



PAN-AMERICAN MANIFESTO FOR RHEUMATIC DISEASES



PANLAR

PAN AMERICAN LEAGUE
OF ASSOCIATIONS FOR
RHEUMATOLOGY

PAN - AMERICAN MANIFESTO FOR RHEUMATIC DISEASES

ISBN 978-958-56920-7-7



Una realización de
(c) PAN-AMERICAN LEAGUE OF
ASSOCIATIONS FOR RHEUMATOLOGY
- PANLAR

First edition, December 2019

Scientific coordinators
Dr. Enrique Soriano,
PANLAR President
Dr. Carlo Caballero Uribe,
President of PANLAR's Education and
Science Committee

Editorial advice
Zoila Sotomayor O.

Design concept
Secretaría Panlar

Copy editing
Eduardo Franco

Text and cover design
Joaquín Camargo Valle

Editorial production
Fundación Luneta 50
(Barranquilla, Colombia)

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Main researcher

Emilia Arrighi, MSc PhD
*MSc PhD, Patient Advocacy Director,
Fundación Hospital Universitario*

Doctor in Health Psychology (Autonomous University of Barcelona, Spain), Specialist in Psycho-Oncology (Istituto Nazionale dei Tumori, Milan, Italy) and Master Trainer in Chronic Disease Self-Management Program (Stanford University, USA).

Dr. Arrighi has over ten-years' experience in Patient Advocacy and patient participation in health policies. She's has worked in health coaching and patient activation, in addition to advising in the development of patient schools and self-care training for chronic patients' programs in Spain and Latin America.

Email: emilia.arrighi@gmail.com

Scientific coordination

Dr. Enrique Soriano
PANLAR President

Dr. Carlo Vinicio Caballero Uribe
President of the Education and Science Committee, PANLAR

Review of scientific literature

Lic. Lucía Wang, Master's Degree in Communication and Culture as well as active patient

Document review

Mrs. Pepita Bernat, *Fundare Colombia, regional patients' representative*
Mrs. Elisenda de la Torre, *president of the Catalan Rheumatology League and speaker of the Spanish Rheumatology League*
Dr. Cristina Drenkard, *Emory University, USA*
Dr. Dora Pereira, *Juntos Group*
Dr. Pedro Santos, *Juntos Group*
Dr. Fernando Gallo Cornejo, *Hospital Universitario Foundation, Argentina*
Dr. Ana Paula León, *Hospital Universitario Foundation, Mexico*

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FOREWORD



Dr. Enrique Soriano
Panlar President



The Pan-American League of Associations for Rheumatology was created on May 31, 1944, after several years of hard work. On August 1955, PANLAR held its first congress in Rio de Janeiro, Brazil. Thirteen years were needed to organize its first congress following its foundation. This is clear evidence that organizations require both time and effort to establish themselves, grow, become strong and evolve.

Today, 65 years later, and thanks to the efforts by many, the vision of a few and the leadership of some, PANLAR gathers societies and associations from 21 countries in 4 regions: North, Center, Bolivarian and South. During this period of time, PANLAR has held 21 Pan-American congresses; it has consolidated 14 extremely active study groups; it has held dedicated workshops and working days; drafted consensuses and clinical practice guides; granted scholarships and study subsidies; has sponsored internships; bestowed awards and prizes, among others. PANLAR has grown from a voluntary

association, without legal status, with its President's address as its own and a sole secretary as its entire support staff, to a non-profit association domiciled in the United States (501C3) that recruits an entire company to provide its secretarial duties and another company to organize its events, as well as translators and web management support (with a modern and appealing webpage). Only in the past few years has PANLAR understood that, in order to advance rheumatology in the continent for the benefit of our patients, we shall work with our patients. A new webpage was created with important information for patients, which has become one of the most visited Spanish-language webpages, in order to continue financial support to the development of educational programs for specific patients (Hablemos de Lúpus). Finally, rapprochement with patient organizations and empowered patients followed. In 2018, during the 20th PANLAR Congress, the first PANLAR Patient's Congress was held. Over 500 patients attended, talks and workshops were held with great success. Moreover, meetings of patient leaders from all over the American continent took place. The foundations for a Pan-American Network of Rheumatic

Patient Associations – ASOPAN – were laid.

This patients' association provides constant joy to PANLAR, and PANLAR wants more! We have embarked in developing the first Latin American school for patients under the certainty that it will become the first Pan-American patient university. Rheumatic patients from Latin America will train to become informed, educated and empowered patients, which will ensure rheumatological progresses have a real impact in their lives.

The work of patient's associations and patient leaders advanced in such a way that during the 20th PANLAR Congress held in Quito, Ecuador, a Second PANLAR Patients' Congress was held. This edition had a distinctive and possibly unique characteristic, at least for the Latin American scenario: The Patients' Congress was organized and determined completely by patients. It was a patients' event, organized by patients with the support of a medical organization. As in Buenos Aires, the patients' congress held in Quito was not sufficient, but it allowed for the drafting of this document, the first Pan-American Manifesto on the needs of people with rheumatic conditions.

It is with great pride that I, as PANLAR president, hereby present this manifesto, which will surely be a milestone in Pan-American rheumatology and will bring to medical societies, social organizations, politicians and governmental agencies the cohesive and firm, but in need of attention, voice of our rheumatic patients.



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PREFACE



Priscila Torres
President of ASOPAN



ASOPAN was created as the result of the patient's meeting during the 20th PANLAR Pan-American Rheumatology Congress. Currently, 35 patient associations participate in it, divided among four geographical regions of the American continent. Each region has a regional representative.

ASOPAN's general purpose is to promote decentralized and open cooperation management focused on people and based on scientific evidence and real life data, in a transparent manner and avoiding all possible conflict of interest.

It is a private, non-profit civic association ready to work towards the following goals and interests: guild, charity, common interests or purposes, and social interests, especially those related to rheumatic disease.

Its main goals are:

1. To develop training that enable professionalization and the development of every patient association in the Pan-American region.
2. To encourage participation and cooperation of associations oriented to improving access to early diagnostics, treatment, self-care, continuous care and basic rights of patients in the Pan-American region.
3. To represent patients and their associations before international authorities.
4. To actively cooperate and support the right to health in each of the member countries.

The *Pan-American Manifesto for Rheumatic Diseases* (PAMRD) provides the opportunity of having a single voice, to work collaboratively towards the common purposes of early diagnosis and integral attention, and achieve our goal: that no one in our continent is disabled due to a rheumatic disease.

The PAMRD enables us to express our needs to authorities with the support of an entire region. It is also a scientific document representing the vision of patients regarding needs for attention, and will help as a tool to improve health policies in all countries in the region.



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PRESENTATION



Dr. Carlo Vinicio Caballero Uribe
*President of the Education and Science
Committee*



Together, patients and doctors

We are presenting to the rheumatologic community in particular, but also all those interested, the first Pan-American manifesto on the needs of the people suffering from rheumatic diseases. For us, from PANLAR's viewpoint, it is a real cause for pride. In the origins of the organization, PANLAR and other leagues had become leagues to fight against rheumatism, and in the initial bylaws there was a committee in charge of community groups that were not necessarily medical or scientific, but that were dedicated to educating patients, their families, their surroundings and that were, of course, linked to patients (PANLAR, 1994).

Fernando Herrera Ramos, one of PANLAR's founders, stated in 1939:

Our responsibility is huge, as it will be necessary to attract the attention of rheumatics, of the members of the different social planes assaulted by the consequences of rheumatological processes, as well as of those responsible for

healthcare, and it will be transcendental if we manage to interest our followers, as the success of an idea, work or creation depends more on those advancing it than on its initiators.

With the creation of the new PANLAR (Caballero-Uribe, 2019), in 2015 we invited a patient, Cecilia Rodríguez (Fundación Me Muevo), to the first PANLAR review course concentrated on examining the challenges we face when dealing with patients with rheumatoid arthritis and on a program centered on reviewing minimum care and joint decision standards that include the opinion of other actors of the healthcare sector, especially patients, as the starting point in the path towards a medicine truly focused on their care. Her presentation was very successful and provided patients with a voice before the scientific community that we continue to encourage. In 2016 we invited her to a PANLAR strategic planning workshop; this was a first for our organization, which grew from the inclusion of an authoritative voice and a genuine representative of what is today known as an expert or empowered patient, as part of what has been called We Are All PANLAR (Caballero-Uribe, 2018). Again, her presentation was a success that continues to open doors within

the organization. Thus, we decided to create the Juntos¹ Group (Caballero-Uribe, 2019), composed of patients and doctors, and, through their unique visions, we approach diseases from different perspectives, with different types of expertise, which can be really dissimilar, but, when working TOGETHER (JUNTOS), these differences complement each other and can generate solutions to the many problems faced by the doctor-patient relationship nowadays.

Our health systems developed under the premise of the treatment of acute conditions. Epidemiology changed and now chronic, non-communicable diseases predominate. The concept of health has also changed, from a charitable option to a fundamental right (Caballero-Uribe, 2013). In this scenario, the manner in which doctors and patients relate starts to reconfigure. With a better relationship (and, with it, better communication), significant progress can be made in other areas, like the making of joint decisions, education and also the areas of spokespersonship or advocacy.

Today we can assert that we have concrete results from all these actions, embodied in an annual congress of

1 Translator's Note: "Juntos" means together in Spanish.

patients with rheumatic diseases that has assembled more than a thousand patients on its two occasions. These have been executed under the “patients included” philosophy, whereby they have been an active player in the design, organization and execution of the academic program; in fact, during the Second Pan-American Patients Congress, another empowered patient, Priscilla Torres (Grupo Encontrar, Brazil), very successfully held the role of president, supported by a committee mainly composed of patients. Supporting these gatherings, in which meetings between the leaders of patients also occur, has allowed for consensuses like the one contained in the PAMRD, and the creation of a dynamic community that expresses itself as well through different social media where the amount of interaction between patients and the organization is surprising, in this manner contributing actively to the dissemination campaigns about rheumatic diseases that are launched every year in the months of May and October, and making us leaders in these type of programs among similar

organizations as well as launching the expert patients program or PANLAR patients school.

In this way, the idea of a permanent work and study group has been consolidated to chart out actions aimed at improving the doctor-patient relationship and communication. The Juntos Group has achieved its own dynamics with these activities and continues facing challenges and actions to overcome, among them, conducting a full census of the different patient organizations in order to get to know each other better, assisting with the joint work of these organizations within the network, continue creating networking opportunities with events, platforms and programs that are shared with the patient organizations comprising the Pan-American Network of Rheumatic Patients (ASOPAN, as per its name in Spanish) and advancing research of topics related with healthcare centered on the patient, like self-care, adherence and joint decisions, among many other common topics among patients and doctors.

Table 1. Actions to be developed by the Juntos Group

<p>1. Census of patient organizations in Latin America. This will allow us to understand:</p> <ul style="list-style-type: none"> a. The current status of such organizations (where, how many, etc.). a. Areas of development (what type of support they provide). a. Areas of interest and training needs.
<p>2. Joint work with patient organizations on social media. This will enable the:</p> <ul style="list-style-type: none"> a. Establishment of a closer bond with PANLAR. a. Generation of collaborative work in the region. a. Joint work in certain topics, which will enable the production of a common regional language.
<p>3. Create campaigns for October, arthritis month, which will enable the:</p> <ul style="list-style-type: none"> a. Strengthening of PANLAR's identity. a. Reinforcing the work on region-specific problems.
<p>4. Provide evidence from the patient's point of view:</p> <ul style="list-style-type: none"> a. Advance on work on patient-reported outcomes and patients' experience. a. Health literacy. a. Publications, reports and work documents with a regional scope.

A large, stylized lowercase letter 'i' in a light gray color, positioned on the left side of the page. The dot of the 'i' is a solid gray circle. The letter is partially overlaid by a blue rectangular block at the top left of the page.

INTRODUCTION

Rheumatic diseases encompass over 200 different diseases and syndromes, which can have severe symptoms, including pain, fatigue, distress, impact on quality of life and, in some cases, the presence of physical limitations and disabilities (European Commission, 2011).

Latin America presents a difficult scenario regarding health and education problems and a series of social needs linked to poverty, among them, chronic-degenerative diseases where rheumatic diseases are especially relevant. For this reason, it constitutes a challenge regarding the priority that these diseases have within health policies (Cardiel, 2011; Caballero-Uribe y Alonso, 2010).

The health systems of the Pan-American region are very different among countries, not only in their organizational structure, but also in their operational complexity, both for the public and private systems. The evidence shows that there are a number of obstacles in the region, such as the early detection of these diseases, access to health, general education of the population, shortage of specialist in rheumatology, access to timely treatment and the impact of the

disease at the economic, social and labor levels due to the possible degree of associated disability (Murray et al., 2013; Pineda and Caballero-Uribe, 2015; Soriano et al., 2008).

According to the World Health Organization (WHO), these diseases affect 15% of the world's population, including children, youth, adults and the elderly (Caballero-Uribe, 2006; Newhall-Perry et al., 2000). The Institute for Health Metrics and Evaluation (2013) warns that the main causes of disability in Latin America and the Caribbean include low back pain, neck pain and other musculoskeletal diseases.

As defined by the European League Against Rheumatism (EULAR) in 2018, rheumatic and musculoskeletal diseases are defined as a diverse group of diseases that frequently affect joints, but can also affect muscles, other tissues and internal organs. There are more than 200 distinct rheumatic diseases, affecting both, children and adults, the most common ones are juvenile arthritis, psoriatic arthritis, rheumatoid arthritis, connective tissue diseases such as lupus, spondyloarthropathy, fibromyalgia, gout, osteoarthritis, vasculitis, among other

syndromes. Rheumatic diseases are commonly caused by alterations of the immune system, inflammation, infections or gradual deterioration of joints, muscles and bones. Many of these diseases are chronic and get worse over time. They are typically painful and limit function. In severe cases, they can lead to significant disability, with a major impact on both quality of life and life expectancy.

According to PANLAR, at least 30% of the world's population suffers from some form of arthritis. In Latin America, the number of people living specifically with adult rheumatoid arthritis (RA) varies greatly. There are

“Musculoskeletal disorders are the most common cause of severe long-term pain and physical disability, affecting millions of people worldwide. They have an enormous impact on individual, social and health systems. There are effective ways to prevent or treat these disabling conditions. But we must act on them now”

Kofi Annan

countries where the prevalence is less than 1%, such as Argentina (0.3%), Brazil (0.46%), Venezuela (0.40%) or Peru (0.55%), and countries where the prevalence is higher, such as Mexico (1.6%). Beyond the regions, RA mainly affects adults between 30 and 50 years of age, and is more frequent in the female population, with a ratio of three women for every man (Chopra & Abdel-Nasser, 2008; Argentinian Society of Rheumatology, 2013).

A recently edited report by the Pan-American Health Organization (PAHO, n.d.) that refers to the economic impact of chronic diseases in Latin America and the Caribbean, draws attention to equity and access to health in our region and mentions the case of the RA. The data show that it affects the poor population the most; in particular, they refer to countries such as Brazil, Ecuador and Uruguay. Difficulties for the poor are presented by lack of insurance or limited health coverage, as well as lack of access to diagnostic tests, medical visits and medicines to treat this disease appropriately (Massardo et al., 2009).

While it is true that the natural history of rheumatic diseases has changed thanks to the emergence of new treatments, these remain closely related

to age. Due to the growing increase in life expectation and the ageing of the population, there is an increase in its incidence, which causes a decrease in the quality of life, reduction in physical functionality, etc. (European Commission, 2011).

Rheumatic diseases have a severe impact on the life of the people who suffer them, mainly because they are diseases that, as they evolve, restrict personal, work and economic autonomy. The impacts derived from these diseases are numerous and affect the different areas of life of the patients and their families (Alfaro et al., 2013).

For this reason, and because of its chronic, progressive and incapacitating nature, these conditions require a personalized and patient-centered care scheme. In these diseases, it is fundamental to offer a multidisciplinary and intersectoral approach to the patient, which involves the coordinated intervention of the rheumatologist with different specialists (psychologists, occupational therapists, nutritionists, pain specialists, physiotherapists). Each patient will have their own strategies and difficulties in the self-management of the disease; however, it will be essential to accompany the particular situation

in which they live, help them to set up routines, look for alternatives at each stage so that they can enjoy and have a full life (Dickens, McGowan, Clark-Carter & Creed, 2002; Santos-Moreno et al., 2015).

In this sense, when talking about the global impact of rheumatic diseases, the impact on quality of life of aspects such as pain, distress, possible progressive deformity and the limitations to normally develop the activities of daily living must be estimated. One of the variables to consider is related to people's capacity to adapt and the way in which their self-esteem can be affected, which can generate social isolation, loss of family roles and depression. People affected by rheumatic diseases may have secondary psychological disorders due to chronic pain, functional disturbances, deformity and loss of independence. In addition, these diseases have consequences for the family and caregivers (Anyfanti et al., 2016; Cadena, Cadavid, Ocampo, Vélez y Anaya, 2002).

Scientific evidence indicates that rheumatic diseases are one of the most important causes of disability, job loss or career interruption. The impact is even bigger when it comes

to manual occupations (Massardo et al., 2009). Some data show that they are also a cause of reduced productivity, which, in the case of Germany, meant a loss of about EUR 24 billion in 2006 and about EUR 650 million per year in losses for days not worked (Declaration of the European Parliament on rheumatic diseases). (2009/C 285 E/11)).

In Europe, rheumatic and musculoskeletal diseases represent an estimated economic cost of EUR 240 billion per year, with an increasing trend. To this situation must be added the costs related to some interventions, such as surgery, physiotherapy, hospitalizations, rehabilitation, etc. (European Agency for Safety and Health at Work, 2010). In the United States, it is estimated that around 52 million people suffer from some form of rheumatic disease. These are one of the main causes of disability and the costs associated with these diseases are around USD 128 billion per year (Barbour et al., 2013).

When it comes to children and young people, the measures of care and approach must also include a protection and guarantee of adaptation of the school environment to ensure correct adaptation and literacy.

It is therefore essential to coordinate psychoeducational interventions that promote the shared management of these conditions and provide children and parents with disease-specific education and the necessary strategies for good self-management (Brunner & Giannini, 2003; Bruns, Hilário, Jennings, Silva & Natour, 2008).

In recent years, the role of patients and their relationship with healthcare professionals has also evolved, from a hegemonic and paternalistic model, where they referred to the indication of treatments, to a model where patients have a more active and participative role in the management of their own health. In this sense, patients are taking much more active care of their own disease and have a more conscious participation in decision making regarding their health (Arrighi, Jovell y Navarro, 2010; Jovell, Rubio, Fernández y Blancafort, 2006).

From this active role, patients want to receive more information, easy to understand and adapted to their context, so that they can make decisions that best suit them regarding their health (Coulter & Collins, 2011).

In this sense, there is clear evidence that patients who receive self-care

education increase adherence to treatment, improve pain control, feel more prepared during the medical visit, and optimize healthcare expenditures. Educational and self-management strategies are also included in the international recommendations of comprehensive approach to rheumatic diseases (Caballero-Uribe, 2019; Hibbard & Mahoney, 2010; Santos-Moreno et al., 2015).

Against this background, it is important to note that the PAMRD, along with the evidence presented, provide essential information for public policy makers, health professionals, researches and scientific societies, with the support of patient organizations, to improve the comprehensive care of people living with rheumatic diseases in the Pan-American region.

This PANLAR initiative follows those developed by global health policy organizations, including the European Manifesto on Rheumatic Diseases (2000) and the consensus of 18 representatives from Latin America and the Caribbean (Chile, 2009), whose objectives focused on identifying problems and providing recommendations for the care of patients with RA, and emphasizing education and treatment. Part of the conclusions of the 2009 consensus was the identification of

strategic areas, whose priorities included early diagnosis, access to multidisciplinary care, creation of a database for the identification of infections through the use of biological agents and raising patient management to international standards.

The same issues were subsequently discussed in 2018, during the First PANLAR Patient Congress, which resulted in a meeting between physicians, professionals and patients, who reviewed the scenarios described above in line with the World Health

The Pan-American League of Associations for Rheumatology (PANLAR) is a society constituted by representatives of 21 countries of America, divided into 4 geographical areas (north, center, Bolivarian and south). Delegates from the 21 countries attended the 20th Pan-American Congress of Rheumatology, where in the previous days the I Pan-American Congress of Patients with Rheumatic Diseases was held.

Buenos Aires, Argentina, April 2018.





Dr. Carlo Vinicio Caballero with Dr. Dora Pereira, president of the I Pan-American Congress of Patients with Rheumatic Diseases. Scala Hotel. Buenos Aires, Argentina, April 2018.



Creation of the Pan-American Network of Patients with Rheumatic Diseases, ASOPAN. I Pan-American Congress of Patients with RD. Buenos Aires, Argentina, April 2018.

Organization's so-called Decade of Healthy Aging 2020-2030 (OPS, 2019; European Manifesto, 2000; Massardo et al., 2009; PANLAR Patient Leaders Newsletter, 2018).

The PAMRD is intended to be a living document, a call to action, so that these premises can be reflected in concrete strategies that directly benefit the care and attention of people living with rheumatic diseases, regardless of their country of residence, social class, educational status or gender.



PURPOSES

The main goal of the PAMRD is to determine the care and rehab needs, the obstacles and the impact on quality of life of rheumatic disease on patients of the Pan-American region.

In order to fully learn about the obstacles faced by people who live with these conditions and improve their attention and follow-up needs, a qualitative study was developed by PANLARs Grupo Juntos, together with the cooperation of rheumatic patient organizations grouped in ASOPAN.

The following were highlighted as specific purposes of the study, among others:

- To identify experiences and needs of people living with rheumatic disease and the impact it may have on their family, social and work life.
- To promote scientific evidence about the experience of sickness, with the participation of those

affected, and identifying improvement strategies.

- To acknowledge information collected by patient organizations with regards to the needs and priorities of patients.
- To promote health policies better suited to the needs of patients and their families.

- To deepen knowledge and social understanding on the conditions.

There is currently a growing trend to reform the health system towards a new paradigm that focuses on patients. The purpose of the PAMRD is to incorporate the patients' vision, as well as to obtain the support of all parties interested in lining up agents involved in the comprehensive care of persons with rheumatic diseases and their families.



Smiles were the common denominator during the closing of the I Pan-American Congress of Patients with Rheumatic Diseases. This image reflects the satisfaction of patients and doctors for the achievements.

Buenos Aires, Argentina, April 2018.



METHODOLOGY

A plan was devised to meet the goals set, which included a qualitative design to collect key information on the needs and experiences of people affected by rheumatic disease and their informal caretakers, through representatives of patient organizations that are aware of global and local realities.

A variation of the “citizen’s jury” technique to collect information, known as “patients’ jury”, was used in this case. It involves the participation of expert scientists, as well as patient leaders that are know the day-to-day reality of people who live with these conditions.

Dialogue among jury members was encouraged by a researcher following a semi-structured method to moderate the exchange of opinions. This researcher, an expert in the use of this methodology, ensured the respect of individual positions and the flow of communication between the different jury members to facilitate the contribution new ideas and enabling agreements when drafting

the *Pan-American Manifesto for Rheumatic Diseases*.

Development of this study has been structured according to the following phases:

- Phase 1: Review of regional and global scientific literature
- Phase 2: Implementation of the “citizen’s jury” qualitative technique
- Phase 3: Information collection and analysis
- Phase 4: Drafting the report

Phase 1: Review of scientific literature

A narrative review of scientific literature was performed in order to identify the most relevant publications related to rheumatic disease and its use as a research subject at the Pan-American and global level. This review was made through searches on database portals to locate the most relevant published papers.

The purpose was to place topics of interest in the general context of the impact they may have on the lives of people with this condition. The information shall be used as a context

framework to identify whether these issues occur in the entire territory.

A search of the Medline database was performed, focusing on documents and review papers in English, Italian and Spanish published during the past decade (2009-2019). Key words use included: rheumatic diseases or disorders, quality of life, patients’ preferences, patients’ needs.

Phase 2: Field work

An adaptation of the “citizens’ jury” technique was used to explore the information collected. A patients’ jury is a formal and structured method based on the citizens’ jury technique (Gooberman-Hill, Horwood & Calnan, 2008). It is formed by a group representing patients’ associations expressing their opinions on a certain argument, in accordance with their own principles, experience and information obtained from a group of experts or witnesses.

This method allows members of the jury a space for thought and debate, as well as the possibility of arriving at a set of recommendations. The patients’ jury is a vehicle for expanding democratic participation and a way to identify deficits and areas of improvement in healthcare.

Members of the jury were identified according to a theoretical sample to guarantee maximum representation of different socio-demographic profiles. The following criteria were considered for selection:

Selection criteria:

- Leader of a patients' organization that is aware of the needs of persons with rheumatic conditions in their country or region.
- Representation of the different rheumatic conditions: rheumatoid arthritis, lupus, juvenile idiopathic arthritis, scleroderma, psoriatic arthritis, arthrosis, among others.
- Geographic representation: a representative or representatives of a national patients' group, from different countries in the region.

The use of qualitative research techniques allows to know the position of patients and citizens with regards to health and healthcare (Coulter & Collins, 2011).

Phase 3: Collection and analysis of information

During the Second Pan-American Congress of Rheumatic Diseases, held in Quito, Ecuador on April 27, 2019,

a second working session was convened with the leaders of 30 patient organizations as jury members. The session's agenda is included as an attachment.

The members of the jury, formed by the representatives of referent patient organizations of the different areas of rheumatic specialties, received updated information on the situation and challenges faced in the detection and treatment of rheumatic diseases on the Pan-American stage. These contributions were the basis of evidence and the specialists, who acted as "witnesses" in this patients' jury, were in charge of offering updated information on the state of rheumatic conditions, the role of patients and the organizations representing them, in addition to the importance of patient empowering and patient schools and their impact on health results.

After receiving this information, jury members met in a separate session and deliberated for two hours in order to identify the barriers and areas of action necessary to improve the quality of life of people having these conditions. The discussion was led by an expert moderator in these kind of techniques and audio for the session was duly recorded.

Members of the jury received an invitation to participate in which they were informed of the study's goals, as well as fact sheet with the schedule and the role expected from their participation in the jury group.

Prior to the session, the information on the study's goals was repeated, and an announcement was made that the meeting was to be recorded, along with a guarantee of confidentiality. Each participant signed an informed consent sheet (attached).

During the discussion, a semi-structured script was followed, beginning with the review of scientific literature, which served as an entry point to address several topics and became,

in addition, the main requirement for an exchange of views between the participants (attachment).

Phase 4: Drafting the report

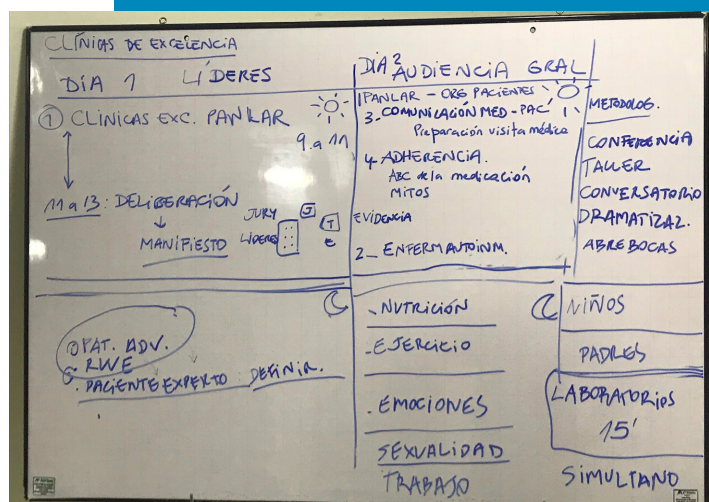
A manifesto was drafted as a result of the work session and, according to the phases of this study, a report on the results that captures the main topics of the discussion process of the members of the jury, as well as a verdict of general conclusions and improvement strategies in the management of chronic diseases. Emphasis has been put on the patients' view on future challenges of the specialty in the Pan-American region. This is stressed from the patient's own point of view.



Dr. Louis Tharp (left) y Seth Gingsberg (right), from the Global Healthy Living Foundation, in the company of Dr. Carlo Vinicio Caballero, during the I Pan-American Congress of Patients with Rheumatic Diseases.



Work meeting with the leading patients to organize the preparation of the PAMRD and the II Congress of Patients with Rheumatic Diseases. Bogotá, Colombia, September 2018.



The preparation of the PAMRD produced debates and proposals that were shared during the meeting held in Bogotá, Colombia, in September 2018. This board is a trace of that process.



RESULTS

During the deliberation process, the jury members were able to discuss the topics of greatest interest, according to a semi-structured script where the thematic areas to be explore were identified. The evidence provided by the specialists was taken as a starting point in order to identify not only the clinical and assistance needs, but also the emotional, family, social and work needs of those affected by rheumatic diseases and their families.

While it is true that the conclusions of this study cannot be extrapolated to the entire population living with these diseases, it provides evidence regarding the experience of having this disease. Currently, clinical decisions are being made not only according to health results, but also considering the experience and needs of those affected and the way in which their quality of life will be impacted. This type of study contributes to a better understanding of how this disease impacts the individual and his environment, whether their social and working life are affected, and what

are the needs for care, monitoring as well as the possible effect on limitations and disability that the disease can bring about (Arrighi et al., 2015).

“Information and education to the population about the signs and symptoms of rheumatic diseases”.

During the deliberation, the jury members identified a number of basic needs, described below:

1. Create and implement information and education systems for the general population about the signs and symptoms of rheumatic diseases.

One of the main concerns identified by patient organizations leaders in each country was the need to provide more information to the general population about the symptoms of rheumatic diseases. The lack of timely detection is still a concern, and this directly influences a person's diagnostic possibilities and prognosis. The jury members raised concerns about the obstacles the patients may face at the time of detection of the disease. In many cases, this process may take months or years depending on the place of residence of the patient and what access he has to education and specialist consultation.

For this reason, they find it necessary to reinforce awareness campaigns aimed at the general population. As is well known, patient organizations conduct regular work in this regard, however, more coordinated actions with other health agents are expected enabling a more continuous flow of information throughout the year, beyond the events organized on the occasion of the world rheumatic diseases day.

2. Educate and train health sciences students and primary care teams about rheumatic diseases to increase the possibilities of timely detection.

The jury members, who represented the very different realities of several countries, agreed that there is an insufficient number of rheumatology specialists in some countries, which poses a difficulty for patients living in rural areas or far from metropolitan areas to have access to specialist consultation.

On the other hand, they warn of the lack of timely referral to a specialist. Specialist consultation will allow an early approach and control of the disease, the prescription of the appropriate therapeutic treatment and the accompaniment and due follow-up throughout the different phases of the disease.

“Promote the study of rheumatic diseases in the school of medicine, and wherever the subject already exists, strengthen it”.

“Training in rheumatic diseases for students, health professionals and primary care teams”.

The jury recommend, as a measure to alleviate this situation, a greater formation in this specialty to health careers students, in addition to a specific preparation to doctors of primary care. This strategy already adopted by some of the countries represented has had a positive impact on increasing the screening of people with these diseases.

Referral to a specialist remains complex. As a result, many patients remain stuck in this stage with no possibility of accessing a specific diagnosis of their disease, neither possibilities of improving their living conditions.

3. Guarantee early detection, timely diagnosis and referral to a specialist for patients with rheumatic diseases.

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. Today, therapeutic possibilities can modify the impact of these diseases in such a way that they can determine the presence or absence of associated disability or, at least, delay it as much as possible, especially in the population of children and young adults.

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. Because these diseases negatively impact the quality of life, sometimes irreversibly, removing the obstacles to obtain early and appropriate specialized treatment is fundamental.

If this situation is evident for adults, it becomes even more complex for children in whom these diseases are less frequent and, therefore, more difficult to identify.

“Detect in time and refer the patient to the specialist”.

“Pediatricians do not diagnose any type of rheumatic disease in children”.

“A health system that guarantees early detection and timely referral to a specialist for rheumatic diseases”.

The jury has emphasized on the “pilgrimage” that some patients make in the search of a diagnosis and that this process, in many cases, can take years. As the jury recognizes, consultation

with a competent specialist is the beginning of good management of the disease, the initial kick to end the deterioration of the patient’s quality of life and the opportunity to begin to live more harmoniously with diseases highly stigmatized such is the case of rheumatic diseases.

The jury also warns the difficulties, not only of accessing competent professionals, but also to transit and interact within the health system that, in many cases, becomes a type of maze. The jury agrees that delay times in diagnosis should be reduced since these significantly affect the future possibilities of good management of the disease.

4. Comprehensive approach to the patient and the family by a multidisciplinary team including at least taking care of the physical, emotional, social and rehabilitation needs of rheumatic diseases.

The comprehensive approach to the patient and the family in rheumatic diseases constitutes an essential quality standard when measuring the impact on the quality of life. This has been stated by the jury members,

who believe that there is still much to be done to respond in a comprehensive and coordinated manner to the needs of people living with rheumatic diseases in the Pan-American region.

“Comprehensive approach to the patient and the family about rheumatic diseases by a multidisciplinary team”.

“The social needs can be also covered by the group of patients”.

“The recognition of disability is very important”.

The jury members emphasize 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.

For many patients with an associated disability, rehabilitation therapies are fundamental and currently offer a number of benefits that improve the quality of life of the patient and his family environment.

A proper follow-up implies consultation with other clinical specialties that will intervene according to the evolution of the disease. It is also essential, as mentioned by different jury members, that patients have good self-care and take a more active role in the management of their disease.

Comprehensive treatment must also provide the tools that allow the patients to continue having a normal life as possible, and for this it is essential that rheumatic patients can receive psychological support, if needed. Another fundamental aspect is related to working life and the opportunities to remain working according to the functionality and possibilities of each person.

“Provide the conditions for the patient to be able to interact within



II Pan-American Patients Congress with Rheumatic Diseases. Quito, Ecuador, April 2019

his environment and continue to be useful at work”.

Guaranteeing access to specialized multidisciplinary teams is one essential condition for increasing therapeutic possibilities and having less associated disability and a greater possibility of access to work and active life opportunities for rheumatic patients.

5. Identify and recognize patient organizations as reference points in relation to information, education, monitoring of needs and advocacy for the rights of rheumatic patients and their families.

The jury members expressed the great contribution that patient



Dr. Carlo Vinicio Caballero with Priscilla Torres, first patient named as President of the II Pan-American Congress of Patients with Rheumatic Diseases.

organizations make, not only to the patients, but also to society in general through the different tasks they perform. On the one hand, there are the awareness-raising actions and campaigns that are generated throughout the year with different rheumatic diseases.

These organizations also carry out informative work, accompanying patients and families, from the suspicion

of the diagnosis and throughout all phases of care, rehabilitation and reintegration into the labor market. In many cases, they organize dissemination days with the collaboration of specialists, in order to delve deeper into matters of interest to the patients or to offer updates on the latest healthcare developments in these diseases.

“The State must, through doctors, be involved in and support patient education”.

“Promote the formality of health education and empowerment”.

“The health system must recognize the work of organizations in self-care education for patients and caregivers and activate the system of joint collaboration”.

The jury members also considered the patient organizations as references in education. The activities organized by these organizations and the selfless work of the volunteers promote the formation of informed patients who

are committed to the treatment of their disease and who are able to anticipate risk situations by consulting professionals. They fight the stigma of the disease and the isolation and increase empathy and resilience among the patients.

On other occasions, patient organizations stood up in defense of the interests of those affected and their families, in situations of lack of access to treatment or situations of employment discrimination, unjustified dismissal or access to benefits related to rehabilitation or disability.

In many cases, patient organizations also offer professional services related to psychological assistance or the development of activities for the control of emotions and well-being, such as yoga, relaxation and leisure and recreation activities, such as painting, drawing and other artistic activities.

This silent and tireless work deserves to be recognized and valued, and this is what the jury members claim. Highlighting the important work done by patient organizations and giving it visibility is an act of justice and a strategy to increase the therapeutic possibilities of those affected

and better coordinate efforts together with care centers, specialists, government policies and the optimization of available resources.

6. Protect the labor and educational rights of people with rheumatic diseases for adults, youth and children.

The protection of labor rights for adults affected by rheumatic diseases is essential, albeit highly complex. In this sense and considering the difficulties that exist in the reinsertion into the labor market, many of the patient organizations count on the collaboration of specialized lawyers who can advise people in cases of conflict.

Work reintegration in rheumatic patients should be approached in a multidisciplinary context, in such a way that the patient can normalize his activity at work as soon as possible, with a targeted support, avoiding the great impact that the disease has in this area. Currently, the Pan-American regions face a great challenge in this context, since the obstacles and difficulties in reintegrating the person into the workplace are complicated and difficult to overcome.

“Protect the labor rights of rheumatic patients”.

“Many employees are not promoted in their jobs due to their condition”.

“Ask the government to develop policies aimed at preserving the job or reinsertion due to disability caused by rheumatic diseases”.

In a similar situation happens in the field of education. Children suffering from rheumatic diseases from an early age, in addition to the difficulties in detection, face obstacles accessing to specialized care tailored to their needs. The work of patient organizations in these cases is also aimed at carrying out information and training work with the educational entity so that teachers can offer the best learning opportunities for these children. Their task is also aimed at the child's environment, at their peers, at how to avoid situations of discrimination and isolation.



Leading patients of the II Congress of Patients with Rheumatic Diseases. Quito, Ecuador, April 2019.

“Today, the world of health recognizes the importance of parental support in the management of chronic diseases”.

Educational programs and social support are also address to the parents of these children who in many cases are alone and lacking the necessary information to face these challenges.

7. Ensure access to health technology for the population with rheumatic diseases.

Patient organizations have the responsibility to participate in decision-making processes regarding access to new technologies. The leaders' participation makes it possible to represent the patients' needs and to democratize health. Although the

opportunity for participation is still scarce in the governments of the region, some countries are incorporating the patients' vision, and this is the challenge that the other countries will have to assume.

“Health technology refers to medicines, innovation and therapies”.

“Access to the required therapies”.

In order to understand these processes, it is essential that both leaders of patient organizations are prepared and aware of what is expected of them and that government agents can systematize in an orderly manner the insights and evidence provided by leaders of patient organizations.

The jury 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.

8. Including patient organizations in decision-making related to public policies and mechanism for civil participation.

For the jury members, it is clear that there is a need to activate permanent mechanisms for participation in decision-making related to public policies, especially in the area of health. While it is a reality that not all the governments of the different countries at the Pan-American region are prepared to assume this challenge, it is true that it constitutes a form of democratization of health and a way of guaranteeing the governability of the system.

In this sense, there is an international tendency to include the insights and priorities of patients in decision-making related to the strategies for tackling the different diseases. What better, then, than to guarantee the participation of the leaders of patient organizations that fully know the problem in each country, each micro-reality

and that can represent the priorities of patients and caregivers.

“Today, patient organizations are perceived to be outside the health system”.

“Instruct rheumatic patient organizations in decision-making related to public policies and mechanisms of civil participation”.

Regarding this aspect, organizations are also aware that they must receive training in order to effectively optimize participation. Leaders can not only be a vehicle for these needs, but also feel prepared to offer alternative solutions and get involved in them and collaborate with the different agents involved.

9. Promote strategic alliances with scientific societies, academy, governmental bodies and other organizations and foundations, for shared decision-making.

The leaders of the patient organizations perceive that there are many actions that are poorly coordinated and that efforts could be optimized if there were a more fluid collaboration

among the different actors involved in the detection, diagnosis and care of people living with rheumatic diseases.

“Promote strategic alliances between public health systems and patient organizations aimed at education and communication and strengthen the empowerment of rheumatic patients”.

“Working coordinately with scientific societies, academy and similar organizations to ensure the best possible quality of life in rheumatic diseases”.

The jury members recognize the need for closer strategic working alliances, for example, with scientific societies and universities. Both are the pillars of good patient follow-up, and it is there that patient organizations can promote community impact and the reinforcement of strategies that are recommended to individual patients.

Many of the strategies that are being implemented today would have a greater impact if the actions were planned in a transversal manner and with the support of the different

parties involved. In this sense, academia and researchers are also called upon to be closer to the real needs of patients and the community in general. In this respect, patient organizations also collaborate in the socialization of knowledge and can facilitate the understanding of the research area with language that seems complex, so that they are closer to patients' interests.

10. Activate joint collaboration strategies in order to ensure the work of patient organizations as a referent in self-care education to rheumatic patients.

The role of patient organizations in the area of education and empowerment is increasingly recognized. In this sense, it is known that patients who can take good self-care improve their quality of life, increase adherence to treatments, are able to incorporate healthy lifestyle habits and prevent acute crisis situations with good follow-up with the specialist. This is how active patients, according to the available evidence, have better health results, while producing a lower cost to the system.



One of the main concerns identified by patient organizations leaders in each country was the need to provide more information to the general population about the symptoms of rheumatic diseases.

“Promoting formality in health education and empowerment”.

“Include patient organizations as a referent in the self-care support of rheumatic patients, relatives and caregivers”.

The educational actions of the organizations tend to promote empowered patients, more aware of their own

condition and with an active role in their healthcare. Empowered patients better organize their visits and treatment plan; they also actively collaborate with the professionals who treat them.

It is worth noting that educational actions carried out by patient organizations do not have as their main objective an exhaustive knowledge of the condition at clinical level, but rather the fact of living with these diseases on a daily basis qualifies them to provide everything related to the experience of having said diseases.

These actions are complementary to therapeutic education, traditionally carried out by nursing staff and, in any case, they intend to replace the educational actions made by specialist

at individual level when treating with each patient.

In this sense, it would also be very beneficial, as already implemented in some countries, a closer relation between health professionals, scientific societies and patient organizations. A clear example of that is the PANLAR group “Juntos”, a strategy of good practice that should be spread at national and subnational levels in the countries of the Pan-American region.

11. Implementing the necessary actions to guarantee the access to pain treatments and palliative care.

In relation to the care of patients affected by rheumatic diseases, who often live with pain and fatigue, it is important to ensure pain management. In this sense, pain management should be part of the patient’s comprehensive care.

“Many children and young people require recognition of their condition, as well as the degree of pain and disability that rheumatic diseases produce”.

The jury members also highlighted the importance of providing palliative care to both adults and young people

in need. In this sense, the comments were aimed at offering the conditions for a final phase respecting the comfort and dignity of the patient.

12. Protect children and young people affected by rheumatic diseases and guarantee all the points specified in the Pan-American Manifesto

During the discussion in the different stages of development of the PAMRD, the jury members draw attention, in each of the themes, to the needs of children and adolescents. Each of the principles that are presented and that refer to the need for more information to the population, more training to professionals for detection, need for timely diagnosis and appropriate treatment, as well as comprehensive care and education of the patient, should be considered in a special way for children and young people with rheumatic diseases including their parents and teachers.

“Rheumatic diseases affect a large number of children and young people that required an early diagnosis”.

“Access to appropriate, timely and effective treatment”.



Participants of the II Pan-American Congress of Patients with Rheumatic Diseases, Quito, 2019

“Diagnosis and timely transition for them”.

“All the points above are valid for children”.

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.

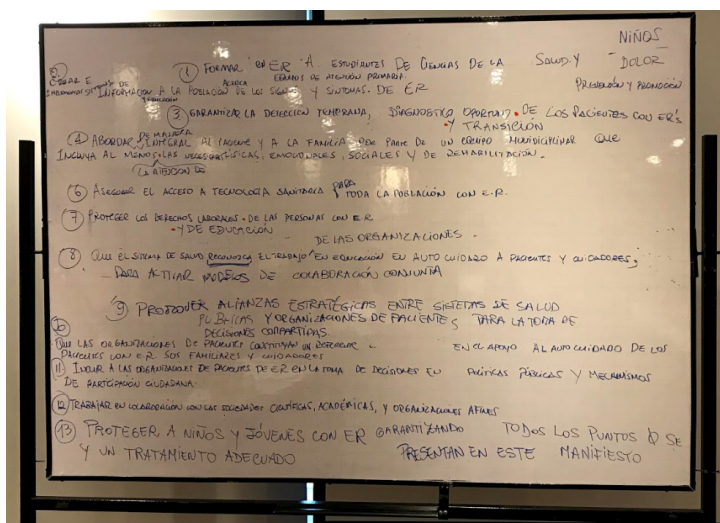
The principles presented in the PAMRD, constitute a call to all actors involved in the care of people living with rheumatic diseases in order to improve detection strategies, care, and thus design care itineraries that can better respond to the needs of patients and their families.



The PAMRD is a call to action and an instrument to improve health policies in the different countries of the region.



At the end of the elaboration of the *Pan-American Manifesto for Rheumatic Diseases*, leader's session, this image remained as a memory of the work developed. Quito, Ecuador, 2019.



The PAMRD emerged from the breakdown of all aspects addressed by the leaders. This image is a trace of the work done.



PAN-AMERICAN MANIFESTO ON THE CARE NEEDS OF PERSONS AFFECTED BY RHEUMATIC DISEASES

The PAMRD on the care needs of people having rheumatic conditions was drafted once the jury ended deliberations behind closed doors and addressed the topics explained in the previous chapter.

The manifesto is structured in 12 points that range from early detection and diagnosis by the specialist, to the need for access to comprehensive treatment of the diseases and a guarantee of improved cooperation and participation among all agents involved, in other words, among scientific societies, public policy makers and patient organizations, to devise strategies that improve the quality of life of those affected with these conditions throughout the Pan-American region.

The PAMRD comprises the following points:

1. Create and implement information and education systems for the general population on the signs and symptoms of rheumatic diseases.
2. Educate and train students of health sciences and primary healthcare teams on rheumatic diseases to improve the chances of early detection.
3. Ensure early detection, timely diagnosis and transition to the specialist of patients with these diseases.
4. To comprehensively address the patient and the family by a multidisciplinary team that includes, at least, the attention of the physical, emotional, social and rehabilitation needs of people with rheumatic diseases.
5. Identify and recognize patient organizations as referents in relation to information, education, follow-up of needs and defense of rights of patients affected by rheumatic diseases and their families.
6. Protect the labor and educational rights of people with rheumatic diseases for adults, youth and children.
7. Ensure access to health technology for the population suffering from rheumatic diseases.
8. Include patient organizations in decision making in public policies and citizen participation mechanisms.
9. Promote strategic alliances with scientific societies, academia, government entities and other related organizations and foundations, for shared decision making.
10. Activate joint collaboration strategies to ensure the work of patient organizations as a reference in self-care education for patients with rheumatic diseases.
11. Implement the necessary actions to guarantee access to pain treatments and palliative care.
12. Protect children and young people affected by rheumatic diseases and guarantee all the points specified in this manifesto.

The PAMRD was drafted, signed and endorsed by over 30 patient organizations representing different rheumatic diseases, from different countries of the region, as presented in Table 2.

Table 2. Patient organizations that endorse the Pan-American Manifesto for Rheumatic Diseases.

	Name	Association	Country
1	Ana Lucia Silva Marçal	Grupo de Apoio ao Paciente Reumático de Ribeirão Preto	Brazil
2	Ana María Acosta	Clamar Artritis Reumatoidea	Uruguay
3	Ana Parra Rodríguez	Pacientes Confm	Venezuela
4	Andrea Stefania R. Lopes	Funcrea AR - Artritis	Ecuador
5	Carlos Eduardo D. Tenório	Associação Brasileira Superando o Lúpus	Brazil
6	Carlos Miguel Vélez	Fundación Un Paso de Fe para Pacientes con Artritis Reumatoide	Dominican Republic
7	Carmen L. Macias Garcia	Fundación Ecuatoriana de Ayuda Paciente Reumático	Ecuador
8	Catia Domínguez Figueredo	Associação de Pacientes com Doenças Reumáticas do Estado do Rio de Janeiro Recomeço	Brazil
9	Cecilia Rodríguez Ruiz	Fundación Me Nuevo	Chile
10	Daniel Hernández	Creaky Joints	United States
11	Emma Pinzón de Torres	Fundación Nacional de Artritis Reumatoide de Panamá	Panamá
12	Eunice Beatriz Parodi	Alianza Federal (Amar Posodor)	Argentina
13	Evelyn Roxana	Psoriasis Nueva Vida El Salvador	El Salvador
14	Farah Haydee Ducasa	Fundación Nacional de Artritis Reumatoide de Panamá	Panamá
15	Gabriel R. Orihuela	Fundación Pacientes Ecuador	Ecuador

Continúa

16	Gina Sicilia Ochoa Galeano	Fundación Colombiana de Apoyo al Paciente Reumático	Colombia
17	Glenda Chávez	Funda Lupus El Salvador	El Salvador
18	Gonzalo Canizo	Agrupación Lupus Chile	Chile
19	Jessica Knezerich Pilay	Asociación Ecuatoriana de Pacientes Reumáticos	Ecuador
20	Marco Aurelio Azevedo	Grupo de apoio ao paciente reumático do Ceará	Brazil
21	María Andrea Defeo	Clamar Kids	Uruguay
22	María Mercedes Rueda	Fundación Colombiana de Apoyo al Paciente Reumático	Colombia
23	Myrna González de Castilho	Artrilup	Guatemala
24	Narcisa López	Funcrea Artritis	Ecuador
25	Priscila Torres da Silva	Grupar-RP/EncontrAR	Brazil
26	Tini Jordan	Artritis Alianza Federal	Argentina
27	Verónica Flores León	Asociación Esclerodemia Ecuador	Ecuador
28	Verónica Molinar Robles	Asociación de Lupus y AIJ Caminanda Santos A. C.	Mexico
29	Wanda Heloísa Rodríguez	Instituto Gruparj Petrópolis	Brazil
30	Yari Pacheco Hernández	Fundación Yanye y Still	Venezuela

PILOT COURSE “FORMADOR DE FORMADORES”, FORMED BY PATIENTS AND PHYSICIANS. PACIENTE EXPERTO PANLAR PROGRAM. PANAMÁ, NOVEMBER 2019



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



Participants of the “Formador de Formadores” Pilot Course.



Together, patients and health professionals, we will work to increase the competencies of patients and caregivers in the self-care of rheumatic diseases.



Aspects of the workdays development.



Doctors from the
PANLAR Paciente
Experto Program.



PANLAR Paciente Experto & Grupo
Juntos executive committee.



CONCLUSIONS AND FUTURE CHALLENGES

As an overall conclusion of the study, the report presents a challenging scenario for the Pan-American region summarized in the five strategies mentioned below:

1. Make rheumatic diseases a priority in public policy and development of a national strategy.

In countries with decentralized health systems there is a wide variation in the treatment, since they are governed by diverging rules and patterns. The integrated approach of rheumatic diseases requires an appropriate measurement of the impact these diseases have on the quality of life of patients and the productive capacity of a country as well as the conviction to tackle the issue as described by the international recommendations (European Commission, 2011; Woolf, 2012).

Providing a national strategy to address these conditions implies being able to establish not only how health



care should be articulated, but also the resources and inputs needed to carry them out, availability of specialists, capacity and distribution of facilities, identification of underserved areas, as well as the availability of diagnostic methods and infusion centers. To have a national strategy that determines a more uniform planning to counteract inequalities of health care and access, as has been done in other countries such as Spain (Ministry of Health, Social Services and Equality, 2013).

2. Comprehensive care by a multidisciplinary health care team in specialized centers.

Rheumatic diseases encompass a range of systemic diseases that require comprehensive care by a

Patient organizations systematically collect the needs and preferences of patients and their families and act as spokespersons in front of healthcare bodies.

multidisciplinary team, making possible to ensure its proper monitoring, as well as the prevention of situations of comorbidity and affection of other organs. It is necessary to be attentive to the patient's signs and symptoms, to make the referral to the appropriate specialist. A needs-based health care is thus needed for patients under continuous monitoring, who

may present other comorbid chronic diseases (Epstein, Fiscella, Lesser & Stange, 2010).

Currently, experiences and good practices can be found in literature such as the clinics of excellence, a model that considers the direction of the rheumatologist and the coordination of other specialists, including specialists in rehabilitation, nutrition and psychology, and so on. This type of models has proved to have a positive impact on patient follow-up, an increase in quality of life and the prevention of chronic situations or situations arising from inadequate control of the disease (Santos-Moreno et al., 2015).

3. Universal Access to health

In order to ensure equity and equal opportunities for patients affected by rheumatic diseases, it is necessary to guarantee timely detection and access to available treatments, regardless of the place of residence, following the line of work being developed by the World Health Organization (WHO) (UHC2030, s. f.).

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 foster active patients involved with self-care (Pineda y Caballero-Urbe, 2015).

Rheumatic diseases must be a priority in public health, since the impact on the patient of the lack of access to adequate treatment can have irreversible consequences related to disability (Massardo et al., 2009).

4. The importance of the patient organizations on patient education.

An active, informed, responsible, empowered patient, who is involved in decisions regarding his health and is committed to his illness may have better self-care. It has been proven that an active patient not only has better health results and adherence to treatments, but also makes better use of available health services, which



With great enthusiasm, patients and doctors will continue to meet until public health policies take rheumatic diseases into account as a priority.

implies lower health expenditure (Hibbard & Mahoney, 2010; Moreno-Chico et al., 2017).

The patient should be the first to know about his disease, the extent of it and the basic care he should have. In order to do so, he must be informed and assume responsibility, with all the importance that this entails and the benefits that it provides. This task should be recognized and articulated with the different organizations and institutions (Escorcia et al., 2006).

Patient organizations help patients and their relatives to learn first-hand about scientific advances related to

their disease, to share their experiences with their peers and to learn about it, which results in very important contention from a different point of view. These organizations must continue to promote patients' rights and provide evidence about their needs, their families and the impact of the condition on daily life. In this sense, patient organizations, such as those members of ASOPAN, must play a transcendental role, not only for the patient and his family, but also for society in general (Kickbusch & Gleicher, 2012; Sienkiewicz & Van Lingen, 2017).

Patient organizations systematically collect the needs and preferences of patients and their families and act as spokespersons in front of health-care bodies. The participation of patients in health decision making is also conveyed thanks to the leaders who represent this voice. The challenge for organizations is to contribute to the generation of evidence by being spokespersons for the experience of getting a rheumatic disease (Richards, Montori, Godlee, Lapsley & Paul, 2013).

5. Systematic participation of patients in public policies

Patients and citizens as users of the health system and as taxpayers are called upon to participate in decision making regarding health policies and strategies (Epstein et al., 2010; Florin & Dixon, 2004).

The needs of the rheumatic patients must be a priority in the health agenda of Pan-American countries and transcend the diversity of the organization and the structure of the systems. It is necessary to work in a coordinated manner among all committed agents, rheumatology professionals, scientific societies, health authorities and patient organizations.

Governments and those in charge of strategies for dealing with rheumatic diseases must identify how to correctly detect this disease and offer continuous treatments that ensure the anticipation of major complications (Pineda y Caballero-Urbe, 2015).

In European countries, such as Spain, in addition to having clinical practice guides, health systems have strategies to incorporate rehabilitation as an essential component of comprehensive care and thus direct their actions at all levels of the systems related to disability management and ensure patients the best living conditions.

In this context, Latin America lives a different scenario, there is still an area of opportunity for disability evaluation systems and difficult obstacles to overcome concerning the agencies that evaluate them, as well as delays and a lag on timely and adequate rehabilitation care, according to the resources available, which distances us from what should be comprehensive health care in the management of disabilities. (Ministry of Health, Social Services and Equality, 2013; Vázquez y Cáceres, 2008).

Modern health systems must provide environments that guarantee the democratization of health allowing so that the needs and priorities of patients, represented in the leaders of their organizations, can be

transferred. Joint work is needed on the design of strategies strictly in accordance with the way patients expect to be treated (Arrighi et al., 2015; Weil, 2016).

Patient organizations help patients and their relatives to learn first-hand about scientific advances related to their disease, to share their experiences with their peers and to learn about it, which results in very important contention from a different point of view.



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ATTACHMENTS

Attachment 1. Work schedule

Salón CIPRESES

27 DE ABRIL DE 2019

Actividad con Pacientes Líderes



Horario	Tema	Médico	Paciente
08:00-08:30	La educación en salud como un apoyo complementario a la salud	Dr. Carlo Vinicio Caballero	Conferencista: Priscilla Torres
08:30-08:45	¿Por qué educar a los pacientes?	Fernando Rodríguez AE	Moderador: Gonzalo Tobar Carrizo
08:45-09:45	Mesa redonda: ¿Qué enseñar y quién debe enseñar?	Dr. Carlo Vinicio Caballero Dr. Daniel Hernandez Dra. Emilia Arrighi	Carmen Macias
			Cecilia Rodríguez
			Enma Pinzón
			Fernando Rodríguez
			Gina Ochôa
			Jessica Knezevich
			Maria Veronica Flores
			Priscilla Torres
Tini Jordan			
09:45-10:30	Centros de excelencia: un modelo de atención integral a las enfermedades reumáticas	Dr. Enrique Soriano	Moderador: Gina Ochôa
		Dr. Carlo Vinicio Caballero	
		Dr. Pedro Santos	
10:30-11:00 Coffee Break			
11:00-11:30	Patient Advocacy ¿Qué es un paciente experto?	Dra. Emilia Arrighi	Priscila Torres
11:30-12:00	Las escuelas de pacientes y la importancia de su acompañamiento en el tratamiento de la enfermedad y empoderamiento del paciente	Dra. Emilia Arrighi	Cecilia Rodríguez
12:00-13:00	Experiencias y Estrategias para implementar escuelas de pacientes en América Latina. Proyecto Paciente Experto PANLAR	Dra. Emilia Arrighi	Cecilia Rodríguez, Tini Jordán, Teresa Mártez
13:00-13:45 Intervalo			
13:45-14:30	Estado de las Enfermedades Reumáticas en la región panamericana Dr. Carlo Vinicio Caballero		
14:30-16:30	Manifiesto de los pacientes con enfermedades reumáticas panamericanos		
	Dirección general: Dr. Carlo Vinicio Caballero Dra. Emilia Arrighi Priscila Torres Cordinación general: Dra. Ana Paula León Representante Grupo Juntos Dra. Dora Pereira	Comité de pacientes líderes Carmen Macias Cecilia Rodríguez Dr. Daniel Hernandez Enma Pinzón Fernando Rodriguez Gina Ochôa Jessica Knezevich Maria Veronica Flores Priscilla Torres Tini Jordan	
16:30-17:00 Coffee Break			
17:00-18:00	Coaching: Comunicación eficaz para una mejor gestión Alcances y tipos de comunicación para evitar conflictos y lograr los objetivos propuestos	Lic. Estela Reyes – Lic. Leila Lipsky	
18:00	Conclusiones		

Attachment 2. Patient information sheet

Participant information sheet

A qualitative study called the *Pan-American Manifesto is being conducted on the needs for care by people suffering from rheumatic diseases*, with the objective of determining what the needs for care are for patients suffering from rheumatic diseases in America.

To achieve this goal, a group activity shall be carried out following the focus group technique. You have been invited to participate in the discussion group to share the information you have on the situation of patients in your country or region.

The session will be approximately two hours long and be moderated by an expert researcher. In order to capture the details of the information you provide us with, the session will be audio recorded.

We remind you that participation in this study is voluntary and that you may withdraw at any time you deem appropriate. Your personal data and the information you provide us with will be kept confidential for all persons outside the research team, shall be used solely in relation to the study's objective and applicable international declarations shall be observed (Nuremberg Code of 1947, the Helsinki Declaration of 1964 and the Tokyo Declaration of 1975).

Thank you for your cooperation

NAME AND LAST NAME:

ID:

Place and date

.....

SIGNATURE



Attachment 3. Patient jury script

Research script

1	Needs related to detection and diagnosis	<ul style="list-style-type: none"> What is the current situation in the detection process of rheumatic diseases? What level of knowledge do you think society has on this type of diseases? What obstacles are faced during diagnosis? What improvement strategies could be implemented in this regard?
2	Needs related to clinical care	<ul style="list-style-type: none"> What deficiencies occur during clinical care? How should the assistance required by patients look like and what professionals should be included in the team? The patient participates in the decisions concerning the treatment. Do you think pain management is correctly monitored? What needs arise during rehabilitation and during check-ups? What strategies are required to deal with disability? What instruments can help identify the population and its needs during the different phases of assistance? Do you believe there is a good monitoring of pain management? What happens when a person is diagnosed with a rheumatic disease? How does that person's life continue? Based on your knowledge, are there changes in the relationship with their couple?

3	Psychological, emotional/spiritual needs	<ul style="list-style-type: none"> What feelings overcome the person? What emotional barriers arise? What factors help you be better? How does the disease impact the family and the principal caregiver?
4	Social and work needs	<ul style="list-style-type: none"> Is the persons social life affected? What are the needs you have identified? Impact on the work environment and on work colleagues.
5	Educational and empowerment needs of patients	<ul style="list-style-type: none"> What role do patient organizations play in the empowerment and active attitude of patients before the disease? Importance of patient schools and the training on self-care.
6	Patient organizations role	<ul style="list-style-type: none"> What strategic role must be played by patient organizations to improve the quality of care of people suffering rheumatic diseases? Is a collaboration relationship with scientific societies required?
7	Quality of life and improvement strategies	<ul style="list-style-type: none"> What are the key recommendations to better care for the needs of those suffering rheumatic diseases and of their informal caregivers?
8	Public policies	<ul style="list-style-type: none"> What is required in relation to strategies and national health plans to respond to an integral care of rheumatic diseases?

PAN-AMERICAN DECLARATION ON HEALTHCARE NEEDS OF RHEUMATIC PATIENTS



CURRENT SITUATION

Rheumatic diseases grouped more than 200 conditions and syndromes that may cause different levels of pain, suffering, disability and poor quality of life.¹

It is estimated that around 52 million people in America live with some type of rheumatic disease.²

The main causes of disability and costs related to these diseases are close to 128 billion dollars per year.²

PURPOSE OF THE DECLARATION

Convey the vision of the patients regarding their needs of comprehensive care and timely diagnosis. The DECLARATION is a call for action and an instrument to improve the health policies in the different countries of the Pan-American region.³



HOW WAS THIS ACHIEVED?

In its development took part more than 30 leaders of rheumatic patient organizations representing the various regions of America, who as experts knowledgeable of the needs of the patients, developed the Declaration through a method known as "citizens' jury".³

PANLAR

The Pan-American League of Rheumatology Associations, founded in 1944, integrates rheumatology scientific societies, health professionals related to rheumatic conditions and rheumatic patient groups from all countries of the Americas.



ASOPAN

The Pan-American Network of Rheumatic Patient Associations arises from the patient leaders' meeting in the 20 PANLAR Pan-American Congress of Rheumatology. 35 patient associations now belongs to ASOPAN, which is organized in four geographic areas of the American continent. Each region has a regional representative.

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PAN-AMERICAN DECLARATION ON HEALTHCARE NEEDS OF RHEUMATIC PATIENTS



Implement the necessary actions to ensure access to pain treatments and palliative care.



Comprehensively addressing the patient and his/her family, with the participation of a multidisciplinary team including at least the attention of the physical, emotional, social and rehabilitation needs of RD.



Ensure access to health technology for population with RD.



Identify and recognize patient organizations as referents in relation with the information, education, monitoring of the needs and defense of the rights of rheumatic patients and their families



Protect the working and educational rights of the people with RD for adults, youths and children.



Protect children and youths affected by RD, ensuring all the points specified in this declaration.



Include patient organizations in decision-making processes regarding public policies and mechanisms of citizen participation.



Establish and implement information and education systems for the general population about signs and symptoms of rheumatic diseases (RD).



Guarantee early detection and timely diagnosis and referral to the appropriate specialist.



Activate joint collaboration strategies to ensure the work of the patients organizations as referents of education in selfcare to patients with RD.



Promote strategic alliances with scientific organizations, academy, government bodies and other organizations and related foundations for shared decision making.



Educate and train health science students and primary care teams on RD, in order to increase the chances of timely detection of these diseases.



[#PanlarSomosTodos](#)

[#CaminemosJuntos](#)

2019