



debraDigest

A newsletter of Debra Singapore
Issue 2021/4

President's Message

Dear members and friends of DEBRA Singapore

When we started our newsletter a year ago in July, I was confident that Covid would only be an unpleasant memory within a year! How wrong I was! The year has been a challenging one for the world but doubly so for those with rare diseases as patients. Our members, like many with rare conditions, have been even more isolated and afraid of the impact of C-19, of the efficacy and possible dangers of the vaccine, etc. We at DEBRA Singapore have done our best to bring information, connect, and support our members despite the challenges of managing and fund-raising.

[Click here to view our merchandise in stock.](#)

I am heartened that our clinicians and supporters have continued to stand by us! Members of the public, and particularly, social influencers joined our virtual Butterfly Run, and our beautiful lightweight satin masks are now being proudly worn around the country! A small donation could secure you one too!

Now as we embark on a nation-wide vaccination drive, we bring both information and reassurance in this newsletter to encourage eligible individuals to get the vaccine with confidence. This newsletter also carries podiatry tips to help manage blisters and care for feet.

DEBRA Singapore is very excited to announce the upcoming launch of our very first multi-disciplinary EB clinic at KK Hospital on 6th Oct, (Wed) afternoon. This clinic, expected to run once every 3 months, will consist of medical specialties and allied health including Dermatology, Orthopaedic surgery, Ophthalmology, Anaesthesia, Dental, Dietician, Physiotherapy, Occupational therapy and Speech therapy. However, for this session, we would like to begin with children and/or women. If there is need and interest among adults and men, we can hold another at SGH in the future. The subsidized cost of the consultations will be totally absorbed by DEBRA.

I request you to let me know your/your child's name if you're interested in participating. I will be in touch with you and communicate with the doctors - and of course, will see you at the clinic!

Finally, as the month of Ramadan dawns on us, DEBRA Singapore would like to reach out to our Muslim friends and wish them peace, harmony and joy. Thank you for standing by us!

Do stay tuned to our upcoming activities and initiatives as we embark on our charity

application and plan an awareness campaign on social media! As always, a sincere shoutout to our friends and benefactors and members of the public for their kind generosity!

On behalf of the advisory board and executive committee,

Dr Ritu Jain
Singapore

President, DEBRA

EB and Covid-19

The current outbreak of the coronavirus has led to great uncertainty and the rise of many questions, especially in families with children or adults who suffer from EB. In this section, we would like to share with you some information and answers some frequently asked questions.

Question: If I have EB, am I at greater risk of contracting Covid-19?

Answer: It is not expected for someone with EB to be at any greater risk than the general population from contracting the virus. As such, no additional precautions are required to be taken by EB patients. While some patients will have no other conditions that may add risk, others will have their hands bandaged, thus hand-washing may not be as frequent as advised. Hence, it is important that patients' hands are kept away from their face, and that caregivers and families practice good hygiene.

Question: If I catch Covid-19, will I suffer from more severe symptoms?

Answer: People with localised EB are unlikely to suffer from more severe symptoms if they contract the virus. However, the same cannot be guaranteed for patients suffering from a more severe type of EB. This is because they are already faced with comorbidities such as anaemia, malnutrition, chronic wound infections and loss of skin barriers. This compromises their immune system, causing them to be more vulnerable to the virus.

In conclusion, it is always better to be safe than sorry. While it is not expected for EB patients to be at any greater risk of contracting Covid-19 compared to non-patients, the best defence for everyone is to avoid contracting the virus in the first place. This can be done through maintaining good hygiene and avoiding unnecessary physical contact with other people. Some of these good hygiene habits include:

	Wash your hands regularly and thoroughly with soap and water (for at least 20 seconds) or with an alcohol-based hand rub.
	If you cannot wash your hands due to wounds, dressings, or bandages, avoid touching your face as much as possible.
	If you cannot wash your hands, change external bandages more frequently if necessary, or use cling film or rubber gloves to protect them.
	Caregivers must wash their hands thoroughly before and after wound care. Keep as much distance and wear a mask if possible.
	Cough or sneeze into the inside of your elbow or use a tissue. Throw the tissue away immediately after use and then wash your hands.

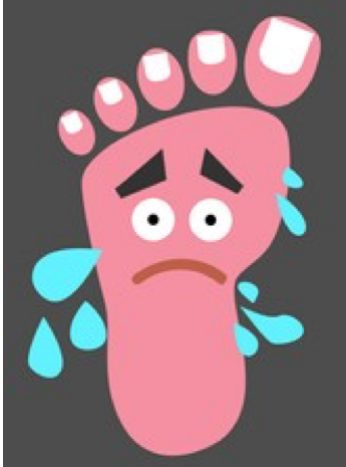
EB patients should also apply protective dressings to areas of skin where the face mask may rub on their skin to prevent blisters from forming on their face.

In addition, it is recommended that they apply a bland moisturizer to their facial skin prior to donning the mask in order to reduce the friction of the mask on their skin. This will help to prevent their skin to peel.

(The information in this section is extracted from the website of Debra International)

Feet Health for EB patients

The most common symptoms for patients suffering



from the milder types of EB are the peeling of skin and blisters on their limbs. Blistering happens in the upper layer of the skin. While they can heal and cause the skin to darken, blisters are however worsened by heat, humidity, and sweating. This make it even worse for EB patients living in Singapore given our tropical weather.

Parts of the body exposed to repeated pressure or friction, such as the feet, are more prone to blisters and hence scarring. The toenails can also be affected in a condition called dystrophic nail.

These problems can thus reduce mobility in EB patients. To improve their quality of life and to be able to continue moving about without assistance for more years ahead, EB patients should therefore take up some preventive measures.

There are some methods that can limit the creation of blisters and the pain and discomfort they bring, as well as treatments to manage these problems.

Management of problematic dystrophic nails include applying medication to the skin around the nails as well as implementing a nail reduction treatment via always keeping their finger-and-toe nails trimmed straight across. EB patients should file their nail surfaces only after softening their nails by soaking them in solutions like warm saline water, baby oil, or in the bath. Applying an emollient or moisturiser daily for adults and weekly for children is recommended. Patients can also use certain creams to hydrate and reduce the thickness of their nails, making them easier to be cut.

As EB blisters are not self-limiting and can spread, intact blisters should be lanced and fully drained even at the areas of the feet and toes. However, EB patients or their caregivers should prepare all dressing materials in appropriate sizes and amounts beforehand to shorten dressing changing times to prevent infections. They can then use a sterile needle to create an entry and exit hole so the fluid can escape. Rolling a soft clean cloth over the blister will help to expel fluid.



The skin should be left on the blister to protect the wound. Finally, EB patients or caregivers can remove dead skin around the open wound.

Last but not least, wound dressings, insoles, and socks are factors that need to be considered by EB patients when using footwear. If dressings are worn daily on the feet then their foot size should be measured with dressings in place when choosing suitable footwear.

Debra Singapore Merchandise

We are very grateful to our generous donors who have donated their products to us to help us raise funds for DEBRA Singapore. **100%** of the proceeds from the sale go towards supporting our patients for their wound dressings, transportation for medical check ups and other related medical expenses.

Debra Singapore is a non-profit charity and we need your generous support. Whether you are getting a gift for a birthday, anniversary or for special occasions, do check out our lovely merchandise. Celebrate your special occasions with a gift from DEBRA Singapore – double the joy ! Check out our merchandise at www.debrasingapore.com/merchandise. Some examples of our merchandise are:



Beautiful set of 3 Debra face masks in satin and linen



Various "statement" T-shirts to choose from



Butterfly sculpture as wall motif or receptacle for small items

www.debrasingapore.com

100 Bukit Timah Road KK Women's and Children's Hospital, Singapore 229899
+65 6513 7310
debrasingapore@gmail.com

You received this email because you signed up on our website or made a purchase from us.

[Unsubscribe](#)

