



International Alliance of  
Patients' Organizations  
A global voice for patients

# South-East Asia Regional Programme Report 2013





## South-East Asia Regional Programme: New Delhi, 2013

### Organized by the International Alliance of Patients' Organizations (IAPO)

#### With our thanks

The IAPO Governing Board and staff team would like to thank everyone who supported this event. In particular, we would like to thank Ratna Devi from the Dakshayani and Amaravati Health and Education Foundation (DakshamA Health) and R. Narendhar from the Alzheimer's and Related Disorders Society of India (ARDSI) for collaborating on the organization of the local meeting in New Delhi, as well as for their overall support for IAPO's Regional Programme in South-East Asia.

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#### Event materials

Presentations and agendas from the event are available online at: [www.patientsorganizations.org/south-eastasia](http://www.patientsorganizations.org/south-eastasia)

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## Introduction

From 16–18 December 2013, IAPO held a series of events in New Delhi, India. This was the first Regional Programme that IAPO had held in the South-East Asia region and the aims were to strengthen the voice of patients in the region and to highlight the value of patient engagement to healthcare stakeholders. These events brought together representatives from patients' organizations from three countries in South-East Asia. The activities in December were:

- A meeting for patients' organizations based in New Delhi which aimed to bring together national patient groups to identify common issues and discuss how they could work together and develop a national network.
- A multi-stakeholder seminar and reception which brought together a wide range of healthcare stakeholders to discuss two healthcare issues: non-communicable diseases (NCDs) and patient safety.
- A two-day patient group workshop to build the capacity of patients' organizations in the region to advocate for patient-centred healthcare and to work towards developing a regional network in South-East Asia.

### What was the need?

Prior to these meetings, IAPO conducted extensive research including a consultation with participants to find out more about the healthcare issues in the region. This ensured that the activities undertaken during the regional programme were appropriate and relevant to the region.

Through this consultation, IAPO was able to identify the issues that patients' organizations were facing. Two key themes emerged from the consultation: the need for better access to healthcare; and the need for improved collaboration between stakeholders to achieve this.

### Access to healthcare

Without exception, all participants in the consultation felt that people in their country did not have equal access to healthcare. Respondents stated that access to quality, affordable healthcare was limited and that many patients faced poor diagnosis and unaffordable treatment options. They further highlighted that the high demand for services, lack of trained healthcare professionals, limited healthcare funding and inefficiencies all contributed to inequalities in accessing healthcare.

For these patients' organizations, the term 'access to healthcare' meant to them that affordable and safe treatment, medicines and facilities should be available to all patients at all times. As one respondent stated: *"In a nutshell, access to healthcare means giving people the ability to cope with illness irrespective of their social, economic and cultural differences."* Limited funding for healthcare was identified as a key concern. In particular, it was felt that civil society groups and non-governmental organizations (NGOs) achieve a great deal without much support or funding and individual patients and families face huge debts from out-of-pocket healthcare expenses.

A further issue highlighted was a lack of awareness and education among patients, often due to limited information available. Illiteracy in populations was also highlighted as an issue that prevented patients from accessing healthcare information. Respondents highlighted the need for innovative solutions to ensure that information is accessible to patients from all backgrounds. Therefore, the activities of patients' organizations have included signposting patients to where they can access treatments and linking them to physicians and hospitals.

In order to address these concerns about standards of health in their countries, patients' representatives suggested that healthcare should be more transparent and accountable. Patients need to be equipped with knowledge and education about self-care and the importance of early diagnosis needs to be disseminated. Respondents highlighted a need for increased collaboration between patients and healthcare professionals and to improve patient safety through the tightening of legislation for medicines. They also suggested that policies need to be developed and implemented that encourage prevention and earlier management of diseases.



### Collaboration

Therefore, in this challenging healthcare context, respondents saw the role of patients' organizations as crucial to organizing, facilitating, and supporting patients. They felt it was essential that they provided the patient voice in the improvement of healthcare services, particularly in improving access to treatment for all patients. They also saw an important role in patients' organizations liaising between patients and healthcare professionals and lobbying governments for change. Respondents highlighted the work that patients' organizations were undertaking to improve access to healthcare. For example, patients' organizations were providing grassroots services to patients, such as encouraging self-monitoring at home for diabetes management.

However, respondents reported that at present they faced challenges in carrying out these functions. Patients' organizations in South-East Asia stated that they did not feel they were regarded as an important stakeholder by governments and healthcare professionals, making it difficult for them to represent the interests of patients.

Patients' organizations would like to explore and develop further networks and collaborations with others in healthcare at all levels; locally, regionally and globally. All those who responded to the consultation reinforced their commitment to forming networks and partnerships with other patients' organizations, and to collaborating with a range of stakeholders. Collaborative activities that they have already initiated included: holding events with other NGOs; running workshops in schools and hospitals; being members of international disease networks and organizations; and working closely with government policymakers and research foundations. It was agreed by all that cross-sector collaboration was crucial in any work on healthcare improvements in the region.



## Case study

**Dr Ratna Devi, Founder and CEO, Dakshayani and Amaravati Health and Education Foundation (DakshamA Health)**

I am Dr Ratna Devi, a public health physician. I have worked for nearly two decades in the government as well as in national and international organizations in India. When I was married 25 years ago, I heard that my father-in-law and three of his brothers suffered from diabetes and all of them passed away at a fairly early age due to complications associated with diabetes. Over the years, all three of my sisters-in-law have been diagnosed with diabetes and are undergoing treatment.

It was only four years ago when my husband was also diagnosed that I realised the enormity of the problem and decided to do something about it. I looked around for a support group that I could become involved in, to learn about management and gather information on medicines, but found none in my country. In 2011, I was introduced to IAPO and was very pleased to interact with many patient-led organizations across the globe.

I then decided to establish my own organization and work with IAPO for the cause of diabetes and chronic diseases in India. I co-founded and am the CEO of the Dakshayani and Amaravati Health and Education Foundation (DakshamA Health) in December 2013. We co-hosted the South-East Asia Regional Meeting in Delhi in December 2013 that brought together patients' organizations and government representatives to discuss the issue of NCDs, universal health coverage and patient safety. It was a big learning experience for me. I understood many concepts like patient-centred healthcare as well as IAPO's advocacy tools and efforts to further patient-centred healthcare. With IAPO as host, my organization received a lot of attention and we could build good credibility, since IAPO is seen as a true patients' organization.

With support from IAPO and learning from their experience in other countries, I have been able to reach out to many patients' organizations in India. I have worked as a patient advocate for many years but having a group of organizations working together has strengthened our voice and we are able to work more effectively on many issues. Since the meeting, my organization has joined IAPO. I have begun the process of forming an alliance of patients' organizations in India and have already had two patient group meetings in Delhi.

I have been able to interact with the Ministry of Health and other government officials. Introducing myself as a member organization of IAPO has provided me with an easy entry because of the credibility IAPO shares across the globe. The issues that IAPO focuses on are close to my heart, and I will continue my association with IAPO, learning and growing my organization and working for NCDs and access in India.



## Regional programme agenda

**16 December 2013**  
**Indian Patients' Organizations Meeting** (held in collaboration with DakshamA Health and ARDSI)

**Aims:** Bring together organizations from across India to identify common issues and to work towards building a national network of patients' organizations  
**Audience:** 13 patients' organizations from across India

**16 December 2013**  
**Multi-stakeholder Seminar and Reception**

**Aims:** Highlight the value of cross-sector partnerships, debate and increase knowledge of important healthcare issues including NCDs, and patient safety, promote multi-stakeholder dialogue and advocacy efforts nationally and regionally  
**Audience:** Over 30 healthcare stakeholders from South-East Asia including patient representatives, policy-makers, healthcare professionals, civil society and industry

**17–18 December 2013**  
**South-East Asia Regional Workshop**

**Aims:** Bring together groups from across South-East Asia to discuss common issues and work towards building a network of patients' organizations in the region. Build the capacity of patient representatives on issues including NCDs and access to healthcare  
**Audience:** 11 patients' organization representatives from three South-East Asian countries





# Highlights from the regional programme

## Advocacy on a national and regional level

Throughout the activities, non-communicable diseases (NCDs) universal health coverage, and patient safety were discussed. At the meeting for Indian patients’ organizations, participants discussed the work of patients’ organizations in the region as well as some of the common issues they faced. They discussed:

- Their successes, such as improving access to treatment in disease-specific areas, including some rare diseases such as multiple sclerosis
- The need for greater support from healthcare professionals, government and other organizations to facilitate the active engagement of patients in decision-making
- The need to improve equitable access to healthcare and address the huge disparities between those who have access to healthcare and those who do not
- Lack of patient information, particularly information that is accessible for patients with low literacy levels

During the multi-stakeholder meeting, there were two panel discussions on non-communicable diseases (NCDs) and patient safety. The panel on NCDs was chaired by Robert Johnstone, IAPO Governing Board Member, and Ratna Devi, Founder and CEO of DakshamA Health. Before handing over to the panellists, both Robert and Ratna shared their experienced of advocacy on NCDs and their thoughts on what action is needed to ensure a coordinated response to the NCD burden.

## NCDs panellists

Dr Damodar Bachani	Director Professor and Head, Department of Community Medicine at Lady Hardinge Medical College and Associated Hospitals
Dileep Kumar	President, Indian Nursing Council
Nilanjana Maulik	Secretary General, Alzheimer’s and Related Disorders Society of India (ARDSI)

Key discussions during the panel included:

- What progress has been made at the national and regional level to prevent and manage NCDs
- What the role of patients’ organizations is in preventing and managing NCDs
- How healthcare stakeholders can come together and advocate for better access to treatment for patients with NCDs

“It has contributed to my understanding of NCDs so much. The lessons I have learnt are the priority to tackle NCDs with action plans in India and in WHO.”  
Orajitt Bumrungskulswat, Heart to Heart Foundation, Thailand

The panel on patient safety was chaired by Hussain Jafri, IAPO Governing Board Member and World Health Organization (WHO) Patients for Patient Safety Champion. Hussain shared his person experience of working to improve patient safety in Pakistan as well as the work of the Patients for Patient Safety Network to improve healthcare safety globally.

## Patient safety panellists

Bejon Misra	Founder, Partnerships for Safe Medicines, India
Prafull Sheth	Vice-President, International Pharmaceutical Federation
Christina Perera	World Health Organization (WHO) Patients for Patient Safety Champion

Key discussions during the panel included:

- The need for action to tackle counterfeit medical products and unsafe medicines in South-East Asia
- The work of a range of stakeholders, including patients’ organizations and healthcare professional organizations to ensure access to safe, high-quality medicine in South-East Asia
- Initiatives by the WHO Patients for Patient Safety programme to improve patient safety globally

“I gained new insights on the principles of patient safety and the importance and role of the patient.”

M. Louis Stanislas, Muscular Dystrophy Foundation of India

The seminar concluded with a lively discussion on the need for patients’ organizations to be further engaged in healthcare policy on NCDs and patient safety. Participants expressed surprise in the number of avenues that there are to engage with patient groups to engage in healthcare policy.

This demonstrates a need for further communications between healthcare stakeholders and patients’ organizations on what the opportunities are for collaboration.





### Building capacity

One of the overall objectives of this Regional Programme was to strengthen the capacity of patients' organizations from across the region. Through group work and discussion, participants had the opportunity to better understand a wide range of issues including learning more about the work of the World Health Organization (WHO), patient-centred healthcare, non-communicable diseases (NCDs), universal health coverage and patient safety.

### Patient-centred healthcare

Participants were introduced to the concept of patient-centred healthcare and the five principles outlined in IAPO's Declaration on Patient-Centred Healthcare of: respect, choice and empowerment, patient involvement in health policy, access and support and information. Participants worked as a group to share what they thought were the essential elements of patient-centred healthcare. These included:

- Patient support to empower them to engage in healthcare policies
- Patient information that is tailored to the needs of the population, including the most vulnerable groups
- Extending high-quality, affordable healthcare for all
- Tackling discrimination and stigma for certain disease areas

Participants agreed that, at the moment, there is not patient-centred healthcare in South-East Asia, but agreed that an important first step was to share the IAPO Declaration on Patient-Centred Healthcare with other stakeholders and amongst patients' organizations to help promote this message. Participants also committed to signing up and supporting the Declaration as well as to translating the Declaration in different languages to ensure its continued reach.

### Working with WHO and patient safety

IAPO also shared information on the role of the World Health Organization (WHO) in developing and implementing global healthcare policy. IAPO explained the processes of developing global policy and shared how patients' organizations can engage with this process. IAPO also explained how the World Health Assembly is an important forum for Member States to debate and agree global policy and is also an important opportunity for patients' organizations to share their positions on a global stage.

IAPO shared examples of how patients' organizations can collaborate with WHO, and on how IAPO and its membership had worked with the Patients for Patient Safety programme. IAPO spoke about the work of the programme to improve patient safety through the advocacy of the Patients for Patient Safety Champions.

Participants were interested in this model and spoke about the ways in which they could engage with the WHO country offices as well as the opportunities to engage in the WHO regional committees.

### Non-communicable diseases and universal health coverage

IAPO held a workshop on non-communicable diseases and universal health coverage to build participants' capacities on these key policy areas and to share global developments. They also shared how patients' organizations can get involved in the movement to ensure access to healthcare for all. On the whole, participants did not know that their governments had committed to developing and implementing strategies to extend universal health coverage. They also agreed that more needed to be done to ensure equitable, high-quality, affordable access for populations across South-East Asia. Participants discussed ways in which they could collaborate to improve access to healthcare in their country including:

- Engaging in the WHO regional committee to draw attention to diseases that had been neglected in the NCD strategy
- Developing joint advocacy plans to amplify the patient voice
- Working with governments to identify hard to reach groups who were missing out on opportunities already in place to improve access to healthcare

### Building networks

During the meeting for Indian patients' organizations, it became apparent that a large number of the organizations had not heard of each other and were surprised to the extent to which they faced similar issues. Therefore, many of the discussions focused on the similarities between the challenges they faced as organizations, such as limited resources and lack of recognition by government and other healthcare stakeholders. In particular, there was a call for the formation of an Indian alliance of patients' organizations to:

- Bring together the large number of patients' organizations currently operating in India in isolation from each other
- Share best practice, successes and identify common challenges
- Advocate collectively for improved access to safe, high-quality affordable healthcare in India

**"Advocacy plays an important role. The more the awareness about the diseases the more people get to know about Multiple Sclerosis (MS). Once people know about MS there are better chances of getting access to healthcare."**

**Renuka Malaker, Multiple Sclerosis Society of India (MSSI)**

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 South-East Asian region.

### Developing shared positions and future strategies

A number of specific shared initiatives were developed during the regional workshop to ensure that the development of a network in South-East Asia is effectively supported. Participants also discussed how they would work together to increase advocacy efforts on a regional level.

Significant time was spent on the development of individual and joint actions plans for activities to take forward. Participants divided into three groups to develop actions to take after the meeting, as detailed overleaf.

### 1. Develop networking in South-East Asia

The activities for this included:

- Starting a blog on patient-centred healthcare to promote the five principles in the region
- Utilising social media such as Facebook and Twitter to share information on patient-centred healthcare and other initiatives
- Developing an e-newsletter on patient-centred healthcare
- Developing a joint calendar on meetings and events to inform patients' organizations when there are important multi-stakeholder events happening
- Identifying key external stakeholders with whom to build relationships

### 2. Raising awareness on the rights of patients

The activities for this included:

- Developing literature on the rights of the patient, including leaflets
- Organizing workshops and meetings for patients' organizations well as other stakeholders to educate them on the rights of patients
- Documenting case studies of patients' experiences and opinions

### 3. Advocacy on non-communicable diseases

The activities for this included:

- Advocating for an inclusive approach to NCDs, including ensuring that a wide range of chronic disease areas are included
- Advocating for the standardisation of costs and services for the management of NCDs, to ensure that services are affordable to patients regardless of their disease area
- Calling for a separate NCD department in all government hospitals

“The experience of attending and participating in the South-East Asia Regional Meeting was wonderful. We gained knowledge on promoting and advocating for patient-centred healthcare.”

Rubby Chawla, Indian Patients Society for Primary Immunodeficiencies (IPSPI)

#### Integration into IAPO's global activities

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

- IAPO's upcoming 6th Global Patients Congress to be held in the UK, 29–31 March 2014 – find out more at: [www.globalpatientscongress.org](http://www.globalpatientscongress.org)
- IAPO's work in other world regions, such as Patient Solidarity Day, held in October 2013 in Africa. For more information, see: [www.patientsolidarityday.org](http://www.patientsolidarityday.org)



## Case study

Rubby Chawla, Founder and President,  
Indian Patients Society for Primary Immunodeficiency (IPSPI)

I am the Founder and President of IPSPI. The personal tragedies in life shook me to the core and left me feeling like I was a dead log of wood. The loss of my beloved sons aged four and ten years from primary immunodeficiency disorders (PID) left me deeply depressed and we are still coming to terms with the nightmare we have faced. I slowly gathered myself for the sake of my third surviving son and promised myself that no parent should suffer the way we had. I, along with my husband, therefore formed an organization to support other patients and families with these diseases: the Indian Patients Society for Primary Immunodeficiency (IPSPI). Since then, we have never looked back and have successfully advocated for PID.

We have been regularly lobbying with the Government to bring PID onto the government agenda and to ensure coverage for treatment for PID. The awareness campaigns have been possible through the support of the Jeffrey Modell Foundation and we appreciate their continued support of our advocacy and awareness campaigns on PID in India. We are the national member organization of International Patient Organisation for Primary Immunodeficiencies (IPOPI) and have participated in the international biennial meetings through IPOPI's support. We were informed by IPOPI about the upcoming IAPO South-East Asia meeting of patients groups in Delhi and we were instantly interested and looked forward to the meeting as we wanted solutions to the issues faced by our PID patients in India. Moreover, we looked forward to the opportunity to share our experiences with other organizations.

The IAPO meeting fulfilled all of our expectations. The education on patient-centred healthcare and universal health coverage was very much appreciated. Furthermore, the knowledge on NCDs gave us the solution for our patients and right from that day we started lobbying with the officials and Health Ministry and have got positive outcomes. We are still working to gain access to treatment for our PID patients, but are hopeful that soon PID patients from different states will have access to therapy for treatment.

IAPO is a unique platform where one feels that one voice for all patients will be strongly heard. This wonderful meeting was one of a kind and personally I look forward to future meaningful meetings. In fact, I had been so much impressed and interested after attending the meet that I have enrolled myself for the postgraduate diploma in public health management. After tackling the issues of coverage of treatment of PID patient, I wish to focus on the efficacy and patient safety of the treatment of the biological products which PID patients regularly use. My organization is now a full member of IAPO and we look forward to the important educative meetings conducted by IAPO. I am sure that our association with IAPO will give us a strong voice to tackle the issues facing patients.





## Next steps

“We have already started working towards developing a patient charter that is to be shared and adapted by our organization and our partners.”  
M. Louis Stanislas, Muscular Dystrophy Foundation India

Based on the lessons learned from these regional activities and the consultation, IAPO will be focusing on a number of immediate and longer term activities:

- Build on the activities discussed and develop an action plan for the region following consultation with members
- Support Patient Solidarity Day as it goes global in 2014
- Support the development of a regional network in South-East Asia
- Follow up with members on individual action plans and support the network
- Facilitate the engagement of IAPO members in South-East Asia with key healthcare stakeholders such as government, the World Health Organization and healthcare professional organizations
- Facilitate the attendance of a member in South-East Asia at the 2014 World Health Organization Regional Committee
- Support the development of a network of patients’ organizations in India (the Indian Alliance of Patients’ Organizations)



## Participant list

Organization	Country	Website
Action for Autism	India	<a href="http://www.autism-india.org">www.autism-india.org</a>
Alzheimer's and Related Disorders Society of India (ARDSI)	India	<a href="http://www.alzheimerindia.org">www.alzheimerindia.org</a>
Anchal Charitable Trust	India	<a href="http://www.anchalindia.org">www.anchalindia.org</a>
Association of Community Pharmacists of India (ACPI)	India	
Dakshayani and Amaravati Health and Education Foundation (Dakshama Health)	India	<a href="http://www.dakshamahealth.in">www.dakshamahealth.in</a>
Cancer Aid Society	India	<a href="http://www.canceraidsocietyindia.org">www.canceraidsocietyindia.org</a>
Indian Patients Society for Primary Immunodeficiencies (IPSPI)	India	<a href="http://www.ipspiindia.org">www.ipspiindia.org</a>
Heart to Heart Foundation	Thailand	<a href="http://www.nhso.go.th">www.nhso.go.th</a>
Multiple Sclerosis Society of India	India	<a href="http://www.mssocietyindia.org">www.mssocietyindia.org</a>
Muscular Dystrophy Foundation of India	India	<a href="http://www.mdindia.org">www.mdindia.org</a>
People's Movement for the Rights of Patients	Sri Lanka	





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