



LUPUS UK Research Strategy

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

- educate and support patients with lupus (in all its forms) and their carers, and to encourage those with the disease to be involved in managing their illness
- raise public awareness about lupus, particularly within the medical profession
- fund research into lupus, its causes, consequences and treatment
- Grant pump-prime funding for specialist lupus nurses within the NHS.

Our vision is that with earlier diagnosis and better treatments, most people with lupus will be able to live their lives without the large physical, emotional and economic burden that this illness has often caused in the past. To achieve this, LUPUS UK funds research into systemic lupus erythematosus in its various manifestations, and damage as a result of the aggressive nature of the disease itself and its necessary medications.

LUPUS UK is an established grant making charity, recognised by the National Institute for Health Research (NIHR) as a non-commercial partner funding research of clear value to the NHS as a result of open competition with high quality peer review. In comparison with some other organisations, LUPUS UK currently does not have sufficient money available for large-scale trials: it will therefore look to support applications which focus on the following:

- Smaller pilot studies which will 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 which would facilitate improvements to the understanding of the causes, prevention and treatment of lupus, and its research

LUPUS UK is willing to work collaboratively with other charities where research interests overlap. LUPUS UK will not fund individual institutions, long-term career posts, travel or open access publication costs.

PROCESS

LUPUS UK has a Scientific Medical Advisory Panel (SMAP) of national experts in the field of lupus including rheumatologists and nephrologists (detailed on our website and Annual Report) which advises the charity on a variety of issues.

The charity also has a Peer Review Panel (PRP) to consider applications for research funding: the likely impact of the research on the understanding of disease mechanisms and reducing suffering and complications of living with the disease. This panel reviews the importance, relevance, originality and impact, together with its scientific rigour and appropriateness. Peer review panel members are appointed for 3 years with the option of a second term of office. They do not receive any payment

and are not permitted to review their own applications, abiding by the charity's Conflicts of Interest policy and procedure. The panel will approach external reviewers for expert comment where necessary, on complex or larger grant applications. Reviewers will provide feedback on the application which the Charity will pass on to applicants. Recommendations to fund will be made by the PRP to the Trustees.

Details of the Conditions of Grant and review processes are available from our National Office or on our website.

Once a project has been approved, the full amount of the award is put into a designated reserve, with the research organisation receiving regular payments as agreed by the Trustees. Thus, if the charity ceased to exist, the commitment to fund agreed research projects would be honoured in full.

Prospective researchers must provide a lay title and summary of the project, as well as copies of the full research proposal. Researchers are encouraged to include patient and public involvement in all aspects of the research study. As a patient-led charity, LUPUS UK is able to put forward the consumer aspect through its Trustees, together with members of local LUPUS UK Groups who are often directly involved in research projects as patient subjects.

LUPUS UK requests progress reports annually, and acknowledgement of its funding in all publications and presentations connected with its funded research. Authors are also asked to write a lay version for publication in the members' magazine, *News and Views*.