



### **New Global Survey Reveals Most People Have Serious Misconceptions about Lupus**

*World Lupus Federation launches to elevate lupus as a serious health concern that deserves increased support*

On Tuesday, May 10, the newly-launched World Lupus Federation - a coalition of global lupus patient groups - announces results of one of the largest global surveys ever conducted looking at awareness and attitudes about lupus among the general public in 16 countries.

Key findings include:

- More than a third of respondents (36%) admitted they did not know lupus is a disease
- More than half of respondents (51%) could not identify or did not know that lupus can result in serious health complications, such as kidney failure, anemia or a heart attack.
- More than a third of respondents (36%) indicated they did not know any factors that may contribute to someone developing the disease.

The survey revealed several social stigmas toward people living with lupus because of a misconception that lupus is contagious. For example:

- 47% feel less than 'comfortable' shaking hands with someone with lupus, compared with 36% who feel 'very comfortable.'
- 44% feel less than 'comfortable' sitting next to someone on a bus who has lupus.
- 1 in 3 people (31%) are 'uncomfortable' sharing food with someone who has lupus underscoring that people strongly believe the disease is infectious.
- 23% of respondents are 'uncomfortable' hugging someone with lupus, with 11% of those respondents feeling 'most uncomfortable.'

“When people hear that lupus is an autoimmune disease, they immediately equate it to other diseases of the immune system, like HIV and AIDS,” said Dr. Susan Manzi, Director of the Lupus Center of Excellence at the Allegheny Health Network in Pittsburgh, Pennsylvania, and medical director of the Lupus Foundation of America. “In the absence of knowledge, people mistakenly believe that lupus is a contagious disease.”

Raising awareness of lupus is a key objective of the WLF, which was organized to elevate lupus on the international stage and deliver a global rallying cry to bring greater attention and resources to combat lupus, a disease that affects more than five million people worldwide. As its first global initiative, the WLF is leading nearly 200 lupus patient groups in the annual observance of World Lupus Day on May 10.

“Public awareness of lupus around the world is low and a range of misconceptions persist about the autoimmune disease,” said Sandra C. Raymond, President & CEO of the Lupus Foundation of America, which is serving as the Secretariat for the World Lupus Federation. “Low awareness of lupus contributes to late diagnosis of the chronic and potentially life-threatening disease and places an additional boundary between people living with the incurable disease and their families, friends, and others who do not realize the many ways lupus can affect the body.”

“It is imperative that we unite lupus patient groups around the world to shine a light on the many issues affecting people living with lupus,” said Kirsten Lerstrøm, Chair of Lupus-Europe and a member of the international steering committee helping to form the WLF. “Through the coordinated efforts of its affiliates, the World Lupus Federation will increase awareness and understanding of lupus, provide education and services to people living with the disease, and advocate on their behalf.”

The WLF unites lupus patient groups around the world to improve the quality of life for all people affected by lupus. The WLF is spearheaded by the Lupus Foundation of America and guided by an international steering committee representing five continents to ensure a coordinated effort among global lupus organizations and enhance their capacity to serve people with lupus through programs of education, awareness and advocacy.

“I congratulate all of the participating lupus organizations on the establishment of the World Lupus Federation,” said Julian Lennon, Global Ambassador for the Lupus Foundation of America. “This is a significant step forward in the global fight against this dreadful disease. I look forward to continuing to work to bring greater attention and awareness to the needs of people with lupus around the world.”

Individuals can help raise awareness of lupus and show their support by signing the petition to the World Health Organization urging them to make lupus an international health priority and ensure that people with lupus around the world are diagnosed and treated effectively.

To sign the petition, learn more about the global lupus awareness survey, and download resources to raise awareness and increase understanding of lupus signs and symptoms, visit the World Lupus Day website, [www.worldlupusday.org](http://www.worldlupusday.org).

### **About Lupus**

Lupus is a chronic autoimmune disease that ravages different parts of the body. It is difficult to diagnose, hard to live with and a challenge to treat. Lupus is mostly hidden from view and undefined, has a range of symptoms, strikes without warning, and has no known cause and no known cure. Its health effects can range from a skin rash to a heart attack. Lupus is debilitating and destructive and can be fatal.

### **About the Survey**

The Survey was conducted by GSK and the results were shared as part of GSK’s ongoing efforts to assist the World Lupus Federation to raise global awareness of lupus. The online, six-question survey was carried out under subcontract by Yolo Communications, an international market research and social media insight agency between March 24th and April 8th 2016. The survey involved 16,911 adults 18+ from 16 nations: Argentina, Australia, Brazil, Canada, Denmark, Finland, France, Germany, Indonesia, Italy, Japan, Spain, South Korea, Switzerland, UK and USA (minimum of 1,000 respondents from each nation).

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