DEBRA INTERNATIONAL CONGRESS Zagreb, September 2016

EBWB : EB Without Borders



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 **<u>EB-CLINET</u>**

- 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







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, Tunesia

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, Philppines

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



This project was financed by a grant from DEBRA International



Conoce más sobre Fundación DEBRA Chile en: www.debrachile.cl

NIÑOS PIEL DE CRISTAL



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.



ROTARY PROJECT: strengthen Rotary and strengthen the

Wellington South Rotary in partnership with other Rotary clubs and with EB Without Borders and DEBRA

A small team including a Dermatologist, EB Nurses from NZ and Australia and Anna Kemble Welch, Director of DEBRA NZ have

Help with hands-on training for clinicians and families is

China, Sri Lanka, Philippines, Indonesia, South Korea, India,

successfully delivered initial EB education and training in Vietnam,

wings of the 'butterfly children

Experience in Training

desperately needed in

www.debra.org.nz

Taiwan.

Malaysia, Singapore and Tonga.

Bskin



Step 3: Workshop in New Zoaland 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 trement of EB.

Step 1: A volunteer multidisciplinary team of experienced clinicians (Dermatologist, 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 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.

DEBRA NZ VI

Successful EB Training Models

multidisciplinary teams have already developed protocols

for training local clinicians in South America, Central and

Eastern Europe and parts of

Experienced mobile

Research for new EB care guidelines

isiting 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 ie 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 -Wounds and infections -Burns

Those who are trained then share their knowledge with colleagues.

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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.



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

DEBRA organization in the World

	Country	Establishment year
	Argentina Australia	
	Australia	2005
	■ Austria ■ Belgium	1995
	Belgium	1999
	Bosnia and Herzeg	ovina
	Brazil	2009
	■ Bulgaria ■ Canada	1995
	Canada	1998
	Colombia	2009
	Costa Rica	2001
	Croatia	1996
	Czech Republic	2004
	Denmark	2003
	Finland	2003
	France	1985
	Germany	1985
	Hong Kong	
	Hungary	1997
	= Chile	1999
	China	
	Ireland	1988
	Italy	1990
	Japan Mexico	
	Mexico	1998
	Mini Romania Netherlands	2007
	Netherlands	1989
	New Zealand	1980
	Norway	1991
	Poland	2004
	Romania	2005
	Russia	2009
	Slovalda	2009
	Slovenia	2005
	South Africa	
*	South Korea	
	Spain Sweden	1993
	Sweden 🖉	1990
	Switzerland	1998
	Turkey	
	United Kingdom	1978
	USA	

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1970 - 1979 1980 - 1989 1990 - 1999 2000 - 2009

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)

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ebwb@debra-international.org

