



ZNM - Zusammen Stark! e.V.

Verein für Zentronukleäre Myopathien

Funding guidelines of the association ZNM – Zusammen Stark! e. V. – preliminary version 05.12.2019

1. ZNM - Zusammen Stark! e. V. ("ZNM") promotes according to §2 Abs 1 b of the articles of association according to these guidelines the science and research for remedies of centronuclear myopathies. The aim is to improve the living conditions of the patients and to support the members of the association.
2. The entire process should be as simple and transparent as possible.
3. The funding should support scientists at universities and other suitable institutions worldwide.
4. The planned projects should be limited in scope.
5. The planned projects should be limited in time. In order to give subsequent members of the Executive Board room for maneuver, the maximum funding period is two years, but can be extended once for a further two years in the second year of funding on renewed proposal by the Research Advisory Board and resolution of the Management Board.
6. To ensure compliance with the guidelines and the call for proposals, a **Research Advisory Board** will be appointed consisting of six lay members from the association and three experts. The lay members are appointed by the Management Board and may not themselves be members of the Management Board. The expert members are appointed together by the management board and the lay members. The nine-member Research Advisory Board formed in this way has legal capacity if at least four members (at least two laypersons and at least two experts) are present. The Management Board may change the composition of the Research Advisory Board. The names of the acting Research Advisory Board shall be published on the homepage of the Association.
7. Call date: In odd-numbered years, the Research Advisory Board, in agreement with the Management Board, will prepare a call for proposals in English each autumn and publish it by the end of the respective year at the latest.
8. fixed submission deadline: Researchers or research groups may submit proposals in accordance with the call by 31 March of the following year.
9. The Research Advisory Board shall decide whether the proposals submitted comply with the call for proposals. Double funding is excluded. Accepted proposals will then be submitted to at least three experts for review. No more than one of these reviewers may be from the Research Advisory Board. The reviewers work on an honorary basis
10. The reviewers shall evaluate the research proposals and submit their assessment to the Research Advisory Board in the form of a score and a comment.

11. In July, the Research Advisory Board submits a ranking list (incl. evaluation) of the proposals available for selection to the Management Board.
12. The Management Board committee shall decide on the basis of this evaluation. Deviations from the order of precedence must be justified at the next general meeting.
13. The applicants will receive feedback on their application (including acceptance or rejection) by September at the latest.
14. A rejection by the Management Board is final.
15. In principle the following are eligible for funding
 - a. Personnel costs for researchers and institute staff working directly and directly on the funded project.
 - b. Investments which are essentially and directly related to the funded project and which are explicitly stated in the research proposal.
 - c. Travel expenses and material costs for the project, according to the research proposal.
16. excluded are
 - a. Funds for construction measures and fixtures
 - b. Funds for the purchase of office furniture and equipment, which are usually part of the basic equipment of universities and institutes.
 - c. Allocations, unless they have been expressly stated in the research proposal and accepted in the funding decision.
17. In principle, co-financing of a project is possible.
18. After approval of the project applications, ZNM concludes a grant agreement (approval) with the funding recipient on the basis of the funding guidelines applicable at the time of receipt of the application. This agreement sets out the rights and obligations of the grant recipient.
 - a. Terms of approval
The grant agreement shall inform the applicant of the conditions attached to the grant. This includes, in particular, the exact wording of the research project and the research objective, the funded investments or expenses per calendar year, the total costs of the research project and the exact name of the research recipient and person responsible for the project.
 - b. Call for funds and use of funds
A maximum of half of the approved funds will be paid to the applicant within 2 weeks of the call being made. A further 45% of the approved amount will be paid out after one year and the achievement of the agreed milestones. The achievement of the milestones is determined by the proposal of the Research Advisory Board and the decision of the Executive Board. Further conditions for a subsequent payment are a calendar-yearly report on the use of funds by the funding recipient (to be prepared and handed over within the month of January), payment of the last 5% is made after completion of the project and submission of proof of I) the use of funds, II) a scientific and III) a layman's final report. If a peer-reviewed publication already exists, the scientific final report may be waived.

- c. Any reallocation of funds in the aggregate amount of 20 percent as well as the use of project funds for cost types not mentioned in the application must be approved in writing by the ZNM Executive Board in advance.
- d. the obligation I) to give a lecture at a family conference of ZNM - Zusammen Stark once during or shortly after the end of the project and II) to publish the achieved findings scientifically (i.e. peer-reviewed) under the name of ZNM -Zusammen Stark! e. V. as funding body
- e. A cost-neutral extension, i.e. the retrieval of approved funds after the end of the project, requires the approval of the ZNM Executive Board.