

COPS NEWSLETTER

PSORIASIS—WAY BEYOND A SKIN DISEASE

The Newsletter of the Community of the Psoriasis Supporters

MYTH

Psoriasis is just a rash

FACT

It is an autoimmune skin condition that contributes to an inflammation under the skin, such as joints.



VISION

To build a strong, nationwide patient voice for psoriasis supporters and caregivers from community to policy level.

MISSION

Providing knowledge, resources, forums, and a platform to psoriasis patients and caregivers to help them make a positive impact in their healthcare environment.

ABOUT COPS

The Community of Psoriasis Supporters intends to bring together psoriasis patients, caregivers, and healthcare providers under one umbrella so that they can share their experiences and perceptions to advocate for better policies to address the access and affordability and bring a better understanding of the condition to mitigate the stigma and discrimination they experience.



THE OBJECTIVES ARE

- Connect various supporters to foster mutual support, exchange experiences and integrate various channels of information available as a comprehensive and easily accessible resource.
- To create a compendium of supporter's stories as a motivational tool for other supporters, as well as to raise awareness about psoriasis and its impact on quality of life among supporters and caregivers.
- Empowering and enabling patient advocates living with psoriasis to better manage their condition and advocate for change.
- Bring together the patient-caregiver voice, and technical specialists' practical ideas to improve the health care and social inclusion of people living with psoriasis in their communities.
- Include Generalized Pustular Psoriasis as a rare condition in the national policy and advocate for access to treatment.

ADVISORY BOARD MEMBERS

The lived experience and the voice of Psoriasis survivors and caregivers needs to be amplified. By guiding and supporting the support group comprised of people who have experienced psoriasis, the advisory board will support in strengthening the patients' voice to be heard at the policy level.

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Director- Professor of Dermatology,
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Dr. Ramesh Bhat

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Dr. Sunil Dogra

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Dr. Ratna Devi

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psoriasis supporter with lived experience



Mr. Varun Verma

Psoriasis supporter with lived experience



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NEWS AND MEDIA

Author: Dr. Ratna Devi and Ms. Tamanna Sachdeva

Published in: Express Healthcare

Title: "India's unmet needs and challenges of people living with psoriasis"

Link: [Express Healthcare | India's unmet needs and challenges of people living with psoriasis](#)

Author: Dr. Ramesh Bhat

Published in: ET health world

Title: "Access to affordable care and recognizing psoriasis under National Health Schemes in India" .

Link: [ET health world | Access to affordable care and recognizing psoriasis under National Health Schemes in India](#)

Author: Dr. Sunil Dogra

Published in: Express Healthcare

Title: "Uncovering Psoriasis on Universal Health Coverage Day" .

Link: [Express Healthcare | Uncovering Psoriasis on Universal Health Coverage Day](#)

WORLD PSORIASIS DAY 2022



On the occasion of World Psoriasis Day, 27th October 2022, the Community of Psoriasis Supporters (Initiative by Dakshayani and Amaravati Health and Education) in collaboration with the 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”. To read the full report please [click here](#) or picture



SESSION 1

Recognizing Psoriasis under India's National Health Policy

The following points were discussed during the first-panel discussion.

- Encouragement to include psoriasis under health insurance policies, and national health policy, and for improved results, interventions and initiatives are necessary.
- Challenges regarding public awareness, early diagnosis, and broad public treatment accessibility and availability.
- The need to consider medications on the National List of Essential Medicines and the best possible approaches.
- A methodical strategy that will help create a better foundation for the distribution of resources and services to patients who need them.

SESSION 2

Bringing the Psoriasis Patient Voice to the Policy Table

The following points were discussed during the second-panel discussion.

- Approach and strategies that should be taken into consideration to bring the patient voice to the policy table.
- Need of research, patient registries for psoriasis in India, and how these registries can help with psoriasis research.
- Need for a clear definition and standard treatment protocols for rare psoriatic disease and strategies to overcome the current challenges.

We had 200+ registrations including psoriasis patients and caregivers' dermatologists, policymakers, patient groups, etc. The event was also live-streamed on Facebook.



ADVOCACY ACTIVITIES AT A GLANCE

Round Table Discussion series

A. Rare Disease Policy- Scope for Inclusion and Treatment of New Rare Diseases

A round table discussion was organized with the theme "Rare Disease Policy- Scope for Inclusion and Treatment of New Rare Diseases" on the occasion of World Rare Disease Day, February 26th, 2022. The intent was to explore opportunities for inclusion of rare diseases not covered by the National Rare Disease Policy, and pathways for inclusion and access to treatments, through the round table discussion. The discussion concentrated on the need for and importance of understanding the challenges and opportunities associated with rare dermatological disorders in India.

[Please click here to read the report](#)

B. Roadmap for the inclusion of new rare diseases - Discussion on stakeholder responsibilities and accelerated regulatory pathways”.

In a follow-up to the first-round table discussion, a second-round table discussion was conducted on July 30th, 2022. The theme of the round table discussion was “Roadmap for the inclusion of new rare diseases—Discussion on stakeholder responsibilities and accelerated regulatory pathways”. The round table discussion focused on the roles and responsibilities of the stakeholders involved in the inclusion of new rare diseases and accelerated regulatory pathways for the inclusion of new rare dermatological diseases.

[Please click here to read the full report](#)

PATIENTS AND CAREGIVERS CORNER

Patient Stories



MS. KOMAL AGARWAL

Komal Agarwal is a beauty content creator. Take a look at her journey! She discusses how making lifestyle changes and practicing yoga and meditation have helped her manage her symptoms.



MR. VARUN

Mr. Varun is a student from Chandigarh. His journey of fighting psoriasis from a very young age till now has surely made him a strong person. He urges all patients to benefit from the availability of affordable medicines as well as timely diagnosis.



MR. SASI KUMAR

Sasi Kumar is working in the automobile industry. He is a highly optimistic person. Listen to his psoriasis story to discover how he managed his psoriasis and overcome the obstacles he encountered.



RESOURCES FOR PATIENTS AND CAREGIVERS

The resources on our website will assist patients and caregivers in managing and learning more about the disease.

- To know more [Click here](#)
- To know more about psoriasis condition, click the link below and check out our FAQs. - [Click here](#)
- Hear our expert sessions: [Click here to access our past expert sessions](#)

Join us & Become a Patient Advocate

PSORIASIS PATIENT ADVOCATE

A patient advocate is responsible for:

- Sharing valuable experiences that bridge the community to make a difference in the management of psoriasis.
- Engagement and empowerment of psoriasis patients.
- Generating awareness on psoriasis in the community.
- Connecting and building a larger psoriasis patients' community.
- Bringing psoriasis patients together to articulate their needs and concerns to decision-makers.

CALL FOR VOLUNTEERS

If you would like to get involved and dedicate time towards improving the lives of the people living with psoriasis. If you are a psoriasis patient or caregiver, you can make a lot of difference in the community. You can be an inspiration to other psoriasis patients. There are many ways to start volunteering, but everything starts with your engagement.



**HELP PSORIASIS SURVIVORS BY JOINING US.
FOR JOINING FILL OUT OUR JOINING FORM**


SHARE YOUR STORY


Encourage other psoriasis survivors by sharing your story, It can help to motivate them.


To share your story reach out to us to record a session or write up your story.

[To join our WhatsApp closed group](#)

contact us!

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