 3 in 4 survey participants indicated they are moderately interested (24.7%) to extremely interested (50.2%) in learning about opportunities to participate in a lupus clinical trial.
- 8 in 10 respondents (79.7%) with lupus have not been asked by their lupus doctor about their interest in participating in a trial.

Effect on Emotional or Mental Well-Being

- 6 in 10 (61.6%) of survey participants with lupus indicated the disease has had 'a lot' of effect on their emotional and mental well-being, while 3 in 10 (31.4%) indicated the disease has had 'some' effect.
- Nearly 7 in 10 people responding indicated that their lupus doctor has a moderate understanding (31.4%) to a good understanding (38.3%) of the emotional effects that lupus has on them.
- 8 in 10 respondents indicated they were moderately interested (30.0%) to extremely interested (49.9%) in participating in a support group that focuses on helping improve the emotional and mental well-being of people living with lupus.

Observations and Commentary:

While there are approximately 40 potential new therapies for lupus in various stages of clinical development and testing, a majority of people with lupus have never participated in a lupus clinical trial or have been asked by their lupus doctor about their interest in participating in such a trial. Of those respondents who have never participated in a lupus clinical trial, nearly half (45.0%) indicated they were extremely interested in learning about new trial opportunities. Of those who already had participated in a lupus clinical trial 62.9% indicated they remain extremely interested in learning new opportunities for participation.

These results suggest there is widespread interest among the lupus patient community to learn about new clinical trials and that programs to educate doctors and their patients with lupus about such opportunities might be well received and productive.

In addition to interest in participating in clinical trials of potential new treatments to control the physical manifestations of lupus, data from this survey also demonstrates keen interest in resources to address the emotional and mental effects of lupus. The survey reveals that 9 in 10 people with lupus feel that lupus has had 'some' effect (29.3%) or 'a lot' of effect (61.6%) on their emotional and well-being.

Despite their perception that their lupus doctor has a 'moderate understanding' to a 'good understanding' (31.0% and 36.0% respectively) of the impact lupus has on their lives, there appears to be widespread interest among survey participants to engage in a lupus support group that deals with this impact of lupus. Among those who feel that

lupus has had ‘a lot’ of impact, 60% indicated they would be extremely interested in participating in a lupus support group that might help with mental issues associated with lupus, with 27% expressed moderate interest.

The data highlights interest in joining a support group that might help people with lupus cope with the emotional and mental stresses of this chronic and unpredictable autoimmune disease.

Survey Data Supports ‘Action Calls’ in New ‘A Vision for Lupus’ Report:

The survey results reinforce patient-centered ‘calls to action’ that are included in a new report, *A Vision for Lupus*, that is being released by GSK on World Lupus Day, May 10. Representatives of the World Lupus Federation served on the Global Multidisciplinary Steering Committee to develop the report, which highlights gaps and inconsistencies in care and areas for action to address the gaps that can often exist for patients and their families living with lupus. Among the action calls are the need to raise awareness of ongoing clinical trials to facilitate access to research participation by people with lupus, and to help people with lupus feel more acknowledged, understood and supported as they travel through their journey with lupus.

Survey Limitations:

Answers to the survey questions represent only the opinions of those individuals who self-identified as having lupus and who chose to participate in the survey. Only those individuals with social media accounts and follow lupus organizations online would be made aware of the survey. The data is not intended to represent the broad spectrum of opinions of the entire global lupus community and only provides a possible insight to their thinking on these issues.

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