



A newsletter of Debra Singapore
Issue 2020/3

President's Message

Dear members and friends of DEBRA Singapore,

As we draw closer to the end of an unusual year, I find myself grateful for the small blessings that have enabled us to get through a difficult phase.

These challenging times have highlighted the resilience of our community and renewed our commitment to raising awareness of rare conditions like EB.

The pandemic related restrictions have also forced us to innovate and find creative solutions to raise funds -- and spirits -- in support of our members. Not only have we managed to continue bringing in wound care products but also held innovative fund-raisers such as the creative art workshop in partnership with our friends from the Rare Skin Conditions Society. The beautiful output of the participating children was translated into reusable tote bags that were snapped up in a matter of days!

Despite the challenging times, Singaporeans have opened their hearts in support of DEBRA. We thank them for their trust and generosity. As we close this year, I wish you a wonderful festive season ahead and an even better 2021! We at DEBRA Singapore will continue to work hard for our members and hope we can count on your support and wishes.

On behalf of the advisory board and executive committee,

Dr Ritu Jain

President, DEBRA Singapore

Foot Care Advice from an EBS Patient by Ira Jain

As an EB Simplex patient, I've had blisters all over my body – on my fingers, along my shins, inside my ears. The most common occurrence of blistering for me though is on my feet. Any EB patient living in Singapore would tell you that the heat is their biggest enemy. Often, when I was younger, I would spend an hour playing in the sun and come home with painfully swollen, red, blistered feet – in a condition that was only exacerbated by the humidity. When it was time for me to start primary school, I quickly realised that I couldn't follow the school dress code regulation of wearing covered white shoes because they would pinch and hurt every day. Instead, I wore comfortable black sandals from Hush Puppies that allowed air flow and didn't trap heat like covered shoes would.

Since primary school, a lot has changed. For one, I can wear whatever shoes I want in college, and through extensive trial and error have discovered which brands and models suit my needs best. I've often wished there was an exhaustive list of shoes that work and ones that don't but unhelpfully, every EB patient is unique in that there is not one pair that is universally suitable to minimize blistering.

However, I could do the next best thing — share with you what works for me. Before we get into my favourite shoes though, here's a tip: choose comfortable socks. For me, these look like short, soft, relatively thick ankle socks that come in a pack of 3 for \$10 at Muji or Uniqlo. I've tried silk-integrated socks but found them too thin. The Foot Care Clinical Practices Guidelines for EB patients recommend Silversocks though, so if you're unsure you should definitely try them and come to your own conclusions. I also wear Mepilex (cut to size) before putting on socks, for extra padding. It's also pretty good at absorbing sweat, which helps reduce the heat trapped in my shoes.

So, what do I wear every day? My go-to shoes are Adidas superstars, bought second hand so they've already been broken in. They're comfortable and relax once worn, and their laces can be loosened as much or as little as you want. Recently, I've also been wearing Nike sneakers, but these are a little narrower near the toes and might pinch when brand new. I've tried other brands like Skechers, but didn't really like the fit, and Vans have no padding at all.

My father on the other hand, who also has EBS, prefers Espadrilles — canvas slip-ons with no laces. These don't work for me though — I find them too thin and what works for EB parents may not work for their EB kids. Another EBS patient found Crocs to be very effective in preventing blisters, their soft rubber soles seemed to reduce friction tremendously. However, her EBS children have a different experience in that the little bumps on the inside of the shoe are very painful.

Despite this, there are some things some EB patients can agree on, like leather soles. Check out companies like Anothersole and Hush Puppies, who specialise in shoes with leather linings. A little known fact — Debra Singapore commits to pay 80% of the cost of shoes for every EB patient (capped at \$150 per year). If you have brand preferences that work for you, feel free to share in the comments below!

Normally yours, Raed.

So what does your 'normal' day look like? The answer would vary depending on whether you were a child or an adult I guess. The answer would also vary depending on your level of 'normal'. In our world of Rare (diseases), normal comes with the additional shadow of EB. The more severe your EB, the more constant is its perpetual shadow. Come, let us take you into the a 'normal Raed+EB shadow day', as shared by his mum Zeehan, shall we? In consideration of your feelings, the narrative will attempt to gloss over the more painful parts but we advise some fortitude to read ahead.

Raed Shanwas, a wise old soul aged 5yrs, 8 months:



Raed lives in an extended family including grandparents, parents, uncle, aunt, and cousins. He wakes up daily for childcare before 7 am but needs some time to build up courage to step into the shower, an agonising experience. The pre-shower ritual requires all his blisters to be treated. This means that blisters -- that crop up regularly all over his body-- are lanced using a sterile needle or blade and the dead skin is snipped off. To distract himself, he watches shows on an Ipad but requests that the his feet and fingers, usually most extensively blistered, be left for after the shower.

That done, he sits in his chair in the shower stall and unusually for those with EB, prefers the water stream through a shower head than the more gentle cascade of water scooped up from a pail. In a very personal rituals, he prefers his head to be shampooed and rinsed before moving on to the rest of his body. He also requests that his mother cup the dressing covered wound with her palm in some sort of a protective barrier over his most severe wounds. He's aware that pain will come and he will put up a brave front but this fear of pain can't be seen by anyone other than those he trusts completely.

The meticulous process of bathing is followed by woundcare comprising removal of the now soaked and relatively-easier-to-remove adhesive dressings. Cleansing and further

trimming of dead skin is followed application of emollients and primary and secondary dressings and eye-drops while the trusty Ipad and toys distract from the inevitable pain. The entire process takes about an hour and half.

Where many parents of EB children prefer to keep their Butterfly home, Raed's have taken the difficult decision to enrol him in half day of childcare in order to teach him independence and socialisation. They know that ultimately, Raed too will need to learn to live in a world where the slightest of bumps, a stubbed toe -- or in a nightmare scenario, a fall -- will lead to the loss of skin on knees, elbows, toes, chin, etc. and excruciating pain. They know that he needs to learn to be independent and that the limit of his dependence is only skin-deep. Raed is told that in all other ways, he is no less than any other child. Every day he brings home wounds is another day in his journey of growth and independence.

Enrolling for a full day of school is still not a consideration as Raed is afraid of nap-time. He's nervous that he may be hurt accidentally by a sleeping child while he himself is asleep and unaware. He enjoys school and looks forward to seeing his friends everyday but isn't yet ready to risk the possibility of an accidental injury during rest. He has learnt the lesson well – protection comes from awareness of your own safety and your surroundings. He refuses to be intimidated by his condition but as we told you, this wise young soul knows he is different.

After school, Raed enjoys lots of play time in and outside of his home. He's spoilt by his grandparents, family, and even his Indonesian helper, Yanti, who dotes on him. But even his play-time takes hard work from them all. His constant wounds have meant he is unable to gain weight, under-developed muscles, and weaker limbs. As a result, Raed has found balancing activities such as stair climbing, bike riding, and various physical activities tough to undertake. To help overcome this, his very involved father, Shanwaz, has created a series of activities to overcome his fear, increase strength and boost Raed's confidence. The daily activities target all of these and help him gain as much independence as possible.

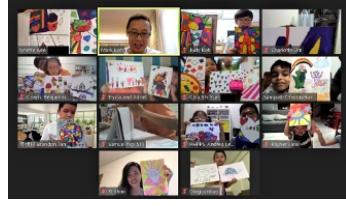


Activities such as cycling, kicking a ball around a field, riding a skate-scooter, and navigating a home obstacle course all help Raed to gradually get better at climbing and increase overall strength and agility. This training has yielded rich rewards and Raed can now climb up and down three levels and three sets each time without needing support from anyone. He's no longer afraid of riding a bike, playing tag, or hide and seek with other children, or even getting on a horse for a small canter!

I don't know about you, reader, but Raed redefined my normal. Comment your own thoughts, and we'll pass them along to Raed and his family!

RSCS Fun Day 2020 – Zoom Art Session

The Rare Skin Conditions Society and DEBRA Singapore joined forced to continue on the series of annual RSCS Fun Day via Zoom with a creative Art Session on the afternoon of 21 November 2020. The event saw participation from RSCS and DEBRA members, doctors and their families come together virtually for an afternoon of art and fun; the enthusiasm from children with skin diseases was remarkable! Two guided sessions were conducted by a professional art teacher, Judy: a Pop Art Style Marker Art session for the younger children and Canvas painting session for the older ones. The interaction and camaraderie among all on an online platform was heartening to watch in the current COVID-19 pandemic. The beautiful artworks, featuring favourite animals, food, places, or even moods, from event has been translated into chic yet functional tote bags showcasing the creativity of little members to raise funds RSCS and DEBRA Singapore. Pictures of the event and of the bags communicate the vibrancy and close bonds of the community!



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