

Fund Francine & Henri Plisnier Fund Dr & Ms Charles Tournay-Dubuisson

CALL FOR PROJECTS 2022

The Fund Francine & Henri Plisnier and the Fund Dr & Ms Charles Tournay-Dubuisson were created to support research into rare diseases.

The Funds are managed by the King Baudouin Foundation with the help of a scientific jury and a Steering Committee. The Funds are launching a first joint call for **action-oriented research in the field of rare diseases**. Focus of this call:

Development of a model of integrated care for patients with a rare disease - Action-oriented research

The model starts with the communication of the diagnosis and seamlessly progresses to the deployment of a care pathway that ensures multidisciplinary, integrated and patient-centered care

Why this research topic?

At the beginning of 2022, the King Baudouin Foundation published a report on the state of affairs for patients with a rare disease in Belgium (cfr publication FR or NL on www.kbs-frb.be)

Five priority actions were defined, one of which can be described as:

Patients with a rare disease have the right to receive integrated, patient centered and qualitative care adapted to their needs; this requires the development and implementation of a model for integrated care according to the principle 'highly specialized care in an expert center if needed, generalized care close to home when possible'.

As the development of an appropriate model of care was described as an urgent need by patients and caregivers, it was decided to focus the call on this topic.

What type of projects are eligible under this call?

Under this call, we welcome large interdisciplinary projects that develop a comprehensive model of care for people with a rare disease. However, smaller projects that address a specific problem and as such lead to a real improvement in a particular area of care, or projects that contribute to the development of the comprehensive model, will also be considered.



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All proposed projects must comply with the following principles:

- **‘Close to home if possible, in a (highly) specialized center if needed’**
Patients with a rare disease need to be guided and get access to expert diagnosis and treatment in a knowledgeable center with adequate expertise. At the same time, expert knowledge on the treatment and care should be transferred to the local setting whenever possible;
- patient-centered and coordinated care must be **based on the care needs of the individual patient**, dependent on the complexity of the condition and the context of the patient and not (solely) on a categorization of the disease;
- the model for integrated care and support takes the needs, questions and goals of the person with care needs (and those close to them) as its starting point. It approaches **this person ‘as a whole’**, taking into account aspects of medical, psychosocial, religious/ideological and cultural nature as well as factors of daily life;
- many, if not most rare diseases have an onset during childhood and in these cases the family is also affected. This should be taken into account in the model by providing links with **family support** (i.e. implication of social services, psychologists, family support, school ...);
- the model should **take into account the current structures and organization of the Belgian care system** and should be implementable in that system. However, the model must not necessarily built further on these structures (e.g. conventions, reference centers, ...)

All rare diseases of children and adults are concerned. **A common approach for more than one rare disease** is strongly recommended. Projects focusing on a single pathology will have to demonstrate their benefit for the care of patients with other diseases.

The proposed project should also provide a realistic calculation of the **costs** : what adequate funding must be provided for real implementation and for which added value compared to the current situation?

What do we mean by action-oriented research?

Under this call, priority will be given to action-oriented research projects that are designed to deliver interventions for the benefit of patients, families and professionals. This means that projects must comply with the following principles:

- the research should be aimed at improving practice. It involves action, evaluation and critical reflection. Based on the evidence collected, adapted models of practice are proposed, implemented, evaluated and further adapted;



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- the research should be participative and collaborative;
- the research should be situation-based and context-specific;
- the research develops reflection based on participants' interpretations;
- knowledge is created through action and at the point of application.

Selection criteria

Scientific quality of the project

Quality of the research

- Design, feasibility and potential of the proposed project.
- The extent to which the research process is participatory, educative and empowering, involving dynamic approaches in which problem-identification, planning, action and evaluation are interlinked.

Relevance & added-value of the research as contribution to a model for integrated care for people with a rare disease

- The research must focus on specificities of patients with rare diseases
- The project clearly addresses identified health and/or psychosocial issues related to the care for patients with a rare disease
- The proposal includes an assessment of the necessity and relevance of the research question by patients or patient representatives

A realistic calculation of the cost of this model: what adequate funding must be provided for real implementation and for which added value compared to the current situation?

Track record

- Track record and career potential of project leader (creativity, management skills, international visibility etc...)
- Potential of the research team & collaborating teams: scientific environment, competence, experience, awareness of the specificities of rare diseases. ¹

Potential impact

- of the research for patients, their families and care professionals
- of the results on diagnosis/treatment/quality of care/quality of life for people with a rare disease

¹ The call is open to any researcher with or without a track record in the field of rare diseases, but the research project has to be focused on rare diseases.



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Communication & implementation of the results

- Plan of communication on the results of the research, and of the implementation & follow up

Involvement of stakeholders

Buy-in from and participation of all relevant stakeholders is essential to ensure that the work being done is translated into policy and practice.

- Identification of the stakeholder field
- Strategies to involve stakeholders and to optimise the use of their expertise, competence and engagement within the research project.

Budget

Adequacy of the budget. A **realistic calculation of the cost** of this model: what adequate funding must be provided for real implementation and for which added value compared to the current situation?

Ethical questions

Are there any ethical questions related to the research and how the applicant intends to take these into account?

Eligible applicants

The call is open to:

Professionals with research experience in medical, human, health or social sciences, professionals in social and medico-social support, healthcare professionals ...

The project leader must be working in an academic centre, a research organisation, a hospital or a health care organization in Belgium. The application should be formally supported by an established researcher (e.g. with a PhD or clear research experience)

The Foundation will only fund not-for-profit organizations. For-profit organizations can be part of a research team but are excluded from funding.

The project has to be initiated and coordinated in Belgium

Collaborative projects are encouraged. The participation of patients and/or patient organisations in the project is mandatory.

Projects that involve collaboration between research teams internationally must be initiated and coordinated by the team based in Belgium.



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Grant

The total amount available for this call is € 260.000. In case of several high-level projects, this amount can be divided among the projects.

The support can be used for all costs related to the project.

No overhead can be deducted from grants up to € 30.000 included. For higher amounts, the overhead cannot exceed 15%.

Procedure

Interested? Submit **an online application** via the website of the King Baudouin Foundation www.kbs-frb.be. Applications should be submitted **in English by 19 May 2022** at midnight at the latest. Candidates will receive an acknowledgement of receipt.

Selection

Applications will be submitted to an independent jury.

The jury will assess the projects and will draw up recommendations for the Fund Steering Committee managed by the King Baudouin Foundation, which will make the final decision. The decision will be published beginning October 2022

Contact

- For technical assistance during the application process:
Contact centre – Tel +32-(0)2 500 45 55 – proj@kbs-frb.be
- For information regarding the call:
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King Baudouin Foundation

Working together for a better society

The King Baudouin Foundation's mission is to contribute to a better society.

The Foundation is an actor for change and innovation, serving the public interest and increasing social cohesion in Belgium and Europe. We seek to maximize our impact by strengthening the capacity of organizations and individuals. We also stimulate effective philanthropy by individuals and corporations.

The King Baudouin Foundation is a public benefit foundation. The Foundation was set up in 1976 on the occasion of the 25th anniversary of King Baudouin's reign.

With thanks to the Belgian National Lottery and to all donors for their valued support.

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