

DAKSHAYANI AND AMARAVATI HEALTH AND EDUCATION

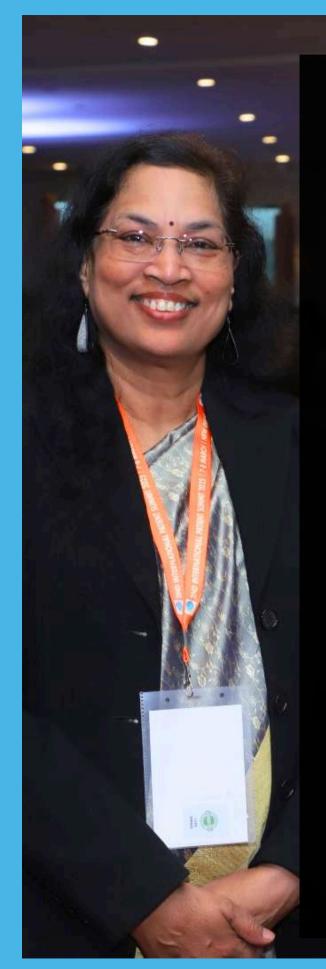
Annual Report 2025



TABLE OF CONTENTS

Letter from the CEO	1
About Us	2
Our Team	3
Our Focus Areas	4
Our Projects	5
Our Publications & Contributions	16
DakshamA Health Representation & Engagements in 2025	18
Contact Information	20





LETTER FROM THE

DakshamA Health is a not-for-profit implementing agency committed to strengthening patient advocacy, delivering on-ground healthcare support, and translating lived experience into meaningful systems change.

Our organization carries the name *Dakshayani & Amaravati* in honour of two women whose resilience and integrity shaped the values we stand for. Their lives inspired our founding team, and their legacy continues to guide our mission: to improve how health is perceived, accessed, and delivered in India.

In 2025, we actively worked to bring patient and caregiver voices to the centre of health decision-making. We focused on building practical solutions for people living with rare diseases, cancer, mental health conditions, and other chronic illnesses—ensuring that care is safe, accessible, and grounded in real patient needs.

As a full member of the International Alliance of Patient Organisations (IAPO), we remain aligned with a global movement that believes patients must be equal partners in shaping health systems. This year has reinforced that belief. Whether through counselling support in hospitals, community outreach, training frontline teams, or co-developing policy materials, our core commitment has stayed the same: to put people first.

Thank you to our partners, supporters, and the communities we work with. Together, we continue to build a healthcare ecosystem that listens, includes, and delivers.

- Dr Ratna Devi

VISION

Empower patients and caregivers with the right knowledge, tools and forums to seek and access healthcare options that suit their needs and through their voices bring about a positive change in the healthcare environment.

MISSION

A world where people live a healthy and disease-free life through knowledge-based choices in an atmosphere of equality, equity and access.

WHY THIS?

01

Millions of patients face chronic or complex health conditions with no psychosocial support.

02

There is limited health literacy and counseling support at the point of care.

03

Vulnerable communities lack access to credible health information or navigation help.

04

Patients' voices are excluded from policy, safety, and system design.



OUR CORE TEAM



Dr. Sita Ratna Devi Chief Operating Officer



Jugesh Mourya
Head Finance and HR



Bikash Prasad
Head IT and Administration



Mugdha Barik Senior Program Manager



Dr. Riya AgrawalProgram Manager



Dr. Mohini SinghProject Officer

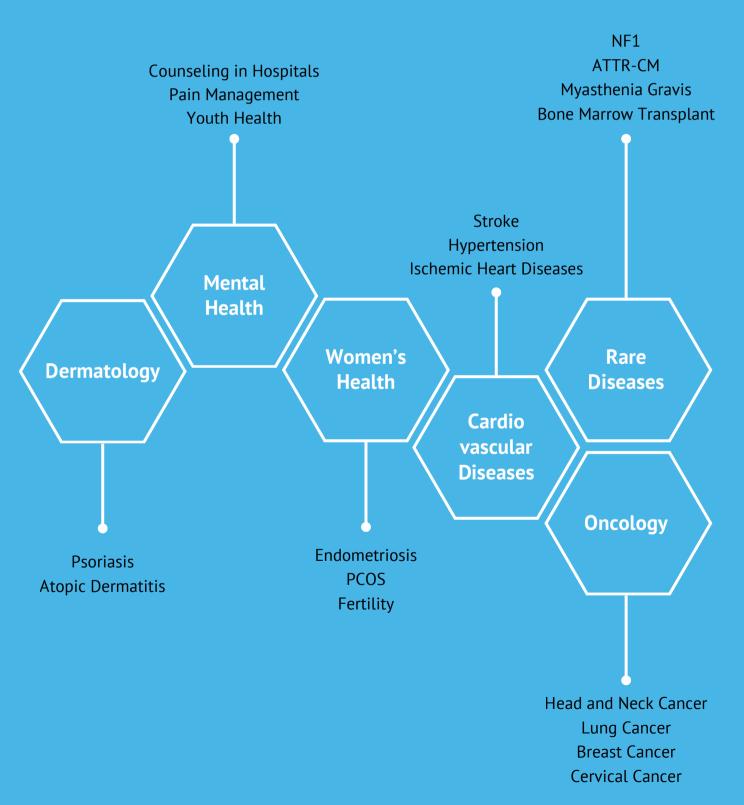


Shantanu Satapathy
Project Coordinator



Rohan Shukla Program Support Coordinator

OUR FOCUS AREAS



OUR PROJECTS

In 2025, we undertook initiatives that brought patient and caregiver perspectives to the forefront of healthcare delivery and systems change.

01

STEP UP FELLOWSHIP PROGRAM

02

SPAN-HNC SUPPORT

03

POLICY ADVOCACY ON REUSE OF SUDs 04

RARE REACH INITIATIVE

05

INTERNATIONAL PATIENT SUMMIT 2025

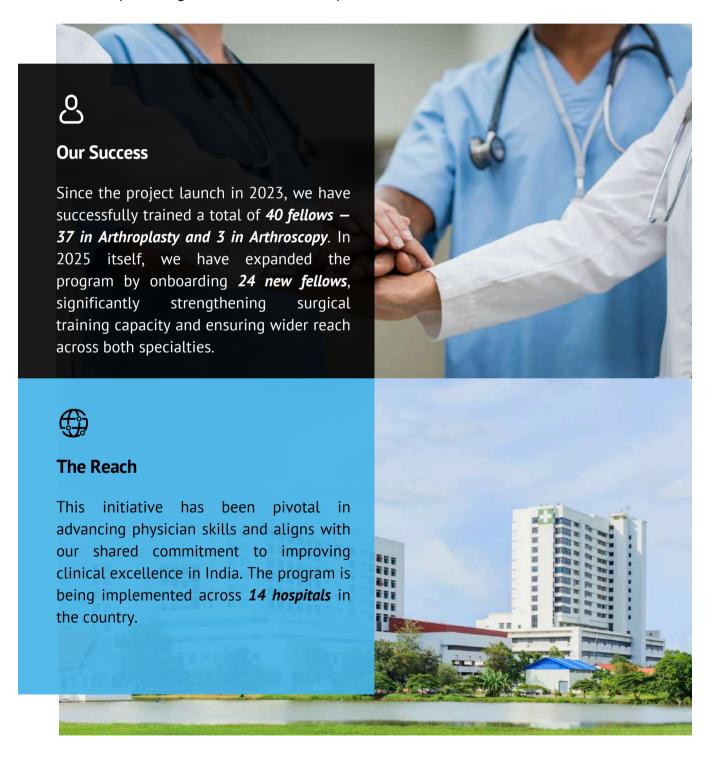
06

PFPSN-INDIA (patient safety)



STEP UP FELLOWSHIP PROGRAM

The *Sustained Training & Education Project – Upgrading Physician Skills* project was designed to enhance surgical skills in arthroplasty and arthroscopy by supporting structured hands-on fellowship training across accredited hospitals in India.



SPAN-HNC SUPPORT

A Brief about our project

The *SPAN-HNC (Screening, Patient Awareness, Nutritional Support- Head & Neck Cancers)* project is a CSR project being implemented by DakshamA Health since 2023, successfully tackling critical barriers in patient care by integrating counseling, nutrition support, awareness, and community engagement into a sustainable and replicable model.





Nutritional and Medical Support Distributed 700+ nutritional supplements to needy among HNC patients, as well as expanded care essentials to include items such as mouthwash and other hygiene materials, strengthening holistic supportive care.

POLICY ADVOCACY ON REUSE OF SUDS(SINGLE USE DEVICES)

THE PURPOSE

 To build regulatory momentum, improve ethical practices, and safeguard patient rights regarding the reuse of single-use medical devices (SUDs) in India.

THE PROGRESS

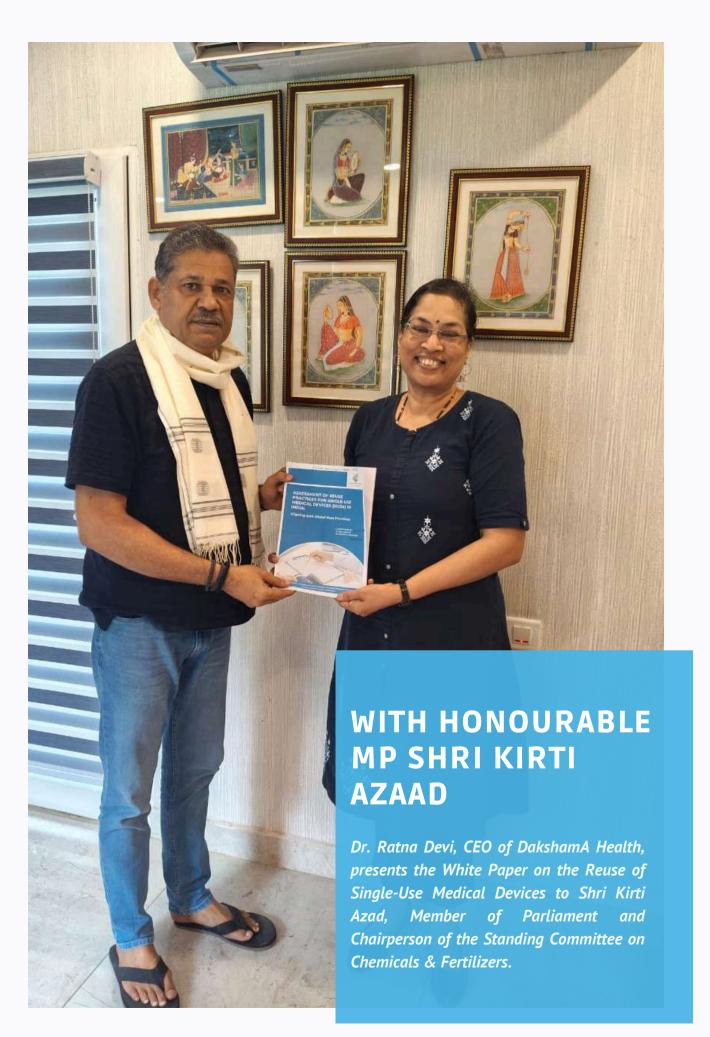
- Final white paper published and disseminated widely (publicly available).
- Stakeholder outreach expanded from 15 to 77 stakeholders, including parliamentarians, regulators, patient groups, and technical experts.
- High-level meetings conducted with:
- 1. Director of Medtech Policy
- 2. Joint Director, National Health Authority
- 3. Patient Safety Secretariat, MoHFW
- 4. Additional DG & Director (EMR), DGHS
- White paper shared with the Standing Committee on Health, IMPF, elected representatives, and CLRA.

KEY MILE STONES

- Meeting with Shri Kirti Azad, Chairperson, Standing Committee on Chemicals & Fertilizers (28 August 2025).
- Resulted in initiation of a draft Private Member's Bill proposing amendments to the Clinical Establishments Act and the Drugs & Cosmetics Act.
- Draft guideline framework for SUD reuse circulated for expert feedback.

THE TAKEAWAYS

- MoHFW formally acknowledged gaps in current regulation.
- CDSCO reiterated that SUDs cannot be reused and misuse constitutes an offence.
- No existing guidelines on safe reuse—creating space for policy change.



RARE REACH INITIATIVE

THE NF1 PROJECT

To build a robust support ecosystem for NF1 patients in India through awareness, early diagnosis, peer support, patient advocacy, and multi-disciplinary clinical coordination.



IMPACT SUMMARY

2025 marked a major acceleration in NF1-focused work at DakshamA Health community formation, engagement, referral expert strengthening, and clear progress toward establishing a long-term national NF1 ecosystem. With patient advocacy, support, and diagnostic strengthening running in the project significantly parallel, deepened national visibility for NF1. A formal MOU was signed with AIIMS New Delhi patient to support navigation.



PUBLISHED ARTICLES

- NF1: A Call for Inclusion in National Policy for Rare Diseases 2021
- The Long Wait and the <u>Struggle of Families Battling</u> <u>NF1</u>



ACHIEVEMENTS

- NF1 Support Group formally launched with a growing community hosted via WhatsApp (56 active members).
- Publication of the first NF1 patient testimonial video on YouTube — amplifying lived experience and public awareness.
- Link: https://youtu.be/e69BsuFjkWM
- Three additional patient testimonies recorded and currently under editing.
- Organized 4 Patient Experience Sessions and 2 Capacity-Building Sessions for NF1 patients & caregivers.
- Conducted the first NF1 Working Group Meeting, initiating the formation of a clinical Multidisciplinary Team (MDT) for diagnosis, referral, and case management.
- Established two NF1 referral desks.
- Running an active NF1 Helpline Desk, a Facebook support group, and Instagram page (NF1 Warriors) for continuous patient support.
- Identified and mentored **2–3 NF1 patient advocates** empowering them to participate in events and support the community.
- Supported patient-led advocacy letters to government requesting access and affordability reforms.

RARE IMPACT 2025

Rare Impact 2025 is a collaborative, *patient-inclusive virtual hackathon* focused on tackling the toughest challenges faced by people living with rare and genetic disorders.

Held under the Rare Reach Initiative of DakshamA Health in partnership with PAIR Academy, this event connected multi-stakeholders from *India, Vietnam, Thailand, Malaysia, Philippines, Singapore, and Nepal* to co-create digital tools, platforms, and systems that drive change.

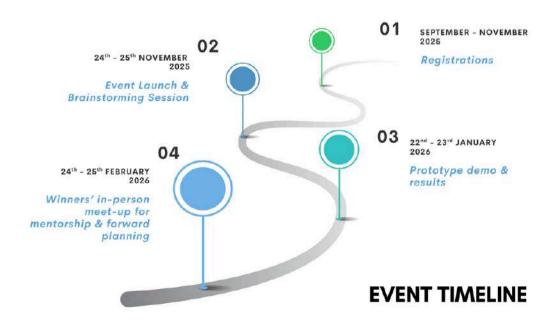
20+ Representatives from Patient Groups

10+ Clinical and Research Experts

5+ Policy & Subject Matter Experts as Mentors

Teams representing 7 countries





HOW THIS WILL IMPACT THE CURRENT RARE DISEASE LANDSCAPE IN INDIA

Rare Impact 2025 is more than a hackathon — it is a systems-building initiative. By bringing together patients, clinicians, researchers, innovators, and policy experts, the event aims to catalyst for long-term transformation across the rare disease landscape in India and the Asia-Pacific region.

Elevating Patient Voice in Innovation

- Ensures solutions are co-designed with patients, not for them.
- Incorporates lived experience into tool building, strengthening relevance and usability.
- Trains patient representatives to participate in tech development, advocacy, and evaluation.



Enabling Scalable, Low-Cost Public Health Solutions

- Teams are encouraged to build lightweight digital tools that can be adopted by hospitals, NGOs, patient groups, and primary-care settings.
- Focus on open-source, interoperable, or policy-aligned designs.

Creating a Pipeline for Innovation & Policy Integration

- Solutions include early symptom identification, referral pathways, clinical decision aids, etc.
- Mentors from clinical specialties guide teams on accuracy and applicability.
- Tackle geographic and socioeconomic barriers that currently limit access.



INTERNATIONAL PATIENT SUMMIT 2025

The 2nd International Patient Summit held on March 7–8, 2025 in New Delhi, served as a landmark platform for advancing the conversation on health, climate change, and patient-centered action in the Asia-Pacific region. Organized under the theme "Health, Climate, Community: Uniting Stakeholders for Action," the summit brought together over 600 registrants, including more than 130 in-person participants from 33 countries. The diverse audience featured patient advocates, policymakers, public health professionals, academics, and industry leaders—each committed to shaping resilient and inclusive health systems in the face of growing environmental challenges.





100+

Patient Advocates

Over the two days, the summit featured a series of high-level panel discussions addressing a range of pressing topics-from universal health coverage and chronic disease management to mental health, digital health equity, and climateresponsive infrastructure. Conversations underscored how community data, local leadership, and technological innovation are essential to both preparedness and accountability. The active participation of speakers from the Ministry of Health and Family Welfare, Government of India, and the World Health Organization further validated the summit's relevance on the global health agenda.















PATIENT SAFETY WEBINAR SERIES

Hosted under the Patients for Patient Safety Network – India (PFPSN-India)



About PFPSN-India

Patients for Patient Safety Network – India (PFPSN-India) is a national patient-led platform working to advance safer, more transparent, and people-centred healthcare across the country.

The network brings together patients, caregivers, advocates, clinicians, publichealth experts, and institutions committed to reducing preventable harm. DakshamA Health serves as the Secretariat for PFPSN-India and leads awareness activities, training, and system-wide advocacy on patient safety.

Purpose of the Webinar Series

The 2025 Patient Safety Webinar Series was launched to strengthen awareness, capacity, and public dialogue around critical patient-safety challenges in India.

Anchored to the WHO World Patient Safety Day 2025 theme — "Safe Care for Every Newborn and Every Child — Patient Safety from the Start" — the series focuses on ensuring safety across maternal, newborn, and child healthcare systems.

WEBINAR 1: Safe
Birth and Neonatal
Care: Strengthening
Health Systems for
Every Newborn

DATE: 13th June 2025 EXPLORE: Click Here

WEBINAR 2:

Minimizing Risks in Medication, Nutrition, and Immunization: Strategies for Children and Adolescents

DATE: 30th July 2025 EXPLORE: Click Here

WEBINAR 3:

Strengthening
Public Health
Systems: Policy,
Partnership &
Strategies

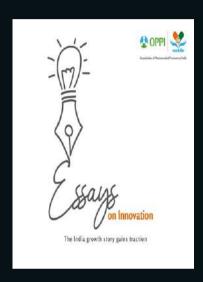
DATE: 19th Sept 2025 EXPLORE: Click Here

In addition to leading the Patient Safety Webinar Series under PFPSN-India, DakshamA Health was also invited to represent patient perspectives at the WHO Virtual Regional Workshop on Patient Safety: "Striving for Zero Avoidable Harm, Quality of Care, and Alignment with National Health Policy / IPC Strategy" held from 1–2 May 2025.

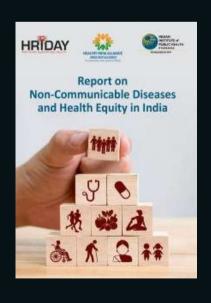
At this workshop, Dr. Ratna Devi delivered a session on "Patient Networks Driving Inclusion of Patient Voice into Patient Safety Programs", highlighting how organised patient groups, including PFPSN-India, play a critical role in shaping safer healthcare systems. Her participation reinforced DakshamA's commitment to embedding lived experience into national safety strategies and positioned the organisation as a regional leader in patient-centred safety advocacy.

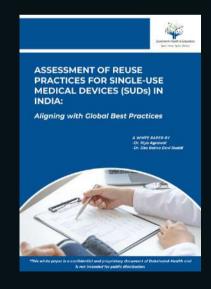
OUR PUBLICATIONS & CONTRIBUTIONS













CONTD.



Together, these publications not only contributed to the evidence base on patient-centred healthcare but also positioned DakshamA Health as a credible voice in national and global conversations. Our growing body of work opened doors for deeper collaboration and visibility, enabling us to represent Indian patient perspectives in key forums throughout 2025.

The following section highlights these engagements—events where our research, insights, and on-ground experience directly informed dialogue, strengthened partnerships, and reinforced our commitment to building a more inclusive and responsive health ecosystem.

By representing patient perspectives in high-level forums, policy dialogues, and multi-stakeholder conferences across India and abroad, we ensured that the insights emerging from our research directly informed real-world discussions.

These engagements not only amplified the voices of patients but also enabled us to build strategic partnerships, learn from global best practices, and bring those lessons back into our programmes.

DAKSHAMA REPRESENTATION & ENGAGEMENTS IN 2025

FEBRUARY

4th Global NCD Alliance Forum | Rwanda



MAY

National Dialogue on Happy ageing among PLHIV & Cervical Cancer among Women Living with HIV | India





MARCH

GLC4HSR Annual Conclave 2025 | India

Life Course Immunization: Pulse of a Resilient Health System | *India*

2nd International Patient Summit 2025 | India



JULY

PACER Workshop 5 | *India*

PHILIPS Future Health Index 2025 | Virtual

AUGUST

FICCI Rare Diseases Conference 2025

India

ICMR National Co-Design Workshop | India



OCTOBER

5th edition Future of Health Asia | *Singapore*



DECEMBER

ESMO Asia Congress 2025 | Singapore
One Day International Conference on
Navigating Cell Therapy in India | India



SEPTEMBER

ICHOM Conference 2025 | Ireland



NOVEMBER

22nd CII Health Summit 2025 | India

Rare Impact 2025 | Virtual

APARDO Conference 2025 | *Indonesia*

GHH Unite Summit 2025 | *Ireland*

IAPO 11th Global Patients Congress | *Philippine*

OPPI Annual Summit | India

Inaugural GCM Participant Gathering | Virtual





THANK YOU

Please reach out to us at:

- communications@dakshamahealth.org
- Mead Office: VANI House, First Floor, Opposite Singla Sweets, Dwarka Sec 8, New Delhi, India 110075 Reg Office: K 203, Mahindra Aura, Sector 110 A, New Palam Vihar, Gurgaon 122017
- 🕲 +91 8130050439 🌐 https://www.dakshamahealth.org