



Trustees' Annual Report for the period

From	Period start date			To	Period end date		
	Day 01	Month 01	Year 2024		Day 31	Month 12	Year 2024

Section A Reference and administration details

Charity name	LUPUS UK
Other names charity is known by	-
Registered charity number (if any)	1200671
Charity's principal address	St James House, Eastern Road, Romford, Essex
Postcode	RM1 3NH

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Elaine Holland	Chair		
2	Wendy Diment	Vice Chair		
3	Kevin Weston	Treasurer		
4	Jenny Ainsworth			
5	Jolene Cheung			
6	Julian Zbar			
7	Jacqueline Coulton			
8	Sue Grewcock			
9	Ricky Chotai			
10	Colin da Silva		19/05/2023	
11	Shaista Ahmad		19/05/2023	
12	Matthew Stinchcombe		19/05/2023	
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20				

Names of the trustees for the charity, if any, (for example, any custodian trustees)

Name	Dates acted if not for whole year

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address

Name of chief executive or names of senior staff members (Optional information)

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Section B Structure, governance and management

Description of the charity's trusts

Type of governing document
(eg. trust deed, constitution)

Constitution

How the charity is constituted
(eg. trust, association, company)

CIO

Trustee selection methods
(eg. appointed by, elected by)

Appointed by the Board

Additional governance issues (Optional information)

You **may choose** to include additional information, where relevant, about:

- policies and procedures adopted for the induction and training of trustees;
- the charity's organisational structure and any wider network with which the charity works;
- relationship with any related parties;
- trustees' consideration of major risks and the system and procedures to manage them.

Opportunities for training are circulated to the trustees to encourage best practice and the trustees each have a copy of the NCVO publication 'The Good Trustee Guide'. New trustees are encouraged to read the Charity Commission publication, 'The Essential Trustee'.

Section C Objectives and activities

Summary of the objects of the charity set out in its governing document

The Charity is established to relieve persons, regardless of class, colour, creed, gender, age or sexual orientation suffering from lupus and to advance the education of the public in all aspects of the disease.

Summary of the main activities undertaken for the public benefit in relation to these objects (include within this section the statutory declaration that trustees have had regard to the guidance issued by the Charity Commission on public benefit)

The charity will take over from LUPUS UK (1051610) and will continue to work closely with the medical profession to raise awareness of the disease to all patients. Membership of the charity is open to all who are interested in supporting its work, whether they have lupus or not. Enquiries about the disease are regularly received from the public; the charity makes information and advice available freely to everyone.

The trustees confirm that they have referred to the Charity Commission's general guidance on public benefit when reviewing the charity's aims and objectives in planning future activities.

To maximise its effectiveness, LUPUS UK is actively involved with umbrella organisations such as National Voices and is a founding member of RAIRDA (Rare Autoimmune Rheumatic Diseases Alliance), along with Scleroderma & Raynaud's UK, Vasculitis UK and The British Society for Rheumatology. Established to improve care for people living with these conditions with the purpose of bringing together clinical and patient organisations and other key stakeholders in order to raise the profile of rare autoimmune rheumatic diseases, influence policy and guide future research.

Throughout 2023, RAIRDA has continued its efforts to have Quality Standards for the diagnosis and care of rare diseases developed and implemented by healthcare services in the UK. In its capacity as secretariat for the Independent Advisory Group (IAG) to the rare disease forum, RAIRDA met with NICE Chief Medical Officer, Dr Jonathan Benger, and secured his agreement that a Quality Standard for rare disease should be a priority for NICE.

As a member of the World Lupus Federation, LUPUS UK aims to link up with other lupus organisations around the world to raise public awareness of the disease.

Additional details of objectives and activities (Optional information)

You **may choose** to include further statements, where relevant, about:

- policy on grantmaking;
- policy programme related investment;
- contribution made by volunteers.

Income will be derived from a variety of sources, and we typically receive tremendous support from various activities and events, which are often prompted by the personal interest of a family member or friend.

LUPUS UK will ensure that it is not reliant on any one source of income. The charity does not use the personal information of members and supporters for marketing purposes and does not use call centre's for fundraising.

The charity will invite applications for the funding of research projects and Specialist Lupus Nurses. Applications for research funding are reviewed against specific criteria and research objectives by the Medical & Scientific Advisory Panel, who make their recommendations to the trustees.

The charity will provide opportunities for people living with lupus to be involved in the development of research or participate in studies and trials. The opportunities will be advertised to the lupus patient community regularly.

Summary of the main achievements of the charity during the year

The charity has not commenced operations but will do so from 1 January 2024.

The transfer of assets and liabilities from LUPUS UK (1051610) to the Charitable Incorporated Organisation (CIO) is progressing well and should be completed in spring 2024, enabling the charities to register a merger with the Charity Commission.

Section E

Financial review

Brief statement of the charity's policy on reserves

There are no finances to report at present.

The charity's policy in respect of the level of reserves will be to aim to retain a minimum sum in the region of one year's expenditure, which will be held on deposit.

Details of any funds materially in deficit

n/a

Further financial review details (Optional information)

You **may choose** to include additional information, where relevant about:

- the charity's principal sources of funds (including any fundraising);
- how expenditure has supported the key objectives of the charity;
- investment policy and objectives including any ethical investment policy adopted.

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Section F

Other optional information

Section G

Declaration

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)

E. Holland.

Full name(s)

Elaine Holland

Position (eg Secretary, Chair, etc)

Chair

Date

19/05/2024