

Thursday June 8, 2017

## **13:30 – 14:30 ECFS Patient Registry – Meeting for Interested Parties**

**The meeting is open to anyone with an interest in the ECFS Patient Registry.**

It is an informative meeting for potential contributors, persons with an interest in obtaining data for research and other interested parties.

**Moderator: Lutz Nährlich, ECFSPR Director, Germany**

13:30 – 13:35: Opening.

Lutz Nährlich, Gießen, Germany

13:35 – 13:45: Introduction ECFS Patient Registry.

Andreas Jung, Zürich, Switzerland

13:45 – 14:00: ECFSTracker, the data-collection software.

Jacqui van Rens, Leuven, Belgium

14:00 – 14:15: Scientific programme and how to apply for data.

Abaigeal Jackson, Dublin, Ireland

14:15 – 14:25: How to set-up a (national) patient registry.

Vincent Gulmans, Baarn, Netherlands

14:20 – 14:30: Questions & Answers