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Media release

Rare diseases: growing interest from research and industry.

Over the past three days, more than 300 experts from around the world attended the RE(ACT) Congress in Basel to discuss research into rare diseases and the development of orphan drugs. The event demonstrated that progress is being made.

Rare diseases have long been seen as the orphan child of medicine: low levels of interest, little research and few active substances. The RE(ACT) Congress proved that the orphan has now grown up. Research, industry and policymakers have all recognized the significance of these diseases and the challenges facing patients. In Switzerland as in other countries, there has been a huge transformation over the past ten years.

Speaking at the opening event of the RE(ACT) Congress, Dr Jörg Reinhardt, Chairman of the Board of Directors of Novartis, stressed how important these diseases are to his company and referred to over 40 research projects currently underway. Other figures also highlight this change. In the USA there are now more than 450 approved orphan drugs and a further 450 are being developed.

Today, other problems are thus coming to the fore, such as the quality of research projects. In order to achieve excellent research results we not only need to apply the latest research methods, we also need good partnerships with patients and their families, foundations, authorities, universities and industry. "This is why congresses such as RE(ACT) are extremely important as they enable new networks to be established", according to Yann Le Cam, CEO of the Eurordis European patient organization. The new "RE(ACT) Community" platform was also introduced at the congress. This is a network aimed at exchanging knowledge, bringing experts together and funding new projects.

The congress organizers, Dr Olivier Menzel (BLACKSWAN Foundation) and Dr Pascale Vonmont (Gebert Rüf Stiftung), are delighted with the results: "At this event we were able to cover all the key areas for improving patients' treatment in the future – from the idea to the finished substance. This is what made this congress unique."

www.react-congress.org
http://react-community.org
www.blackswanfoundation.ch
www.grstiftung.ch

Media Liaison

advocacy ag
Adrian Heuss
Glockengasse 7
4051 Basel
heuss@advocacy.ch
061 268 99 83