



DEBRA SINGAPORE NEWSLETTER



PRESIDENT'S MESSAGE

Dr. Ritu Jain, DEBRA President

Dear Members of the DEBRA Family,

While these are trying times for all of us in Singapore and beyond, I still hope that all of you are well and safe.

The global pandemic also means that we will be celebrating the fifth anniversary of Debra Singapore virtually. We are proud to share that over the past 5 years, we've gone from having almost no resources to enough for funding dressings and most EB related needs of our members. Many of you may not be aware that we fund all dressings (e.g., Mepilex, Mepitel, Polymem), ointments (Keragel), moisturisers (Lipikar) as well as reimburse medical and dental consultations, diagnostic and pre-natal tests. We also reimburse taxi expenses of those who find commuting by public transport a challenge.

Other than support, we have also raised a significant amount of

awareness. Many Singaporeans around us now are familiar with the 'butterfly children' as the news reports and the [CNA documentary](#) has helped spread awareness of EB.

Our annual fundraisers, the butterfly run, and our [social media](#) has helped to draw attention to the condition. You will be proud to know that we now mentor patient groups in the neighbouring countries to set up their Debra groups also fund dressings for a few patients in various countries.

There is much more we have planned ahead that will be shared via emails and social media: the upcoming AGM, the launch of our photobook in conjunction with the Rare Skin Conditions Society, a possible photo exhibition with the Silvana Foundation, and our very first virtual Butterfly Run!

Going forward, I hope that this newsletter will become a regular feature to update you on planned activities and initiatives. However, I am appealing to you all to step forward and make DEBRA *your* organisation – come help us by sharing stories with our extended Debra family, tell us how we may serve you better, and if possible, step forward and contribute your time.

I also take the opportunity to thank our supporters who have made our work possible: members of the public who have generously donated money, and offered to volunteer; the pharma partners and social organisations who have sponsored our organisation and events; and most of all, the clinicians and researchers without whose support we would not be here today!

Finally, I'd like to highlight the very heartening spirit of community care and selflessness that we have been blessed to receive in the holy month of Ramadan. One of our young Muslim supporters Nazura, touched by the plight of those with EB and the work we do regionally, has raised S\$3,100 from her family and friends. Further, another gentleman, who prefers to remain anonymous, has generously donated S\$10,000 to our organisation.

I do look forward to seeing you all at the first virtual AGM next month and welcome you to get in touch with requests, offers to volunteer, or just to chat! Thank you and on behalf of DEBRA's Executive Committee

and our Advisory Board, I wish everyone health and to our Muslim friends, Selamat Adilfitri !

Yours sincerely

Dr Ritu Jain

President – Debra Singapore



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