COPS ANNUAL REPORT FEB-DEC 2022

DakshamA Health

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INTRODUCTION

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 2014, the World Health Assembly recognized psoriasis as a critical NCD and issued a resolution to improve the lives of individuals living with the condition which in turn brought the public health impact of psoriasis into focus. WHO recommended solutions and strategies to be adopted by various policy makers and patient organizations to overcome the increasing prevalence of psoriasis, but there is a huge gap that needs to be bridged and a lot more to be done?

In India rather than well-defined, large population-based studies, data on psoriasis prevalence currently comes from hospital-based studies. There is a dearth of data on Indian psoriasis patients' genetics, epidemiology, disease kinds, associations, and severity. There is a significant lacuna in the treatment of psoriasis. Studies on risk factors are rarely conducted, which would aid in the identification of preventative strategies that are critical for chronic non-communicable illnesses with no definite cure. Psoriasis and Rare Psoriasis Disorders (PRPD) patients confront various challenges, including lack of disease knowledge, delayed accurate early diagnosis, delayed access to appropriate treatment, and coping with social stigma and mental stress/anxiety.

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 WHOs 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:

Objective 1	**PRPD Patient Group Formation**
Objective 2	**Awareness amongst the psoriasis patients and caregivers**
Objective 3	**Advocacy around the 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.

Objective 1: PRPD Patient Group Formation

1. **Project deliverable: Patient group and patient advocates**

Patient Advocates: - 5

	Mr. Varun Verma
	Ms. Shrestha Tiwari
	Mr. Vivek Tank
	Ms. Alka Dhupkar
	Mr. Sasi Kumar

Patients and Caregivers

WhatsApp Group	50 psoriasis patients and caregivers
Facebook	232 psoriasis patients and caregivers
Webinar	400+ as webinar registrants
GPP patients	5 GPP patients identified

2. **Survey of Dermatologist**

   This 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. **The questionnaire was sent to approximately 300 dermatologists in India.**

   Link for the survey: https://forms.office.com/r/sPm1yqQBUc

3. **IEC materials**

Pamphlets of stroke: Pamphlets developed to raise awareness on psoriasis among the community/psoriasis patients and their caregivers. https://cops.dermatologypatients.co.in/resources.html	**Resources on psoriasis** Developed resources for the stroke survivors and caregivers. All the resources are shared on the website under resources page: https://cops.dermatologypatients.co.in/resources.html
Videos on psoriasis and GPP Developed videos on psoriasis and GPP to raise awareness. https://cops.dermatologypatients.co.in/resources.html	**Newsletter COPS** An annual newsletter was developed to showcase the initiative efforts and was shared with several stakeholders. COPS Dermatology News Letter

Objective 2: Awareness amongst the patients and caregivers

Website: https://www.cops.dermatologypatients.co.in/
No of post on social media channels: 200

1. **HCP sessions and patient story**
    - **7 webinars** including dietary and meditation sessions.
    - **9 patient stories** recorded of psoriasis patients and **1 GPP patient** story recorded.
    - **4 open house meetings** with psoriasis patients and caregivers.

2. **Articles published**

    - **Author: Dr. Ratna Devi and Tamanna Sachdeva "**
      Published in: **Express Healthcare**
      "India's unmet needs and challenges of people living with psoriasis"
      https://www.expresshealthcare.in/news/indias-unmet-needs-and-challenges-of-people-living-with-psoriasis/436791/

    - **Author: Dr. Ramesh Bhat**
      Published in: **ET health world**
      "Access to affordable care and recognizing psoriasis under National Health Schemes in India"
      https://health.economictimes.indiatimes.com/news/industry/access-to-affordable-care-and-recognizing-psoriasis-under-national-health-schemes-in-india/95173077

    - **Author: Dr. Sunil Dogra**
      Published in: **Express Healthcare**
      https://www.expresshealthcare.in/news/uncovering-psoriasis-on-universal-health-coverage-day/437274/

3. **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.

Partnerships	Indian Association of Dermatologists, Venereologists and Leprologists (IADVL)
National	
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

	Hospital, Raji Gandhi Medical college, Yenopaya medical college, Sucheta Kriplani & Kalawati Saran Children Hospital, Apollo Hospitals- Chennai
International	APARDO, IFPA, Global skin, Rare Cancers Australia

Objective 3: Advocacy around the psoriasis and rare psoriatic disease

1. **Patient Advisory board of COPS**

   By guiding and supporting the support group comprised of people who have experienced psoriasis, the advisory board supported us in strengthening the patients’ voice to be heard at the policy level.

   3 Meetings conducted:
   04th May 2022, 07 pm IST
   13th July 2022, 07:30 PM IST
   13th September 2022, 07:30 PM IST

   OUR MEMBERS:

   - **Dr. Rashmi Sarkar**, Director- Professor of Dermatology, Lady Hardinge Medical College, Delhi
   - **Dr. Ramesh Bhat**, Vice Dean, Father Muller Medical College, Kankanady, Mangalore, Director ILDS, Past president IADVL
   - **Dr. Sunil Dogra**, Prof. at PGIMER Chandigarh
   - **Ms. Alka Dhupkar**, Assistant Editor, Times Internet Limited (ToI Plus) and psoriasis supporter with lived experience
   - **Mr. Varun Verma**, Psoriasis supporter with lived experience
   - **Dr Ratna Devi-** CEO DakshamA Health and psoriasis supporter with lived experience

2. **Networking conferences**

1	**HAE Society of India-PIGIMER Chandigarh**	**May 2022**
2	**APARDO & Rare Cancers Australia**	**May 2022**
3	**APARDO Conference**	**November 2022**

3. **Meeting with experts and policy makers**

   - Round Table meeting: CPR-ASHOKA- DST "Rare Diseases in Public Health: An Indian Context".
     Date: 19th February
   - Round Table meeting: "Rare Disease Policy- Scope for Inclusion and Treatment of New Rare Diseases"
     Date: 26th February
   - USISPF Roundtable discussion: Rare Disease Policy: Rare Disease Policy: Provisions to Enable Institutional Donations.
     Date: 25th March
   - National Consortium for rare diseases by ICMR.
     Date: 30th June
   - Round Table meeting: “Rare Disease Policy: Conceptualizing the Scope & Implementation of Technical Support Units”.
     Date: 8th July

- Round table discussion: “Roadmap for the inclusion of new rare diseases—Discussion on stakeholder responsibilities and accelerated regulatory pathways”.
  Date: 30th July

4. **World Psoriasis Day event 2022**
   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

5. **Meeting with Dr. Madhulika Kabra**
   Agenda: Inclusion of Rare Dermatological conditions into the National Policy for Rare Diseases
   The meeting was to better understand the criteria and prerequisites for GPP's inclusion in the National Policy for Rare Diseases.

6. **Analysis of the current structure of COEs**
   The structure of COEs was analyzed, gaps brought to the notice of the advisory board members. Steps for inclusion in the core committee of COEs is being undertaken.

7. **Meeting with Dr. Rashmi**
   Dr Rashmi agreed to support us in writing a letter to COEs on behalf of IADVL and proposed developing a standard treatment protocol for the GPP with the help of Dr. Sunil Dogra’s assistance in formulating these guidelines.

FUTURE SCOPE OF THE PROJECT

1. There is still a long journey to cover to advocate for GPP in the community and among policymakers.
2. The scope for GPP to be included in the NPRD is good. Credible evidence must be produced around well-known treatments available, the cost of diagnosis and treatment, the infrastructure and human capacity required, and a treatment protocol specific to GPP in order to be classified.
3. Patients are hesitant to share their stories with the community, thus more advocacy and awareness campaigns must be undertaken to increase the visibility of the cause.
4. GPP patient journeys must be documented. It might be challenging to have a GPP patient group as proposed, given the very small number and language barriers.
5. A GPP casebook can be developed with verbal and text story lines.
6. Members of the advisory board developed as part of this effort can assist us formulate the standard treatment guidelines for the GPP.
7. Scope for physical meetings needs to be built for the connect with patients