

Press release
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New members join the Rare Disease Action Forum

In January 2017, Alexion Pharmaceuticals, Amicus Therapeutics and Sanofi Genzyme joined the Rare Disease Action Forum (RDAF). With this growth, the Forum now includes eight member companies that are all important contributors in the field of rare diseases. Using a multi-stakeholder approach, the RDAF aims at developing and implementing solutions to improve access to diagnosis and treatment for patients with rare diseases in Switzerland.

Founded at the beginning of 2016, the RDAF offers a multi-stakeholder platform to define and implement ideas and actions with the aim of improving the situation for patients with rare diseases in Switzerland. For more than a year now, the Forum has promoted the exchange of views and ideas between experts from patient organizations, health insurers, physicians, biopharma companies and additional stakeholders. Alexion Pharmaceuticals, Amicus Therapeutics, and Sanofi Genzyme became members of the RDAF in January 2017. The three new member companies bring the size of the Forum to eight, adding to the five founding members Curatis, Santhera Pharmaceuticals, Shire, Vertex Pharmaceuticals, and SFL.

The RDAF has organized several multi-stakeholder workshops that focus on different topics related to patient access to diagnosis and treatment for rare diseases. In the workshops, invited experts from diverse areas exchanged their everyday experiences concerning the hurdles and difficulties faced by patients, and developed and discussed specific approaches to solve them.

With increased membership, the RDAF wants to reinforce its contribution with proposals for sustainable solutions for the improvement of the situation of patients with rare diseases in Switzerland.

About rare diseases:

A rare disease is defined as a condition that affects less 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 identified worldwide. It is estimated that around 500,000 people in Switzerland are affected by a rare disease.

For further information:

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