



What's been happening in the DebRA NZ World?

June 2009 - Report from the Director, Anna Kemble Welch

DebRA NZ is slowly growing in size with several new babies born with EB and some families with older children as well as adults who had not previously been in contact with DebRA. New parents have really appreciated talking to others with children with EB who care and know the challenges they're facing.

We have also had contact recently with a nurse working in Dunedin Hospital, Stephen Gill, who worked with children with EB in Birmingham before emigrating to NZ. It's great to discover another medical professional in NZ with this depth of experience with EB care.

DebRA NZ Nurses

The DebRA NZ Specialist EB nurses Jacqui Finnigan in Auckland (with the north and central North Island as her region) and Sharon Cassidy in Christchurch (with the lower North Island and the South Island as her region) have been kept busy providing an invaluable service to support and advise those living with EB, as well as the medical professionals, schools etc involved in their lives.

Jacqui Finnigan: 021 486 799 jacqui.finnigan@xtra.co.nz

Sharon Cassidy: 03 3523 651 or 027 295 5857 sosnursing@xtra.co.nz

Deanna Forsyth is enjoying life with her gorgeous little girl Lexa as well as working as a nurse on Whakapapa ski field again this winter. Deanna has resigned from her role as a part time EB nurse at this stage but is keen to keep in touch as a part of the DebRA family.

Holly's new bathroom

Holly Gilshnan has a fabulous new bathing and bandaging room – fundraised for by a family friend who not only raised the money needed from the Greymouth and Christchurch communities but also arranged many donations of materials and labour to build the new room. This has meant a very welcome donation to DebRA NZ of the surplus funds.

Vodafone Warriors Christmas party 2008



The Brooke family travelled from New Plymouth to join several Auckland DebRA families for a disco party with the Warriors players in December. The kids all had a fabulous time.

It is wonderful that the Warriors have chosen DebRA NZ as one of the 3 charities they will support under their one community programme for the next 3 years.



DebRA International

I had the privilege of attending the DebRA International Conference in Mechelen, Belgium, in October 2008. There is a separate full report of the conference for anyone who would like to know more about it.

I then visited the UK, spending time at Great Ormond Street Hospital for Sick Children to sit in on their EB clinic, and St Thomas's Hospital where teens with EB transition to adult care. I also visited the DebRA UK office, discussing current and future projects on the local and international fronts with John Dart. It was particularly interesting to talk about their new centralised dressings ordering and distribution process; their support systems for people with EB including the team of specialist

EB nurses, social workers and counseling, and the holiday home set up specifically for DebRA families. DebRA UK has a large network of Charity shops selling second hand goods, and fortunately these continue to make money despite the current economic times.

I was elected Deputy President of the Executive Committee of DebRA International. The committee meets monthly by phone conference and through a google-group and email to discuss issues between meetings. I am also part of a Welfare & Care group that is tasked with helping develop support for individuals with EB in countries that don't yet have their own national networks, and improve EB care in countries where this is minimal or non-existent. As the only representative from this side of the world, my particular interest is to connect with DebRA organisations and individuals with EB as well as medical professionals with experience with EB in Australasia and the Asia & Pacific region.

DebRA Japan

Humphrey Hanley was a guest speaker at a Dermatologists meeting in Hokkaido, Japan, in February 2009. While living in Japan last year as a university exchange student, he was active in helping the new DEBRA Japan organisation to get established. Humphrey is now back home in NZ to complete his degree at Victoria University.

EB Research in Australia

Ashley Worthy has been participating in research trials in Sydney with Dr Dedee Murrell. Thank you for being such a brave guinea pig, Ashley, and we'll be very interested to hear the results of the trial as soon as they are known.

DebRA Australia

We have been helping DEBRA Australia with lobbying their Federal government to fund dressings supplies for people with EB – with wonderful results. They were successful in having over \$4 million per year for the next 4 years allocated in the last budget - \$16.4 mil to pay for EB dressings over the next 4 years as a trial period.



DebRA Australia Conference

A couple of NZ families participated in the recent DebRA Australia conference as well as DebRA NZ nurses Jacqui & Sharon helping present a nursing workshop. Martin and I ran a series of workshops on EB and Independence. The conference was a great success and their next is planned for 2011 in Melbourne.

DebRA NZ website

There have been some technical glitches getting in the way of the website being kept up to date, but we are in the process of having a re-design that will mean it will be much easier to stay current with news and events. The website is still an important way for people to make contact with DebRA NZ and hopefully before long it will also be a good way for members to keep in touch with each other.

Helpful hints

Nichola Andersen in Rotorua is currently in the process of compiling a list of “helpful hints/tips” for people and families who deal with EB in their life. Nichola would be really appreciative of any hints you may have to offer to others that may have worked for you. Please email these to granic@clear.net.nz so she may have a list available to those who want it at the DebRA NZ Conference.

EB Clothing Survey

We have been working on a project with Cheryl Wilson of Otago University (Director, Consumer & Applied Sciences Programme and Senior lecturer in Clothing and Textile Sciences), to discover the common factors for comfortable clothing for people with EB. As a first step, a survey about factors affecting suitability of fabrics against non-wounded EB skin was completed by a number of DebRA NZ members. Thanks to everyone who has participated so far. This is the first step in what we hope will be an ongoing project leading to the design and possibly manufacture of clothing specifically designed for children and adults with EB.

Publicity

Several newspaper articles have appeared over the last year, including a feature story in the Christchurch Press in May this year, and most recently a story in the Auckland East and Bays Courier featuring Saimon Lasso and May Dijkgraaf (May Cheah's new married name). In the days leading up to the conference, Jacqui will be appearing with one of the children with EB on TV1's Breakfast show. Keep an eye out for the new star!

DebRA NZ Conference 2009, 9 - 12 July, Waipuna Hotel and Conference Centre, Auckland

A hard working team in Auckland is putting the final details together for the DebRA NZ conference. Jacqui Finnigan, May Dijkgraaf, Bernadette Mark and Faye Gordine have given many hours to make this conference a success. Thanks for all their hard work and we look forward to seeing everyone there.

If anyone has not yet let us know of their intention to come along, please contact me asap.



Members Planning Session at the conference

Several DebRA members have 'volunteered' (not too much arm twisting required!) to help out with some of the core tasks needed to keep the DebRA NZ organisation running smoothly in the future. Anyone who would like to become more involved in the organisation would be very welcome.

Some examples and suggestions:

- Jon Riordan has agreed to take over the book keeping/treasurer role with Louise's help.
- Nichola Anderson has offered to help with newsletters and is collecting helpful hints from members (with help from Lisa King).
- When the new website is up and running there will be roles for moderators of a members forum, content editing and news updating in an easily managed format.
- Fundraising offers endless opportunities for anyone with some time and energy and can be very challenging and very satisfying.
- Co-coordinating occasional meetings in your own district, or offering to be the contact person for any families in your area.
- Lobbying the Ministry of Health to pay for the specialist EB nurses
- DEBRA NZ 30th Anniversary in 2010 - planning for a healthy future
- . . . and any other ideas to help improve the quality of life for people living with EB

Please think about this and if you would like to be more involved, contact Anna, Jacqui or Sharon or make your availability known at the planning session during the Conference.

Fundraising 2008/2009:

- **Lottery Ministers Discretionary Fund** covered travel and some accommodation costs for Jacqui Finnigan to attend training in EB care and treatment in the Netherlands and meet EB nurses in UK in March 08.
- Sadly the **Butterfly Ball** planned for August 2008 was canceled due to lack of confirmed participants and the high cost of overheads – a warning of tough financial times to come for business community.
- **Lottery Ministers Discretionary Fund** also funded Anna's travel and conference expenses to participate in the DEBRA International conference in Oct/Nov 08 and visit DEBRA UK.
- **J R McKenzie Trust:** \$15,000 for admin, office costs & part time salary for Director
- **Perry Foundation:** \$35,244.00 to pay Jacqui Finnigan as part time EB nurse for 2009
- **Pub Charity:** \$6222.22 funding for DebRA NZ website re-design.

Funding for DebRA NZ Family Camp in Christchurch, April 2008

- **Newmans Own Foundation:** \$10,313.27 (\$8000 US)
- **Youthtown:** \$12,000
- **Sargood Bequest:** \$2500

Funding for DebRA NZ Conference 2009

- **Air NZ :** \$20,025.00 (donation following the Warriors semi-finals game last year)
- **HiFX Ltd:** \$5000.00
- **Mainland Foundation:** \$3000.00 (for travel to Akld for Chch families)
- **Molnlycke Healthcare:** \$980
- **Bamfords:** \$500

And other fantastic donations from individuals and businesses:

- Surplus funds from Holly's bathroom: \$36,499.10
- Mark Ockleston of Sharper Cleaning: \$200 donation every month
- Newtown Festival site marshal crew: \$4500.00
- Charity auctions on Trade Me in August 08 (organized by Faye Gordine): \$3000.00
- KPMG: \$2106.50
- REM Systems Ltd: \$1500.00
- Jon & Louise Riordan make a regular monthly donation as well as Louise and her sister making a donation to DEBRA NZ for every Sign Here Bear they sell.
- generous individuals have made personal donations and gifts of time and services



I would like to extend a huge thank you to all the people and organisations that have supported DebRA NZ over the last year. Your help makes a huge difference to the lives of children and adults living with EB.

Anna Kemble Welch
Director, DebRA NZ
123 Daniell St, Newtown
Wellington 6021
Ph: 04 389 7316
Email: debranewzealand@gmail.com