



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

Work Programme 2016-2017	Developments / actions	Report on Work Programme 2016-2017 by April 2017
<b>9. EURORDIS,</b> European Organisation of Rare Diseases	<b>Actions:</b> 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.	<p>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).</p> <p>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.</p> <p>A regular communication occurred between members of the IFSW Europe's team for EURORDIS and Raquel Castro, the Social Policy Manager of EURORDIS.</p> <p>A web meeting between the IFSW Europe's Representative and Raquel Castro took place on the 15<sup>th</sup> March 2017 to evaluate the existing partnership with the 2 organisations</p>



		<p>and actual working relationship between the Representative and the Executive Committee of IFSW Europe.</p> <p>a) Contribution as Associate Partner to the European conference on rare diseases - 8th European Conference on Rare Diseases &amp; 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;</p> <p>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 Ågrenska, Gothenburg (Sweden) – 8-9 of September 2016. Ian Johnston attended this workshop;</p> <p>c) Promoting Rare Diseases Day and many other EURORDIS’s events and</p>
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		<p>EURORDIS. Requests for feedback from this important event have not received any response from IFSW Europe or Global.</p> <p>g) IFSW Europe has been offered a place at an INNOVCare workshop in Romania in June (1-2) organized by EURORDIS.</p>
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