



Working for a life free of pain.

## Cannonball Charity Ride



The Cannonball Riders – tough on the outside, goody on the inside

All we can say is...WOW! We are thanking our lucky stars that DEBRA has been brought together with the Cannonball Charity Ride. After a jaw dropping 6,000km off road dirt bike journey from Bribe Island to the beautiful Barossa via Uluru, these amazing riders and their support crew have raised over \$34,000 for DEBRA's National EB Nurse Program! And as importantly, they raised lots of awareness of DEBRA and EB along the way. Thanks to Kate and the Cannonballers and their sizable donation, we can keep the National EB Nurse Program running. As DEBRA is made up of mainly volunteers and very limited resources this is a huge benefit for our small organisation.

This donation will allow for the 2 part-time specialised nurses to travel anywhere in Australia to educate and support EB families. The EB Nurses are an essential part of care for the families living with this rare genetic painful blistering skin condition. This one-on-one nursing contact, on a national basis, is the first of its kind in Australia.

### DEBRA goes along for the ride

Simone Baird (DEBRA VIC) and Sue McKenna (DEBRA Australia) were a part of the support crew for this, their first Cannonball experience. They weren't quite sure what to expect, but they came away from the experience feeling positive, motivated and grateful for the great effort and amazing reward they saw from the Cannonball Charity Ride.

Along the way, the Cannonballers had a chance to learn more about DEBRA and EB from Sue and Simone and to understand

why they are raising these much needed funds. By meeting our EB Nurse Samantha, Dean, Michael & Bree, Connor, Wayne, Eliza & Ellie, Kate and some of our members along the ride the Cannonballers appreciated what a good cause ours is and saw exactly where their donations were going.

Sue & Simone tell us that the lovely Cannonballers made them feel very welcome and they felt they were in safe hands. Kate and her officials successfully led the whole team from one side of Australia to the other, offering lots of laughs and great times along the way. We can now appreciate how much hard work and dedication goes into organising an event like this.

### DEBRA's supporters & sponsors

Lindenberg & Co Mitsubishi generously sponsored the fuel and officials fees for the DEBRA crew. Local businesses in the Pittsworth District also offered their support which meant that DEBRA could be involved in the ride, and help spread the word about DEBRA in all of the communities they stopped in along the way.

DEBRA's fantastic volunteer photographer Lindsey did a wonderful job as you can see by the photos in the newsletter; and Marco got some great film footage for a DEBRA documentary which will be finished soon. If you'd like to see more photos from the trip, head to DEBRA's Facebook page.



### VISION

A world where no one suffers from the painful genetic skin condition Epidermolysis Bullosa (EB)

### MISSION

We support the provision of specialist care. We give support to improve quality of life for all. We are committed to supporting research which develops innovative treatments and will one day find a cure.



DEBRA Australia (National Dystrophic Epidermolysis Bullosa Research Association of Australia) Incorporated.  
ABN: 94 140 980 920

## About EB & DEBRA

*Can you imagine your child living with skin so fragile that it blisters at the slightest touch? Could you handle watching your child living in debilitating pain every day? Can you imagine your child's favourite teddy bear feeling spiky against their soft skin?*

This is the reality for our children who live with **Epidermolysis Bullosa (EB)**, a rare genetic condition which causes the skin to blister at the slightest friction or even spontaneously. Children with EB live in constant pain and require high quality care by medical specialists.

**DEBRA** (Dystrophic Epidermolysis Bullosa Research Association Inc. Australia) is a not-for-profit organisation, established in 2005 and dedicated to supporting children and adults with EB. DEBRA is run solely on public donations which go towards providing important member services, EB nurses and funding research into effective treatments and ultimately a cure for EB.

## CONTACT DETAILS

### Postal Address:

DEBRA Australia PO Box 226 Pittsworth QLD 4356  
Phone: (07) 46 937 003 Email: [secretary@debra.org.au](mailto:secretary@debra.org.au)  
[www.debra.org.au](http://www.debra.org.au)

Michael Fitzpatrick (President) Phone: 0425 270 182

### OFFICE BEARERS - DEBRA Australia

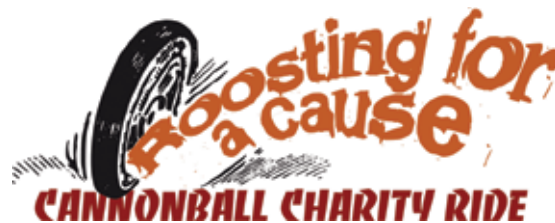
Michael Fitzpatrick (NSW)	President
Sue McKenna (QLD)	Secretary / Coordinator
Michelle Pickles (SA)	Treasurer
Roger Trevor (SA)	Public Officer
Anna Kemble-Welch (NZ)	Honorary Member

## CONTENTS

Cannonball Charity Ride	1-2
About DEBRA and EB	2
DEBRA Mega Raffle 2011	2
National EB Nurse Program Update	3
Thank you to Bernadette Hogan	3
Follow Your Dreams Update	3
DEBRA NZ News	4
SA Research News	5
St George Hospital Research News	5
DEBRA National News	6
News from the States	
QLD	7
VIC	8
NSW	9
SA	10
Donors and Supporters	11
Donations	12
2011 Calendar	12



The Amazing Cannonball Team- still smiling after nearly 6,000kms!



## Cannonball Charity Ride 2012

Riders and officials have already started raising funds & creating awareness for next year's ride which is scheduled for the end of March 2012. We look forward to working closely with Kate to make the 2012 event - **Paradise to Perth with a little Bight** - even bigger and better.

If you'd like to be involved in the 2012 Cannonball Charity Ride, contact Kate on 0402 750 900 or email [katie@cannonballride.com.au](mailto:katie@cannonballride.com.au). You can head to [www.cannonballride.com.au](http://www.cannonballride.com.au) for more details about the 2012 ride or to register your interest.



EB is an orphan disease due to the rarity of the condition. On behalf of everyone at DEBRA, thank you to all the Cannonballers for adopting DEBRA and making a difference for families in Australia living with EB.



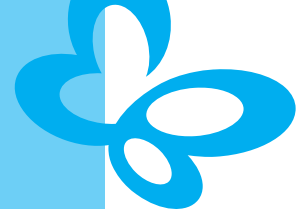
**IT'S BAAAAAACK!** The mega raffle, to help raise funds and awareness for EB and DEBRA, is on again and it's bigger and better than EVER. The top prize on offer this year is an LG 47" 3D LED TV. In plain English, that is a HUGE flat screen TV on which you can watch movies and play great games in 3D!! Now tell me, who doesn't want one of those?!

### WE NEED YOUR HELP

We need an army of volunteers to sell these tickets and raise money and awareness for DEBRA and EB. This is the only raffle we organise and it's only held once a year so we need to sell as many tickets as possible. With such an awesome prize, tickets will be EASY to sell!! So please, order some ticket books (each book has 50 tickets), and sell tickets to your family members, friends, neighbours, workmates, your sporting clubs, gym buddies... whoever!

 **To purchase your lucky raffle tickets or to sell tickets for DEBRA, contact your DEBRA State Representative or the DEBRA Secretary on [secretary@debra.org.au](mailto:secretary@debra.org.au) or 07 46 937 003.** 

**DEBRA MEGA RAFFLE TICKETS WILL SELL**



## DEBRA Nurses Making an Impact

Our two national EB nurses, Helen O'Grady and Samantha Hay, have been on board for about nine months now, and they are making excellent progress in expanding the support available for EB patients. Sam's main focus thus far has been to develop contacts with EB families in Queensland and improve procedures so that the EB clinic at the Children's Hospital is running smoothly. She has spent a lot of time assisting families with applications to join for the National Dressing Scheme and helping to sort out biopsy procedures. She is also working on ideas to help with support of older patients and has also written some clinical procedures for EB management for Queensland Health, which will be shared with other hospitals and health professionals in the State and can be consulted when new patients are identified.

Helen's focus has been on national needs, as well as acting as a back-up in Sydney when needed. She has met with health professionals and families in South Australia and Victoria, and was invited to attend two EB clinics at the Royal Children's Hospital in Melbourne, to assist the local team with case reviews. A project is also underway to standardise a "care pack" and information which can be sent rapidly to hospitals with newborns suspected of having EB.

The nurses have identified the need to improve the taking of biopsy samples for EB diagnosis. A confirmed diagnosis is essential for patients to be accepted onto the National Dressing Scheme. Clearer and more detailed instructions will be available for anyone involved in the biopsy procedure with the aim of reducing the number of inconclusive results.

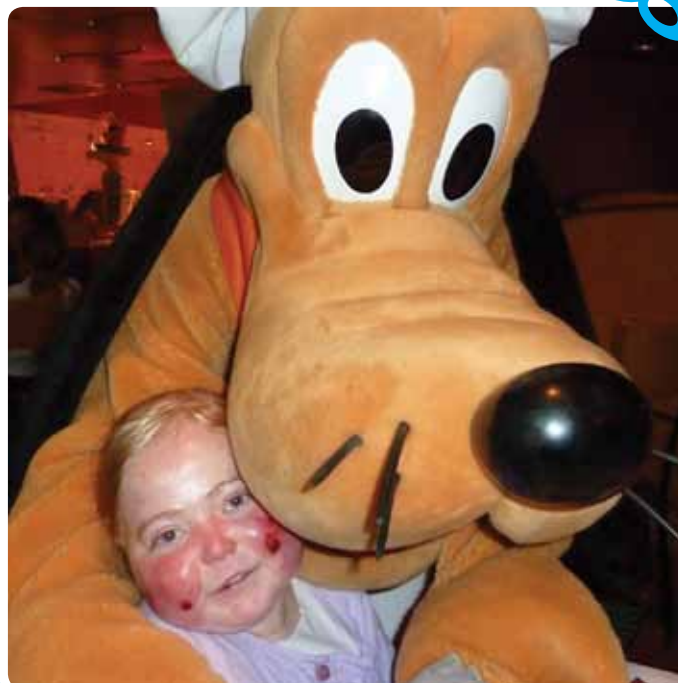
A workshop for health professionals is being planned in conjunction with DEBRA's next Conference and Kid's Camp in April 2012, to provide more information about some of the new projects the nurses have been working on and foster discussion about clinical and research developments.

## Thank you to Bernadette Hogan

We are indebted to Bernadette Hogan, a good friend of DEBRA, who sadly passed away recently. Bernadette left a very generous \$75,000 research donation to DEBRA Australia as part of her Estate.

We would like to send our condolences to Bernadette's lovely family and to let them know that this donation is a blessing, and will be used to help fund our new Research Grant Program which will be introduced in 2012. This grant program will help DEBRA to fund promising research projects specifically aimed at researching treatments and ultimately finding a cure for EB.

Thank you Bernadette.



## Thanks to the major sponsors of the National EB Nurse Program



st. george  
Foundation



## Follow Your Dreams

Eliza Baird (pictured above) was the lucky recipient of the Follow Your Dreams grant in 2011, and along with the Make a Wish Foundation, the Follow Your Dreams grant was able to help send Eliza and her family on a dream holiday to Disneyland in Florida, USA! They had an amazing time, we hear, and Eliza was so excited to be following her Disneyland dream!

If you would like to apply for the Follow Your Dreams grant in 2012, please go to our website [www.debra.org.au](http://www.debra.org.au) and follow the links to the application form. Applications close at the end of January each year. If you can donate to the Follow Your Dreams fund, to help our EB kids follow their dreams, please contact [secretary@debra.org.au](mailto:secretary@debra.org.au) or phone 07 46 937 003.

FOR ONLY \$2 EACH OR 3 TICKETS FOR \$5. IT WILL BE DRAWN ON NOVEMBER 16.



## DEBRA NZ Conference, 8 - 10 April 2011

Each year we have a get-together, a family camp or conference for DEBRA members. This year about 25 families spent the weekend at Waipuna Hotel in Auckland for our DEBRA NZ Conference.

Presentations on oral health, advocacy services, EB dressings and wound care, stress management, home adaptations including treatment rooms, emergency and earthquake preparedness, managed clinical networks for EB, and a discussion on the future goals for DEBRA NZ, were balanced by the real highlights - breakfast with some Warriors players then going to their game on Saturday night. The Warriors beat the Roosters - very exciting! DEBRA NZ being included in the Vodafone Warriors One Community programme has been a fun and rewarding partnership for us.



Younger members of the DEBRA NZ family enjoy catching up again at the 2011 Conference.

DEBRA nurses Jacqui Finnigan and Sharon Cassidy meet some of their Warriors heroes.

## 'Awakening Australia to Rare Diseases' conference in Perth, 17 - 20 April 2011

This meeting, to ensure rare diseases are included in funding for health care and research, was a great opportunity to meet people involved in other rare disorders support groups. We realised we all face similar challenges. My attendance was partly funded by NZORD, the NZ Organisation for Rare Disorders. This conference was triggered by the current focus in Europe for rare disease groups to prepare national health care plans. European DEBRA groups are very involved in the EURORDIS momentum for creating Europlans.

## DEBRA NZ Nurses

With Ministry of Health funding secured for our EB Nursing Service we have been able to employ a third nurse part-time as a specialist in EB to advise and support families and clinicians in best care and treatment practices. **Rhonda Malloy** is the new member of the nursing team. She is based in Auckland with Jacqui Finnigan but they also cover the north and central North Island.

Our 3 DEBRA NZ nurses spent a day in Sydney recently meeting with the Australian EB nurses, hosted by Brightsky. Creating a network to share information and learn from each other's experience is a valuable way to expand their skills and to make it easier to support each other in the future.

## Vietnam visit

There is very little awareness of EB in most Asian countries. This is slowly changing. I was delighted that Prof Dedee Murrell and EB nurse Lesley Rhodes volunteered to join me on a visit to Vietnam to educate and train some of the local doctors and nurses about EB. It was really rewarding and a learning experience for us too.

(See page 9 for the article about our Vietnam visit)

## Local news snippets

Christchurch is still rocking and rolling with earthquakes and aftershocks then the city was blanketed by snow twice in the last few weeks. EB families were isolated in their homes with caregivers unable to visit for several days while snow covered the ground and paths were treacherous with ice. It was beautiful but the novelty wore thin quite quickly.

Ashley Worthy has been very busy in the winterless north with his radio station, co-ordinating all the people involved in delivering programmes and arranging advertising, but he still finds time for socialising with his mates.

Ashley's mum Kathy hosted a couple of children from the DEBRA NZ family during the school holidays - all went well until her pet pig ate the fish they'd caught. Despite this setback they are keen for another EB friendly holiday.

Best wishes to all of you,

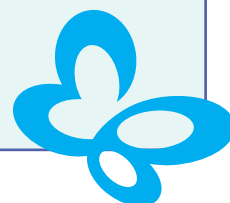
**Anna Kemble Welch**

Director, DEBRA NZ President, DEBRA International

## DONATING MADE EASY!

We find many people truly want to donate but they find it hard remembering to make regular payments.

Well, now you don't have to think about giving, just set up a regular payment with the **'Workplace Giving Program'**. All you need is a commitment from your employer to encourage your colleagues to participate and the rest is taken care of. There are lots of benefits all round. So just do it! It's a great feeling knowing you are making a difference. Email [secretary@debra.org.au](mailto:secretary@debra.org.au) or call Sue on (07) 4693 7003.





Congratulations to PhD student Nadira Ruzehaji who was awarded the Trevor Prescott Freemasons Memorial Scholarship for 2011. This scholarship will allow Nadira to spend time in a laboratory in Canada to further her research studies into angiogenic responses in diabetic wound healing. She will also now be able to attend two wound conferences in 2012 to present her research first in Italy at the European Society for Dermatology Research and in Australia (Joint Australasian Wound & Tissue Repair Society and Australian Society for Dermatology Research). Nadira was also a finalist in the "3 minute thesis" competition and won the People's choice award at the recent University of Adelaide Faculty of Health Sciences Post-graduate conference.

Dr Alex Cameron has also been awarded scholarships from the Royal Australasian College of Surgeons to continue his PhD studies next year to study the mechanisms underlying hypertrophic scarring. Alex is keen to develop new therapeutic approaches to reduce scarring in both children and adults. Alex also won the Best Poster prize at the University of Adelaide Faculty of Health Sciences Post-graduate conference earlier this month.



Nadira Ruzehaji presenting her '3 Minute Thesis'

A paper describing the investigations of Dr Zlatko Kopecki has been accepted for publication in the Journal of Pathology which is a top international journal. This paper which involved researchers from Sydney (Prof Murrell), Freiberg (Prof Bruckner-Tuderman) and Lubeck (Profs Zillikins and Ludwig) in Germany revealed for the first time that a protein called "Flii" which we have previously shown to be harmful to wounds has now been identified in the wounds and skin of patients with all forms of EB. This study showed that reducing the level of this protein improved the healing of blisters using animal models of EB. Zlatko is continuing with these studies and we are currently trying to raise funds to start human clinical trials next year. In addition to Zlatko's paper, two further papers have been submitted for publication in international journals. One outlines research performed by Jessica Lindo and other lab members detailing the development of our new Flii antibody (FAB) treatment which when applied to the surface of porcine wounds helps them to heal better with reduced scar formation, the other describes a collaborative study with Dr Rachael Murray in Sydney which shows that Flii directly affects the inflammatory response during wound healing.

I attended the recent Smith & Nephew Wound Forum in Melbourne which focussed on the importance of Infection Control. It was a fascinating opportunity to learn more about these processes from wound practitioners and researchers. Dr Stuart Mills and I will also be attending the upcoming

European Tissue Repair Society Conference which is being held in Amsterdam in October. Both Stuart and I will be giving presentations about our work and it provides an exciting opportunity to meet other researchers and share our studies with our international peers.

**Prof Allison Cowin**  
**Head Wound Healing Laboratory**  
**Women's & Children Health Research Institute**

## St George Hospital & Premier Dermatology Research News

### Vietnam Mission

Dedee and Lesley volunteered with Anna from NZ for the first EB mission to Vietnam at which we taught about EB, saw many EB children, taught about EB biopsies and dressings, and the lab diagnosis and new treatments for EB. The trip was funded by Helping Orphans Worldwide and FV Hospital, Ho Chi Minh.

### City to Surf 2011

All 5 of Dedee's family, 4 from Yorkshire, and fellows Liz Intong, Ben Daniel and Ayees Mendoza completed the 14km City to Surf run to raise awareness of EB and to raise money for research. We all enjoyed our BBQ lunch chez Dedee, at the end of the race.

### Media Update

Dedee was interviewed by Natasha Johnson for a feature on the ABC 7.30 report about her cell therapy research project in RDEB, which also featured two of our RDEB families. Thanks to Nikki and her family and Billy and his family for agreeing to participate. St George Hospital was featured with the clinical area and lab.

### PhD Graduation for Dr Helen Yan

Dr Helen Yan's graduation was on 16th August 2011, and included the lab aspects of the cell therapy trial for RDEB. Thanks again to all our patients who participated and to DEBRA NSW, VIC, SA and NZ for supporting travel costs for patients and carers!

Dr Hellen (Wenfei) Yan with Prof Dedee Murell at Hellen's PhD graduation in August



### Uptodate in EB

Uptodate in EB is an online resource available to most teaching hospitals around the world. Dedee has been editing and co-authoring this and it will be live shortly.

### Podiatric assessment in EB

Dr Tariq Khan spent his 6 month sabbatical from Great Ormond St Hospital with Dedee and they have been assessing patients with EB for their podiatric problems.



## 'Project National' Update

At the AGM in June the State membership voted unanimously that a new entity DEBRA Australia Limited be established and when appropriate DEBRA Australia Inc. should wind up.

The benefits of establishing the new Limited organisation will be to streamline processes and avoid duplication thereby maximising both financial and human resources. The new entity will also facilitate representation of all members particularly in states where no DEBRA organisations currently exist (eg. NT, WA, TAS, ACT).

A national body will also bring more opportunities to lobby the Government for improvement in EB Services and corporate entities for more support.

Membership of the new national body will be on an individual basis and States have agreed to pay the first year's membership fees for current State members. There will be a new board of directors which will include current State representatives as well as some well qualified interested supporters who have agreed to become Directors.

Work is progressing on establishing the new entity. We are currently waiting for a draft constitution from the lawyer who is doing this work pro bono for us and when we have this it will be circulated via State executives for review.

**Shay Zulpo**  
Project National Co-ordinator

## Thank you Laraine!

The Cannonball Charity Ride was an amazing event which helped raise over \$34,000 for DEBRA's National EB Nurse Program. A big part of DEBRA's involvement in the event was the staging of the Cannonball Carnival which welcomed the riders into the Barossa Valley at the end of their 6000km journey. DEBRA's Laraine Frost went above and beyond the call of duty to organise this fantastic day from the ground up. We would like to say a big THANK YOU from all of us at DEBRA, and from the Cannonball riders. We all had a fabulous time and we really appreciate all of the hard work and time you put into organising such an amazing event.



Laraine at the Cannonball Carnival

## 2012 EB Family Camp & Conference – REGISTER TODAY!

The next EB Family Camp and conference will be held 27<sup>th</sup> – 29<sup>th</sup> April 2012 at the Novotel in St Kilda, Melbourne. You will find your registration form for the conference inside this newsletter. Please fill it in as soon as possible with details of everyone who is travelling in your group and send it to Sue at the national office (details on registration form). Registrations will be capped at 150 attendees due to our budget, so if you intend on coming, please register right away to avoid missing out. As usual, we have organised some great supervised outings for the kids, as well as some activities in the children's room inside

the hotel for the ones who may not be able to attend the outings. For the parents and carers there will be workshops addressing topics such as EB dentistry, genetics, dressings and wound care, as well as guest speakers. We are really looking forward to getting together with all of our members again and we're sure the next conference will really be worth the effort for everyone who attends.

We hope to see you there!

**The 2012 DEBRA Conference and Kid's Camp is supported by the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs.**

## Thanks to St George Foundation



The St George Foundation awarded DEBRA Australia a \$20,000 grant which will be used to fund the National EB Nurse Program. Thank you so much to the wonderful people at the St George Foundation for their support, the money will offer much needed specialist EB nursing care to many isolated Aussie families.

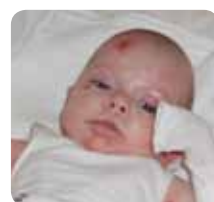
## Bunnings Fundraiser

On Sunday 27<sup>th</sup> March 2011 some eager DEBRA worker bees were up bright and early to hold a fundraising sausage sizzle at Bunnings in Glendale, near Lake Macquarie in NSW. We'd like to thank them for their hard work in raising money and awareness for EB and DEBRA. Thanks also to Woolworths Cardiff, Target Glendale, Tip Top Bakeries and Frame Promotional Products for donating vouchers and goods for the sausage sizzle.



The awesome DEBRA team at Bunnings, Glendale

## THANK YOU DEBRA Australia!!



I wish to personally thank all members and DEBRA Australia and the DEBRA States who have donated dressings and money to help an EB baby in Bosnia. Through generous donations of dressings and \$1900 AUD we have helped the Karanovic family and their baby, Ema, with some much needed assistance. My mother has visited the family in Sarajevo, Bosnia and they have expressed sincere gratitude for our assistance. This generous help means that baby Ema will receive the best dressings available and this should take some pressure off the parents for this year. Ema's mother Ajana has sent a thank you email through the DEBRA Australia website and passed on regard through myself. The family has now been in contact with DEBRA Croatia who will assist them in obtaining the biopsy and EB type diagnosis for little Ema. We have also advised them of the DEBRA co-coordinator in Bosnia who will help them with their future needs. I was very proud to see the international assistance and generosity for EB children in other countries where the support is not available to the same level we have here in Australia.

Kind regards, **Dr Zlatko Kopecki**



## Era of a New Dawn

It is with a great deal of excitement that I report to everyone that DEBRA QLD is moving forward to come under the banner of the new National DEBRA Ltd which is now being established. This will save on the doubling up of paperwork and increase our combined resources to be more beneficial for members on a national basis.

DEBRA Australia, along with State organisations, has worked hard over the years to increase EB Services and with the EB Dressing Scheme and the new National EB Nurse Program we are well underway to achieving our united goals.

I would like to take this opportunity to thank our valued supporters over the years and to put their minds at ease that they can still support and donate to DEBRA Ltd, knowing that the QLD families will continue to receive the help they need. The priority of all of DEBRA is to support those in need wherever they are.

Thank you especially to the volunteers of DEBRA QLD and to our lovely supporters, we wouldn't have achieved what we have over the years without you all. We look forward to working with DEBRA Australia and our supporters in the future to continue striving for improved EB Services, a better quality of life for our members and ultimately one day a cure.

**Kathy Hagan**  
DEBRA QLD President

## Our Beautiful Renae



Renae at 1 day old

On the 30<sup>th</sup> August 1994 our first child came into our world, and straight into ICU. Renae was born without skin on most areas of her arms and legs; some patches missing from her tiny bottom and from her baldy scalp. My obstetrician did not think she would survive. Treatments, bandages and splints were expertly applied by the Burns Unit at Royal Children's Hospital, and while Renae cried in pain I would sob. After three days they told us Renae's white blood cell count had dropped dramatically and she was open to infection. Our Renae never gave up; her dad never gave up on her either, sitting and talking to her most of the time. At 10 days old, Renae was diagnosed with Epidermolysis Bullosa Simplex (further diagnosis three years later; Dowling Meara – Köbner). It not only took a few attempts to get our tongue around the diagnosis but also our head around how this happened. Genetic counselling offered up a few answers; her condition was dominant; a "fresh gene mutation", a 1-in-360,000 chance. Having our beautiful new daughter referred to as a "fresh **mutation**" did not rest well, my thoughts drifting off to the ridiculous – Teenage **Mutant** Ninja

We're so proud of our beautiful Renae – now all grown up

Turtles and **mutant** comic book heroes, but our daughter was neither green nor deformed. For some months Blue Nurses called on us 3 times a week but in the end **I** was telling **them** what to do, and by the age of 2 Renae was telling **us** what to do. In the early days we were told she may need a wheelchair to prevent injuring her feet – I was a mother obsessed with the overwhelming thought my daughter will never dance. Scarring caused at birth was a major drawback, especially for a girl; new shoes always caused devastation to her feet and then there was the devastation caused by the insensitive boy on the school bus who made fun of her thinning hair. Despite the sad, disheartening prognosis and the bad manners of some kids and medical professionals alike, Renae has grown into a beautiful, kind and compassionate 17 year old, who has her first boyfriend, a wonderful circle of friends and is such an expert at applying make-up that friends "book her" when they have a special occasion.

And now to today, 30<sup>th</sup> August 2011, Renae is sitting the Year 12 Queensland Core Skills exams on her birthday! She attended a dance last Saturday night, she gets spray tans to cover scars and always looks like the fashion diva in scarves and head bands to cover her scalp. Seventeen years ago it was hard to imagine this day, and despite the occasional tears, Renae is resilient and has overcome the blisters and the "why me's", and we are so very proud of her.

**Kim Horwood**



## Thank you to our Generous Donors

DEBRA Qld would like to thank the following donors for their generosity and continuing support from March 2011 – August 2011.

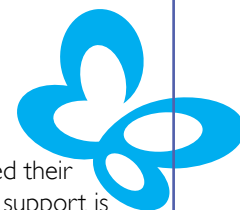
### Organisations

Worthy Matron & Worthy Patron  
Morayfield Lioness Club  
Redcliffe Chapter No.85 Order of the Eastern Star

### Individuals

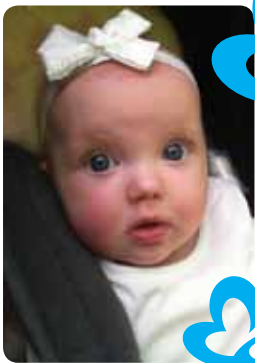
Helene Grayson & Russell Short  
Kathy & David Hagan  
Mrs Tauber  
Susan & George Meehan

Thank you to the members who have renewed their memberships and also made a donation, your support is very much appreciated.



## Meet DEBRA Vic newest member...

Tilly is the latest addition to the Victorian EB families. Tilly was born on the 14th of February 2011 with Simplex EB and has become our youngest member. She is the fourth child of Kelly and Corey and has 3 older siblings Harvey 8, Kurtis, 6 and Lexi, 4. The family is heading off to QLD in the next couple of weeks for some fun and relaxation. We hope Tilly and her family have a fantastic holiday.



Beautiful little Tilly



A big welcome to Tilly and her family to the extended DEBRA family

## Thank you to Amelia & Stiefle Research

Stiefle Research is a Medical research company located in Rowville who hold "orange day" which supports local charities. Amelia was part of the DEBRA Australia planning session at the Novotel in St.Kilda this June and attended as our official minute taker. She did a wonderful job and it was great having her involved. We look forward to Amelia and Stiefle Research being involved with DEBRA Australia & Victoria in the future and thank Amelia for volunteering her time and contributing to our planning session.

## Carmel Harris Memorial Fund & Make A Wish....



The Baird family & Margaret at Disneyland

Our family and one of Eliza's carers were fortunate enough to fly to LA Disneyland this April for 10 days courtesy of the **Follow Your Dreams** Carmel Harris Memorial Fund and the

**Make a Wish** foundation. Eliza's favourite doctor, Tom Connell, referred her to **Make a Wish** earlier in the year and they did a fantastic job of making our trip a wonderful experience. We flew aboard the Qantas A380 airbus on the way over and returned business class on the way home. We enjoyed 2 days at Disneyland sharing a fun filled breakfast with Goofy, Chip n Dale, Pluto and other friends in Goofy's kitchen. Eliza and her 6 year old sister Ellie enjoyed a magical tea party with the Disney princesses and had lunch in the Disney Rain Forest Cafe which came to life every 20 minutes with rainfall; gorilla's beating their chests and elephants blowing their trunks.

Eliza was given what we called the "**golden ticket**" which enabled the whole family to board any ride without waiting in queues. We also spent 1 day at Universal Studios, downtown LA, Hollywood Blvd and Rodeo Drive. Eliza managed to stay well during her time away but had lots of treatment to catch up on when she returned home.

Thank you to everyone who made this event possible and also to DEBRA Vic who kindly donated a night in the city for our family before our early departure.

## Cannonball Ride...

I was fortunate enough to participate in the 2011 Cannonball Ride alongside Sue McKenna. This was in aim to raise awareness and much needed funds for DEBRA Australia and the Rapid Response Nurse Program.



Sue and Simone with their support vehicle at Oodnadatta Station

This year's route was from Bribie Island QLD to Barossa SA via Alice Springs. Two weeks, 6000kms of dirt and dust, hard work (a different kind of hard work!) and many laughs but most importantly mingling amongst communities and other travellers informing them about this rare condition.

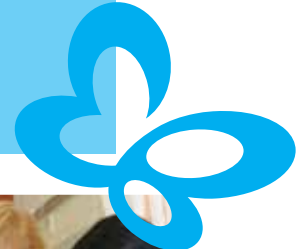
Trail Boss "Kate" and the riders made both Sue & I feel very welcome and we now have a great appreciation of how much hard work goes into coordinating such an event. Thank you to Lindenberg & Co Mitsubishi and other Pittsworth businesses who all contributed toward Sue & me attending the ride.

## FT Gully Nissan....

In July this year DEBRA Vic were fortunate enough to be asked to participate in the Annual Community Ferntree Gully Nissan fundraiser again. Thank you to everyone who sold tickets and a special thanks to Lisa Brains & Audrey Saunders who braved our cold winter to sit in shopping centres to sell these tickets and raise awareness and funds for DEBRA Vic. It was a great success being our highest fundraiser in this current financial year.

Thank you to the wonderful individuals and businesses who have donated to raise funds, equipment and medical supplies for people with EB:

- 5 Star Gym
- Mac Corner Store
- Rotary Club of Mont Albert & Surrey Hills
- Terra Culture



## DEBRA Trivia Night

DEBRA is once again holding their annual trivia night in 2011. So come along and bring your friends (only your smart ones!!!) for a great night out. There'll be raffles, games, auctions and of course, a bit of trivia.

Date: Friday 28th October 2011  
 Venue: St George Leagues Club,  
 124 Princes Highway KOGARAH NSW  
 Cost: \$20 per person (this includes supper)  
 Time: 7pm (for a 7.30pm start)  
 To reserve your place (there will be tables of 10), contact:  
 Kylie Gibson 9548 6553 or 0421 800 476  
 Mary Woods 9546 5107

## Vietnam Epidermolysis Bullosa (EB) Mission

A charity called HOW – Helping Orphans Worldwide co-founded by Hillary Joi Brown was the vehicle for a recent EB mission to Vietnam. HOW is a registered 501(c)3 non-profit organization in the USA and an approved Irish Charity for tax exempt donations, [www.helpinghow.com](http://www.helpinghow.com)



Huy at FV Hospital in Ho Chi Minh with Anna, Dedee, Lesley and Dr Orioux and one of the paediatricians, behind.

Sam Ottawa, an expat Vietnamese man based in Canada, alerted Hillary after reading of the plight of 11 year old boy Huy from Ho Chi Minh City, who has recessive dystrophic EB and was wrapped up in newspapers. Sam was able to arrange Vietnamese language newspaper Thoi Bao Canada to sponsor the EB training mission.

Dr Mai Tram Dang, physician and HOW volunteer in HCM City, was instrumental in persuading the private French FV Hospital in HCM City to donate a year of free care to two boys with RDEB, Huy and Phuoc and to sponsor a symposium at FV Hospital for educating doctors and nurses about EB. Vietnamese newspaper Thanh Nien also donated money to assist the children with EB.

DEBRA International President, Anna Kemble Welch from New Zealand, was invited by Prof Nguyen Thanh Liem, Director of National Hospital of Paediatrics in Hanoi to visit Vietnam to see EB patients and to educate the local doctors and nurses about EB. Anna requested the help of an EB doctor and nurse team, and Professor Dedee Murrell volunteered,



Lesley demonstrating some non-stick dressings on Phuoc to the nursing and medical staff

along with her EB nurse, Lesley Rhodes. Together, they spent the first 3 days at FV Hospital in Ho Chi Minh City, speaking at a 2 day seminar chaired by FV Head dermatologist, Dr Guillaume Orioux, on the diagnosis and management of EB and demonstrating dressing changes on two RDEB patients and dressing options to over 60 doctors and nurses.



Dedee presenting the Grand Rounds lecture on EB at the National Paediatric Hospital in Hanoi, Vietnam. Lesley is seated in the purple shirt.

The last 3 days were in Hanoi, at the National Paediatric Hospital, where over 100 doctors and nurses attended a lecture on EB by Prof Murrell.

Many children with EB were brought in for diagnosis and management suggestions.

The patients were surprisingly clean, given the relative paucity of separate bathing facilities and access to affordable non-stick dressings. One of the pathologists will learn how to do IF mapping for diagnosis of EB from Dedee Murrell at St George Hospital, Sydney.



Dedee, Lesley, Anna with 4 of the EB infants at the National Paediatric Hospital with the medical/nursing team

We hope to return to Vietnam again in a couple of years. If you are interested in helping Huy, Phuoc and other Vietnamese children with EB go to [www.helpinghow.com](http://www.helpinghow.com)

## DEBRA VIC NEWS cont

### Notebook....

DEBRA Vic has recently purchased a notebook computer for Nureanu Istar. This will make writing and school work easier for Nureanu who sometimes, like many kids with EB, has problematic fingers. The Istar family was most appreciative of this and DEBRA Vic was only too happy to help and we hope she has lots of fun using it.

South Australia was able to boast a highly successful year when its AGM was held in the beautiful foothills setting of Carrick Hill on Sunday 21st August last.

In his President's Report, Zlatko Kopecki referred to some of the most notable successes, including a very profitable fund-raising effort, mostly due to our Treasurer, Laraine Frost, whom he congratulated for her untiring work as a fund-raising guest speaker; as well as organiser of the highly successful national Cannonball Ride carnival at its Barossa Valley destination. The carnival provided a substantial contribution towards the overall achievement of that national fund-raiser event.

A Credit Union Lottery was also held for the first time this year, successfully raising a further \$1 600 for research.

Other notable events this year included the agreement in principle to support the establishment of DEBRA Australia Ltd. This was done at a well-attended meeting with Project National Co-ordinator, Shay Zulpo, at the home of Public Officer Roger Trevor, a member of the Project National Committee.

Zlatko also was pleased with the SA support for the Bosnian EB family and noted the appointment of top TV personality Leigh McClusky as our new Patron and his attendance at the Rare Diseases Symposium at Fremantle in WA.

Amazing support has been forthcoming from Chris McDermott of the Little Heroes Foundation, who is working on a trial with Zlatko which could have national benefits. He proudly announced that DEBRA (SA) has, as a first, established an in-home nursing program that will kick-start in September. After working hard with Little Heroes Foundation, he has gained their support for a three-month program in SA that could ultimately be developed into a national program. Suitable nurses are currently being recruited and it will all be funded by the Foundation.

Last year's committee was returned to office, with the addition of Lauren Busch as Publicity Officer. Lauren is a welcome new member of the committee.

A Special General Meeting is proposed for early November, when this State will formally declare its intentions in support of the aims of Project National.

Projects for the coming 12 months include International EB Awareness Week, another major lottery, support again for the Cannonball Ride and, of course, the committee will be encouraging a strong SA contingent for the significant National Conference in April next year.

Roger S. Trevor

## DEBRA Australia is on Facebook!

Go to DEBRA Australia's website [www.debra.org.au](http://www.debra.org.au) and click on the facebook link to become a fan of DEBRA's fan page today! Then invite your friends to become a fan of DEBRA too!



Our 'Meeting of Great Minds'  
Michael Fitzpatrick, Dr Lachlan Warren, Chris McDermott, Dr Zlatko Kopecki, Prof Allison Cowin

## In-home nurse care program for EB patients

I am excited to announce that my initiative as a founder of this program is officially beginning in September 2011. My idea for the program started earlier this year and was followed by a meeting between DEBRA SA and Little Heroes Foundation in March 2011 where Chris McDermott (Head of Little Heroes Foundation and former AFL star) had a chance to meet and chat with Kate Turner. This was followed up by a "meeting of great minds" between Chris McDermott (Little Heroes Foundation), Prof Allison Cowin (Head of wound healing laboratory, WCHRI), Dr Lachlan Warren (Head of Dermatology, WCH) and DEBRA-SA to brainstorm how we can best improve the services for EB children in SA. I have since made a project proposal and Little Heroes Foundation has agreed to come on board and fund our 3 month state trial in-home nurse care program.

We are proud that our close collaborations with Little Heroes Foundation and Nursing Agency SA - Healthcare Australia has resulted in our first in-home nurse care program for EB patients. The nurses have been interviewed and selected with the involvement of the families and we have organised the training session for the nurses by EB specialist nurse Ms Louise Stevens (BrightSky Australia) who has kindly agreed to help us out. Our three month trial will start in late September, with two three-hour weekly visits assisting families and EB patients during dressing changes and providing much needed respite for the family. We will have surveys in place to ensure the efficacy of the trial and hope that this will become a permanent service to most severely affected EB patients in SA. We are also working with Dr Lachlan Warren (Head of Dermatology, WCH) to establish a multidisciplinary EB clinic for EB patients in SA. We also have had discussions and pending on the outcome of the trial we hope we could take this service to the national level and directly help families in need. It has been a lot of work but I am pleased the trial is starting and I have hope for the future.

THANKYOU Little Heroes Foundation and Nursing Agency SA - Healthcare Australia!!

Kind regards  
Dr Zlatko Kopecki



## Thank you to the following donors for supporting Debra Australia

### Donors from March 2011 – September 2011

#### Organisations

- St George Foundation
- Link Healthcare P/L
- Fredrick Gordon P/L
- Nu Skin Enterprises P/L
- Energy Australia Staff
- REPCO
- Reactive Vision
- Mascot Hangers Social Club

Thank you to all the DEBRA organisations for further contributions to Project National

#### Workplace Giving Program

- Ausgrid
- Department of Infrastructure, Transport, Regional Development & Local Government
- Telstra
- Department of Health & Aging

#### Private donors

- Anon donor
- Chris Byrne
- Robert Andujar
- Michael Kamenjarin
- LV Hann
- Marie Rak
- Miss D Stephens
- Stephanie Wotzke
- Margaret Brealey
- Amelia Jones
- Alex Roberts
- Cynthia Carter

Other donations received via the website and Everyday Hero  
All of the Cannonball Charity Ride Donors

#### High School Student Volunteers

- Katie & Fraser McIntyre, Rebecca & Toby Whitton, Lieghanna & Vanessa Ruhle, Garth Weir and Thomas Degnian from Pittsworth State High School

#### Thanks for the memories - the Cannonball Charity Ride 2011

We received many donations to help us along in our Cannonball Charity Ride fundraising effort. Not to mention the lovely contribution of donations that were made by each individual rider of \$1,200. Many people put their hands up to contribute toward the fundraising or to sponsor the event in some way and we would like to thank each and every one of you for that. Unfortunately we would need a 100 page newsletter to list all of our donors individually, but you know who you are.

We would like to thank these amazing folks, who made the Cannonball Charity Ride the success that it was. Thanks to;

- Kate Warfield & the wonderful Cannonballers
- Lindenberg & Co. Mitsubishi
- Morayfield Lioness Club - Helen Wilkinson & Elizabeth Chappell for organising a hearty breakfast on the send-off from Bribie Island on the first day. Eggs were provided by McLean's farms
- Simone for filming the home video of the trip
- Sue for volunteering her car as a support vehicle, and
- The lovely Lindsey Collier – a super-talented volunteer photographer who not only took wonderful photos but put together a great slide show with a broken laptop!

Thank you to the following organisations who contributed very generously toward the Cannonball effort; we couldn't have done it without you.

- Telstra Country Wide
- Beef City
- Goodyear Auto Service Centre Pittsworth
- Chalala Bakery
- Anggatha Estates Winery
- Steric P/L
- Ashton's Meats Pittsworth
- Diageo Australia Ltd
- R & N Contractors
- AUSCO
- Drakesbrook Tavern
- Central Scaffolding
- Mabic
- Neubau
- Barcoo Plant Hire
- Glenco P/L
- Corona Cabinets
- Joy Constructions
- Kiwanis Club of Barossa
- Angaston & District Lions Club
- Eramanga State Primary School
- Tanunda Lutheran School
- Embroidery Place Pittsworth

Our thanks also go to long-time DEBRA supporters Nicci & Stephen Radeski for helping to transport some of the DEBRA crew and riders back to the airport at the end of the ride.

Another friend of DEBRA who has been entertaining DEBRA members over the years is Tom Lee Archer who, along with Mike Mulhare, entertained the troops on the first night at Westmar after a huge day going through tracks and across rivers. Thanks for keeping our spirits high guys!



# DONATIONS

I WOULD LIKE TO SUPPORT ADULTS & CHILDREN WITH EB

Name: \_\_\_\_\_

Telephone No: ( \_\_\_\_ ) \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Postcode: \_\_\_\_\_

Email: \_\_\_\_\_

CHEQUE

CASH

AMOUNT \$ \_\_\_\_\_

SIGNATURE \_\_\_\_\_

Please make cheques payable to: **DEBRA Australia Inc.**  
and mail to: DEBRA Australia Inc.  
PO Box 226,  
Pittsworth QLD 4356

All donations over \$2.00 are tax deductible.

# CALENDAR

## 2011

### October

**DEBRA Mega Raffle** –

Drawn 16 November

24 – 31

**EB Awareness Week**

28

**DEBRA Trivia Night** –

St George Leagues Club,

Kogarah NSW – see page 9 for details

### November

**DEBRA Mega Raffle** –

Drawn 16 November

## 2012

### March

**End of March:**

**Cannonball Charity Ride 2012** –

Paradise to Perth

### April

27-29

**DEBRA Conference & Kids Camp** –

Novotel, St Kilda.

## Follow Your Dreams Grant

Applications for the 2012 Follow Your Dreams grant are now open. If you would like to apply for, or donate to, the grant, go to [www.debra.org.au](http://www.debra.org.au) and follow the links. Applications close at the end of January 2012 and the grant recipient will be announced at the 2012 DEBRA Conference in April.

You can read the current issue and past issues of DEBRA News online and read more about DEBRA's important work by visiting our website.

Make [www.debra.org.au](http://www.debra.org.au) your default website homepage so you can keep up to date with all the news!

## WITH THANKS

*DEBRA Australia is very grateful to the following companies for their ongoing sponsorship. The support they have provided since DEBRA Australia officially formed as a National Body has just been amazing. We look forward to these sponsors continuing their support with us and providing a better future to all who are affected by EB.*



**NU SKIN**  
THE DIFFERENCE. DEMONSTRATED.™



**MÖLNLYCKE**  
HEALTH CARE

## Save the trees!

If you no longer wish to receive DEBRA News, or if you would rather receive it by email, please email the Secretary at [secretary@debra.org.au](mailto:secretary@debra.org.au) or phone (07) 4693 7003.

Edited by Jacqui O'Loughlin from 'Elite Virtual Executives'

Produced by Nu Skin Enterprises

©2011 Nu Skin Enterprises Australia, Inc. Incorporated with limited liability in Utah, USA ABN 90 057 203 531

