

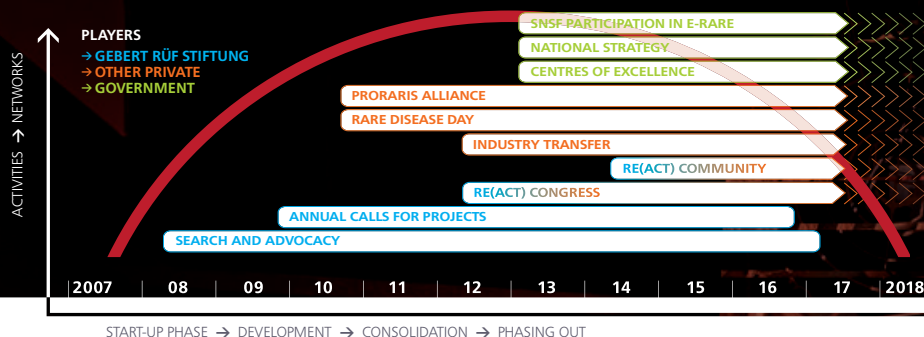
— GEBERT RÜF STIFTUNG —

WISSENSCHAFT. BEWEGEN

GRSTIFTUNG.CH
SHORT REPORT 2013
ENGLISH



THE LIFE CYCLE OF THE AREA OF ACTIVITY "RARE DISEASES"



MISSION COMPLETED

Since the launch of the "Rare Diseases; New Approaches" programme in 2008, a great deal has been happening in Switzerland in this once-neglected area – thanks not least to Gebert RUF Stiftung's programme work centring on an annual call for research proposals. Accordingly, the foundation is to begin phasing out this area of activity in 2015. Today there are already signs, that general awareness of rare diseases is now much higher in Switzerland:

SWITZERLAND: AT A HIGH LEVEL


Education, research and innovation (ERI) are a political priority in Switzerland.

In recent years, the ERI budget has increased by an average of 5% each year. In 2010, the Swiss Federal Government invested a total of CHF 6.3 billion, while the cantons and municipalities contributed CHF 27.7 billion. Switzerland is among those countries whose spending on research and development (R&D) as a percentage of gross domestic product (GDP) is the highest in the world. Let us not forget the startlingly huge sums contributed by business: more than two thirds of research and development financing in Switzerland comes from industry.

GRANT-MAKING FOUNDATIONS: PROVIDING FRESH STIMULUS

A private foundation wishing to be active in Switzerland's healthily financed ERI sector must have a clear grant-making strategy if its scarce resources are not to be swallowed up without making an impact.

Foundations cannot generate impetus with large budgets. Instead they need to provide fresh stimulus through well chosen activities (focus and selection). They should also assume the risks that government grant-making agencies cannot take. Without risk, innovation creates nothing genuinely new, but remains simply renovation. In their role as risk-takers, foundations benefit from their independence.



POLICY – The establishment of ProRaris, an umbrella association of Swiss patient organizations which is focused on rare diseases, has given the people affected a strong voice in the public and political arena. Now also held in Switzerland, International Rare Disease Day not only sensitizes a broad public to the issues faced, it also brings together the various stakeholder groups. And in 2013, the Federal Office of Public Health (FOPH) began drafting a national strategy for improving the health situation of persons with rare diseases.

RESEARCH – The 30 projects that will have been completed by conclusion of the programme (2016) have galvanized research into rare diseases. Individual centres of excellence have meanwhile been set up in Switzerland, and the Swiss National Science Foundation (SNSF) joined the European E-Rare programme in 2013. The International Congress on Research of Rare and Orphan Diseases, initiated by Gebert Rüf Stiftung in cooperation with the BLACKSWAN Foundation in 2012 and to be held in 2014 for the second time, has mobilized Swiss researchers working in the field.

AREAS OF ACTIVITY

Gebert Rüf Stiftung pursues its foundation purpose with a grant-making strategy comprising focused and networked areas of activity. The first step is research: where are the gaps, possibilities and opportunities that could be locked into to make a particular impact?

Specialists with specific knowhow are reached out to and encouraged to take part in the foundation's activities within the framework of programmatic time-limited areas of activity (enabling). The aim is not to fabricate demand or dependencies, but to provide the resources to help leverage promising potential drivers of social and economic innovation. Each area of activity is also phased out, allowing the foundation to rechannel its funds.

PORTFOLIO

- **venture kick**; Science Entrepreneurship
- **BREF**; Brückenschläge mit Erfolg (Universities of Applied Science)
- **Rare Diseases**; New Approaches
- **ASCN**; Academic Swiss Caucasus Net
- **Scientainment**; reaching people with science communication
- **Wissenschaft & Design**; integration of design into research
- **Stiftungsführung & Politik**; legitimization of foundation activities
- **Stiftungswissen & Kompetenz**; philanthropic knowhow

The Gebert Rüf Stiftung **"Rare Diseases – New Approaches"** programme, project list: grstiftung.ch; **International Congress on Research of Rare Diseases RE(ACT)**: react-congress.org; **International Rare Disease Day in Switzerland**: proraris.ch; **ProRaris**, Alliance for Rare Diseases Switzerland: proraris.ch; **National Strategy**, Federal Office of Public Health (FOPH): bag.admin.ch; Participation of Swiss National Science Foundation in the **European E-Rare programme**: erare.eu; **Industry transfer**, e.g. Geneva Biotech Center: genevabiotechcenter.com

KEY FIGURES IN THE 16TH FINANCIAL YEAR

Funds totalling CHF 14.6 million (2012: 11.1; 2011: 11.3) were used for the foundation's activities (cash-out). CHF 13.6 million (10.2; 10.4) were channelled into direct and implementation grants for 66 (47; 50) support projects. Of these projects, 14 (14; 16) were \leq CHF 50,000, 50 (31; 31) between CHF 50,000 and CHF 500,000 and 2 (2; 3) \geq CHF 500,000. Total foundation expenditure amounted to 7.1 % (8.5; 8.2) of the funds used, of which 2.1 % (2.6; 2.5) were administrative expenses and 5.0 % (5.9; 5.7) were direct project expenses for the themes supported. Foundation assets as at 31.12.13 amounted to CHF 173.4 million (170.6; 170.0). In the year under review, a net portfolio performance of 8.06 % (8.07; 1.08) was achieved with a largely passive asset allocation.

SELECTION

The evaluation of projects is based on a grant-making strategy appropriate to the areas of activity. It comprises a two-stage process of selection by the board of trustees in consultation with external experts. If a project proposal is approved, an invitation is extended to submit a detailed application. Not all projects that meet the grant-making strategy criteria can be financed. This is why, in a final step, a ranking is drawn up which in many cases leads to the exclusion of applications as "approved but not funded".

TRANSPARENCY

The website grstiftung.ch presents the foundation's policy and strategy (target domains, areas of activity), openly discloses the support criteria and provides information on procedures. The following information is given for every project supported: project managers, total grant amount, abstract, project status and results. All information reported, which is structured by project stages, is continuously updated.

GOOD GOVERNANCE

Gebert Rfif Stiftung complies with the Swiss Foundation Code 2009, is a member of Swiss Foundations and works closely with the University of Basel's CEPS (Centre for Philanthropy Studies). Relying on an internal control system (ICS), the board of trustees carries out an annual risk assessment of all foundation activities.

MANAGEMENT

Board of trustees: Prof. Dr. Rudolf Marty (since 2005; chairman), Prof. Dr. Peter Forstmoser (since 1997; deputy chairman), Prof. Dr. Richard Bfhrer (since 2011), Prof. Dr. Susan Gasser (since 2006), Dr. Katja Gentinetta (since 2013), Prof. Dr. Jfurg Schifferli (since 2007), Prof. Dr. Roland Siegwart (since 2012); Executive Team: Dr. Philipp Egger (CEO/Director), Dr. Pascale Vonmont (Deputy Director), Jacqueline Grollmund (Project Support/Controlling), Corinne Burkhardt (Assistant/Back Office); Committees and Advisory Boards: Chairman's Committee, Finance Committee, Eastern Europe Committee, "venture kick" Strategy Board, "Modellprojekte Fachhochschulen" Advisory Board, "Rare Diseases" Advisory Board

EXTERNAL UNITS

Investment concept/Strategic pooling partner: ECOFIN Portfolio Solutions AG, Zurich; fund management: Swiss & Global Asset Management AG, Zurich; asset management: State Street Global Advisors (SSgA), Boston (global equities and bonds); Bank Syz AG, Zurich (CHF bonds); investment controlling: ECOFIN Investment Consulting AG, Zurich; accounting: Bourcart Treuhand AG, Basel; auditors: Copartner Revision AG, Basel; supervisory authority: Swiss Federal Supervisory Board for Foundations, Berne

PUBLISHING DETAILS

The present short report by the foundation's management is also available in German and French. The full annual report of the board of trustees in accordance with Swiss GAAP ARR can be downloaded from grstiftung.ch.

Zurich/Basel, 3 March 2014