Spreading the Word of Rare Diseases Internationally Rare Disease Day 2008 & 2009

# Virginia Llera, MD "Promoting the cause of rare diseases over Latin America"

V ICORD – Rome, February 23<sup>rd</sup>,2009 fundgeiser@yahoo.com.ar.

### **GEISER Foundation**

Latin American & Caribbean (LA&C) NGO

Non profit

Improving QOL in people living with RDs

Founded in 2002

### World Rare Disease Day (WRDD)

**GEISER** subscribe to WRDD

because it may fit with "the mirror" model to LA&C NGOs.

### The mirror stage model

**During** the mental development of a subject...

The integration of it corporal image is given by the mirror stage model... allowing him to better interact with it environment.

Likely,

During the development of organizations (NGOs), "mirrors" helps to recognize and integrate its owns resources.

### The mirror stage model

During the development of organizations (NGOs), "mirrors" helps to recognize and integrate its owns resources.

Allowing...

Best outcomes.

Broader impacts in their activities.

Maximize efforts.

Increase the accuracy of aims.

# In which "mirrors" an organization could be reflected?

**Supra-level organizations** 

**Supra-level actions** 

# Which are adequate "mirrors" for LA&C NGOs?

## An Adequate mirror

Those organizations or actions willing to invest in a process of mutual recognition and respect.

Those promoting the integration of actions against isolated achievements.

The supra level organization or action should benefit the "level" organization, not viceversa.

Supra-level organizations or actions should guarantee the mission compliance.

#### **GEISER** as a mirror for LA&C NGOs

GEISER launching meetings at Colombia uniting ONGs working with academia for the WRDD.

GEISER unite ONGs in order to produce a video for WRDD at Brazil.

Provincial tour for RD at Panama by NGOs and Government.

Argentinean WRDD celebrated in the streets, with media and government support.

#### WRDD at LA&C - conclusions

Supra level actions has critical impact in LA&C.

A good mirror help to grow.

A broken mirror may bring disadvantageous.

Therefore,

Supra level organizations or actions should spend enough time to consider the benefit for the "level" organizations, as mistakes will be afforded for such level only.