

# Global Approaches for Rare Diseases and Orphan Products

4th International Conference on  
Rare Diseases and Orphan Drugs  
Washington DC, May 20-22, 2008

Report from Latin American Congress (ER2008LA)

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# ER2008LA Objectives:

From invisibility to inclusion



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# ER2008LA **Main features:**

Date: March 27-29, 2008

Venue: Fac. of Medicine (UBA) Buenos Aires

Attendance: 460 from 13 countries

Organizers: GEISER Foundation & C.O.





Image NASA

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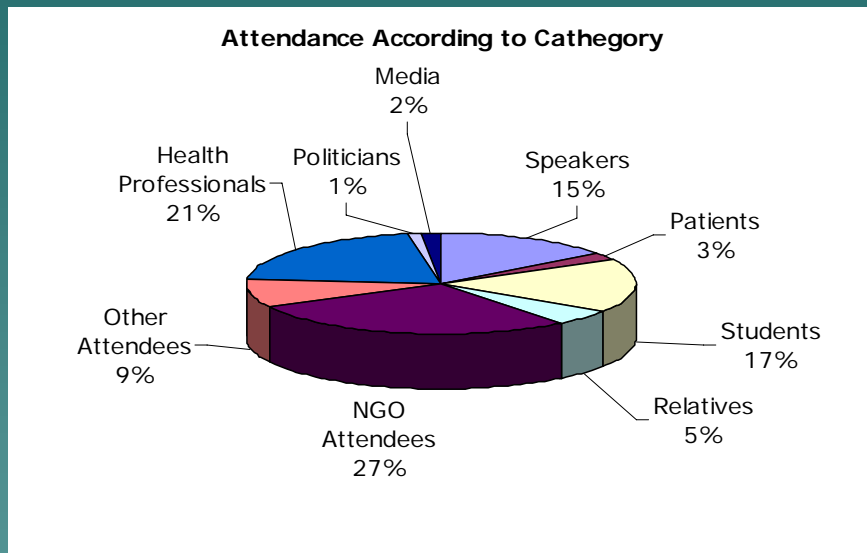
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13°01'16.91" S 80°49'22.73" O

Alt. ojo 11001.00 km

# Attendees Latin American Congress RD 2008 Total:460



Attendees European  
Conference RD-  
Luxemburg 2005

total: 300

patient organization	145
health care prof.	111
policy maker	23
industry	19

# ER2008LA Pre-congress meetings:

- With Decision Makers
- With Academy
- With Patients Organizations

# ER2008LA Program Structure

## Session I

Diagnosing RD: Finding the Way Out of the Maze

## Session II

Research on RD: Odyssey or Reality?

## Session III

Treating RD: From Troy to Public Health

## Session IV

NGO: The Trojan Horse

## Session V

Accessibility: Building Strategies. Conquering the Walls

## Session VI

Information and the Media at the Service of Health in RD



# ER2008LA Program Structure

## Satellite Symposium I

Development and Accessibility to OD.  
International State of the Art and Latin  
American Insertion

## Satellite Symposium II

Cooperation between Academy, Industry and  
Government in ND.

## Specific Workshop I

## Specific Workshop II

## Specific Workshop III

Bone Metabolism

Dermatology

Pediatrics Experience

# ER2008LA Program Structure

Latin American Assembly.

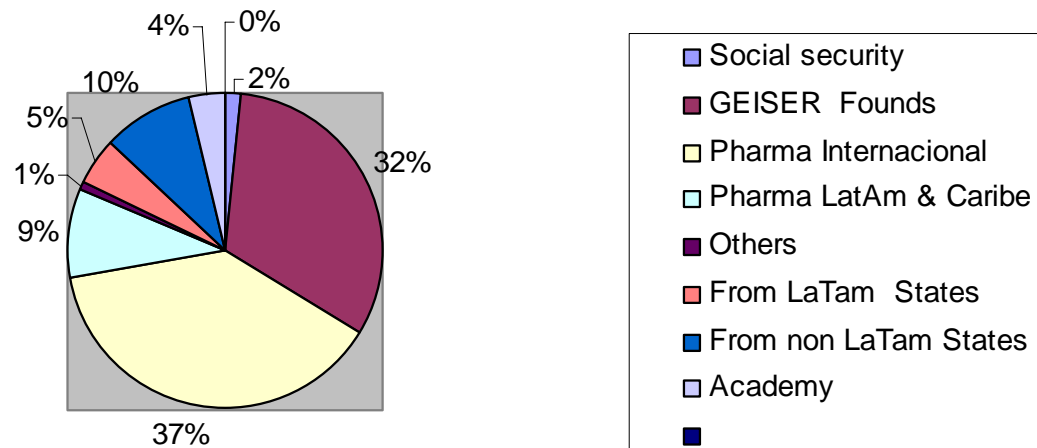
56 attendees from 10 countries

Latin American Platform of Patients,  
Organizations, Science and Industry  
(PLAPOCI)

# ER2008LA Financial Support

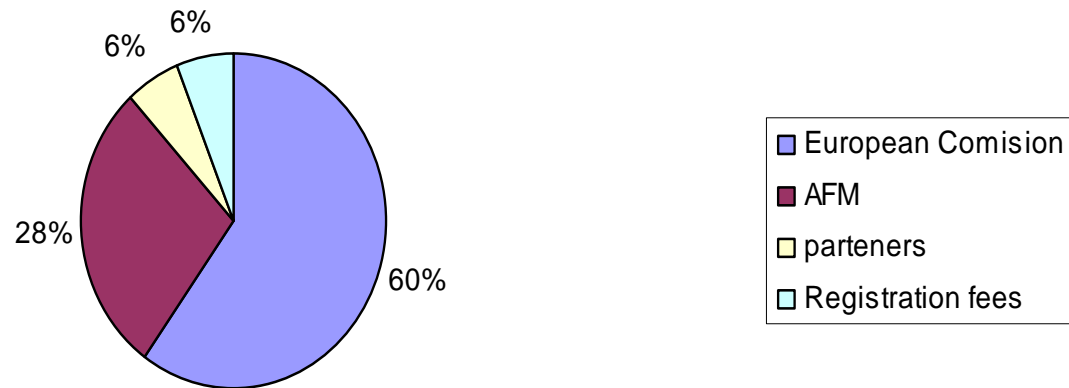
	Sub-total	Total (%)
<b>From Industry</b>		165.861 (48,3)
Pharma international	132.661	
Pharma Lat Am & Caribbean	30.200	
Others	3.000	
<b>From Governments</b>		48.940 (14,3)
Lat Am States	15.900	
Non Lat Am States	33.040	
<b>From Academy</b>		12.300 ( 3,6)
<b>From Social Security</b>		6.000 ( 1,7)
<b>From Civil Organizations (GEISER)</b>		110.280 (32,1)
Lat Am & Caribbean CO	13.500	
Non Lat Am CO	10.880	
GEISER funds	14.190	
Donations/volunteers	69.500	
Congress registrations	2.210	
<b>Total (Argentinean Pesos)</b>		<b>343.381 (100,0)</b>
Equals to	66.676 €	or 107.306 USD.-

# Support Latin American RD Conference



# European Conference RD Luxemburg 2005

Total cost : 416.640 E



# ER2008LA **Conclusions**

- 1- The need of a Master Plan for RDs (mostly at continental instead of at national levels)
- 2- The need to know the magnitude of the problem, and socio-economical impact in the region
- 3- The need of identifying resources and sci/tech possibilities, and linking them to the international scenario
- 4- The need of laws and norms harmonized in the region



# ER2008LA **Conclusions**

- 5- Review of IP issues
- 6. Review of financial managements
- 7- Most RDs and OPs are neglected, and not current priorities in LA&C political agendas
- 8- States, Governments, Academia and C.O. need to be linked and coordinated

# ER2008LA **Conclusions**

- 9- Some isolated efforts are costly but not profitable (many islands do not make a continent...)
- 10- Most C.O. are not well supported and prepared
- 11- The States lack of specific departments and trained human resources
- 12- Investment in Sci/tech is not organized

# ER2008LA **Conclusions**

13- Local Industry is not stimulated (complex of inferiority?)

14- RDs are becoming visible

15- There are more offers of cooperation from NIH, ISS, FEDER

16- There are more offers of cooperation from Academy, PABSELLA, SI


# ER2008LA **Conclusions**

17- PLAPOCI platform is under construction

18- There is an arising awareness of RDs in the media (and among the public?, politicians?)

# ER2008LA **Future Steps**

- 1- Strengthening C.O
- 2- Confirming PLAPOCI
- 3- Working with the States, Academy and Industry
- 4- LA&C data base
- 5- Sci/tech data base

An aerial photograph of a vast, rugged mountain range. The peaks are covered in snow, and the valleys are deep and shadowed. The lighting is bright, suggesting a clear day. The text is overlaid in the center of the image.

**48 millions of Latin American  
patients with rare disease  
thanks you for letting us come  
into view**





[www.fundaciongeiser.org](http://www.fundaciongeiser.org)