

Reflections about rare diseases organizations and their impact on the policies. The ICORD experience in LA&C.

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Disclosure of interest

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Consultant: yes (government of Argentina, Peru, Ecuador, Panama, Columbia, Brazil)

Employee No;

Speaker Bureau no

- Medical Doctor , Psychiatrist . Private practice .
- Mother of an affected child.
- Founder of the first non profit, NGO devoted to the welfare of people living with rare diseases in LA&C GEISER Foundation .

Introduction:

- Rare diseases socially appeared as a concept since 10 years ago in LA&C.
- GEISER first developed the strategies for rare diseases awareness in the region.
- The process followed by GEISER includes national and international meetings.
- That's why we have the opportunity to evaluate the results of the interactions GEISER / ICORD .

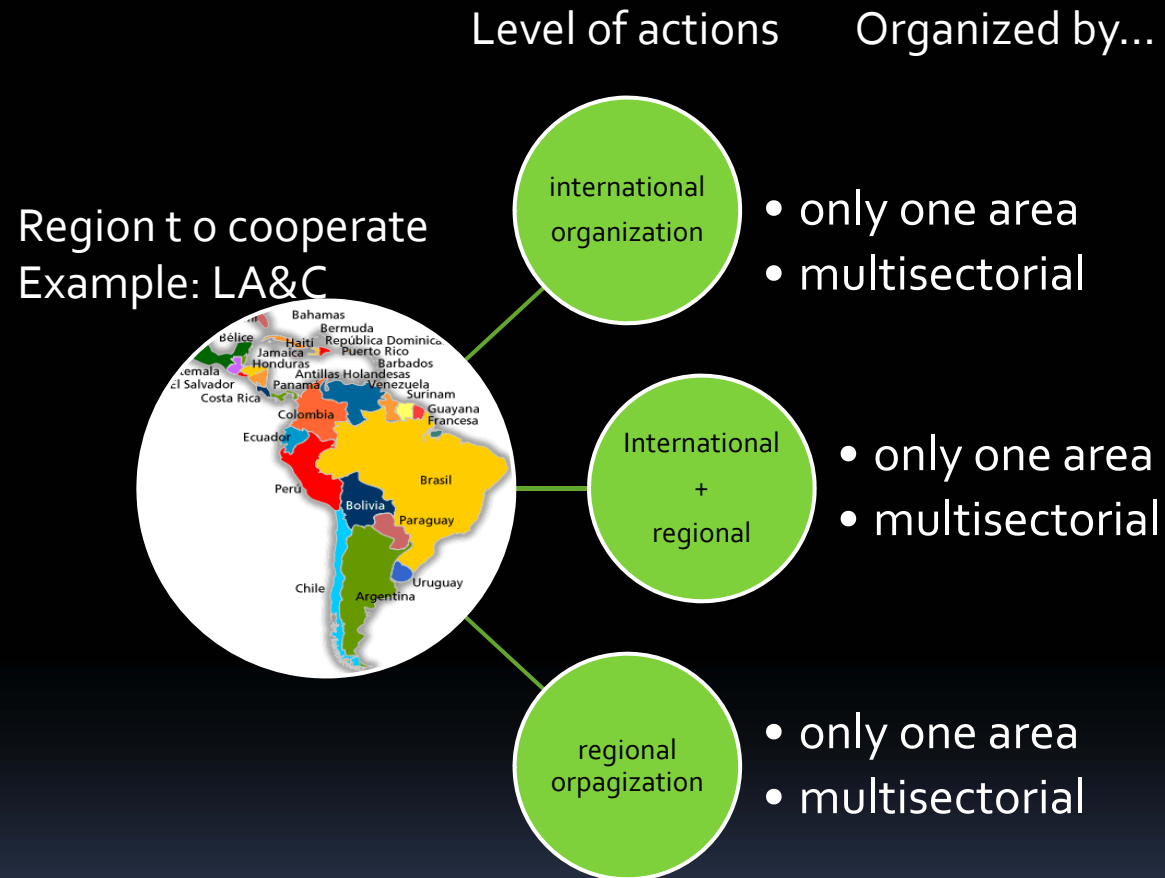
Introduction:

- ICORD is an international forum devoted to rare diseases and orphan drugs.
- The effects of its potential interrelation with peer organization working in different cultural, and socio-economical environments has not been well discussed yet.
- Therefore, our experience organizing the VI ICORD at Buenos Aires will serve as a model.

Introduction:

- This presentation will take into account the **qualitative aspects** on the interrelationship, independently of the current magnitude of the actions.
- Aiming to highlight the relevance of ICORD institutional profile for the generation of qualitative changes in a given region.

Map the of more common strategies developed for rare diseases and orphan drugs awareness in the LA&C



Areas of interest: Academy, Industry, NGO, Governments.

Events done by different types of organization and their performance in practice.

Organization level	structure	Local consensus	actions	Outcomes
International	Single (NGO, Academy, gov or industry) More than one.	With or Without	Information Awareness Education Cooperation	Good impact Low specificity of local needs Ignore opportunities
National or regional	Single More than one	With or without	same	Minor impact Better specificity/ envision of local needs
International & regional	Single More than one	With	same	Sustainable impact Cooperation, master plans

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- **It sounds logical that...**

A Rare Diseases action organized by a single area, without consensus with the local players will not produce the same benefit that cooperation plus participation of the four areas of interest.

The ICORD profile.

- International organization .
- Cooperate with local organizations and including the local features and needs.
- Include the 4 stakeholders (academy, governments, industry and patient groups) and keeps the balance between them.
- Main aim is the quality of life of the affected and its care-givers, all over the world.
- Its members are RDs experts from different countries.

Some characteristics of ICORD

Annual meetings of ICORD favors:

- Learning
- Personal contacts useful for the development of international and national initiatives.
- Mutual understanding between international and national levels, as a process.

VI ICORD 2010 at Buenos Aires

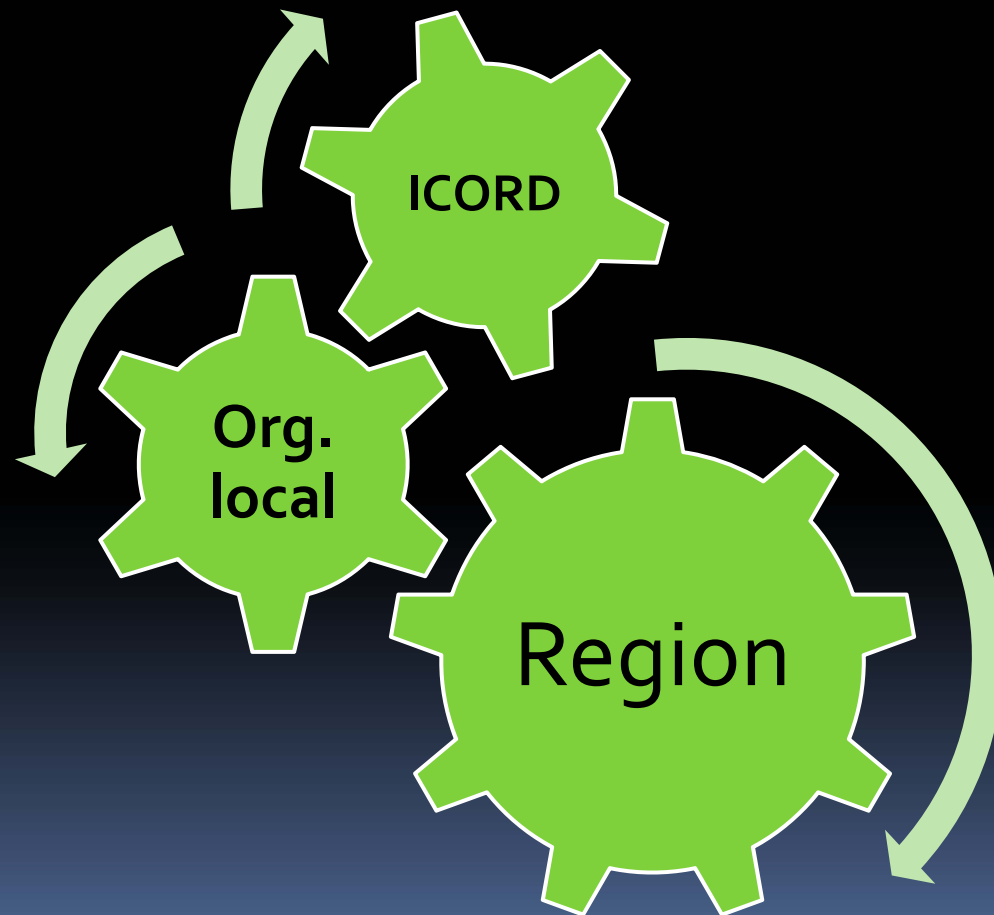
March 2010 – Buenos Aires city, Argentina

Attendance: 300, plus 120 from 2nd LA&C meeting & preliminary courses. Countries: around 35

Support From Ministry of Health, Education and Science, PAHO/WHO, Embassies, Universities, Patients groups from 12 regional countries, and other institutions.

Program included sessions, working groups, courses & special meetings with academic and political authorities. Participation of journalists.

ICORD – Regional impact



ICORD 2010, outcomes in LA&C

Impact on policies and regulations.

ICORD 2010: Support from PAHO/WHO,
outcome of the specific symposium:

- PAHO started a survey of rare diseases for LA&C

ICORD 2010:

- **Before:** Only Columbian RD law
- **After:** New RDs National Laws in Argentina, Equator, Peru, Mexico (in parliament), Panama (project presented). Orphan drug regulations scheduled at ANMAT – Argentina.

ICORD 2010, outcomes in LA&C Impact in patients community.

ICORD 2010

Before:

GEISER, and associations in
Uruguay, Columbia and
Panama

After:

New national federations
arising in Argentina (2),
Brazil (2) and Columbia ,
Peru, Mexico, and Equator.



ICORD 2010, outcomes in LA&C

Impact on RDs research

ICORD 2010

Before : mainly isolated initiatives

After: Some private and public commitments started to show a different paradigm. More funds become available for scientists.

Patients organizations are being involved.

HTA and Orphan Drugs included in programs (ABEST-FP7).

The issue is incorporated into medical congresses program.



Accessibility

ICORD 2010

Before:

The lack of specific RD laws did not allow to formally include this conditions in the health covertures agenda and accessibility.



After:

In several countries the Governments are now calling to the specific organizations and activists aiming to start giving responses in RD issues. This is a major cultural change in the region.

Conclusions

The joint effort of both, international and regional organizations, linking the 4 key stakeholders (academy, governments, industry and patients groups), acting together in the same space of interchanges and learning, expedite the regional processes.

To make this is an institutional success but also a good practice of a prudent organizer.

Thank you !

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