## Report on Work Programme 2016-2017 for IFSW Europe e.V.

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| 9. EURORDIS, European Organisation of Rare Diseases | **Actions:**
To promote the contribution of social work and social care to the support of people suffering from rare diseases and their carers by:
Contributing as Associate Partner to a European conference on rare diseases - 8th European Conference on Rare Diseases & Orphan Products (ECRD 2016) to be held at the Edinburgh International Conference Centre (EICC), Scotland from 26 to 28 May 2016;
IFSW Europe have been awarded complimentary places at this conference and we are doing a joint poster presentation.
Participating at a meeting with social services and stakeholders: INNOVCare - Innovative Patient-Centred Approach for Social Care Provision to Complex Conditions Improving Integrated Care for People Living with a Rare Disease and with Complex Conditions that will take place in Ågrenska, Gothenburg – 9-10 June 2016;
Participating in Webinars organized by EURORDIS, as invited keynote speakers;
Promoting Rare Diseases Day through IFSW Europe social media. | Cristina Martins from Portugal was appointed as the Representative of IFSW Europe to EURORDIS and Ian Johnston from the UK as a support member of the team at last year’s Delegates Meeting (May 2016).

IFSW Europe and EURORDIS have been working together to promote awareness about rare diseases amongst the social care workforce and the need for social services support for people living with a rare disease and their families as well as educating sufferers about the help that social workers can offer people of all ages at times of crisis.

A regular communication occurred between members of the IFSW Europe’s team for EURORDIS and Raquel Castro, the Social Policy Manager of EURORDIS.
A web meeting between the IFSW Europe’s Representative and Raquel Castro took place on the 15th March 2017 to evaluate the existing partnership with the 2 organisations. |
and actual working relationship between the Representative and the Executive Committee of IFSW Europe.

a) Contribution as Associate Partner to the European conference on rare diseases - 8th European Conference on Rare Diseases & Orphan Products (ECRD 2016) held at the Edinburgh International Conference Centre (EICC), Scotland from 26 to 28 May 2016;
IFSW Europe was awarded 2 complimentary places at this conference. Ian Johnston and Fran McDonnell attended and Ian delivered a joint poster presentation with colleagues from EURORDIS based in Norway and Romania;

b) Participation in a workshop with social services and stakeholders: “Improving Integrated Care for People Living with Rare Diseases and Complex Conditions” that took place in Ägrenska, Gothenburg (Sweden) – 8-9 of September 2016. Ian Johnston attended this workshop;

c) Promoting Rare Diseases Day and many other EURORDIS’s events and
developments through IFSW Europe social media mainly through IFSW Europe’s Facebook group page;

d) News from EURORDIS has been disseminated to members through IFSW Europe’s communication tools. However these have not included notes written by the Representative;

e) An abstract for the IFSW European Conference 2017 in Iceland about IFSW Europe’s partnership with EURORDIS, has been accepted, under the title: "Empowering Partnerships: Putting people with a rare disease in the driving seat";

f) Supporting the relationship EURORDIS is establishing with the UN through connecting with IFSW UN Representatives;
The inauguration of a CoNGO’s new NGO Committee for Rare Diseases took place at the UN in New York on 11th November 2016 and Michael Cronin, IFSW’s Representative at UN in New York, registered for the event and was sent full details of IFSW Europe’s partnership with
| EURORDIS.
Requests for feedback from this important event have not received any response from IFSW Europe or Global.

g) IFSW Europe has been offered a place at an INNOVCare workshop in Romania in June (1-2) organized by EURORDIS. |