

## 2019 Global Survey of People with Lupus

### Top Line Results

#### **Purpose:**

The World Lupus Federation is a coalition of approximately 200 nonprofit lupus organizations around the world. It recently conducted an online survey to measure community interest in joining a clinical trial of a potential new treatment for lupus and to gain insight into the emotional and mental effects of the disease on people living with lupus and their interest in joining a support group dealing with this topic.

#### **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 indicated they had lupus. Of these surveys, 4,559 surveys were completed sufficiently to be included in the data tabulation. 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 lupus clinical trial.

##### Effect on Emotional or Mental Well-Being

- 6 in 10 (61.6%) of survey participants with lupus indicated the disease had had 'a lot' of effect on their emotional and mental well-being, while 3 in 10 (29.3%) reported the disease had had 'some' impact.
- Nearly 7 in 10 people responding believe their lupus doctor has a moderate understanding (31.4%) to a good understanding (38.3%) of the emotional impact lupus has on the mental well-being.
- 8 in 10 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, most people with lupus have never participated in a lupus clinical trial or have been asked about their interest in participating in such a trial. Of those respondents who have never participated in a clinical trial, nearly half (45.0%) indicated they were extremely interested in learning about new trial opportunities. Of those who had already participated in a lupus clinical trial, 62.9% reported they remain extremely interested in learning about additional opportunities for participation.

These results suggest there is widespread interest among the 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 a 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 impact (29.3%) or a lot of impact (61.6%) on their emotional and well-being.

Of the people who feel that lupus has had 'a lot' of effect on their emotional and mental and mental well-being, 31.0% feel their lupus doctor has a 'moderate' understanding of this impact while 36.0% feel their doctor has a 'good' understanding. Among those who feel that lupus has had 'a lot' of effect, 60% indicated they would be 'extremely interested' in participating in a lupus support group that might help with mental issues associated with lupus, while 27% expressed moderate interest.

The data confirms the interest in participating in 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 these gaps that can often exist for people with lupus and their families. 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 the disease.

## **Survey Limitations:**

Answers to the survey questions represent opinions of only 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.