

Policy: ENMC as PAO Umbrella in EU-projects

Background

In the past and also recently, the ENMC office received requests from researchers to support their research grant calls being the umbrella of patient advocacy organisations (PAO). This happened for research grants funded by EJPRD, GCC and Horizon2020. Also a supporting letter was provided for the EURO-NMD consortium.

The rationale for including a PAO in a grant call is to i) better understand patient needs and patient-based outcomes and ii) keep the community informed about research progress and potential clinical trials which might be derived from this research.

ENMC as PAO Umbrella

One good way of achieving this would be by submitting workshop applications to the ENMC to organise workshops with patients and patient representatives invited. One workshop could be organised in the beginning of the project to optimise the patient involvement in the early phase of the project. A second and if needed a third workshop could be organised to discuss the progress of the project and the results coming out of the project.

Involving ENMC as PAO Umbrella, and hence co-labelling of your workshops with the ENMC signature, implies mandatory prior evaluation of EU project-related workshop applications by the ENMC Research Committee and validation by its Executive Committee. These EU project-related workshop applications should compete with the regular ENMC workshop applications during the bi-annual review rounds. ENMC may help co-fund these workshops, however, the ENMC workshop budget is maximized.

In summary, ENMC can be involved as PAO Umbrella in grant calls for EU-projects, but it should be strictly limited to reviewing applications, organising workshops and disseminating the outcomes of the workshops via its mandatory lay and full scientific reports.

Phased project submissions

Letter of Intent

The letter of Intent (LOI) briefly states the partners and their budget estimates for this project. The managing director will set up the workshop budget based on a) the number of workshops that need to be organised within the project, b) the number of participants involved at each workshop and c) the duration of each workshop.

In the PAO section of the LOI, the following points should be addressed by the project applicants:

- A proposal for an ENMC workshop will be submitted by the consortium to insure proper dissemination of the consortium results, progress of the projects and the future actions to be taken.
- If such proposal is positively evaluated and selected by ENMC, the applicants plan to co-fund it with EU-project budget to allow an ambitious workshop with sufficient participants (particularly patients representatives). The managing director can be of help to assign the right additional persons to be invited.
- ENMC will ensure the proper dissemination of the workshop conclusions to both scientific and patients communities by means of its mandatory lay and full reports.

Submission full application

If the project is selected for a full project submission, ENMC should write a support letter stating the expertise of ENMC in workshop organisation, securing the quality stamp by its review process, ensuring active patients involvement, and disseminating information through its mandatory lay and full reports.

The workshop will be labelled as an ENMC workshop with the name of the European project in the title. Four representatives of the consortium will be the workshop organisers and they will also be the authors on behalf of the consortium of the full paper to be published in Neuromuscular Disorders. The members of the consortium will be listed in the full report in a separate section.

If you are interested in involving ENMC as PAO Umbrella in your grant call submission, and/or have any questions, please don't hesitate to contact us at enmc@enmc.org. You may also contact the Managing Director Dr Alexandra Breukel directly at +31-6-31901121 or breukel@enmc.org.