

# debra**D**igest

A newsletter of Debra Singapore  
Issue 2020/1

Dear members & friends of Debra,

I want to thank everyone for attending our AGM last month and for responding to the survey. My follow up conversations with many of you helped me understand that we need a regular and effective means of communication to share updates on Debra initiatives, activities, research, and stories. To meet this goal, I am delighted to announce that this newsletter marks the first of six annual newsletters. I sincerely thank our sponsor, Dr Mandeep Singh Duggal, for his generous contribution that makes this possible.

The editions will also help us stay in touch in the absence of face-to-face meetings and events. So, please read, share with friends and on social media, offer feedback, and, most of all, contribute to making this a newsletter for you and by you. I wish you health and well-being and look forward to connecting online.

Yours sincerely

**Dr Ritu Jain**

President - Debra Singapore



## Complications of Studying with EB – by Ira Jain

An onlooker watching me wrap my fingers with tape might assume I was preparing to partake in a boxing match, or some other equally impressive mixed martial arts sport. The reality of my fight was much less exciting – I was getting ready for a long day of pre-exam revision. As someone with EB Simplex, the most problematic areas of my skin are on the soles of my feet and the skin on my writing hand. Studying a subject like Chemistry, which requires copious amounts of molecule and diagram drawing, blisters often crop up on the skin on my inner thumb and ring finger, or wherever I grip my pen. After a long revision session, I often find my hands sweaty from the heat trapped by the bandaging and cramping from



alternating among the various strange ways I hold my pen.

The truth is, my experiences are so normalised that I find it hard to describe them in words. In fact, if I were slightly less lucky, I might even have no choice in the type of pen and brand of paper that I use. Through trial and error, I've managed to narrow down the type of stationary that hurts my skin the least – pens that are smooth and padded, paper that is thick – so after many email threads and a lot of red tape, the Ministry of Trade and Industry granted me permission to buy the 'non essential' comfortable gel pens and a stack of A-zone foolscap pads.

Many an EB patient might find themselves jumping through hoops to fulfil their unexpected skin-related needs fairly often – be it in school, or a professional or social context. The simple truth is that individuals with rare diseases also have rare needs that sometimes can't be foreseen and often can't be met, especially in these unprecedented times, and the effort of meeting those needs can be even more burdensome than the broken skin and open wounds.



## Virtual Butterfly Run 2020

If you've been following Debra's fundraising efforts for a while, you probably know about the yearly Butterfly Run event – where individuals, teams, or families register and make a small donation, and are given race packs in exchange. Typically, race packs have been drawstring bags that contain items like sunscreen, a Debra t-shirt, and body wash, a good mix of items that are both useful and trendy.



This year, however, due to COVID-19, circumstances are anything but typical – so we've gone online! The Butterfly Run 2020 is now virtual, and it couldn't be easier to sign up. All you need to do is scan this QR code.

You can sign up as an individual (\$25), as a 'twin' (with one friend, \$40), or as a 'family' in a group of 4 (\$75). According to the category you register in, you'll receive 1, 2, or 4 caps respectively after you send in evidence of your run.

After that, it's simple: run or walk a distance of 5km. How you do so is up to you – outdoors or on a treadmill, all at once or spread over multiple days, alone or with a pet.

Simply send a screenshot of your treadmill or running app to [secretariat@debrasingapore.com](mailto:secretariat@debrasingapore.com), and receive a Debra cap in the mail.

All proceeds raised will go towards subsidising medical



expenses and wound dressings for EB patients in Singapore. Your support is important to them, and you can stay fit for a good cause!



## Raising Money during Ramadhan – by Naz Ura



It started with a simple conversation with my parents about the challenges and hardships that people go through. That conversation led to my research on charitable organisations in Singapore. In my research, I stumbled upon children with Epidermolysis Bullosa (EB) and DEBRA Singapore. I was deeply saddened to read about their pain and suffering and realised how much we take for granted simple things like showering or walking. After researching and reading up from the websites and watching the documentary, I decided to start a fund raising for DEBRA. Since it was the holy fasting month of Ramadhan, we are encouraged to increase our good deeds and I am also confident that there will be more people who will step forward to support, regardless of our religion beliefs.

I started the project with an interview with Dr Jain, the President of DEBRA to understand some of the challenges and achievements of the organisation. Thereafter, I message family members and close friends to garner their support for the fund raising for children with EB. Besides the fund raising, I also tried to create awareness of EB and sharing of video & news links as well as DEBRA's website in the message so they can find out more about EB and DEBRA. I am truly humbled that collectively, we were able to raise \$3100 within a week. We also encouraged our friends and family to donate directly to the website and hope this small sum will help these special children.

There were many learning points and valuable experiences for me throughout this initiative. Firstly, I learnt more about EB, and about the children who have EB. Secondly, I learnt how DEBRA has helped children who have EB. I was blessed to be given the opportunity to spread awareness about people who have EB. Though the sharing of these information, more people would know about EB and be more accepting to them, and the world would be more empathetic for those less fortunate. Most importantly, I am reminded to be grateful for what we have been blessed with. There will always be people who have more than us but there are

others who have much less than us. Hence, we should always appreciate what we have and not take things for granted.

Once again, thank you for giving me the opportunity to embark on this fund raising as well as sharing information on EB and DEBRA.

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