



MEMORANDUM OF UNDERSTANDING

BETWEEN

European Organisation for Rare Diseases (EURORDIS)

AND

International Federation of Social Workers Europe (IFSW-Europe)

WHEREAS the European Organisation for Rare Diseases (henceforward EURORDIS) is a patient-driven alliance of Patient Organisations and individuals active in the field of Rare Diseases. The Objectives of EURORDIS are to build a strong pan-European community of people living with rare diseases, to be this community's voice at the European level and directly or indirectly to fight against the impact of rare diseases by improving access to information, to services, to diagnosis, to treatment and care, and by promoting research and the exchange of good practices. It was founded in 1997 and is supported by its members and by the AFM-Telethon, the European Commission, corporate foundations and the health industry. EURORDIS represents 695 patient organisations in 63 countries providing a voice to the approximately 30 million people living with rare diseases in Europe alone.

WHEREAS the European Region of the International Federation of Social Workers - the global federation of national organisations of social workers - (henceforward IFSW-Europe) is a non-profit organization registered in Germany in the Court of Berlin under the title of IFSW e.V (Registration No. 28800B). IFSW-Europe currently has 37 member associations in 35 countries (22 of the 27 EU member countries) and is in touch with an extensive network of social workers throughout Europe. IFSW-Europe's mission is to strive for social justice and challenge the abuse of human rights through the development of best practice in social work and international co-operation. IFSW-Europe aims to promote the knowledge and expertise of social workers to policy makers and society in general and secure social work legislation that advances social cohesion. IFSW-Europe is a member of the European Social and EU Fundamental Rights Platforms, European Anti-Poverty Network (EAPN), Fundamental Rights Agency (FRA), European Network for Social Action (ENSACT), links with the European Federation of Nurses (EFN) and represents the social work profession in the Council of Europe.

Social Work is a human rights profession, having as its basic tenet the intrinsic value of every human being and as one of its main aims the promotion of equitable social structures which can offer all citizens security and an opportunity to contribute and be valued.

THEREFORE, EURORDIS and IFSW-Europe agree to the joint signing of a Memorandum of Understanding for the purpose and aims detailed within this document.

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1. PURPOSE OF MEMORANDUM

The purpose of this Memorandum is to underpin the development of what is hoped will become a long-term partnership between EURORDIS and IFSW-Europe. It therefore sets out matters of agreed principle and policy, reflecting the spirit of co-operation between EURORDIS and IFSW-Europe, but it is not intended to be legally binding.

2. AIMS OF THE PARTNERSHIP

EURORDIS and IFSW-Europe agree in good faith to work together to promote or develop awareness on rare diseases and the need for social care provision for people living with a rare disease and their families as well as on the important role of social workers in supporting people of all ages at times of crisis and protecting children and vulnerable adults from neglect and abuse.

In particular the following actions fall within the scope of this partnership:

- EURORDIS and IFSW-Europe will share mutual experiences through the invitation of EURORDIS and IFSW-Europe representatives to participate, at the European Conference on Rare Diseases and Orphan Products (ECRD) (*"Academics/ Health care professionals / government workers / policy makers / payers / regulators"* fee), and at IFSW-Europe conferences and other events;
- EURORDIS and IFSW-Europe will, when relevant, align their policy actions through joint publications, mutual support in review of policy papers and submission of joint abstracts to conferences dedicated to Health, Rare Diseases, Social Work and Social Care;
- EURORDIS and IFSW-Europe will share each other's relevant publications through available and adequate channels;
- IFSW-Europe will share information with its members and contacts (namely via social networks) on relevant initiatives organised by EURORDIS, such as the campaigns on Rare Disease Day and for the European Year for Rare Diseases 2019;
- EURORDIS will share information with its members and contacts (namely via social networks) on relevant initiatives organised by IFSW, such as those arranged to celebrate World Social Work Day;
- Both EURORDIS and IFSW-Europe will strive to support each other in workshops, training courses and capacity building activities, when relevant and when considered feasible in terms of use of resources;
- IFSW-Europe proposes to review documents developed by EURORDIS when a social worker input or scientific validation is needed;
- EURORDIS offers to participate in planning of IFSW-Europe conferences and to provide advice to the IFSW-Europe whenever relevant;
- EURORDIS and IFSW-Europe will inform each other and, when relevant, collaborate in the planning of grant applications dedicated to social care in rare diseases.

3. AGREEMENTS BETWEEN EURORDIS AND IFSW-Europe

Any such future joint activities of EURORDIS and IFSW-Europe will be, where deemed necessary by either party, covered by appropriate legally binding agreements.

4. SENIOR CONTACTS

EURORDIS and IFSW-Europe will each designate a representative to be responsible in practice for ensuring effective liaison between them: preserving the underpinning principles outlined here and maintaining an overall perspective on developments initiated through this Memorandum.

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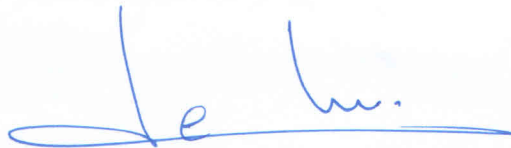
5. GENERAL

- IFSW-Europe shall be entitled to use EURORDIS name and logo only as specifically agreed in advance in writing by EURORDIS. EURORDIS shall be entitled to use the IFSW-Europe name and logo only as specifically agreed in advance in writing by IFSW-Europe;
- The EURORDIS and IFSW-Europe partnership will be presented on both EURORDIS and IFSW-Europe websites and communicated to the members of each organisation;
- Ordinarily this Memorandum may be terminated by either party upon giving 1 month written notice to the other. However, both parties reserve the right to terminate the memorandum with immediate effect in exceptional circumstances;
- The terms of this Memorandum may be amended at any time by agreement in writing between the parties;
- Nothing in this Memorandum is intended to or shall be deemed to establish an exclusive relationship between the parties or to restrict any activities that either party would otherwise be able to undertake. Nothing in this Memorandum is intended to or shall be deemed to establish any partnership or joint venture between the parties or constitute any party as an agent of the other party;
- The parties irrevocably agree that this Memorandum, and any disputes arising under or in any way connected with the subject matter or formation of this Memorandum, shall be governed by and construed in accordance with French law. Each party submits to the exclusive jurisdiction of the courts of France in relation to any disputes or other matters arising out of or in connection with this Memorandum.

6. SIGNATURES

Authorized Signatory for EURORDIS

Signature



Name in capitals YANN LE CAM
Position Chief Executive Officer
Date 19 January 2016.

Authorized Signatory for IFSW-Europe

Signature



Name in capitals CRISTINA MARTINS
Position President
Date 19 January 2016