



International Survey Shows Low Global Understanding about Lupus
16-Nation Survey to be Released May 10 by World Lupus Federation

Washington DC, May 10 – A large-scale international survey reveals that low awareness of lupus results in public misconceptions about the disease. The lack of understanding contributes to the stigmatization of people with lupus, often leaving them feeling isolated from family and friends. The full 16-nation survey results are being released on the occasion of World Lupus Day, May 10, by the World Lupus Federation (WLF) at worldlupusday.org.

Key survey findings include:

- While lupus is a global health problem, more than half (51%) of survey respondents were not aware that lupus is a disease
- Of those surveyed that knew lupus is a disease, almost half (48%) over the age of 55 did not know of any complications associated with lupus

Despite the overall lack of awareness, the survey revealed that more than 40% of respondents aged 18-34 were aware that kidney failure is a frequent complication of lupus. The familiarity among this group likely results from celebrities like American singer and actress Selena Gomez speaking out about lupus on social media. Gomez announced last September that she had a kidney transplant after lupus severely damaged her kidneys.

“This global survey and the Federation's outreach efforts are critical to ensuring everybody understands lupus and engaging people around the world in fighting this terrible disease,” said Julian Lennon, photographer, author, musician, philanthropist and global ambassador for the Lupus Foundation of America, the WLF’s Secretariat.

The survey, one of the largest of its kind ever conducted in lupus, was commissioned by GSK which shared the results as part of its commitment to supporting the WLF and helping to improve the lives of people with lupus.

The survey also revealed social stigmas toward people living with lupus because of a misconception that lupus is contagious. Of those people surveyed who were aware that lupus is a disease:

- Only 57 percent were very comfortable or comfortable hugging someone with lupus
- Less than half (49%) were very comfortable or comfortable sharing food with someone with lupus
- 1 in 10 (11%) respondents believed that unprotected sex might contribute to the development of lupus

“There is a clear need to increase understanding of lupus to prevent misconceptions, tackle the stigma and help to encourage social integration for those living with the disease,” said Jeanette Anderson, Chair of Lupus Europe, one of the founding members of the World Lupus Federation.

Despite low public knowledge about lupus, the survey found broad support among survey participants for efforts to raise awareness.

- Among of survey participants, 76% of respondents thought that more should be done to highlight and explain the impact lupus has on people living with lupus.
- 65% of respondents felt the best way to increase understanding of lupus is by sharing more information online, on social media and via traditional media.

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In response, WLF member organizations are ramping up efforts to improve understanding of lupus and its impact. “We are elevating support for people living with lupus through education, services, and advocacy programs,” said Teresa Gladys Cattoni, President of the Asociacion Lupus Argentina, (ALUA) and member of the nine-nation WLF steering committee.

Individuals can show their support by pledging to learn more about lupus. To add your name to the pledge list, obtain additional survey data, and download resources to raise awareness of lupus, visit the World Lupus Day website, www.worldlupusday.org.

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About the World Lupus Federation

The World Lupus Federation (WLF) is a coalition of approximately 250 lupus patient organizations from around the world, united to improve the quality of life for all people affected by lupus. Through coordinated efforts among its global affiliates, the Federation works to create greater awareness and understanding of lupus, provide education and services to people living with the disease, and advocate on their behalf.

About the Survey Data

- Yolo Communications conducted an online, nine-question public opinion survey for GSK and involved adults from 16 countries from across the world.
- The 2018 World Lupus Day Survey generated 35,506 respondents over the age of 18
 - Question 1 was answered by 35,506 adults.*
 - Questions 3-7 were answered by 16,814 adults* (1000+ from each country) who were aware that lupus is a disease.
 - Questions 8-9 were answered by approx. 20,191 adults* (1000+ from each country who were aware that lupus is a disease and 200+ from each country who were not aware that lupus is a disease).
 - 16,814 who were aware that lupus is a disease*
 - 3,377 who were not aware lupus is a disease*
 - The market research company capped the number of respondents progressing to questions 8&9 at approx. 200 per market for those who were not aware lupus is a disease.

**non-lupus patients*

The full data report is available upon request. Please contact Duane Peters at peters@lupus.org.

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