

# GENERET AWARD FOR RARE DISEASES 2025

## *Guide for applicants*

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# Introduction

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## Context

Rare diseases, even concerning over 300 million people around the globe, are highly misunderstood, under-identified and under-treated. This leaves not only patients but also families, health care providers, researchers and developers of therapies with numerous questions and needs.

Trying to understand and treat rare diseases is extremely challenging, but also very valuable and rewarding as unanswered needs are always met and research in rare diseases often provides a model for more common conditions. Conversely, research in common diseases can also bring valuable insights to the field of rare conditions.

The Generet Fund aims to boost research in rare diseases by releasing an amount of 1 million euros each year. This should give a top researcher the opportunity to realize pioneering work in rare diseases and thus meet the many needs and questions in this field.

## Objective Of The Call

The Generet Fund invites established researchers to develop a high-level project in the field of rare diseases to better understand the processes (causes and mechanisms) underpinning rare diseases and translating fundamental discoveries into better prevention, diagnosis or treatment for patients.

The call is aimed to two categories of researchers: confirmed researchers in rare diseases and confirmed researchers with a track record in more common pathologies who can demonstrate that their research will have a substantial added value for rare diseases and can accelerate research in this particular field.

## Scope Of The Call

Rare diseases are considered to be life-threatening or chronically debilitating diseases affecting no more than 1 in 2.000 people.

Potential research domains are, for example (non-exhaustive list): metabolic disorders, neuromuscular disorders, cardiovascular disorders, bone diseases, connective tissue and musculoskeletal disorders, lung diseases, neurological disorders, skin disorders, primary immune deficiencies, auto-inflammatory and auto-immune diseases...

Are excluded for this call: research on rare cancers; research on rare adverse drug events.

The research project may include all stages, from "bench to bedside".

## Main Features Of The Award

The Generet Award will be granted to independent investigators of any nationality working in Belgium to support a research project in the field of rare diseases in Belgium.

- **Funding:**

The Award amounts to 1.000.000 € over 4 years. However, a first instalment of 500.000 € will be credited for 2 years. The second instalment of 500.000 € will be subject to the positive evaluation of a mid-term scientific, financial and communication report. The laureate is also requested to submit a final report at the end of the project.

- **Eligible expenses:**

Eligible expenses encompass personnel costs, running costs and equipment. Up to 30% of the Grant's amount could be outsourced for supporting international or intranational expenses (personnel costs and running costs) including the private sector if they charge at cost price.

- **Overheads:**

A max. of 10% overheads may be applicable to this amount but this will need to be negotiated with the Generet Fund and be mentioned in the agreement between the Generet Fund and the beneficiary. The amount of overheads is included in the Prize money and does not come on top of it.

- **Portability of the Award:**

The Award beneficiaries could keep the benefit of the Award if they transfer their research activities to another eligible Belgian institution. The Award cannot follow the beneficiaries if they transfer their research activity to a private company or abroad.

## Schedule of the call

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- Opening of the call: March 20, 2025
- Pre-proposals deadline: May 12<sup>nd</sup>, 2025
- First Panel meeting: End of June 2025
- Invitation for full proposals: Following the first Panel meeting
- Full proposals deadline: August 11<sup>th</sup>, 2025
- Second Panel meeting: End of November 2025
- Start of the research: January 1<sup>st</sup>, 2026

# How to apply?

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## Application Process

Candidates will undergo a two-steps application procedure encompassing a phase of a pre-proposal (open to all) and a phase of full proposal (accessible to shortlisted applicants from the first stage).

- **Pre-proposals:**

Each candidate must submit a letter of intent of max 3 A4 pages focusing on the scientific proof of concept of the research project and attach a relevant core bibliography and short CV information.

The pre-proposal must be submitted electronically in English using the online application system no later than **May 12<sup>nd</sup>, 2025**, midnight, Brussels time (this is a strict deadline). A PDF version of the pre-proposal form is available on the Generet Award website for information. This document only aims at providing an overview of the different sections. It should not be used to submit an application.

A « save and continue » module allows the applicants to quit the system and to come back working on their application at a later stage. Once the applicants quit the system, an automatic e-mail is sent to their e-mail address with a link to return to their application form.

All pre-proposals will be checked to ensure that all eligibility criteria are met before being processed to the evaluation stage.

- **Full proposals:**

A shortlist of applicants will be invited early July 2025 to submit a full proposal with comprehensive information on all aspects of the research project, bibliography, and CV.

The full proposal must be submitted electronically in English using the online application system no later than **August 11<sup>th</sup>, 2025**, midnight, Brussels time (this is a strict deadline). A PDF version of the full proposal form will be available on the Generet Award website for information. This document only aims at providing an overview of the different sections. It should not be used to submit an application.

A « save and continue » module allows the applicants to quit the system and to come back working on their application at a later stage. Once the applicants quit the system, an automatic e-mail is sent to their e-mail address with a link to return to their application form.

All full proposals will be checked to ensure that all eligibility criteria are met before being processed to the evaluation stage.

## Eligible Candidates

- Candidates must be:
  - Internationally established investigators, with outstanding scientific achievements and multiple seminal contributions in the field of rare diseases
  - Internationally established investigators with outstanding scientific achievements and multiple seminal contributions in common diseases, who can demonstrate that their research will have a substantial added value for rare diseases and can accelerate research in this particular field.
- Candidates must have a scientific seniority of min. PhD + 10 years of research activities (career breaks such as maternity leave or long-time illness not included).
- Candidates must be affiliated to a Belgian University, a Belgian University Hospital or any of the following Research Institute:
  - Institute of Tropical Medicine Antwerp
  - LABIRIS
  - Flemish Institute for Biotechnology (VIB)
  - Flemish Institute for Technological research (VITO)
  - de Duve Institute
  - Bordet Institute
  - GIGA Institute
  - Sciensano
  - Belgian Nuclear Research Center (SCK CEN)
- Candidates must be affiliated to their institution until December 31st, 2029.
- Candidates must not reach the retirement age limit during the project.
- In case of international collaboration, the project must be initiated and coordinated and by the team based in Belgium.

## Valuable Features

- Translational approach: referring to a research methodology integrating a basic science approach as well as clinical considerations. It encompasses all stages from bench to bedside. Beyond a better understanding of the disease, translation of the research results into benefit for the patients is a key objective of the Generet Fund. As such, a clear description of the translational strategy is a plus.
- Multidisciplinarity: referring to the use and application of different scientific disciplines as a substantial element of the research methodology.
- Multicentric cooperation: referring to the close collaboration with centres of excellence located in Belgium or abroad. In case of international collaboration, the researcher working in the Belgian Institution must remain the coordinator of the project.

- Communication: referring to a communication plan about the research within the scientific community but also towards patients and a broader public (conferences, articles, video with success stories, etc.).

Once the application file is submitted, the applicant receives a notification of receipt, and an administrative eligibility check is performed. The applicants will be informed whether their application file is complete and eligible on the administrative level or if documents are missing.

## Evaluation process

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### Selection principles

The selection process follows the highest international standards in terms of fairness, transparency, impartiality, consistency, and independence in order to identify an established researcher (irrespective of gender, age, beliefs, nationality) who guarantees the Fund and the community to develop a high-level project in the field of rare diseases.

It is based on a two-step evaluation procedure performed by international experts.

### Evaluation process

#### **Pre-proposals**

All pre-proposals will be evaluated by a gender-balanced independent high-level international Panel of max. 10 members. This Panel will be composed of non-Belgian high-level experts working outside Belgium with different profiles to ensure a broad coverage of the scientific spectrum pertaining to rare diseases.

All experts involved in the evaluation process will have to sign a non-disclosure agreement, a data protection agreement, a non-conflict of interest form and will be informed of the confidentiality chart of the FNRS.

Prior to the Panel meeting, each pre-proposal will be evaluated by 3 to 5 Panel members acting as:

- Rapporteur (1): responsible for scoring, commenting, and introducing the application during the Panel meeting.
- Co-rapporteur (1 or 2): responsible for scoring, commenting, and discussing the application during the Panel meeting.
- Reader (1 or 2): responsible for reading and discussing the application during the Panel meeting.

Max. 2 representatives of the Generet Fund, managed by the King Baudouin Foundation, will attend the meeting as observers. In order to ensure the independence of the Panel, the observers remain neutral. They do not participate in the evaluation and are not involved under any form in the selection process. Their role is to witness the compliance of the evaluation to the regulations and its conformity to the highest expected standards. They are also expected to formulate comments regarding the improvement of the procedure for the next calls. Observers report directly to the King Baudouin Foundation and to the Board of Trustees of the Generet Fund.

The scores and comments will be provided by the rapporteurs and co-rapporteurs prior to the Panel meeting during a remote evaluation phase allowing the experts to evaluate the applications in a simple blind mode (i.e., the experts will know the identity of applicants but not the other experts' identity).

The Panel meeting will allow for a consolidation phase during which all experts will discuss all applications pre-ranked on basis of the remote scores.

At the end of this meeting, the Panel will identify, either via consensus or a vote, a shortlist of applicants to be invited to submit a full proposal.

The applicants not reaching the second stage will be informed accordingly and will receive an evaluation summary report.

### **Full proposals**

The shortlist of full proposals will undergo a two-phase evaluation procedure with a rebuttal stage.

During the first phase, each full proposal will be evaluated by (a target of 3) independent, high level, international and specialized remote experts evaluating the application in a simple blind mode.

The anonymized remote evaluations will then be sent to the applicants for information and allow them to submit a 1 A4 page of comments on these assessments before the file passes on to the second stage (rebuttal phase).

During the second phase, all full proposals will be evaluated by an international expert Panel.

This Panel will be composed of max. 5 members, some coming from the Stage 1 Panel and other being new, more specialized, high level and international experts selected to better match the scientific scope of the full proposals.

Prior to the Panel meeting, all Panel members will read and score all applications in a simple blind mode. Each application will also be assigned to a Panel member acting as rapporteur whose role will further include the introduction of the application during the Panel meeting.

The Panel meeting will allow all experts to discuss all applications leading to the identification of a laureate either via consensus or via a vote. The non-selected applicants will be informed accordingly and receive an evaluation summary report.

The laureate will be contacted by the Generet Fund, but his/her identity will remain confidential until the Award ceremony.

All experts involved in the evaluation process will have to sign a non-disclosure agreement, a data protection agreement, a non-conflict of interest form and will be informed of the confidentiality chart of the FNRS.

Max. 2 representatives of the Generet Fund, managed by the King Baudouin Foundation, will attend the meeting as observers.

No redress procedure is foreseen.

## Evaluation criteria

The evaluation of the pre-proposals will be made using the following evaluation criteria:

- 50% Principal Investigator (CV and achievements)
- 35% Research Project (originality and methodology)
- 15% Potential impact (for science, health professionals, patients, society)

The evaluation of the full proposals will be made using the following evaluation criteria:

- 50% Principal Investigator (CV and publications, international recognition, main research achievements)
- 35% Research Project (feasibility, originality, methodology, design of the study, data treatment and management)
- 15% Potential impact (for science, health professionals, patients, society)

## Scoring

The Generet Foundation is awarding truly outstanding scientists. Scoring will be based on elements such as frequent first/last/corresponding author papers in the top journals (top 5-10%), number highly cited papers, overall citation score, international competitive Prizes/Awards.

## Final decision

The Award will be granted by the Steering Committee of the Generet Fund on basis of the recommendation of the international Panel.



## Research integrity

Research integrity is of utmost importance. All experts involved in the evaluation process will be notified and asked to pay specific attention to scientific misconduct such as fabrication, falsification, plagiarism, or misrepresentation of data. The evaluation of the mid-term report will also be an opportunity to check on it.

Funded researchers are expected to strictly comply to all institutional rules and regulations that apply in terms of research integrity. In case of integrity breach suspicion or allegation, the Generet Fund will take the appropriate measures.

## Open Science

The scientific outputs stemming from research supported by the Generet Award should be valorised to maximise societal benefits.

To this end the Generet Fund supports the publication in Open Access, with a preference for the deposit requirement of publications resulting from the funded project (Green Open access).

The facilitation of the free access to these research outputs not only aims at the benefit of the scientific community but is also meant to increase both national and international visibility of the researchers.

## Valorization

The potential impact of the scientific output of research supported by the Generet Award should be maximized through the implementation of a strong utilization and valorization strategy.

## Ethics

Research projects may require prior consideration of ethical problems that might arise or that are inherent to the submitted research project. The possible ethical problems may relate to the use and storage of private data, the handling of substances that may cause environmental or biodiversity damage and the research on animals or human beings (non-exhaustive list).

Applicants to the Generet Award who are concerned by ethical issues will be required to submit an ethical clearance provided by their local ethics committee. This process is aimed at ensuring that all the research and innovation activities under this Award comply with ethics principles and relevant national and international legislation.

# Contact information

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**The Generet Fund** is administrated by the **King Baudouin Foundation** whose mission is to contribute to building a better society in Belgium, Europe and elsewhere in the world. The Foundation is an actor for change and innovation, serving the public interest and increasing social cohesion.

For any information pertaining to the Call for Rare Diseases launched by the Generet Fund, please contact:

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**The Generet Award** is administrated by the **Fund for Scientific Research-FNRS**. Incepted in 1928, its mission is to support basic research in the French-speaking Community of Belgium. Among its manifold activities, it manages around 30 scientific instruments sponsored by private Patrons under the umbrella brand of FNRS.awards.

For more information on the Generet Award (application process, eligibility issues, follow up of the files, etc.), please contact:

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