

LUPUS UK

Charity No's. 1051610 & SC039682

**TRUSTEES' REPORT AND FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 DECEMBER 2022**

**REFERENCE AND ADMINISTRATION DETAILS OF THE CHARITY, IT'S TRUSTEES
AND ADVISERS FOR THE YEAR ENDED 31 DECEMBER 2022**

CHARITY REGISTRATION NUMBERS: 1051610 & SC039682

ADDRESS St James House
Eastern Road
Romford
Essex RM1 3NH

TRUSTEES:
(throughout the year) Elaine Holland (Chair)
Wendy Diment (Vice Chair)
Jenny Ainsworth (Secretary)
Kevin Weston (Treasurer)
Jolene Cheung
Kim Opszala
Julian Zbar
Jacqueline Coulton
Sue Grewcock
Ricky Chotai
Lucy Manning

CEO: Mr P Howard

AUDITORS: Messrs Hillier Hopkins LLP
51 Clarendon Road
Watford
Hertfordshire
WD17 1HP

BANKERS: Barclays Bank plc
Romford Business Centre
Romford
Essex RM1 1RF

CAF Bank Ltd
25 Kings Hill Avenue
Kings Hill
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ME19 4JQ

REPORT OF THE TRUSTEES

FOR THE YEAR ENDED 31 DECEMBER 2022

The trustees present the annual report and the audited accounts of the charity for the year ended 31 December 2022. The financial statements have been prepared in accordance with the accounting policies and comply with the charity's Constitution and applicable law.

THE CHARITY

LUPUS UK is the national charity for all people affected by lupus in England, Wales, Scotland and Northern Ireland. Its objectives are:

- To increase awareness of lupus amongst patients, health professionals and the public.
- For all people with lupus in the UK to have a timely diagnosis and equitable access to high quality treatment.
- To empower people living with lupus.
- To support families and carers impacted by a diagnosis of lupus.
- To influence at policy level, ensuring that the voices of those living with lupus are heard.
- For LUPUS UK to represent the whole lupus community.

The original charity, British SLE Aid Group was founded in 1978 and registered as LUPUS UK from 1996 with the new Constitution approved on 14 October 1995. The Constitution has been amended periodically since then.

Vision A world where people with lupus can lead full and active lives.

Mission To empower people by providing information about lupus and offering support, so their voices are heard and their condition diagnosed and managed effectively.

At the Annual General Meeting in May 2022, the membership voted overwhelmingly in favour of LUPUS UK changing its legal form to become a Charitable Incorporated Organisation (CIO) and they adopted a new Foundation model Constitution. The membership authorised the trustees of LUPUS UK to transfer all assets to the new CIO and dissolve the original charity upon completion of the incorporation. During 2022, a new CIO was registered with the Charity Commission with the same charity name, "LUPUS UK" and the registered charity number 1200671. It is expected that the charity will complete the incorporation and begin operating with the new Constitution in summer 2023.

Trustees

The trustees of the charity who served during the year ended 31 December 2022 are shown on page one.

The maximum number of trustees permitted is twelve, of which eight were elected by the membership at the Annual General Meeting, with the remaining four being appointed by the Board. The trustees are elected/appointed by rotation and serve a period of three years, at which point they are eligible to either stand for re-election or step down.

The Board held their four formal meetings during the year, together with additional meetings to make decisions as required by the charity.

The trustees have also continued with several Committees which meet to discuss priority topics in more depth and make recommendations to the Board. At present there are Committees for; Key Performance Indicators; Incorporation; Equity, Diversity & Inclusion; Ambassadors; Centres of Excellence; Patient Involvement in Research; Finance & Resources; Devolved Nations; and Welfare.

In spring 2022 James McCarthy, Janet McComiskey, Jan Roberts and David Hopkins stepped down from the Board. The Board expressed their gratitude for the commitment and effort they demonstrated during their time in the role.

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At the Annual General Meeting held in Bury on 14th May 2022, Kevin Weston was re-elected, and Julian Zbar, Jacqueline Coulton and Sue Grewcock were elected to the Board. Following the AGM, the Board re-appointed Kim Opszala and appointed two further trustees: Lucy Manning and Ricky Chotai. The Board also welcomed Kim Sharrier as an Associate Trustee for a term of one year. As an Associate Trustee, Kim can participate in meetings but may not vote on Board matters and does not have the full legal and financial responsibility of a trustee.

Following Kevin Weston's re-election as a trustee, the Board re-appointed him as Treasurer. Sammy Ainsworth was appointed as Secretary by the Board after the resignation of David Hopkins.

At present, all trustees either have lupus or have family members living with the disease.

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'.

LUPUS UK's trustees continue to implement the recommendations from the governance review conducted by Cass Business School in summer 2021.

Management

The daily management of LUPUS UK is under the control of the CEO see page one, who is responsible for staff and the running of National Office, and reports to the trustees.

Key Management Remuneration

Remuneration for key management personnel is benchmarked against the voluntary sector and is set by the trustees.

OBJECTIVES, ACTIVITIES AND PERFORMANCE

Systemic Lupus Erythematosus (SLE) usually referred to as lupus, is an autoimmune disease where the immune system is dysfunctional, mistakenly identifying the body's own tissues as foreign invaders and attacking any part of it. At present, there is no known cure. The diversity and intensity of symptoms and damage to organs can make it a very difficult and potentially disabling disease to live with. Most people who have lupus require life-long medication, the side-effects of which can lead to potential problems.

Due to the complexity of the disease, lupus will typically be diagnosed by a consultant based on classification criteria. It can sometimes affect one system of the body more intensely than others. If the kidneys are affected, it is usually referred to as lupus nephritis. If the skin and hair are the dominant parts affected, it is usually referred to as cutaneous lupus (of which discoid lupus is a recognised sub-type). Other terms may be used by clinicians to define particular aspects of the disease.

Being diagnosed with lupus can be a lonely experience as the newly diagnosed are unlikely to know anyone else with the disease. The main purposes of the charity are to bring together, support and help people living with lupus, and their families, and to advance awareness and education of the public and particularly the medical and health professions in all aspects of the disease. There are several keyways in which the charity does this, including its telephone helpline, Group meetings in various parts of the country and information in a range of formats. LUPUS UK provides funding for medical research into the causes and consequences of lupus and improved medication, and for Specialist Lupus Nurses within the NHS.

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FOR THE YEAR ENDED 31 DECEMBER 2022

Activities

In December 2021 the charity recruited Alida Horne in the new role of Volunteer Coordinator. This new staff role was important to increase the capacity of the National Office and allow for improved support of volunteers in various roles throughout the organization. The Volunteer Coordinator can work closely with current volunteers and aid the recruitment of new volunteers, which is essential for the growth and sustainability of LUPUS UK. Throughout 2022, Alida was instrumental in the development of new Coffee & Chat groups to increase our provision of regional peer-led support. New groups were started in Harrogate, Leeds, Darlington, and Sutton.

Several Regional Groups of the charity re-started in-person activities which had been paused earlier in the pandemic. Meanwhile, some groups continued to provide virtual meetings or a mixture of event formats. The charity's Annual General Meeting was held in Bury and included a Lupus Information Day event, featuring expert guest speakers discussing a range of lupus-related topics and a question-and-answer panel. The event was well attended although numbers had not recovered to pre-pandemic levels as some people from the lupus patient community continue to take extra precautions. The Enfield Lupus Group also hosted a small Lupus Information Day event during Lupus Awareness Month in October with the support of staff.

The British Society for Rheumatology (BSR) annual conference returned in 2022 and LUPUS UK joined with other members of the Rare Autoimmune Rheumatic Diseases Alliance (RAIRDA) for an exhibition stand. Paul Howard, Chief Executive of LUPUS UK attended on behalf of the charity, attending several sessions about lupus and networking with many clinicians and researchers.

Throughout 2022, LUPUS UK continued to prioritise updating information resources about COVID-19 vaccinations and treatments because of a significant need from the lupus patient community. Whilst access to booster vaccine doses improved in 2022 there were many reports of lupus patients having difficulty accessing priority testing and treatments following a positive test. LUPUS UK contributed to NHS England stakeholder meetings to ensure these experiences were heard and service provision improved.

In the second half of the year, we joined a coalition of charities and patient groups campaigning for access to the COVID-19 preventative prophylaxis treatment, Evusheld. The treatment was approved for use by the MHRA in March 2022, but the UK Government did not procure it, citing a lack of evidence for efficacy in the Omicron variants. Evusheld represented the best chance of addressing the inequity experienced by many people who are immunosuppressed who have inadequate protection from the COVID-19 vaccines and frequently continue to have restricted lives to reduce risk of exposure to coronavirus.

LUPUS UK contributed to the NICE health technology appraisals for Evusheld and COVID-19 therapeutics, highlighting the experiences of people living with lupus and the importance of having a range of treatment options available for this heterogeneous population to avoid creating further inequity.

Also in 2022, NICE began the health technology appraisal for the new lupus nephritis treatment, voclosporin. As a stakeholder organisation, LUPUS UK nominated patient and clinical experts to be part of the committee meeting and made submissions on behalf of the lupus patient community, collating the experiences of many people with lupus nephritis as well as people who care for them.

The charity was delighted to award grants for several research initiatives relating to innovations in treatment, addressing the challenge of cutting diagnosis times, improving clinic appointments, and providing psychosocial support for people with lupus.

Treatment innovations

- **Could the intestine be a new target for lupus prevention and treatment?** Institute of Immunity and Transplantation, Division of Infection and Immunity, UCL, London; £22,881 over 12 months.

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- **Understanding how lymph node B cells in lupus patients malfunction and whether they could be a target for developing new treatments.** UCL Institute of Immunity and Transplantation; £20,576 over 12 months.
- **Using blood markers and artificial intelligence to better understand differences in disease between patients with childhood-onset lupus.** Centre for Adolescent Rheumatology, UCL; £24,942 over 12 months.

Improved diagnosis

- **Characterising individual immune cells in patients with lupus - investigating the metabolic changes in the immune cells of SLE patients using single cell-based techniques.** Kennedy Institute of Rheumatology, University of Oxford; £25,000 over 12 months.

Improving clinic appointments

- **Testing whether communication training for rheumatologists and lupus patients can improve symptom reporting and satisfaction with care.** Department of Public Health and Primary Care, University of Cambridge; £25,000 over 12 months.

Psychosocial support for people with lupus

- **Working with lupus patients to develop support for mental wellbeing.** University of the West of England (UWE) & RNHRD; £24,827 over 48 months.

A five-year grant was awarded to Alder Hey Children's Hospital NHS Trust to support their appointment of a Paediatric Lupus Clinical Nurse Specialist. The new role will increase the support offered to young people and families in their clinics and aid with research undertaken by the Early Arthritis Treatment Centre (EATC) for Children.

In the last few months of 2022, LUPUS UK National Office migrated their CRM database to a new provider after support for the previous software was withdrawn. The eTapestry system from Blackbaud offers a range of new features and, in time, should improve efficiency for staff at the charity.

Key Performance Indicators

Our online presence has continued to grow throughout the year. At the end of the year the number of followers on social media was: Facebook 38,441 (2021: 36,816), Twitter 10,705 (2021: 10,382), Instagram 9,997 (2021: 8,841), HealthUnlocked 30,129 (2021: 29,110) and LinkedIn 1,085 (2021: 702). There were 379,537 (2021: 558,632) unique visits to the LUPUS UK website during 2021. There were also 31,175 (2021: 42,599) downloads of our patient publications.

LUPUS UK is a charity for everyone affected by lupus but members who pay an annual subscription remain very important. During 2021 we had 221 (2021: 368) people join the charity as paying members. There is a dedicated group of members who have supported LUPUS UK over many years and our service to them remains very important.

The CEO and trustees are developing a new dashboard of key performance indicators during 2023 to give a broader perspective of how the charity is progressing with each of its objectives and to aid in the management and mitigation of risk.

Funding

Our income is 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. Income has not recovered to pre-pandemic levels, partially due to some of our patient

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community remaining at a higher risk from COVID-19 and continuing to take additional precautions. Recovery of the charity's income has also been weakened by the cost-of-living crisis in the UK, resulting in many people needing to reduce charitable contributions as household expenditure rises rapidly. In 2022 we did see income from charitable activities improve from the previous year. This was largely helped by a very successful year for LUPUS UK's London Marathon runners. The trustees ensure that the charity 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 centres for fundraising.

In addition to the London Marathon, in the autumn of 2022 we had plenty of participants in large, organised events such as the Great North Run and Royal Parks Half Marathon.

Virtual challenges which started during the pandemic such as the 10-day challenge for World Lupus Day and the 31-mile challenge during Lupus Awareness Month continue to be a popular way for people to fundraise and support the charity.

Information

The LUPUS UK website (www.lupusuk.org.uk) is packed with information and guidance and includes the Eclipse – Light Sensitivity area for those with light sensitivity problems. LUPUS UK was accredited by the Information Standard, a scheme which closed in 2021. After some false-starts, the charity is now progressing with its assessment for the scheme's replacement, the Patient Information Forum (PIF) Tick Scheme. These accreditations enable the charity to display information on NHS websites and help the public to identify reliable sources of evidence-based information.

LUPUS UK keeps in regular contact with lupus specialists and lupus nurses, who may, via the LUPUS UK website, link into the section 'Information for Medical Professionals', which includes information and the procedure for grant applications. The charity is grateful for the advice and help of its Scientific and Medical Advisory Peer Review Panel for assessing grant applications and additional matters, along with the support of other medical professionals. Recognising the importance of lupus awareness within both the medical profession and the wider public, one of the charity's aims is to provide literature and information to all people with lupus via lupus and rheumatology clinics.

LUPUS UK works closely with the UK JSLE Cohort Study: a collaboration between 23 paediatric hospitals around the UK, looking into the incidence, causes and treatment of lupus in children and young people, of which over 800 are now enrolled on its various research projects. This will give further information about how they are affected by lupus, standards of care and best treatment.

LUPUS UK gives its Centres of Excellence award in recognition of the excellent care of lupus patients and productive research into the disease. Ten hospitals have so far received this recognition: Queen Elizabeth/City Hospitals, Birmingham; Manchester Royal Infirmary; Alder Hey Children's Hospital, Liverpool; University College London Hospital; the Louise Coote Lupus Unit, Guy's & St Thomas' Hospital, London; the Royal National Hospital for Rheumatic Diseases, Bath; Addenbrooke's Hospital, Cambridge; University Hospital Southampton; Great Ormond Street Hospital; and Barts Health Lupus Centre, Mile End Hospital, London.

LUPUS UK continues to be an active member of Lupus Europe.

Risk Management

In 2022 the Board of Trustees formed the Finance & Resources Committee. One of the priorities of this Committee was to review the charity's Risk Register and provide recommendations for how we can monitor and mitigate risk more effectively. A further revision of the Risk Register was undertaken,

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significantly improving functionality. The Finance & Resources Committee is due to meet again in 2023 to discuss the areas of highest risk and recommend actions to mitigate these to the Board.

The Risk Register covers five key areas: Operational, Governance, Legal & Regulatory, Financial, and Environment & External. In each area the trustees consider the likelihood and impact of risks and consider ways to mitigate any potentially adverse effects. As examples, the charity ensures that it is not reliant on any one source of income, also all payments over the value of £5,000 require the second signature/authorisation of the Treasurer or Chair. LUPUS UK continues to review its requirements under GDPR (General Data Protection Regulation) and ensure its policy is practiced by all.

LUPUS UK has a robust reserves policy to ensure ongoing financial viability. Please see below.

Grant Making Policy

In 2022 the charity returned to its practice of two annual research funding rounds: spring and autumn. This was recommended by members of the Medical & Scientific Advisory Panel to provide more opportunities for grants whilst researchers are struggling with a challenging climate for securing lupus funding.

During 2022 the trustees approved grants totaling £407,829, following recommendations of the Medical & Scientific Advisory Panel. At the end of 2022 the charity's commitment to fund Grants over the next five years stands at £1,145,312. We continue to receive more applications than we have funds available.

The charity invites 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.

As LUPUS UK does not have sufficient funding available for large-scale research projects; it will continue to support applications that focus on the following:

- pilot and observational studies to provide evidence for novel hypotheses which may lead to applications to major funders for large-scale research trials.
- enabling grants for basic science support, which would enable larger projects by providing essential data for large grant applications.
- medical meetings that would facilitate improvements to the understanding of the causes, prevention and treatment of lupus and its research.

LUPUS UK is a partner of the National Institute for Health Research (NIHR) and a patient group partner of the Scottish Medicines Consortium.

The charity funds Specialist Lupus Nurses within the NHS and seeks a commitment that these posts will become permanently funded by the Hospital Trusts at the end of the five-year funding period. Six Specialist Lupus Nurses are currently being funded or have had funding agreed.

LUPUS UK is prudently managed with research and other grants only being approved by the trustees if funds are already held. Once the commitment has been announced, the funding is placed in a special reserve. Like most other charities, LUPUS UK has been impacted by the pandemic and economic climate and the trustees have taken account of this with regard to future budgets and will ensure that the charity tailors its commitments to its resources.

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FOR THE YEAR ENDED 31 DECEMBER 2022

FINANCIAL REVIEW OF ACCOUNTS

The state of the charity's affairs as of 31 December 2022, with comparative information for the previous year, is shown in the accompanying financial statements. The COVID-19 pandemic continued to impact income during the year, and this has been further compounded by the cost-of-living crisis.

Total funds received during the year were £733,743 against £859,130 in the previous year. Voluntary income (Donations received, Membership and Gift Aid, see note 2) was down by £109,764 on 2021, due mainly to a decrease in legacy income of £96,792. Donations were down slightly by £11,422. Investment income was up by £900. Charitable Activities (Fundraising) was down by £13,257 on 2021. Income from Charitable Activities (Sales) was down by £2,511, reflecting an ongoing reduction in demand for Christmas cards.

Total overall expenditure was up by £345,805. Within this figure the cost of generating voluntary income was up by £18,779 as the number of face-to-face meetings of the trustees and members increased. Fundraising costs were up by £12,113. Charitable Activities – Support and Administration costs were up by £314,913, due mainly to an increase in Grants attributable for the year of £280,963, to £433,705.

The overall deficit of income over expenditure was £205,829, compared to the surplus of £265,363 for 2021, before considering a change in the value of investments. The value of investments on 31 December 2022 stood at £1,086,026, which includes the reinvestment of dividends received of £18,415 during the year, along with a reduction in value of £196,785 that has been accounted for. The trustees anticipate that the value will rise in the coming years as the investments are of a long-term nature.

Reserves Policy

The charity's reserves on 31 December 2022 were £1,027,168 (2021: £1,429,782). LUPUS UK needs reserves to maintain its current activities and provide funding committed for longer term projects to progress them to completion, as well as enabling the trustees to meet their day-to-day responsibilities and ensure that the charity can operate as a going concern. The trustees have considered their policy in respect of the level of their reserves and aim to retain a minimum sum in the region of one year's expenditure, which will be held on deposit at the best available rate. The reserves as of 31 December 2022 meet this policy.

Investment Management

The Investment Portfolio is controlled by Rathbones Investment Management Ltd, and quarterly valuations are forwarded together with various reports. Our investments decreased in value by £196,785. Dividends received for the year totaled £18,415, which were reinvested into the investment portfolio. Interest received for the year was £1,145.

PUBLIC BENEFIT

The charity continues to work closely with the medical profession to raise awareness of the illness 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.

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To maximise its effectiveness, LUPUS UK is actively involved with umbrella organisations such as National Voices and is a founder 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.

In 2022, RAIRDA published a policy paper, "Resetting the Balance" addressing the imbalance with the UK Rare Diseases Framework which is strongly focused on genomics and therefore lacking recommendations for rare autoimmune rheumatic diseases such as lupus which are predominantly non-genetic. The paper provides recommendations for action in the following areas:

- Protection against the ongoing threat of COVID-19 and other viruses.
- Quicker and more effective processes for diagnosis.
- Better access to treatments – including new and innovative drugs across the UK.
- Better co-ordination of care.
- Improving access to specialist care and knowledge within the workforce.
- Reducing inequalities in access to high quality care and treatment.

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.

RELATED PARTIES

There were no related party transactions.

FUTURE PLANS

The trustees are making good progress with the incorporation of the charity by establishing a Foundation model Charitable Incorporated Organisation (CIO) and merging with the original charity. This will significantly reduce personal liability of the trustees if something were to go wrong. By taking this step the role of trustee should be made less onerous and could reduce deterrents to potential trustees volunteering to join the Board.

The charity is recruiting new staff at the National Office to increase capacity and provide additional support for the CEO. A new Office Manager role will improve the current management structure and provide additional support for staff. A Health Information Officer will enable the charity to enhance its provision of information and education resources. A Young People and Family Support Officer will provide dedicated support for a group which has been underserved by the charity historically. These staffing changes will help ensure the long-term sustainability of the organisation.

LUPUS UK will continue to raise lupus awareness and to advise and inform people about the disease.

The funding of lupus research and Specialist Lupus Nurses continues to be a priority. Funding for these is dictated by income and the charity will not commit to such expenditure unless the funds are already held.

VOLUNTEER INVOLVEMENT

The National Council of LUPUS UK is made up of trustees and representatives from the Regional Groups (which may be managed by a volunteer committee, who are mostly lupus patients) and Regional Coordinators, who are also often lupus patients. In total, including the nationwide network of telephone Contacts who offer a listening ear, around 100 people with lupus and a smaller number of

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supporters conduct the affairs of the charity at local and national levels across the usual range of the charity's educational, social and fundraising activities.

The charity is frequently provided with opportunities for people living with lupus to be involved in the development of research or participate in studies and trials. The opportunities are advertised to the lupus patient community regularly and volunteers enthusiastically sign-up.

The trustees would like to record their thanks to those people who commit their time and energy to the charity in a variety of ways, particularly those who assist in the running of its local Groups, especially the Group Chairs and Regional Coordinators. We welcome offers of help from those willing to work with and support the charity in this way.

The trustees recognise the commitment and dedication of our many volunteers and are very grateful to all who take on these various roles.

DONATIONS

The charity greatly appreciates the many people, companies, trusts, and other organisations who have made valued donations and support of people with lupus during the year.

E Holland

Elaine Holland
Chair/Trustee

Date 26/05/2023

K Weston

Kevin Weston
Treasurer/Trustee

Date 26/05/2023

STATEMENT OF TRUSTEES' RESPONSIBILITIES IN RELATION TO THE FINANCIAL STATEMENTS AS AT 31 DECEMBER 2022

The Trustees are responsible for preparing the Annual Report and financial statements in accordance with applicable laws and United Kingdom Accounting Standards (United Kingdom generally accepted accounting practice).

Law applicable to charities in England & Wales requires the Trustees to prepare financial statements for each financial year, which give a true and fair view of the charity's financial activities during the year and of its financial position at the end of the year. In preparing these financial statements, the trustees are required to:

select suitable accounting policies and then apply them consistently;

observe methods and principles in the Charities SORP;

make judgements and estimates that are reasonable and prudent;

state whether applicable UK accounting standards and statements of recommended practice have been followed, subject to any material departures disclosed and explained in the financial statements; and

prepared the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The trustees are responsible for keeping accounting records which disclose with reasonable accuracy the financial position of the charity and which enable them to ascertain the financial position of the charity and which enable them to ensure that the financial statements comply with the Charities Act 2011. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Kevin Weston

Treasurer

K Weston

Date

20/05/2023

Independent Auditor's Report to the Trustees of LUPUS UK for the year ended 31 December 2022

Opinion

We have audited the financial statements of Lupus UK (the 'charity') for the year ended 31 December 2022 which comprise the Statement of Financial Activity, Balance Sheet, Cash Flow and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 *The Financial Reporting Standard applicable in the UK and Republic of Ireland* (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charity's affairs as at 31 December 2022, and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charity's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

The other information comprises the information included in the trustees annual report, other than the financial statements and our auditor's report thereon. The trustees are responsible for the other information contained within the annual report. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Matters on which we are required to report by exception

We have nothing to report in respect of the following matters in relation to which the Charities Accounts (Scotland) Regulations 2006 require us to report to you if, in our opinion:

- the information given in the financial statements is inconsistent in any material respect with the trustees' report; or
- proper accounting records have not been kept; or
- the financial statements are not in agreement with the accounting records; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of trustees

As explained more fully in the trustees' responsibilities statement set out on page 11, the trustees are responsible for the preparation of financial statements which give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charity or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

We have been appointed as auditor under section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and report in accordance with regulations made under that Act.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The specific procedures for this engagement and the extent to which these are capable of detecting irregularities, including fraud is detailed below:

- We have assessed the nature of the industry and sector, control environment and business performance including the remuneration incentives and pressures of key management;
- The primary responsibility for the prevention and detection of fraud rests with both those charged with governance of the entity and management. We consider the results of our enquiries of management about their own identification and assessment of the risks of irregularities;
- Any matters we identified having obtained and reviewed the charity's documentation of their policies and procedures relating to:
 - identifying, evaluating and complying with laws and regulations and whether they were aware of any instances of non-compliance;
 - detecting and responding to the risks of fraud and whether they have knowledge of any actual, suspected or alleged fraud;
 - the internal controls established to mitigate risks of fraud or non-compliance with laws and regulations;
- The matters discussed among the audit engagement team regarding how and where fraud might occur in the financial statements and any potential indicators of fraud.

As a result of these procedures, we considered the opportunities and incentives that may exist within the organisation for fraud and identified the greatest potential for fraud. In common with all audits under ISAs (UK), we are also required to perform specific procedures to respond to the risk of management override, including testing journals and evaluating whether there was evidence of bias by the trustees that represented a risk of material misstatement due to fraud.

We also obtained an understanding of the legal and regulatory frameworks that the Charity operates in, focusing on provisions of those laws and regulations that had a direct effect on the determination of material amounts and disclosures in the financial statements. We focused on laws and regulations that could give rise to a material

misstatement in the financial statements, including, but not limited to, the Charities Accounts (Scotland) Regulations 2006.

Because of the inherent limitations of an audit, there is a risk that we will not detect all irregularities, including those leading to a material misstatement in the financial statements or non-compliance with regulation. This risk increases the more that compliance with a law or regulation is removed from the events and transactions reflected in the financial statements, as we will be less likely to become aware of instances of non-compliance. The risk is also greater regarding irregularities occurring due to fraud rather than error, as fraud involves intentional concealment, forgery, collusion, omission or misrepresentation.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: www.frc.org.uk/auditorsresponsibilities. This description forms part of our auditor's report.

Use of our report

This report is made solely to the charity's trustees, as a body, in accordance with Regulation 10 of the Charities Accounts (Scotland) Regulations 2006. Our audit work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Hillier Hopkins LLP

Hillier Hopkins LLP
Statutory Auditor

Radius House
51 Clarendon Road
Watford
Hertfordshire
WD17 1HP

Date: 07/06/2023

Hillier Hopkins LLP is eligible to act as an auditor in terms of section 1212 of the Companies Act 2006.

**STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31 DECEMBER 2022**

	UNRESTRICTED FUNDS £	RESTRICTED FUNDS £	TOTAL FUNDS £	2021 £
Income and endowments from:				
Donations and legacies	457,136	-	457,136	566,900
Charitable activities	246,207	-	246,207	259,464
Investments	2 19,560	-	19,560	19,415
Other trading activities	10,840	-	10,840	13,351
Total	733,743	-	733,743	859,130
Expenditure on:				
Cost of raising funds				
Costs of raising voluntary income	3 22,689	-	22,689	3,910
Fundraising costs.	4 150,046	-	150,046	137,933
Charitable activities	5 766,837	-	766,837	451,924
Total	939,572	-	939,572	593,767
Net income/(expenditure)	(205,829)	-	(205,829)	265,363
Other recognised gains/(losses):				
Gains/(losses) on investment assets	9 (196,785)	-	(196,785)	127,538
Net movement in funds	(402,614)	-	(402,614)	392,901
Fund balances January 2022	1,402,805	26,977	1,429,782	1,036,881
Fund balances December 2022	15 1,000,191	26,977	1,027,168	1,429,782

BALANCE SHEET AS AT 31 DECEMBER 2021

	Note	UNRESTRICTED FUNDS £	RESTRICTED FUNDS £	TOTAL FUNDS £	2021 £
FIXED ASSETS	7	2,566	-	2,566	5,098
INVESTMENTS	9	1,086,026	-	1,086,026	1,264,396
		1,088,592		1,088,592	1,269,494
CURRENT ASSETS					
Stock	10	13,745	-	13,745	13,662
Debtors	11	73,224	-	73,224	96,961
Cash at bank and in hand		934,572	26,977	961,549	1,211,772
Cash at bank and in hand held by Regional Groups		66,051		66,051	42,780
		1,087,592	26,977	1,114,569	1,365,175
CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR	12	(595,430)		(595,430)	(560,043)
NET CURRENT ASSETS		492,162	26,977	519,139	805,132
NET ASSETS		1,580,754	26,977	1,607,731	2,074,626
CREDITORS: AMOUNTS FALLING DUE AFTER MORE THAN ONE YEAR	13	(580,563)	-	(580,563)	(644,844)
		1,000,191	26,977	1,027,168	1,429,782
REPRESENTED BY:					
FUND BALANCES	15	1,000,191	26,977	1,027,168	1,429,782

The notes on pages 17 to 26 form part of these financial statements.

These financial statements were approved by the Trustees on: 2.6.23/2023

Kevin Weston
Treasurer/Trustee

K Weston

STATEMENT OF CASHFLOWS

YEAR ENDED 31 DECEMBER 2022

	2022	2021
	£	£
Cash flow from operating activities	(227,079)	261,045
Interest paid	-	-
Net cash flow from operating activities	<u>(227,079)</u>	<u>261,045</u>
Cash flow from investing activities		
Payments to acquire tangible fixed assets	(1,018)	(5,663)
Payments to acquire fixed asset investments	(18,415)	(19,315)
Interest received	1,145	100
Dividends received	18,415	19,315
Net cash flow from investing activities	<u>127</u>	<u>(5,563)</u>
Cash flow from financing activities	<u>(226,952)</u>	<u>255,482</u>
Net increase/ (decrease) in cash and cash equivalents	(226,952)	255,482
Cash and cash equivalents at start date 01/01/2022	1,254,552	999,070
Cash and cash equivalents at end date 31/12/2022	<u>1,027,600</u>	<u>1,254,552</u>
Cash and cash equivalents consists of:		
Cash at bank and in hand	1,027,600	1,254,552
Short term deposits		
Cash and cash equivalents at end date 31/12/2022	<u>1,027,600</u>	<u>1,254,552</u>

NOTES TO THE FINANCIAL STATEMENTS 31ST DECEMBER, 2022

1 ACCOUNTING POLICIES

1.01 Basis of preparation of the financial statements

The financial statements are prepared on the accruals basis and under the historical cost convention with the exception of investments, which are included at market value. The financial statements have been prepared in accordance with the Statement of Recommended Practice, Accounting Standards and Reporting by Charities SORP (FRS102) effective 1 January 2019, and applicable accounting standards and the Charities Act 2011.

LUPUS UK is a charity registered in England and Scotland. The address of the charity is detailed on page one of the accounts. The nature of the charity's operations is to help relieve persons who have lupus and to advance the education of the public and the medical profession in all aspects of the disease

The financial statements have been prepared on a going concern basis as the trustees believe that no material uncertainties exist. The trustees have considered the level of funds held and the expected level of income and expenditure for 12 months from authorising these financial statements. The budgeted income and expenditure is sufficient with the level of reserves for the charity to be able to continue as a going concern.

1.02 Incoming Resources

Donations & Legacies, Charitable Activities, Investments and Other Trading Activities are included in incoming resources when they are receivable, except when the donors specify that they must be used in future accounting periods or donors conditions have not been fulfilled, then the income is deferred. The income and fundraising ventures are shown gross, with the associated costs included in fundraising costs. Grants are treated as income irrespective of the source of the grant.

1.03 Resources Expended

Resources expended: Cost of generating voluntary income, Fundraising costs and Charitable activities are included in the Statement of Financial Activities on an accruals basis, inclusive of the disallowable portion of VAT.

Expenditure which is directly attributable to specific activities, has been included in these cost categories. Where costs are attributable to more than one activity, they have been apportioned across the cost categories on a basis consistent with the use of these resources.

Grants payable are charged in the year when the conditions attaching to the grant is fulfilled. Grants offered subject to conditions which have not been met at the year end are noted as a commitment, but not accrued as expenditure.

1.04 Stock

Stock is valued at the lower of cost and net realisable value.

1.05 Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

NOTES TO THE FINANCIAL STATEMENTS 31ST DECEMBER 2022
(Continued)

1.06 Creditors

Creditors and provisions are normally recognised at their settlement amount after allowing for any trade discounts due.

1.07 Tangible Fixed Assets

Depreciation is provided on all tangible fixed assets at rates calculated to write off each asset over its expected useful economic life as follows:

Furniture, fittings & equipment 33.3% straight line basis.

1.08 Investments

Investments are stated at market value at the balance sheet date. The statement of financial activities includes the net gains and losses arising on revaluations and disposals throughout the year.

1.09 Fund accounting

Generally funds are unrestricted which are available for use at the discretion of the Trustees in furtherance of the general objectives of the charity and which have not been designated for other purposes.

Designated funds comprise restricted funds that have been set aside by the Trustees for a particular purpose.

Restricted funds are those which are only to be used for specific purposes as laid down by the donor. Expenditure which meets the criteria is charged to the fund, together with an equitable allocation of management and support costs.

1.10 Taxation

The charity's surpluses are derived from, and are applied towards, the maintenance of charitable activities and as such are not subject to taxation.

1.11 Operating Leases

Rentals under operating leases are charged to the statement of financial activities on a straight line basis over the lease term.

1.12 Judgements & Estimates Note

Estimates and Judgements are continually evaluated and are based on historical experience and other factors, including expectations of future events that are believed to be reasonable under the circumstances.

1.13 Financial Instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value with the exception of bank loans which are subsequently measured at amortised cost using the effective interest rate.

NOTES TO THE FINANCIAL STATEMENTS 31ST DECEMBER 2022

20

(Continued)

	2022	2021
	£	£
2 VOLUNTARY INCOME		
Donations	234,902	246,324
Legacies	148,551	245,343
Membership Income	39,269	44,373
Gift Aid Income	34,414	30,860
	<u>457,136</u>	<u>566,900</u>
INVESTMENT INCOME	£	£
Listed investment income	18,415	19,315
Bank interest	1,145	100
	<u>19,560</u>	<u>19,415</u>
	2022	2021
	£	£
3 COST OF VOLUNTARY INCOME	<u>22,689</u>	<u>3,910</u>
	2022	2021
	£	£
4 FUNDRAISING COSTS		
Cost of goods sold	6,089	6,242
Fundraising costs:		
Staff salaries and national insurance (note 6)(30%)	70,498	66,682
Fundraising and publicity costs	61,597	52,687
Printing, stationery and postage (30%)	11,862	12,322
	<u>150,046</u>	<u>137,933</u>
5 CHARITABLE ACTIVITIES		
Support Costs	2022	2021
	£	£
Rent, rates, service charge and insurance	51,224	46,490
Staff salaries and national insurance (note 6) (70%)	164,497	155,592
Printing, stationery and postage (70%)	27,679	28,752
Telephone	2,669	2,608
Electricity (Light & Heat)	2,976	2,245
National Office Overheads	12,310	12,244
Depreciation	3,549	3,912
Professional fees	417	390
"News & Views" magazine	36,967	31,526
RAIRDA Membership Costs	15,632	9,711
Audit Fee	6,009	5,712
CIO Incorporation Costs	9,203	-
	<u>333,132</u>	<u>299,182</u>
Research and Welfare Grants (Details below)	433,705	152,742
	<u>766,837</u>	<u>451,924</u>

Research and Welfare Grants

	Paid 2022	1 Year	Future Commitments
Prof C Gordon Birmingham SLICC Research Nurse	6,743		
Dr R Al-Jayyousi Specialist Lupus Nurse Leicester		20,828	
Dr Y Ahmad, Spec Lupus Nurse, North Wales		46,953	83,014
Dr H Harris S&E Scotland Spec Lupus Nurse	108,977	56,967	85,143
Dr B Rhodes Spec Nurse QE Birmingham	39,232		
Dr E Bell & Dr C Riddell Musgrave Park Belfast	72,653	58,017	46,584
Dr S Hamour Renal Lupus Nurse Royal Free Hospital	57,500	58,300	
Dr A Kaul St Georges Tooting Spec Lupus Nurse	61,911	60,004	110,089
Alder Hey Childrens Hospital Spec Nurse		55,302	207,181
Prof D Isenberg UCL-SLICC	10,000	10,000	
Dr's Walker & Price Hull Uni Transitions to Illness		1,093	
Prof A Rahman UCL CVR in patients with sle		13,171	
Dr's Jury & Pineda Torra UCL Blood Fats JSLE		2,994	
Dr C Ciurtin et al UCL androgen receptors JSLE		6,196	
JSLE Beresford Uni Liverpool		1,335	
R Gilman City Hospital, Birmingham		3,120	
Giles, Cohen & Co UCL Obstetrics outcomes	6,217		
Reynolds&Co Uni Birmingham cell-cell interactions		5,800	
Summer 2021			
Prof D'Cruz & Co Guys & St Thomascomp APS/SLE	18,743		
Dr N Jordan & Dr D Robbins Addenbrookes	6,914		
Pros A Rahman & Dr C Wincup iron deficiency		7,172	7,172
Pros S Sutton & Co Cambs Unip sychosocial interevention	6,249	18,746	
Drs A Wadley & J Reynolds & Co remote monitor exercise	6,249	18,748	
Dr Y Yusof & Co Chapel Allerton skin investigation	12,500	12,500	
M Shipa & Prof M Ehrenstein UCL plasmablast	17,164	5,721	
Mauri Piper & Oleinika, UCL		22,816	
Prof D Isenberg Festschrift	1,500		
Spring 2022			
Dr J Arnold & Co Leeds SLE Criteria improved access	25,000	-	
Dr G Robinson & Co UCL multi-omic prognosis JSLE		12,471	12,471
Dr P Blair & Co UCL lymph node target therapy SLE		10,288	10,288
Dr C Flurey & Co UWE psychosocial support SLE		6,207	18,621
Autumn 2022			
Drs Psarras & Clarke, metabolic profiling Uni Oxford		25,000	
M Sloan & Co SEEN Trial Uni Cambridge		25,000	
Peer Review Panel Expenses			
Lupus Nurse Network Group			
Welfare Grants	3,153		
	460,705	564,749	580,563
Opening commitments at 1st January 2022	- 1,172,312		
Commitment at 31 December 2022	1,145,312		
	433,705		

6 EMPLOYEES	2022	2021
	£	£
Staff Costs:		
Wages and salaries	220,264	208,508
Social security costs	14,731	13,766
	<u>234,995</u>	<u>222,274</u>

The average number of employees,
by function, was:

	No.	No.
Fundraising	3.5	3.5
Support	5.5	5.5
	<u>9</u>	<u>9</u>

The Charity considers its key management personnel comprise the trustees and Chief Executive Officer. The total employment benefits including employer pension contributions of key management personnel were £61,110 (2021: £56,238)

One employee earned over £60,000 in 2022 and none in 2021.

None of the Trustees received any remuneration for their services.

Expenses incurred by the Trustees for travel, accommodation and subsistence totalled £10,609 (2021: £2,068) were reimbursed by the charity.

7 FIXED ASSETS	Office Furniture and Equipment
	£
Cost	
01-Jan-22	48,428
Disposals	-
Additions	1,018
31-Dec-22	<u>49,153</u>
Depreciation	
01-Jan-22	43,331
Disposals	-
Charge for the year	3,549
31-Dec-22	<u>46,587</u>
Net Book Amount	
31-Dec-22	<u>2,566</u>
31-Dec-21	<u>5,098</u>

8 FINANCIAL INSTRUMENTS	2022	2021
	£	£
Financial instruments measured at amortised cost	1,100,824	1,352,565
Financial liabilities measured at amortised cost	1,175,993	1,204,887

Financial assets measured at amortised cost comprise bank and cash, trade debtors, other debtors and accrued income.

Financial liabilities measured at amortised cost comprise trade creditors, other creditors, accruals and grant commitments.

	2022	23
	£	2021
		£
9 INVESTMENTS		
Carried forward from previous year	1,264,396	1,117,543
Add: Additions at cost	141,653	107,543
Less: Disposal proceeds	- 161,337 -	42,602
Realised/unrealised gain/(loss)	- 196,785	127,538
Net movement in cash held for investment	38,099 -	45,626
	<u>1,086,026</u>	<u>1,264,396</u>

Disposals during year	Units	price as at 31-Dec-21	Total value 31-Dec-21
JP Morgan GBL Emerging Markets Inc 1p Ord	4700	1.45	6,827
BMO Inv Funds (UK)	18940	1.87	35,399
Vodafone Group PLC USD 0.2095238 Ord	1622	1.12	1,821
Tesco PLC 6.333 Ord Shares	3236	2.90	9,381
Greencoat UK Wind PLC 1p Ord Shares	7788	1.41	10,950
Ishares PLC	961	26.32	25,294
Mercantile Investment Tst PLC 2.5p Ord Shares	12,000	2.69	32,220
Findlay Park Funds ICAV	180	148.18	2,667
M&G PLC 5p Ord Shares	800	2.00	1,596
Abcam PLC 0.2p Ord Shares	320	17.33	5,546
Haleon PLC 1p Ord Shares	790	n/a	n/a
Persimmon PLC 10p Ord Shares	570	28.56	16,279
Foresight Solar Fund Ltd Ord Shares	8,274	1.01	8,390
Renewables Infrastructure Grp NPV Ord Shares	5,750	1.34	7,728
			<u>164,098</u>

	2022	2021
	£	£
Investments held as follows:		
Securities listed on UK Stock Exchange	279,391	386,225
Cash	60,380	22,280
UK Fixed interest	175,535	168,323
Overseas Equities	388,150	542,682
Alternatives	182,570	144,886
	<u>1,086,026</u>	<u>1,264,396</u>

MATERIAL INVESTMENTS	2022	2021
	£	£

- -

Investments are held in a managed fund administered by Rathbone Investment Management Limited.