DEBRA INTERNATIONAL CONGRESS
Zagreb, September 2016

EBWB :
EB Without Borders

Working for a life free of pain.
EB Without Borders

Mission:

• To help patients, families and doctors in countries where there is no DEBRA structure, and assist them to form and develop new DEBRA groups to access better information, support, care and treatment.

• To ensure all requests for information and support from around the world are responded to, connecting individuals with what help and support might be available in their country or region.

• And to encourage co-operation between existing DEBRA groups.
Capacity building for new and developing DEBRA’s

Advocacy & Networks: Connect families together and to clinicians
- there is a better chance to change government policies and improve access to health care
- raise awareness and funds for EB care
- becoming part of a worldwide network of EB support groups

Education about EB: Connecting people with information
- individuals and new DEBRAs
- links to useful websites and available material
- encourage translation into local languages

Medical expertise: Connecting with EB-CLINET
- seek out experienced local clinicians and hospitals who can provide diagnosis, care and treatment
- help develop relevant guidelines and training in EB for clinicians and families
Contrasting environments & access to resources & healthcare
EBWB, education and training - why?. . . . . . .

- 30 yrs ago parents everywhere were told EB children would die young

- Understanding of woundcare, avoiding infection & good nutrition can make a BIG difference to quality of life & health

- EB is rare but in many countries with large populations, hundreds of babies are still sent home with no hope of survival.

Together we can make a huge difference.
International Co-ordinator:
A central hub to receive requests from people from around the world.

**ebwb@debra-international.org**

Depending on the type of request, language skills and experiences with a specific country or region, the co-ordinator and EBWB team define the best person to fit the needs, who will then act as a source of mentoring support.

Currently working with people and developing DEBRAs:

Algiers, Albania, Montenegro, Moldova, Lebanon, Sri Lanka, Singapore, China, Vietnam, India, Pakistan, Indonesia, Philippines, Turkey, Cuba, Cambodia, Peru, Venezuela, Bolivia, & refugees from Iran, Syria & Afghanistan displaced into Europe

We work closely with EB-CLINET when the need is for contact with a clinical expert or education and training for clinicians about EB care.
Work-flow : EBWB - EB-CLINET

Facebook
E-Mail
Website
Phone

General requests
Clinical requests
DEBRA requests

EBWB Coordinator
EBWB Coordinator

Answer through 1,2,3,4,5 cc to EBWB Coordinator

Coordinator informs original request receiver about the status
EBWB team 2015/16:

**Back row**: Anna (New Zealand), Vlasta (Croatia), Ingrid (Belgium)

**Front row**: Lea (international co-ordinator, New Zealand), Ritu (Singapore), Polona (Slovenia), Evanina (Spain), Loreto (Chile) and not in photo, Gena Brumitt
Regional Ambassadors:

Some team members have particular geographic regions, some depend on the language spoken, to help develop EB care and DEBRA groups in those regions.

**Loreto & Evanina:** South & Central America – Colombia, Argentina, Brazil, Peru, Paraguay, & Spanish speaking countries

**Vlasta & Polona:** Central & East Europe, Baltic States
- Albania, Bosnia and Herzegovina, Serbia, Montenegro, Moldova, Macedonia, Rumania, Greece, Bulgaria, Ukraine, Poland

**Ingrid:** French speaking countries – Morocco, Algeria, Tunisia

**Anna:** South East Asia/Pacific region - Vietnam, Malaysia, Singapore, Sri Lanka, China, Pacific Islands, also Turkey (with Lea)

**Gena:** Middle East - Iran, Iraq, Saudi Arabia, United Arab Emirates; Israel, Gaza, Georgia, Libya, South Africa, Caribbean

**Ritu:** Indonesia, India, Pakistan, Philippines
Experiences of the EBWB team’s Regional Ambassadors
Project: Collaborative trip “Debra Chile - Debra Colombia”
Bogotá, 2012 and 2014

Participants: Dr. Francis Palisson
Dra. Mª Joao Yubero
Dra. Susanne Krämer
Dr. Matías Orellana
EU Eugenia Elizalde
EU María José Gana
Aim of the Project

- Joint attention of both medical teams (DEBRA Colombia-DEBRA Chile)
- Mentoring the health team in the areas of dermatology, dentistry, pediatrics, physiotherapy and nursing
- Workshop for parents
- Discussion of cases and care planning of patients evaluated
- Strengthening the work of DEBRA Colombia

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IX Simposio Internacional de Epidermolisis Bulosa

Niños Piel de Cristal

Save the Date 15-16 Diciembre 2016

Para mayor información: vlarrain@debrachile.cl

Conoce más sobre Fundación DEBRA Chile en: www.debrachile.cl
EBWB Ambassadors Vlasta Zmazek (Croatia) & Polona Zakosek (Slovenia):
Central & East Europe, Baltic States:
Bosnia and Herzegovina, Serbia, Montenegro, Macedonia, Rumania, Greece, Bulgaria, Ukraine, Poland, Russia
2015 – EBWB visit to Turkey to meet Adem & Nessie, to provide mentoring & support for developing a strong DEBRA Turkey.
The new DEBRA Turkey – Adem & Nessie bring families together to meet for the first time.
Lea and Anna join DEBRA Turkey to meet with Directors of Ministry of Health and discuss access to dressings for EB.
Plight Of The Butterfly Children
Strengthen Our Wings

What is EB?
Severe EB is a terrible genetic condition, one of the worst afflictions you could ever be born with. Skin can be so fragile that a touch can cause blisters that become wounds, like severe burns. Even mild EB can be life threatening without clean dressings or clean water to wash with. Infection and malnutrition are killers.

Step 1: A volunteer multidisciplinary team of experienced clinicians (Dermatologists, Paediatrician, EB Nurse Specialist, Nutritionist, and ideally including a Dentist, Ophthalmologist, Plastic Surgeon and Geneticist) from New Zealand and Australia travel to other countries for a week at a time to deliver hands-on training and expert mentoring to local EB clinicians.

NZ Care
In New Zealand and Australia, DEBRA has ensured that children and adults with EB receive a good quality of care.

Asia Pacific Care
In many countries in the Asia-Pacific region there is no knowledge of EB and no help given. Clinicians think it is hopeless and send the babies home with no information for the parents on managing the blistering skin, wound-care or avoiding infections. Children are sent home to die. Doctors and Nurses often know nothing about the genetic basis of EB and families believe they have been cursed.

Step 2: The model as outlined in step 1 will be used as an exemplar to extend the project to other countries in the Asia-Pacific region.

Step 3: Workshop in New Zealand for clinicians from Asia-Pacific Region. Seminars will be held for multidisciplinary clinicians from Asia, Pacific and Australasia offering basic and advanced training in the care and treatment of EB.

Research for new EB care guidelines
Visiting clinical team develop templates for training modules and Best Practice Guidelines for care in countries with minimal access to resources. This invaluable two way learning process will lead to greater knowledge world-wide at any time access to bandages is short in war zones or natural disasters when the population needs to fall back on first principles of safe and effective wound care with the most basic of materials.

Knowledge Spreads
Invaluable knowledge gained by the local medical teams is transferable to treatment of other children with:
• Variety of skin conditions and rare genetic disorders
• Burns
• Wounds and infections
Those who are trained then share their knowledge with colleagues.

Successful EB Training Models
Experienced mobile multidisciplinary teams have already developed protocols for training local clinicians in South America, Central and Eastern Europe and parts of Asia.

Global Access to EB Care
Around the world, access to EB care is improving with the setting up of DEBRA groups and training of local clinicians.
DEBRA NZ expertise mentored Japan and Australia in the importance of free bandages for EB and developing a specialist EB nursing service.

ROTARY PROJECT: strengthen Rotary and strengthen the wings of the ‘butterfly children’
Wellington South Rotary in partnership with other Rotary clubs and with EB Without Borders and DEBRA

Experience in Training
A small team including a Dermatologist, EB Nurses from NZ and Australia and Anna Ramble Welch, Director of DEBRA NZ have successfully delivered initial EB education and training in Vietnam, Malaysia, Singapore and Tonga.
Help with hands-on training for clinicians and families is desperately needed in China, Sri Lanka, Philippines, Indonesia, South Korea, India, Taiwan.

www.debra.org.nz

2015 / 2016 - EBWB visits to Sri Lanka and China (funded by Rotary in NZ)
Meeting with members of DEBRA China & sharing experience and expertise
China – talking to families about dressings and woundcare with locally available products – in the internet age, personal contact is still important.
Simple but essential - clean bath, clean water, clean hands, saline to reduce stinging.
Sri Lanka - DEBRA NZ helping 2 families for some years, then EBWB arranged a visit by an EB Specialist Nurse from NZ
Lady Ridgeway Hospital - Colombo

Dermatology Team – Skin Clinic

Larger group than 2 families!
Meeting and consulting with clinicians and patients
Improving EB management, changing lives
- a new way to bathe
Less than a year on – DEBRA Sri Lanka is about to become a reality
Next steps - developing DEBRA India
A very recent enquiry from Yemen asking for help for 2 brothers
(step 1 is establishing veracity of the contact)