

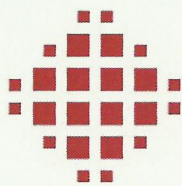


**IAPG**

**INDIAN ALLIANCE**

— of patient groups —

*Supported By*



PARTNERSHIP TO FIGHT  
CHRONIC DISEASE

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## Indian Alliance of Patient Groups: the journey so far

*The Indian Alliance of Patients Groups (IAPG) has been created to represent patient organisations across disease areas. It stands for all patients, working to support their cause, highlight their needs and allow them a voice. IAPG brings attention to chronic Non-Communicable Diseases (NCD) as well as rare and neglected diseases and believes that patient must be at the centre of the healthcare conversation.*

*The IAPG secretariat resides within Dakshayani and Amaravati Health and Education. This secretariat operates with a core group of five organisations: Alzheimers and Related Disorders Society of India (ARDSI), Indian Organisation for Rare Diseases (I-ORD), Multiple Sclerosis Society of India (MSSI), National Thalassemia Welfare Society and Dakshama Health (Dakshayani and Amaravati Health and Education). IAPG has grown to become a 17-member organization that represents the interests of over 200 million patients - including 70 million people with rare diseases, 2.5 million cancer patients, 30 million diabetics and 60 million sufferers of mental ailments. We strive to promote the cause of all patients in India, with focus on patient empowerment as well as healthcare safety, quality and policy.*

### Background

*The patient movement in India has shown some initial success and is poised to move forward with support from the National Health Mission (NHM), which includes among its objectives: "protection of patients' rights that guarantee appropriateness of care, patient choice, portability and continuity of care". The High Level Expert Group on Universal Health Coverage recommends that we "ensure strong linkages and synergies between management and regulatory reforms and ensure accountability to patients and communities". The Government of India, through the National Rural Health Mission (NRHM), has RogiKalyanSamitis and Hospital Management Committees (HMCs), where patient representatives inform the functioning of hospitals at district and sub-district levels. The HIV movement, with its large network, has been a success story - bringing patient voices to the policy platform and also addressing issues like stigma, rehabilitation, livelihood and workplace policies to address discrimination.*

*Patient movement in the NCD arena has not been so proactive or cohesive thus far. Many disease-focused groups are doing excellent work in specific areas, but a combined effort to unite these groups on a common platform, with a single strong voice, has been lacking. The IAPG is built, along the lines of other successful patient group alliances around the globe, to bridge this gap and construct an alliance that will work on areas of common interest to all patients. This platform will enable disease-specific patient organisations to retain their independence while strengthening their voice. The intent is to support both government and private sector efforts toward a robust and accessible healthcare system that benefits patients, policy-makers and healthcare providers across India.*

## IAPG Launch

November 12, 2014 saw 17 organisations come together in New Delhi, to discuss the formation of a national patient group alliance. The anticipated outcome from this initial meeting was to identify one healthcare issue that all groups could agree upon and call on the government to address. The day-long meeting started with an opening plenary by noted healthcare authority, Professor David Taylor, which provided an overview of the healthcare system in India, followed by two panel discussions. The first panel dealt with the topic of "health reform in India - steps to achieving universal healthcare in India and improving access to health services and supplies for the poor and marginalized communities". The second addressed "the role of patient advocates and best practices in advancing patient-centered principles in healthcare reform". Modalities for the advancement of this new alliance and next steps were also discussed. This Delhi event was followed by a soft launch in Mumbai on October 8, 2015, where media was present and the objectives and principles of the organization were formalised.



**Vision:** Universal access to safe and quality healthcare with dignity.

**Mission:** To promote and facilitate patient engagement with healthcare providers and policy makers

### Objectives:

- Unite to speak with one voice, using unified strength to move forward together
- Identify health policy opportunities to include the patient voice
- Share best practices to support advocacy-related work by individual groups, perhaps through a patient forum
- Address the need for individual advocacy organisations to provide more information to their consumers

## IAPG Principles of Patient-Centred Healthcare

- 1. Promoting Patient Engagement in Health Policy Decision-Making:**  
*Patients are the focal point of any healthcare system. They should share responsibility for health policy decision-making, through meaningful engagement at all levels, to ensure that healthcare programmes are designed with patients at the core.*
- 2. Supporting Access to the Best Available Care across India:**  
*Patients and their advocates should promote and help design programmes that are suitable to local conditions and ensure the availability of healthcare workers as well as access to diagnostics, medicines and treatment options.*
- 3. Promoting Health Literacy and Ensuring the Availability of Health Information:**  
*Accurate, relevant and comprehensive information is essential for enabling patients and their families to make informed decisions about treating and managing their condition. In particular, patients need access to their own medical records and information.*
- 4. Advancing Choice and Empowerment of Patients and their Advocates:**  
*Through collaboration and shared knowledge and best practices, patients and their advocates need the information and the confidence to participate as partners in making the healthcare decisions that affect their lives.*
- 5. Raising the voice for a patient-centred healthcare system, at national and state levels:**  
*National and state level policy makers need the support of informed patients to build an effective and responsive healthcare system that meet the needs of the Indian population.*

## IAPG in the News

IAPG has been covered widely in print and social media, with the October 2015 launch event finding mention in over 60 publications. An article on healthcare financing, authored by Dr. Ratna Devi, was published in April by the Financial Express: *Is the Modi govt doing enough for healthcare? Needs to look at new ways for affordability.*

<http://www.financialexpress.com/article/fe-columnist/is-the-government-doing-enough-for-healthcare/245126/>

An article, *Dementia: When memory fails and world crumbles*, authored by R. Narendhar from ARDSI and carried in *Governance Now*, was widely read and appreciated.

<http://www.governancenow.com/news/regular-story/dementia-when-memory-fails-world-crumbles>

An IAPG Online Q & A was organized on January 14, 2016 with panelists from IAPG (Founder Dr. Ratna Devi), the Partnership to Fight Chronic Disease (Executive Director Kevin Walker) and the International Alliance of Patients' Organizations (CEO Kawaldip Sehmi), as well as other patient organisations. <http://www.patientsandresearch.org/qa/iapgqa>. This had 78,000 impressions, 105 tweets, 54 contributors. The FB page received 14,600 likes and the twitter account @IAPGindia - has 2800 followers

## Work on Rare Diseases

*IAPG remains an active member of the rare diseases and orphan drugs movement in India and has participated actively in several related forums:*

*It was represented at the inaugural Asia Pacific Association of Rare Disease Organisations (APARDO) meeting in Singapore, May 2015, as well as its Annual General Meeting, March 2016*

*Through Dakshama Health, IAPG is present as a member in APARDO and Advisor in Indian Organisation for Rare Diseases (I-ORD). A consensus document on the principles of collaboration between the regional organisations and Rare Disease International (RDI) was drafted jointly, to agree that rare diseases would receive the priority they deserve and this will be represented strongly in all forums*

*IAPG board member, Dr. Ramiah Muthyala, founder and Chairman of IORD sits on the Board of RDI and introduces synchrony across the regions, on rare disease advocacy.*



*IAPG has also contributed to several discussions in India, notably the National Conference on 'Raising the Awareness on Rare Diseases', March 20, 2015 at Hyderabad, where a white paper on orphan drug policy was presented to the Late President Shri Abdul*

*Kalam [http://www.orpha.net/actor/Orphanews/2015/doc/Hyderabad\\_meeting.pdf](http://www.orpha.net/actor/Orphanews/2015/doc/Hyderabad_meeting.pdf),*

*The Indo-US conference on Rare Diseases, 'Realizing The Potential of Rare Disorders in India', September 8-9, 2015, in New Delhi*

*The national seminar on rare diseases, 'Awareness on Rare Diseases - Towards Policy Initiatives on Innovation of Orphan Drugs', January 11, 2016, in New Delhi. The activity served to introduce I-ORD and IAPG to the Delhi audience. The discussions revolved around the need for an Orphan Drug policy and for patient organisations to work together to help shape this policy. The event drew participation from the government, private sector, academia and patient organisations. Dakshama Health and IAPG were represented by Dr. Ratna Devi, who spoke on the importance of patient organisations participating in policy making. The event received considerable media coverage and concluded with a pledge to take forward the policy initiative on rare diseases.*

*On the occasion of International Rare Disease Day, February 28, 2016, patients, academicians, physicians and industry came together for a dialogue on community approaches to rare diseases. The event was organised jointly by Dakshama Health and Education, I-ORD, and IAPG. This roundtable discussion forms a step towards increased communication and collaboration among civil society groups and stakeholders. A Rare Disease Delhi consortium was formed. A patient survey on retinal disorders was conducted in Indore to understand access to medicines for patients suffering from Acute Macular Degeneration and Diabetic Macular Edema the leading causes of adult blindness in India.*



## Policy Advocacy and NCDs in India

*Effective prevention and control of disease requires leadership and multi-stakeholder engagement at several levels, including individuals and communities. IAPG aims to become the platform, creating opportunities for its member organisations to share and speak about the issues they need addressed, by the government and other stakeholders. In the early stages, the advocacy will focus on persuading organisations to join the movement and work together for the cause of patient safety and access in India. As the Alliance matures, it will move towards specific areas of importance, such as Healthcare Access, Financing, Quality of Healthcare and Patient Empowerment through appropriate Knowledge and Information.*

- *Policy and advocacy: We will form clear positions on relevant healthcare policies and processes. We will then advocate for change, with a strong patients' voice at regional and national level*
- *Capacity building: We will provide resources and training to our members, based on their needs, to help them thrive in their own fields*
- *Cross-sector alliances and collaborative working: We will support our members' efforts to further the agenda of patient-centred healthcare. This includes organising events, such as regional meetings, round table discussions and short seminars, where organisations can share best practice, gain insights, and speak up on behalf of patients.*

*IAPG is represented directly and through DakshamA in the Country Advisory committee of Medtronic's Healthrise Project toward changing outcomes for Diabetes and Hypertension using a multi-stakeholder approach. IAPG is closely associated with initiating a patient empowerment component of the project.*

*IAPG and DakshamA are represented on the governance committee of Healthy India Alliance (HIA) and are drafting the patient engagement and palliative care component for policy on NCD care and management.*

*IAPG was invited to participate in the civil society consultation by WHO in July 2015 and April 2016. IAPG led a panel discussion on patient empowerment and Palliative Care.*

*IAPG's Dr. Ratna Devi was a speaker and participated in Second AIIMS-PGI National Course on Public Health Approaches to NCDs, teaching participants the importance of engaging patients in decision making and care management.*

*IAPG was on the panel at the OPPI National Law School Panel Discussion, April 25, 2016 for Innovation in Pharma, IPR and access and part of the 7th Patient Global Congress of the International Alliance of Patients' Organizations (IAPO) in UK, London - with a poster presentation.*

*Other noteworthy events: ICMR-INDIAB (India Diabetes) Dissemination Workshop, April 15, 2016; ICMR-Dissemination of Cancer Registry Data, May 18, 2016; International Seminar on Tackling Chronic Diseases in India, May 23, 2016 by ICRIER; India's Phytonutrient Report: A Snapshot of Fruits and Vegetables Consumption, Availability and Implications for Phytonutrient by ICRIER; ICRIER Special Roundtable on Importance of Strong Drug Regulatory Systems, November 3rd, 2015; ICRIER Dissemination Seminar on Drug Regulatory Reforms in India, September 25, 2015; ICRIER Workshop on Drug Regulatory Reforms in India, May 1, 2015.*

## IAPG Partnership at Awareness Events

- *World Health Day, on April 7, 2016 was celebrated in nine Indian states, in partnership with the Medical Students Association of India. More than 230 medical students conducted a questionnaire-based health session and discussion on diabetes mellitus, for over 8500 students across the country, in the age group of 12-19 years. The programmes were conducted in medical schools, nursing schools and high schools. Rallies were conducted in several public places.*
- *World Kidney Day was celebrated in partnership with Sir Gangaram Hospital New Delhi on April 19, 2015. Over 100 children suffering from chronic kidney disease participated in a painting competition. A patient education book on managing hydration in children, and steps to prevention, was released.*
- *Arthritis and prevention -partnerships were forged with key hospitals to promote physician and patient awareness and training, for the prevention and management of chronic arthritis.*

## Going Forward

*IAPG will continue to expand the Alliance and enroll more organisations to represent patients and promote change for their betterment. It will conduct a needs assessment for patient organisations, to understand their capacity for advocacy, and hold workshops and seminars to enhance this. It will work to create the tools (policy briefs, white papers and position papers) for use by all members. IAPG aims to conduct a patient awareness survey on health policies in India. It will disseminate information and knowledge through a web portal and member organisations. It will continue to organise and participate in Health days and International events and also support the member organisations for greater participation.*

## IAPG Members

- *Dakshayani and Amaravati Health and Education*
- *Alzheimers and Related Disorders Society of India*
- *National Thalassemia Welfare Society*
- *Indian Organisation for Rare Diseases*
- *Indian Patients Society for Primary Immunodeficiency Syndrome*
- *Cancer Aid Society*
- *People for Better treatment India*
- *Multiple Sclerosis Society India*
- *Seek a Miracle Ataxia Group*
- *Think Foundation*
- *Anchal Charitable Trust*
- *Action for Mental Illness India*
- *Muscular Dystrophy Foundation India*
- *Lysosomal Storage Disorders Support Society*
- *Fibromyalgia Awareness*
- *Pallium India*
- *Nada India Foundation*



ISSUED IN PUBLIC INTEREST BY

MEDICAL STUDENTS ASSOCIATION OF INDIA



# THIS WORLD HEALTH DAY

7TH APRIL 2016



## DIABETES

### THE SILENT KILLER

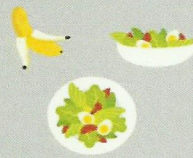
WHAT WOULD YOU CHOOSE?

A HEALTHY REGIMEN



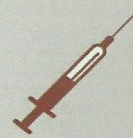
EXERCISE

HEALTHY DIET



LIFELONG TREATMENT

DAILY MEDICATION



INSULIN  
INJECTIONS

PREVENTION IS BETTER THAN CURE

BE ACTIVE | EAT HEALTHY  
FOLLOW MEDICAL ADVICE



DakshamA Health & Education  
*Your Voices Your Choices*



## Core Group

