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## DIFFERENT CONTINENTS BUT UNIVERSAL PROBLEMS

PATIENT ORGANISATIONS' CHALLENGES AND ACTIVITIES IN LATIN AMERICA

**Panamerican Region**

Presented By: Maria Mercedes Rueda







“

**Gonzalo Tobar Carrizo**  
**ASOPAN Board Member**

Spokesman of Lupus Chile  
Chair of the Chilean Network of Rheumatic Patients  
Head of South Cone Zone of ASOPAN  
Brother of a young woman with SLE

”





I have no conflict of interest to declare for  
this presentation





# Pan American Network of Rheumatic Patients Associations

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ASOPAN was born in Buenos Aires Argentina in 2018



The Panamerican Association of Rheumatic Patients - ASOPAN rises as the result of the union of leaders of patient organizations in the 1st Pan American Congress of Patients with Rheumatic Diseases organized by PANLAR, the Pan American League of Associations of Rheumatologists in its 20th Congress.





## Pan American Network of Rheumatic Patients Associations



ASOPAN was created with the following main aims:

- To promote a network of Pan American patients rheumatic associations;
- To work in the the promotion of a better quality of life for our patients;
- To represent our patients at international organizations with an unified voice.





Asopan's Management Commitee



66 Association Members



17 Countries in the panamerican region



Priscila Torres  
President - Brazil



Maria Mercedes Rueda  
Vice president - Colombia



Cecilia Rodriguez  
Chile



Gonzalo Tobar  
Chile



Gina Ochoa  
Colombia



Enma Pinzón  
Panamá



Teresa Mártez  
Dominican Republic



Tini Jórdan  
Argentina



Veronica Robles  
Mexico



Daniel Hernández  
U.S.A



# Latin America Demography

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**32 countries**



**650 million people**

8.3% of world population



**Inequality**

According to the ECLAC, Latin America is the most unequal region in the world



**Every country**

A different reality.





## Availability of rheumatologists in our region



Latin America has a mean rate

**1 Rheumatologist**

**106,838 people**

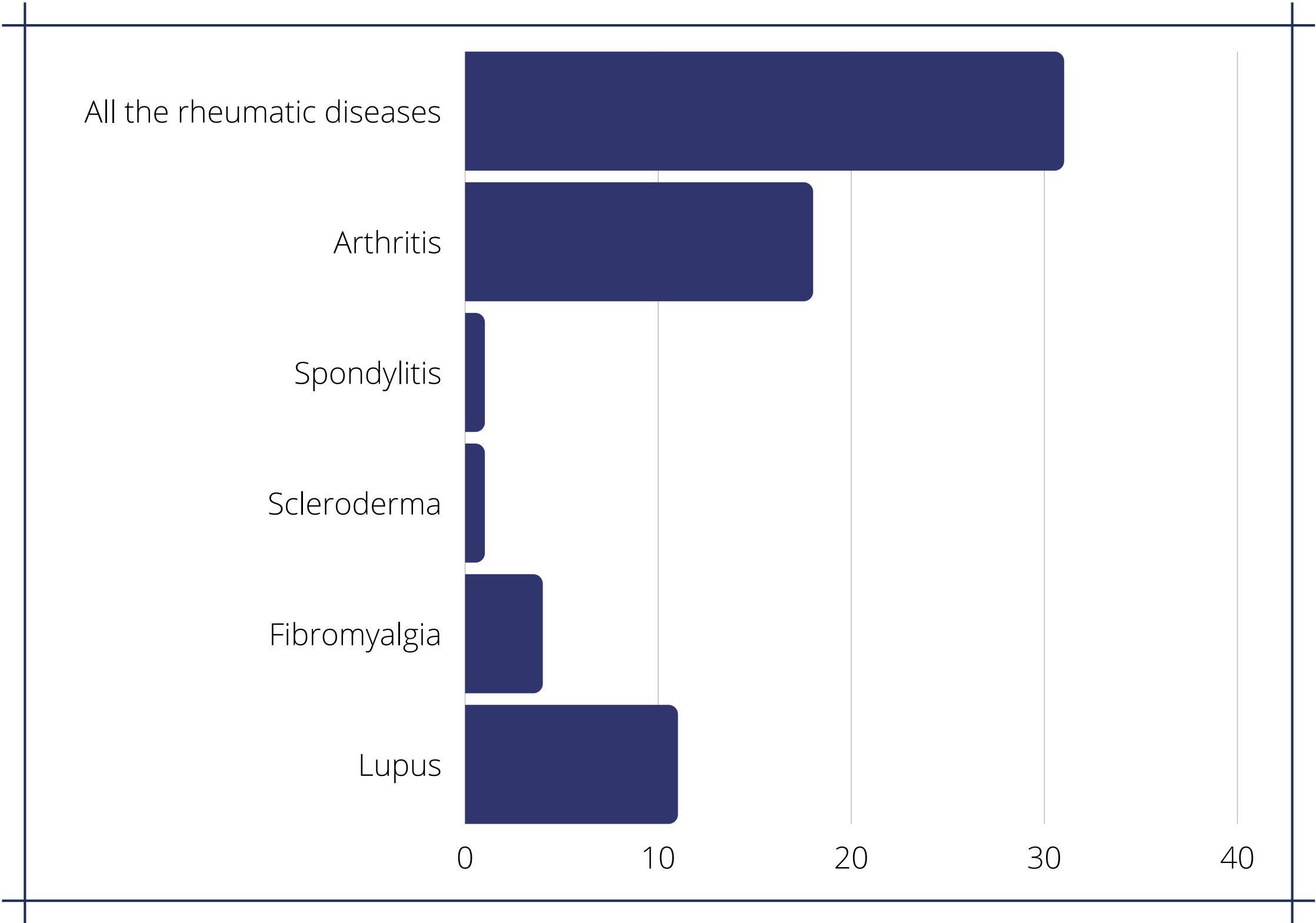


Most common rheumatic diseases



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Rheumatic diseases of our 66 association members

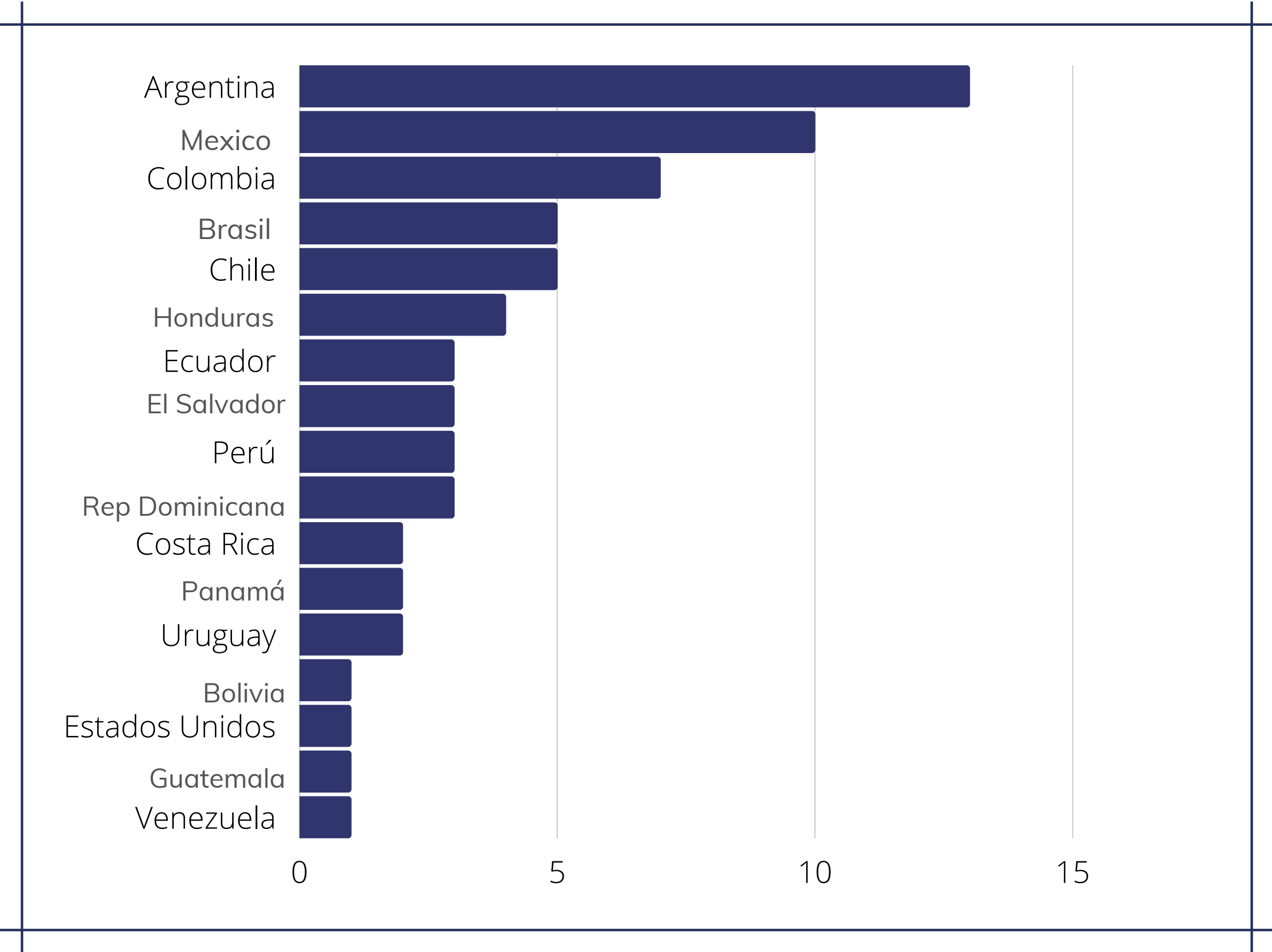




ASOPAN Member Associations



17 Countries represented with associations supporting rheumatic patients





## Pan American MANIFESTO for Rheumatic diseases: Scientific document made by doctors and patients, pointing out the care needs of rheumatic patients in the Pan American region



In 2019 at the 2nd PANLAR's Pan American Congress of Patients with Rheumatic Diseases, the leaders of ASOPAN had a meeting to assess the current situation of rheumatic disease patients in Latin America.

In this meeting, 12 challenges to improve were established.

These aims were raised to PANLAR to create the Pan American Manifesto of Needs of Patients with Rheumatic Diseases.







# 12 points about the care needs for rheumatic patients

## Pan-American Manifesto for Rheumatic Diseases - PANLAR

- 1 Information and education**  
signs and symptoms of rheumatic diseases.
- 2 Educate and training**  
Health sciences students and primary care teams about rheumatic diseases to increase the possibilities of timely detection
- 3 Guarantee early detection**  
Timely diagnosis and referral to a specialist for patients with rheumatic diseases.
- 4 Multidisciplinary team**  
Comprehensive approach to the patient and the family including (physical, emotional, social and rehabilitation needs).
- 5 Patient organizations reference**  
Points in relation to information, education, monitoring of needs and advocacy
- 6 Labor and educational rights**  
Of people with rheumatic diseases for adults, youth and children.
- 7 Ensure access to health technology**  
for the population with rheumatic diseases
- 8 Including patient organizations in decision-making** related to public policies and mechanism for civil participation.
- 9 Promote strategic alliances**  
With scientific societies, academy, governmental bodies - for shared decision-making.
- 10 Activate joint collaboration strategies**  
In order to ensure the work of patient organizations as a referent in self-care education to rheumatic patients.
- 11 Access to pain treatments**  
Implementing the necessary actions to guarantee to pain treatments and palliative care.
- 12 Protect children and young people**  
Affected by rheumatic diseases and guarantee all the points specified in the Pan-American Manifesto.



## Situation delay in diagnosis



Receiving a correct diagnosis has been one of the priorities on which the discussion among the jury members have focused. This is a common problem in the region and must be addressed seriously.

The possibility of access to specialist consultation is complex for many patients, especially those living in the periphery or rural areas. This fact causes a lot of frustration in those patients who, after consulting different non-specialized doctors, do not find any improvement to their situation.

At least the pandemic offered the chance to the telemedicine.



## Difficulty in accessing the pediatric rheumatologist

The comprehensive approach to children and adolescents suffering from rheumatic diseases is an urgent necessity and must be guaranteed since it is related to the normal development of the personality and the best therapeutic opportunities.





## Access to medicines for the treatment of rheumatic diseases



One of the major challenges in the Pan-American region is marked by the vastly different characteristics of the health systems that coexist in each country. Beyond this diversity, patients need to receive quality care and the best opportunities for medical, physical, psychological and social rehabilitation.

Patient education is also promoted through systematized programs to have active patients involved with self-care.



# Challenge of access to multidisciplinary and non-pharmacological treatment

We constantly are asking for a comprehensive approach to the patient and the family in rheumatic diseases, because constitutes an essential quality standard when measuring the impact on the quality of life. That these diseases affect the patient in every aspect of his daily life, making it necessary to have a rheumatologist leader who can articulate the other specialists. In this sense, a comprehensive approach includes not only the aspects related to the best therapeutic options for each case, but also psychological, emotional, social and employment assistance, if necessary.





# Financial impact of rheumatic diseases

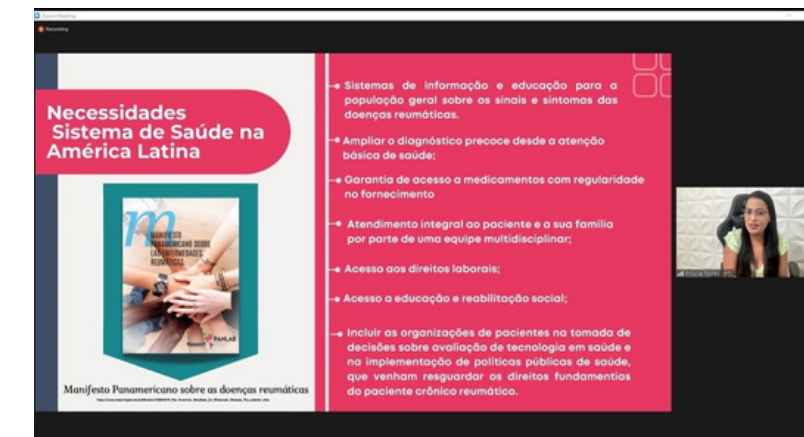


The members are aware of the funding difficulties faced by health systems in the different countries, but, in turn, they consider that access to innovation and better quality of life conditions for people affected by these diseases are necessary.

- “Instruct rheumatic patient organizations in decision-making related to public policies and mechanisms of civil participation”.
- “Today, patient organizations are perceived to be outside the health system”.  
**THIS HAVE TO CHANGE.**



We present the Pan American Manifesto on rheumatic diseases during the informal consultation of the PAHO/WHO with a workgroup called People who live with non communicable deseases and mental health problems in Latin America, which preceded the 75th World Health Assembly.



## WHO Informal Consultation with People Living with NCDs and Mental Health Conditions Regional Consultations February - May, 2022





# Working coordinately with scientific societies



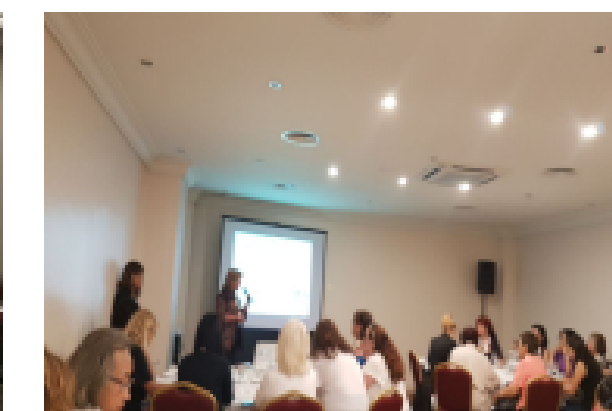
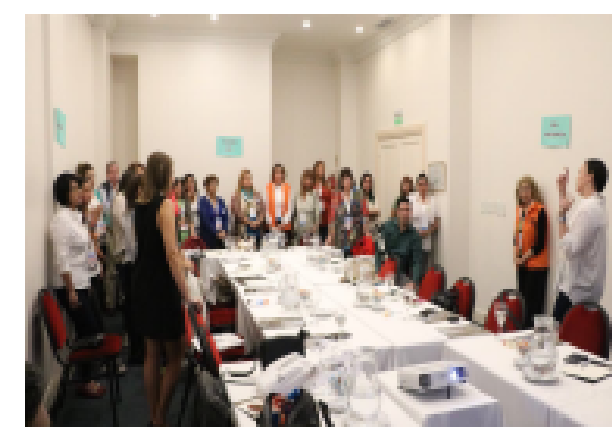
## ASOPAN and PANLAR Work Together

- **PANLAR Patients' Congress**
- **ASOPAN Patients Congress**
- **Pan American manifesto on rheumatic diseases**
- **Expert Patient Program, addressed to leaders**
- **Active Patient Program, addressed to all patients**
- **Every member works with its own Rheumatic National Society**



# Patients' Congress

ASOPAN and PANLAR have held, since 2018, patient congresses with special panels for leading advocate patients





## Online Patient Congress

ASOPAN and PANLAR have held, since 2018, patient congresses with special panels for leading advocate patients





# We perform instructive live throughout the Covid-19 pandemic

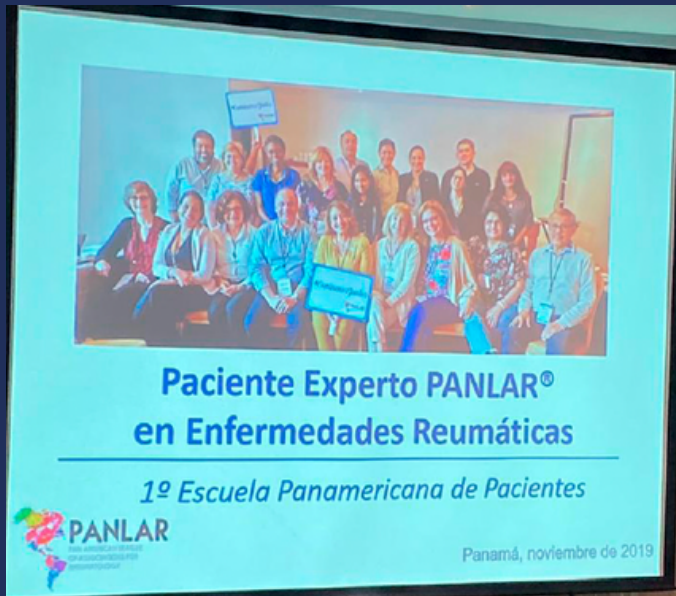


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II Congreso de Pacientes de	Día mundial de la	Esclerodermia desde el	Síndrome de fibromialgia	Lupus Eritematoso
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Revolución Digital en la Salud	Decisiones Compartidas: no	Una enfermedad Crónica es	Afectación del paciente por	Higiene articular en espacios
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# Expert Patient Program in rheumatic diseases, by PANLAR

This project was born from the review of international programs developed by Stanford University (United Kingdom) and based on more than 10 years of experience implemented in Spain by the Universidad de los Pacientes. PANLAR looks to empower some leaders of patients of ASOPAN so they can help to manage people in their own self care.



Group of patients of the PANLAR Paciente Experto Pilot Program from Argentina, Brazil, Colombia and Panama.



Participants of the “Formador de Formadores” Pilot Course.



# Active Patient Program, by PANLAR

This program looks to empower the patients with the knowledge, habilities and testimonials from people who have a rheumatic disease and leaders o patients associatiions and healthcare profesionales. This was launched this Tuesday 31st of May.



CURSO

## Programa Paciente Activo

**OBJETIVO**

Empoderar a los pacientes a través de conocimientos, habilidades y testimonios de personas que conviven con enfermedades reumáticas, junto a líderes de organizaciones de pacientes y expertos profesionales.



CURSO

## Programa Paciente Activo



3 Módulos



Vídeo clases



Foro interactivo



Evaluación



Curso certificado por Panlar



CURSO

## Programa Paciente Activo

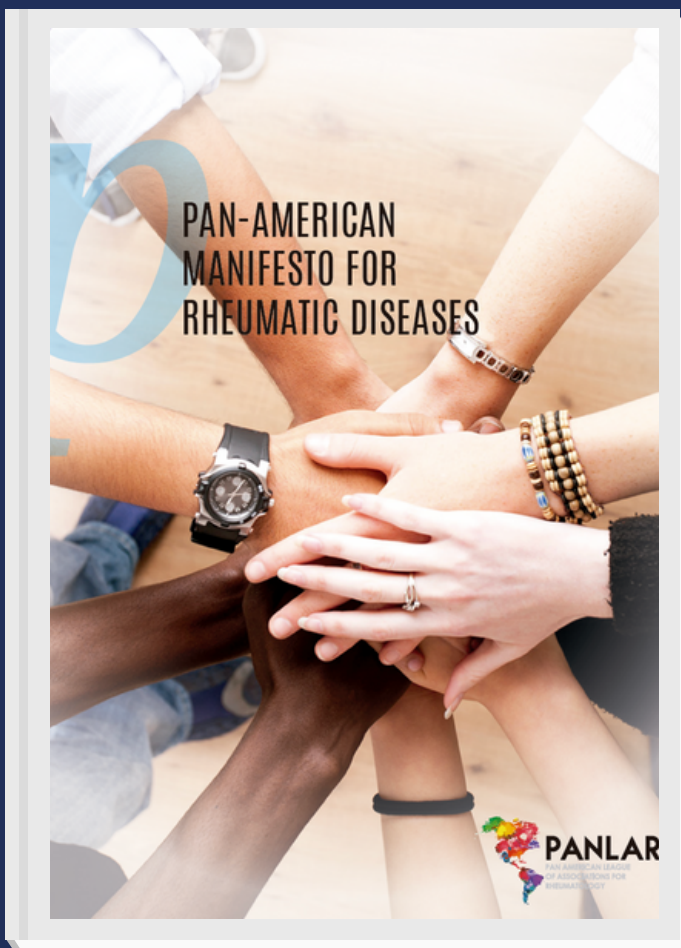
**PROGRAMA**



Módulo I	Escuela de pacientes
Módulo II	Estrategias de autocuidado 1
Módulo III	Estrategias de autocuidado 2

- Patient school
- Self-care strategy





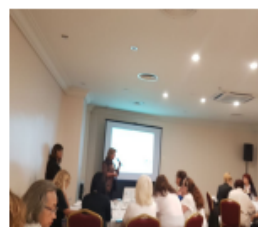
## Next activities

- 5th Pan American Congress of Patients with Rheumatic Diseases
- A new ASOPAN Advocacy Congress
- We want to work with the World Health Organization to the care needs of Pan American rheumatic patients be included in the WHO chronic non-communicable disease guidelines.
- We will support PANLAR in the next steps of its Expert Patient Program, training new patients for leadership.
- We hope to learn from PARE of EULAR the ways to help us overcome the challenges in our continent.
- We want to create Panamerican work groups of diseases, with the nationals leagues of each one





**And this is how ASOPAN works with PANLAR to have a better future for our patients and that no one in our continent be left disabled by a rheumatic disease.**







# Thank You eular | PARE

Mr. Gonzalo Tobar Carrizo  
Member of ASOPAN

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