Request Form for GFCNI Involvement in Research Projects

GFCNI welcomes inquiries for patient representation in research projects. In this form, we ask for information about your proposed project and the role and tasks you would like GFCNI to take on. The information you provide here will help us better understand your project and expectations, guiding us in our decision-making process. We will prioritize research projects where GFCNI can play an active role and form part of the budgeted project activities. Of course, we assure you that your inquiry and any information you provide will be treated with the utmost confidentiality.

Please **fully** complete this request form and send it to research@gfcni.org. Incomplete forms cannot be processed. GFCNI will assess whether the requested involvement in your project is feasible for us at this time and will **respond within ten working days**.

We ask for your understanding that requests can only be processed if the **submission deadline is at least eight weeks** from the date GFCNI receives this request form.

A) Contact Details of Principal Investigator / Coordinator	
Organization / Institution	
Name	
Email address	
Address	
Phone number	

B) Project	
Title of the research project *(Please spell out if an abbreviation or acronym is used.)*	
Objective(s) of the project	
Short description / summary of the project	
Potential benefits of the project for maternal health (before and during pregnancy), newborn infants, and / or their families	
Type of project / trial / study ☐ Clinical trial ☐ Randomized controlled trial ☐ Blinded ☐ Placebo-controlled ☐ Phase I ☐ Phase II ☐ Phase III ☐ Phase IV ☐ Pre-clinical study ☐ Observational study / data collection ☐ Other *(Please specify.)*	
Number of planned patients / trial participants	
Countries / clinical sites planned to be involved	
Funder / funding scheme *(e.g., national funding, Horizon Europe, other (EU) funding instrument …)*	
Total amount of the (proposed) funding	
Estimated budget planned to be allocated to GFCNI	

To assess whether GFCNI's funding contribution could be subject to Value Added Tax (VAT), please indicate in which role GFCNI would participate: ☐ Participation as a "Beneficiary;" in this case, please specify the role (*e.g., work package lead, work package member ...*) ☐ Participation as a "Third Party" *(e.g., as subcontractor of affiliated partner of an institution)*	
Submission date for proposal *(1- or 2-stage application?)*	
Approximate decision date on success of proposal	
Planned start date of the project	
Total duration of the project	
If applicable: other partners planned to be involved in the project *(e.g., research partners, patient representatives, industry partners)* Are industry partners involved in the project? ☐ Yes *(Please specify.)* ☐ No	

Please note: As a foundation representing the voices of patients and their caregivers, we need to ensure that the patient perspective is included at several stages of the research process. Thus, it is important that we are involved **from the very beginning, are regularly updated, and have the option to contribute** (the extent of which depends on the budget).

In the following table, you will find a list of possible tasks we could take on or areas where we could assist. Please note that there are some "**must-be-involved**" points for us to fulfil our mission of adequately representing the patient perspective.

C) Tasks Envisioned for GFCNI

Please indicate the tasks / topics where you wish to involve GFCNI in your project.

	Mandatory Involvement	**Additional Possibilities of Support**
Research Design and Planning	Review of grant application Review of study protocol design	☐ Input to application to Ethics Committee ☐ Input on patient's journey and quality of life ☐ Workshop for investigators
Research Conduct and Operations	Set-up and coordination of a patient and parent advisory board Assistance in the development or review of participant information Representation of the patient's voice in the steering committee Representation of the patient's voice in the data monitoring board	☐ Building a patient network of affected families ☐ Assistance in the development of a patient recruitment strategy ☐ Assistance in the development of a patient retention strategy ☐ Study reporting (to funders)
Data Analysis and Presentation	Review and / or support in the writing of scientific manuscripts	☐ Support for the analysis and interpretation of data
Dissemination, Communication, and Translation into Action*	Dissemination and communication	☐ Awareness building ☐ Advocacy
Other *(Please indicate.)*		

***Please note:** *If you envision GFCNI to take primary responsibility for these tasks, a **work package lead** may be required.*

Thank you for taking the time to answer our questions.

Please send this form to research@gfcni.org. **Please do not hesitate to contact us via this email address should you have any questions.**