

CALL FOR PROPOSALS : GREAT JOINT PROJECT 2018

1. FONDATION PARALYSIE CEREBRALE/FONDATION MOTRICE

La Fondation Paralyse Cérébrale*/Fondation Motrice, a recognized public interest foundation was founded by APETREIMC- ENVOLUDIA, SESEP, CDI et PASSE R' AILE.

Its missions are:

- To promote and support research and innovation in the field of the prevention, management of Cerebral Palsy (CP), and the improvement of the situation and quality of life of people with CP and their relatives. The fields in this research are including medical and biomedical sciences, social sciences and humanities, educational sciences, technology and engineering research.
- To work for the improvement of the quality of care and support, the quality of the education, the dissemination of best practices and development of knowledge.

Since more than ten years, La Fondation Paralyse Cérébrale/ Fondation Motrice has been committed to support research in the field of CP, particularly through its annual calls for projects focusing on CP in general but also on pain, motor rehabilitation or development of cognitive skills.

** Fondation Paralyse Cérébrale is the new name of Fondation Motrice*

2. CONTEXT OF THE CALL

In the context of recognition of equal opportunities and equal rights for persons with disabilities and the development of Evidence Based Medicine, research must be able to lean on the possibility to raise questions and to provide answers on the mid and long term. In the field of Cerebral Palsy, only a small number of studies estimating therapeutic, or educational strategies or modalities of support of the concerned people allowed to identify clearly a profit for them and their families.

In this context, La Fondation Paralyse Cérébrale/Fondation Motrice decided to dedicate a **massive and unprecedented support for research on CP** by launching a call for a great joint project in 2018.

This call for proposals will evaluate:

- **Projects with a total budget between € 500 K to € 1.5 million maximum over a period of 3 to 5 years**
- **Large scale projects in the field of clinical research, translational research, public health or social sciences assessing intervention(s) aimed at**
 - **Improving the impairments, the activities and the participation of concerned people** (as defined by the International Classification of Functioning, Disability and Health of WHO), **preventing, reducing or mitigating the mid and long term consequences of CP.**
 - **Preventing the occurrence of CP in at-risk populations.**

Furthermore, La Fondation Paralysie Cérébrale/Fondation Motrice wishes to encourage

- collaborative projects, including multidisciplinary research teams,
- projects with high scientific impact, likely to improve / change the management of at-risk patients or patients suffering from CP,
- projects to explore innovative management ways for people with CP and their families in the domains of care, education, inclusive practices and improvement of the quality of life,
- projects with reasonable modalities of applicability in the management of patients.

3. SCOPE OF THE CALL

Proposed projects will cover all ages from fetal life to adulthood.

This will involve **large scale projects in the field of clinical research, translational research, public health or social sciences assessing intervention(s)** focusing on one of the two following areas:

Area A: Improving the impairments, the activities and the participation of concerned people (as defined by the International Classification of Functioning, Disability and Health of WHO) for the concerned people or their family, preventing, reducing or mitigating the mid and long term consequences of CP (secondary and tertiary prevention *).

For example Prevention of the complications of CP or associated disabilities, or of the effects of premature aging or social disadvantage of persons with CP; or reduction of the limitations of activity, restrictions on participation or reduction of environmental barriers.

Area B: Preventing the occurrence of CP in high-risk populations (Primary Prevention *).

For example: Pre-conceptional or prenatal intervention, perinatal neuroprotection, early intervention during the first months of the life, etc.

Projects will include an **intervention study** (evaluating a practice). We mean by “any change (i) in the usual management of patients at risk of CP or with CP, (ii) in their human, physical or societal environment/support. Any form of intervention is eligible if it has not yet been assessed and is clearly justified and predefined. This may be a pharmacological treatment, physical care, educational or organizational care, etc.

This intervention study could be associated with other related objectives (feasibility studies, short or medium term ancillary studies, validation of biomarkers, etc.).

** According to the glossary of the Data Bank in Public Health (BDSP)*

- *Primary prevention* Actions to reduce the frequency of a disease or health problem in a healthy population by reducing the causes and risk factors.
- *Secondary prevention:* Actions aimed at the detection and early treatment of a disease or a health problem. Secondary prevention involves identifying the disease or health problem at its earliest stage and applying prompt and effective treatment to limit its consequences.
- *Tertiary prevention:* Actions to reduce the progression and complications of the known disease or a health problem. It consists of measures to reduce disability and inconvenience and to improve the quality of life. Tertiary prevention is an important aspect of medical care and rehabilitation.

4. BENEFICIARIES OF THE CALL — COMPOSITION OF THE TEAMS

This call for research proposals addresses any certified research team situated in the European countries such as defined in the program Horizon 2020 of the European Union (member states of the European Union or countries associated in Europe, as defined in Appendix 1).

However, international cooperation will be welcomed. Only the teams of the countries (such as listed in Appendix 1) can be financed by la Fondation Paralysie Cérébrale/Fondation Motrice. The non European teams will have to justify their own financing to be a member of the project. Projects will be based on a consortium whose coordinator will be a leader working in France.

Project Leader

The project leader (or coordinator) must be a principal investigator (PI) of a public research or higher education institution located in **France**: university, university hospital, scientific and technical public institution (EPST), public industrial and commercial (EPIC). He will devote at least 25% of his time to the project.

In addition to its scientific and technical role, the project leader will be responsible for establishing working arrangements between the participating teams, the production of the required documents (scientific and financial reports), promotion and communication of results.

The project leader may participate in only one project in this call.

Project partners

Partners teams within the consortium will be French, European or even international (see above) and from different disciplines. Particular attention will be paid to the complementarity of the teams involved in the proposed project and to the multidisciplinary aspect.

The tasks performed by any person involved in the project must be clearly identified and explained in the application for funding. Each person involved in the project must be responsible for at least one task and devote at least 10% of his/her time.

Partner teams may participate in several separate projects to be submitted for this call

5. FUNDING and FINANCING AGREEMENT

Projects must be sized for funding between € 500 K and € 1.5 million over a period of 3 to 5 years. The relevance of the project to the characteristics of the call as described in paragraphs 2 and 3 and the scientific excellence of the project and of the consortium will be the main criteria for the selection of the project (s). La Fondation Paralysie Cérébrale/Fondation Motrice reserves the right not to award funding if the quality of the submitted files is deemed insufficient by the experts. A financing agreement will be signed between la Fondation Paralysie Cérébrale/Fondation Motrice and the organizations or institutions managing the funding. Selected project (s) will negotiate with la Fondation Paralysie Cérébrale/Fondation Motrice a detailed protocol describing the activities of the project which will be annexed to the financing agreement.

6. FUNDING MODALITIES

A detailed budget broken down by expenditure heading must be presented. The funds may cover:

- Operating costs (consumables);
- Staff costs (Personnel) recruited specifically for the project (technicians, research engineers, master 2 students, PhD students, post doctoral students);
- Purchase of equipments necessary to the research (if the amount exceeds **10% of the total amount requested, it must be justified**)
- Mission expenses (travels) and publication (maximum **5% of the total amount requested**);

La Fondation Paralysie Cérébrale/Fondation Motrice usually requests the cancellation of the management fees (overheads) taken by the institutions and organizations from its grant. In case of strict impossibility, the rate of management costs attributable to the project will be capped at 4% of the total amount requested. On this point, an agreement of the institution or organization is required in the application file.

Institutional or industrial co-financing are possible since conflicts of interests are considered, but the part of the financing paid by la Fondation Paralysie Cérébrale/Fondation Motrice will have to remain the majority.

As far as possible, the project leader will manage the funds allocated in connection with its supervision, including the distribution of the funds to the partner teams involved in the project and belonging to different organizations. Should the opposite occur, every participating team benefiting from a part of the allocated funds will have to indicate its managing organization in charge of receiving the funds. Each managing organization will then have to sign an agreement with la Fondation Paralysie Cérébrale/Fondation Motrice. The granted budget will be paid in several terms according to the duration, the methodology of the project and the total amount of the funding.

The first payment will be made after the signature of the financing agreement, subject to receipt by la Fondation Paralysie Cérébrale/Fondation Motrice of the administrative documents authorizing the start of the project (in particular for clinical projects: ethics committee, drug regulatory agencies). The documents needed to start the project have to be obtained and provided within the 12 months following the signature of the agreement. If this period is exceeded, la Fondation Paralysie Cérébrale/Fondation Motrice reserves the right to cancel the financing of the project.

The payments will be made according to the following timetable:

- 10 to 20% to initiate the project after the signature of the financial agreement with the Foundation,
- several terms according to the duration and the amount of the financed project, after receipt by la Fondation Paralysie Cérébrale/Fondation Motrice of a scientific report showing the progress of the project and a report justifying the use of the already paid funds. These terms correspond to 70 to 80 % of the total allocated amount,
- 10% at the end of the project, after receiving a full report and a public summary.

7. CRITERIA FOR ADMISSIBILITY OF THE PROJECTS

- The application shall be written in English and must follow the plan given in the application form. The public summary will also be written in French.
- The project leader may submit only one application in the context of this call
- The projects outside of the scope of the call will not be assessed.
- The incomplete applications will not be handled.

8. EVALUATION OF THE PROJECTS

The selection of the proposals will be conducted by 3 bodies:

- A panel of independent, international experts, who will judge the scientific quality of the projects,
- The scientific committee of la Fondation Paralysie Cérébrale/Fondation Motrice (list of members in Appendix 2) which will propose a list of one or several project(s) susceptible to be financed,
- The executive Board of la Fondation Paralysie Cérébrale/Fondation Motrice who will choose one or several project(s) to be financed.

The expertise of the files will take place at 2 times:

- An expertise of the files by the International panel of experts, followed by a pre-selection by the Scientific Committee.
- A hearing in French or English of the pre-selected project leader(s) in front of the members of the Scientific Committee. This hearing will include
 - The oral presentation of the project in French or English,
 - An exchange of questions / answers based on the expertise of the files (which will previously have been communicated to each project leader).

9. CRITERIA FOR EVALUATION AND SELECTION OF THE PROJECTS

Particular attention will be paid to the relevance of the research project and the question asked in regard of the current state of the art, the quality of the used methodology, and the potential impact on the management and quality of life CP patients and their relatives.

The evaluation of the project by the Scientific Committee of la Fondation Paralysie Cérébrale/Fondation Motrice will cover:

- adequacy to the call,
- relevance and innovation in regards to Cerebral Palsy,
- potential benefits for the concerned people and their families and benefits in terms of public health,
- ethical aspects,
- project leader qualities (training, publications, national international fame, ability to federate and coordinate the consortium, communication ...). Particular attention will be paid to the recognition of the PI in the field of cerebral palsy.
- quality of the involved teams and laboratory (ies) (scientific, publications, fame),
- adequacy of financial resources to the scale of the proposed project in order to ensure its feasibility. Any project of an amount upper to that asked to la Fondation Paralysie Cérébrale/Fondation Motrice will have to justify current, on-going or future co-financing(s). Co-financing(s) must be entirely declared in the application form. The part of the project corresponding to the financing of la Fondation Paralysie Cérébrale/Fondation Motrice must be clearly documented.

PARTICULAR POINTS

- The eligibility criteria of the studied population should be carefully defined using specific clinical classifications for Cerebral Palsy (for example
- The range of age and the number of people to be recruited will have to be justified.
- Projects should specify the used strategies "From the protocol to the publication to apply the principles of "free access and of "open data

10. PROPOSAL SUBMISSION AND TIMELINES

Between September 15th and October 15th, 2017, the project leader will have the opportunity to address to the Scientific Committee of la Fondation Paralysie Cérébrale/Fondation Motrice any question relating to the call (exclusively via e-mail at the following address: directionscientifique@lafondationmotrice.org).

Before sending the application file, it will be asked to send by e-mail **before November 30th, 2017** indicating the project title, the teams involved as well as the project leader, the discipline and the main theme of the project, its relevance to the areas A and B mentioned above, 5 keywords as well as the names of potential reviewers. Although not entering the selection process, this project synopsis is compulsory and only the projects whose synopsis has been received will be evaluated.

The application file, dated and signed, must be sent before **January 15th, 2018**. Its content will have to follow the plan and the specifications of the form. The project (Excluding administrative data, bibliographic references, budget presentations and CV's which will be provided in appendices) **should not exceed 20 pages** (single-spaced, Arial 11 minimum). Only complete applications will be evaluated.

The project synopsis and the application forms can be downloaded on the website of the Foundation: <http://www.fondationparalysiecerebrale.org>

In case of download difficulties, the Foundation may be contacted by e-mail at the following address directionscientifique@lafondationmotrice.org

The whole project (scientific document of 20 pages and appendices) must be sent in 2 copies :

- **One copy, PDF format signed and dated** by e-mail to directionscientifique@lafondationmotrice.org (**Before January 15th, 2018, 1 pm, Paris Time**)
- **One hard copy** with original signatures by mail out to: FONDATION PARALYSIE CEREBRALE/ FONDATION MOTRICE Appel d'offre Grand Projet 2018, 67 rue Vergniaud, 75013 Paris, France (Before January 25th, 2018; sending date will be attested by postmark date).

Summary of the timelines

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| Launch of the call | June 15th 2017 |
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| Candidates' questions about the call for the Foundation and the Scientific Committee | September 15th to October 15th, 2017 |
| Project synopsis : Deadline for submission | November 30th 2017 pm, Paris time) |
| Application files : Deadline for submission | Electronic version: January 15th, 2018 pm, Paris time) Hard copy January 25th, 2018 |
| Expected date for information on the pre-selected projects for the oral hearing | April 15th, 2018 |
| Expected date for the hearing of the pre-selected projects | End of May, 2018 |
| Expected date for information on the Project (s) selected for funding after the decision of the Scientific Committee and the Board of Administrators | End June, 2018 |
| Establishment of Financing Agreements | July –November, 2018 |

The notification of acceptance or refusal of funding will be sent by e-mail to the Project leader (address of follow-up indicated in the file). If decided to support a project, mail of notification will specify the amount of the grant. This notification letter will mark the beginning of a negotiation period (definition of milestones and evaluation points, justification of expenditure) which will end with the signature of the financial agreement (s).

11. SCIENTIFIC AND FINANCIAL FOLLOW-UP- VALUATION OF THE RESEARCH

Accurate, scientific and financial interim reports have to be produced by the project leader according to the timetable agreed in the agreement of funding. The satisfactory progress of the project (compared to the steps outlined in the grant application form) and the respect of the planned budget will condition the payment of the following funding. The final payment will be made after the main results have been disseminated in the form of reports and publications.

- A final research report and a public summary in English and French of the results must be produced by the project leader respectively 6 months and 3 months after the end of the project.
- According to the duration of the project, works related to the project (s) funded (s) will have to be the object of at least 3 to 5 international scientific publications of high quality. Publications relative to the intermediate stages of the project and to its terminal realization are encouraged.

The financed teams are deeply encouraged to propose scientific communications in national and international congresses. Project leader(s) could be invited to present their final results during a dedicated scientific day and will be asked once a year to present the project in connection with the foundation for information of the general public and donors of the foundation.

The team(s) of researchers will commit to mention the support of in all the publications and communications in connection with the funded project.

CONTACT or ngenes@lafondationmotrice.org

Appendix 1 Countries for receiving funds from la Fondation Paralysie Cérébrale/Fondation Motrice

Countries members of the European Union : Germany, Austria, Belgium, Bulgaria, Cyprus, Croatia, Denmark, Spain, Estonia, Finland, France, Greece, Hungary, Ireland, Italy, Lithuania, Latvia, Luxembourg, Malta, the Netherlands, Poland, Portugal, the Czech Republic, Romania, Slovakia, Slovenia and Sweden.

Countries non members of the European Union: Albania, Bosnia and Herzegovina, Faroe Islands, Former Yugoslav Republic of Macedonia, Iceland, Israel, Moldavia, Montenegro, Norway, Serbia, Switzerland, Turkey, United Kingdom, Switzerland

Appendix 2 List of members of the Scientific Council as 2017, June 15th

Pr Olivier Baud (Paris, France), Chairman
Dr Valérie Achache (Paris, France)
Dr Stéphane Armand (Geneva, Switzerland)
Mr Eric Bérard (Lyon, France), Family representative
Pr Sylvain Brochard (Brest, France)^o
Dr. Javier De la Cruz (Madrid, Spain)
Dr Jessica Dubois (Saclay, France)
Dr. Joël Fluss (Geneva, Switzerland)
Pr Jean-Michel Gracies (Créteil, France)
Pr Patricia Limousin (London, UK)
Dr Régine Scelles (Nanterre, France)
Dr. Anita Truttmann (Lausanne, Switzerland)