



RESEARCH STRATEGY



2023 - 2028

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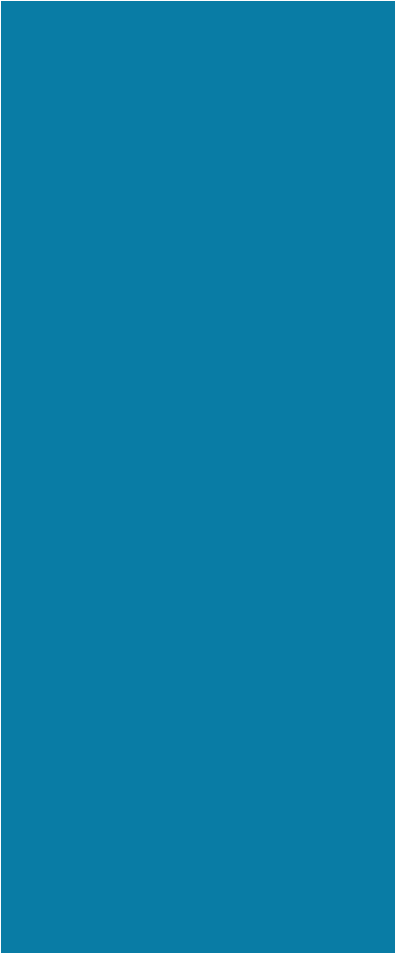
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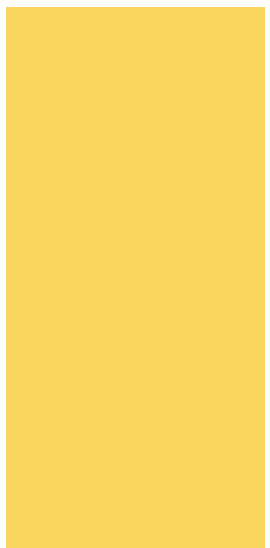
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OUR STORY



As one of the largest vasculitis patient support charities in the world; Vasculitis UK was established primarily to offer support to patients. Support is offered to patients through provision of information, advice and education.

The charity also plays an active role in raising vasculitis awareness and fostering interest in vasculitis among medical and associated healthcare professionals.

In addition to these core roles the charity offers funding for vasculitis related research. By virtue of our fantastic relationships with both vasculitis patients and clinicians and scientists, Vasculitis UK is uniquely placed to identify vasculitis research needs and assess the relevance of proposed projects.

We have a modest funding pot, made up entirely from donations which can offer researchers an opportunity to run short term or small studies and feasibility projects. Vasculitis UK will also consider larger projects as a partial funder and encourages this collaboration.

Since we began our research strategy in 2015 we have funded 30 studies, increasing our knowledge of vasculitis and advancing the science around diagnosis and testing.

OUR DIRECTION

The **lived experience of patients** should serve as a vital source of insight and support to researchers, combining with their skills and expertise to enable the development of practical, impactful, and accessible real-world solutions.

We are committed to ensuring that researchers incorporate the views of people with lived experience into their research; ensuring patient & public involvement (PPI) in the **design, production and dissemination** of their studies.

In this way people with vasculitis can be confident that the research we fund will benefit both them and **future generations**.

Ensuring vasculitis research has **direct patient benefit** is crucial in advancing treatment and care. By putting the patient at the centre - studies can address real-world challenges faced by those with vasculitis. This approach will help identify effective therapies, improve diagnostic tools, and develop personalised treatments.

Ultimately, fostering a strong connection between research and patient care leads to **improved quality of life**, increased treatment success, and enhanced support for those living with vasculitis.

Research and healthcare professionals are vital to our community. Their **expertise and dedication** drive advancements and improve lives.

Currently there are only a small number of talented, established vasculitis researchers. We are keen to be part of training and retaining the best minds in vasculitis research and **actively encourage early career researchers from all fields** of health care to apply to our grant call.

By nurturing the next generation of talent, we aim to bolster the depth and breadth of vasculitis research.

People with vasculitis face **significant challenges** in accessing information, treatment, and support, making self-management vital. Improved resources, tools, and services are necessary to facilitate effective **self-management**.

Enhancing the **management of chronic pain, fatigue and mental health issues** requires exploration of alternatives beyond medical treatment alone.

We need to understand the social and psychological factors that influence **disease progress and outcomes**, enabling **research-driven solutions** to improve patients quality of life.

Vasculitis Patient Journey



Pre-diagnosis

Diagnostic odyssey. Symptoms can come and go (and often get dismissed) over a long period of time or mimic symptoms for other conditions, making diagnosis challenging.



Diagnosis

Diagnosis can be overwhelming. Support needed to access information and peer support to assist in adapting and adjusting to new normality.



Treatment

Initial treatment aiming to put you in clinical remission fast, then maintenance treatment. Early and correct treatment gives better prognosis. Increased risk of infection because of treatment.



Living with vasculitis

The vast majority of a patient's journey is spent in this stage - there is a real need for research to improve patients lives in this stage. Monitoring of vasculitis activity, management of flares and side effects of treatment is essential.

Research Priorities

1 Improving quality of life for patients post-diagnosis

2 Developing and testing more effective treatments

3 Early diagnosis of vasculitis

4 Improving understanding of the causes of vasculitis

1 Improving quality of life for patients post-diagnosis

Living with vasculitis can have a profound impact on both the physical and mental wellbeing of patients, affecting their independence and ability to enjoy everyday activities.

Unfortunately, the importance of quality of life is often overlooked when treating chronic conditions. The challenges of vasculitis can impact patients at every stage of their journey, from diagnosis to long-term management. Addressing the impact on quality of life is crucial in providing comprehensive care and support to those living with this condition.

By considering the holistic needs of patients within their research, healthcare professionals can strive to improve overall well-being and enhance the resilience of individuals facing the challenges of vasculitis.

Vasculitis UK will fund research on possible treatments and interventions which could improve quality of life, as well as the development of new and more effective outcome measures.





2 Developing & testing more effective treatments

We will encourage research that includes a range of therapies to treat vasculitis. This is inclusive of all healthcare professionals.

We wish to support research to treat types of vasculitis for which there is currently little evidence to support any specific treatment approach, and to improve current treatment regimens including drug and non-drug based therapies.

We also wish to develop new and better treatments for intractable problems such as fatigue and pain.

We will support research into the long term outcomes of patients with vasculitis, including patient reported outcomes, disease assessment tools and patient education.

By supporting this aspect of research we hope to encourage development of novel therapies and to improve both the efficacy and safety of current treatment regimens.





3 Earlier diagnosis of vasculitis

Early accurate and prompt diagnosis of vasculitis leads to a better **outcome** for the patient.

This priority supports research into methods by which vasculitis may be diagnosed earlier - this may involve the development of different/improved **non-invasive methods** of imaging to better understand the changes in blood vessel structure and function in vasculitis.

This priority will also support research into the **development and application of biomarkers** to help diagnose patients. Biomarkers may also play a role in assessing disease progression and response to therapy, which will also be considered under this priority.

This priority will also support research into **reasons for delay in diagnosis** and how to address this including educational programs for health professionals.





4 Improving understanding of the causes of vasculitis

For some types of vasculitis significant advances have been made in our understanding of the underlying disease mechanisms, but for many others we have made little progress.

Further research is essential to unravel the contributing mechanisms and factors involved in vasculitis. By uncovering potential risk factors, researchers can identify individuals at higher risk of developing vasculitis, leading to earlier diagnosis and intervention. This, in turn, can prevent or mitigate long-term organ damage and disability.

Understanding the complex interplay of genetic, environmental, and immune system factors will allow for the development and refinement of more targeted and personalised therapeutic strategies.



Funding Opportunities



BURSARIES

Training and/or travel expenses for research and healthcare professionals.

YEARLY GRANT CALL

Support for 3 projects of up to £50,000.
Applications must address the priorities set out in our research strategy.



Links



WEBSITE

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GRANTS EMAIL

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