



NGO COMMITTEE FOR
RARE DISEASES

Tackling Rare Diseases internationally through National and Regional Strategies (Latin America)



Migdalia Denis
Pulmonary Hypertension Latin Society
President

A Committee of **CoNGO**



CoNGO
The Conference of NGOs
in Consultative Relationship
with the United Nations



Evolution



2005



2006

Brasil
Mexico
Venezuela

2009

Argentina



Evolution

2011

**Paraguay
Dominican
Republic**

2012

Colombia

2013

**Chile
Uruguay
Mexico**



Evolution

2014

**Perú
Colombia**

2015

**Panamá
Costa Rica**

2016

Mexico



Successful action

2016



**(18 ONG's
2 Support Groups)**

14 countries have NGO's of PH
This represents 70% of Latin countries



Successful action

Development, translation and elaboration of the bibliographic material as support for the patient with Pulmonary Hypertension in Spanish, which include

Teenagers
guide



Caregivers
guide



Survivors
guide



Mass media
guide

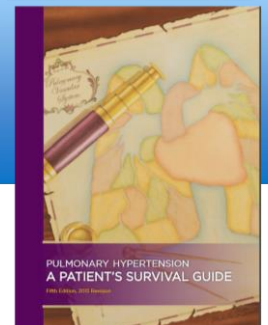


Laughter, health
and life guide

Risa, salud y vida



Patients
guide



Development, translation and elaboration of the bibliographic material as support for the patient with Pulmonary Hypertension in Spanish



HIPERTENSIÓN PULMONAR EN NOTICIAS

BOLETÍN DE LA SOCIEDAD LATINA DE HIPERTENSIÓN PULMONAR

PUBLICACIONES MÁS RECENTES...



BOLETÍN ESPECIAL #3
(Otoño-Invierno 2012)



BOLETÍN ESPECIAL #4
(Marzo de 2013)



BOLETÍN ESPECIAL #5
(Enero-Abril 2013)



BOLETÍN #1



BOLETÍN #2



BOLETÍN #3

Successful action - alliances



Successful action- Awareness Campaigns

Sin Aliento



Quédate Sin Aliento



“Un Aliento para vencer”



Successful action

Mass Media / Press Conferences



World Day 2015- Mexico
29 Journalist
113 Articles
19 million readers

This is a powerful evidence of the
great impact that the event has
in the Latin community



Empowering leaders & Developing talents



Successful action- Labor in Public Politics

Efforts with Parliament of Mexico



Efforts with Inter- American Commission on Human Rights



Successful action- Labor in Public Politics



World Health
Organization

We was be in the general assembly of WHO as a member of the board of
IAPO and Latino patients.

We had **two opportunities to speak in this important general assembly**

September 25th. Washington DC



Successful action- Labor in Public Politics



Meeting with Inter-American Commission on
Human Rights - Guatemala



Rare Diseases in Latin America

According to the World Health Organization (WHO):

There are more than **7,000 ‘rare diseases’**, which is a large amount **that makes at least 7% of the population suffer from at least one of them.**

(This means that there are more than 43 million cases in Latin America.)

(Latin America’s population is approx. 626, 657,000)



Rare Diseases in Latin America

Country

Population
with RD

Brazil	14,490,840
Mexico	8,604,120
Colombia	3,434,690
Argentina	3,067,610
Peru	2,216,200
Venezuela	2,186,520



Challenges

1. Early diagnosis and timely action
2. Knowledge about Rare Diseases
3. Obstruction of access
4. Establish legal frameworks
5. Fragmentation of health services
6. Lack of trustworthy statistics



Actions required

Rare diseases go through a series of deficiencies in all levels:

1. Coverage
2. Early diagnosis
3. Long waiting processes for the approval of medicines
4. Indefinite buying processes
5. Distribution
6. Reduced costs in the chain



Actions required

We want our health systems to be sustainable.

We need for committees of joint purchase to allow lower prices and reduce inequity.

It is time to apply those principles of equality and consistently implement and guarantee the patients the right to live by respecting their right to have health.





Thank you!



Contact us



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