



UZ  
LEUVEN



# EB in Leuven : 1998-2008

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UZ  
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UNIVERSITY HOSPITALS LEUVEN



- First contact with EB for our team was in december 1997 with the birth of Merel, a baby that was admitted from another hospital because of wound care problems.
- This care was mainly focused on the neonatal care for these children.
- Prof Eggermont, the former head of the department of Paediatrics, took care of different patients with EB more than 20 years ago.

# NEONATAL CARE



- Our first goal was to define a good neonatal care scheme for babies with EB.
- This resulted in :
  - A treatment protocol
  - The further development of Annick De Jonge and Denise Tison from neonatal nurse to EB-nurse
  - The formation of a group of neonatal nurses that learned the care of babies with EB.
  - The use of our neonatal pain scale for these children.
- At that moment there were also the first contacts with Debra Belgium, who helped us tremendously since then.





PLAAT I.



1



2



3



4



5



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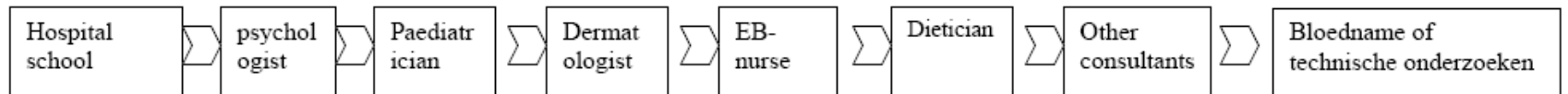
# A multidisciplinary consultation

- Because there was a need for further follow-up and treatment for children with EB, a multidisciplinary consultation was started with the following specialisms :
  - Pediatrics
  - Dermatology
  - EB nurses
  - Dentist
  - Dietician
  - Social worker
- Therefore we were helped by the organisation of the EB-team in Groningen (The Netherlands), who still are in support for difficult treatment decisions.





## MULTIDISCIPLINARY CONSULTATION EPIDERMOLYSIS BULLOSA



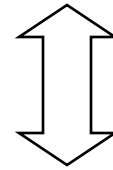
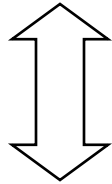
### Other consultants :

- dietician
- physiotherapist
- ophthalmologist
- paediatric gastro-enterologist
- social worker
- genetician

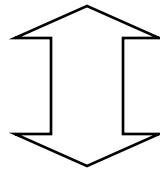
These consultants can be planned beforehand if necessary.

PAEDIATRICIAN

DERMATOLOGIST



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MULTIDISCIPLINARY TEAM  
GRONINGEN

D  
E  
B  
R  
A



# PSYCHOLOGICAL SUPPORT

- The emotional burden of EB was underestimated in the first years.
- Psychological support was asked for both parents and children.
- The hospital school was asked for evaluation of the children and to find solutions for school.





# EB IN THE HOSPITAL

- EB patients flew through the hospital specialisms like a butterfly, unpredictively and freely from one person to another, and this led to the personal involvement of different people from different specialisms :
  - Anesthesiology
  - Plastic surgery
  - Paediatric gastro-enterology
  - Ophthalmology
  - Physiotherapy
  - Anatomopathology
  - Paediatric haematology
  - ....

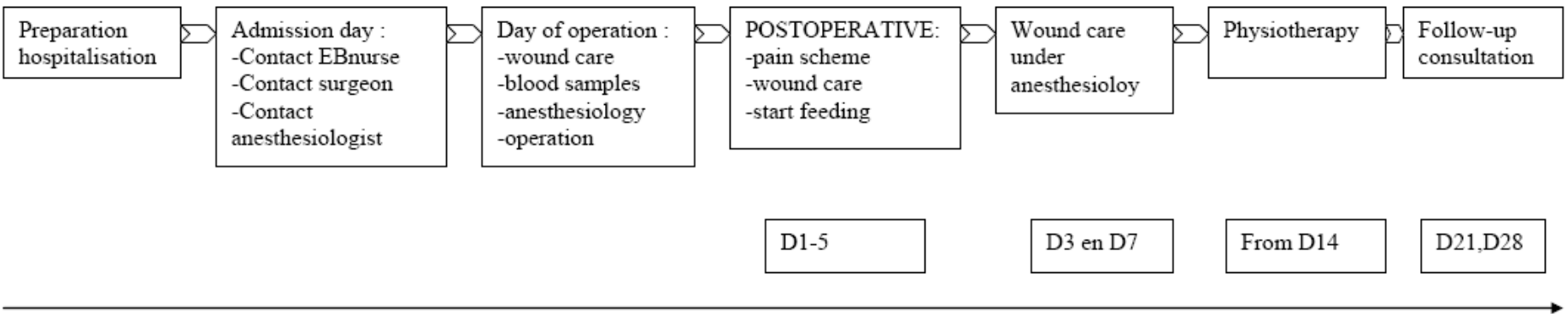


## EB IN THE HOSPITAL

- New procedures were made for hospitalisation :
  - Procedures for the anesthesiologist
  - Procedures for the paediatric nurses (infusion care, ...)
  - Procedures for hand operation.



## HAND OPERATION FOR DYSTROPHIC EB PATIENT



Preparation admission :  
-Information nurses by EB-nurse  
-Airconditioning in the room  
-Hospital school  
-Ordering bandages.

Anesthesiology procedures.

Scheme for physiotherapy.

Blood samples and infusion under anesthesiology.

Pain score  
Pain treatment scheme



## EB NURSE

- For better coördination and caretaking for the patients with EB, two EB nurses were sponsored by DEBRA Belgium for 0,2 FTE.
- This changed the care for EB-patients dramatically.

# EB-NURSE



Contact via e-mail :  
[ebnurse@uz.kuleuven.ac.be](mailto:ebnurse@uz.kuleuven.ac.be)

# EB NURSES



- Organisation of the consultation.
- Procedures for hospitalisation
- Home visits
- Advice for wound care
- EB care day
- Teaching other professionals
- EB-box for wound care.

# PALLIATIVE CARE TEAM



- Also palliative care is sometimes needed.
- 2 neonates died (junctional EB) in the neonatal unit.
- 2 children with dystrophic epidermolysis bullosa died at home in palliative care at the age of 9 and 11 years old.
- Therefore we worked together with the palliative care team of the unit child oncology, who have a lot of experience in the home setting.
- Furthermore the team of child psychiatry is also involved in this support.



# THANK YOU



- Stief Dirckx
- Ingrid Jagenau
- Daniel Bauwens
- Yvonne Dendooven
- Mats Wakare
- Tanguy and Nirmala Wolters-Huart

# THANK YOU



## MULTIDISCIPLINARY TEAM EB

Paediatrics and coördination: Prof Gunnar Naulaers

Dermatology: Dr. Morren

EB-nurses : Annick De Jonge en Denise Tison

Plastic surgery: Prof Hierner

Paediatric Gastro-enterology : Prof Hofman

Dietician : Miss Tessa Bosmans

Dentists : Miss Verhaeghe, Prof Declerck en Prof Vinckier

Paediatric Ophthalmology : Prof Casteels

Physiotherapy : Arlette Corniere, Sofie Vuylsteke

Sociaal Work: Inge Droesbeke

Genetics : Prof Legius

Anatomopathology : Prof Van den Oord en Prof Vos

Anesthesiology: Prof Van de Velde en Dr Vekeman

Child Psychiatry : Prof Adriaensens and Dr Katrien Verstraeten,

Hospital School: Hilde Schotte



# THANK YOU CHILDREN AND PARENTS

We learned more from the children and their parents than they learned from us.

Not only about the disease and its treatment, but also about life and values.