



UN General Assembly on NCDs

Annual Report 2018

**Dakshayani & Amaravati Health and
Education
Indian Alliance of Patient Groups**

Dr.Ratna Devi, Founder IAPG



DakshamA Health & Education
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IAPG
INDIAN ALLIANCE
— of patient groups —

We bring our 2018 Annual report with great pride. Our advocacy efforts brought new accolades, our voices were heard in India and abroad at various platforms and we developed new voices and ambassadors. We had three key areas of focus for 2018

- Expanding membership base and working on increasing its influence as a patient alliance
- Raise awareness on key public health issues through workshops and seminars
- Engage with stakeholders and influencers to bring attention to healthcare and policy change needed for the country.

➤ **Expanding membership base and working on increasing its influence as a patient alliance**

The IAPG secretariat actively reached out to several member organisations to increase its membership base using popular social media tools like Facebook (<https://www.facebook.com/IndianAllianceofPatientGroups/>) and Twitter @IAPGIndia as well as direct outreach through conferences, meetings and seminars. The website www.iapg.org.in was launched. Current membership strength stands at 42 with a wide spectrum of organisations representing rare diseases, neurological, autoimmune disorders and NCDs. *We received special accreditation from the UN High Level meeting on NCDs and were invited by WHO SEARO as well as the India Office to attend various meetings representing the patient voice.*

Dr Ratna Devi, the CEO of Dakshama Health and Founder IAPG, is on the Board of International Alliance of Patients' Organisations (IAPO) and a member on Board of Asia Pacific Alliance of Rare Disease Organisations, APARDO- A Singapore based charity. She is a member of the WHO's Global Coordinating mechanism - Communities of Practice- "Meaningful involvement of people living with NCDs. She is also the founding Board Member for the ISPOR Asia Pacific Patient Round table. Ten members of the patient alliance were invited to speak or represent at various forums. Seema Chhabra attended the advocacy training in London by World Obesity Federation, Komal Kanitkar won the Bakken award and attended an advocacy training in Hawaii, four members attended the advocacy training in Geneva, Switzerland, Vindhya Vatsayan from Nada India Foundation, a member organisation attended the Sharjah Youth Forum. Four members from the Rare Disease groups attended a management training in Mumbai.

➤ **Raise awareness on key public health issues through workshops and seminars in 2018**

- December 7th 2018- Patient Solidarity Day: IIMR (International Institute of Health Management Research) and IAPG jointly organized an essay competition for children of first and second year of Public health course on the topic “Safe Medications and healthcare for all”. 22 essays were received and five best entries were awarded prizes. This was followed by a round table discussion with patients, civil society and policy makers on the need to focus on safe medication as a key for quality healthcare for all under the Universal health program of India. We participated in a photo contest by International Alliance of patient Organisations and secured the second place.



- December 5th, 2018 – Dr. Ratna was invited as a panelist for the discussion Patient engagement and advocacy in Middle East – opportunities and challenges in Dubai, UAE. The panel explored patient groups in the gulf region and learnings from India that could help the groups engage more strongly for raising patient voice.
- November 29th 2018 – **The Road Towards Good Health – a panel discussion at the shared value summit’ which deliberated on the challenges faced by Indian Healthcare System, government spending on healthcare and outcomes, high out of pocket expenditure, co-existence of obesity and undernourishment, child development etc.** The panel discussed how industry and government can work together to promote better access to healthcare. Dr. Amitava Banerjee, advisor on board IAPG attended the panel discussion.

- November 12th – 14th 2018 EEPO meeting Belgrade. Dr. Ratna Devi was invited as a keynote speaker and panellist for the topic - How the healthcare environment is changing: opportunities and challenges for patient organisations. She addressed over 70 patient representatives from 40 different organisations across eastern Europe.
- October 27th, 28th 2018. IAPG member I-ORD, was represented by Dr. Ramaiah Muthyala in the Asia Pacific Organisations for Rare Diseases board meeting in Singapore. Dr. Ramaiah is also an advisory board member of IAPG. He was elected as the member secy of APARDO.



- October 5th, 6th 2018 Healthcare Sabha Express public health awards. Dr. Ratna was invited as a jury for Express Healthcare's Public Health awards. She was also a panellist for the session New Age, New realities: The changing dynamics and priorities of Public Healthcare and methods to deal with it
- September 25th – 29th 2018. United Nations High level meeting on Non Communicable Diseases (UNHLM on NCDs). Two representatives from Dakshama Health were invited to attend the High level plenary as well as the Civil Society presentations. Dakshama Health also received an invite and a special accreditation to attend the civil society hearing on July 5th 2018 at New York. The representatives from IAPG, Dr. Ratna and Narendhar also attended several side events organised by WHO, industry and other Civil society organisations.
- September 20th 2018- **MTai MedTekon 2018, Role of Medical Technology Industry in the successful implementation of Ayushman Bharat'**. Dr. Ratna was invited as a

panellist to the session- Importance of quality patient outcomes being at the center of Universal Health coverage programs. She spoke about redressal mechanisms, importance of patient safety and quality and the role patient organisations can play in achieving the same.

- September 10th, 11th ISPOR Asia Pacific Patient Round Table, Tokyo Japan. Dr Ratna was invited to make a presentation on Health Care systems and measures to ensure quality. She spoke about Health technology assessment and the need for evidence based care. She is the founding board member of the Asia Pacific Round table.



- September 3rd – 7th 2018. WHO's Seventy first Regional Committee meeting for South East Asia. Two members attended the SEARO Regional meeting and presented three statements on behalf of civil society and patient organisations.
- August 18th 2018- Andhra Pradesh Patient Safety launch and workshop. Dakshama Health and IAPG were commissioned by government of Andhra Pradesh to plan and launch the Patient safety initiative, the focus being on safe injection practices. The Chief Minister Shri Chandrababu Naidu launched the AD (auto disable) syringes project and appreciated the work being done by IAPG
- May 24th 25th 2018. Global Patient Congress Miami. Dr. Ratna attended the congress as a member on board International Alliance of Patient Organisations. She spoke as a panelist in two sessions and also made a poster presentation with the subject-importance of Alliances in furthering the agenda for patient groups and

organisations. The congress was attended by a member organisation ARDSI represented by Narendhar.



- DakshamA Health organised three workshops on patient safety in April, July and December 2018 in partnership with International Institute of Health Management Research. The reports have been submitted as recommendations to the government and to NITI Ayog
- US India IP dialogue by FICCI on 30th November 2018
- Feb 28th, 2018 World Rare Disease day organised by Indian Organisation of Rare Diseases.
- **Engage with stakeholders and influencers to bring attention to healthcare and policy change needed for the country**
 - Engaged with several stakeholders to increase focus on patient engagement and strengthen the patient movement
 - DakshamA Health featured in NCD Atlas for Case study on Best practices. The Atlas is widely disseminated and read by a large number of organisations.
 - Engaged with Niti Ayog for a discussion on science and research being fundamental for innovative medicines and better health outcomes.
 - As founding Board member of HIA (Healthy India Alliance) is involved in policy discussion for NCD at National and International level
 - DakshamA Health and IAPG were part of the drafting committee for National Civil Society engagement guidelines for multistakeholder engagement in NCDs and are actively involved in engaging stakeholders for the National Rare Disease Treatment Policy.



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