



DEBRA NZ Newsletter

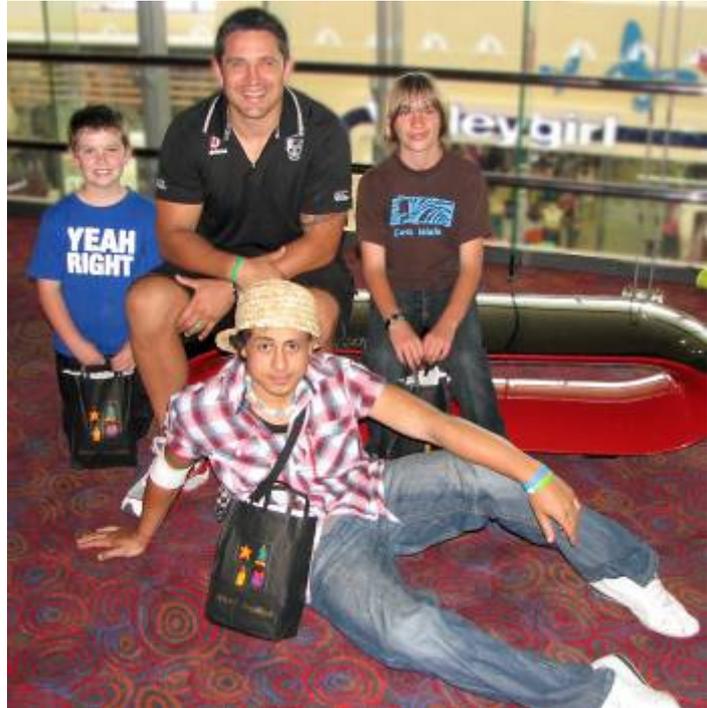
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I hope you all have a very joyful Christmas and New Year and a relaxing summer holiday.

The Vodafone Warriors Christmas Party.



Saimon Lasso meets Michael Luck.



Harry and Tim Nalder and John White meet Steve Price.



May, Elizabeth and Anna meet Steve Price, Warriors Captain 2009.

INSIDE THIS ISSUE:

Vodafone Warriors 1

Letter from the Minister of Disability Issues 2

Payroll Giving 3

ZONTA group raises funds 3

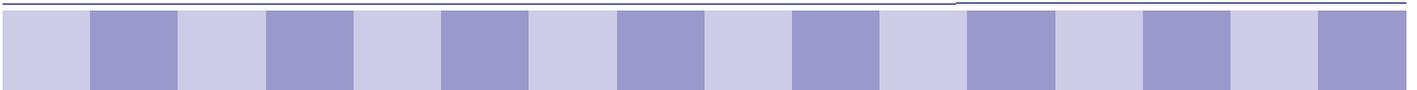
Message from the Director, Anna Kemble Welch 4

Events Calendar 2010

Website progress report 5

Welcome to new members

Contacting the DEBRA Nurses 6





10 DEC 2009

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Tēnā koutou katoa, i ngā āhuatanga o te wā

I am writing to congratulate Anna Kemble Welch and DebRA New Zealand on her amazing success in being elected President of DebRA International.

Tangata i akona ki te kāinga, tūnga ki te marae, tau ana. This means a person trained at home will stand on the marae with dignity. I believe it represents the special training that Anna has had to prepare her for this role.

Since the birth of her son, Humphrey, over 27 years ago Anna and her husband have worked to gain improved access to health, education and disability care for Humphrey and subsequently all children born with Epidermolysis Bullosa in Aotearoa.

Throughout that time they note they have achieved a number of improvements being:

- Improved access to quality bandages
- Improved access to medical treatment
- Increased nursing care
- Increased awareness by more health professionals than ever before of Epidermolysis Bullosa ensuring early diagnosis
- Introduction of an educational book to inform people about life with Epidermolysis Bullosa
- Meetings between individuals and families that have Epidermolysis Bullosa

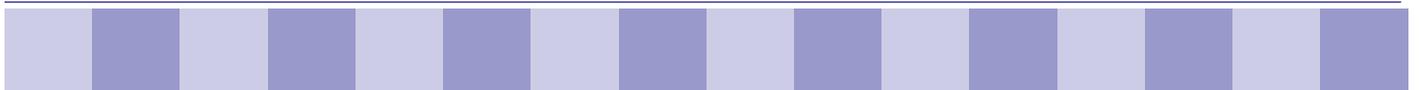
Anna's appointment also recognises the work of her predecessor Jillyan Hing who established DebRA New Zealand and of the work of New Zealanders with Epidermolysis Bullosa and their parents.

DebRA New Zealand has grown into an organisation that works on behalf of 120 people with Epidermolysis Bullosa.

I wish Anna and DebRA New Zealand all the best for the future.

Heoi anō

**nā Hon Tariana Turia
 Minister for Disability Issues**



Payroll giving: it's now even easier to give a little

From January 2010 payroll giving will be available as an option for charitable

donations. This is an easy and beneficial way for both donors and recipients to give money, as donations go directly from an employee's gross pay to their chosen community organisation.

The scheme will be administered through the PAYE tax system, so tax rebates on your donation are immediate rather than annual.

Payroll Giving is voluntary and will only be available for organisations that file their PAYE returns online.

In October employers will have received information from the Government about the new system. If you would like to support Debra New Zealand through payroll giving then ask your employer more about the scheme.

All you need to do is ask if your work is set up with Payroll Giving and provide them with the following details:

THE DEBRA NZ TRUST

The National Bank of New Zealand

06-0513-0192618-25

There are many ways to raise funds

In the New Year the ZONTA Club at Avonside Girls' High School will give \$750 to DebRA NZ with the prerequisite that it goes towards helping the wider DebRA community.

After much discussion Christchurch's DebRA families decided the donation should go towards creating a DVD for new families, carers and health professionals on basic care of EB.

The donation came about because Holly Gilshnan's carer, Rachel Cooper, attends Avonside Girls' High School and she arranged for the EB specialist nurse, Sharon Cassidy to visit the group several times throughout the year.

Sharon will give us an update in the New Year with progress on the DVD.

Well done all concerned and please take the time to visit www.zonta.org.nz to find out more about this fantastic organisation.



ZONTA Club members 2009, Avonside Girls' High School.

Dear DEBRA New Zealand members and supporters,

2009 has been a year of challenges and some potentially great developments for EB care and treatment both here and internationally. For me the biggest challenge has been my election as President of DEBRA International at the Conference in Prague in September.

To give this role anything like the attention it requires I will need a lot of help and support from everyone here to make sure DEBRA New Zealand continues to thrive as well.

The recent newsletter from DEBRA International is attached for you to read when you have some time. It includes several pages of information about the latest EB research happening around the world.

On the home front, our DEBRA Nurses Jacqui Finnigan and Sharon Cassidy continue to do a wonderful job within the limited time we can afford to pay them. They are only employed part time and funding is tenuous, depending on grants and donations. The number of people with EB who they help is growing. Some have lived with EB for years and eventually get in touch for advice and to try the latest dressings, but also we are finding more babies being diagnosed with EB. Awareness of EB among the medical professions seems to be increasing. The great reputation of the EB nurses has spread and they are being contacted more often by hospitals or families when a new baby shows symptoms of blistering skin.

Exciting developments ahead for DEBRA NZ

A symposium was organised by NZORD in November to bring representatives of rare disorder groups like DEBRA together with the movers and shakers in the Ministry of Health to discuss the delivery of health services for people with rare disorders. Jacqui Finnigan and Dr Nick Birchall helped Martin and I to present the case for why we need a nationally funded nursing and multi-disciplinary health service with specialist expertise in EB. Dr Diana Purvis and Sharon Cassidy also helped us to prepare our presentation.

The Chair of the Advisory Board for the new National Health Board, Murray Horn, attended part of the meeting. He agreed to fund one or two pilot studies nominated by NZORD. The meeting unanimously recommended that EB should be the first rare disorder to receive funding under the new scheme. The model developed for accessing services could be applied (with some variations) to other groups in the future. With a small number of people and no high tech infrastructure required, EB is a very manageable pilot for the new NHB to trial and assess the provision of national care. This is very positive and we hope the details can be finalised early next year.

Best wishes for 2010!

Anna Kemble Welch, Director, DEBRA NZ and President, DEBRA International

DEBRA NZ Calendar 2010

February 27: Warriors pre-season Carnival, North Harbour Stadium

February 28: International Rare Diseases Day

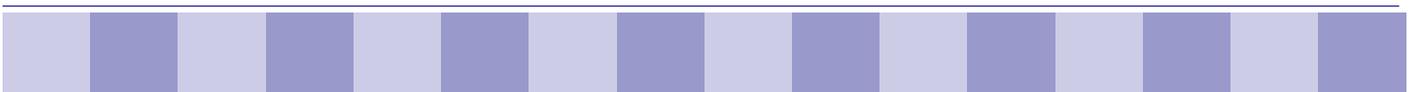
April: Family Camp & Conference, lower or central North Island

(Note a decision will be made in the New Year on the venue and exact date of our annual conference.)

August: Adventure & Ski Camp for teens and young adults

Oct 25 - 31: International EB Awareness Week and 30th Birthday Event for DEBRA NZ

Nov 16 - 18: DEBRA International Conference, Santiago, Chile



Website progress report: www.debra.org.nz

Thank you for your feedback about the proposed new web site. The team at Motive (Justine Flanagan and Andy Kirkwood) are currently building the site and all going well it will be ready for launch in the New Year.

The site has been redesigned for many reasons:

- To provide those with EB and their families with more information about EB, nursing services, skin care, handy hints and things to be aware of.
- The site will double up as an educational tool for parents of newborns with EB as well as other care-givers, teachers and relatives.
- The site will be a point of contact between members with a discussion forum, and a place for announcements and / or appeals for help.
- The online donation section will be simplified to ensure those wanting to donate can do so easily.
- The new site will also provide a better profile for our sponsors.

Importantly DEBRA volunteers will be able to update the website on an as-and-when needed basis, ensuring it is easily maintained and kept up-to-date in a cost-effective manner.

Holly Gilshnan's uncle Daniel O'Regan is one of the people helping with the website and newsletter.

If you have any photos that you think might be suitable for the website please email them to Daniel:

daniel@conv.co.nz



The new international DEBRA logo will be used on the re-designed website.

Haere mai ki te whānau DEBRA NZ

We'd like to welcome some of the newest members of the DEBRA NZ family.

Wellington:

Emily Cook was born 7th October 2009, daughter of Amy and Aaron.

Dunedin:

Zoe Bligh Martin was born 11th April 2009, daughter of Alex and William (who also has EB). *Pictured below left.*

Levin:

Lachlan Mark was born 11th July 2009, son of Melissa and Chris (who also has EB). *Pictured below right.*

Christchurch:

Caleb Morris was born 22 January 2008, son of Tania and Wayne.



Contacting the EB Nurses

We hope the nurses hours can be extended when the government funding finally happens, but until then Jacqui and Sharon are still available to give support and advice if and when you need. If it is non urgent, please try and contact them in normal work hours, but if you need to contact them urgently they are very willing to help any time.

Sharon is away until the 11th January but Jacqui is only away over New Year and working through the summer.

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DEBRA Nurses Sharon Cassidy and Jacqui Finnigan

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Jacqui can also be contacted on 0800 EB Nurse (0800 32 68773). Please do leave a message if you don't receive an answer, and if you text and don't get a reply, ring them. Jacqui will try to not drop her phone overboard when she goes sailing this summer!



The DEBRA NZ Conference, Waipuna Hotel, Auckland, July 2009