PROGRAMME **RARE DISEASES – NEW APPROACHES** AN INITIATIVE OF GEBERT RÜF STIFTUNG

CALL FOR PROJECTS 2014

SUBMISSION OF APPLICATIONS

- The documents must be submitted by a member of the project management team.
- The application should include a letter of recommendation from the Institute/Department Head.
- An application form can be downloaded from the Gebert Rüf Stiftung website: grstiftung.ch.
- The final date for submission is August 8, 2014.

PROJECT EVALUATION AND MONITORING

- The projects will be evaluated by the programme Advisory Board.
- The Foundation's decision will be communicated in early November 2014.
- Managers of the successful projects will be invited to negotiate contracts with Gebert Rüf Stiftung, which will define the deliverables and reporting requirements.
- All copyrights, patent rights and rights of use remain with the project management.

ADVISORY BOARD

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PROGRAMME MANAGEMENT

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MAKING SCIENCE EFFECTIVE

Gebert Rüf Stiftung aims to help applied scientific projects with major potential to achieve a market breakthrough. The funding strategy is based on time-limited areas of activity, such as "Rare Diseases – New Approaches".

RARE DISEASES – NEW APPROACHES

IMPETUS FOR SWISS RESEARCH INTO RARE DISEASES

With CHF 2 million p.a., the programme promotes applied research aimed at developing and implementing innovative approaches or technologies. Target: improving diagnosis and treatment of rare diseases. The call is open to researchers at Swiss universities, university hospitals, federal institutes of technology, universities of applied sciences and to research institutions affiliated with Swiss universities.

Application deadline: August 8, 2014

PROGRAMME OBJECTIVES

The goal of the current initiative, "Rare Diseases – New Approaches", is to improve the diagnosis and treatment of rare diseases.

The programme is aimed at bridging the worlds of basic and clinical research: Projects with new approaches or technologies that focus on a clinical or diagnostic application will be supported. Project results should lead to a better understanding of the genetic, molecular and bio-chemical processes underlying these diseases and pave the way towards new diagnostics and new forms of treatment. The ideal project scenario would lead to drugs and diagnostic tests that would benefit patients suffering from a rare disease.

The focus must be on innovation, feasibility and effectiveness, while maintaining high scientific and technological standards. The call is directed at researchers developing and implementing novel approaches or technologies to address currently unresolved needs.

The programme "Rare Diseases – New Approaches" was established in 2009 as a five-year area of activity. The 2014 call is the 6th and last of this programme.

SUPPORT CRITERIA

- The grants will be awarded to projects that develop and/or implement novel approaches or technologies for the diagnosis, characterisation and/or treatment of rare genetic diseases.
- To qualify for support, the project must be rooted at a Swiss university, university hospital, federal institute of technology, university of applied sciences or at a research institution affiliated with Swiss universities.
- Support is not restricted to existing research groups but is also open to new groups.
- The programme will finance the costs of salaries, consumables and equipment; infrastructure costs must be covered by the host institution.
- Preference will be given to clearly defined projects with a maximum budget of CHF 500,000 for a period not exceeding three years.
- The project may be concurrently supported from other sources (Swiss Confederation, cantons, foundations, industry); however, the programme will not support gap financing.
- Projects must comply with the regulations commonly in force in the research sector and have the necessary authorisations.

LAST RARE DISEASES CALL 2014: REVIEW AND OUTLOOK

Programme achievements

In 2009, Gebert Rüf Stiftung began funding research in the often-neglected area of rare diseases. The goal of this programme initiative was to develop new diagnostics and drugs. Since then, five annual project calls have taken place and some 338 proposals from Swiss research groups have been submitted. Over these five years, 26 projects have been accepted with a budget totalling CHF 10.3 million. Of these, almost half have achieved a diagnostic or therapeutic success. Project database: grstiftung.ch

Transfer to market

In order to promote the development and the transfer to market of promising projects, a cooperation has been launched with the newly-formed biotech company, Geneva Biotech Center. With the help of investors, potential drugs and therapies reach market maturity earlier than they would otherwise.

Awareness for the topic

These past years have not been dormant: Significant successes have been achieved at many levels, and progress continues to evolve. Indeed, the development of a long-overdue national strategy has been launched by the government. The umbrella organisation, ProRaris, was founded in 2010. In March 2014, the 2nd International Congress on Rare Diseases RE(ACT) will take place in Basel, bringing together the world's leading scientists and other stakeholders. And, last but not least, there is a clear trend towards establishing centers of excellence. Their aim is to improve the care and treatment of patients afflicted with rare diseases, and to establish Switzerland as one of the world hubs of research in this area.

What is missing

Nevertheless, gaps still exist. To address these shortcomings, the RE(ACT) community was formed. This project, initiated by BLACKSWAN Foundation and Gebert Rüf Stiftung seeks to improve the networking and financing opportunities between the research community in academia and industry with the afflicted patients and their organisations as well as with donors. On a specific section of the platform, the community will offer visibility concerning issues of crowd funding and of research projects declared eligible for funding by the RE(ACT) Scientific Advisory Board.