

# 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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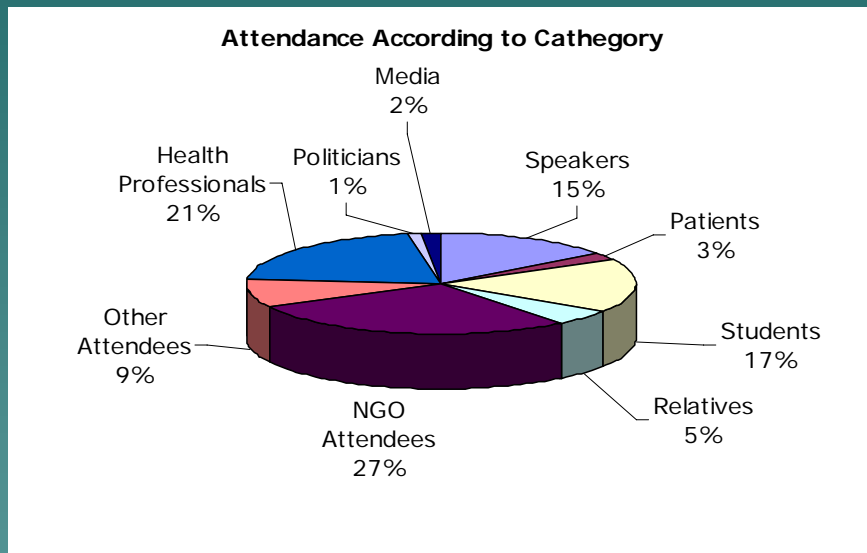
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13°01'16.91" S 80°49'22.73" O

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.

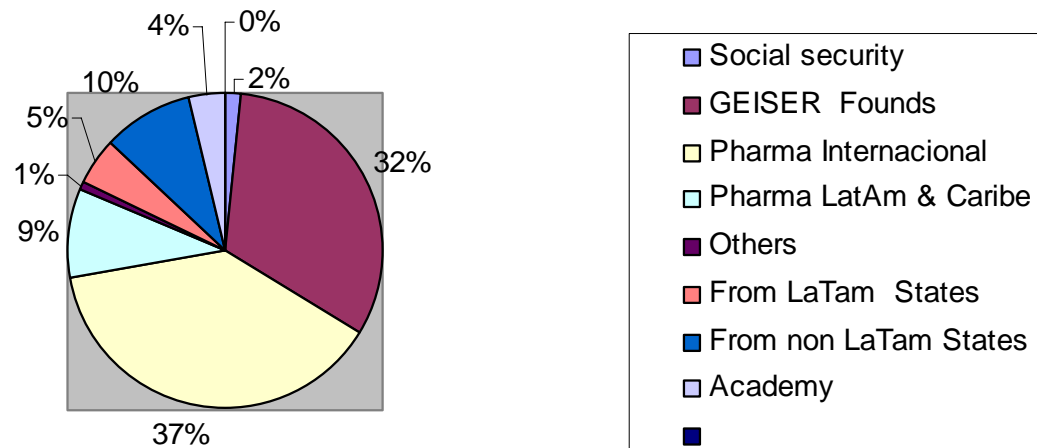
56 attendees from 10 countries

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

# ER2008LA Financial Support

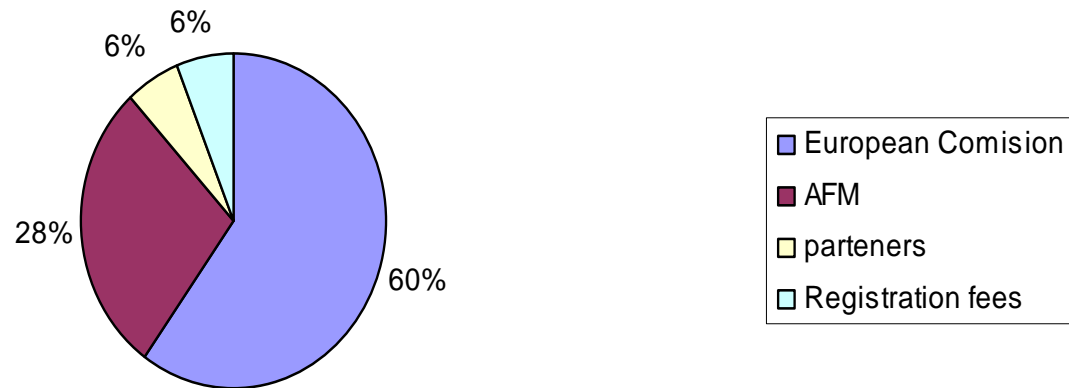
	<b>Sub-total</b>	<b>Total ( % )</b>
<b>From Industry</b>		165.861 (48,3)
Pharma international	132.661	
Pharma Lat Am & Caribbean	30.200	
Others	3.000	
<b>From Governments</b>		48.940 (14,3)
Lat Am States	15.900	
Non Lat Am States	33.040	
<b>From Academy</b>		12.300 ( 3,6)
<b>From Social Security</b>		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, creating strong contrasts between the sunlit slopes and the dark shadows. The overall scene is one of natural grandeur and isolation.

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



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