



Fifth National Family & Children's EB Camp & Conference

Sunshine Coast

11th – 13th September 2015

Conference Program

Pelican Waters Golf Resort & Spa
38 Mahogany Drive
Pelican Waters CALOUNDRA QLD 4551



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Welcome!

DEBRA Australia would like to welcome you to the Fifth National Family & Children's EB Camp.

We hope that your stay is thoroughly enjoyable and we look forward to hearing your feedback at the end of the camp. During your stay you will have invaluable opportunities to learn more about EB care, dressings, pain management, how to access services amongst other topics.

Late book out time will be 11am Sunday or if you would prefer to check out earlier luggage can be stored at reception.



DEBRA Australia is committed to make a difference for families with EB and work towards our vision of "A world where no one suffers from the painful genetic skin condition Epidermolysis Bullosa (EB)"



Your feedback would be greatly appreciated

A feedback form will be emailed to you after the camp. We encourage you to please complete this form to enable us to evaluate the success of the EB Camp and to take into consideration changes required for further planning. The online survey will be easy to complete and we look forward to sharing the outcomes with you at a later date via the newsletter. No names are required to ensure confidentiality.

Children's Activities

Children's activities will be on offer, free-of-charge, on Saturday and Sunday commencing at 8.45am each day. A Toddlers room will be provided onsite, where the entertainment will come to them! Older children will meet at the foyer to commence their session of exciting activities.

Qualified Nurses/Carers and Volunteers will be in charge of the daily activities so you can relax in the knowledge your children will be safe and having a great time.

Please refer to more information about these activities on page 8.

*Any food for special diets that cannot be catered for at the children's activities venues will need to be taken by the carer attending to the child.

**All children requiring a carer must be accompanied by that carer for the day's activities.



Displays

Guests will be able to access information from health care companies who will have trade displays and information available on Saturday 12th September.

Friday 11th September 2015 - Family Day Out

Underwater World

An activity for all the family – Underwater World entry fee will be covered by DEBRA Australia. A bus will be made available to transfer those going from Pelican Waters Resort in the morning and will return in the afternoon. A light lunch will be provided in a designated area or there is a cafe available to purchase other options at your own expense.

Bus will be departing from Pelican Waters Resort at 10am and will be leaving Underwater World at 2pm to return to Pelican Waters where there will be time to catch up socially in a designated outside area for pre-dinner drinks.

Meet & Greet Friday Night

4:00pm - 6:00pm	Registrations
6:30pm	Dinner (Casual BBQ dinner on the deck)
7:15pm – 7:20pm	Welcome by Dr Jennifer Marty (DEBRA Australia Chair of the Board)
7:20pm	Guest Speaker: Matt Bevilaqua



Saturday 12th September 2015

Conference Program	
8:00am – 9:00am	Registrations / trade displays
9:00am – 9:20am	Welcome and update on DEBRA Australia
9:20am	Guest speaker: Dr Simon Cohen Specialist and Paediatrician – VIC Pain Specialist Clinic Melbourne Topic: EB Pain Management
9:50am	Guest speaker: Dr Tamara Lang Psychologist - Sydney Royal Children's Hospital Topic: Psychological Aspects of Pain Management
10:30am	Morning Tea and time to look at displays
11:00am	Guest speaker: A/Prof Andrew South Thomas Jefferson University USA Topic: Update on the International EB Research Progress
11:30am	Guest Speaker: Dr Gabriela Pohla-Gubo EB House Austria and University Clinic Dermatology Salzburg Topic: EB Clinet – The EB International Clinical Network
12:00 midday	Lunch and time to look at displays



Saturday 12th September 2015

Afternoon Workshops

1pm

Participants make their way to the workshop group sessions starting at 1pm.

Workshops – Participants will be divided up into two groups to ensure smaller numbers for more one on one discussion. Each group can attend the 2 different workshops on offer on Saturday afternoon.

A group number will be allocated to each participant during the registration process on arrival to the conference. If not attending all of the workshops this is an ideal time to look at the trade displays which will be available Saturday until 5pm. *Please note a third workshop will be held Sunday morning 9 – 10am for those families would like to know more about accessing services.*

Workshops

<u>Groups</u>	1:00pm – 2:00pm	2:15pm – 3:15pm
Group 1 DDEB/SEB	Dressings <i>(Lorikeet Room)</i>	Pain Management <i>(main conference room)</i>
Group 2 RDEB/JEB	Pain Management <i>(main conference room)</i>	Dressings <i>(Lorikeet Room)</i>
3:15pm – 5:00pm	Afternoon tea / Time to look at displays Social gathering on patio / networking	

Please collect children from the children's room by 5pm

Saturday 12th September 2015

Dinner Program

6:30pm

Dinner and entertainment - All welcome

Guest speaker: Dean Clifford

Band: David Drollet

Announcements:

- 2015 Follow Your Dreams Grant Announcement
- 2015 Raffle
- DEBRA Australia 10th Anniversary

**Last drinks will be called at 11.30pm and dinner finishes at midnight.*



2015 EB Cross Country Adventure Rides raising funds for the EB Nurse Program

Sunday 13th September 2015

Conference Program	
9:00am – 10:00am	Workshop: Accessing Services (applicable for those families requiring services) Simone Baird (Family Support Program Coordinator) and Michael Fitzpatrick (Board Member)
10:15am	Guest speakers: Samantha Hay / Lauren West / Margaret Norris <ul style="list-style-type: none">• National EB Nurse Program Dr Jenny Marty <ul style="list-style-type: none">• Little Heroes Foundation In-Home EB Nurse Program Simone Baird <ul style="list-style-type: none">• Family Support Program
11am	Morning tea
11.15am	Michael Fitzpatrick <ul style="list-style-type: none">• DEBRA International update
11:30am	DEBRA Australia Ltd AGM <ul style="list-style-type: none">• General members meeting
11:45am	<ul style="list-style-type: none">• What do Members want?• Where to from here?
12:30am	Close of Conference
12:30am	Lunch



Children's Activities

Saturday 12th September 2015

Children are to meet at the front foyer of the Pelican Waters Resort at 8.45am for 9am departure to Laser Skirmish and Aussie World. Children are to be collected no later than 5pm from the children's room.

Laser Skirmish and Games 8:45am – 11:30am

Aussie World 12:00 midday – 4:00pm

Sunday 13th September 2015

Onsite Activities

Children to meet in the foyer for the morning activities which will be held onsite. Animal farm and photo booth are just some of the activities. Children will be able to meet up with parents for lunch on the patio outside at midday.



DEBRA Australia Programs

DEBRA Australia was registered in February 2005. Programs currently in place include:

- EB Family Support (including Follow Your Dreams Grant and Kate Turner Fund Grant)
- EB Camp
- EB Health Professionals Conference
- EB Nurse Program (In home and hospital)
- Research Program
- Fundraising & Marketing Program



2015 DEBRA Australia Board Members and Staff

From left: Sue McKenna (Administrator from QLD), Mary Woods (Family Member from NSW), Shay Zulpo (Mentor from QLD), Dr Jenny Marty (Mentor/Chairperson from NSW), Samantha Drake (Mentor from QLD), Simone Baird (Family Support Coordinator from VIC), Michael Fitzpatrick (Family Member from NSW), Karen Frost (Family Member from SA), Dr Zlatko Kopecki (Mentor from SA), Melinda Oxford (Family Member from VIC), Rodney Sheaves (Mentor from NSW)
Absent from photo: John Bacon (NSW – mentor)



**DEBRA Australia would like to thank and acknowledge
the following 2015 EB Conference / Camp supporters**

MC – Peter Zulpo

Photographers - Kris Morriss, Lindsey Collier & Joanne Sturgess

Entertainment – David Drollet

Children’s Volunteers - for assisting with the activities

Pelican Waters Golf Resort & Spa

DEBRA SA

Wilson Foundation

Xantha Maree Foundation

Thelma Carr

Guest Speakers

Matt Bevilaqua, Dean Clifford, Dr Simon Cohen, Dr Tamara Lang,
A/Prof Andrew South, Dr Gabriela Pohla-Gubo

EB Nurses from Australia and New Zealand

DEBRA Australia Ambassadors



Tasma Walton



Brock McLean



Matt Bevilaqua



John Platten



Kate Moloney

DEBRA Funded EB Nurses



Lauren Weston
Melbourne Royal Children's
Hospital



Margaret Norris
St George Hospital Sydney



Samantha Hay
Lady Cilento Children's Hospital Brisbane

DEBRA Employees

Sue McKenna – Administrator / Secretary
Simone Baird – Family Support Coordinator



Family Support Coordinator Simone Baird with Dean Clifford visiting Youngcare

DEBRA Contractors

Scott Macfarlane – Marketing Contractor (website & graphics)
Joanne Sturgess – Administration Contractor

DEBRA Representatives

NSW	Kylie Gibson
SA	Laraine Frost Linda Turner Roger Trevor
QLD	Jenny & Dean Clifford Kathy & David Hagan Sarah Logan Jo Macri
VIC	Tagen & Darren Woodward Melissa Willcocks Tony Baric Stef Burvil Michelle Pickles

Thank you to the following major sponsors for making the 2015 Fifth National Family & Children's EB Camp & Conference possible

Major Sponsors



Please remember to complete your feedback form which will be emailed to you after the event. Thank you in advance for your input and for attending the 2015 EB Camp.

See you next time!



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