1. ZNM - Zusammen Stark! e. V. supports science and research for treatments of centronuclear myopathies according to §2 Abs 1 b of the statutes of the association. 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 shall 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 Management Boards flexibility, the maximum funding period is three years, but may be extended once in the second year of funding for a further two years upon renewed recommendation of the Research Advisory Board and resolution by the Management Board.

6. A **research advisory board** is appointed to ensure compliance with the guidelines and the call for proposals, consisting of six lay members from the association and four experts. The lay members are appointed by the Management Board and may not be members of the Management Board themselves. The experts are appointed by the Management Board and the lay members together. The nine-member Research Advisory Board formed in this has legal capacity if at least five members (at least three lay members and at least two experts) are present. If this constellation cannot be achieved in the meeting, written consent to the decisions can be obtained from other members of the Research Advisory Board, so that a quorum of the Research Advisory Board can also be achieved in this way. The Management Board may change the constellation of the Research Advisory Board. The names of the Research Advisory Board in office will be published on the Association's website.

7. **Call for proposals**: If a minimum tender amount of at least 125,000 Euro is available in the Association's account for research, a call for proposals in English will be prepared by the Research Advisory Board in the following fall and published at the latest by the end of the respective year.

8. **Fixed submission deadline**: The submission deadline will be published together with the announcement for the submission of research proposals.

9. The Research Advisory Board decides whether the submitted proposals comply with the call for proposals. Double funding is excluded. Accepted proposals are then given 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 a voluntary basis.
10. The reviewers evaluate the research proposals and submit their evaluation in the form of a score and a commentary to the Research Advisory Board.

11. The Research Advisory Board submits a ranking list (incl. evaluation) of the proposals for selection to the Management Board.

12. The Management Board decides on the basis of this evaluation. Deviations from the ranking list must be justified at the next general meeting.

13. At the latest 5 months after submission, the applicants will receive feedback on their application (incl. acceptance or rejection).

14. A rejection by the Management Board is final.

15. The following costs are generally eligible
   a. Personal costs for researchers and institute staff working directly and immediately on the funded project
   b. Travel costs and material costs for the project, according to the research proposal
   c. Subcontracting through services directly related to the funded project.

   excluded are
   d. Funds for construction and fixtures
   e. Funds for the purchase of office furniture and equipment that is customarily part of the basic equipment of universities and institutes
   f. Special allocations, unless they have been explicitly identified in the research proposal and accepted in the funding decision.

16. Co-financing of a project is generally possible.

17. After approval of the project applications, ZNM – Zusammen Stark! e. V. signs a grant agreement (approval) with the grant recipient on the basis of the grant guidelines in effect at the time the application is received. This agreement contains the rights and obligations of the Grantee.

   a. Grant conditions

   In the grant agreement, the applicant is informed of the conditions associated with the grant. This includes, in particular, the exact formulation of the research project and the research objective, the funded expenses per calendar year, the total costs of the research project, and the exact name of the person responsible for the project.

   b. Call for funds and use of funds

   A maximum of half of the awarded funds will be disbursed to the applicant within 2 weeks after the grant agreement has been signed. An additional 45% of the awarded amount will be disbursed upon acceptance of the interim report and achievement of agreed-upon milestones. The achievement of the milestones is determined by the proposal of the Research Advisory Board and the decision of the Management Board. Further conditions for a follow-up payment are two reports on the use of funds by the grantee, an interim report and a final report. Payment of the final 5% will be made upon completion of the project and submission of evidence of I) use of funds, II) a scientific final report, and III) a lay final report.
c. Any reallocations of funds in the aggregate amount of 20 per cent, as well as the use of project funds for types of costs not specified in the application requires prior written approval by the ZNM Management Board.

d. The obligation I) to give a presentation at a family conference of ZNM - Zusammen Stark! e. V. once during or shortly after the end of the project and II) to publish the achieved findings scientifically (peer-reviewed) mentioning ZNM - Zusammen Stark! e. V. as the funding body.

e. A cost-neutral extension, which means the retrieval of approved funds after the end of the project, requires approval by the ZNM Management Board.