RDI Membership Meeting 2017 Barcelona
3rd Annual Meeting
June 4th, 2017
Environmental Scan of Rare Diseases Around the World
Regional and international developments, influences, barriers, opportunities
Aliber did the study:
Normative analysis of the EERR in Iberoamerica.

Six areas of study:

1. Rare Disease Reference Laws
2. Nomenclature and definition of EERR
3. Institutions that insure the right to health
4. Nomenclature and definition of orphan drugs
5. Procedures for access to orphan drugs
6. Problem of access to orphan drugs

12 Countries Involved: Latin America: Argentina, Brazil, Chile, Colombia, Ecuador, Guatemala, Mexico, Peru, Uruguay and Venezuela. (10 countries) Europe: Spain, Portugal. (2 Countries)
### Rare Disease Reference Laws

**2 countries** have made **important progress** in reference to regulation of laws (Spain and Portugal).

**6 countries** have **initiated processes aimed at regulating laws**. With **little success**, in **many of them they have no regulation**. (Argentina, Brazil, Chile, Colombia, Ecuador and Peru)

**4 countries** are in a **preliminary phase with some initiatives**. (Guatemala, Mexico, Uruguay and Venezuela)

### Nomenclature and definition of EERR

The study determined that there is no standard for the definition and nomenclature of the EERR

- Rare diseases
- "Infrequent" diseases (EPF)
- High cost and minority
- Catastrophic diseases

### Health institutions that provide social security

The study determined that in the **12 countries** the responsibility is of the state
Nomenclature and definition of orphan drugs

The study determined that there is no uniform criterion for the nomenclature of orphan drugs

Procedures for access to orphan drugs

The study determined that there is no standard for availability and access to orphan drugs

Problems of access orphan drugs

The study determined that there is a great variety of barriers for the access of orphan drugs
Efforts with **office of the united nations high commissioner for human rights**: *Guatemala and Chile* (With Venezuela was not possible)

Signed agreement with the Chilean Parliament to promote the Law on rare diseases in Chile  
(FECHER- SLHP- ALIBER & RDI)

Framework Law on Socio-Sanitary Care of Rare Diseases in Latin America and the Caribbean.  
Approved by the Health Committee in the Latin Parliament in November 2015
CHALLENGES - Needs not covered in LatAm

01 KNOWLEDGE
Knowledge about Rare Diseases

02 DIAGNOSIS
Early diagnosis and timely action

03 COVERAGE
Getting coverage for LatAm health systems

04 ACCESS
Uniform access to safe and affordable drugs for LatAm patients
Rare diseases in LatAM have many barriers at different levels

**BARRIERS IN LatAm**

**LONG WAITING**
Long waiting processes for the approval of medicines

**BUYING**
Indefinite buying processes

**DISTRIBUTION**
Long distribution chains that increase costs

**FRAGMENTATION**
Fragmentation of health services

**STATISTICS**
Few and poor statistics of the population with EERR in LatAm

**REGULATIONS**
Laws and regulations that are nonexistent or unstable
OPPORTUNITIES

FIRM UP
To firm up and promote of the LatAm network of patient organizations

PROMOTE
To continue efforts with Inter-American Commission on Human Rights

CONNECT & EFFORTS
To continue efforts with Latin Parliament and all LatAm countries to create regulations and laws

VISIBILITY
To create strategic alliances in order to align rare diseases as a LatAm priority in public health, research and medical and social care policies.

EMPOWERING
To empowering leaders & Developing talents
It is urgent to do activities for, by and from the LatAm region. With contributions and results that are reflected in actions.

**HOW CAN WE DO IT?**

01. To promote a meeting with the committee rare diseases United Nations LatAm

02. Awareness campaigns uniform and consistent throughout the year

03. Mass Media / Press Conferences
Gracias!