LEGAL INCORPORATION

Zoe Alahouzou, Deputy to Chief Executive 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 authorities)
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