

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 [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](mailto:ebwb@debra-international.org)**

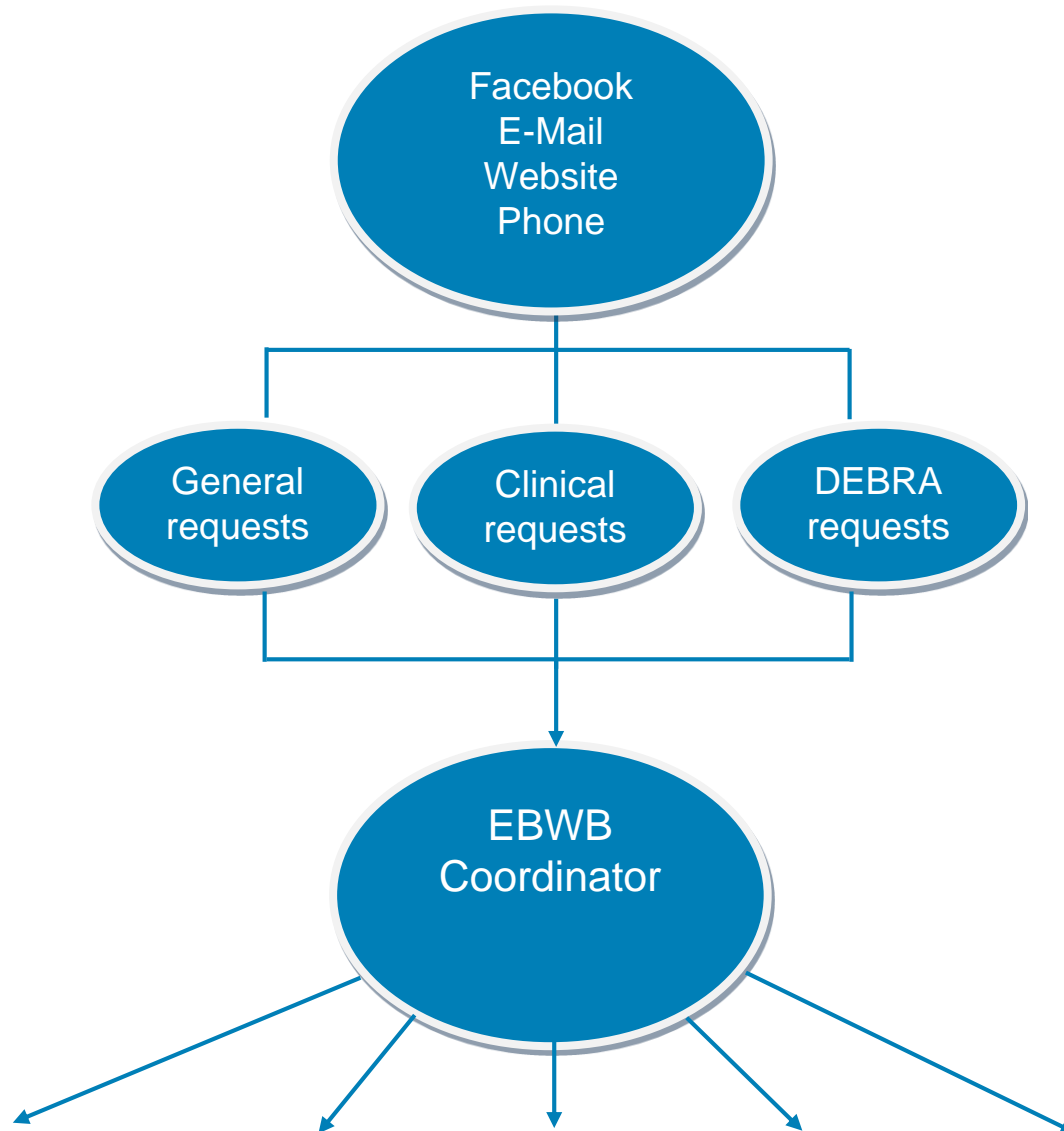
Depending on the type of request, language skills and experiences with a specific country or region, the co-ordinator and EBWB team define the best person to fit the needs, who will then act as a source of mentoring support.

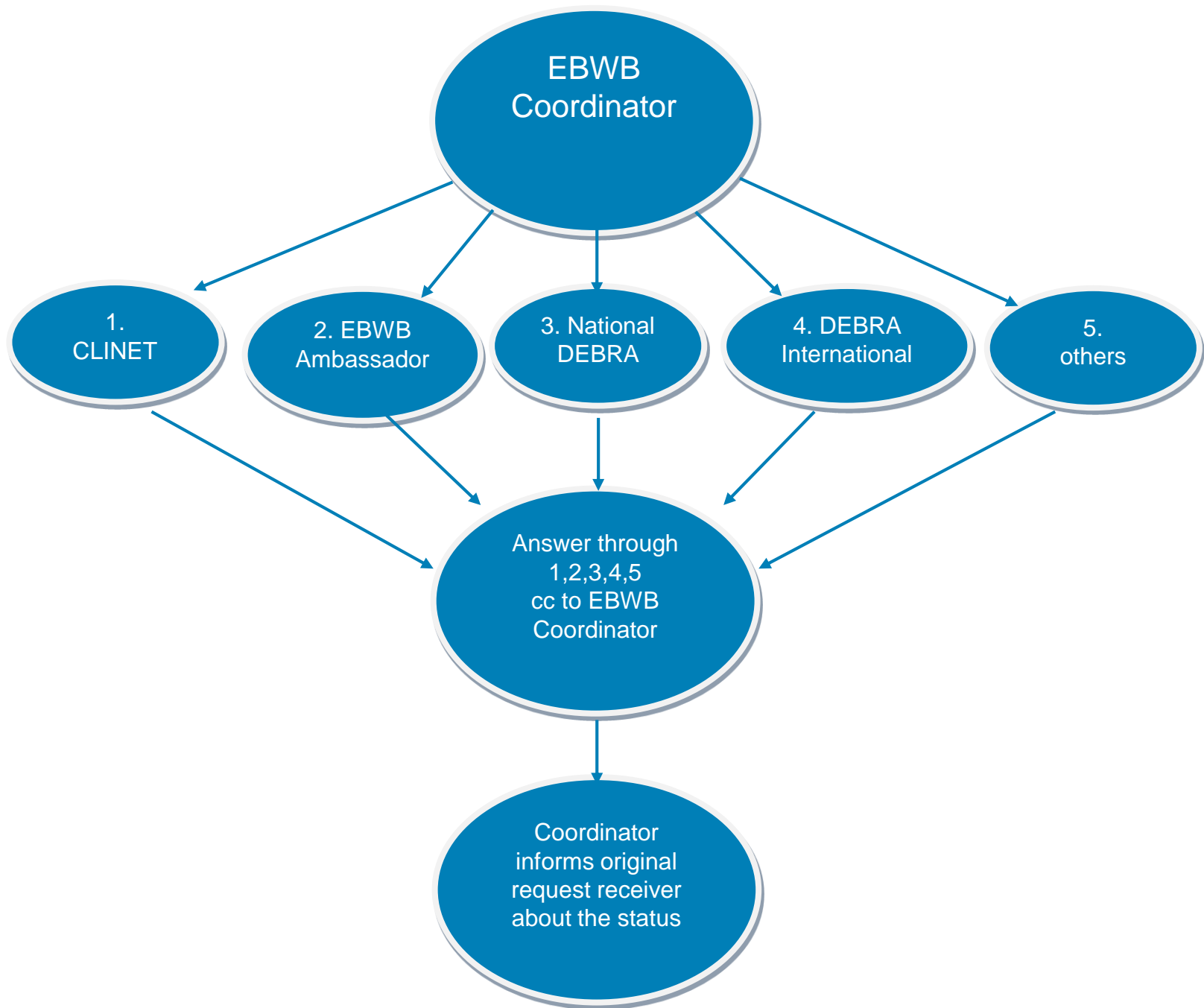
Currently working with people and developing DEBRAs :

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, 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. M<sup>a</sup> 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**



# IX SIMPOSIO INTERNACIONAL DE EPIDERMOLISIS BULOSA



NIÑOS PIEL DE CRISTAL

SAVE  
THE DATE

15-16

DICIEMBRE

2016



DeBRA  
Chile

PARA MAYOR INFORMACIÓN: [vlarrain@debrachile.cl](mailto:vlarrain@debrachile.cl)

Conoce más sobre Fundación DEBRA Chile en: [www.debrachile.cl](http://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.





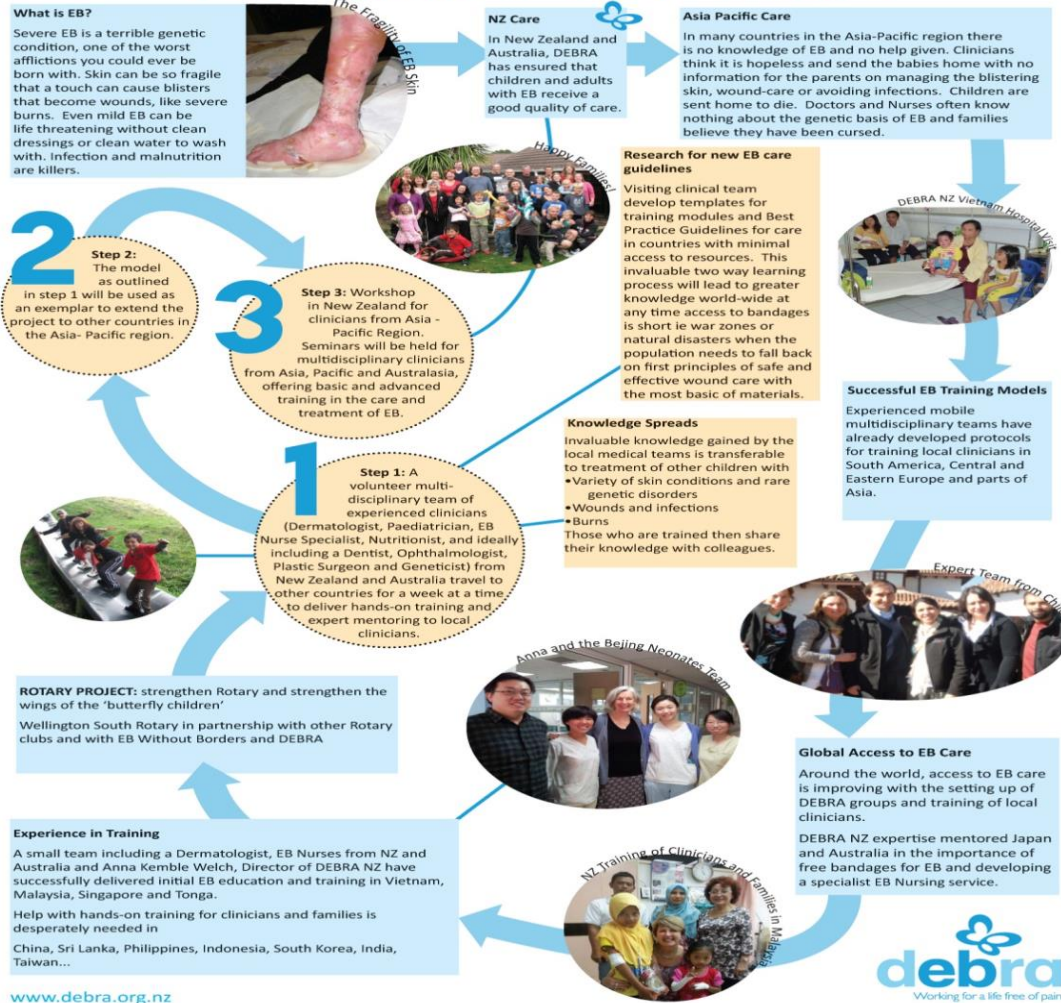
The new DEBRA Turkey – Adem & Nessie bring families together to meet for the first time.



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



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



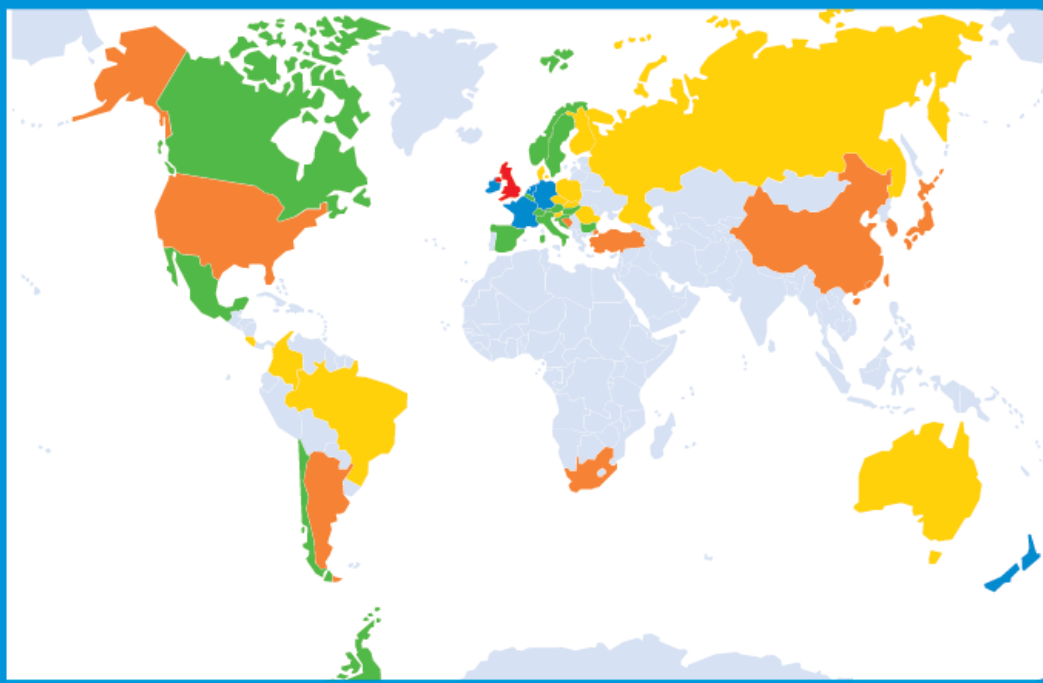


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Less than a year on – DEBRA Sri Lanka is about to become a reality

## DEBRA organization in the World



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

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 )

# **EB Without Borders**

[ebwb@debra-international.org](mailto:ebwb@debra-international.org)

