

7th Global Patients Congress

9-11 April 2016



Selsdon Park Hotel, South London, UK • www.globalpatientscongress.org #GPC2016

IMPACT OF THE PULMONARY HYPERTENSION LATIN SOCIETY

Migdalia Denis

President, Pulmonary Hypertension Latin Society

How was the PHLS born ?



Goals of the SLHP

7th Global Patients
Congress

Support the patient



Support in:

- patient organizations
- patients themselves

Create new groups of patients



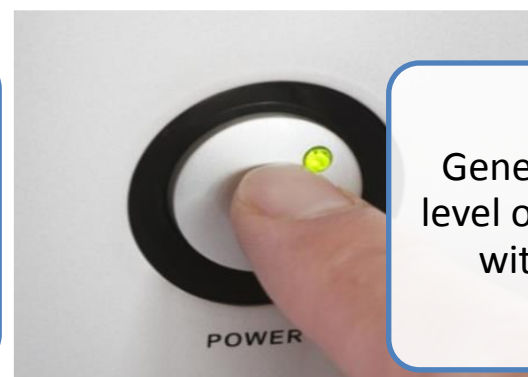
Educate and encourage the creation of patient groups

Awareness



Promote awareness towards PH

Patient Empowerment



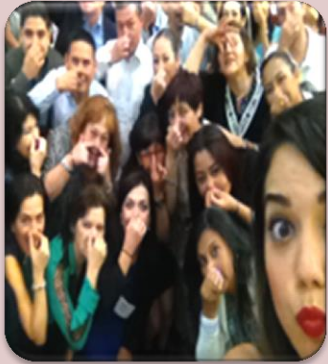
Generate an optimal level of care for people with the disease

Our principles and values

INFORMATION
TRANSPARENCY
FREEDOM AND SUPPORT
HUMANITARIAN SENSE
SOLIDARITY
HUMAN RIGHTS
PLURALITY
INDEPENDENCE
PROFESSIONALISM
EQUALITY
COOPERATION
LOYALTY
COMMITMENT
RESPONSIBILITY
INTERACTION
COHERENCE

What inspires us?

7th Global Patients
Congress



PEOPLE

SOLIDARITY

FACILITATE
INTERACTION

NEW WAYS

SOCIAL
MEDIA AND
TECHNOLOGY

What inspires us?

7th Global Patients
Congress



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

Evolution



16 ONG's

11 Countries

2 Support Groups
(Guatemala & Ecuador)

Structure

Strategic plans

Contributions /
actions

Innovation

Alliances

Social
Media

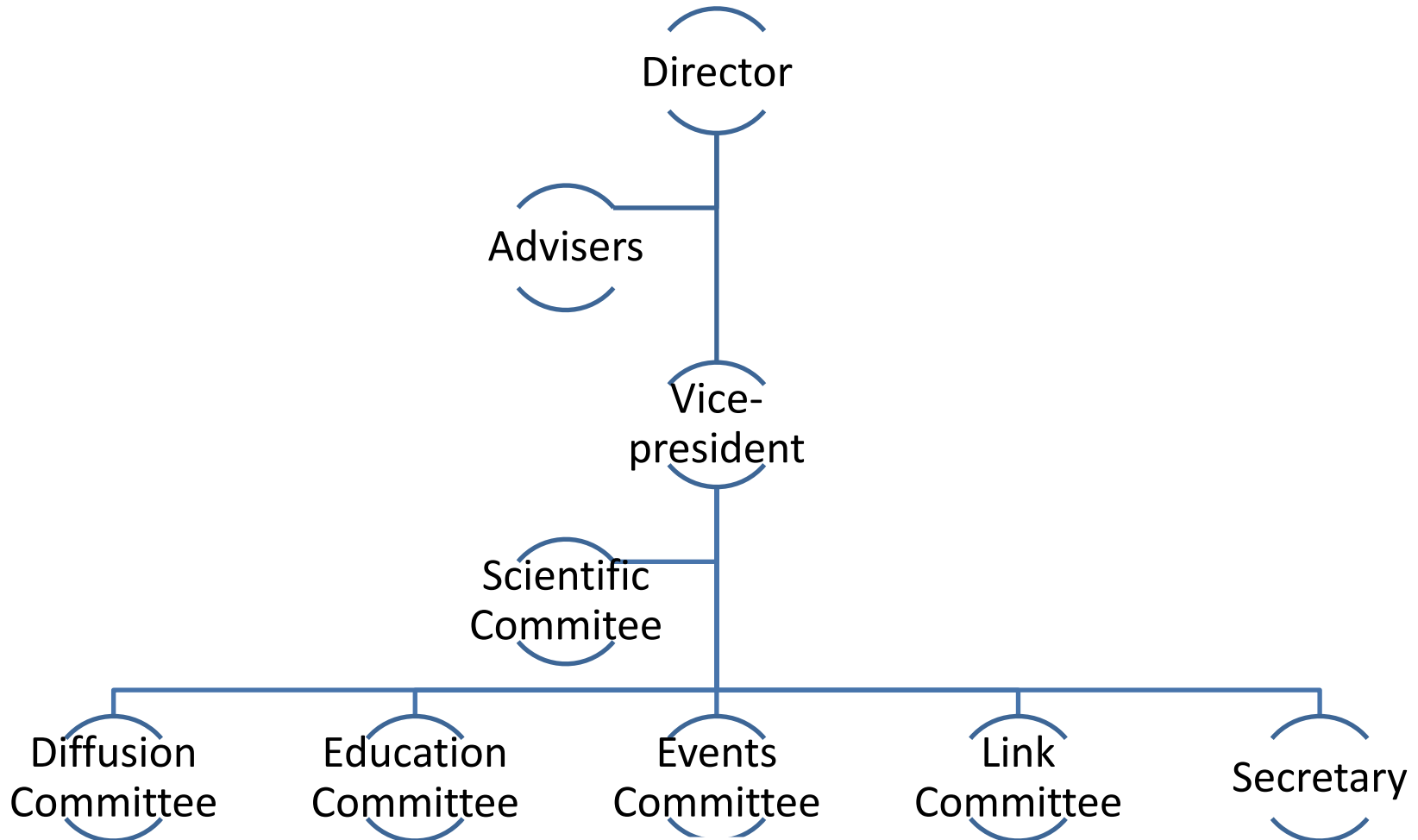
Empowering leaders

Develop talents

Combination of:
service and complaint

Communication

Structure of the PHLS



Strategic plans FY 2016

4 LINEAS ESTRATEGICAS



Institutional
projection axis



Training and
comprehensive
uncut formation



Cooperation and
patient support



Advocacy and
public politics



Contributions / actions

1



Educational Materials

Guide for teenagers



Guide for caregivers



Guide for the newly diagnosed



Guide for survivors



Risa, salud y vida



GUÍA DE MEDIOS DE COMUNICACIÓN



Contributions / actions

1



Educational Materials

2



White Paper



2014

Objective

1. Achieve earlier diagnosis
2. Optimal treatment
3. Integrated management of patients with PH in Latin America

Review important aspects for people affected by PH. Analyze the issue and provide messages in **6 different areas** and from **3 different perspectives**



Contributions / actions

1 → Educational Materials

2 → White Paper

3 → Bulletins

Contributions / actions

1 → Educational Materials

2 → White Paper

3 → Bulletins

4 → Mass Media/ press
conferences



29 Journalist

113 Articles

19 million readers

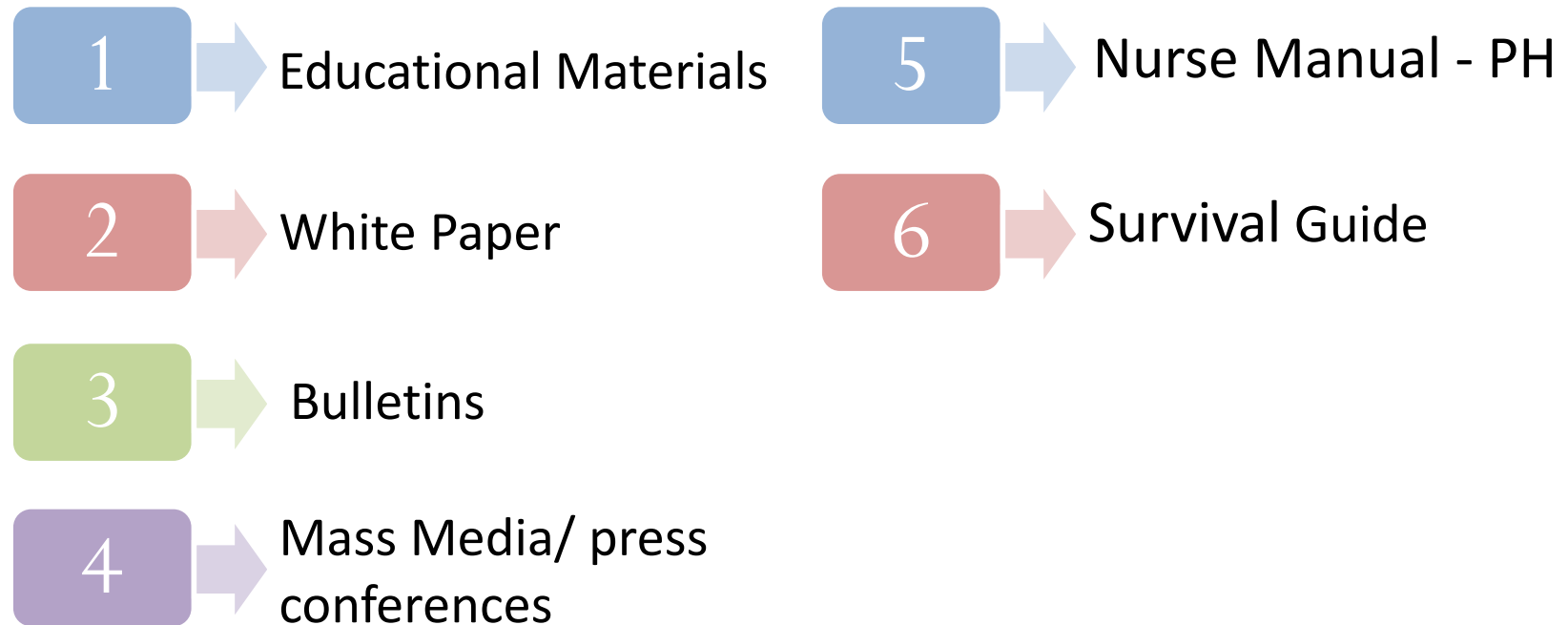
This is a **powerful evidence of the great impact**
of the event in the Latin community.

Contributions / actions

- 1 → Educational Materials
- 2 → White Paper
- 3 → Bulletins
- 4 → Mass Media/ press conferences
- 5 → Nurse Manual - PH

Enfermería H. 12 Octubre (España)

Contributions / actions



topic

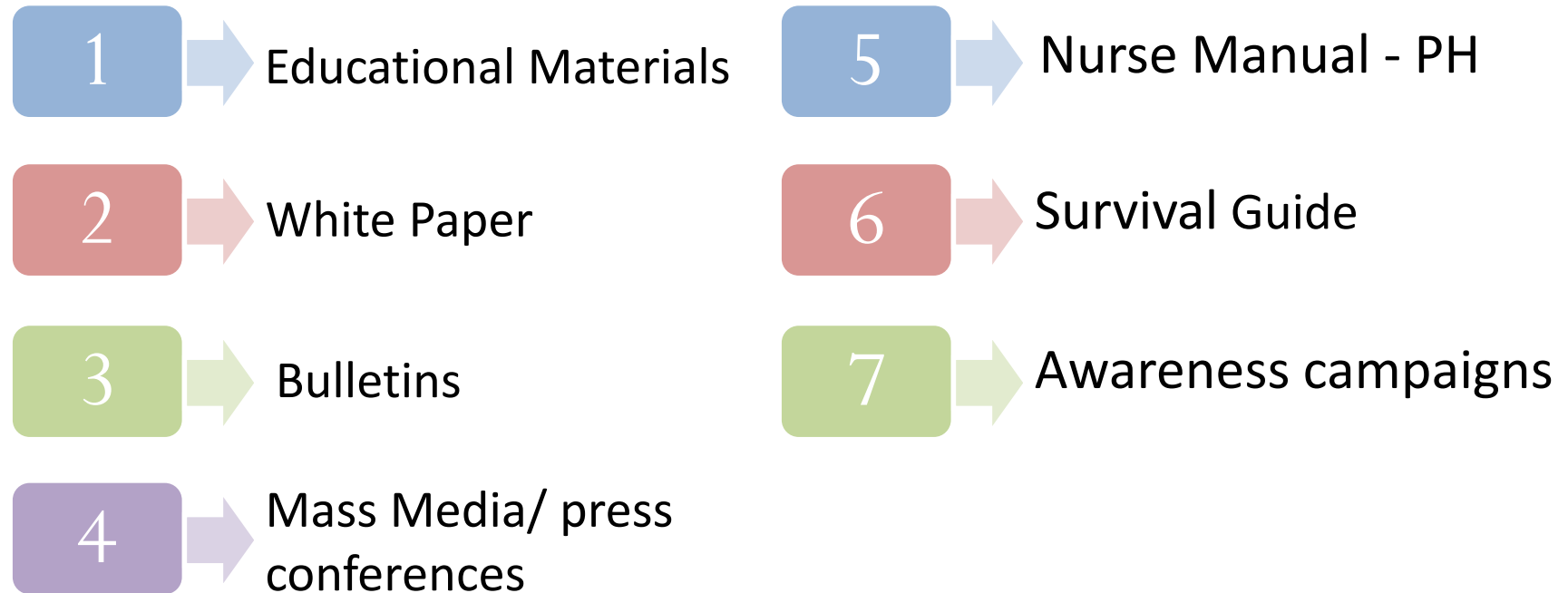


**PULMONARY HYPERTENSION
A PATIENT'S SURVIVAL GUIDE**

Fifth Edition, 2013 Revision

Michelle S. Smith

Contributions / actions



Sin Aliento



Quédate Sin Aliento



“Un Aliento por la vida”



“Un Aliento por la vida” Campaign

It is the Latin American digital campaign to support 2016 World Pulmonary Hypertension Day. It leverages the power of the crowdcampaign platform **Thunderclap** and the gaming trend with an **app** to amplify the PH message across social media, broadcasting the message to a larger audience, thus, increasing campaign reach and awareness.

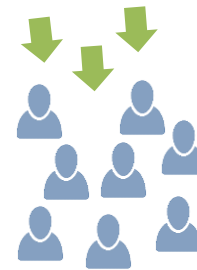


“Un Aliento por la vida” Thunderclap Campaign



What is Thunderclap?

It is a tool that allows people to support a particular social issue or campaign. By signing-up, the user allows the tool to automatically share a single message through his/her social platforms. Rather than users having to remember to send a tweet, or Facebook post update at exactly the same time, Thunderclap automates the process, creating a pre-planned ‘trending’ topic and massively amplifying the message.



VIDEO: <https://www.youtube.com/watch?v=IPwlszezQE8>



knight x pawn

The “Un Aliento por la vida” Challenge

Step 1

Enter the “Un Aliento por la vida” Challenge website on your mobile phone



Step 2

Blow on your phone's microphone to start playing



Step 3

The longer you blow, the longer your dandelion flies. Test your lungs and challenge your friends through your social media!



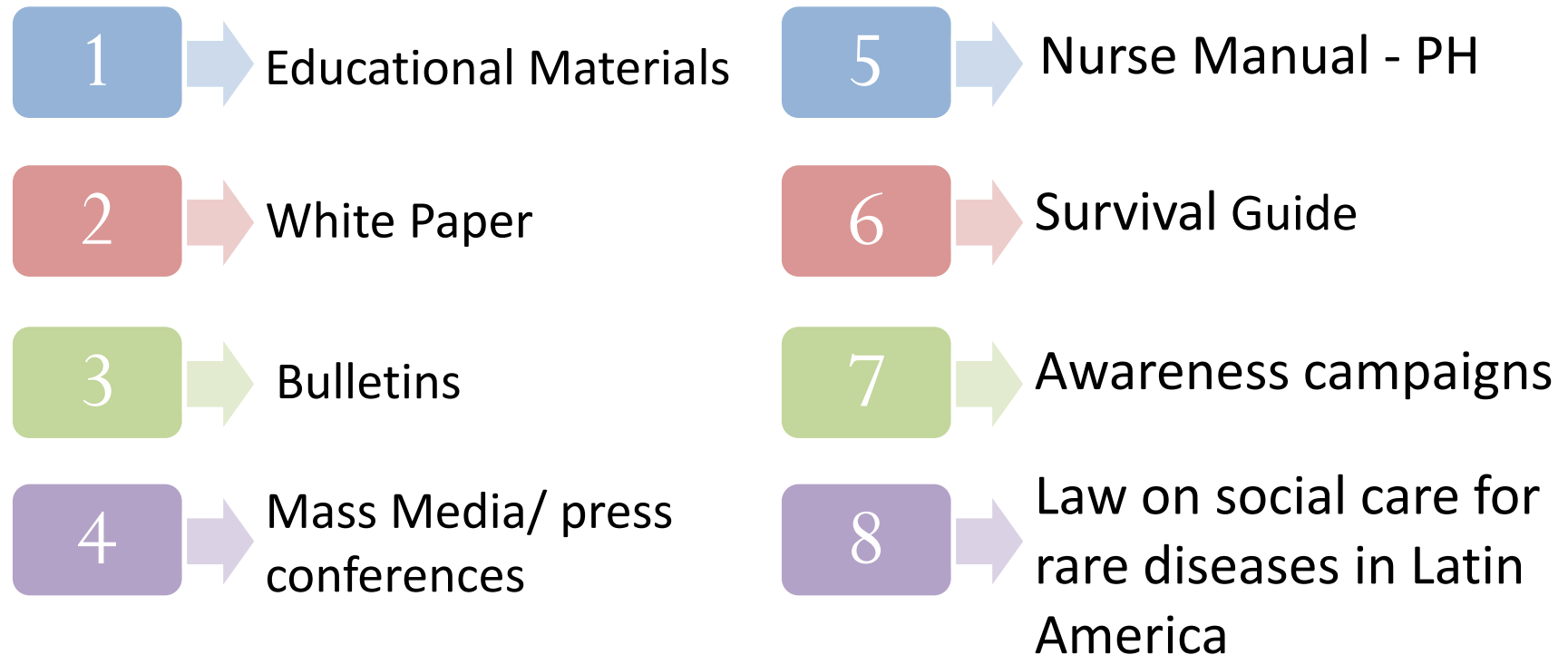
Step 4

The app will invite participants to:

- 1) Support the SLHP change.org petition.
- 2) Learn more about HPTEC
- 3) Share/ invite friends to do the challenge



Contributions / actions



Latin-American Parliament
Health Commission
Framework Law on social care for
rare diseases in Latin America and
the Caribbean



Labor in Public Politics

Gestiones ante Parlamento de México



Gestiones ante La Comisión Interamericana de Derechos Humanos



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Alliances
Unite



UNITED NATIONS



Pulmonary Hypertension Association
Empowered by hope

early diagnosis • best treatment • better quality of life • finding a cure

PHA EUROPE *for the patients*
European pulmonary hypertension association

CIDH Comisión Interamericana de Derechos Humanos



EURORDIS
Rare Diseases Europe



United Patients
Online academy

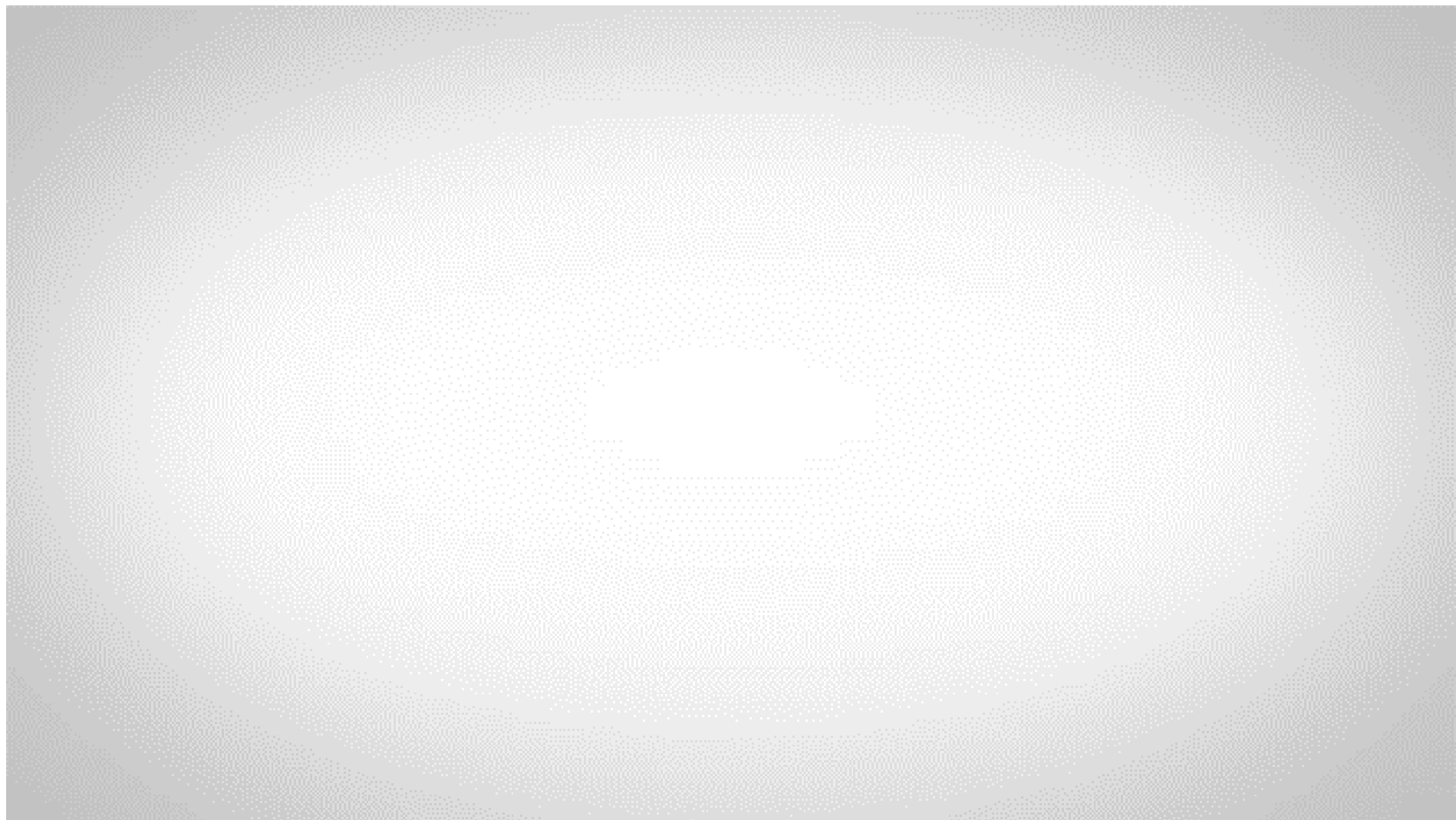


Parlamento Latinoamericano



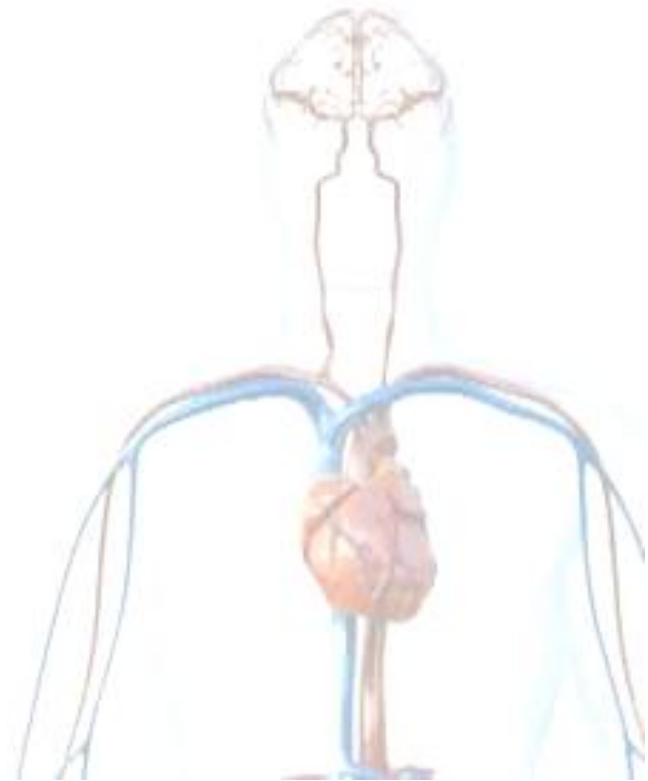
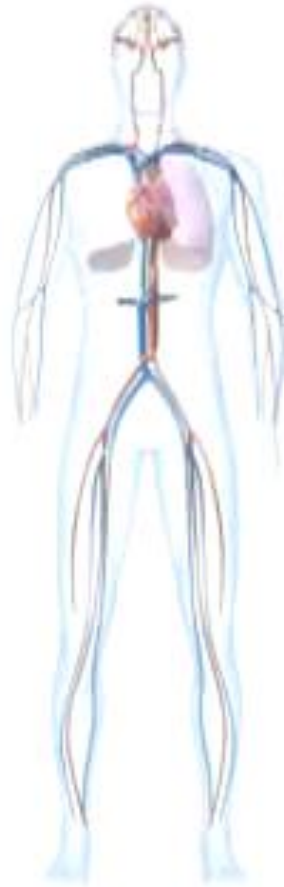
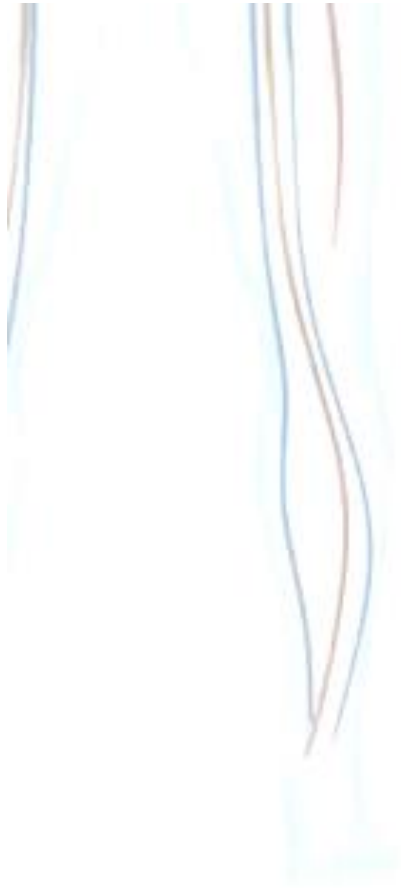
SOCIAL MEDIA AND TECHNOLOGY

Which is the Pulmonary Hypertension



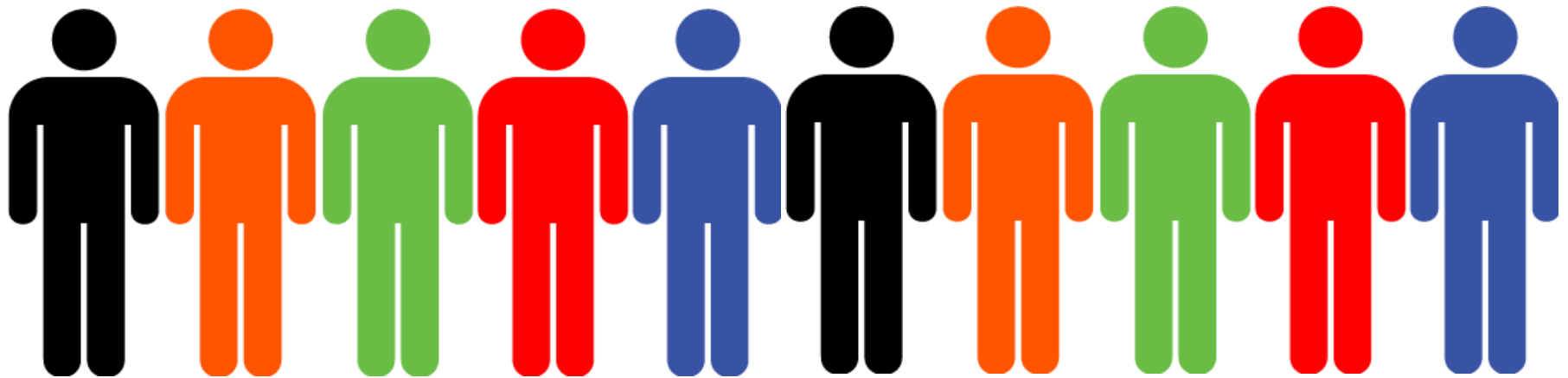
How we feel pulmonary hypertension

Our hearts and pulmonary hypertension



The prevalence is about

55 cases per million

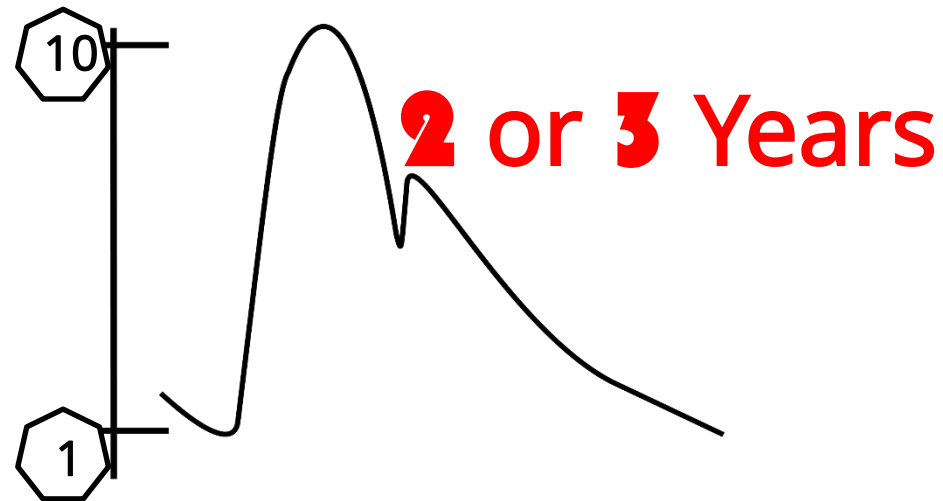


There are **33,293** possible cases of PH in Latin America and only **15.77%** have been detected.



23,008 people could be dying **within two to three years** due to lack of treatment.

With out treatment, the average life expectancy for a person with PAH is only



But timely diagnosis and appropriate treatment of the disease can significantly improve this time.

Contact us

Please visit our website to find out more:

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<http://www.worldphday.org/>



Sociedad Latina de Hipertension Pulmonar
Hipertension Pulmonar



@sociedalatina



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Thank you