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The latest news from DEBRA Australia

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DEBRA News September 2021

DEBRA AUSTRALIA supports individuals living with EB **'the worst disease you've never heard of'**. For more information about EB and our life changing programs click [here](#).

Family Support

The Family Support Program have recently launched the new and exciting 'Youth Crew' program and 'Butterfly Break' respite program! These have both received very positive responses from EB families around Australia. The Butterfly Break will provide a much needed 'circuit breaker' for families to escape from the day-to-day struggle of living with EB, and the 'Youth Crew' program is led by our ambassadors, providing peer to peer support for youths living with EB.

Besides working on these new initiatives, the Family Support Program recently assisted many families with various EB related items which help to enhance their quality of life. We have also assisted many families as they have either transitioned or attended plan review appointments with the National Disability Insurance Scheme.

We send our deepest condolences to Bob, Joy and Clare Howe after the passing of their daughter and sister Nikki on 24th July. Nikki was strong, brave and

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Peace Nikki.

If you require more information about the Family Support Program, or would like to learn more about any of these programs, please email Simone.baird@debra.org.au or call Simone on 0413 967 609.



Rest in Peace, Nikki.



IMPORTANT UPDATE!

EB FAMILY CAMP & CONFERENCE

The banner features a light blue background with three stylized blue butterfly-like icons. The text is centered and in white, bold, uppercase letters.

Please note, due to the circumstances surrounding COVID-19, DEBRA has had to postpone the much anticipated EB Conference & Camp.

The new dates for the EB Conference & Camp are:

29th April - 1st May, 2022.

The EB Health Professionals Symposium will be held on **Friday, 29th April 2022.**

We are monitoring, and heeding, the advice of the State and Federal

Wound Awareness Week

We are so pleased to announce that we received some exciting news coverage throughout Wound Awareness Week, which was held 24th - 30th August!

Here at DEBRA, our community is acutely aware of the daily struggles of living with severe wounds.

In honour of this week, DEBRA Australia was featured in an article on 9.com, highlighting the moving story of Butterfly Child Lylah & her mother Lara. To read this beautiful piece, [please click here.](#)

We were also lucky enough for a story to feature in online publication, The Advocate, which highlighted the DEBRA Youth Wellbeing program, and featured comments by our GM Lise & Ambassador (and Youth Crew mentor!) Dean Clifford. To read this piece, please be sure to [click here.](#)

We would also like to make mention of this statement by Minister Greg Hunt, as he acknowledges the burden of wounds in our community and the need for better support for people suffering from chronic wounds. [Please click here](#) to view the message.



Gorgeous Butterfly child, Lylah.





DEBRA Youth Crew!

DEBRA Australia has set up as a private Facebook Group built just for young people living with EB! It's a space that's safe, free and private for peer-to-peer support.

Youth Crew members will be able to connect with other young people to chat about living with EB, plus it will be supported by our very own Ambassadors, Dean Clifford & Matt Bevilacqua - also EB warriors.

We are so pleased to be embarking on this new journey, and look forward to all our Youth Crew members having an amazing experience!

If you are between the ages of 12 - 22 and would like to join the crew, click the button below to apply today!

[Join the Crew Here!](#)

Butterfly Children Documentary

A fascinating and moving documentary film has been produced in Singapore, entering the lives of 4 families in Singapore living with Epidermolysis Bullosa to hear their struggles, and their triumphs.

To watch this documentary, [please click here.](#)



DEBRA INTERNATIONAL VIRTUAL CONGRESS 2021

16-19 September 2021

Worldwide / Moscow, Russia

DEBRA International Congress!

We are very pleased to announce that the [#DEBRAInternationalCongress](#) will be held 16th - 19th September!

This is the world's largest conference on EB, connecting hundreds of experts in research, healthcare professionals, clinical management, and the EB community.

This exciting event features; workshops and roundtables, 30 invited speakers as well as opening and closing ceremonies! Plus, the sessions are recorded for you to watch them in your own time zone!

The DEBRA International Conference is completely FREE for all participants so be sure to register here, today: <https://debracongress2021.ru/register>

In memory of Nikki Howe

A fundraising page has been created in memory of Nikki Howe, who sadly lost her battle with EB on July 24th surrounded by loved ones.

Nikki loved to collect Trollbeads & Pandora beads, with a particular love of all things iridescent. In memory of Nikki, each individual who donates to DEBRA Australia via this page will go in the running to win a unique collection of Trollbeads collected by Nikki's friends.

To donate to Nikki's fundraiser, head to: <https://for-nikki-howe.raisely.com/>

[Subscribe](#)[Past Issues](#)[Translate ▼](#)*In Loving Memory of**Nikki Louise
Howe**1st November 1986 -
24th July 2021*

Major Donors

Many thanks to our Major Donors for their generous donations...

- Molnlycke Healthcare P/L \$10,000
- Todd family - \$5,000
- Thelma Carr Foundation - \$2,000
- Cheryl Bridgart - \$650 in kind donation



Beau Krapez

We extend a massive congratulations to Bridge 2 Brisbane participant, Beau, for already going great guns with his fundraising! Beau's raised \$1,210 of his \$2,000 target for DEBRA, running in memory of his beautiful niece, Alexis. 🦋

Help Beau reach his goal, and support him here today:

<https://bridgetobrisbane.gofundraise.com.au/page/BeauKrapez>

SAVE THE DATE!



SAVE THE DATE! We're kicking off our EB Awareness Week with an exciting Family Trivia Night on Saturday 23rd October 2021, followed by our LIVE and Virtual Walk For Wings Events on Sunday 24th October.

This EB Awareness Week we want to get people talking about EB and bring our community together, whilst having some fun - no matter what state you're in!

More details to come **THIS WEEK**, so stay tuned...🦋

The Azny Family in 'That's Life!'

We are so proud to highlight one of our wonderful EB families, the Azny's, who featured in this month's **'That's Life!'** Click the images below to read the full story.

"I couldn't be prouder of my brave little butterflies. And, like butterflies, they're delicate - but they're also beautiful and unique." - Kida Azny on her children, Azraqee & Siddiqah 🦋

LITTLE BUTTERFLIES CHILDREN

When Kida's babies were diagnosed with a rare condition, Aussie doctors helped

Kida Azmy, 36, Bex NSW

My husband, Aidil, 35, squeezed my hand as the sonographer ran the wand over my belly. "Congratulations," she said. "You're having a boy!" Six months pregnant with our first child, I was just happy to see a healthy baby in the scan. I could tell Aidil was delighted though!

Living in Malaysia, we'd met through friends four years earlier and had always said we wanted a family. In February 2012, our beautiful 2.4 kilo baby was born.

"It's a girl!" the midwife said. I started to laugh, thinking about what Aidil, who'd had to wait outside, would say. But when I saw my sweet baby girl, she was bright red and her skin looked raw. "Don't touch the baby," a doctor said. "Something's wrong."

Still leaking blood from the birth, I passed out in shock. When I came to after a few minutes, my daughter had been taken to ICU. "What's wrong with her?" I asked. But no-one had any answers.

Back on the ward, Aidil and my mum, Zakiyah, conformed me while we waited for news. It was 12 hours before we were allowed to see our daughter, who we'd named Siddiqah. My tiny girl was covered from head to toe in bandages. "We think she has some sort of infection," a doctor said.

She had to be transferred to a bigger hospital in Kuala Lumpur, and it was there we finally got a diagnosis. "Your daughter has epidermolysis bullosa," a specialist told us.

Known as EB, it meant Siddiqah's skin was so fragile it could tear or blister at the slightest touch. During birth, the skin on most of her lower body had essentially been pulled off as she'd moved down the birth canal.

I had so many questions but the specialist didn't have answers, so we went online. We discovered EB is genetic, which means both of us are carriers, although we had no symptoms.

There is no cure – and many babies with EB don't survive the first few hours after birth, as their skin is so damaged and susceptible to infection.

"It says here that children with EB are known as butterfly children," I said to Aidil. "It's because their skin is as fragile as a butterfly's wings."

Back home, our precious butterfly baby needed to be wrapped head to toe in dressings every day. A slight touch could cause a blister, or irritate an existing wound. I worried I was hurting her and whenever she cried, it felt like there was nothing I could do to comfort her.

After a few months, we sold everything and moved in with my parents so we could afford to keep buying the dressings she needed.

Because of her sore skin, Siddiqah didn't start to crawl until she was two. But she could smile and giggle just like any other bub.

My heart ached. Back home, I explained to Siddiqah that we had to be extra gentle with him. "Your brother is a butterfly baby," I said. "Just like you."

Having two little ones with EB was challenging, but we were a well-oiled machine by now.

Each morning, we'd change their dressings, which could take three hours as we had to be so slow and careful. People would ask us in the street if they'd been burnt. "What happened to your

Many babies don't survive the first hours after birth

They're happy children who love to run

Getting a family day out



Knowing and looking



My precious bub's life



Getting ready for our first birthday



Getting ready for our first birthday



Getting ready for our first birthday



Are your children dealing with a shock diagnosis? Tell us at thatlife@ambrella.com.au

DEBRA Australia, a not-for-profit that supports people living with the disease, has been invaluable. Having people who understand EB makes such a difference.

Despite their condition, they're happy children who love to run, jump and ride their bikes.

Siddiqah loves painting and colouring, and wants to be an art teacher. Azraqee is brimming with energy, and would love to be a police officer or a fireman when he's older.

I couldn't be prouder of my brave little butterflies.

And like butterflies, they're delicate – but they're also beautiful and unique. ●

Now Siddiqah, 7

Matt in Men's Health!



We are so pleased to share this incredible article featuring our very own Ambassador, [Matt Bevilacqua](#), for [Men's Health!](#)

"When I was 16 I became the youngest person at the time to win the Tasmanian Open Ironman title – a race I went onto win three years in a row. From there I moved away to QLD to chase my dream of becoming a professional Ironman..."

Click the link below to read this awesome piece and learn more about Matt's journey. <https://www.menshealth.com.au/whats-its-like-living-with...>

EB Research and Education

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DEBRA Australia is pleased to announce that applications are now open for our 2021 round of research grants. **Two grants of up to AUD\$40,000 each** are available for projects to be undertaken in 2022.

Applications close on **11 October 2021 at 5pm EDST**. Please read the [attached guidelines](#) and [application form](#) carefully before completing your application.

Projects may be laboratory based, a clinical study, or a combination. As DEBRA Australia is keen to create a more robust and collaborative EB research environment in Australia, projects which involve Australian or international collaboration are encouraged.



DEBRA is pleased to announced that DEBRA Australia memberships are now open! Membership is free and new members are more than welcome.

For those that are already Members of DEBRA Australia you don't need to renew again.

[Signup here today](#) and learn about your entitlements as a DEBRA Member.

What's On

**Please note – events are dependent on COVID-19 travel restrictions.*

2021

- 16 - 19th September: DEBRA International Virtual Congress
- 7 October: AGM Date
- 23 October: EB Awareness Week Launch Party Trivia Night
- 24 October: Walk for Wings
- 29 April 2022: Health Professionals Symposium
- 29th April - 1st May 2022: DEBRA's 7th Annual Family Camp & Conference

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