



RARE
DISEASES
INTERNATIONAL

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»



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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 insure 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** ?*



RDI FELLOWS AT EURORDIS SUMMER SCHOOL - BARCELONA - JUNE 2017



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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?

