Latin American Regional Programme: Mexico, 2013
Organized by the International Alliance of Patients’ Organizations (IAPO)

With our thanks
The IAPO Governing Board and staff would like to thank everyone who supported this event. In particular, we would like to thank Luis Adrián Quráz Castillo and colleagues at Red de Acceso for collaborating on the organization of the local meeting in Mexico City, as well as for their overall support for IAPO’s regional programme in Latin America.

We would also like to thank and acknowledge the sponsors of the event, AbbVie, Novartis and the Pharmaceutical Researchers and Manufacturers of America (PhRMA).

Finally, we would like to thank the IAPO members and all participants and speakers for their commitment, contributions and engagement in the event. Special thanks go to those who were part of the Planning Committee and for their help in developing and framing the event. It was a great privilege to learn more about the important work being done on the ground, and to work closely with you.

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Introduction

On 23 to 25 September 2013, IAPO held the third Latin American regional meeting, forming an important element of our ongoing Regional Strategy. Twenty-one patients’ organizations from ten Latin American countries, 15 local Mexican patients’ organizations and over 70 multi-stakeholders from around the world came together at this meeting in Mexico City to increase their capacity, particularly that of the patients’ organizations, strengthen collaboration between groups, and develop strategies to improve patient-centred access to healthcare in Latin America.

The September programme built on the outcomes of two previous IAPO Latin American regional network meetings, and highlighted the next steps for the IAPO Latin American Regional Strategy in 2014 and beyond. The activities in September included:

- A national level meeting for patients’ organizations from Mexico. This aimed to build strategies to address common issues and to strengthen national patient networks. The meeting of Mexican patients’ organizations was held in partnership with Red de Acceso, a local network of Mexican patients’ organizations who work to promote human rights in healthcare in Mexico. The meeting brought together 15 patients’ organizations from across Mexico, representing seven disease areas.

- A regional healthcare advocacy meeting and reception, with over 70 multi-stakeholder participants, addressing the theme of ‘patient-centred access to healthcare in Latin America’ with a specific focus on non-communicable diseases (NCDs), health technology assessment (HTA) and biological and biosimilar medicines.

- A two-day workshop for patients’ organizations from throughout Latin America with the purpose of working together to build a 2014 action plan, developing joint actions, raising the capacity of patients’ organizations and further strengthening the IAPO Latin American Regional Network. Twenty-one patients’ organization representatives from ten Latin American countries, representing 14 different disease areas, came together for this workshop. The participants were made up of IAPO’s members in the region and other key patients’ organizations.

What was the need?

Prior to these meetings, IAPO conducted extensive research, including consultations, to find out more about healthcare issues in the region. This was done in order to ensure that the issues addressed during the activities were appropriate and relevant to the region.

Non-communicable diseases (NCDs) are long-term, slowly progressing diseases that can create severe complications for those they impact, as well as for wider society. They account for around 35 million, or 63%, of all deaths worldwide and 76% of all deaths in the region of Latin America and the Caribbean.

NCDs have a severe impact on life expectancy and quality of life of patients. Social inequality, and within this unequal access to healthcare, is a large contributing factor in exacerbating NCD risk factors, and Latin America is recorded as having the highest level of social inequality of any region in the world.

Promoting early diagnosis and treatment of NCDs among those more at risk will help to reduce mortality rates and improve quality of life for patients. Collaboration between civil society groups, patients’ organizations, healthcare professionals and policymakers is therefore crucial in raising awareness among the general public about basic prevention measures for NCDs, particularly throughout decision-making mechanisms in healthcare.

In order to ensure that the health systems, medicines, and technologies in Latin America are the best available, it is important that decision-makers, such as government policymakers, implement practices that are informed by the most recent and reputable research. The most common example of this kind of research is health technology assessment (HTA), a method of evaluating medical technologies for their effectiveness, appropriateness, efficiency, safety, cost-effectiveness and other economic and ethical aspects and standards. However, in Latin America, the majority of HTA is conducted by academics, policymakers or industry – and rarely incorporates the views of the patients.

Knowledge and understanding of NCDs from pre- and post-meeting consultation

- Pre-meeting: 60% of patients’ organizations felt that they had some knowledge and only 40% felt that they had good knowledge.
- Post-meeting: 100% stated that the programme clarified and extended their knowledge of NCDs, and that the statistics provided would help them disseminate information to others.

With the growing threat of NCDs to the Latin American region, affordable and safe access to biological and biosimilar medicines is becoming increasingly important. Biosimilar medicines, also known as ‘similar biopharmaceutical products’, are medicines that are highly similar to a biological medicine that has already been approved in terms of quality, safety and efficacy. They are used to treat a range of diseases, including cancer, diabetes, Crohn’s disease and autoimmune diseases.

However, these biological medicines also involve new challenges for healthcare decision-makers due to their higher complexity in structure and function than conventional chemical medicines. It is evident that in certain countries, including in Colombia, Bolivia, Chile, Peru and Mexico, some new biosimilar products have already been licensed before appropriate regulations have been put into place, and without adequate clinical testing. By enhancing their knowledge of the importance and impact of biosimilar medicines, patients’ organizations in Latin America can hope to see improved access to safe, affordable and efficient treatment, and have a stronger voice on healthcare policies and decision-making in their countries.

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Knowledge and understanding of HTA from pre- and post-meeting consultation

- Pre-meeting: 40% of patients’ organizations said they had some knowledge and 20% said they had no knowledge at all of HTA.
- Post-meeting: 70% felt that their knowledge of HTA was extended to the point that they could begin to promote and advocate for the issues. However, 30% stated that they felt they needed further training on the subject.

The HTA that predominantly exists in the region operates on international or European models and guidelines which have been criticised by some for creating policies that are not specific enough to patients’ needs in a variety of regional and national contexts. In a context such as Latin America, where poverty and social exclusion affect millions of people, access to health services and technologies is varied and often limited. As such, there are calls for the HTA of new technologies and treatments – such as biosimilar medicines – to be developed beyond a cost-benefit analysis, and instead to evaluate the quality, safety and efficacy of technologies, as well as their impact on enabling a more fair and inclusive society.

Knowledge and understanding of biosimilars from pre- and post-meeting consultation

- Pre-meeting: 80% of patients’ organizations said they had some knowledge, but no one involved in the survey felt that they had good knowledge of biosimilars.
- Post-meeting: All who answered the post-meeting evaluation felt that their knowledge and understanding of biological and biosimilar medicines was greatly increased, despite the complexity of the topic.

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3 Ibid.
4 Osvaldo Artaza, representative of LAQC.
Case study

Edgar Joel Tapia Escoto,
Tamil Neonatal y Fenilconiutonuria, AC (PKU)

“My son has Phenylketonuria (PKU), a rare disease that was detected at his birth in the USA, although we live in Mexico. I became engaged in the promotion of Phenylketonuria because I realised that in Mexico not enough attention is given to this disease. I am now the President of the AC Tamil Neonatal y Fenilconiutonuria in Mexico (there are only two NGOs working on PKU in Mexico).

Attending the IAPO meeting in Mexico this year was crucial for my understanding of IAPO’s strategy and also for learning from other patients’ organizations in Latin America. Despite my involvement in changing a health law earlier this year, my advocacy efforts are not being taken seriously by the Mexican health authorities. This is why I felt it was important to learn from other organizations in the region and widen my network of contacts. It is necessary for my association to belong to an international network of patients’ organizations so that the Mexican health authorities can see that not only do I have my individual capacity, but I also have the support of IAPO, an international network that is open, serious and morally sound.

During this meeting I learned a great deal about organizational strategy, which will help in moving my objectives forward and differentiating between biological and chemical medication. The latter was something I had no information about before. I will also take my association’s advocacy strategy forward at the national level by arranging forums in universities, to talk on, and promote, the subject of PKU. Given that PKU is a rare disease, it is important that students in the disciplines of Medicine, Social Sciences, Economics and Administration are targeted because these are the future doctors, public policymakers and government workers who will be able to make changes to the current situation. They are not being taught about rare diseases, yet they are the ones who will need to treat patients in the future with these rarities.

For me, it is very important to count on the support of IAPO for us to carry out our advocacy initiatives.”

Regional programme agenda

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<td>23 September 2013</td>
<td>Mexican Patients’ Organizations Meeting (held in collaboration with Red de Acceso)</td>
<td>Strengthen the national network of patients’ organizations, discuss past and current activities of the network and develop future actions.</td>
<td>13 patients’ organizations from across Mexico.</td>
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<td>23 September 2013</td>
<td>Multi-stakeholder Seminar and Reception: Patient-centred access to healthcare in Latin America</td>
<td>Highlight the value of cross-sector partnerships, debate and increase knowledge of important healthcare issues including NCDs, HTA and biosimilar medicines, and build advocacy efforts nationally and regionally.</td>
<td>Over 70 healthcare stakeholders from across Latin America including patient representatives, policymakers, healthcare professionals, civil society and industry.</td>
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<td>24-25 September 2013</td>
<td>Regional Patients’ Organizations Workshop: Strengthening the IAPO Latin American network, 2014 and beyond</td>
<td>Strengthen the IAPO regional network in Latin America, build the capacity of patient representatives on issues including NCDs, HTA and biosimilars and develop key materials and tools for the network moving forward (including a joint statement and a 2014 Action Plan).</td>
<td>21 patients’ organization representatives from 10 Latin American countries, representing 14 different disease areas.</td>
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Highlights from the regional programme

We would like to share some of the key highlights from the regional programme in 2013, which are cross-cutting through a number of the activities that were undertaken.

Increasing advocacy on a national, regional and international level

Throughout the activities, three key issues related to access to healthcare in Latin America were addressed: non-communicable diseases (NCDs), health technology assessment (HTA), and biological and biosimilar medicines.

At the meeting for Mexican patients’ organizations, discussions focused on Red de Acceso’s work on biological and biosimilar medicines, which included:

- Information disseminated about a forum on this topic, held by Red de Acceso. This brought together patients’ organizations, academia, industry representatives and the government, and led to the development of a declaration on biosimilar medicines. Read the declaration at: www.patientsorganizations.org/latinamerica
- The need for patient empowerment and education on biological and biosimilar medicines
- Highlighting the importance of pharmacovigilance and adverse event monitoring
- Discussions held around how to build a culture of awareness

During the multi-stakeholder meeting, there were two panel discussions on HTA and biological and biosimilar medicines.

HTA panelists

- Dr Osvaldo Artaza Barrios Pan American Health Organization/World Health Organization Mexico
- Ricardo Pérez Cuevas Inter-American Development Bank
- Gisela Ayala Mexican Federation of Diabetes
- Kin-Ping Tsang IAPO Chair

Key discussions during the HTA panel included:

- What HTA is and how it can be used in Latin America
- HTA as a tool to help make better decisions
- The role of HTA in increasing universal health coverage and access to healthcare in the region
- The importance of multi-sectoral collaboration and patient involvement in decision-making bodies and processes
Biological and biosimilar medicines panelists

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<td>Dra Mireya López Gamboa</td>
<td>The Center for Research and Advanced Studies of the Instituto de Cancerología de Mexico</td>
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<tr>
<td>Gustavo Adolfo Campillo</td>
<td>Antioquia Social Help Net Foundation, Colombia</td>
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<tr>
<td>Jo Groves</td>
<td>Chief Executive Officer, IAPO</td>
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Key discussions during the biological and biosimilar medicines panel included:

- An explanation to the current situation in Mexico regarding these medicines
- How they are produced and regulated
- The differences between generic and biosimilar medicines
- The need for regulation in the Latin America region that is aligned with that of the WHO
- The importance of working together to educate patients, doctors and government regarding what these medicines are and their potential to increase access in the region

"We need to educate in order to empower, educate to have a stronger dialogue."

Gustavo Adolfo Campillo, Antioquia Social Help Net Foundation, Colombia

Cross-sector collaboration and high-level support

As is evident, there was significant and varied support for the events from a variety of stakeholders, more specifically:

- An opening address was delivered by Dr Luis Rubén Durán Fontes, Under Secretary of Integration and Development of the Health Sector, who highlighted the importance of patient-centred healthcare and multi-sectoral collaboration to improve access to healthcare across the region.

"When civil society, NGOs, academia and the public sector act together we can have a special platform of decision-making that is collaborative and ensure the best possible treatment for patients and citizens."

Dr Luis Rubén Durán Fontes, Under Secretary of Integration and Development of the Health Sector

- A statement of support was developed specifically for these events and shared during the seminar from Dr Oleg Chestnov, Assistant Director-General for NCDs and Mental Health, World Health Organization. To read Dr Chestnov's full statement, please visit: www.patientsorganizations.org/latinamerica

"I call on all international partners to support governments in their national efforts in setting these national NCD targets, and developing national plans to achieve these targets. I hope we all will seize this opportunity to make a meaningful difference that will help people with NCDs, and that will protect future generations from dying too young."

Dr Oleg Chestnov, World Health Organization

Building capacity

One of the overall objectives of the regional programme was to strengthen the capacity of patients’ organizations from across the region. This was done both through specific capacity-building sessions throughout the programme, as well as more generally through knowledge-sharing and discussions on how patients’ organizations can learn from each other and from IAPO, across the region.

During the two-day regional workshop, there were dedicated capacity-building sessions held on NCDs, HTA and biological and biosimilar medicines. The content and level of these sessions was determined by a pre-workshop consultation with participants. For example, the level of knowledge on HTA was deemed rather low, therefore the capacity-building session focused on outlining what HTA is, how it is used, the implications for patients and how patients’ organizations could be involved. Plenty of time was allocated for question and answer sessions to ensure all participants felt confident about their understanding of these complex issues. The level of knowledge about biological and biosimilar medicines was much higher however, so this session provided a general overview as well as delving deeper into the complexities and issues in the region.
Patients’ organizations also brainstormed together to assess the achievements of the IAPO Latin America Network since its creation in June 2012, and around what more could be achieved in the coming years. Participants highlighted that achievements will be dependent on working cohesively as a network and ensuring that all the resources and tools within the network are used effectively.

Most importantly, significant time was spent on the development of a comprehensive action plan for the remainder of 2013 and beyond in 2014; linking to both region-specific plans and IAPO’s global activities. This action plan included discrete, time-specific tasks which should ensure progress within the network in the coming year. These sessions also included time for each workshop participant to develop individual actions that they could commit to fulfilling for the IAPO Latin America Network. They worked in groups to look at priority activities for 2014 and, within this, they also developed an overall goal for the end of 2014 and any resources that are necessary to support these areas. The areas focused on included:

- Overall coordination of the IAPO regional network and necessary infrastructure
- Integration of the Latin American patient voice into the global activities of IAPO
- Communication and education
- Engagement with WHO and PAHO
- Access to healthcare
- Biological and biosimilar medicines

“We are able to appreciate the needs of other organizations and their respective countries, and see how we can work together through collaborative efforts to the same purpose.”

“Achieving universal health coverage and access to essential quality medicines are the pillars of effective primary healthcare. Only through a patient-centred approach will WHO be able to capitalise on the achievements we have made so far in providing better access to healthcare.”

Excerpts from the Declaration developed by the IAPO Latin America Network:

“We are able to appreciate the needs of other organizations and their respective countries, and see how we can work together through collaborative efforts to the same purpose.”

“Achieving universal health coverage and access to essential quality medicines are the pillars of effective primary healthcare. Only through a patient-centred approach will WHO be able to capitalise on the achievements we have made so far in providing better access to healthcare.”

View the full declaration at: [www.patientsorganizations.org/latinamerica](http://www.patientsorganizations.org/latinamerica)

**Strengthening networks**

As national and regional networks develop, in order to bring a stronger, more unified voice to important healthcare issues, it is important for patients’ organizations to understand the benefits and challenges of working in networks towards common aims.

During the meeting for Mexican patients’ organizations, there were discussions on the unification of the national health system in Mexico, and how organizations could work together to meet this challenge. These included:

- Information regarding what changes to the Mexican health system will look like
- How to promote patient-centred healthcare to ensure access for all
- The development of a survey of patients’ organizations and patients in Mexico to gather opinion and develop a position paper

“How will the unification ensure access to healthcare for the general population? What resources will be allocated? Patients need to be part of this process; they need to be heard at every point in the discussion. It is time to talk about patient-centred healthcare.”

Luis Adrián Quiroz, Red de Acceso

In the regional workshop, there was a session focusing on the importance of working in networks. This highlighted how sharing experiences and learning, as well as joining forces towards a common goal, can lead to improved healthcare in the Latin American region.

**Developing shared positions and future strategies**

A number of specific shared initiatives were developed during the regional workshop to ensure that the IAPO network in Latin America is effectively supported moving forward in the future, and as well as to increase advocacy efforts on a regional level. Three specific examples include:

- Group work to develop and finalise an intervention which IAPO made at the 52nd Directing Council of the Pan America Health Organization (PAHO), 65th Session of the Regional Committee of World Health Organization. This intervention was on health in the post-2015 development agenda. The contribution of workshop participants ensured that it represented the views of patients’ organizations in the region.

“Patients cannot be seen as passive subjects in the development of healthcare, they are the essence and purpose at the same time, and patient-centred spaces must be created.”

Gustavo Adolfo Campillo, Antioquia Social Help Net Foundation, Colombia

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Integration into IAPO’s global activities

Information about the next steps in the global patients movement was provided. This focused on:

- IAPO’s 6th Global Patients Congress, to be held in the UK, 29–31 March 2014: www.globalpatientscongress.org
- IAPO’s work in other world regions, such as Patient Solidarity Day, held on 30 October 2013 in Africa. For more information, visit: www.patientsolidarityday.org

Case study

Evelyn E. Benmergui, Venezuelan Federation of Associations and Foundations for Persons with Intellectual Disabilities (FEVEDI)

“I am the fifth of six children in my family, one of whom had an intellectual disability. When I was ten years old, my parents founded the Venezuelan Association of Parents and Friends of Exceptional Children (AVEPANE) because of my sibling’s needs. After studying psychology at a number of institutions, including Johns Hopkins University in the USA, I returned to Venezuela to take over the family responsibilities. I am currently the President of FEVEDI, Executive Vice-President of AVEPANE and Vice-President of the Avepane University Institute (a three-year degree College).

I attended the IAPO Latin American regional programme in order to represent FEVEDI as their newly appointed President to the best of my abilities and to learn as much as I could about universal health coverage from the standpoint of the patient. I felt committed to absorbing as much information as possible regarding patient-centred healthcare, new technologies and biological and biosimilar medicines. Most of all, I wanted to engage in group discussions to find out about effective strategies and successful action plans undertaken by fellow participants. I also wanted to personally meet key IAPO authorities who work on behalf of patients worldwide.

The complex topics addressed were easily understood due to the thoughtful team of experts and everything was done with impeccable organization. The acquired information and learned experiences will help us set goals, plans and strategies to pressure for patient-centred healthcare. FEVEDI felt privileged to be invited to exchange ideas and to confer with the wide variety of representatives from across Latin America and to realize that we are not alone, that we can unite and strengthen our efforts to reach a stronger impact in a lesser amount of time. For example, as we did in developing the Declaration for the Pan American Health Organization.

Actions which FEVEDI have taken so far as a result of this experience include: promoting the results of the activities on FEVEDI’s social networks; developing a survey to assess the issues which affect patients in Venezuela; and arranging meetings with high-level national stakeholders in Venezuela in order to ensure that policies, healthcare schemes and related activities are developed with the patient at the centre. The IAPO meeting was therefore a wonderful opportunity that had fruitful results. We value and appreciate our affiliation to IAPO and hope to continue joining forces to improve the quality of care for persons with disabilities.”

Next steps

Based on the lessons learned from these regional activities and the associated consultation, IAPO will be focusing on a number of immediate and longer-term activities. This will be in order to ensure that the regional network continues to develop and that members in the region receive support to conduct activities towards the regional strategy.

In the development of future plans, the resources necessary for these activities were examined. This included IAPO staff and Governing Board time, materials and financial resources. Although IAPO has capacity to support certain activities within the 2014 Action Plan, additional funding is required to complete some of the more significant but also most valuable activities towards the 2014 objectives. In the remainder of 2013, IAPO and the regional network will:

- Fully develop the action plan for the region in 2014 using the consultation undertaken during the meeting and begin fundraising to support these activities
- Further disseminate the joint statement developed for the PAHO Directing Council with national stakeholders
- Conduct small-scale activities in order to support Patient Solidarity Day 2013 in Africa
- Develop a framework for ongoing coordination and support for members in the region
- Follow up with members on individual action plans and support of the network in 2014

In 2014, IAPO has planned a number of activities (some of which are subject to funding), including:

- Recruit a Regional Coordinator (located within one of our member organizations in the region) to coordinate many of the activities outlined in the Latin American action plan for 2014
- Hold a Regional Meeting in mid-2014 which will help IAPO to continue to build a solid base for other activities and enable the network to become more unified
- Conduct issue-based research projects examining country-level strategies to regional initiatives and support
- Hold a grant process for small projects for its member patients’ organizations to conduct national and regional activities in the run-up to and on Patient Solidarity Day in October 2014
- Deepen engagement with regional and national healthcare stakeholders in order to further share the value of patient-centred healthcare and to encourage patient engagement at all levels of healthcare
- The development of webinars and toolkits in Spanish on a number of topics in line with the 2014 Action Plan, which will aim to be both advocacy and capacity-building focused

Further information on these activities, including participant details, slides and media materials can be found at: www.patientsorganizations.org/latinamerica

If you would like to discuss IAPO’s activities in Latin America, please email us at: info@patientsorganizations.org
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