



ANNUAL REPORT 2022



Dakshama Health & Education

Your Voices Your Choices

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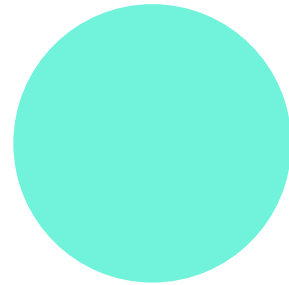
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INTRODUCTION



Dakshayani & Amaravati Health and Education is a non-governmental organization registered under the Companies Act (1956) of India.

DakshamA Health aims to bring a change in the way health is perceived and delivered in the country. It strives to bring together patient and caregiver voices and make healthcare accessible, safe and within the reach of person who needs it. It is a full member of IAPO (international Alliance of Patient Organisations) a global voice for patients and is represented in various capacities at the World Health Organisation, UN and other International agencies.

Established in 2012, It has strived to bring a paradigm shift and create a space for inclusion, equity and integration of the patient voice into policy, research and health system strengthening



MISSION

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.

VISION

A WORLD WHERE PEOPLE LIVE A HEALTHY AND DISEASE-FREE LIFE THROUGH KNOWLEDGE-BASED CHOICES IN AN ATMOSPHERE OF EQUALITY, EQUITY, AND ACCESS.

MESSAGE FROM THE CEO

Dear esteemed stakeholders,

I am thrilled to present our 2022 Annual Report, which highlights our achievements and progress in advancing our mission of providing accessible and quality healthcare to all.

Over the past year, our dedicated team at DakshamA Health has worked tirelessly to bring innovative and effective solutions for patients and caregivers, and I am proud to see the positive impact we have made. Our commitment to research and development has allowed us to bring new treatments and technologies to market, improving the lives of countless individuals.

We have also continued our efforts to raise awareness and promote equitable access to healthcare, particularly for marginalized communities. Our partnerships with leading organizations in the field have allowed us to make significant progress in advancing this important mission.

We remain committed to providing the highest level of care and service to our patients and communities. I would like to thank all our stakeholders for their continued support and partnership, and I look forward to more inclusion of the patient voice and lived experiences in the years to come.



Dr. Ratna Devi
CEO & Co-founder

FOCUS AND OBJECTIVES OF DAKSHAMA HEALTH

INFORMATION	CAPACITY	RESEARCH	PARTNER	ADVOCACY
<p>Develop and disseminate accessible, well-structured and user-friendly information and education resources on therapeutic innovation, access to care and safe medicines</p>	<p>Build competencies and expert capacity among well informed patients and the public about pharmaceutical R&D, self-care and home-based care.</p>	<p>Conduct research and Gap analysis on needs and policy for access and equity.</p>	<p>Build cross-sector alliances and working collaboratively with like-minded medical and health professionals, policymakers, academics, researchers, and industry representatives.</p>	<p>Advocate nationally with a strong patient voice on all aspects of healthcare policy, with the aim of influencing national, regional and state health agendas and policies.</p>

PROJECTS

- Stroke Support Alliance
- Atopic Dermatitis Need Assessment Study
- Integrated Health Care
- Community Of Psoriasis Supporters
- Patient Safety
- Advocacy for Rare diseases

STROKE SUPPORT ALLIANCE



Stroke is a leading cause of mortality and disability worldwide and the economic costs of treatment and post-stroke care are substantial. Every year, approximately 1.8 million people suffer from stroke, which is the second most common cause of death after coronary artery disease (CAD) globally. Stroke has become the 5th leading cause of death in 2016 from 12th cause in 1996 and claims 119-145 lives in every 100,000 population.

A policy recommendation paper was developed based on the deliberations from three multi-stakeholder roundtable discussions held in South (28th August), North (18th September) and West (18th July). The regional discussions were followed by a National Consultation and attended by 14 experts. The meeting was organized by DakshamA Health and Indian Stroke Association jointly and supported by Healthy India Alliance, PAIR- Patient Academy for Innovation and Research and Bombay Stroke Society. The paper reflects upon the urgent need for addressing Stroke as a health crisis and the possible tangible interventions suggested by the group of experts. Key takeaways were presented to various stakeholders to address the challenges and find solutions that could help increase access, provide information in simple language and help people reach hospitals within the golden hours.

The National stroke guidelines are welcome guidance for specialists; however, the outcome of stroke is very dependent on the patient reaching the hospital on time and well within the golden hours so that appropriate interventions can be undertaken. Initial research at the commencement of the project indicated that most patients lose precious time due to a lack of awareness amongst themselves as well as family members on the warning signs of stroke

National Stroke Guidelines 2019 have undergone a recent revision as per discussions and meetings with specialists, the Ministry of Health and Family Welfare and the Directorate General of Health Services. The updated guidelines will cover treatment alterations such as dose modifications and concrete standard protocols for delivering stroke care. The Stroke project was conceived and delivered to increase awareness through the participation of stroke survivors and family caregivers using a multipronged approach that included developing a website and use of social media channels. It nurtured patient advocates to bring their voices into the policy discussion as they addressed some of the gaps in the stroke management ecosystem.

THE PROJECT GOAL & OBJECTIVES



Create a strong National Voice through Patient Leaders for Stroke Warriors and Caregivers.

- 20 webinars including rehab sessions with 16 survivor stories including 12 videos and 4 text stories were recorded. 160 specialists were approached to understand the challenges for access to patients who suffered stroke and were unable to reach a hospital on time.
- 4 scholarships were awarded to Stroke survivors (Ms. Akansha, Mr. Arvind, Mr. Bhavesh and Mr. Mohan) on World Stroke Day as an encouragement their skills to enable them to lead a better life and meet the demands of the family.
- Social Media assets – Website, Facebook, WhatsApp group and Instagram was developed for disseminating information and reaching out to people.
- Resources on Stroke ready hospitals, availability of physiotherapy, speech therapy and occupational therapy services were gathered and widely disseminated.
- Advocacy with State and National governments for increasing the number of Stroke ready hospitals, inclusion of neurology packages into Ayushman Bharat Yojana and access to rehabilitation services was undertaken throughout the year

IEC materials on Stroke were developed which included 15 different pamphlets with different messages. A multilingual booklet on surviving stroke was also developed for the vernaculars. A podcast was recorded which was uploaded on Spotify which was uploaded and didn't had any monetization for the social good of the community. A short film on Stoke Awareness was created in both English and Hindi.

2 articles were penned one by Dr Jeyaraj Pandian on "Stroke is a leading cause of disability and death in India" which was published in News9 and another article "Are post stroke complications pushing young stroke survivors towards lowered quality of life and disability?" was coauthored by Dr. Ratna Devi and Tamanna Sachdeva which was published in Express Healthcare.

ATOPIC DERMATITIS NEEDS ASSESSMENT STUDY

Atopic dermatitis (also known as AD) is the most common type of eczema and typically begins in childhood, usually in the first six months of a baby's life. Even though it's a common form of eczema, it's also severe and long-lasting. Often, it disappears as a child grows older, though some children will have atopic dermatitis flares into adulthood. It exists with two other allergic conditions: asthma and hay fever (allergic rhinitis). An estimated 10% of all people worldwide are affected by atopic dermatitis at some point in their life.

Dakshama Health conducted needs assessment in 2022 to understand the gaps in access to diagnosis and treatment of patients with of Atopic Dermatitis. The goal of this needs assessment was to determine the level of awareness around AD, the impact of it on patients' quality of life, and the potential for advocacy initiatives focused on AD survivors and caregivers. The assessment was conducted over a period of two months through patient interviews and mini focus discussions covering 21 moderate AD patients and 3 severe AD patients. The study included various participants from different areas of the country and represented age groups ranging from 13 years old to 60 years old.



Key Findings of the assessment study

Awareness

Various levels of awareness of the disease can be seen across socioeconomic classes. Higher socioeconomic classes have moderate awareness, while lower socioeconomic classes have minimal to no awareness.

Patient Journey

Patient waits and watch assuming 'allergy' and low awareness. Visiting a GP depending on severity of pain/flare ups. Home remedies by most for initial week. Increased symptoms-visiting doctor (mostly family physician). Compliance with medicines/lifestyle change suggested by a GP. Dermatologist post referral from GP. Patients with mild symptoms get relief both at symptom and emotional level. Stop using medicine once symptoms subside. Visiting doctor/medication continuation post flare ups. Moderate patient tries lifestyle changes. Associated stress, anxiety continue for patient and caregivers for those suffering with severe symptoms

Doctor's patient interaction

Patients and caregivers go to the GP/family doctor and ask questions about the causes, triggers, treatment. Basic medicine given by GP to control symptoms. Patients go to the specialist (dermatologist) as suggested by GP if infection spreads. Doctors do not discuss the disease's etiology or causative factors. The amount of time spent varies depending on the severity of the patient's condition. Patients continue with the medicine prescribed in case of uncontrolled flare-ups, without further visits.

Treatment

Understanding the source and progression of 'allergy' might take up to 3-4 months for patients and caregivers. The first step is to see a doctor and start taking medication, which is usually applied topically. The amount of time spent on medication depends on the severity of the symptoms and whether it has spread to other parts of the body. The ideal outcome would be for the patient to be entirely cured, but for many, treatment will last a lifetime. The ultimate goal is to provide the best quality of life possible while dealing with the disease.

Patient expectations

The patient expects a doctor to spend adequate time with patients and listen to them. They expect a medication both effective and holistic and provides long-term relief from pain and symptoms. Prevention and treatment of frequent flare ups and itching sensations, complete cure of the disease. The cost of the treatment (medicines and doctors) should be reduced. Medication should be available everywhere and not just with few chemists/hospitals.

ROUND TABLE MEETING

COLLECTIVE ACTION TOWARDS INTEGRATED CARE

On August 30, 2022, Healthy India Alliance and DakshamA Health (an HIA member) held an in-person Round Table meeting aimed to identify the barriers and drivers, as well as a research agenda, to enable successful HIV/TB-NCD integrated care, including successful community engagement mechanisms.

"Collective action towards integrated care- Cross learnings from NCD, TB, and HIV programmes" was the theme of the Round Table meeting.



For the purpose of facilitating cross-learning across various health sectors on how to successfully increase investments in the sectors and community engagement strategies that meaningfully involve people with lived experiences, numerous stakeholders working on HIV, TB, and NCDs, including those with lived experience of HIV, TB, and NCDs, came together.

People living with NCDs, and PLWHIV/TB and NCDs shared their experiences and insights on effectively involving individuals who have lived experiences. The deliberations and the findings of the discussions have been captured in a report.

The meeting included pathways and evidence around increased investment for health and NCDs, successful community engagement, and mapping commonalities and specificities between the three sectors, for what can be adapted and translated from HIV and TB, as well as recognising the nuances of challenges in the community engagement for NCD sector, as well as recommendations toward successfully synergising health sectors for collective action toward. The round table meeting not only provided insights into policy recommendations and improvement for integrated programmes, but it also emphasized on the need for more high-quality HIV/TB-NCD research.

- NCDs, including HIV/TB, are preventable diseases that can be addressed through multisectoral and multistakeholder participation. Effective prevention requires addressing common risk factors and addressing social and economic determinants. The healthcare system and community needs influence the relevance of integrated care, and community participation should be encouraged. Ayushman Bharat-PMJAY can be an entry point for treating co-morbidities, improving efficiency, and generating data. Political commitment and funding are needed for the integration of healthcare services. There is limited data on the implementation and feasibility of integrating other NCDs into screening programs. It is important to assess the acceptability and relevance of integrated services from both the provider and patient perspectives.
- Following the pandemic, new models of global health support are likely to emerge, with the roles of existing global health funding mechanisms being reconsidered and other funders potentially stepping forward. Stakeholders and policymakers must now assess what has been learned about developing better integrated services that meet the needs of the poorest. Integrating NCD services into established, funded disease-specific programmes can provide critical priority health interventions to key groups and communities. Such efforts can serve as a starting point by fostering relationships and trust among people working in different disease areas who must collaborate if the journey to UHC is to be successful.



COMMUNITY OF PSORIASIS SUPPORTERS



Psoriasis is a non-communicable, common inflammatory skin disease affecting 2-3% of the population worldwide, i.e., approx. 125 million people. The prevalence of psoriasis in India among adults varies from 0.44 to 2.8%. Rare Psoriasis Disorders have an even lower prevalence and incidence. It is characterized by an unpredictable course of symptoms, a variety of extrinsic triggers, and severe comorbidities, such as arthritis, metabolic syndrome, cardiovascular disease, inflammatory bowel disease, and depression.

In order to have an inclusive, all-round approach to disease management, a patient-centered strategy with an equal voice for individuals living with the condition has been recognized as the best approach globally. In India, patient engagement has been inconsistent, particularly in dermatological disorders. Lived experience is impacting global policy, as evidenced by the recent informal consultation of people living with NCDs organized by WHO and several other high-level meetings held globally.

A similar effort is being made to lead a patient initiative for people living with Psoriasis and Rare Psoriasis Disorders (PRPD) patients in India, with the goal of raising awareness and engagement from a wide range of stakeholders.

The NPCDCS focuses on five major diseases as defined by WHO's 5*5 strategy and misses the inclusion of dermatological and autoimmune conditions like psoriasis that are chronic, progressive debilitating conditions with effects on heart, joints and other systemic organs. The effect on quality of life is very high with loss of income, stigma and issues of mental health like depression.

Project goal: Create a strong patient voice of people living with psoriasis and rare psoriasis disorders.

Project Objectives:

- PRPD Patient Group Formation
- Awareness amongst psoriasis patients and caregivers
- Advocacy around psoriasis and rare psoriatic disease



Key outcomes of the project

Stakeholders were reached out, and a database of organisations, psoriasis support groups, and dermatologists in India was developed. Psoriasis patients and their caregivers were approached as a part of the initiative. Community of Psoriasis Supporters was named as a part of the umbrella organisation, and as part of this initiative, online meetings with dermatologists and patients were conducted to facilitate outreach to psoriasis patients.

A patient group formation was made with 5 patient advocates. 50 psoriasis patients in a WhatsApp Group and caregivers Facebook group of 232 psoriasis patients and caregivers was formed with 400+ registrants in a webinar, 5 GPP patients identified. A survey “**Understanding gaps and challenges for psoriasis management in India (Needs assessment)**” was developed for dermatologists to understand more about psoriasis treatments available in India. Patient videos, newsletter, pamphlets and different resource material was developed.

Partnerships and outreach to national and international organizations: 250+ specialists were reached out during the project to increase the visibility of the cause amongst various stakeholders.

Partnership with Indian Association of Dermatologists, Venereologists and Leprologists (IADVL)

Policy makers: MoHFW, CDSCO, DGHS, COEs, NHA, ICMR, DBT, Centre of excellence of rare diseases

Hospitals: AIIMS Delhi, AIIMS Bhopal PGIMER Chandigarh, LHMC, MAMC, JIPMER, Father muller medical college and hospital, BJ Medical College-Civil.

International: APARDO, IFPA, Global skin, Rare Cancers Australia

World Psoriasis Day Event On the occasion of World Psoriasis Day, 27th October,2022, Community of Psoriasis Supporters in collaboration with Indian Association of Dermatologists, Venereologists and Leprologists (IADVL) successfully organized a virtual event with the theme “**Uniting for Action- Building A Voice for Psoriasis Patients in India**”. [Click here to access the report.](#)



PATIENT SAFETY WEBINAR SERIES 2022

A series of webinars were conducted from 2021 to 2022 by International Alliance of Patients' Organizations (IAPO) and Patient Academy for Innovation and Research (PAIR Academy) in partnership with DakshamA Health. Dr. Ratna Devi represented DakshamA Health in these webinars. The purpose of the webinars was to introduce the Strategic Framework of the Global Patient Safety Challenge—Medication Without Harm, which is aligned with the World Patient Safety Day 2022's slogan "Medication Without Harm".

SAVE THE DATE

1st Patient Safety Webinar 2022

"Medication without Harm"
"An approach towards medication safety for Patients and Family"

Mar 19, 2022
11:30 - 12:30 GMT

Online Webinar Series

REGISTER NOW FREE



SAVE THE DATE

2nd Patient Safety Webinar 2022

"Medication without harm"
"Role of healthcare professionals in ensuring medication safety"

April 23, 2022
11:30 - 12:30 GMT

Online Webinar Series

REGISTER NOW FREE



SAVE THE DATE

2nd Patient Safety Webinar 2022

"Medication without harm"
"Role of healthcare professionals in ensuring medication safety"

April 23, 2022
11:30 - 12:30 GMT

Online Webinar Series

REGISTER NOW FREE



GLIMPSE OF THE YEAR

CEO, DakshamA Health was invited by WHO Geneva in December 2022 for the Global Expert Consultation for implementing the global patient safety action plan 2021-2030: Pandemic and beyond where she represented the country by giving a perspective on the present condition of patient safety In India and what can be done in the Southeast and Indian sub-continent to position the region better in this domain.

CEO was selected as a panelist for the High-Level Summit on UHC We Can, organized by WHO SEARO in December 2022. The summit focused on promoting multisectoral collaboration and raising public awareness on the importance of Universal Health Coverage in the SEA Region. During her participation, Dr. Devi shared her insights on the subject and emphasized the need for collaboration between various stakeholders to achieve Universal Health Coverage in the region. Her expertise and experience in the field of healthcare and her commitment to promoting equitable access to medical care made her a valuable addition to the panel. The inclusion of Dr. Devi in the High-Level Summit organized by WHO SEARO highlights her standing as a leading expert in the field and her dedication to advocating for the health and well-being of all individuals.



CEO was invited to participate in a discussion on the role of stakeholders, including different players and start-ups, in the cancer ecosystem to reduce the burden of lung cancer. The discussion was organized by ASSOCHAM as part of a larger event focused on awareness, prevention, challenges, and treatment of lung cancer. During the discussion, Dr. Devi shared her expertise on the subject and emphasized the importance of collaboration between various stakeholders in addressing the burden of lung cancer. Her insights on the role of startups in developing innovative solutions to prevent and treat lung cancer were well received by the audience. The participation of Dr. Devi in the event organized by ASSOCHAM highlights her commitment to improving the lives of those affected by lung cancer and her dedication to promoting awareness and prevention efforts in the community.



The Diabetes Fighters Trust, in association with Dakshama Health, organized an event to educate and raise awareness about Type 1 diabetes. This event aimed to provide a platform for individuals affected by Type 1 diabetes to better understand the condition and learn about the latest developments in management and care. CEO from Dakshama Health was invited as a moderator to share her expertise and knowledge on the topic. The event was well attended and received positive feedback from the participants, who appreciated the opportunity to learn more about Type 1 diabetes and connect with others who share similar experiences. Overall, the event was a successful collaboration between the Diabetes Fighters Trust and Dakshama Health, with a shared goal of improving the lives of individuals with Type 1 diabetes.

THANK YOU

