

PRESS RELEASE



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'A Vision for Lupus' report, published ahead of World Lupus Day, highlights an important need to improve quality of care for lupus patients

To support patients, care givers and healthcare professionals on World Lupus Day, an expert-led report, 'A Vision for Lupus', has today been published to help highlight 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, a chronic, inflammatory, autoimmune disease that affects approximately five million people globally.^{1,2} GSK conceived, developed and led the 'A Vision for Lupus' initiative in collaboration with a Global Multidisciplinary Steering Committee, and the report outlines three specific, patient-centred Calls to Action to the lupus community:

- 1) Raise awareness of lupus amongst the general public, people living with lupus, their families and healthcare providers to support early diagnosis and help people with lupus feel more acknowledged, understood and supported;
- 2) Improve access to specialist and multidisciplinary lupus clinics to address the aspects of this complex, multisystem disease;
- 3) Raise awareness of ongoing clinical trials to facilitate access to research participation enabling people with lupus to make autonomous decisions in the management of their condition.

Professor David D'Cruz, Chair of the 'A Vision for Lupus' Steering Committee and Consultant Rheumatologist at Guy's and St Thomas' Hospital, London, UK said: "There is an important need to address the significant barriers to high-quality care that can still exist for people with lupus. By highlighting Calls to Action, we hope that the 'A Vision for Lupus' report will stimulate discussion to drive positive change in three key areas; disease awareness, service delivery and clinical research. We urge people to visit www.visionforlupus.org to access the report so as to understand opportunities for playing a part in improving the quality of life for people with lupus."

Duane Peters, Senior Communications Strategist at the Lupus Foundation of America Inc. and Staff Coordinator for the World Lupus Federation said: "I am pleased to support the launch of the 'A Vision for Lupus' report on World Lupus Day, an important international platform to generate awareness about the condition. Lupus can be a devastating autoimmune disease disproportionately impacting women in the prime of their lives, compromising everyday plans, social lives and aspirations for a career and family."

World Lupus Day was established in 2004 to raise awareness of the disease and its impact on patients, with the aim of improving the quality of life for people affected by this potentially fatal disease. More needs to be done to bring the condition into the public eye; over half (51%) of respondents to a recent global survey were unaware that lupus is a disease, and amongst those who were aware, 41% could not name any complications associated with the condition.³ Public misconceptions about lupus may contribute to a lack of empathy for people with lupus, whose symptoms are often "invisible" to others, leading to them feeling frustrated, inadequately understood, isolated and alone.⁴

Alain Cornet, General Secretary, Lupus Europe and Steering Committee member said: "The 'A Vision for Lupus' report is an important step towards changing the future for people with lupus, so that they have an improved quality of life, feeling acknowledged, understood and supported. We hope that this report will help as many people as possible get access to specialist and multidisciplinary lupus clinics where they can receive quality care for all aspects of this complex multisystem disease, and where they are encouraged and supported to take part in managing their own disease, whether through therapeutic education or participating in clinical research."

PRESS RELEASE



Ravi Rao, Immunology and Specialty Medical Head, GSK said: “GSK is extremely grateful to all members of the Steering Committee who have contributed to the development of the ‘A Vision for Lupus’ report. The report highlights the need for improvement in diagnosis, better multi-disciplinary management and the importance of clinical research in lupus. As part of GSK’s commitment to help the 5 million people affected with lupus worldwide, we will continue to play our part to address these calls to action. We hope this report will help raise the global voice of the lupus patient community and drive a much-needed change to improve the lives of patients living with lupus.”

Notes to editors

About Systemic Lupus Erythematosus (SLE)

Systemic Lupus Erythematosus (SLE), also known as lupus, is a chronic, inflammatory, autoimmune disease affecting 5 million people worldwide with 70%-90% of these cases appearing in females.^{2,5,6} The body produces antibodies that attack its own healthy cells and tissues in addition to producing antibodies to protect against infection.^{2,7} Lupus can affect many different parts of the body, including the joints, skin, kidneys, heart, lungs, brain and blood vessels.

The most common symptoms include painful and swollen joints, extreme fatigue, skin rashes, anaemia, and kidney problems. Typically, people with lupus have periods of illness, called flares, and periods of relative wellness, called remission.⁸ Severity of the illness can vary; some people with lupus can continue to live a normal life, while others experience frequent, life-threatening flares that require critical care.⁸ As there is no cure for lupus,⁵ the goals of treatment are to achieve and maintain disease remission, prevent flares and prevent damage to the body’s organs and tissues.⁹

About ‘A Vision for Lupus’

In 2018, GSK convened a global multidisciplinary Steering Committee comprising a person with lupus, a patient advocacy expert, representation from international lupus patient organisations and clinicians specialising in the condition to discuss the future ‘A Vision for Lupus’. The two advocacy groups that form part of the Steering Committee are the Lupus Foundation of America and Lupus Europe, both of whom are members of the World Lupus Federation, a global coalition of patient groups which coordinate efforts on World Lupus Day. Both the World Lupus Federation and Lupus Europe have received grants from GSK.

The Chair of the ‘A Vision for Lupus’ Steering Committee is Professor David D’Cruz, Consultant Rheumatologist at Guy’s and St Thomas’ Hospital, London, UK. Other members include Dr. Chiara Tani, Rheumatologist, University of Pisa, Italy; Dr. Patricia Cagnoli, Rheumatologist, University of Michigan, USA; Duane Peters, Senior Communications Strategist at the Lupus Foundation of America Inc. and Staff Coordinator for the World Lupus Federation; Alain Cornet, General Secretary, Lupus Europe; and Neil Betteridge, Patient Engagement Expert. A person living with lupus, who wished to remain anonymous, contributed to early discussions on the report.

About the World Lupus Federation

The World Lupus Federation is a coalition of lupus patient organisations from around the world. They are united with the mission to improve the quality of life for all people living with lupus. The World Lupus Federation coordinates awareness, education and advocacy initiatives with support from its global affiliates.¹⁰

PRESS RELEASE



About World Lupus Day

World Lupus Day is held annually on 10 May. This year will be the 16th annual observance of World Lupus Day, a global call-to-action on behalf of the millions of people around the world who are affected by lupus. The day serves as an opportunity to rally stakeholders around the world for the common purpose of drawing attention to and directing resources to end the suffering caused by this disabling and potentially fatal disease.¹¹

GSK – one of the world’s leading research-based pharmaceutical and healthcare companies – is committed to improving the quality of human life by enabling people to do more, feel better and live longer. For further information please visit www.gsk.com.

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GSK cautions investors that any forward-looking statements or projections made by GSK, including those made in this announcement, are subject to risks and uncertainties that may cause actual results to differ materially from those projected. Such factors include, but are not limited to, those described under Item 3.D 'Principal risks and uncertainties' in the company's Annual Report on Form 20-F for 2017.

References

¹ Lupus Foundation of America. Facts and Statistics. Available at: <https://www.lupus.org/resources/lupus-facts-and-statistics> Last accessed: April 2019

² Lupus Foundation of America. What is lupus? Available at: <https://resources.lupus.org/entry/what-is-lupus>. Last accessed April 2019

³ World Lupus Federation, World Lupus Day International Survey (2018)

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⁸ McElhone K, Abbott J, Gray J, *et al*. Patient perspective of systemic lupus erythematosus in relation to health-related quality of life concepts: a qualitative study. *Lupus*. 2010;19:1640-7

⁹ Cunha, JS. *Et al*. "Systemic lupus erythematosus: A review of the clinical approach to diagnosis and update on current targeted therapies." *Rhode Island Medical Journal* 99.12 (2016)

PRESS RELEASE



¹⁰ World Lupus Federation. United Lupus Groups Around the World. Available at: <https://worldlupusfederation.org/>

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¹¹ World Lupus Federation. World Lupus Day: About Lupus. Available at: <http://www.worldlupusday.org/about-us.html>

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