

# Vasculitis UK Research Strategy 2016 - 2021

## Foreword

Vasculitis UK is a registered charity which was established primarily to offer support to patients suffering from any of the many different types of vasculitic disease. This support is given by means of information, advice and education about all aspects of vasculitis to patients, frequently on a personal, one to one basis.

The charity also plays an active role in raising vasculitis awareness and fostering interest in vasculitis among medical and associated healthcare professionals. This entails having a close relationship with clinicians, scientists and organisations with an interest in vasculitis.

In addition to these core roles the charity offers funding for vasculitis related research through an open structured application process. By virtue of the direct contact with vasculitis patients, both newly diagnosed and long term, and with clinicians and scientists, Vasculitis UK is uniquely placed to prioritise vasculitis research needs and assess the relevance of any proposed projects.

Although Vasculitis UK is one of the largest vasculitis patient support charities in the world, resources are inadequate to fund large or long term research projects. Thus the charity is particularly keen to fund pilot or feasibility studies which would be the basis for applications for funding of larger studies from other sources thus enabling much more research into the many different types of vasculitis.

**This strategy document is a 'living document' and will be reviewed annually by the SAB and Trustees on behalf of patients and carers.**

## **Key objectives**

To realize our goal of supporting research in vasculitis, we have developed four main threads to our research strategy

- A. Set clear research priorities
- B. Maximize outcomes from research
- C. Ensure high quality research
- D. Support researchers

### **A Setting clear research priorities**

The resources available to us for research are limited and it is vital that we use these most efficiently, we have therefore identified 3 key research priorities for the period 2016-2021.

The priorities have been developed by Vasculitis UK Scientific Advisory Board (SAB) in partnership with people with vasculitis. We conducted a survey of patients, carers and vasculitis health professionals asking about their priorities for research. Membership of the SAB comprise Clinicians, patients and trustees. The current members are Professor David G I Scott, chair, Dr David Jayne, Dr Richard Watts, Mr John Mills, Mr Michael Patnick and Ms Jane Elsom.

**Priority 1**  
**Developing and testing more effective treatments**

We will encourage research that includes a range of therapies to treat vasculitis.

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 treatment for intractable problems such as fatigue.

This priority will we hope encourage development of novel therapies and improve both the efficacy and safety of current treatment regimens.

We will also support research into the long term outcomes of patients with vasculitis, including patient reported outcomes, disease assessment tools and patient education which can be linked to treatment as part of this priority

**Priority 2**  
**Improve the 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.

**Priority 3**  
**Improving the 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.

This priority will support research in areas such as the molecular and biochemical bases for different types of vasculitis, and also the further identification and characterization of genes involved in causing vasculitis. Such research can include genotype and phenotype investigations of patient populations as a precursor to clinical trials.

## **B Maximizing the potential from our research**

### **1 Offering a variety of funding streams**

Our resources are necessarily limited but in order to maximize our outcomes we will offer a range of funding. Our main research funding stream will be an annual grant round open to researchers based in the UK. Each year we plan to make an open call for research project proposals that seek to address one or more of our research priority areas. In any year we look to receive applications for a range of funding streams that may include:

Project grants  
PhD studentships  
Travel Bursaries

The research budget will be determined each year by the Board of Trustees and a decision as to which of the above schemes will be supported informed by advice from the SAB.

### **2 Working partnership**

We recognize that as a small charity, in order to maximize our impact we need to work in partnership with other charities working in the vasculitis field. We understand that the costs of many projects are beyond our current resources and therefore we will encourage applications which seek funding partners. We seek to work with industry for the benefit of patients.

### **3 Maximising dissemination of research**

As a charity funded by public donation it is critical that our research reaches the broadest possible audience in as quick a manner as possible. Researchers funded by Vasculitis UK will be encouraged to publish in open access journals, to present their work at national and international conferences and to interact with patients and media. Vasculitis UK will also work actively to communicate the results of research to the public and health professionals.

### **4 Monitoring research outputs and outcomes**

In order to maximize both the outputs in terms of new knowledge (publication, presentations, patents) and outcomes (improvements in health care) it is important that we have a systematic means assessment.

We will monitor research projects through annual and final reports and report the outcome of our research via the SAB to Trustees and members on a regular basis.

## **C Ensuring scientific quality**

Research awards made by Vasculitis UK through our annual grants round are subjected to open competition and a rigorous peer review process which is reassuring to our supporters and should enable researchers and universities to access other funding streams.

## **D Our research support**

We wish to ensure that vasculitis research attracts and retains top quality clinical researchers and biomedical scientists. Vasculitis research is multidisciplinary and we therefore welcome applications from any researchers in any area of medicine which is relevant to vasculitis. This process is overseen by the SAB.

### Project grants

Project grants are intended to provide support for up to 3 years for a major study. Support may include the salary of the applicant (s), and/or research assistant(s) (but not PhD students), the running costs of the project, allowance for travel to scientific meetings and purchase of essential equipment.

### PhD studentships

PhD Studentships are designed to encourage the best young science graduates to embark on a career in vasculitis research. These awards for three years provide practical research training, under the direct supervision of a senior and experienced researcher and lead to a doctoral qualification. Applications should be made by the prospective supervisor. It is not necessary to name a student at the time of application. This award is only made to institutions that provide evidence of a graduate training programme. The award provides a tax-free stipend for the candidate student, university bench fees and an allowance for travel to scientific meetings.

### Travel Bursaries

Travel bursaries will provide allowance for travel to scientific meetings relevant to the field of vasculitis for early career researchers. They are not restricted to holders of Vasculitis UK grants.

## **The grant application process**

We will operate response mode funding. Research can include any type of research relevant to vasculitis as long as it is clearly linked to one of our priorities.

Funding decisions are made by the Vasculitis UK peer review committee which comprises both scientific and lay members. In making decisions the committee will consider the charities research priorities and the recommendations of the peer reviewers based on the scientific excellence of the application.

The use of independent peer reviewers to obtain advice from experts knowledgeable in a particular research area is a fundamental part of Vasculitis UK's decision-making process in deciding what research to fund.

Funding opportunities and deadlines for submission of applications are published on our website, external websites and emails to researchers on our database. Application forms and, guidelines and terms and conditions can be downloaded from [www.vasculitis.org.uk/research/applications](http://www.vasculitis.org.uk/research/applications) for funding

Whilst the written reviews from external referees are an important element, they are by no means the sole criterion, for deciding the success or failure of an application.

Applications are judged on the merits of the proposal submitted.

## **Timescales**

There will be an annual call for applications for project grants ,usually announced in the autumn with awards made by May/June. Calls for PhD studentships and travel bursaries will be advertised as and when available.