

Global Approaches for Rare Diseases and Orphan Products

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Rare Diseases and Orphan Drugs
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VI. Stimulating Awareness and Research on Rare Diseases and Orphan Products Through the Media

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- GEISER is the first, non profit organization in Latin America working towards the quality of life of people living with rare diseases (RD).
- GEISER was born in Mendoza - Argentina, in 2002 .The founders were people affected with different RD and all of them professionals too.
- From the beginning, GEISER aimed at diagnosing the actual position of RD knowledge in our country, and in the rest of Latin America & Caribbean regions (LA&C).

IN THE HUNT FOR INFORMATION



- GEISER developed national and international meetings/forums.
- As a result the information and work available in LA&C refers only to specific RD, but there was no initiative to join all the RD common needs as a policy.
- Thus, GEISER decided to include a process of public sensitization, in order to promote RD in the region, for this reason GEISER involves mass media within its responsibilities.

REACHING THE AFFECTED PEOPLE



- **The strategy for an efficient process, with low resources, was to include the journalist into the Foundation working team.**
- **Journalist analyzes the impact of articles published in different media, and then design strategies to reach the community.**

MAKING TEAMS WITH JOURNALIST



Working with the media: Objectives

1. Working with GEISER as a Trade-mark, or if possible as a Love-mark, in order to identify and join all the current separated efforts under a single entity. (We need a continent not many islands)
2. Having a LA&C scope. (Creating a proper space for strong developments)
3. Installing RD in the Public agenda. (Visibility)
4. Restoring RD in the mind of health professionals (Back to essence)

**(“WITH MEDIA” IS BETTER THAN
“TROUGH THE MEDIA”)**

Working with the media: Objectives

5. Introducing RD in people's hearts (In search of social responsibility)
6. Connecting RD in the schedule of industry (Work for some is doing it for everybody)
7. Approaching LA&C to the international RD network (same disease, same world)

**(“WITH MEDIA” IS BETTER THAN
“TROUGH THE MEDIA”)**

Working with the media: Example of Targets, Methods and Outcomes

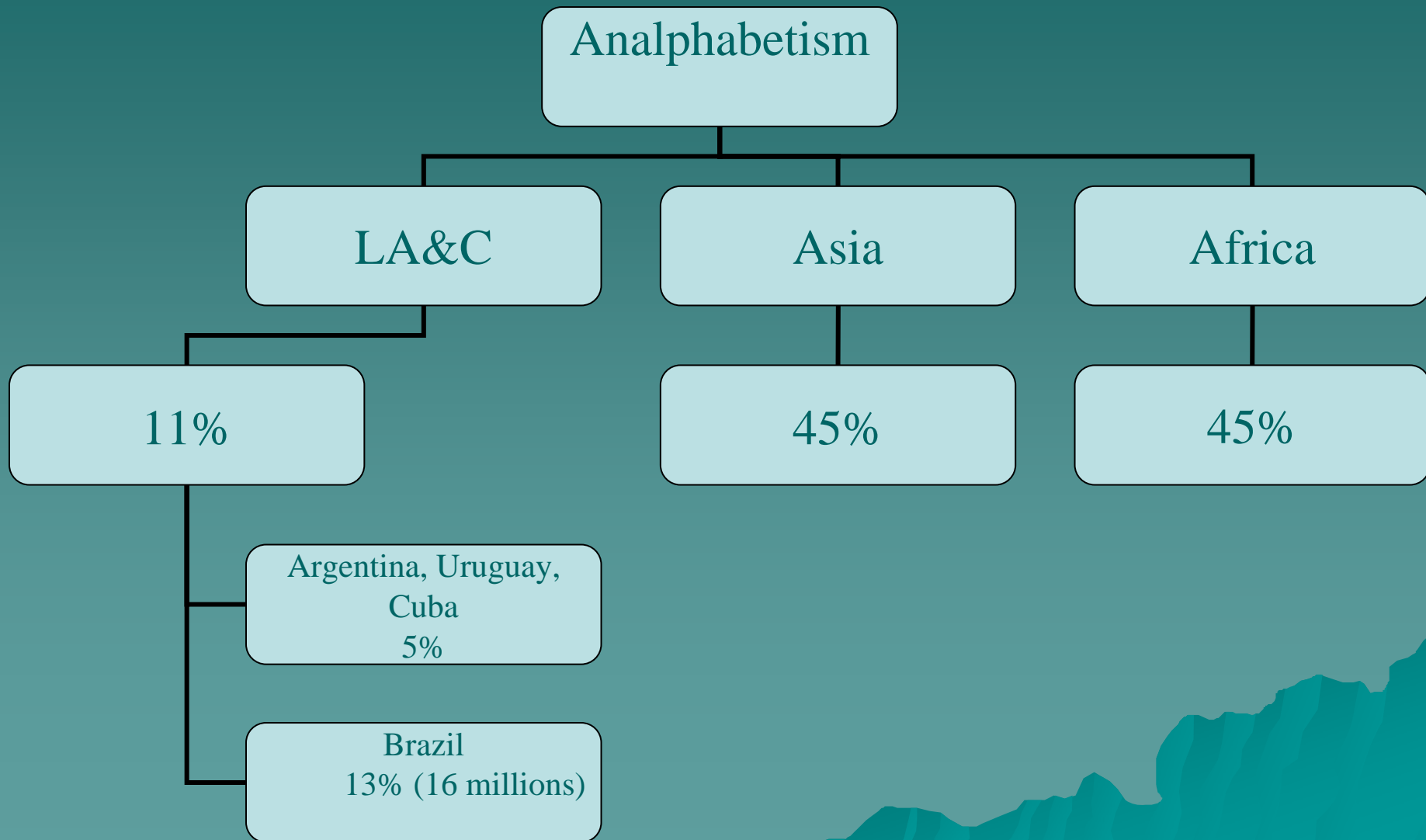
Social target	Objectives	Strategies	Up to date Outcomes	Comments
<p>GEISER and its allied organizations</p>	<p>GEISER as a common identity</p>	<p>Design and study of GEISER as a mark by an advertising agency</p>	<p>RD in LA&C is beginning to be linked to GEISER</p>	<p>3 advertising agencies bestow their search of mark and logo.</p>
	<p>GEISER as a Love-mark (Kevin Roberts-Sachi&Sachi)</p>	<p>Promoting Videos Films</p>	<p>Not available yet.</p>	<p>LA&C has a lot of internationals film schools. The post production is cheaper than in other countries. GEISER still needs to have a sustainable growth to become a Love-mark</p>

Social target	Objectives	Strategies	Up to date Outcomes	Comments
Public Agenda	<p>Changing prejudices:</p> <ol style="list-style-type: none"> 1. Working in RD is thought of as a huge waste of resources for few people, while actually working in RD is an investment in everybody's health. 2.and efforts for RD can play the role of a catalyst for other domains. 3. From being Rare because of its low frequency, to be rare as a challenge to gain knowledge 4. From RD in isolation, into an opportunity for international cooperation. 	<p>GEISER promoted specific forums with well known Journalists: “Which is the story that tells about RD in our Culture”, and invites Journalist as conference coordinators in its meetings</p> <p>Promoting articles in Newspapers TV programs Web-sites International publications Technical Books</p>	<p>Now, There are 3 on-going legislative projects in different LA&C countries (Argentina, Uruguay, Brazil)</p> <p>Now, there are 6 States involved in RD issues (Argentina, Uruguay, Brasil, Paraguay, Chile, and Colombia)</p>	<p>Around 80% of current RD articles publish in LA&C refers to GEISER</p> <p>But,</p> <p>It is difficult to find an independent press.</p> <p>The press still prefers to show an RD as the “Elephant man”</p> <p>GEISER needs to work more with the contents.</p> <p>International publications are always very useful and influential in the region.</p>

Working with the media: Example of Targets, Methods and Outcomes

Social target	Objectives	Strategies	Up to date Outcomes	Comments
<p>The Community</p>	<p>To reach to the mass of citizens</p> <p>To build a critical mass</p> <p>To empower people giving them another vision (option).</p>	<p>see the graphics</p>	<p>The number of consults received by GEISER increase from 1-2/month (2004) to 6/week (2007), coming from different countries (2007)</p>	<p>The LA&C population is characterized by its diversity and heterogeneity: different cultures, languages, economical levels and educational messages .may demand different strategies.</p>

Profile population: 90% adults alphabets



Mass media

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graph TD; A[Mass media] --- B[Internet users  
16%  
(96 million)]; A --- C[Television owners  
(1999)  
51%  
(Guatemala, Honduras,  
Nicaragua, Bolivia,  
Equator and Dominican  
Republic)]
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Internet users

16%

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Working with the media: Example of Targets, Methods and Outcomes

Social target	Objectives	Strategies	Up to date Outcomes	Comments
The Industry	To work together at different levels: National, LA&C, and Internationally.	Promoting News in Economic or Industrial Journals or Newspapers	GEISER is starting to build a mutual agenda with some industries..	“Everybody talks about China or India as an emergent potency but LA&C is vital for growth.” K. Roberts.

Working with the media: Example of Targets, Methods and Outcomes

Social target	Objectives	Strategies	Up to date Outcomes	Comments
<p>The Health Care Professionals</p>	<p>To generate, promote and distribute... Scientific Information Links Interest on RD and Orphan products</p>	<p>Working with academic publications Web publications: As SIIC, Intramed, Orphanet Technical Books</p>	<p>GEISER is now including more than 20 scientific advisors from different countries in its staff Is Involved in Research programs Is Creating RIERLA</p>	<p>Links between Academia and GEISER To sign contracts between GEISER and Academia (UBA)</p>

Working with the media:

Example of Targets, Methods and Outcomes

Social target	Objectives	Strategies	Up to date Outcomes	Comments
<p>The International organizations</p>		<p>Working with Orphanet EURORDIS FEDER</p>	<p>Now GEISER has more international links. Multinational experience: Latin American Congress Potential International programs: FEDER/GEISER</p>	
<p>LA&C organization</p>	<p>To enable broader networks. To inspire LA&C community in order to build up national organizations of RD.</p>	<p>Services from Web-sites. GEISER news letter (bulletin)</p>	<p>Now, affected in Uruguay, Chile, Colombia, and Brazil are working towards a National RD Organization.</p>	<p>Recent lunching of PLAPOCI a project for a LA&C platform.</p>

Working with the media: conclusions

- Many RD are still issues not solved in Public Health.
- Lack of solutions can be a technical issue but most likely seems to be a problem of priorities and interest in the problems of minorities.
- Prevalent conditions are mostly solved by demands of the market, but this rule does not apply for RD.
- Therefore, there is a need of impacting on the public opinion and consequent change in mankind thought.

**WITH A LEVER (MEDIA) WE CAN MOVE
THE WORLD (OUR FUTURE)**

Working with the media: conclusions

- Specifically at LA&C, there is a need of learning more about the population profile: culture, education, resources, etc. That in turn will give the chance of selecting the right way of getting people involved with the RD message.
- But it is also true that LA&C people have a tradition of human solidarity, sensibility and capability of reaction, every time we know that there is a need among us. Hence, information is a key tool for RD.

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