

A Vision for Lupus

Calls to action to improve lupus care



What is lupus?

Systemic Lupus Erythematosus (SLE), or lupus, is a chronic, inflammatory autoimmune disease¹ which affects approximately five million people globally²

5m



In SLE the body produces antibodies that attack its own healthy cells and tissues in addition to producing antibodies to protect against infection^{2,3}



BRAIN



HEART



KIDNEYS



MUSCULO-SKELETAL

70-90%



It is estimated that **70-90%** of lupus cases are in females

with the highest incidence during a woman's most productive childbearing and professional development years⁴

Signs and symptoms

Symptoms can vary greatly. Some of the most common symptoms of lupus are:¹

Painful and swollen joints (arthritis)



Extreme fatigue

Skin rashes

Anaemia

Kidney problems



Persistent SLE disease activity is associated with a higher risk of organ damage and mortality⁵

In some groups, mortality can be up to 10 times higher compared with the general population⁶

10

times higher compared with the general population

Background to A Vision for Lupus

In 2018, GSK conceived, developed and led this report in collaboration with 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 'Vision for Lupus'.



- ✓ CURRENT GAPS AND INCONSISTENCIES
- ✓ CALLS TO ACTION

The Vision for Lupus Steering Committee and GSK developed a report highlighting:⁷

1. Current gaps and inconsistencies in lupus care
2. Patient-centred Calls to Action to improve quality of care

Despite the progress that has been made in the management of lupus in recent years, **the following challenges still exist:**



Lack of awareness of the condition amongst general public and healthcare professionals which may lead to people with lupus feeling misunderstood, isolated and alone



Limited access to specialist and multidisciplinary care

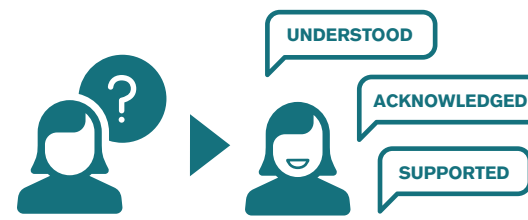


Limited awareness of and barriers to participation in clinical research

Three key Calls to Action to improve lupus care

Awareness

Raise awareness of lupus amongst key audiences, to help achieve early diagnosis and help people with lupus feel more acknowledged, understood and supported



An example of how we can get there:

Build on the success of engagements with celebrities with lupus, cultivating a group of public figures who are willing to talk about the condition



Service Delivery

Improve access to specialist and **multi-disciplinary lupus clinics** to ensure people with lupus are receiving the best quality care possible that addresses many aspects of this complex disease



An example of how we can get there:

Utilise specialist lupus 'triage' nurses to take a leading role in exploring what matters most to the patient, therapeutic education and linking to further services



Clinical research

- Raise awareness of ongoing clinical trials enabling people with lupus to make autonomous decisions in the management of their condition
- Ensure patients in the study design of lupus clinical trials, to ensure they address the aspects of the disease which matter most to patients.



An example of how we can get there:

Provide education about clinical research opportunities for patients at specialist centres



Meet the Steering Committee



Prof. David D'Cruz,
Consultant Rheumatologist,
Guy's and St Thomas' Hospital, UKⁱ



Alain Cornet,
General Secretary, Lupus Europe^{iv}



Dr. Chiara Tani,
Rheumatologist,
University of Pisa, Italyⁱⁱ



Neil Betteridge,
Patient Engagement Expert^v



Dr. Patricia Cagnoli,
Rheumatologist,
University of Michigan, USⁱⁱⁱ

A person with lupus (anonymous)



Duane Peters,
Senior Director of Communications,
The Lupus Foundation of America, Inc.
and Staff Coordinator for the World
Lupus Federation^{iv}

ⁱ Consultancy fees received from Eli Lilly, GSK, Human Genome Sciences, Aspreva, BristolMyersSquibb, Actelion and Teva. He has also participated in clinical trials sponsored by these companies; ⁱⁱ Consultancy fees received from GSK Italy; ⁱⁱⁱ Consultancy fees received from GSK and Crescendo; ^{iv} GSK has provided financial support to the World Lupus Federation, Lupus Foundation of America and Lupus Europe; ^v Consultancy fees received from Amgen, the Global Alliance for Patient Access, Grunenthal, Heart Valve Voice, Lilly, Pfizer, Roche, Sanofi Genzyme, Sanofi Regeneron.

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