



RARE
DISEASES
INTERNATIONAL

LEGAL INCORPORATION

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Officer,
EURORDIS- Rare Diseases Europe
RDI Membership Meeting , Vienna
May 10, 2018

LEGAL INCORPORATION OF RDI

- Decided by Council in December 2017
- Approved by EURORDIS BoD in March 2018
- Establish RDI as a fully-fledged NGO with moral and legal personality and financial responsibility
- Legal incorporation in France
- Timeline:
 - Adoption of Statutes by Members - May 2018
 - Submission of Statutes to French authorities and legal steps completed Sept - Dec 2018



STATUTES

- Under French law
- 'Boiled down version of the By-Laws'
- By laws will be modified accordingly in Sept-Dec 2018
- Contains:
 - Objectives and Means of Action of the organisation
 - Membership criteria and procedures
 - Governing Council (role, powers, elections)
 - Operational entities (committees and working groups)
 - Rules of the General Assembly
 - Annual Report and Accounts (submitted to French



MOU WITH EURORDIS

- EURORDIS Support (MoU - 5 years 2019-2023)
- EURORDIS will continue to provide professional services:
 - a) employ 1 FTE staff (RDI Director)
 - b) provide financial & administrative services for management of accounts
 - c) provide hosting, maintenance and update of website
 - d) provide public affairs staff for advocacy (depending on availability)
 - e) provide communications and other specialised support (ie Social Policy, digital health, research)

➤ EURORDIS in kind contributions to be included in

MOU WITH EURORDIS: FINANCIAL SUSTAINABILITY

EURORDIS will continue to secure:

- Corporate Support (Pharma and Biotech)
 - Dedicated fundraiser (part-time) in 2018
 - As of April 2018 requesting funding from ~10 companies (already supporting RDI + companies in IFPMA RD WG)
- Other Private Sources
 - Research and reach out to ~ 5 potential foundations
- 'Economic valuing' of volunteer time
- EURORDIS contributions will be included in RDI Financial accounts
- Cash flow: RDI direct expenses from cash in bank. EURORDIS will not make cash advances, unless exceptional circumstances

