

For better access to diagnosis and treatment of rare diseases – forum founded

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In the context of the International Rare Disease Day on 29 February 2016, the Rare Disease Action Forum (RDAF) was founded by Curatis, Santhera Pharmaceuticals, SFL, Shire and Vertex, companies active in the pharmaceutical and biotechnology sector. Within the scope of RDAF, the founding members want to develop and implement solutions to improve access to diagnosis and treatment for patients with rare diseases in Switzerland, together with experts from patient organizations, health insurers, regulators, physicians and additional stakeholders.

Patients with rare diseases are confronted with numerous challenges. In particular in the areas of equitable and timely access to diagnosis and treatment, there is still a great need for action in Switzerland.

RDAF wants to offer a platform to define and implement ideas and measures that contribute to the improvement of the situation of affected patients. With RDAF, the founding members want to promote the exchange of ideas and facilitate networking of different experts active in the area of rare diseases. How this can contribute to the improvement of the situation of affected patients was shown in four workshops covering a range of relevant issues, which took place prior to the forum's foundation. Invited experts from diverse areas exchanged their everyday experiences concerning the hurdles and difficulties faced by affected patients, and developed and discussed specific approaches to solutions.

RDAF builds on these positive experiences and valuable results and in the future wants to reinforce its contributions with sustainable solutions for the improvement of the situation of patients with rare diseases.

About rare diseases:

A rare disease is defined as a condition that does not affect more than 5 per 10,000 persons and that is life threatening or chronically debilitating. To date between 6,000 and 8,000 rare diseases have been described worldwide. It is estimated that around 500,000 people in Switzerland are affected by these conditions.

For further information:

Shayesteh Fürst-Ladani, president of the association RDAF, +41 61 544 20 32

Rare Disease Action Forum (RDAF)
c/o SFL Regulatory Affairs & Scientific Communication GmbH
Margarethenstrasse 47-49, CH-4053 Basel, Switzerland
info@rda-forum.org, www.rda-forum.org