About the Rare Diseases Latin American Day: Building a regional identity.
An example of a communicational campaign

- Virginia A. Llera
- GEISER Foundation
- Xth ICORD
- Semana Global de EERR, Mexico
- ISSSTE, October 15, 2015
Background:

• 2009, EURORDIS (France), instituted on February 29 as World Day for Rare Diseases.

• A very useful and incredible tool to develop awareness all around the world.

• After 7 years, difficulties has been detected in the Latin American region.

• The activities does not achieves the impact needed in the region. The local priorities are not being expressed in the global context (ER2013LA and ER2015LA conclusions).
Differences on numbers

International RDD

Latin American RDD
Alcance de la publicación
El número de usuarios a los que se mostró tu publicación.

PUNTO DE REFERENCIA
Se compara tu rendimiento medio a lo largo del tiempo.

<table>
<thead>
<tr>
<th>Orgánico</th>
<th>Pagado</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Basis:

- Latin America and the Caribbean need to develop its own knowledge about what is the regional situation on Rare Diseases and Orphan Drugs: how many are we, where we are, what are our regional needs and current priorities.

- The region should support its own communication and strategies creating a proper identity.
- The region should perform campaigns with impact on the community.
- The region needs real and measurable impacts.
Cultural aspects

• Two main languages
• Common histories
• Similar social economic situations
• Carnival/holly week
• An LA communicational stile
• Regional own and common symbols
Other aspects : Geographical situation

LA &C Includes North and South Hemispheres.

- Huge geographical territories /small ones
- Different summer-time periods: Jan/Feb on South, Aug/Sep on North (in southern countries Feb 28/29 is not an adequate day to develop health issues awareness)
Proposal:

• Introduce the Rare Diseases regional issues in LA&C agenda
• A mass media campaign: Latin American RDD
• To use a common symbol
• To work-out positive messages
• To use very easy language expressions
• To perform easy actions helping the replication of the message along the region
• To provide communication tools for crow founding.
• The campaign
• The day of "yes it is possible": August 13
• August 13 is the Latin American Day of ER. The day was chosen because it is the day of the first "yes", A governmental document stating a recognition of an institution dedicated to the RDs subject in Latin America. A positive anniversary. (First RDs ONG approval by the Mendoza Ministry of Health, 2003)
• "An Uncommon Pass Out" is the pass that will take place between all stakeholders from LA countries, joining from South (Argentina) to North (Mexico), passing GEMMA (a soccer ball) as our ambassador, until October 12. Gemma will be received at Mexico after spreading the message.
• Objective: To raise awareness about the existence of RDs and facilitate its treatment in our region.

• Adoption statutes GEISER, it is the first document to recognize people with these diseases, and the first public document involving the Ministry of Health recognizes the importance of NGOs dedicated to rare diseases. Also small area could do an step forward to RD and be successful.

• The message:

• One step in any small area could be a great opportunity for a lot of people far away.
The details

A common object: A Soccer Ball

Description of the action

• How this pass will be done?:
• All patients, doctors, politicians, government, celebrities, teachers, journalists, athletes, researchers, etc. participating.
• They receive the ambassador (GEMMA), accepting the challenge of the Uncommon pass, and after saying a few words through photos/videos/pass GEMMA to a friend keeping the message roll
• The pass are being recorded and reproduced in all media as possible.
“The Uncommon pass” on Social networks: Material

#UnPaseFueraDeLoComún
Día Latinoamericano 2015
DE ENFERMEDADES RARAS

CAMPAÑA DE DIFUSIÓN Y EVENTOS PERIFÉRICOS
Día Latinoamericano de Enfermedades Raras 2015
Mass media TV
Día Latinoamericano de Enfermedades Raras 2015

“UN PASE FUERA DE LO COMÚN”

Para concientizar sobre las enfermedades raras
<table>
<thead>
<tr>
<th>Medida</th>
<th>Valor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sesiones</td>
<td>1.049</td>
</tr>
<tr>
<td>Usuarios</td>
<td>921</td>
</tr>
<tr>
<td>Número de páginas vistas</td>
<td>2.481</td>
</tr>
<tr>
<td>Páginas/sesión</td>
<td>2,37</td>
</tr>
<tr>
<td>Duración media de la sesión</td>
<td>00:02:09</td>
</tr>
<tr>
<td>Porcentaje de rebote</td>
<td>65,40 %</td>
</tr>
<tr>
<td>% de nuevas sesiones</td>
<td>85,32 %</td>
</tr>
</tbody>
</table>
GEMMA TRAVEL

Lion, one of the best Jockey player
ARGENTINA

GEMMA MEXICO
Gemma Campaign conclusions

• More information and interaction.
• Better knowledge of local situation. Increases in regional consultancies.
• More regional options.
• Better quality of local data.
• A learning process about communication. Understanding the regional profile.
• Learning about trends.
• A refreshed tool to know about LA&C.
General Conclusions

• LA&C needs to express its true priorities.
• Regional meetings show differences in needs and priorities.
• These differences must be expressed in the international scenario.
• Therefore, a LA&C Day complement the IRRD (August 13 to complement February 28/29).
• This is a pilot experience to develop communicational strategies which will be evaluated during 2015-2016.
¡GRACIAS!