



## Summary ICORD ACCORD workshops with ICORD's different stakeholders ICORD Meets Industry

**June 18, 2014, Karolinska University Hospital, Stockholm, Sweden**

*ICORD is a global organization, in which all stakeholders within the field of rare diseases (patients, academia, health care professionals, industry, government agencies, healthcare authorities etc.) have the possibility to interact on equal levels. ICORD's mission is to improve the welfare of patients with rare diseases and their families world-wide through better knowledge, research, care, information, education, and awareness. Since the first ICORD conference in 2005, ICORD has been involved in several global RD activities and created many international events, and ICORD's position has been disseminated through publication in journals and on the ICORD website.*

The voice of ICORD belongs to its members. Therefore, member dialogue is central for the development of ICORD's work. In order to augment the progress in the rare disease field and the spreading of best-practices, also taking into account the diversities of the different regions of the world, the most critical aspects of rare diseases and orphan drugs need to be examined. To continue its work and in order to support its members' needs, ICORD will be developing 'ACCORD' workshops with its stakeholders.

The first event in the series of ACCORD workshops took place on June 18, 2014, at the Karolinska University Hospital in Stockholm, Sweden, when ICORD met delegates from companies involved in orphan drug development. Representatives from Axelion, Bayer, Biomarin, Celgene, CSL Behring, Genzyme, Pfizer, Shire, and SOBI, together with ICORD members and invited experts from the Karolinska Institutet and the Karolinska University Hospital discussed the needs of the industry and how ICORD could further develop its role in the area.

During the workshop ICORD's unique position as the only global multi-stakeholder organization was appreciated. The publication of policy documents, e.g. the Yukiwariso document, was considered important as such documents help companies in their priorities. The rare disease community needs infrastructure, and establishment of global approaches is necessary. Although a lot of progress has been made in Europe, the rare disease field needs support in many other areas of the world. The industry would like assistance to establish contacts among patient groups, researchers, medical doctors, authorities etc. As ICORD has experience from countries in different levels of development, ICORD can assist in sharing also this experience. One important aim of the ICORD meetings is to showcase good examples, share best-practices, and support countries in their work for patients with rare diseases. Thereby, ICORD contributes to global harmonization which is appreciated but still needs to be developed and is lacking in some areas; a few mentioned include clinical trials and guidelines. Research was another topic for discussion. With current existing initiatives on development of diagnostics and treatments for rare diseases, there is an additional interest to extend the focus on basic research, as well as additional clinical research. The pharma companies would appreciate support from ICORD to understand how to prioritize research efforts.

ICORD wishes to express its gratitude to all the participants for a productive workshop and also wish to recognize Dr Emilio Roldan for his valuable work of developing the ACCORD workshops, and the Karolinska University Hospital for hosting the workshop. Another ACCORD is planned with academia and will be held at Leiden University in the Netherlands in the beginning of 2015.