



Research Grant Application Form 2020 Biennium 2021-2022

1. Title of the Project (Maximum 350 characters)

2. Principal Investigator(s) (Maximum 600 characters)
(Title, Department and Institute, Address, Telephone and email, % effort on the project)

3. Total Financing requested - maximum €100.000

4. Research Budget (Maximum 1.000 characters)
(Please detail the budget for the first and second years: **personnel** (data manager, training etc.), **bioinformatic support** (database development and maintenance etc), **travel and meetings** (conferences, scientific missions, training opportunities, etc) and **other expenses** (publications, promotion, etc.). Please note that budget should be fully justified and coherent with the project and will represent a criterion for evaluation of the project.
Also please note that the Mariani Foundation does not finance overhead, institutional charges or indirect costs.

Note: Any substantial changes in the specific budget over the course of the research project must be approved by the Mariani Foundation's Scientific Committee and can be proposed once a year).

5. Collaborators from above mentioned Institute (Maximum 2.000 characters)
(Please specify if full-term employees, recipients of bursaries, scholarships, fellowships, etc. and % effort on project for each of them)

Last Name, First Name, Title and details on the above - % effort (time)

6. Network: list of partners actively contributing to the development of the registry (Maximum 2.000 characters)

(Please specify the Institute)

Name/Title, Department and Institute, Address and email, % effort on the project (time)

7. Coordination and Organization (Maximum 1.500 characters)

(Provide a clear picture of the management and overall organization of the project, and present the specific contribution of each partner directly involved in the first stage of registry development)

8. Co-financing (budget and duration) (Maximum 800 characters)

Indicate co-funding from ongoing research projects and potential overlaps or interactions with the development of the registry

9. Abstract of the project (Maximum 1.500 characters)

10. Background (Maximum 1.500 characters)



Fondazione
Pierfranco e Luisa Mariani
neurologia infantile

Introduce the disease or group of diseases that will be the object of the registry. Highlight their impact in terms of prevalence, morbidity and socio-economical assets, as well as current flaws in diagnosis, prognosis, treatment and management of patients.

11. Reasons for the project, Innovation and Benefits (Maximum 2.000 characters)

Rationale for launching the database, indicating the need for an expert network in the area and the added value of the project networking. In particular, besides the obvious epidemiological purposes, specify the short-term and long-term research objectives that the registry proposes to address, and the expected translational benefits that will arise from the project

12. Preliminary data (Maximum 1.500 characters)

Describe already existing resources on which the registry can build upon, such as research networks, local databases, interactions with family associations etc, which can represent a solid start to populate the registry

13. Research Plan including Methodology, Feasibility and long-term sustainability of the registry (Maximum 4.000 characters)

Describe: 1) the informatic platform that will be chosen and the server which will be hosting the registry; 2) the structure of eCRF allowing a longitudinal collection of clinical and instrumental data; 3) strategies for harmonization of collected data among contributing centers; 4) regulations to guarantee equal access to data to all contributors, including procedures to ensure transparency and traceability of access; 5) adherence and compliance to GDPR regulations for data protection; 6) plans for long-term sustainability of the registry; 7) potential interface with international registries.

14. Expected Results and Deliverables (Maximum 1.000 characters)

List realistic deliverables to be obtained at the end of the first and second year of funding

15. Interaction with ongoing research project (Maximum 1.000 characters)

Describe potential interactions with ongoing research projects and explain how the registry could potentially benefit such projects and vice versa.

16. Dissemination (Maximum 1.500 characters)

Describe planned strategies: 1) to make the registry as inclusive and widely accessible as possible at the national level (in order to involve also small centers on the territory); 2) to disseminate the scientific outcomes of the registry to the lay audience.

17. Gantt Chart

Upload a pdf file with a Gantt chart.

18. Keywords (Maximum 500 characters)

19. List of Abbreviations and Glossary of unusual terms (Maximum 500 characters)

20. List of References of Principal Investigator(s) (Maximum 10 references relevant to the proposal, from the past 10 years)