THE ROLE OF RDI IN SUPPORTING RARE DISEASE PATIENT ADVOCACY ORGANISATIONS

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RDI’S GENERAL OBJECTIVES

- To **promote** rare diseases as an international public health and research priority
- To **represent** members and people living with RD at international levels
- To **enhance** the capacities of members

«*To be a strong common voice for rare disease patients across the world*»
WHY IS RDI NEEDED?

- To **unite, expand and reinforce** the RD movement of patient organisations
- To **enable** the emergence of RD as a public health & research priority internationally and emerge as a strong common voice on behalf of the +300 million people living with rare diseases around the world
- To **inform and guide policy on RD** at national, regional and international levels
- To **influence** the agenda of international organisations (i.e. UN, WHO)
- To **enable** the local rare disease patient groups to act at national, regional, international levels with other areas in the field of RDs
BENEFITS FOR PATIENT GROUPS IN DEVELOPING WORLD

- **RDI plays a complementary role to what the patient groups are doing from the ground up.**

- **RDI presents opportunities for patient organizations to**
  - leverage an international voice to raise awareness, support, and action locally
  - to collaborate on regional issues and ensure RDs are included in health & economic policies (e.g., UHC)

- **RDI can highlight the RD challenges endemic to low and middle income countries** and encourage international attention to address them.

- **RDI provides opportunities for patients in countries that are just emerging in RDs to learn from and get support from others who are further down the line.**
MORE DIRECT AND TANGIBLE SUPPORT

We also aim to initiate a fellowship program for patient advocates to acquire training that in turn will help them in their advocacy efforts and to help shape and/or inform policy at their national levels.

- **2016 ICORD South Africa**: 25 fellowships for African patient reps to attend the conference + capacity building workshop on how to get a patient group off the ground, basic management and fundraising.

- **2017 EURORDIS Summer School**: 15 fellowships for patient reps to attend one-week seminar on drug development, clinical trials and regulatory affairs.

- **2018 ?**
SO WHAT CAN RDI DO FOR YOU?

- *Twinning/ Mentoring Program?*
- On-line educational modules?
- Webinar policy briefs?
- *Travel and Project Grants?*
- Training Grants?
- Course/Conference Grants?
- Fellowship Programme supported by a company?