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Forum: Those with incurable skin conditions find society inclusive but treatment costly

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I suffer from ichthyosis, a rare genetic skin condition that affects one in a million people worldwide.

While a cure for rare skin conditions remains a dream for patients like me, a more readily achievable goal is for those with such conditions to be accepted by society.

I have been researching the socioeconomic impacts of rare skin conditions on patients since 2022, under Dr Mark Koh, head of dermatology at KK Women's and Children's Hospital. The study was designed to assess the social and healthcare needs of about 50 patients with such conditions here and their caregivers.

The survey provided optimistic data regarding societal inclusion here, with the majority of patients viewing Singapore as having inclusive work and school environments. About 86 per cent of patients felt they have been treated fairly in school and the workplace.

The results are positive as patients with ichthyosis can struggle to be fully accepted and integrated into society.

However, there are gaps in financial inclusivity, with about 86 per cent saying that their medication was unaffordable, with costs ranging from \$300 to \$1,200 a month. This is particularly difficult since their conditions are lifelong.

Currently, the limit for MediSave funds that can be used for outpatient visits for complex disorders is \$700 a year, a fraction of what patients with rare skin conditions spend. Only a few genetic disorders are on the list for the Rare Disease Fund and ichthyosis is not covered.

Increased government funding, together with a raised MediSave limit, would help many struggling families. Improving the funding system would not only dramatically improve the lives of patients and their families but also mark Singapore as a truly inclusive society.

Aliya Shahnaz Kraybill

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