



Basel, February 2014

Invitation to the media

Rare diseases: research brings hope for patients

2nd International Congress on Research of Rare Diseases in Basel (5-8 March 2014)

Syringomyelia, Prader-Willi syndrome, glass bone disease – did you know that around 500,000 people in Switzerland suffer from a rare disease, a large number of whom are children? For most of these diseases, there is no prospect of a cure even today. All too often, there is simply not enough known about how the disease develops and the course it takes.

Conducting research into rare diseases is very difficult in many cases. How is it possible to build up a network of experts if there are only a handful of patients worldwide? How can the small number of patients who live in different language and time zones engage in networking and mutual support? What can the government and the public authorities do to help improve on the situation for researchers and patients?

These are the questions that the second International RE(ACT) Congress on Rare Diseases will be looking at. "The congress is aiming to network experts from all over the world in Basel", say the organisers Pascale Vonmont (Gebert Rüt Stiftung) and Olivier Menzel (BLACKSWAN Foundation). "Leading experts from the universities and industry and also patient representatives will be sharing their experiences and discussing new therapeutic approaches. It is this configuration that makes the RE(ACT) Congress unique anywhere in the world. And, in the best case, we will be providing renewed impetus to research into rare diseases and giving the patients some hope." All in all, more than 300 experts are expected in the Gehry Building on the Novartis Campus.

Highlights for the media: opening event, Swiss Showcase

On 5 March, an **opening event** is being staged from 18.00 to 20.00. Jörg Reinhardt, Chairman of the Novartis Board of Directors will be providing insight into 50 years of research into rare diseases at Novartis; Yann Le Cam, CEO of the European patient organisation, Eurordis, will be presenting the challenges from the patient's point of view, and Stephen Groft, Director of the "Office of Rare Disease Research" at the US National Institutes of Health (NIH) will be taking a look at current research efforts. [Registration](#) via the congress website is necessary for those wishing to attend the free opening event.

On 6 March (12.00-14.00) the **Swiss Showcase** is being held, highlighting Switzerland's strong position in this area of research. Just like a window shopping spree with lunch laid on, visitors will be given an overview, in brief presentations, of nine selected projects conducted by Swiss research groups.

Programme and registration

The congress programme is available for you [here](#). Media representatives can attend the congress free of charge. For organisational reasons, however, it is necessary to [register](#) in order to be granted access to the congress building on the Novartis Campus.

Media folder and media release

If you are unable to attend the congress but would like to have a media folder, you can order this at heuss@advocacy.ch. A media release will be issued on 7 March 2014 with information on a number of congress highlights.



Getting there and the congress venue

The event is being held in the Gehry Auditorium on the Novartis Campus in Basel. For the media: the Gehry Building can be accessed via Maingate (tram 1, tram stop Novartis Campus). No parking spaces are available.

Novartis Campus Basel
Kohlestrasse
4002 Basel

Organisers

The event is being organised by the [BLACKSWAN Foundation](#) and the [Gebert Rűf Stiftung](#).

Media contact

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Advance notification of International Rare Disease Day

On 1 March 2014, the international Rare Disease Day is being held at the Inselspital in Bern. For more information see: proraris.ch