

Lupus Knows No Boundaries e-Report

Together we can make lupus an international health priority to ensure that people with lupus around the world are diagnosed and treated effectively.

May 10, 2017

**World
Lupus
Federation**



e-Report commissioned by the World Lupus Federation in association with GSK

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Foreword

by Sandra C. Raymond and Kirsten Lerstrøm,
Co-Chairs of the World Lupus Federation



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President & CEO, Lupus Foundation
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Kirsten Lerstrøm

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There is no boundary to the impact of lupus.

Lupus is a global health problem that affects people of all nationalities, races, ethnicities, genders and ages. Lupus can affect any part of the body in any way at any time, often with unpredictable and life-changing results. While lupus knows no boundaries, knowing all we can about lupus can help control its impact.

Lupus is difficult to diagnose, hard to live with and a challenge to treat – invisible to others and striking without warning, its cause is unknown and it has no cure. This complex, debilitating disease can be fatal, and yet levels of public awareness about it are extremely low relative to the life-changing impact lupus has on the lives of people living with it.

A 2016 global survey highlighted that over half of respondents (51%) were unable to identify the complications associated with lupus and more than a third (35%) did not even know that lupus was a disease.

This lack of understanding in society means health concerns expressed by people with lupus often are greeted with scepticism by family and friends; **to address the many misperceptions about lupus we need to talk about it.**

The *Lupus Knows No Boundaries* report brings together the firsthand experiences of people with lupus, their advocates and those that treat them, to tell the real story of lupus and highlight the ongoing physical and emotional needs of those affected. By building the conversation about 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.

Whilst research programmes and effective medications do exist, we must continue to increase awareness and understanding about lupus and it is through milestones like World Lupus Day, that we can come together to improve the quality of life for people affected by lupus.

On this annual awareness day, through coordinated efforts of its global affiliates, the World Lupus Federation works to create greater awareness and understanding of lupus and break the boundaries of public perceptions for the lupus community.

In recognition of World Lupus Day taking place on 10th May 2017 we're calling for everyone to unite and take action on behalf of those affected by lupus around the world with a common purpose of bringing greater attention and resources to help end the suffering caused by this disabling and potentially fatal autoimmune disease.

To support us in our efforts, join us and the World Lupus Federation by urging the World Health Organisation to make lupus an international health priority and to ensure that people with lupus around the world are diagnosed and treated effectively. Sign the petition here and learn more at: worldlupusday.org.

Thank You

On behalf of the World Lupus Federation and GSK, we acknowledge, with extreme gratitude, all contributors to this report for sharing their insights and experiences.

Without their valuable contributions, this report would not have been possible.

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Lupus Knows No Boundaries e-Report

Lupus: Disease Background

Disease background

Lupus knows no boundaries. It is a chronic, life-threatening autoimmune disease that can affect any part of the body – the vital organs, the skin and the joints – and can touch all races, ethnicities, genders and ages.¹

What is lupus?

Lupus is an autoimmune disease which is:^{1,8}

- ✓ CHRONIC
- ✓ INCURABLE
- ✓ UNCOMMON



5m

At least **five million** people worldwide are thought to have lupus.¹ However, the exact number of people living with lupus globally is not known.¹

In many cases of lupus, more than one organ system can be affected, including the **kidneys, heart, lungs, and brain.**² Blood and blood vessels also can be affected.^{2,3}



Lupus can be associated with potentially **disabling and life-threatening medical complications**, which may include kidney failure, heart attacks, strokes and seizures.^{1,3}

Lupus develops more frequently among people from **specific racial and ethnic groups** for reasons not yet fully understood.²

Lupus strikes mostly **women of childbearing age.** However, men, children, and teenagers develop lupus, too. Most people with lupus usually will develop the disease between the ages of **15-44.**^{2,4,5,6}



When suffering from lupus, the body is at war with itself. Something has gone wrong with the immune system and instead of protecting the body from illness and infection, the antibodies it releases wrongly identify healthy tissue, cells and organs as foreign invaders and attack them, causing inflammation.⁷

Although some progress in understanding has been made over the last few decades, the causes of lupus are still largely unknown. Experts believe there could be a number of factors at work that can trigger and influence the disease, including hormones, genetics and environment.⁸



“We don’t completely understand what causes lupus yet – but we know much more now than we did. Lupus is like a puzzle – if you have enough of the pieces the full picture will appear.”

Dr. Susan Manzi, Chair of the Department of Medicine of Allegheny Health Network, and Co-Director of the Lupus Center of Excellence and, Medical Director of the LFA

A disease of diverse symptoms



“Many people describe their disease as having continuous flu-like symptoms.”

Sandra C. Raymond, President & CEO, Lupus Foundation of America

The symptoms of lupus can vary widely from person to person.⁹ Symptoms can be devastating, from hair loss, disfiguring skin rash and mouth ulcers, to painful or swollen joints, chest pain, breathing difficulties, headaches and sun- or light-sensitivity. Some patients experience all of these, while others have fewer and milder symptoms. However, the **vast majority** will **experience extreme fatigue and low-grade fevers.**³

Cognitive problems are also a serious issue for many. Often described as ‘**lupus fog**’, symptoms of memory loss or difficulty concentrating can stop patients thinking clearly, making them unable to process information or make decisions, in turn affecting their ability to work and take part in social activities.³

“Lupus is a disease that waxes and wanes. There are periods when it is active and others when it is not – you never know what to expect. Disease activity is not predictable and this is what is so ruinous to quality of life.”

Sandra C. Raymond, President & CEO, Lupus Foundation of America

“Every time an individual with lupus has a flare, they are experiencing damage internally to one or more organs, and that accumulated damage causes devastating effects later in the course of the disease.”

Sandra C. Raymond, President & CEO, Lupus Foundation of America

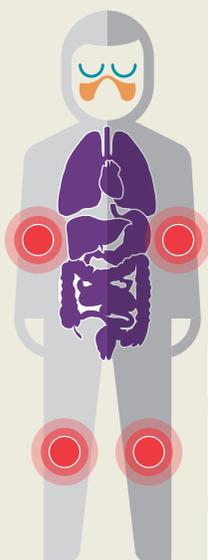
Lupus is unpredictable because it is characterised by periods of illness, called flares, and periods of wellness, or remission.^{3,10} Uncontrolled it can cause irreversible tissue and organ damage and can lead to premature death.¹¹



“Some of the long-term consequences of active disease can include: decreased health-related quality of life; long-term use of medication with possible side-effects; chronic symptoms and damage to various organs can occur.”

Dr. Ronald van Vollenhoven, Professor and Director, Amsterdam Rheumatology and Immunology Center ARC, The Netherlands

Signs and symptoms



SLE can affect **any of the major organs** in the body and **symptoms can vary greatly** in severity and intensity.^{1,9}

Some of the most common symptoms include:³

Debilitating fatigue

Butterfly-shaped facial skin rash

Joint pain

Lupus: Disease Background

Diagnosing an invisible disease



“Lupus can go from a mild condition to a life-threatening condition very quickly and without warning – it’s very unpredictable. Some of the most serious symptoms people experience include chest pain, which can feel like a heart attack, or a psychotic episode so severe that the patient doesn’t understand where they are or how they got there.”

Duane Peters, World Lupus Federation

Lupus is often described as an ‘invisible’ disease, because with symptoms that come and go, and change over time it is **difficult for physicians to diagnose**.

When presented in isolation, lupus symptoms are non-specific and similar to those of many other less serious conditions. Therefore, diagnosing and treating lupus often requires a team effort between the patient and several types of health care professionals.³ When lupus is finally identified, the disease has often progressed, and uncontrolled, it is likely to have had a damaging impact on the patient’s organs.

Diagnosis

The **early diagnosis of SLE is difficult** due to the non-specific symptoms, such as malaise, joint pain or fatigue.¹¹ **External signs of the disease may be few.**^{1,3,9}



Many patients experience **significant delays in diagnosis**.



“It took a year to get a diagnosis and then there was a lot of trial and error with my treatment; it wasn’t until at least four years after my diagnosis that I received appropriate medication.”

Dalilah Kalla, Lupus Alert, Mauritius



“I was wrongly diagnosed for about six years, since many of the doctors that treated me didn’t know about lupus at that time. It was only in 1994, when one doctor finally diagnosed me with lupus, that everything began to make sense; the invisible disease started to reveal itself.”

Ayu Bisono, Yayasan Lupus Indonesia

Recognising and reporting symptoms



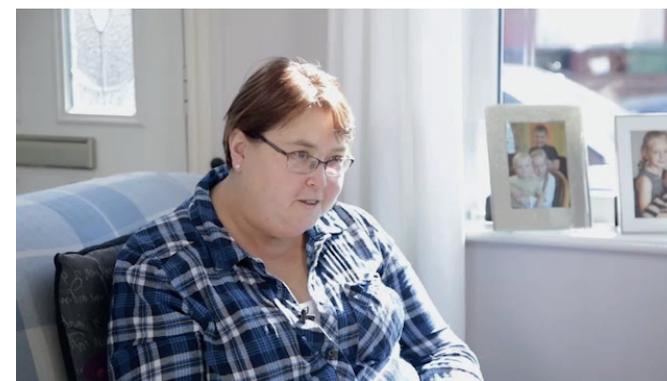
Findings from a global survey showed that **SLE patients often do not report all of their symptoms** to their doctors, as they do not associate them with the disease.



Almost three quarters of SLE patients agreed that they only report the symptoms that annoy them the most and often minimise their symptoms when talking with their doctor.



Fatigue, sensitivity to light and muscle and joint pain are most likely to be reported by SLE patients as **severe symptoms**.



VIDEO | Elaine Holland – ‘Think lupus’

[Problem viewing? Click here](#)

Lupus: Disease Background

Managing the impact of lupus

There is currently no cure for lupus, but in most cases, it can be managed successfully with early diagnosis and expert medical care; treatment should be aimed at reducing disease activity, treating symptoms and minimising flares in order to reduce the risk of developing long-term organ damage.¹²

Most current treatment options, including antimalarials, glucocorticoids (anti-inflammatory medications) and immunosuppressants (drugs that suppress the immune system) were not originally designed for lupus. They treat the immediate symptoms of disease, but do not proactively target the underlying cause.⁷ Treatments used depend on the severity of disease and the areas of the body that are affected and some may cause toxicity and associated side effects.



*“We need to **intervene early and aggressively** to control the disease. If you delay treatment, the inflammation can cause damage to your organs. As long as there is inflammation we can reduce the disease activity, but if the disease starts causing damage to the kidneys, for example, they can start losing their function and become fibrotic and this can become irreversible; patients are then on a slope towards dialysis, transplant, renal failure – that’s very dangerous.”*

Dr. Paul R. Fortin, CHU de Québec Research Center, Canada



“As physicians, it is important that we don’t let the disease smoulder. We need to get control of the underlying inflammation and autoimmune attack in order to avoid worse consequences.”

Dr. Susan Manzi, Chair of the Department of Medicine of Allegheny Health Network, and Co-Director of the Lupus Center of Excellence and, Medical Director of the LFA

“It is important to remember that people die from lupus and that the medications used to treat it can also cause additional problems; these are very powerful drugs – chemotherapy, drugs used for transplant patients and steroids – and they can cause heart attacks, bone thinning and a higher risk of developing cancer.”

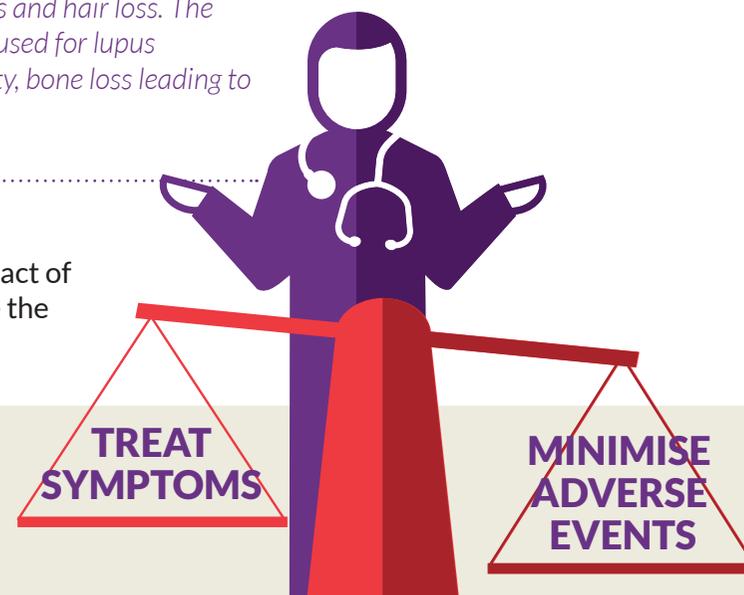
Dr. Susan Manzi, Chair of the Department of Medicine of Allegheny Health Network, and Co-Director of the Lupus Center of Excellence and, Medical Director of the LFA



“People are dealing not only with the manifestations of lupus but also the side effects of those medications. For example, steroid use causes such effects as significant weight gain, sleeplessness, bone loss and hair loss. The use of a chemotherapy, most often used for lupus nephritis (lupus kidney disease) may cause infertility, bone loss leading to osteoporotic fractures, hair loss and more.”

Sandra C. Raymond, President & CEO, Lupus Foundation of America

Physicians therefore face a difficult balancing act of treating symptoms while also trying to reduce the side effects of those same treatments.¹³



Lupus: Disease Background

About lupus

What is lupus?

Lupus is an autoimmune disease which is:^{1,2,3,4}

- ✓ CHRONIC
- ✓ INCURABLE
- ✓ UNCOMMON

The most serious and common form of lupus is called **Systemic Lupus Erythematosus (SLE)**⁵

It principally affects women (9 in 10 patients are female), with highest risk for onset of SLE during childbearing age.^{2,3,6}

SLE is driven by **immuno-inflammation**.⁷ Instead of producing normal antibodies to protect the body from infection, in patients with SLE, 'auto-antibodies' are produced and attack healthy cells.⁸

This causes **irreversible tissue and organ damage** and can lead to **premature death**.^{9,10}

Prevalence

SLE is **uncommon**, affecting approx. **40-100** people in every **100,000**.^{3,11,12}

SLE is the most **common** and **serious** type of lupus, affecting approximately **70%** of lupus patients.⁷

The incidence and prevalence of SLE are higher in **African-Americans**, along with other **ethnic minorities**, compared to caucasians.^{3,11}

Signs and symptoms

SLE can affect any of the **major organs** in the body and **symptoms can vary greatly** in severity and intensity.

Some of the most common symptoms include:^{13,14,15}

- Debilitating fatigue
- Butterfly-shaped facial skin rash
- Joint pain

Diagnosis

The **early diagnosis of SLE is difficult** due to the non-specific symptoms, such as malaise, joint pain or fatigue.¹⁶ **External signs of the disease may be few.**

Classification is based on **evidence of 4 of 11 objective criteria** devised by the American College of Rheumatology.¹⁷

Many patients experience **significant delays in diagnosis**.^{18,19}

Recognising and reporting symptoms

Findings from a global survey showed that **SLE patients often do not report all of their symptoms** to their doctors, as they do not associate them with the disease.²⁰

Almost three quarters of SLE patients agreed that they only report the symptoms that annoy them the most and often minimise their symptoms when talking with their doctor.²⁰

Fatigue, sensitivity to light and muscle and joint pain are most likely to be reported by SLE patients as **severe symptoms**.²⁰

The burden of SLE on daily life

Global survey findings have demonstrated:

- **7 in 10 patients** agree SLE affects their self-esteem and over half feel alone and powerless.²⁰
- **61%** have had to make adjustments around the house to cope with lupus.²⁰
- **40%** of SLE patients quit working or retired earlier than planned.²⁰

SLE survival

95% chance of surviving 5 years.²¹

85% chance of surviving 15 years.²¹

In those under 40, mortality is **10 times higher** than the general population.^{22,23,24}

Treatment

Current treatment for SLE **varies widely**. Treatment goals include:^{25,26,27}

1. reducing disease activity
2. treating symptoms and flares
3. reducing organ damage

Physicians face a **difficult balancing act** of treating symptoms while attempting to minimise adverse events.^{25,28}

TREAT SYMPTOMS vs **MINIMISE ADVERSE EVENTS**

A full-size version of the infographic is available to download from worldlupusday.org

Page references

1. American College of Rheumatology Ad Hoc Committee on Systemic Lupus Erythematosus Guidelines. Guidelines for referral and management of systemic lupus erythematosus in adults. Arthritis Rheum 1999;42:1785-96. 2. 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;19:1640-8. 3. Danchenko N, Satia JA, Anthony MS. Epidemiology of systemic lupus erythematosus: a comparison of worldwide disease burden. Lupus 2006;15:308-18. 4. Lerang K, Gilboe I, Garen T, et al. High incidence and prevalence of systemic lupus erythematosus in Norway. Lupus 2012;21:1362-9. 5. Lupus Foundation of America. Statistics on lupus. Available at: <http://www.lupus.org/about/statistics-on-lupus> Last accessed April 2015. 6. Yelin E, Trupin L, Katz P, et al. Work dynamics among persons with systemic lupus erythematosus. Arthritis Rheum 2007;57:56-63. 7. Tsokos GC. Systemic lupus erythematosus. N Engl J Med 2011;365:2110-21. 8. NHS Choices. Lupus: introduction. Available at: <http://www.nhs.uk/conditions/lupus/pages/introduction.aspx> Last accessed April 2015. 9. Mok CC, Lau CS. Pathogenesis of systemic lupus erythematosus. J Clin Pathol 2003;56:481-90. 10. Nossent J, Kiss E, Rozman B, et al. Disease activity and damage accrual during the early disease course in a multinational inception cohort of patients with systemic lupus erythematosus. Lupus 2010;19:949-56. 11. Manzi S. Epidemiology of systemic lupus erythematosus. Am J Manag Care 2001;7:5474-9. 12. Rahman A, Isenberg DA. Systemic lupus erythematosus. N Engl J Med 2008;358:929-39. 13. Uribe AG, McGwin G Jr, Reveille JD, et al. What have we learned from a 10-year experience with the LUMINA (Lupus in Minorities: Nature vs. nurture) cohort? Where are we heading? Autoimmun Rev 2004;3:321-9. 14. Gallop K, Nixon A, Swinburn P, et al. Development of a conceptual model of health-related quality of life for systemic lupus erythematosus from the patient's perspective. Lupus 2012;21:934-43. 15. Cervera R, Khamashta MA, Font J, et al. Morbidity and mortality in systemic lupus erythematosus during a 10-year period: a comparison of early and late manifestations in a cohort of 1,000 patients. Medicine (Baltimore) 2003;82:299-308. 16. Bertias G, Cervera R & Boumpas DT. Systemic lupus erythematosus: pathogenesis and clinical features. EULAR textbook on Rheumatic diseases. 2012. 17. Petri M, Orbai AM, Alarcón GS, et al. Derivation and validation of the Systemic Lupus International Collaborating Clinics classification criteria for systemic lupus erythematosus. Arthritis Rheum 2012;64:2677-86. 18. Lateef A, Petri M. Unmet medical needs in systemic lupus erythematosus. Arthritis Res Ther 2012;14 Suppl 4:S4. 19. Arbuuckle MR, McClain MT, Rubertone MV, et al. Development of autoantibodies before the clinical onset of systemic lupus erythematosus. N Engl J Med 2003;349:1526-33. 20. 2014 Global Systemic Lupus Erythematosus (SLE) Survey. GSK data on file. 21. Kasitanon N, Magder LS, Petri M. Predictors of survival in systemic lupus erythematosus. Medicine (Baltimore) 2006;85:147-56. 22. Lopez R, Davidson JE, Beeby MD, et al. Lupus disease activity and the risk of subsequent organ damage and mortality in a large lupus cohort. Rheumatology (Oxford) 2012;51:491-98. 23. Bernatsky S, Boivin JF, Joseph L, et al. Mortality in systemic lupus erythematosus. Arthritis Rheum 2006;54:2550-7. 24. Urowitz MB, Gladman DD, Tom BD, et al. Changing patterns in mortality and disease outcomes for patients with systemic lupus erythematosus. J Rheumatol 2008;35:2152-8. 25. Doria A, Gatto M, Zen M, et al. Optimizing outcome in SLE: treating-to-target and definition of treatment goals. Autoimmun Rev 2014;13:770-7. 26. Kalunian K, Joan TM. New directions in the treatment of systemic lupus erythematosus. Curr Med Res Opin 2009;25:1501-14. 27. Merrill JT. Treatment of systemic lupus erythematosus: a 2012 update. Bull NYU Hosp Jt Dis 2012;70:172-6. 28. van Vollenhoven R, Mosca M, Bertias G, et al. Treat-To-Target in Systemic Lupus Erythematosus: report from the T2T/SLE Working Party. Arthritis Rheum 2013;65:S663.

Lupus Knows No Boundaries e-Report

Disease Perceptions: Society's View

The challenge of low awareness



"Lack of awareness of lupus is a huge challenge. People don't understand how lupus can affect individuals and their families. People lose friends, lose families. People just don't have a good enough understanding of what it is."

Tanya Carlton, Lupus Canada

Estimates show:



1.7 million people worldwide suffer with meningitis¹⁴

5 million people are living with lupus¹

However, **30%** of people believe that meningitis is a more common disease than lupus.¹⁵

"If a young woman looks well, her lupus is often dismissed. It is often not seen as very severe or a major health issue. It is often thought of as a disease that causes a little rash or a bit of joint pain."

Dr. Susan Manzi, Chair of the Department of Medicine of Allegheny Health Network, and Co-Director of the Lupus Center of Excellence and, Medical Director of the LFA

And it is not just the public that lack knowledge about lupus...



"Often, our outward appearance does not show the inner battle that is facing our body, so we suffer the incomprehension of our family, social network, work colleagues and even medical professionals, who sometimes dismiss the multiple manifestations of our disease."

Teresa Gladys Cattoni, Asociación Lupus Argentina (ALUA)

A 2016 global survey, which involved more than **16,000 adults** from **16 different countries**, highlighted public lack of awareness and understanding of lupus:¹⁵



36% of the general population are not aware that **lupus is a disease**, with **11%** believing that **lupus is a type of bacteria**



8% of people believe that **lupus is a type of plant**



51% could not identify or did not know the complications associated with lupus such as **kidney failure, anaemia** or a **heart attack**



Only around a third (**39%**) of people were aware that **lupus affects the joints**



13% believe that having **unprotected sex** contributes to someone developing lupus

As a society, our knowledge and understanding of lupus remains extremely low. Although awareness is slowly increasing thanks to the educational efforts of advocacy groups such as the World Lupus Federation, people with lupus continue to experience a degree of prejudice and discrimination. The reason for this is simple: for many with the disease, lupus is invisible.

And while nowadays, most people will say that they have heard of lupus, they won't really know very much about it. Few realise just how serious a disease it is – that it can affect any organ, or that it can potentially threaten a person's life.¹ It is often assumed to be a mild inconvenience – that patients just need to 'get on with it'.

Disease Perceptions: Society's View

“But you don't look sick...”

Although a rash on the face, scalp, wrists and hands is a common feature of lupus,⁷ many symptoms are invisible. When others can't see your illness, it's hard to explain what is wrong with you. Those people who experience extreme fatigue, for example, talk of the frustration they feel when they are viewed as being lazy – the mischaracterisation of their symptoms can be devastating for those affected.



Duane Peters, World Lupus Federation

“The biggest problem I hear is that people say, “You don't look sick.” This comes across to patients as, “You must be faking it”, or, “it's all in your head.” This stigmatises patients because they feel they are being branded as a hypochondriacs or attention-seekers. In reality they are very seriously ill with a life-threatening disease.”



“Just because I look good, doesn't mean I feel good.”

“I wish people understood that people with lupus are not lazy people. We are not lazy, we just can't do things.”

Tanya Carlton, Lupus Canada



Elaine Holland, Lupus UK

“People look at me and think I look well, but they don't know what I'm feeling inside and what the fatigue is doing to me. I get funny looks if I use the disabled toilet in a restaurant – people think, ‘there's nothing wrong with her, why is she using it?’, but they don't understand what it's like to live with.”



“People tend to see me as a spoiled person that is always giving my health condition as an excuse. Some others cannot accept the fact that I am too weak to do my normal activities.”

Ayu Bisono, Yayasan Lupus Indonesia

Discrimination in the workplace

As surprising as it is, many people with lupus still report that as a result of the disease, they experience discrimination – or that they fear discrimination – in the workplace. And although anti-discrimination laws exist in many countries to protect the workforce, people still feel that deciding whether or not to tell their employer they have lupus is a difficult decision to make.



“People need to decide whether they disclose they have lupus or not. If they do disclose it, not everyone will be sympathetic.”

Dr. Paul R. Fortin, CHU de Québec Research Center, Canada



“From the outside we are completely healthy, so patients need to decide whether or not to tell people they are ill. Some employees may be at risk of losing their jobs or being discriminated against. If they decide not to tell anyone at work, then they need to act as though they are completely healthy, which is not always possible, because they may need to rest during the day. It is not easy to find a compromise.”

Francesca Marchiori, Lupus Italy



“I do feel there is a stigma associated with lupus. In the past people have been very reluctant to talk about it because they were afraid of some sort of repercussion – either from their family members or from their employers.”

Sandra C. Raymond, President & CEO, Lupus Foundation of America



“There is a lot of misinformation and prejudice associated with lupus. For example, the ignorance of a large part of the population makes them believe that lupus is contagious, which brings with it discriminatory situations in social and working environments.”

Teresa Gladys Cattoni, Asociación Lupus Argentina (ALUA)

Disease Perceptions: Society's View

What lupus is not...

As a result of low public awareness of lupus, the disease is very poorly understood. Lupus is complex and complicated, but contrary to the beliefs of many people, lupus is not for example, contagious.¹



"A lot of people have a misunderstanding about the illness itself – some think it's leprosy, some think it's closely linked to HIV/AIDS. Levels of ignorance and lack of understanding about lupus are very high."

Reeanna Harrilal, The Voice of Lupus Foundation, Trinidad and Tobago



"There's a stigma because of a misunderstanding of what lupus is. As soon as you mention your immune system people confuse it with other diseases like AIDS, which for some people still has a stigma attached to it."

Elaine Holland, Lupus UK

"There is a stigma attached to lupus. I always talk about my illness and explain it to people first; I tell them it's an autoimmune disease but it's not contagious and I can't pass it on to them."

Francesca Marchiori, Lupus Italy



VIDEO | Elaine Holland – 'The stigma associated with lupus' [Problem viewing? Click here](#)



"Raising awareness about lupus is an essential step for change. We need campaigns to increase public understanding about the disease and educational support for patients and their families."

Dr. Eloisa Bonfá, Professor of Rheumatology, Brazil

The global survey revealed the stigma associated with lupus resulting from widespread misconceptions that it is contagious:¹⁵



23% of people are 'uncomfortable' hugging someone with lupus



47% feel 'less than comfortable' shaking hands with someone with lupus



1 in 3 people (31%) are 'uncomfortable' sharing food with someone who has lupus



44% feel 'less than comfortable' sitting next to someone on a bus who has lupus

As always, the solution to ignorance and misperception is education and awareness. Around the world, physicians, advocacy groups and people with lupus themselves are working to increase knowledge and understanding about the disease to ensure that patients are treated with compassion and without fear of discrimination.

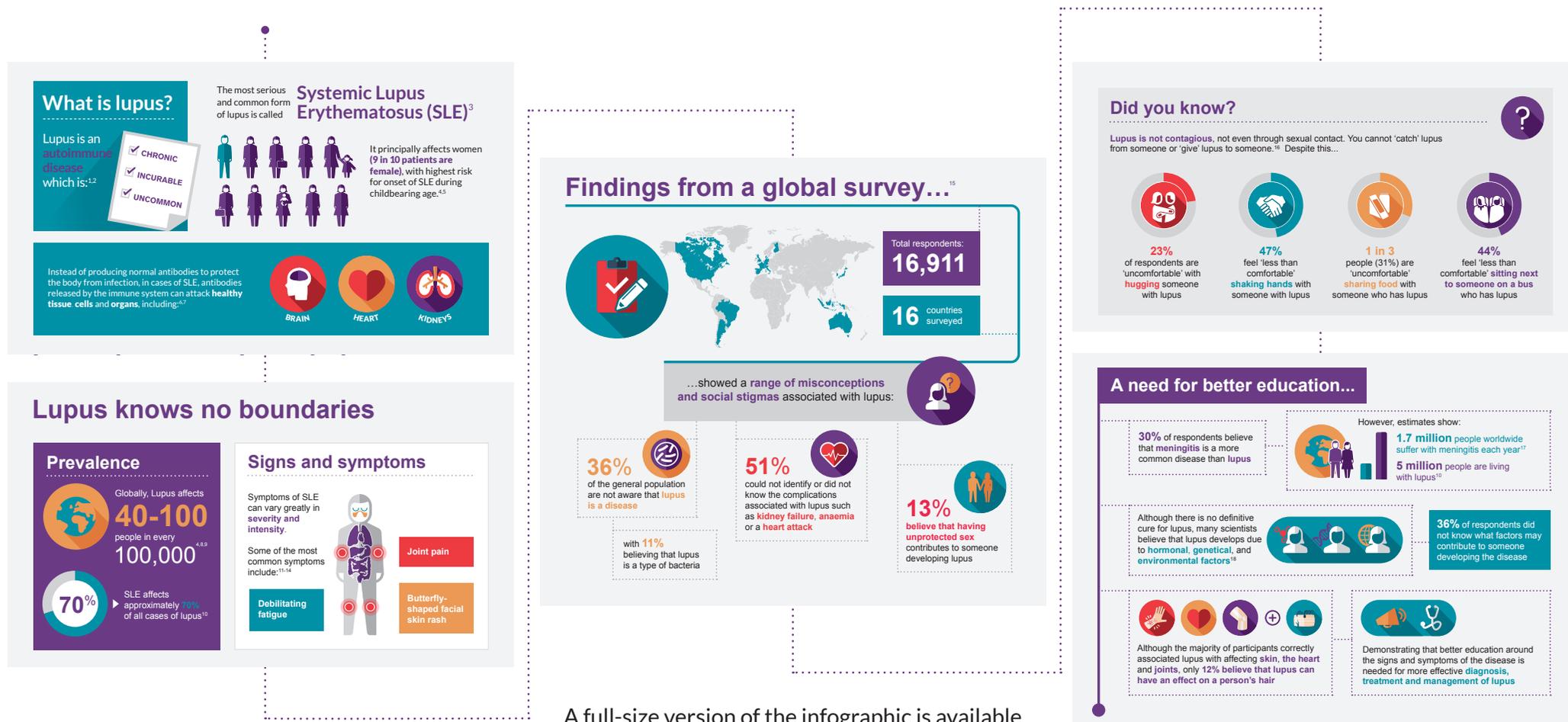


Lupus is not...¹

- ✗ contagious – you cannot catch it or give it to anyone else
- ✗ similar or related to HIV/AIDS
- ✗ similar or related to cancer
- ✗ a form of arthritis – lupus can damage any organ or tissue

Disease Perceptions: Society's View

How much do you know about lupus?



A full-size version of the infographic is available to download from worldlupusday.org

Page references

1. American College of Rheumatology Ad Hoc Committee on Systemic Lupus Erythematosus Guidelines. Guidelines for referral and management of systemic lupus erythematosus in adults. Arthritis Rheum 1999; 42:1785-96 2. 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;19:1640-8 3. Lupus Foundation of America. Forms of lupus. Available at: <http://www.lupus.org/answers/entry/forms-of-lupus>. Last accessed April 2016 4. Danchenko N, Satia JA, Anthony MS. Epidemiology of systemic lupus erythematosus: a comparison of worldwide disease burden. Lupus 2006; 15:308-18 5. Women's Health.gov. Factsheet: Lupus. Available at: <http://www.womenshealth.gov/publications/our-publications/fact-sheet/lupus.html> Last accessed April 2016 6. NHS Choices. Lupus: introduction. Available at: <http://www.nhs.uk/conditions/lupus/pages/introduction.aspx>. Last accessed April 2016 7. Mok CC, Lau CS. Pathogenesis of systemic lupus erythematosus. J Clin Pathol 2003;56:481-90 8. Manzi S. Epidemiology of systemic lupus erythematosus. Am J Manag Care 2001;7:S474-9 9. Rahman A, Isenberg DA. Systemic lupus erythematosus. N Engl J Med 2008;358:929-39 10. Lupus Foundation of America. Statistics on lupus. Available at: <http://www.lupus.org/about/statistics-on-lupus> Last accessed April 2016 11. Uribe AG, McGwin G Jr, Reveille JD, et al. What have we learned from a 10-year experience with the LUMINA (Lupus in Minorities: Nature vs. nurture) cohort? Where are we heading? Autoimmun Rev 2004;3:321-9 12. Gallop K, Nixon A, Swinburn P, et al. Development of a conceptual model of health-related quality of life for systemic lupus erythematosus from the patient's perspective. Lupus 2012;21:934-43 13. Cervera R, Khamashta MA, Font J, et al. Morbidity and mortality in systemic lupus erythematosus during a 10-year period: a comparison of early and late manifestations in a cohort of 1,000 patients. Medicine (Baltimore) 2003;82:299-308 14. Bertias G, Cervera R & Boumpas DT. Systemic lupus erythematosus: pathogenesis and clinical features. EULAR textbook on Rheumatic diseases. 2012 15. 2016 GSK Global Disease Awareness Survey 16. Lupus Foundation of America. Get answers. Available at: <http://www.lupus.org/answers/entry/is-lupus-contagious> Last accessed: April 2016 17. Confederation of Meningitis Organisations. Meningitis Factsheet. Available at: <http://www.comeningitis.org/media/67567/meningitis-factsheet-final-april-2013.pdf> Last accessed April 2016 18. Lupus Foundation of America. What causes lupus? Available at: <http://www.lupus.org/answers/entry/what-causes-lupus>. Last accessed: April 2016

Lupus Knows No Boundaries e-Report

Disease Perceptions: The Reality

Disease Perceptions: The Reality

Addressing the lack of lupus awareness



“It’s our responsibility to get involved and do whatever we can to help fight this unpredictable and misunderstood disease. 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.”

Julian Lennon, photographer, author, musician, philanthropist and Global Ambassador for the LFA

Although it is thought to affect at least five million people worldwide,¹ the results of the 2016 awareness survey show a clear lack of understanding of the disease, and highlight that more needs to be done to address this problem.¹⁵ Many of those living with lupus continue to experience stigma and discrimination, instead of the support, understanding and care they need to help them manage this debilitating disease.

The role of the media

Educating the general public and changing perceptions is challenging, but the media can play a powerful role in sharing accurate information about diseases such as lupus. Sadly, until now, lupus has been largely ignored by the media. Where it has been featured, lupus has often been misrepresented, or characterised as a trivial condition.

“Unfortunately, lupus often is not portrayed accurately on television or in films, or it is the punch line of a joke. That mischaracterisation contributes to misconceptions by the public about how serious and debilitating lupus can be, or it minimises the devastating impact lupus has on people’s lives.”

Julian Lennon, photographer, author, musician, philanthropist and Global Ambassador for the LFA

The rise of social media, however, could present a turning point in the awareness of lupus. Sites such as Facebook and Twitter are providing people with lupus with a platform from which they can talk to other people with lupus, share experiences, learn from each other and build their own support networks.

“Through social media, many people have been able to share their personal stories and their daily struggles, and that has helped millions of people around the world begin to learn what lupus is and appreciate how lupus can impact a person’s life.”

Julian Lennon, photographer, author, musician, philanthropist and Global Ambassador for the LFA



“When it comes to being an advocate, social media is one of the most useful tools to educate and inform people; when I was diagnosed, nobody was talking about lupus or sharing their experiences. When I started looking for information all I found were depressing blogs that left me with zero hope. I want to encourage others and address the positives so that people don’t just focus on the negatives.”

Tiffany Peterson, #LupusChat, US



“I think the way that lupus is portrayed on social media is getting better. People are responding and beginning to pay attention. It’s getting out there that lupus is a very serious problem and we need to continue to educate and learn more about it.”

Shannon Boxx, Olympic Gold Medalist and LFA Ambassador

Lupus advocates: a powerful voice for change

The efforts of the lupus community to increase awareness are being helped tremendously by the support of a number of high profile advocates who are using their voices and influence to improve understanding and effect change.

Before her retirement from professional sports in 2015, Shannon Boxx was a member of the United States women's national soccer team, winning three Olympic gold medals among many other sporting accolades. But for most of her professional career, she was secretly carrying the burden of a lupus diagnosis.



Shannon Boxx, Olympic Gold Medalist and LFA Ambassador

"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."

Julian Lennon decided to become an advocate for those with lupus after a childhood friend was struck down with the disease.



"I first came to know lupus through my childhood friend, Lucy Vodden, about whom the song Lucy in the Sky with Diamonds was written. It was Lucy's struggles that opened my eyes to how devastating the burden of lupus is on millions of individuals and their families. After she passed away from complications of lupus, I just knew I had to get involved to help spread awareness of lupus and bring attention to the suffering of people who are affected by this terrible disease."

Julian Lennon, photographer, author, musician, philanthropist and Global Ambassador for the LFA

As well as raising awareness, one valuable contribution that lupus advocates can make is to offer hope and demonstrate that a diagnosis doesn't mean you can't achieve your aims.



"I hope that I can inspire people to go back out there and do what you can. Don't feel that life is over. Still live your life."

Shannon Boxx, Olympic Gold Medalist and LFA Ambassador



Find out more about the awareness-raising activities of the [Lupus Foundation of America](#), [#LupusChat](#) and [Shannon Boxx](#).



Lupus Knows No Boundaries e-Report

Living with Lupus

Living with lupus



“The symptoms are completely unpredictable – one day you feel well and the next day you feel terrible. Before diagnosis, I would make an appointment with the doctor, but by the time I got to the surgery, the symptoms would have gone.”

Yvonne Norton, Lupus UK



VIDEO | Elaine Holland - 'Getting a diagnosis' [Problem viewing? Click here](#)

Living with lupus isn't easy. Many patients we have spoken to report that the disease has a debilitating impact on their physical and emotional health, often leading to **depression, stress and anxiety**.¹⁶

The symptoms of lupus are so varied and so unpredictable that the disease can affect every aspect of a person's life, from relationships with friends and family – many of whom find its impact difficult to understand – to their ability to work. It can therefore have an impact on financial stability, as well as a person's social life.^{16,2}

The burden of SLE on daily life

Global survey findings have demonstrated:

- **7 in 10 patients** agree SLE affects their self-esteem and over half feel alone and powerless.
- **61%** have had to make adjustments around the house to cope with lupus.
- **40%** of SLE patients quit working or retired earlier than planned.



VIDEO | Beth Willis - 'The unpredictability of lupus' [Problem viewing? Click here](#)

But despite the many challenges that people with lupus may face, life can still be happy, productive and fulfilling. With the right support and education, coping strategies can be put in place that help to lessen the impact of the disease.



Living with a chronic illness does change your outlook on life, and I think, for me, it's actually made me a more positive person. I think I appreciate the little things more. I appreciate my family and friends more, and I value the good days. When you're having a good day, you really have to embrace that, because you don't know how long a good spell might last.

Beth Willis, Lupus Patient, UK

‘Why me?’: Coming to terms with diagnosis



Coming to terms with a diagnosis of lupus can be extremely difficult. It is a disease for which there is no cure, and which will need long-term medication to manage.¹⁷ The vast majority of patients are young when the disease is first identified, making this life-changing diagnosis all the more difficult to handle.

A common initial reaction is that of relief – a feeling that at last their symptoms have been diagnosed and confirmed as a known disease. However, some people admit that initially, they refuse to accept their diagnosis and take their medication, not realising that uncontrolled, the disease could have a serious long-term impact on their health, including irreversible organ damage.¹⁸



Teresa Gladys Cattoni, Asociación Lupus Argentina (ALUA)

“When you are first diagnosed, you suddenly feel that you have lost everything - work opportunities, family harmony, any projects you have planned in life. Also, the way you relate to others changes radically.”

Despite improvements in disease management and survival rates over the last decade,¹⁸ lupus remains a very serious and challenging disease. For many patients, feelings of helplessness and hopelessness can be helped by better understanding the disease. Recognising not only their **limitations** but also what they are still able to do can help people with lupus to organise their lives around their condition, and come to terms with their diagnosis.

Yvonne Norton of Lupus UK always gives the following advice to newly diagnosed patients: “Find a good doctor, sort out your medication and then **put lupus in a little box and get on with your life.**”

Unpredictability of symptoms



Many patients we have spoken to agree that one of the most devastating aspects of their lupus is its unpredictable nature. They say that just when the disease appears to be under control, symptoms can flare up and worsen without warning. This has an inevitable impact on a person’s ability to plan their lives – holidays, day trips and social activities are all affected because patients don’t know how they are going to feel from one day to the next.

“My symptoms can change hour to hour; I can wake up in the morning not experiencing too much pain and feeling refreshed, but within an hour I’ve lost all my strength and brain fog has set in; then two hours later it might have cleared up again – it really is unpredictable and changing all the time.”

Elaine Holland, Lupus UK

A recent Twitter poll* of people with lupus highlighted their biggest concerns about the disease:

Almost half (**43%**) worry most about inactivity and isolation

Over a quarter (**26%**) worry most about dying

The impact of fatigue



Although people with lupus can experience many different symptoms which affect their day-to-day lives, according to the physicians we have spoken to, one challenge that almost every lupus patient will experience is fatigue. And it is not the ‘tired after a busy day at work’ type of fatigue, they describe it as a **‘hit the wall, can’t function’ fatigue** which often requires a period of complete rest.



“During a flare, fatigue can prevent us from doing the most simple, everyday things such as taking a shower, brushing our hair, brushing our teeth, getting dressed or getting out of bed.”

Teresa Gladys Cattoni, Asociación Lupus Argentina (ALUA)



“When my symptoms flare, I cannot do any activity at all; I sometimes have to take a month’s bed rest without knowing what has caused the symptoms to get worse.”

Ayu Bisono, Yayasan Lupus Indonesia



“When I have a flare I’m not able to do anything; I struggle to do household chores, my husband has to do everything, my dog doesn’t get taken for a walk – I have to take to my bed sometimes, to rest and recover.”

Elaine Holland, Lupus UK

Working and social activities



“At the end of the day you are tired and want to go to bed rather than go out to the cinema or see friends.”

Francesca Marchiori, Lupus Italy

Lupus strikes most frequently among young women of childbearing age (15-44).^{2,4} The serious symptoms it causes are therefore all the more debilitating because they coincide with a point in life at which most patients hope to be going out with friends, building their careers and making plans for the future.

According to people with lupus, symptoms such as joint pain, fever, fatigue and serious rash can severely encroach upon their ability to work and to socialise. Some people even report losing friendships because of a lack of understanding of the limitations that lupus places on their lives. As a result, it can be hard to gain independence, and many people report feeling worried about becoming financially unstable and socially isolated.

Regaining control

Although there is no magic solution that works for every patient, the physicians and patient group representatives that we have spoken to advise that making some lifestyle adjustments can often help people with lupus to cope better with their disease from day to day. These strategies include:

- 
- ✓ Take medication correctly and at the right time
 - ✓ Appropriate regular exercise
 - ✓ Reduce stress
 - ✓ Eat well
 - ✓ Stop smoking
 - ✓ Drink alcohol in moderation
 - ✓ Use sun protection
 - ✓ Don't try to do too much – take time to rest



“You can feel guilty that you have this disease, that there must be something you can do to improve it – eat different food, take extra vitamins, invest a lot of money in using alternative ‘cures’. A lot of people around you will always have a lot of ‘good advice’ on what you should and shouldn’t do or eat to help your symptoms. They don’t understand why you don’t try their suggestions, but the reason usually is because you could provoke a flare.”

Kirsten Lerstrøm, Chair, Lupus Europe

“You have to find a way to cope and make changes to your lifestyle – you learn how to live life the best way you can with lupus. You have to get as much rest as you can, but on the other hand you have to try not to let it stop you doing anything.”

Yvonne Norton, Lupus UK



“Keeping busy also helps, trying new things and getting involved in clubs. Don’t stay at home all the time; that is when you can start thinking negative thoughts.”

Dalliah Kalla, Lupus Alert, Mauritius

“You have to try and structure your day and one of the main ways to do this is by getting your medication right. Most of us take an awful lot of drugs but many people are not taking them at the right time - that’s when their lupus goes awry. If you get into a routine and get organised it will help you get through the day.”

Yvonne Norton, Lupus UK

Living with lupus – a patient perspective

Watch Elaine’s story in full:



VIDEO | Elaine Holland – ‘My lupus journey’

[Problem viewing? Click here](#)



Lupus Knows No Boundaries e-Report

Patient Support



Patient support



"I see people with lupus struggling; they are not able to maintain their jobs, they are stressed, they are not able to fulfil what is demanded of them."

Kirsten Lerstrøm, Chair, Lupus Europe

For someone experiencing the diverse, debilitating and often invisible symptoms of lupus, receiving an accurate diagnosis is just the start of a journey that is physically, psychologically and emotionally challenging.^{16,2}



VIDEO | Beth Willis – 'The challenge of diagnosis' [Problem viewing? Click here](#)



"After diagnosis patients have to accept that there is now a 'new normal' – there are going to be things that they are no longer able to do. Providing them with emotional support and walking them through the process of grieving for their loss of health is important in getting patients to understand and accept their diagnosis. Once they accept the new normal, they are able to focus on all the things they need to do to stay healthy."

Duane Peters, World Lupus Federation

Learning to live with lupus and adapting to the limitations it imposes on 'normal' life requires long-term support from healthcare professionals, friends and family; with their understanding and assistance, the burden of disease can be eased and the patient's quality of life can be improved considerably.⁷



VIDEO | Sandra Raymond – 'Patient support' [Problem viewing? Click here](#)

Communicating effectively with healthcare professionals



"Being able to get the message across to healthcare professionals to 'think lupus' when a patient presents with these kinds of symptoms would be really helpful. They need to be thinking, 'It could be lupus.'"

Elaine Holland, Lupus UK

When a diagnosis of lupus has been made and patients are finally able to put a name to their symptoms, a common concern among those affected is that physicians don't really understand what it is like to have lupus or appreciate the significant impact it has on every aspect of their lives.

Physicians are also often limited in the assistance they can offer to patients, other than writing a prescription, as a result of their busy schedules and short consultation times. However, patients we have spoken to advise that there are a number of proactive steps that others with the disease can take to ensure they receive optimal support and care from their healthcare professionals.

Patient Support

Communicating effectively with healthcare professionals continued...



“Physicians don’t have much time. When patients go to see their doctor, they should write down the questions they want to ask and a list of all of their symptoms beforehand so they don’t forget.”

Tanya Carlton, Lupus Canada



“I advise patients to keep a diary of their symptoms to discuss with their healthcare professional. I only remember what has happened with my lupus in the last couple of days, not what has happened in the last 6 months so I write it down.”

Francesca Marchiori, Lupus Italy

A recent Twitter poll* of people with lupus showed that:



Nearly half (**47%**) say that the aspect of lupus they feel is most misunderstood by their physician is the impact on their daily life



Almost one third (**30%**) say the emotional impact is most misunderstood



Almost half (**47%**) are not satisfied with the management and treatment options available to them through their physician

More than medication



“People with chronic lupus should have access to a team; we need a social worker, we need a physiotherapist, an exercise physiologist, a psychologist and a nurse. It is easy to write a prescription but that is not enough.”

Dr. Paul R. Fortin, CHU de Québec Research Center, Canada

People with lupus often require a team of specialists to manage the wide-ranging physical effects of the disease; however, one aspect that is often overlooked is the psychological impact that lupus often has, despite patients saying that this is an area in which they need a lot of support in order to cope with the daily challenges they face.¹⁶



VIDEO | Susan Manzi – ‘A team effort’

[Problem viewing? Click here](#)



“Having a psychologist attached to clinics could be really helpful. Lupus is not an easy disease to live with and consultations with a psychologist to help you through the difficulties would be useful.”

Kirsten Lerstrøm, Chair, Lupus Europe



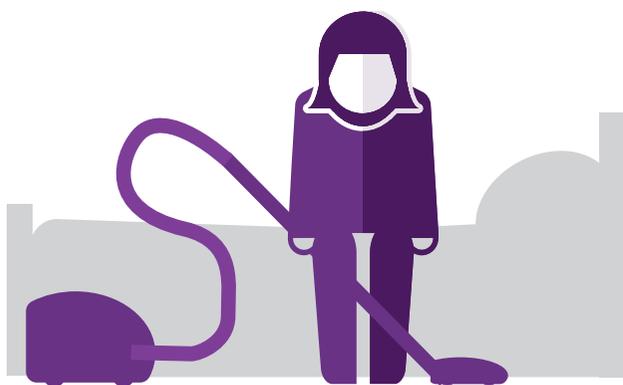
“Mental well-being is equally as important and physical well-being when treating patients. Depression is a serious complication of lupus; it affects many people who have the disease. It needs to be taken seriously.”

Barbara Ward, President, Lupus Association of New South Wales, Australia

“Psychological support is very important - having the regular support of a psychologist helps a lot.”

Francesca Marchiori, Lupus Italy

Family matters



A major scientific needs assessment, recently conducted by the Lupus Foundation of America among 3,000 people with lupus, indicated that emotional support is the one thing patients need the most.¹⁹ Yet many patients report that their friends and families underestimate the severity of lupus and have trouble understanding just how profoundly it affects their daily life.²⁰

Lupus primarily targets women² and one of the most significant challenges reported by patients we have spoken to is the lack of support they receive in their own homes. In many cultures where women are the primary caregivers and homemakers in their families, the debilitating fatigue that lupus causes can make it impossible for patients to fulfil the roles expected of them.² As a result, they are often mischaracterised as ‘lazy’ by those around them, and the lack of understanding, empathy and support can adversely affect relationships and adds to the emotional toll of the disease.¹⁶



“Sometimes family members don’t understand. In Mauritius, young married women with lupus may be criticised by their husbands or mothers-in-law and told they are too lazy to do the housework.

So education is very important, which is why we talk to patients and their families.”

Dalilah Kalla, Lupus Alert, Mauritius

“Patients need to understand that they are not the same person they were before they had lupus. In Italy, women are often expected to be many things, a wife, a mother and a worker, and with lupus you can’t do everything, so you need to find a compromise.”

Francesca Marchiori, Lupus Italy



“In Bangladesh, particularly in rural families, women are in charge of household chores. It is difficult for families to understand why a woman with lupus is unable to do the things she is expected to do. It can also be difficult for a young, unmarried woman to tell people about her lupus because it may affect her chances of getting married.”

Mohammad Lutfullah, Lupus Foundation of Bangladesh

Extending education to help address such perceptions is therefore critical. Physicians we have spoken to say that involving families in medical consultations from the point of diagnosis can help patients feel their symptoms have been legitimised, and ensure that those around them understand just how severely the disease can impact on a person’s ability to function.



“We have to reach patients’ families and social networks because often when women are sick the whole household comes to a halt.”

Dr. Susan Manzi, Chair of the Department of Medicine of Allegheny Health Network, and Co-Director of the Lupus Center of Excellence and, Medical Director of the LFA



While physicians, friends and family all have a role to play in offering physical and emotional support to people with lupus, no one else will ever truly understand the complexity and challenges of the disease unless they experience it themselves. Patients report that talking to other people with lupus in order to share experiences and advice, either face to face in a support group setting or via social media, is an invaluable source of support.

continued...

Living with Lupus

Family matters continued...

"You need a good support network around you in the form of family and friends, especially of lupus' unpredictable nature. You need people there that can help and understand what's going on for you."

Elaine Holland, Lupus UK

Accessing online communities to reach out to other lupus patients, family members of those with lupus and healthcare professionals interested in or involved in treating lupus can provide a safe outlet for those looking for advice on managing symptoms and living with the disease.

Forums such as **#LupusChat** can offer a platform for patients and caregivers to share experiences and advice with each other. It was launched in May 2012 by patient advocate, Tiffany Peterson.



"#LupusChat allows lupus patients all across the globe to connect to discuss lupus and how it affects different aspects of their lives. #LupusChat occurs every other Sunday at 3pm ET on Twitter during which we discuss various topics pertaining to lupus. Patients, caregivers, healthcare professionals, and all are welcome to the conversation."

"It helps talking to fellow patients about things like not sleeping. You need to know about the problems and adjust your life around them."

Tiffany Peterson, #LupusChat, US



"It would be a very positive step if, every time a lupus diagnosis is made, physicians tell the patient that there is a group of other patients that they can communicate with to help them to understand and cope with their disease. To know that you are not the only one with lupus, to see others with a disease the same as yours, to know that you can feel better than you do today is very important for patients' mental health; it will help them to live in peace with this disease and eventually have a better quality of life."

Gonzalo Andrés Tobar Carrizo, Lupus Chile



"Connecting patients with each other often gives a better result for them; when patients communicate with each other, many issues can be resolved just by exchanging information and experiences. Patient networking is an effective platform for psycho-social counselling."

Mohammad Lutfullah, Lupus Foundation of Bangladesh

Lupus support groups can offer a place to talk, share experiences and to learn from others dealing with the same challenges so that members can manage and live with their condition together. A list of local support networks aimed at assisting people living with lupus, their families, colleagues, and healthcare providers can be found on the World Lupus Day website, at:

<http://www.worldlupusfederation.org/lupus-groups-around-the-world.html>



Lupus Knows No Boundaries e-Report

The Role of Industry



Shining light on the invisible disease

Awareness of lupus has long been low. It is misunderstood, and can be an unpredictable disease that is difficult to spot, with many symptoms that are diverse and non-specific, and many patients report waiting years for an accurate diagnosis. But even after the uncertainty has ended and lupus has been identified, patients must come to terms with living their life with a disease for which there is no cure, and limited options for treatment.



Researchers and pharmaceutical companies have faced numerous obstacles over the past decades in their bid to gain a better understanding of the disease. Despite years of research and countless potential medicines being studied, the exact cause of lupus is still unknown and it remains incredibly difficult to successfully bring new medicines to patients. Only one treatment developed specifically to manage lupus has received regulatory approval since the 1950's.²¹



As a result, physicians have had to rely on 'borrowing' drugs from other disease areas to treat the condition. Cancer treatments, drugs for transplant patients, antimalarials and steroids are often used to reduce the impact of symptoms.^{22,17} However, these treatments tend to be very powerful and often come with side effects that can cause other health complications that may be worse than the disease itself. Physicians are therefore faced with the challenge of balancing symptom control with the damage caused by the toxicity and side effects of the drugs¹³ – even though they do little to address the underlying cause of the disease.



Dr. Susan Manzi, Chair of the Department of Medicine of Allegheny Health Network, and Co-Director of the Lupus Center of Excellence and, Medical Director of the LFA

“One of our challenges has been that we don't have enough drugs to treat lupus. In part, that's because lupus is such a complex disease. It appears differently in so many patients. Some patients may only have heart involvement. Some patients have kidney involvement, so conducting the trials and actually getting the results you need to get drugs past regulatory agencies has been difficult.”



Tiffany Peterson, #LupusChat, US

“There is a great need for research and funding for treatments because we do not have enough options, and most of those we do have were approved by the FDA in the 60s, 70s and 80s – this is unacceptable.”

The Role of Industry

A helping hand from industry

Motivated by growing awareness and understanding of the enormous impact lupus has on patients' lives, and new learnings from advances in science such as cell biology and DNA sequencing, more pharmaceutical companies are actively working on lupus research. A number of drugs are being studied and there is hope that with increasing interest in lupus by the biomedical and pharmaceutical industries, more new treatments will be delivered in the coming years – specifically developed for lupus – that will help improve quality of life for patients.



“We need to continue to invest time and resources into the search for better treatments that target the drivers of disease, regardless of the number of people it might affect.”

Dr. Vlad Hogenhuis, Global Franchise Head Specialty Care, GSK



VIDEO | Elaine Holland – ‘A positive future’

Problem viewing? [Click here](#)

Collaboration is key

But more needs to be done. Many patient groups believe that as well as developing new and effective treatments, the healthcare industry can and should work towards having an impact that extends beyond medicine. With privileged access to the very latest research and expertise in lupus, pharmaceutical companies are uniquely placed to share their knowledge, and contribute to increasing the lupus community's collective understanding of the disease.



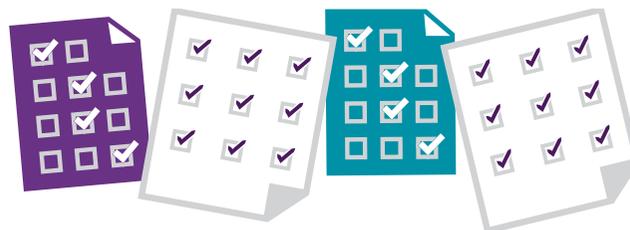
“Pharmaceutical companies have much greater resources than academic resources and so we need to find better ways of partnering with each other to raise awareness in a product neutral way.”

Dr. Susan Manzi, Chair of the Department of Medicine of Allegheny Health Network, and Co-Director of the Lupus Center of Excellence and, Medical Director of the LFA



“The pharmaceutical industry needs to open the channels of communication with patients to figure out what their needs are, and provide them with information and resources.”

Tiffany Peterson, #LupusChat, US



Duane Peters of the World Lupus Federation believes that the pharmaceutical industry has an important role to play in raising public awareness of lupus, and also in “improving the lives of patients through the development of physician education materials and tools, on symptoms, diagnosis and management options.”

And industry is receptive. Dr. Vlad Hogenhuis, Global Franchise Head of Specialty Care at GSK, says for him, the reason to invest in research to find solutions for diseases like lupus is the opportunity to have a direct impact on individual patients' lives. By building awareness among the public about the signs and symptoms of lupus and ensuring physicians are better trained in what to look for, pharmaceutical companies can bring their knowledge to bear, and positively contribute to improving quality of life.

He notes: “The important thing is to look at each patient, to see the value of what we do in every single case. However common or uncommon a disease is shouldn't affect our devotion to finding solutions, which is why raising awareness, conducting research and sharing scientific insights that spur the educative process are so important.”

Against this backdrop of growing interest from the pharmaceutical industry, the future is looking bright for lupus patients. With increased education and awareness comes the promise of better support and greater understanding, and as science forges ahead, the possibility of new treatments that will change the course of the disease once and for all.

Lupus Knows No Boundaries e-Report

Report Summary



Report Summary

There is no boundary to the impact of lupus. Lupus is a global health problem that affects people of all nationalities, races, ethnicities, genders and ages. Lupus can affect any part of the body at any time, often with unpredictable and life-changing results.¹

While lupus knows no boundaries, knowing all we can about lupus can help control its impact.

The *Lupus Knows No Boundaries* report brings together the firsthand experiences of people with lupus, their advocates and those who treat them, to tell the real story of lupus and highlight the ongoing physical and emotional needs of those affected.

A recent Twitter poll* of people with lupus showed that:



On average, **43%** of people fear inactivity and isolation most when it comes to lupus.

Lupus: Disease Background



Lupus mostly affects **women of childbearing age**, but men, children, and teenagers develop lupus, too. Most people with lupus usually will develop the disease **between the ages of 15-44**.^{1,2}

There is no cure and the causes are largely unknown; however, experts believe **hormones, genetics and environment** likely are involved with the disease.⁸



At least **five million** people worldwide are thought to have lupus.¹



“Lupus is a disease that waxes and wanes. There are periods when it is active and others when it is not – you never know what to expect.”

Sandra C. Raymond, President & CEO, Lupus Foundation of America

Disease Perceptions

As a society, our knowledge and understanding of lupus remains extremely low.

A 2016 global survey highlighted:¹⁵



36% of the general population is not aware that **lupus is a disease**.



51% could not identify or did not know the leading health complications associated with lupus, such as **kidney failure, anaemia or a heart attack**.

Although awareness is slowly increasing, thanks to the educational efforts of advocacy groups such as the World Lupus Federation, people with lupus continue to experience a degree of prejudice and discrimination.

The global survey revealed the stigma associated with lupus resulting from a widespread misconception that the disease is contagious:¹⁵



47% feel ‘less than comfortable’ **shaking hands** with someone with lupus.



44% feel ‘less than comfortable’ **sitting next to someone** who has lupus.



“There are some myths about lupus as a result of low levels of public awareness, such as: lupus is a cancer, it’s the same as AIDS, it only affects women, it’s a genetic and hereditary illness, it is contagious. The stigma of lupus can be removed with more information and awareness.”

Gonzalo Andrés Tobar Carrizo, Lupus Chile

Report Summary

Lupus in the Media



“Unfortunately, lupus often is not portrayed accurately on television or in films. That mischaracterisation contributes to misconceptions by the public about how serious and debilitating lupus can be. On the plus side, through social media, many people have been able to share their personal stories and daily struggles, and that has helped millions of people around the world. It’s really important for people with lupus to speak out.”

Julian Lennon, photographer, author, musician, philanthropist and Global Ambassador for the LFA

Around the world, physicians, advocacy groups and people with lupus themselves are working to increase knowledge and understanding about the disease to ensure that patients are treated with compassion and without fear of discrimination.



Living with Lupus

Living with lupus isn’t easy. Many patients report that the disease has a debilitating impact on their physical and emotional health, often leading to depression, stress and anxiety.¹⁶



“Fatigue can prevent us from doing the most simple, everyday things, such as taking a shower, brushing our hair, brushing our teeth, getting dressed or getting out of bed.”

Teresa Gladys Cattoni, Asociación Lupus Argentina (ALUA)

“You have to find a way to cope and make changes to your lifestyle – you learn how to live life the best way you can with lupus and you have to try not to let it stop you doing anything.”

Yvonne Norton, Lupus UK



Patient Support

Adapting to the limitations lupus imposes on everyday life requires support from healthcare professionals, friends and family; with their understanding quality of life can be improved.⁷

Accessing online communities and support groups can provide a valuable resource for those looking for advice on managing symptoms and living with the disease.



“My initial reaction when I was told I had lupus was relief – I finally had an answer that made sense and now I could fight it. It scared me because there’s no cure, but I could figure out what medication may help me with it, I could join a support group, I could talk to people who have it to really figure out what it was and what it was doing to my body.”

Shannon Boxx, Olympic Gold Medalist and LFA Ambassador

A list of local support networks can be found on the World Lupus Day website, at:

<http://www.worldlupusfederation.org/lupus-groups-around-the-world.html>



“Connecting patients with each other often gives a better result for them; when patients communicate with each other, many issues can be resolved just by exchanging information and experiences.”

Mohammad Lutfullah, Lupus Foundation of Bangladesh

Report Summary

The Role of Industry



“Pharmaceutical companies have much greater resources than academic resources and so we need to find better ways of partnering with each other to raise awareness.”

Dr. Susan Manzi, Chair of the Department of Medicine of Allegheny Health Network, and Co-Director of the Lupus Center of Excellence and, Medical Director of the LFA



“When we in the pharmaceutical industry talk to individual physicians about diseases such as lupus, we need to think less of impersonal data and presentations, and more about the specific changes we can make to people’s lives, asking questions and looking for individual signs.”

Dr Vlad Hogenhuis, Global Franchise Head Specialty Care, GSK



“Find a good doctor, sort out the medication and then put lupus in a little box and get on with your life.”

Yvonne Norton, Lupus UK

In recognition of World Lupus Day taking place on 10th May 2017 we’re calling for everyone to unite and take action on behalf of those affected by lupus around the world with a common purpose of bringing greater attention and resources to help end the suffering caused by this disabling and potentially fatal autoimmune disease.

To support World Lupus Day, join the World Lupus Federation by urging the World Health Organisation to make lupus an international health priority.

Sign the petition here and learn more at: worldlupusday.org

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.

References

1. Lupus Foundation of America. What is Lupus? Available at: http://www.resources.lupus.org/entry/what-is-lupus?utm_source=lupusorg&utm_medium=answersFAQ. Last accessed April 2017
2. Lupus Foundation of America. Lupus statistics and facts. Available at: <http://www.resources.lupus.org/entry/facts-and-statistics> Last accessed April 2017
3. NIH National Institute of Arthritis and Musculoskeletal Diseases. Handout on health: systemic lupus erythematosus. Available at: http://www.niams.nih.gov/Health_Info/Lupus/ Last accessed April 2017
4. Danchenko N, Satia JA, Anthony MS. Epidemiology of systemic lupus erythematosus: a comparison of worldwide disease burden. *Lupus* 2006;15:308–18.
5. Yelin E, Trupin L, Katz P, et al. Work dynamics among persons with systemic lupus erythematosus. *Arthritis Rheum* 2007;57:56-63
6. 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;19:1640–8
7. NHS Choices. Lupus: introduction. Available at: <http://www.nhs.uk/conditions/lupus/pages/introduction.aspx> Last accessed April 2017
8. Lupus Foundation of America. What causes lupus? Available at: http://www.resources.lupus.org/entry/what-causes-lupus?utm_source=lupusorg&utm_medium=answersFAQ. Last accessed April 2017
9. NHS Choices. Lupus Symptoms. <http://www.nhs.uk/Conditions/Lupus/Pages/Symptoms.aspx> Last accessed April 2017
10. Mok CC, Lau CS. Pathogenesis of systemic lupus erythematosus. *J Clin Pathol* 2003;56:481–90
11. Bertias G, Cervera R & Boumpas DT. Systemic lupus erythematosus: pathogenesis and clinical features. EULAR textbook on Rheumatic diseases. 2012
12. Antonis Fanouriakis & George Bertias. Treat-to-target in lupus: what does the future hold? *International Journal of Clinical Rheumatology*. 2015.
13. WebMD. Lupus Medications. <http://www.webmd.com/lupus/guide/lupus-systemic-lupus-erythematosus-medications> Last Accessed April 2017
14. Confederation of Meningitis Organisations. Meningitis Factsheet. Available at: <http://www.comeningitis.org/media/67567/meningitis-factsheet-final-april-2013.pdf> Last accessed April 2017
15. World Lupus Federation. Global Disease Awareness Survey 2016
16. WebMD. Lupus and Mental Health Concerns. <http://www.webmd.com/lupus/guide/psychosocial-aspects-lupus#1> Last accessed April 2017
17. NHS Choices. Lupus treatment. Available at: <http://www.nhs.uk/Conditions/Lupus/Pages/Treatment.aspx>. Last accessed April 2017
18. Nossent J, Kiss E, Rozman B, et al. Disease activity and damage accrual during the early disease course in a multinational inception cohort of patients with systemic lupus erythematosus. *Lupus* 2010;19:949–56
19. Lupus Foundation of America. Patient and Caregiver Survey Research. National Needs Assessment on Lupus. June 2016
20. Lupus UK. Friends and Family. Available at: <http://www.lupusuk.org.uk/family-and-friends/> Last Accessed: April 2017
21. Benlysta SPC. Available at: <http://www.medicines.org.uk/emc/medicine/24769> Last accessed May 2017
22. Lupus Foundation of America. Finding the right treatment approach for you. Available at: http://www.resources.lupus.org/entry/treatment-options?utm_source=lupusorg&utm_medium=answersFAQ. Last accessed April 2017

* Twitter poll of people living with lupus, conducted via 12 patient advocacy groups in nine countries, with a total of 2048 votes cast. Please note that although this social media poll gives us valuable insights, it is not statistically significant or demographically representative.