

Criteria for the awarding of funding for research by the John Grube Foundation

The John Grube Foundation (JGF) supports research in the field of vasculitis by awarding doctoral scholarships, granting research contracts and issuing calls for research proposals. Furthermore, it annually awards the John Grube Research Prize.

Criteria for research funding have been established for this purpose. The relevance of the project to those affected by vasculitis is the first and most important consideration in any decision on possible funding.

Structure of the criteria:

1. general funding conditions of the JGF
2. funding of projects within the framework of calls for proposals
3. funding of doctoral scholarships
4. awarding of research contracts by the JGF and funding applications by third parties
5. thematic areas of research funding
6. structure of applications

1. General funding conditions of the JGF

- 1.1. Funding is available for projects that are not supported by other funding bodies, such as the German Rheumatology Foundation, DGRh, or the pharmaceutical industry, as well as for projects that are to be supported by co-funding.
- 1.2. Excluded from funding are - except for scholarships (see point 3) - personal emoluments for the applicant, funds for building and furnishings, general administrative expenses and basic equipment.
- 1.3. Recipients of material and personnel costs commit to use the funds exclusively to carry out the research project applied for.
- 1.4. Funded fellows and project leaders commit to report in layman's terms on the status of the research work and the results achieved so far at the intervals stipulated in the contract. If the time intervals are not specified in the contract, a half-yearly reporting obligation applies.
- 1.5. If the project proposal has already been submitted to another funding body or if it is planned to be submitted to further funding bodies, this must be stated in the project proposal.
- 1.6. If partial funding by other funding bodies is planned after the project has been

approved by the JGF, this must be agreed with the JGF in advance.

1.7. Recipients of funding for the implementation of research projects undertake to

1.7.1. uphold the principles of good scientific practice and the criteria of the current version of the Declaration of Helsinki.

1.7.2. ensure that data protection and ethical regulations are observed.

1.8. For the separately awarded funds for material costs, the grant holder or the project leader shall submit a proof of use no later than six months after the last grant, unless otherwise stipulated in the contract.

1.9. As part of the final proof of use, the research results as well as the associated documentation and a final report in layman's terms will be submitted. The finished work will be made available to the JGF in electronic form.

1.10. Since the research results from the funded projects are to be made accessible to all those interested in researching relevant topics for people suffering from vasculitis, the JGF reserves the right to publish the comprehensible final reports on its website.

1.11. The grant recipients will work towards the publication of the research results through scientific publications. They shall inform the JGF of all publications and send a copy. In publications and presentations of research results, reference must be made to the JGF funding by name. An electronic copy of publications must be sent to the JGF after publication. If this is not possible for data protection reasons, 5 copies (or more if required) of the publication should be sent to the JGF as free copies after publication.

1.12. In addition, the grantee is entitled to reuse published results for any purpose, in particular for professional qualification purposes. The JGF is entitled to inform the public about the research results and to share the use of the results.

1.13. The JGF reserves the right to reclaim funding that has not been used for the intended purpose and in accordance with the funding conditions.

1.14. The JGF's research funds are allocated by the JGF's Board of Directors. The Advisory Board advises the Board in its decision.

2. Funding of projects within the framework of calls for proposals

2.1. The JGF continuously invites applications for projects to be funded.

2.2. Project applications to JGF calls for proposals shall take into account the principle of participatory research (see point 5).

2.3. The maximum volume of total funding per call for proposals is 30,000 Euros.

- 2.4. Several project proposals on the thematic focus may be funded with the funding volume. Each project needs to be specified individually in the application.
- 2.5. Prior to awarding, the applications will be submitted to the Advisory Board of the JGF for review. Both the Executive Board and the Advisory Board shall vote independently of each other. The decision on funding is made by the Board of the JGF.

3. Funding of doctoral scholarships

- 3.1. Funding may be provided for doctoral projects that are expected to produce relevant results in the field of the topics listed under 6. Selection is based on the relevance of the planned research project to the JGF, the scientific quality of the application and the feasibility of the project.
- 3.2. Applications for doctoral funding may be submitted to the JGF.
- 3.3. The award of the fellowship is conditional on the fact that if further fellowship applications for the submitted research work have been submitted to other bodies and/or have already been approved, this must be indicated (see also points 1.5 and 1.6).
- 3.4. The funding can amount to up to 1,000 euros per month. If the scholarship holder is employed at a higher education institution or otherwise comparably employed for remuneration, the funding application must in any case be prorated accordingly. Contributions to social or health insurance cannot be covered by the JGF.
- 3.5. In cases of hardship, up to 500 euros per month can be applied for as an additional cost supplement for compensation of disadvantages.
- 3.6. A lump sum of 100 Euros per year is provided for material costs. In the case of special expenses, material costs, e.g., postage and printing costs, up to a maximum of 100 euros can be applied for at the same time as the scholarship.
- 3.7. Funding is initially provided for one year. In justified cases, it can be extended for one year at a time and for a maximum of two years in total.
- 3.8. The extension of the funding must be justified in an application. The application must include information on the status of the project (report) and information on the further procedure in the project with a description of the time schedule.
- 3.9. The JGF may advertise specific doctoral topics.
- 3.10. The funding of advertised doctoral topics includes the financing of a doctoral position with a maximum of 1,500 euros per month. Material costs can

be awarded according to 3.5.

3.11. The evaluation and awarding of doctoral scholarships is carried out according to 2.6.

4. Awarding of research contracts by the JGF

4.1. Although the focus of research funding is on project proposals received in response to JGF calls for proposals (point 2), the JGF may actively award research contracts or approve third-party initiative proposals. These research proposals relate to the selection of topics listed in point 6 and are characterised by a particular relevance for the persons concerned and/or health policy intentions in the sense of the persons concerned.

4.2. Initiative applications for research projects are accepted by the Board of the JGF.

4.3. The maximum volume per application may not exceed 30,000 Euros.

4.4. The JGF also accepts applications for partial funding of research projects of other sponsors. These must be in the catalogue of topics listed in point 6. The application must explain in detail and in layman's terms what the special interest of people with rheumatism is in this research project. In addition, points 1.5. and 1.6. must be observed.

4.5. The evaluation and awarding of applications is carried out according to point 2.6.

5. Thematic areas of research funding

The JGF focuses on the following fields of research:

5.1. Health care research

5.1.1. Analysis of care structures for vasculitis patients

Objective: To investigate the medical care of vasculitis patients and to identify deficits and reasons for undersupply to improve care.

Since the vasculitides belong to rare diseases and are difficult to recognise for non-experts, the diagnosis is often delayed for several months or years. This not only leads to a longer period of suffering for the patient, but also to situations that are sometimes vitally threatening and an overall poorer prognosis. Therefore,

early diagnosis and initiation of therapy is crucial for optimising prognosis and quality of life now and in the future.

5.1.2. Projects to optimise care structures for vasculitis patients

Goal: The implementation of projects that lead to improved care for vasculitis patients.

In particular, late attendance to specialised centres often leads to long suffering and poor prognosis for vasculitis patients. Projects that lead to a shortening of the time between the first symptom and diagnosis are just as important as projects that support the optimisation of medical care for patients with a known vasculitis diagnosis.

5.1.3. Outpatient specialist care

Objective: To evaluate the implementation of outpatient specialist care and its benefits for vasculitis patients in order to achieve good care.

In particular, vasculitis patients with severe forms of progression or rare rheumatic diseases often require interdisciplinary care by medical staff with special qualifications in order to ensure optimal medical care. With the entry into force of the Act on the Improvement of Care Structures in Statutory Health Insurance (GKV-VStG) on 1 January 2012, the previously valid regulation of outpatient treatment in hospitals in § 116b SGB V was replaced by outpatient specialised medical care (ASV).

The Federal Joint Committee (G-BA) adopted the guideline on ASV, which regulates the requirements for diagnosis and treatment of patients in more detail. The annex specifies the diseases with severe courses and rare diseases that require highly specialised services. This also includes vasculitides. An evaluation of ASV should show whether this approach enables and is suitable for the good care of those affected with rheumatic diseases and whether those affected are satisfied with this type of care.

5.1.4. Interlocking of interfaces in medical care

Aim: To explore how the different actors in the health care system work together to provide optimal care for people with vasculitis.

A number of professions from different sectors (outpatient, day-care, inpatient) of the health care system are involved in the care of people with vasculitis. These include general practitioners and specialists, hospitals, rehabilitation clinics, physiotherapists, occupational therapists, psychotherapists, pharmacists, health insurance companies, but also self-help organisations, etc.

Interlocking of the different interfaces, good communication between the individual actors and good cooperation are essential to ensure optimal care. So far, there is a lack of research results on possible obstacles and evaluations of interlinking approaches in practice.

5.1.5. Implementation of guidelines

Aim: To explore optimal ways of disseminating and implementing guideline-based medical care for vasculitis patients, so that therapies are aligned with the latest medical knowledge.

Although national and international guidelines exist for some vasculitides, they are not widely known or implemented in practice. Data on barriers to guideline implementation could help to improve implementation.

5.2. Self-help research

5.2.1. *Supporting patients through self-help groups*

Aim: To study the structures of self-help and their development, as well as the effect of self-help on the quality of life of those affected.

In order to enable people with vasculitis diseases to participate fully in society despite their illness, various pillars in the health system play crucial roles. In the meantime, self-help has been recognised as a great complement to the health care system. However, valid data describing the structures of self-help, its development and importance for people with rheumatic diseases are still lacking. There is also no data on the effect of self-help on medical care and the management of the disease.

5.3. Information and communication

5.3.1. *Improving the dissemination of information*

Aim: To explore and evaluate sources of information that people with vasculitis diseases use to inform themselves about all areas of life that are affected by their disease (therapies, care, socio-legal aspects, etc.), so that both access to information and the information itself can be optimised.

People with vasculitis diseases must have access to information about services, therapies and facilities that support their disease management and enable them to live their lives with this disease in a self-confident and active way. This information must not be filtered by intentions and distorted by interests but must focus on the well-being of those affected according to the latest scientific findings. An important task of self-help is the provision of such high-quality information. So far, there are too few studies that look at the quality of information and access to information and make comparisons.

5.3.2. *Patient orientation in doctor-patient communication*

Aim: To explore doctor-patient communication in order to obtain data that identify barriers to successful doctor-patient matching and to explore factors that underpin successful communication.

The inclusion of people with vasculitis in upcoming decisions regarding their medical care is becoming increasingly important nowadays. The traditional paternalistic model of the doctor-patient relationship, in which the doctor has sole

authority and decision-making sovereignty over the patient's medical care, is increasingly being replaced by the model of participatory decision-making, in which doctor and patient agree on examinations and therapies as partners. This model is particularly desirable for chronic diseases, such as those of the rheumatic type since those affected are accompanied by examinations and therapies throughout their lives. Studies on doctor-patient communication can provide data for improvement.

5.4. Medical research

Topics from medical research are also conceivable. Some examples are given here. The relevance for vasculitis patients must be worked out separately.

5.4.1. Therapy evaluations - effectiveness of therapies

Aim: To investigate the effects and side effects of therapies (especially drug therapies) in order to provide recommendations for the optimal care of vasculitis sufferers on a better data basis.

In rheumatology, there are high-quality studies on therapies in a few areas. Considerable research gaps exist in off-label prescribing, especially in the treatment of rare diseases. New therapies and therapeutic concepts are desirable for patient-centred or personalised medicine.

5.4.2. Causes of rheumatic diseases

Goal: Research into the causes of vasculitides to expand the understanding of vasculitides and future therapy options in the future.

Knowledge of the causes will enable the development of effective methods of diagnosis and therapy. Considerable progress has been made in recent years in researching the causes of vasculitides. However, there are still research gaps.

5.4.3. Side effects and long-term consequences of therapies and forms of care

Objective: To evaluate therapies and forms of care for vasculitides with regard to their long-term effects in order to gain knowledge about side effects whose relevance only becomes apparent after years and positive effects compared to other therapies.

Long-term effects and side effects of innovative new drugs as well as of drugs that have been on the market for several years have not yet been researched sufficiently, nor have non-drug therapies and combinations of therapy options. If valid data on long-term effects are available, the benefits can be assessed more comprehensively and better and weighed against possible side effects.

6. Structure of the proposals

6.1. The JGF only accepts research proposals that formally comply with the guidelines in section 6. Proposals that do not comply with this form will not be considered during the review process.

6.2. Research proposals have the following structure in terms of form and content (unless explicitly required otherwise in a call for proposals):

6.2.1. A short summary of the research project (abstract, in German or English) with a brief presentation of the objectives, background, research question or hypotheses, methodology and what impact the results of the project have on the research field (no more than 250 words).

6.2.2. A brief presentation of the current state of research.

6.2.3. A brief description of the relevance of the project to vasculitis patients.

6.2.4. A detailed description of the project, including the research question or hypotheses, the objectives and methodology of the project, and expected results

6.2.5. A working plan and time schedule that reflects the realistic implementation of the project in terms of time.

6.2.6. A financing plan. In particular, it should be clear here how the research project can be implemented with the requested funding. The JGF also accepts applications for (partial) funding of research projects of other funding organisations. In this case, the financing plan must include the funds that have been approved or are expected to be approved by other agencies and it must be clear for which items the requested funds will be used in total. Points 1.5 and 1.6 also apply.

The financing plan must include all costs of the project calculation. Costs that have not been included cannot be taken into account for funding at a later date.

6.2.7. The application with the outline must not exceed 10 pages and must be written in layman's language.

In addition:

6.2.8. depending on the project, if applicable, an appendix containing only existing survey instruments.

6.2.9. A one-page curriculum vitae with the applicant's key scientific data and the most important publications of the last 5 years relevant to the project.

6.2.10. Publications of the last 5 years (in the case of several applicants, one one-page CV per project partner).

6.2.11. The application must be submitted in printed and electronic form. In addition, an anonymised version of the proposal (no naming of the persons or institutions involved) must be submitted in electronic form (by e-mail, USB, CD, etc.).

6.2.12. For applications for doctoral scholarships, the following documents must also be enclosed with the application:

6.2.12.1. Copies of certificates (university copies).

6.2.12.2. Confirmation from the research institution at which the scholarship holder will carry out the research work.

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