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## **'A Vision for Lupus' backgrounder**

### **What is lupus?**

Systemic Lupus Erythematosus (SLE), or lupus, is a chronic, inflammatory, autoimmune disease.<sup>1</sup> This means that the body's immune system is 'out of balance' leading to the production of auto-antibodies which target the body's own healthy tissue in addition to producing antibodies to protect against infection.<sup>2,3</sup> Over time, the disease can potentially affect many different organs and tissues of the body<sup>2</sup> Some of the most common symptoms of lupus are painful and swollen joints (arthritis), extreme fatigue, skin rashes, anaemia and kidney problems. Typically, people with lupus alternate between periods of illness, called 'flares,' and periods of relative wellness, or 'remission'.<sup>4</sup> Severity of illness can vary; some are mildly affected and continue to lead normal lives, whilst others have frequent or life-threatening flares that require critical care.<sup>4</sup>

There is no cure for lupus,<sup>1</sup> so the goals of treatment are to achieve and maintain disease remission or the lowest disease activity, prevent disease flares, prevent damage to the body's organs (that leads to more damage and early mortality),<sup>5</sup> and thus, improve quality of life for people with the disease.

There is no single diagnostic test that can determine whether a person has lupus; the diagnosis is the result of clinical reasoning, combining a patient's symptoms, physical signs and laboratory data.<sup>5</sup> In this respect, it may take months or even years for a person to have a confirmed diagnosis.

### **Who is affected by lupus?**

Globally, approximately five million people are thought to have lupus.<sup>6</sup> It is estimated that 70 to 90% of cases are in females,<sup>7</sup> with the highest incidence during a woman's most productive childbearing and professional development years. The prevalence of lupus is thought to be increasing, which may be due to the improved survival of people with lupus or the ageing population. This increase supports the idea that "lupus is no longer a 'rare' disease".<sup>8</sup>

### **The patient impact of lupus**

Lupus has a substantial impact on many aspects of people's lives, as well as the lives of their families and carers.<sup>9</sup> It can affect every day plans, compromising their social life, and aspirations for a career and family, leading to a degree of fear and uncertainty about the future. On any given day, people with lupus may not be able to carry out daily activities or commit to plans, or may struggle to function as a parent, friend, partner or colleague. Moreover, increased SLE disease activity is associated with a higher risk of organ damage and mortality;<sup>10</sup> mortality risk for people with lupus can be up to three times higher than the general population, and up to 10 times higher than in people aged under 40.<sup>11</sup>

### **An overview of the 'A Vision for Lupus' report**

GSK conceived, developed and led the 'A Vision for Lupus' initiative in collaboration with a Global Multidisciplinary Steering Committee who received a fee for their services. The initiative aims to highlight current gaps and inconsistencies in lupus care and a vision for improving the future for the estimated five million people living with lupus.

In 2018, GSK convened the 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 how to tackle these barriers and propose patient-centred Calls to Action in an expert-led report.

Although progress has been made in the management of lupus in recent years, the Steering Committee identified the following challenges that still exist:

- Lack of awareness of the condition amongst general public and HCPs which may lead to people with lupus feeling misunderstood, isolated and alone
- Limited access to specialist and multidisciplinary care

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- Barriers to participation in clinical research

The Calls to Action in the 'A Vision for Lupus' report is intended to stimulate conversations with various stakeholders globally, including the general public, people living with lupus, their families, healthcare professionals and policymakers.

### **Calls to Action to improve lupus care**

1. **Awareness:** Raise awareness of lupus amongst the general public, people living with lupus, their families and healthcare providers to help achieve early diagnosis and help people with lupus feel more acknowledged, understood and supported.
2. **Service Delivery:** Improve access to specialist and multidisciplinary lupus clinics to ensure people with lupus are receiving quality care that addresses all aspects of this complex, multisystem disease, thereby improving overall quality of care.
3. **Clinical research:** Raise awareness of ongoing clinical trials, encourage people with lupus to consider taking part in research and facilitate easier access to these trials, in turn, empowering people with lupus to make autonomous decisions in the management of their condition.

### **How will the 'A Vision for Lupus' report be launched?**

GSK launches the 'A Vision for Lupus' report on 10 May 2019 to coincide with World Lupus Day, a key international platform to raise awareness of the disease and the patient impact.

GSK will also be bringing the report to the medical community at EULAR during a satellite symposium, highlighting best practice examples of specialist/multidisciplinary care and giving advice to healthcare professionals wanting to drive change in lupus care in their own country e.g. by setting up a multidisciplinary clinic.

### **What is World Lupus Day?**

The World Lupus Federation (WLF), a coalition of patient groups united to improve the quality of life of people living with lupus, invites everyone around the world to participate in World Lupus Day on 10 May 2019. The WLF coordinates awareness, education and advocacy initiatives with support from its global affiliates.<sup>12</sup> This is the 16<sup>th</sup> annual observance of World Lupus Day and a global call-to-action on behalf of the estimated five million people around the world living with lupus.<sup>12</sup> The World Lupus Foundation says: "While lupus knows no boundaries, knowing all you can about lupus can help control its impact". World Lupus Day serves as an opportunity to rally stakeholders around the world for the common purpose of drawing attention to and directing resources to improve quality of life for people with this potentially fatal disease.

### **References**

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