



Annual Report 2017

Indian Alliance of Patient Groups (IAPG)



We bring you our second Annual report with great pride. As we grew in strength adding new members, we were heard more widely, invited to strategic platforms to present our views and engaged with stakeholders to increase our reach. The Indian Alliance of Patient Groups (IAPG) had three key areas of focus for 2017

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

⇒ **Expanding membership base and working on increasing our 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. Current membership strength stands at 32 with a wide spectrum of organisations representing rare diseases, neurological, autoimmune disorders and NCDs. A Google group to engage rare disease organisations was created and has active participation of 17 rare disease organisations. Desk research was undertaken to update the previous base of 167 patient-led organisations and the list was updated to 219

Dr Ratna Devi, the CEO of DakshamA Health and Founder IAPG was elected to the Board of International Alliance of Patients' Organisations (IAPO) in November 2017 for a two-year term starting Jan 2018. She will be the voice of patients bringing her experience and passion for the cause of patients to many more people.

IAPG added a sixth principle in its **Principles for Patient Engagement-**

Advocating the for new drugs, diagnostics and treatments for providing patients a better quality of life

Supporting innovation and working with relevant or

organisations to build a robust innovation framework

Knowledge-sharing with Health Care Providers and participating in the healthcare dialogue with policy makers and other stakeholders.

Advocating and participating in research through active dialogue at various levels.

An advisory board has been created for IAPG to bring in representation from various sectors to help and guide the vision of IAPG. The members of the advisory board are

Dr. Sanjeev Kumar-Director, International Institute of Healthcare Management Research, Delhi; former Executive Director, National Health Systems Resource Centre

Dr. Ramaiah Muthyala-President of Indian Organisation of Rare Diseases; and Research Associate Professor, Department of Experimental and Clinical Pharmacology, University of Minnesota

T S Padmapriya-Country Head, Sanitation First UK, board member DakshamA Health

Shobha John-Consultant, World Health Organisation, NCD Alliance

Dr. Amitav Banerjee-Professor, Community Medicine, Dr DY Patil Medical College

Anita Sanghi-Vice President & CFO, NTT Data Services

R Narendhar-Executive Director, Alzheimer's and Related Disorders Society of India

IAPG actively engaged with media through articles, events and opinion pieces in 2017

<http://www.firstpost.com/business/pm-modi-in-us-why-india-should-push-for-strong-healthcare-cooperation-between-the-two-countries-3747217.html>

<http://www.huffingtonpost.in/bloggers/ratna-devi/>

<http://health.economictimes.indiatimes.com/health-files/author/1391/dr-ratna-devi>

[Health Files by Dr. Ratna Devi | ET Health Worldhealth.economictimes.indiatimes.com](http://Worldhealth.economictimes.indiatimes.com) Latest

Health Files: Tackling the Anti-Microbial Resistance in India <http://m.thehindubusinessline.com/specials/pulse/the-case-for-safe-patientsensitive-biosimilar-medicines/article9672283.ece>

<http://m.thehindubusinessline.com/specials/pulse/the-case-for-safe-patientsensitive-biosimilar-medicines/article9672283.ece>

[The case for safe, patient-sensitive biosimilar medicines. m.thehindubusinessline.com](http://m.thehindubusinessline.com/specials/pulse/the-case-for-safe-patientsensitive-biosimilar-medicines/article9672283.ece)



[Stent price capping will put patients in jeopardy: Experts ...www.business-standard.com](http://www.business-standard.com)

http://www.dailypioneer.com/print.php?printFOR=storydetail&story_url_key=missing-the-woods-for-the-trees§ion_url_key=COLUMNISTS

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

<http://iscrconference.org/upimages/122175626410th%20ISCR%20Annual%20Conference%20Program%20and%20Agenda%203rd%20Feb%202017.pdf> INDIAN SOCIETY FOR CLINICAL RESEARCH 10 Annual Conference ...iscrconference.org

Multiple Sclerosis Society (MSSI), interview, Women's Day by online magazine: The Health Site - <http://www.thehealthsite.com/news/womens-day-special-sheela-chitnis-of-mssi-shares-her-inspiring-journey-housewife-to-social-worker-b0317/>

⇒ **Raise awareness on key public health issues through workshops and seminars in 2017**



- December 2nd 2017- Patient Solidarity Day: Nada India Foundation and Dakshama Health in partnership with Muskan Foundation organized Patient Solidarity day to stand together in solidarity to express and work together for the benefit of patients. In an exchange of experiences, several patients related their stories and life journey and personal experiences on how they overcame challenges to manage their conditions
- November 8th, 2017 – ET Health World Webinar, Patient Empowerment, Myth or Reality – Dr. Ratna Devi covered what we need to know about patient empowerment, why patient empowerment is important, health vs medical care and role of empowered patients, how patient empowerment can be incorpo-

rated into healthcare policy and lastly the role of patients and patient groups as advocates for patient empowerment. The webinar was covered in social media, news as well as IAPO newsletter.

- October 29th and 30th 2017 – “Our Views Our Voices” (OVOV) workshop for patient representatives by NCD Alliance in Geneva. Four participants from three organisations attended the OVOV workshop organised by (Non Communicable Diseases) NCD Alliance in Geneva. The workshop focused on the needs and agenda from the perspective of the people suffering from NCDs themselves or caregivers to people suffering from NCDs. Several powerful personal stories were shared by participants on how they overcame the challenges of the diseases and became strong advocates for bringing treatment and diagnostics to people in their countries. Discussions focused on identity, participation, voices, prevention, treatment, advocacy and commitment. The participants were divided into groups to discuss and debate on the agenda items and arrive at consensus as a larger group. The debates were invigorating and the group as a whole drafted the final advocacy agenda in its language, content and important points to be presented at the NCD Forum in Sharjah. Dr. Ratna and Dr. Kanitkar from Dakshama, Hemant from NADA India and Beeta from Indian Cancer Society participated in the workshop.



- August 18th, 2018 FICCI HEAL- Ratna Devi was invited to speak at the conference with a broad focus on the Patient as a Healthcare Consumer. The central theme of the conference was “Indian Healthcare: A Patient’s View”. Dr. Ratna addressed the session on ‘New wave of transparency: Pricing in healthcare’ as a panellist. Adopting a strategy to provide clarity in pricing is crucial to increase patient engagement, safeguard doctor-patient relationship and optimize revenue in a healthcare ecosystem, which is significantly consumer and market driven.



- August 16th 2017, OVOV Delhi - IAPG members ARDSI (Alzheimer's and related disorders society India), NADA India Foundation and Dakshama Health jointly organised this workshop at Indian Cancer Society premises and brought together over 15 patients voices for discussion and to better understand their needs, challenges and expectations from the healthcare system in India.
 - August 10th, 2017- Health Sector Financing - (Partnership for Chronic Diseases) PFC Event -Ratna Devi was invited to speak as a panelist, PFC conducted a multi-stakeholder roundtable discussion, titled “Pre-Pooling – Innovative Financing Mechanisms to Improve Health Coverage in India”, to explore financing options for health cover to all sections of patient groups and consumers. Some of the topics discussed during the event were - Feasibility of establishing risk pooling/pre-pooling mechanism in a diverse and high-burdened country like India and the benefits and challenges of such mechanisms. The role of the center and state governments and the private sector, especially commercial insurance companies and healthcare providers, were also discussed.
 - August 5th 2017 – Seminar on Patient safety- Indian Alliance of Patient Groups (IAPG) and Lady Hardinge Medical College jointly organised a seminar and a panel discussion on patient safety on 5th August 2017. IAPG believes that ZERO preventable deaths are not just a worthy goal, but with the right people, ideas, and technology, it's an attainable goal. Solving this problem is a matter of connecting the dots around patient safety. IAPG is working to connect these dots in a number of ways: by collaborating and breaking down information silos that exist between hospitals, medical technology companies, the government, and other stakeholders and by promoting a culture of patient safety
- After a brainstorming session by experts on the concept and need for patient safety, the global and Indian perspectives, the pharmacovigilance and nursing view point, Government and corporate initiatives and legal and civil society angles, a declaration was prepared for submission to WHO and the Government of India to move forward and create a culture of patient safety among all stakeholders while keeping patients at the center of the system.
- August 4th 2017- Unlocking India's Potential in Biomedical Science & Innovation to Improve Health Care in India and for the World, A Multi-Stakeholder Roundtable – Dr Ratna was invited as a panelist to highlight the patients'

perspective on the need for a focus on innovation for access to better and more effective treatments. She stressed the need to increase focus on biomedical science and biopharmaceutical innovation including global advancement in developing and delivering new ways to detect, treat and cure disease.



- July 11th & 12th 2017 – National Civil Society Consultation HIA (Healthy India Alliance). The consultation brought together civil society, government and other stakeholders like the WHO to deliberate the “Role of Civil Society” in making the commitments to SDG goals for healthcare a reality. It had a special focus on non-communicable diseases and the need for multistakeholder response. Dr. Ratna led a panel on patient advocacy and the need to include patients as a voice in policy making.



- June 9th, 2017- The Sixth OPPI Access Summit witnessed participation from more than 600 delegates and brought together government representatives, policy-makers, leaders from the healthcare and pharmaceutical industries, global healthcare experts and other distinguished professionals who came together to converse on the need to **ACT** now to contain the growing burden of NCDs in India. The summit was supported by the Ministry of Health and Family Welfare, and the



Department of Pharmaceuticals, Ministry of Chemicals and Fertilisers. The Summit had engaging discussions with representatives from the medical fraternity, Government and Patient Groups on ways to tackle this grave public health concern. Dr. Ratna was invited as a panelist for the topic -‘Policies into Practices: Best Practices in Non-Communicable Diseases (NCDs)

- April 26th & 27th, 2017– National Rare Disease Consultative meeting. IAPG was invited to the policy discussion on drafting the National Policy for Rare Diseases. Dr Ratna chaired a session for patient engagement and led the discussion on patient groups engagement and the need for inclusion of the patient voice in the drafting of the policy. She was also part of the drafting committee for the National Policy on Rare Diseases.
- March 26th – April 10th, 2017– AMR Redline Campaign. DakshamA Health and IAPG in partnership with IMA (Indian Medical Association), MSAI (medical Students Association India), OPPI(organisation for Pharmaceutical Producers India), ACPI (Association for Community Pharmacists India and TNAI (Trained Nurses Association India) launched a media campaign on Facebook and Twitter to raise awareness for the rational use of antibiotics

Key messages were drafted and posts tweeted to reach out to audience across the country. Twitter had a reach of 393,800 with 896400 impressions and 603 contributions. Facebook had a reach of 323202 with 374800 impressions and 116313 engagements. Around 200 people also pledged to contribute to the cause on the website.

Feb 23rd, 2017- “Evolving Policies for Cure of Rare Diseases”, New Delhi – Ratna was part of a working group on policy issues of rare diseases. The meeting resulted in a set of recommendations for implementation by the government. The meeting was hosted by IAPG member, Alok Bhattacharya, Schools of Life Sciences & Computation & Integrative Sciences, Jawaharlal Nehru University and founder GNE Myopathy

Feb 26th, 2017 World Rare Disease day organised by LSSD Society. Lysosomal Storage Disorders Support Society (LSSDS), India (Kerala Chapter), held an awareness meeting as part of Rare Disease Awareness Day. Vijay Rupani, Chief Minister, Gujarat State issued a message to recognize that the Institute of Human Genetics, Ahmedabad is recognized as a Center supporting patients with rare diseases with appropriate diagnostic help.

- Feb 10th, 2017– 10th Annual ICSR (Indian Society for Clinical Research) conference on Need for Research in rare diseases in Mumbai. Dr. Ratna was invited to chair a panel for patient representatives and researches to debate on the Need for increased research on Rare Diseases. The conference program focused on various clinical trial reforms towards building future research enterprise as well as discussions on emerging research opportunities in India. The conference was attended by over 500 delegates from medical institutions, ethics committees, biopharmaceutical industry, government, patient organizations and clinical research organizations. Ratna’s views and insights helped to shape the conference deliberations towards building future research enterprise in India.





- ⇒ **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.
 - IAPO engaged with IAPG and its member Pallium India for the development of a global pain management resource toolkit. Pallium India contributed its Indian resources and the experiences from India
 - Exchange visit to Varanasi to understand PSM India's work on Universal Healthcare Coverage (UHC) and explore likely areas of collaboration.
 - Invited as panellist to Pfizer Forum -Emerging Healthcare Landscape in India to explore opportunities for patient engagement in the vision of Pfizer in India.
 - Engagement with NIRD (National Institute for Rare Diseases) for the development of a civil society roadmap for rare disease policy implementation.
 - IAPG is recognised by WHO SEARO and WHO country office India as the Patient Coalition working in India and invited to several meetings.
 - As founding Board member of HIA 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

Principles of IAPG Patient Centred Healthcare

- ◆ **Promoting Patient Engagement in Health Policy Decision-Making**
- ◆ **Supporting Access to the Best Available Care Across the Country**
- ◆ **Promoting Health Literacy and Ensuring the Availability of Health Information**
- ◆ **Advancing Choice and Empowerment of Patients and their Advocates.**
- ◆ **Building a strong voice in support of building a responsive, patient-centred national and state healthcare system**
- ◆ **Advocating the need for new drugs, diagnostics and treatments for providing patients a better quality of life**

IAPG Member Organisations

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| 1. Dakshayani and Amaravati Health and Education | 21. Social Welfare Services Association |
| 2. Alzheimer's and Related Disorders Society of India | 22. Citizens awareness group |
| 3. National Thalassemia Welfare Society | 23. Cancer Aid Society |
| 4. Indian Organization for Rare Diseases | 24. Thalassemia and Sickle cell society |
| 5. Indian Patients Society for Primary Immunodeficiency Syndrome | 25. National Coalition of People living with HIV (NCPI+) |
| 6. People for Better treatment India | 26. CanKids |
| 7. Multiple Sclerosis Society India | 27. Thallasemics India |
| 8. Seek a Miracle Ataxia Group | 28. MERD India (Metabolic Errors and Rare Diseases organisation) |
| 9. Think Foundation | 29. Indian Rett Syndrome Foundation |
| 10. Anchal Charitable Trust | 30. Sjorgen Group |
| 11. Muscular Dystrophy Foundation India | 31. Cystic Fibrosis India |
| 12. Lysosomal Storage Disorders Support Society | 32. Fragile X syndrome |
| 13. Fibromyalgia Awareness | 33. Interstitial cystitis India (Painful Bladder Syndrome) |
| 14. Pallium India | |
| 15. Nada India Foundation | |
| 16. Indian Cancer Society | |
| 17. Scleroderma India | |
| 18. World Without GNE Myopathy | |
| 19. Dystrophy Annihilation Research Trust (DART) | |
| 20. Association of Community Pharmacists of India | |



Chandu George from Seek a Miracle Ataxia Foundation receiving the patient champion award