EURORDIS
Rare Diseases Europe

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Find solutions to common problems

EURORDIS and Undiagnosed Patients

- Greater visibility and strategic priority for undiagnosed patients
  - Development of a position paper to increase visibility and uncover the veil on this “hidden” population by tackling the diagnostic odyssey
  - RD Action - ERNs - European Commission Expert Group on Rare Diseases: consider how the UDP needs are met through this new healthcare infrastructure, clarify policy and guidelines for this population
- Greater ownership within member states and key stakeholders
  - Ability to influence in advocacy with a wide reach (European and MS) - build on involvement in various EU projects

Patients' Position Paper

- Objectives
  - Raise awareness of the needs and priorities of patients without a diagnosis
  - Promote responsible and ethical international data sharing
  - Advocate the needs to develop and support UDP at National, and International levels
  - Support the development and active engagement of an international network of patients representatives
- International Scope
  - "Short" Joint declaration with NORD, CORD, RVA and JPA + RDI (initiative submitted to RDI Pre-formation Group) and others

• Approach

- Coordinate with NORD, CORD, RVA, JPA + others RDI members for the development of key messages
- Input from organisations and key individuals
  - ✓ Short interview national alliances, helplines and patient associations
  - ✓ Online communities - Creation of a dedicated RareConnect community for undiagnosed patients
- Build on existing resources and ongoing initiatives:
  - ✓ Extract relevant information from EUROPLAN and State of the Art reports, National plans, EURORDIS_Care survey and others
  - ✓ SWAN UK/SWAN Europe
  - ✓ Directive on patients' rights to cross boarder healthcare and recommendation on cross boarder genetic testing
  - ✓ EuroGentest, ESHG, GA4GH…

Key messages

1. Making the needs of the UD Patients visible to the international community
2. Dedicated Undiagnosed Disease Programmes and Networks (National and International) are essential
3. Clear integrated approach to healthcare and research infrastructures for the Undiagnosed Population
4. Enable faster access to diagnosis by reducing the number of inappropriate tests and treatments and creating a more efficient system

Work together
and learn from each other

Thank you!