



Inactivity, Isolation and Impact on Daily Life are Top Concerns for People Living with Lupus

World Lupus Federation issues global report for World Lupus Day highlighting the life-altering effects of lupus and the challenges people with lupus face every day.

(Washington DC) Almost half (43%) of people living with lupus responding to a recent poll indicated that they worry the most about physical inactivity and social isolation due to the debilitating effects the autoimmune disease has on the body. Nearly half (47%) of the participants also felt that the impact lupus has on daily living is most misunderstood by their physician, while almost one-third (30%) believed that the emotional impact is most misunderstood.

Almost half (47%) of those who responded to the World Lupus Federation (WLF) poll indicated they want better management and treatment options available to them through their physician. Only one treatment developed specifically for lupus has received regulatory approval since the 1950's.

These opinions are included in the "***Lupus Knows No Boundaries e-Report***," developed through a collaboration between the WLF GlaxoSmithKline (GSK) and for World Lupus Day (May 10). The report brings together firsthand experiences of people with lupus, their advocates and those who treat them, to tell the real story of lupus, highlighting the ongoing physical and emotional needs of those who are affected by this incurable disease. The full report is available online at worldlupusday.org.

"I first came to know lupus through my childhood friend, Lucy Vodden, about whom the song *Lucy in the Sky with Diamonds* was written," said Julian Lennon, photographer, author, musician, philanthropist and global ambassador for the Lupus Foundation of

America. “It was Lucy’s struggles that opened my eyes to how devastating the burden of lupus is on millions of individuals and their families.”

Shannon Boxx was a member of the United States women’s national soccer team, winning three Olympic gold medals before her retirement in 2015. But for most of her career, she was secretly carrying the burden of a lupus diagnosis. “I decided to speak publicly about lupus because I was tired of hiding it. I was at a point in my career where I knew I probably wasn’t going to play much longer and I felt I had a real responsibility, being in the public eye, to talk about lupus and bring more awareness,” said Boxx.

Public awareness of lupus remains stubbornly low, contributing to public misunderstanding and misconceptions about the disease. A 2016 global opinion survey* found that over half of the respondents (51%) were unable to identify the physical complications associated with lupus and more than a third (35%) did not even know that lupus was a disease.

The World Lupus Federation, a global coalition of lupus patient groups, is working to raise the public profile of the disease. “We’re calling for everyone to unite and take action on behalf of those affected by lupus,” said Sandra C. Raymond, President & CEO of the Lupus Foundation America which serves as the Federation’s Secretariat. “By shining a light on lupus we can ensure that friends and family, healthcare professionals, employers, government officials, health insurers and pharmaceutical companies are aware and informed of the many and varied challenges that people with lupus face.”

“The e-Report and Twitter Poll findings show that there is more that can be done to raise awareness, understanding and prioritization of this debilitating disease and to give patients the confidence to speak up about the impact of their symptoms,” said Dr. Alex Liakos, Global Medical Affairs, GSK. “At GSK, we are delighted to have been able to collaborate with the World Lupus Federation and look forward to continuing to support the needs of those living with lupus in future campaigns.”

“It’s our responsibility to get involved and do whatever we can to help fight this unpredictable and misunderstood disease,” said Julian Lennon. “It is my goal to keep fighting and bringing attention to lupus so we can raise the money needed to develop better treatments, provide support to people affected and fund the research that someday will bring an end to lupus and its brutal impact on people’s lives.”

Learn more about lupus by downloading the **“Lupus Knows No Boundaries e-Report”** at worldlupusday.org and sign the petition to urge the World Health Organization to make lupus a global health priority.

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*** About the Poll and Survey Data**

The Twitter poll was conducted by 12 patient groups in nine countries, with a total of 2,048 votes cast. Although a social media poll provides valuable insights, it is not statistically significant or demographically representative. The 2016 online, six-question public opinion survey was conducted by Yolo Communications for GSK and involved 16,911 adults from 16 nations.

About the e-Report

The **“Lupus Knows No Boundaries e-Report”** has been co-created by the World Lupus Federation and GSK as part of a range of collaborative activities being coordinated around this year’s World Lupus Day, with the aim of raising awareness of the global impact of lupus, addressing public misconceptions about the disease and empowering the lupus community to take action to help address the needs of those living with lupus.