



Bayside Star (Sandgate)

Thursday 22/08/2019

Page: 1
Section: General News
Region: Brisbane, AU
Circulation: 37419
Type: Suburban
Size: 795.00 sq.cms.



slice

CUT STRAIGHT TO YOUR NEWS

press clip



Walking mates Mia McCabe, Sophie Becker, Johanna Cleaver and Talia Oertel.
PICTURE: AAP/RICHARD WALKER

RUN IS FUN WITH FRIENDS

Johanna Cleaver, 9, will tackle the Sunday Mail Bridge to Brisbane fun run on Sunday, but what most people won't see is her incredible courage. Johanna has a rare disease where her skin blisters and peels at the slightest touch, and just walking in shoes is a challenge.

PAGE 3

Johanna prepares for fun run despite pain

ANDREA MACLEOD
andrea.macleod@news.com.au

ON Sunday nine-year-old Johanna Cleaver will put on a big smile and her walking shoes to tackle the Bridge to Brisbane, but what most people won't see is her incredible courage.

Suffering the rare disease Epidermolysis Bullosa (EB), where her skin blisters and peels at the slightest touch, just walking in shoes is a challenge.

Last year, as she walked her first Bridge to Brisbane in the pouring rain, her

boots filling with water, she suffered blistering that took more than two weeks to heal. But pain is not something that will stop her.

Johanna and seven of her closest friends will put on their walking boots to shine a light on EB and raise money for research and the volunteer charity support group DEBRA.

From people wondering if they can catch the disease from her, to tackling questions about why she is often

covered in blisters that look like third-degree burns, Johanna has a strength and courage beyond her years.

"I have delicate skin," Johanna said.

So delicate, that someone brushing by hurriedly in the shops can cause her skin to tear or an accidental catch of a shoe on her heel will tear

away layers leaving open wounds. Affecting all three layers of skin and internal mucosal linings, DEBRA

(the volunteer-based organisation providing help for those with the blistering disease) likens it to "living with third-degree burns".

A fall recently while playing with friends resulted in the skin tearing from Johanna's hip, playing tennis was done with gloves and playing the violin results in blisters.

"But everyone gets blisters playing the violin. It's more when people rush past



Bayside Star (Sandgate)

Thursday 22/08/2019

Page: 1
Section: General News
Region: Brisbane, AU
Circulation: 37419
Type: Suburban
Size: 795.00 sq.cms.



slice

CUT STRAIGHT TO YOUR NEWS

press clip

and don't really see me," she said.

The brushing past, Johanna says, is something she hopes to make people more aware of for EB sufferers.

"Sometimes I don't feel the bumps, but then there is

a blister and I wonder 'where did I get that?'"

Johanna said having the support of DEBRA and her friends at school, who "stick around me trying to help" when she hurts herself had made living with EB much easier.



Johanna Cleaver is taking part in this year's Sunday Mail Bridge to Brisbane fun run.

PICTURE: AAP/RICHARD WALKER