

Could you be our new  
**PATIENT/PUBLIC  
INVOLVEMENT &  
ENGAGEMENT OFFICER?**



**Patient/Public Involvement & Engagement (PPIE) Officer**  
**(24-month Fixed Term Contract)**

**Candidate Information Pack**



# A MESSAGE FROM OUR CEO >>>



Thank you so much for expressing an interest in joining our fantastic, ambitious and committed team at LUPUS UK.

Lupus is a chronic autoimmune disease which is uncommon, complex and poorly understood. It affects the immune system and can cause lasting damage to the kidneys, skin, heart, lungs and/or brain. Lupus disproportionately affects women and people from Black African, Caribbean, and Asian ancestries. Around 50,000 people in the UK are thought to have lupus (approximately 1 in 1000).

At Lupus UK our ambition is for a world where people with lupus can live full and active lives. We work hard to empower people by providing information about lupus and offering support, so their voices are heard and their condition diagnosed and managed effectively.

We are currently developing the next stage of our organisational strategy and this exciting new role will build on an existing programme of supporting patient engagement in research, clinical trial development and clinical trials for lupus at a time of increased interest and activity in this area.

Thank you for your interest in working with Lupus UK.

It's an exciting time for the charity and we look forward to meeting you.

*Caroline Olshewsky, Chief Executive*



# ABOUT US

LUPUS UK is a registered not-for-profit charity established in 1990.

## OUR VISION

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

## OUR MISSION

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

## OUR VALUES

- We believe in improving the lives of people who have lupus.
- We believe that lupus patients are entitled to specialised care and treatment.
- We believe that lupus patients are entitled to the best possible information about their condition.
- We believe in informing and educating the medical profession and the public about lupus and its effects.
- We believe in bringing people with lupus together so they are not isolated.
- We believe in listening to people who want to talk about lupus.



# ABOUT LUPUS

Lupus is a chronic autoimmune condition where the immune system mistakenly attacks the body's healthy tissue, which can result in inflammation and damage. It can impact any area or organ of the body, including the joints, skin, and kidneys, and can have a range of symptoms that mimic other conditions. Anyone, at any age, can be affected by lupus, but it disproportionately affects women and people from Black African, Caribbean, and Asian ancestries. There is no cure, but early treatment can help to manage and control the symptoms.

Lupus is an uncommon, complex, and poorly understood disease. Around 50,000 people in the UK, and 5 million people worldwide, are thought to have lupus. As such, many healthcare professionals may not recognise the early signs resulting in a delay to referral and diagnosis. During this time, active lupus can cause damage to the kidneys, skin, heart, lungs and/or brain which may be irreversible.

We produce a range of publications that help people understand the different ways that lupus can impact and how it can be managed: <https://lupusuk.org.uk/publications/>.



Watch this  
YouTube video to  
find out more about  
lupus and how it  
affects 5m people  
worldwide



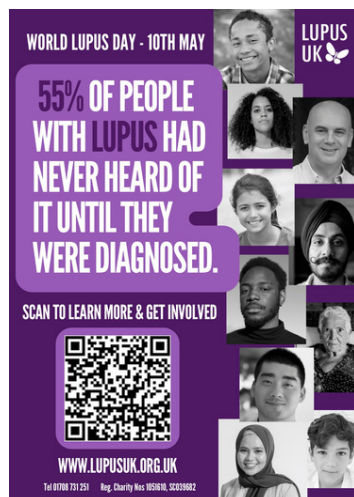
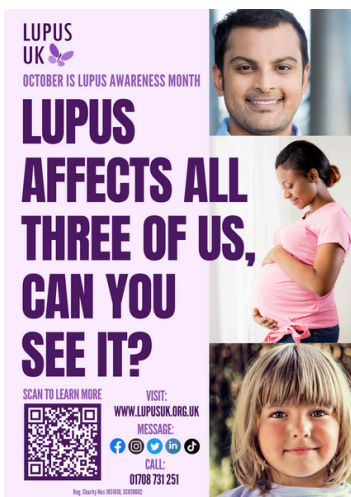


# WHAT WE DO


We deliver a wide range of activities to achieve our vision. Our charitable 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.

## Some examples of our work...



- Guidance for people with lupus.
- Campaigns to raise awareness.
- Lobbying and influencing work to impact public policy decisions.
- Providing grants to research projects.
- Supporting groups and communities for people living with lupus.
- Events and activities.



Meet other  
young people  
with lupus

Sunday 21st April 2024  
2pm to 4pm

St Pancras Church House London  
NW1 1NA

# HOW WE ARE RUN

## Finances

We receive money through a number of different streams including membership subscriptions, donations and fundraising, and grants and trusts. Our usual income per year is around £650,000. Our financial position is very stable and you can view [our latest annual accounts here](#).

## Governance

We are governed by our Constitution which sets out our charitable objectives and how we operate. We have a Board of Trustees that oversee the running of LUPUS UK. We have recently been through the process of incorporation and operate as a CIO (Charitable Incorporated Organisation).

## Our Trustee Board

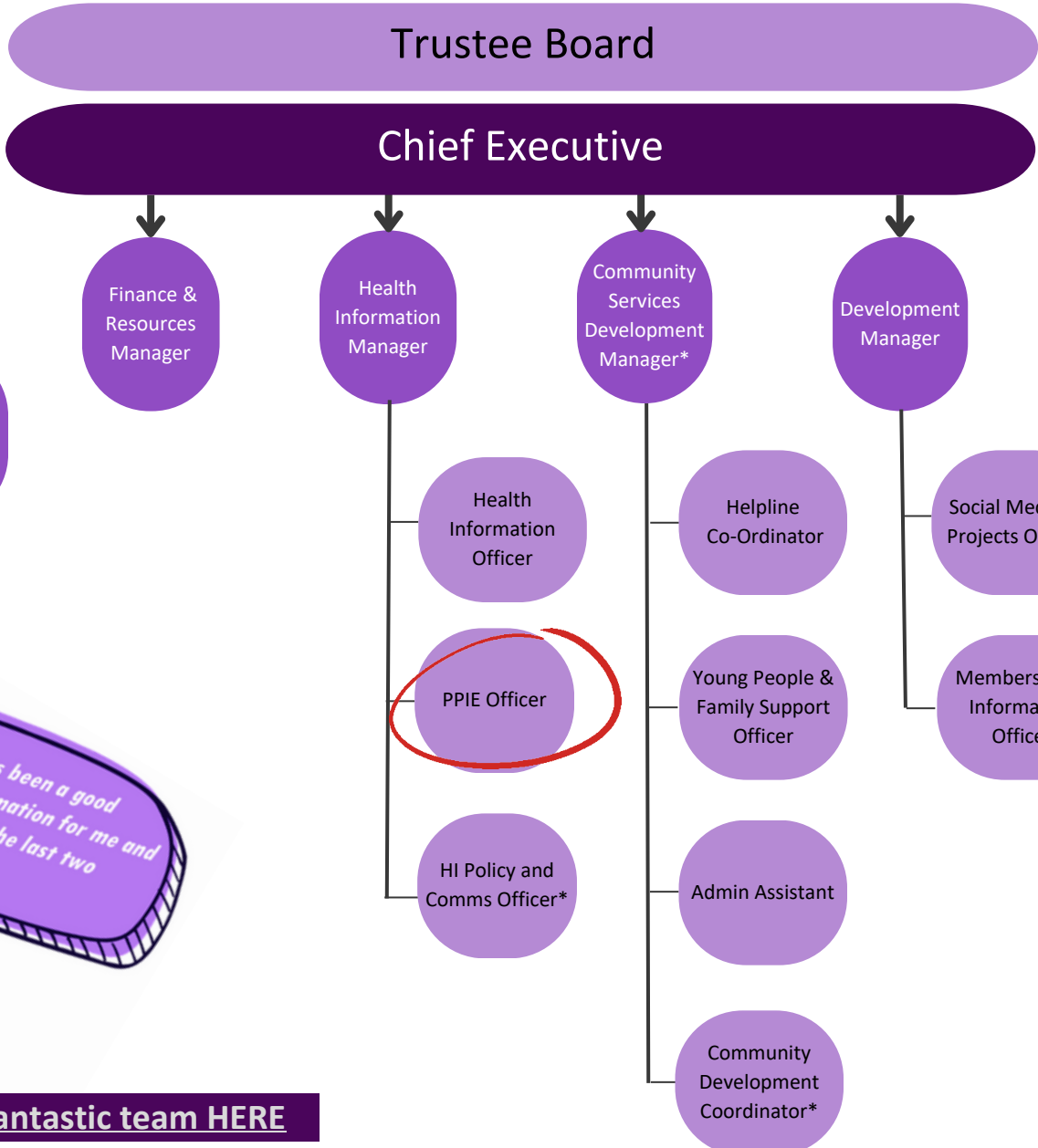
The Board of Trustees ensure that we are operating properly and in the best interests of our beneficiaries. They oversee the work of staff, through the Chief Executive, who is responsible to the Board. The Trustees have responsibility for oversight of the budget, governance and strategy of LUPUS UK.

[You can find out more about our Trustee Board here.](#)





# OUR STRUCTURE



"LUPUS UK has been a good source of information for me and my family over the last two years"

[Meet our fantastic team HERE](#)

Roles marked with \* are future roles within our team.



# WORKING AT LUPUS UK

Our success hinges upon having a team of brilliant people, working together to ensure our charity has the biggest possible impact. Our aim is to be a great place to work – where we respect work / life balance, support training and learning, and promote an inclusive and positive working environment. We have a small and dedicated staff team. We value developing our people, rewarding them well, and encouraging long-term career opportunities.

## LOCATION

Our main office is currently in Romford Essex. We support fully office-based, hybrid, or fully remote working, with an expectation of attending 4 in-person team days per year for remote workers.

## BELONGING

We're committed to ensuring our workforce reflects the diversity of the world and community we serve. We also aim to ensure that people are valued, included and supported by creating an environment where everyone can bring their authentic selves to work.

We respect everyone's individual identity and celebrate difference, and encourage applications from all candidates irrespective of background. We particularly welcome applicants from an ethnic minority and/or people living with a disability or chronic illness.

## BENEFITS

We have a fantastic range of benefits for staff including:

- 20-days of annual leave (increasing by one for each year of employment, up to 25) plus bank holidays.
- 5% matched pension.
- 4 x salary death-in-service policy after 6-months employment.
- Flexible working arrangements.
- Enhanced wellbeing package including sick pay.
- Lots of learning and development opportunities.

## BALANCE

We understand that balancing work and home life can be tricky, and LUPUS UK is a great place to achieve that balance. We genuinely care about our people being able to thrive both at work and at home, so we welcome suggestions and requests for flexible working, including part-time working, job shares, condensed hours and hybrid working.



# ABOUT THE ROLE

## JOB TITLE

Patient/Public Involvement & Engagement Officer

## REPORTS TO

Health Information Manager

## RESPONSIBLE FOR

n/a

## SALARY & CONTRACT DETAILS

c.£25,00 p/a (based on experience);  
24-months Fixed Term Contract

## WORKING HOURS

35 hours per week

## ROLE PURPOSE

This is an exciting new role which will build on an existing programme of supporting patient engagement in research, clinical trial development and clinical trials for lupus at a time of increased interest and activity in this area.

## KEY RESPONSIBILITIES

### Delivery

- Act as the first point of contact for researchers and pharma companies seeking to involve members of the public in their research or trials.
- Work to build a network of patients around the UK with an interest in being involved with PPIE.
- Work with the Health Information Manager to identify and facilitate any support needs of the PPIE network.
- Support and facilitate PPIE in all stages of lupus research.
- Support PPIE in Lupus UK's research grants process.
- Support engagement with diverse under-served communities.
- Ensure equality, diversity, and inclusion considerations in PPIE methods and communications

### Other

- Uphold the values and expectations of LUPUS UK.
- Carry out other duties relevant to your post as reasonably required.
- Occasional evening and weekend working and travel may be required to support our broader activities.



*"It's good to read about the experiences of others with my condition. It helps me to feel empowered and better informed"*

# ABOUT YOU

## QUALIFICATIONS AND EXPERIENCE

- Experience of working directly with patients and/or members of the public.
- Experience of supporting Patient and Public Involvement and Engagement (PPIE) activity.
- A relevant postgraduate qualification or equivalent experience (**desirable**).
- Experience of working in PPIE within a similar environment (**desirable**).
- Experience of working within research or the health sector (**desirable**).
- Experience of working with stakeholders, such as healthcare organisations, public groups, and professional networks (**desirable**).

## KNOWLEDGE AND SKILLS

- A strong understanding of best practice in PPIE within research.
- Knowledge of different types of research and the various stages of the research process.
- Excellent verbal and written communication skills, with the ability to tailor communication for diverse audiences.
- A demonstrable commitment to promoting diversity, equity, and inclusion in all engagement activities.
- Strong organisational and time management skills.
- Exceptional attention to detail.
- The ability to facilitate focus groups, workshops, and public forums (**desirable**).
- An understanding of NHS patient care pathways, clinical research processes, or clinical trials (**desirable**).

## VALUES AND BEHAVIOURS

- Able to uphold and champion the values of LUPUS UK, demonstrating high standards of integrity, accountability, respect for others, courtesy and professionalism.
- Passionate about the work of LUPUS UK and working in a non-profit environment with a focus on health and disability.
- Demonstrable empathy for service users and a commitment to understanding and addressing the challenges they experience.
- Actively committed to the growth of equality of opportunity and diversity.
- An enthusiastic and flexible approach and willing to support colleagues.
- Commitment to continual professional development and willing to give and receive constructive feedback.
- A positive, can-do attitude and willingness to help with tasks outside normal duties.



*"I learned almost everything I know about lupus from LUPUS UK and that knowledge gave me the confidence to get control back in my life and do almost everything I used to be able to do including running. It also helped my husband, family and employer to know what lupus is and how we can make life work together"*

# HOW TO APPLY

The closing date for applications is: **Monday 17th March 2025 (10am).**

Please reserve the following dates in your diary when you apply:

**Interview Dates** Tuesday 1st and Wednesday 2nd April 2025

*There will be a single stage interview. Interviews will be held on one of two interview dates and can be held remotely or in-person at our Romford office, as most convenient to the candidate*

## YOUR APPLICATION

Please ensure you have read the full Recruitment Pack before applying. To apply, please submit your CV and a short (maximum 2-page) personal statement to [stevie@lupusuk.org.uk](mailto:stevie@lupusuk.org.uk).

Your personal statement is an opportunity to outline your motivation for the role and to set out how you meet the person specification of the role. We would encourage you to align your personal statement, as far as possible, to the criteria set out in the person specification.

Please note that we are unable to sponsor or take over the sponsorship of employment visas. Applicants must have the right to work in the UK and should confirm this in their application.



If you have any queries or would like to arrange an informal discussion about the role please contact the line manager for the post, via e-mail:

[debbie@lupusuk.org.uk](mailto:debbie@lupusuk.org.uk).



LUPUS  
UK 

[www.lupusuk.org.uk](http://www.lupusuk.org.uk)