

DECEMBER 2020

# LATIN AMERICAN PATIENT ADVOCACY SUMMIT





# DAY ONE

**The Global Alliance for Patient Access hosted its 5th Annual Latin American Patient Advocacy Summit virtually October 21-22, 2020, bringing together patients, advocates, clinicians and experts from across Latin America, the United States and Europe.**

The first day's meeting welcomed 45 patient representatives from BIONETWORKS across Latin America. Attendees represented various disease states, including rheumatology, oncology, rare disease, dermatology and autoimmune diseases.

The meeting sought to:

- Strengthen collaboration
- Share best practices
- Build a common agenda to address ongoing challenges



## Presenters & Topics

### **Eva Maria Ruiz de Castilla**

*Strategic Advisor, Global Alliance for Patient Access, Latin America*

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### **Arturo Loaiza-Bonilla, MD**

*Chairman, Global Alliance for Patient Access*, welcomed participants. They encouraged participants to use the meeting for an in-depth discussion of biologics and biosimilars in Latin America.





### **Dr. Gilberto Castañeda**

*Clinical Pharmacologist, CINVESTAV*, updated the attendees on the current status of biologics, biosimilars and copy attempts in Latin America. He explained that copy attempts continue to threaten patient health and safety in the region and that efforts must be made to stop the commercialization of these products. That requires countries to implement a robust pharmacovigilance system, ensuring the safety and efficacy of medications for patients.



### **Dr. José Josán**

*UPCH Peru*, addressed biologics, biosimilars and interchangeability. He explained that biologics are considered complex drugs due to their size and the number of atoms they contain. No two biologic drugs are exactly the same, he explained, but rather considered to be biosimilar. Dr. Josán emphasized that the most important element for both biologics and biosimilars is the safety of the product.

Dr. Josán explained interchangeability, a regulatory term, which is defined by the regulatory agency of each country. The consequences of interchangeability, he explained, can be policies such as non-medical switching and automatic substitution. Both can be disruptive to a patient's treatment process.

Presentations were then given by representatives of the six BIONETWORKS: **BIORED CAC, BIORIED MEXICO, BIORIED COLOMBIA, BIORIED PERU, BIORIED BRAZIL, and BIORIED SUR** chapters from Argentina and Chile. Each representative provided an update on the COVID-19 pandemic's impact on access to treatment for their patients. They also highlighted what they were doing as a network to collaborate and look for solutions.





# DAY TWO

## Presenters & Topics

The second day's events welcomed patients, clinicians and disease-specific organizations to discuss the challenges and opportunities that health care systems may face in a post-pandemic future.



### **Brian Kennedy**

*Executive Director, Global Alliance for Patient Access*

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### **Eva Maria Ruiz de Castilla**

*Strategic Advisor, Global Alliance for Patient Access, Latin America* welcomed attendees and provided a brief overview of GAFPA.

The first panel of the day, **The Future of Health Care Systems in Latin America**, explored the COVID-19 global pandemic's impact on the health care systems in Latin America and lessons learned for the future.



### **Dr. Maria del Carmen Calle**

**Executive Director, ORAS-CONHU**, talked about how the pandemic brought to light many of the structural inequalities in the health care system. It also has brought health care to the forefront for policymakers, providing a unique opportunity for stakeholders from different areas to come together to find solutions. Dr. Calle encouraged participants to embrace the opportunity and work together to find sustainable solutions for the long term.



### **Dr. Diana Cárdenas**

**Director, ADRES**, reiterated how the COVID-19 pandemic has heightened awareness of the determinants of health, showing how different regions have been impacted in different ways. Dr. Cárdenas noted that Latin America has the unique advantage of already having substantial cooperation among countries, and that advocates should leverage this cooperation to find policy solutions. Dr. Cárdenas also emphasized the need to plan for potential future pandemics.



### **Dr. Julio Valdez**

**Advisor, Management of the Guatemalan Social Security Institute**, urged collaboration toward a common goal – across multiple areas and sectors, not only the health sector. Dr. Valdez noted that the opportunity to collaborate and find solutions to gaps in the health care systems has always existed, but now the pandemic has brought it to light. He encouraged participants to work together as a region, bridging the gaps between different political areas, to address all the ways the pandemic has impacted Latin America.

The second panel of the day, **Challenges and Opportunities for Health Systems Post-Pandemic**, examined current best practices for regional and international organizations, as well as the challenges that countries will face as they recover from the pandemic.



### **Dr. James Fitzgerald**

*Director, Health Systems and Services, PAHO/WHO*, detailed what the Pan American Health Organization and World Health Organization have been doing at the international level to address the pandemic. Both groups have looked at the short-term needs, helping to mobilize personal protective equipment at the global level and establishing joint purchasing systems for COVID-19 tests. The two groups have also looked to long-term needs, such as analyzing the impact of COVID-19 on social services such as the treatment of cancer care. Dr. Fitzgerald noted that, when countries begin to transition out of the COVID-19 pandemic, patient groups will have a fundamental role in advocating for access to necessary care and ensuring that patients are not overlooked as health care systems get restructured.



### **Mar Martinez**

*Health Officer, Directorate General for International Cooperation and Development, European Commission*, reinforced the important role that patient groups have in strengthening health systems, both now and after the pandemic. Ms. Martinez noted that patient groups can hold policymakers and health systems accountable, making sure they respond to the real needs of the population. By cultivating relationships with policymakers and other health care decision makers, patient groups can help inform decisions about integral services based on the needs of patients and the public.



### **Dr. Rubén Torres**

**Rector, University ISALUD**, made the point that many of the problems brought to light by the pandemic actually already existed. From an academic perspective, Dr. Torres explained, there needs to more incorporation of preventive medicine and health care, and a greater demand for accountability. Dr. Torres reiterated the important role that patient groups have in establishing the priorities for public systems, making sure that patients have an active role and making sure that optimal health is a priority.



### **Dr. Michael Reich**

**Research Professor of International Health Policy, Department of Global Health and Population, Harvard T.H. Chan School of Public Health**, focused on confidence in health systems. Dr. Reich explained that the pandemic has reduced confidence, which is often difficult to rebuild. People no longer trust public information regarding health care, Dr. Reich argued, referring to skepticism about vaccines and arguments about wearing face coverings to prevent COVID-19 transmission.

Maintaining a sustainable health care system requires confidence in preventive measures, Dr. Reich emphasized. Patient groups are in a strategic position to increase confidence, helping to provide and share education and information to their patient populations.





The final panel of the day, **The Responses of Patient Groups During the Pandemic**, explored best practices and the initiatives that patient groups have put in place since the pandemic to assist their patient populations.



### **Edith Grynszpancholc**

**Founder and President, Fundación Natalí Dafne Flexer, Argentina**, talked about the work her organization has done since the pandemic to support children with cancer, their patients and their families. The group's main goal was to remind policymakers that children with cancer cannot wait for access to their treatment. Members decided to bring together different cancer patient organizations from throughout Argentina, hosting periodic meetings, and eventually establishing a proposal for changes to the health system.



### **Regina Prospero**

**President, Instituto Vidas Raras, Brazil**, discussed how, at the beginning of the pandemic, her organization worried about how it would support rare disease patients. The group's first step was to provide educational materials in various languages, including a guide explaining in simple language what the pandemic was and how patients could keep themselves safe. Through their advocacy efforts, the group succeeded in getting home infusion for many of the rare disease patients, allowing them to continue with their treatments without leaving home and risking COVID-19 exposure.



### **Denis Silva**

**Spokesman, Pacientes Colombia**, laid out the lessons that his organization had learned from the COVID-19 pandemic. One was the need to reinforce networking and collaboration. By working together with other health care stakeholders, members were able to participate in the dissemination of draft resolutions and decrees that were published during the pandemic.





## KEY THEMES

The day's presentations and discussion centered on several main ideas.



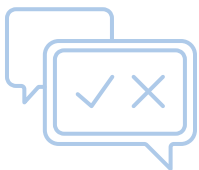
### **Strengthening Collaboration**

Addressing current challenges requires strengthening collaboration efforts and relationships among stakeholders. These relationships should span across the region, disease states and stakeholder groups, bringing together policymakers, patient advocates, topic experts, industry and academia. The goal is to foster an active, engaged network across Latin America and that shares best practices.



### **Pharmacovigilance**

Strong pharmacovigilance policies are needed to ensure the safety and efficacy of medications. Targeted advocacy tools can help to improve pharmacovigilance programs and regulations.



### **Patient-Clinician Decision Making**

Many of the attendees expressed concern about non-medical switching and automatic substitution. Both policies interfere with the patient-clinician decision making process and can disrupt pharmacovigilance. Patient advocates contend that the treatment decisions need to remain with the patient and their clinician to offer the best chance of success.

## CONCLUSION

The meetings provided a valuable opportunity for stakeholders from different areas of the health care space to come together and discuss how to work together to address and learn from the COVID-19 pandemic. Moving forward, the best practices and recommendations discussed during the virtual event should be implemented and encouraged as advocates work together to address the challenges patients face during the pandemic.

The meeting highlighted the need for continued collaboration, confidence, and a strong involvement by the patient community and patients organizations. The Global Alliance for Patient Access will continue its work to bring these patient organizations together, foster collaborative relationships and provide platforms for important discussions.

*Support for related GAFPA initiatives is provided by Sanofi and Amgen.*



### About the Global Alliance for Patient Access

The Global Alliance for Patient Access is an international platform for health care providers and patient advocates to inform policy dialogue about patient-centered care.



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