



Duchenne
PARENT
PROJECT **España**

IV Call for Grants for Research Projects **DUCHENNE SPAIN 2020**

1. PURPOSE OF THE CALL

Duchenne Parent Project Spain (DPPS) is due to establish the concession of aids in order to promote and encourage the development of the research and innovation in Duchenne Muscular Dystrophy (DMD) and Becker Muscular Dystrophy (BMD) field by funding the research projects in competitive concurrence system

2. FINANCING

2.1 The funding for this call is 250,000€. This amount of money will be divided up between the final projects, after the evaluation of the Assessor Committee. The funded amount will be the total or partial quantity of the indicated budget. It will be charged to Duchenne Parent Project Spain (DPPS).

2.2 The financial contributions will not exceed 50,000€ for the winning projects and will be developed within a maximum period of two years.

2.3 DPPS will deliver the amount in two payments: the first one will be done, once that the presentation of the explanatory report of the project to be developed in the first year. The second payment will be done at the beginning of the second year, after the presentation of the first year results and the planning and development of the second one.

3. BENEFICIARIES

3.1 The principal investigator (PI) will be the receptor of the fund and the responsible of the management. As an alternative, and by the request of the PI, the Investigator Centre that belongs the PI, can receive the funding amount of the call under the authorisation of the Investigator Centre and DPPS.

3.2 In the case that the PI would be the funding receptor, the fiscal treatment would be as the current legislation allude, as creation of patrimonial profit subjected to the applicable regulation of the Personal Income Tax "Impuesto sobre la Renta de las Personas Físicas (IRPF)"

3.3 The same investigator must not present more than one project as PI and he/she will not take part as an associated in the request of more than two projects. The investigator will be able of receiving the funding for one project.

3.4 The project has a duration period of two years.

3.5 If the PI or researcher group has already a project funded by public entities, and it is thematically related to the one presented here, the quantity and the funding certificate received or requested for must be explicitly specified. In the case of allocation, can request an accreditation to the main investigator.

3.6 In case that any of the presented projects reach enough scientific value, DPPS can declare null and void the current call.

4. RESPONSIBILITIES OF THE PRINCIPAL INVESTIGATOR AND THE INVESTIGATOR CENTRE

4.1 The PI is responsible of the content of the application, the researcher's team coordination, as well as the project implementation. PI would be the responsible of the fulfilment of the objectives and obtaining results. PI must also make a proper use of the budget focusing on the funding investigation and in concordance with the funding certificate. The PI is the contact person with DPPS.

4.2 The PI have to send, at the end of the year since the beginning of the project, a report which contents the updated situation if the investigation project, the justification of the expenses, the diffusion plan and the transfer of the results.

4.3 At the end of the project will send out a final report in a period of 30 days. This report has to go before of an executive abstract, redacted in a didactic and informational way. In this abstract must be highlighted the main results of the investigation and the implication to the development of the health results.

Also, it must contain the modifications of the objectives, the conclusion, the publications or the content which is published. They also must send a final financial report which contains the money distributions that is paid by DPPS.

4.4 The purpose is to ensure that the effective development on the requested terms and attributed. If the PI do not present the annual report a time, the rest of the aid will be cancelled. Another consequence of it, is that the PI cannot be able to present another project to the next investigation call and/or aids call of a group work's aid as the PI, as well as the devolution of the quantity obtained by DPPS.

4.5 The PI will be involved to the fulfilment of all the requirements of this call.

4.6 The PI is responsible of verify the support received by DPPS in all the publications and presentations of the results.

4.7 The Investigator Centre is committed to supporting the successful implementation of the activity in case that the aid is granted. It also, is committed to fulfil all the requirements of this call and is responsible for the veracity of the data related to the PI and the team.

4.8 The technical or financial modification, must be requested and justified by the PI and it must to be approved by the Assessor Committee.

4.9 In case of a total or partial unfulfilment, DPPS can cancel the aid as well as request or the devolution of the quantity provided

5. ETHICAL AND LEGAL ASPECTS OF RESEARCH PROJECTS

The research projects that are requesting for the aid, should respect the fundamental principles set out in the Declaration of Helsinki and in the Council of Europe Convention related on Human Rights and Biomedicine, the UNESCO Universal Declaration on the Human Genome and human rights, as well as obey the requirements of the Spanish legislation in the field of medical research, the protection of personal data and bioethics, in accordance with Law 14/2007 3 July, of Biomedical Investigation and others requirements of Spanish legislation in biomedical research.

All the investigations, in which requires deal with personal data, it has be governed by the current law, Regulation (UE) 2016/679 of the European Parliament and Council of 27 April 2016 of Data Protection (RGPD)

6. FORMULATION AND SUBMISSION OF THE APPLICATION

6.1 The PI must submit:

- a. The requested application form, including the report of the Research project following the template.
- b. Curriculum Vitae of the PI and all the members of the research team.
- c. Report of the Committee of Ethics and Clinical Trials.
- d. Report of the Committee on Animal Experimentation.
- e. Photocopy of the NIF of the Principal Investigator.
- f. Photocopy of NIF Centre Institution.

g. The funding may cover the following items:

- Acquisition of goods and recruitment of services, duly justified. The inventoried equipment acquired under the assistance will be owned by the Investigator Centre that is the executor of the project.
- Purchase of perishable material and supplementary costs, such as publication costs.
- Supporting travel and diet's costs due the fulfilment of the objectives and the communication of the results. The maximum quantity will be €1,000 per year.
- Salary for scientific (including pre-doctoral or post-doctoral fellows) or technician staff whose work is directly related to the funded project could be requested up to a maximum of 50% of the grant.

6.2 The applications, with the respective annexes, shall be submitted by email to research@duchenne-spain.org during the period specified on the website www.duchenne-spain.org. It will not be accepted the projects reached by other way.

7. DEADLINES

Projects may be submitted, from the publication of the current call until 2 pm on April 30th, 2020.

8. ASSESSMENT OF THE PROJECTS

8.1 The concession of the projects will be done through the competitive concurrence procedure

8.2 The received projects will be reviewed by the Research Department of DPPS to validate their compliance with the requirements of this call. After this process, the projects will be evaluated.

8.3 The evaluation of the projects will be carried out by the Scientific Advisory Committee, composed by international evaluators who made the assessment of scientific and technical aspects of projects, so that the applications must be written in English.

8.4 Aspects to be considered in the evaluation:

- Translational character of the research projects.
- Viability of the proposal.
- The main investigator and the researcher team capacity, especially in the period of the last five years, and the feasibility of the researcher group in relation to the proposed project.
- Adaptation of the methodology, research design and work plan in relation to its objectives.
- Adaptation of the budget for the proposed activities.

9. AWARDS ALLOCATION

9.1 The resolution of the call will be individually notified to every participant and it will be published in the website, since 30th of June 2020.

9.2 The decisions of the Scientific Advisory Committee and DPPS shall not be subject to any appeal or challenge by the applicants.

10. AGREEMENTS

10.1 The selected projects, will sign an agreement where it appear the general and specific conditions that will be governed the concession of the aid between the main investigator, the Investigator Centre and DPPS.

10.2 Any amendment to the methodology and/or work plan must be previously communicated and approved by DPPS.

10.3 The PI of the selected projects must submit an annual report and a final report within the deadlines specified in the agreement, which also will consider the conditions governing the payment of aid.

10.4 The scientific report, according with the model provided to the PI, will include different sections that must be completed in full. It will be accompanied by a financial report, which must be certified by the centre where the project takes place.

10.5 The annual report will be evaluated both by the Research Department of DPPS and the Scientific Advisory Committee. The results of these evaluations will make a condition of the next payment of the project by DPPS.

10.6 The researcher undertakes to participate in the Congress organized by DPPS in order to report his progress once the period of financing of projects under this call has finished.

10.7 DPPS Association, will monitor, through its scientific director, though the Scientific Director who is will settle down the quarterly meetings with the main investigator in order to be able to analyse the design of the project as well to discuss future actions.

11. INTELLECTUAL PROPERTY

11.1 All the rights of intellectual property arising from the funded projects will be distributed according to the rules and agreements of the Investigator Centro and the PI.

11.2 If any of the projects selected by the call, turned out the creation of a patent or any other form of commercial exploitation, the 5% of profits obtained will correspond to DPPS.

12. RESPONSIBILITIES

12.1 The PI and the Investigator Centre, as a subsidiary institution of the project, will be responsible for all purposes to DPPS, including the compliance of the legal aspects applicable to staff recruited under the project.

12.2 The failure to comply with these rules may result in no award or termination of funding the project, if it is considered by DPPS.

12.3 On the assumption that the project is not carried out under the conditions laid down in the agreement, DPPS may request a full or partial repayment of the award.

13. PROTECTION OF PERSONAL DATA

The main Investigator and the rest of the group, will authorise the treatment of the personal data by DUCHENNE PARENT PROJECT SPAIN, in the compliance of the Regalement (UE) 20167679 of the European Parliament and the Council, 27 April 2016, related to the protection of physical individual, as well as recipient of the information provided, with the objective of carrying out a selection process, and if it is concerned, dealing with the concession of the aid and the monitoring of the aid, just as it is established in the basis of the call.

The Responsible of the Treatment is DUCHENNE PARENT PROJECT SPAIN, addressed in C/ Embajadores, 128, local, 28945, Madrid

The personal data of the beneficiary will be conserved as long as it is into force the aid concession, and five more years.

The personal data of the non-beneficiary, will be eliminated within a period time of a week since the aid concession

In case of do not submit the requested consent, it will not be possible to have the data of the possible beneficiary, so the members who do not hand over it, will not be beneficiary of the aid.

The legal base for the treatment of the data is the benefit of the consent of the interested person.

It will not be communicated the data to third party, unless legal obligation.

It is planed the communication of the data to other collaborated recipient of DPPS for the same objectives previously written such a: professional of the Association, companies hired by the Association, volunteers, supported worker, and other entities who are necessary to give support in order to fulfil the aim described.

The interested person can apply, the next rights: access, cancellation, elimination, limitation, rectification, portability and forgotten right. It can be requested by any person. The procedure is attaching a photocopy of the ID or passport and giving to the following address: C/ Embajadores, 128, local, 28945. Madrid.

Any interested can go to the Control Authority in Data Protection subject competent (in Spain is competent the Spanish Agency of Data Protection, AGPD). You can contact to this entity through the website: www.agpd.es

Madrid, 26th of February 2020



Join the #DesafíoDuchenne

to end the Duchenne and Becker
Muscular Dystrophy



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