

**Cross Border healthcare – Why and How
to advocate at national level**

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Patient organisation perspective

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Children with different types of EB



**> 20 genetic
skin
diseases**

**No cure, only
care**

- By a multidisciplinary team

**EB in a
nutshell**

**Low
prevalence**

- 1/17.000 – 1/50.000 ?
- In Belgium 3 to 4 new babies/year

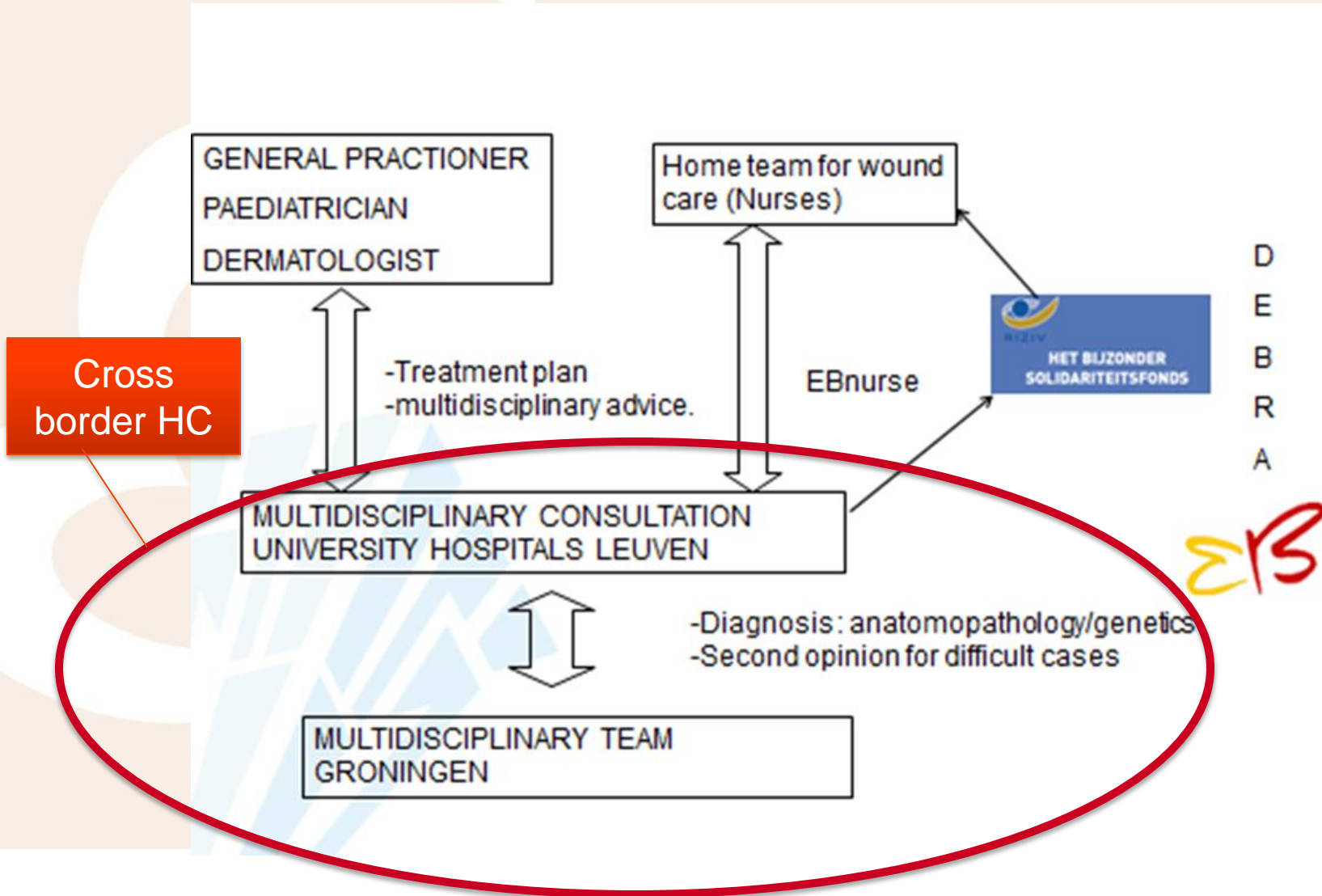
**Easy
diagnosis**

- Clinical
- Skin biopsy
- Blood sample (DNA)

Main objectives:

- ✓ Advocating for reimbursement of dressings
- ✓ Coordinating the EB-center
- ✓ Supporting families

EB treatment: no cure but care !



Why cross border care?



- **Diagnosis** (skin & blood samples sent to lab in Groningen, NL)
- **Multidisciplinary consultation** (in case of very complex and severe form of EB)
- **Special interventions** (idem, e.g. oesophagus dilatation via gastric button)

Casus: consultation in Groningen (NL)

- **Planned care** (consultation) on prescription of EB-specialist in Belgium => always prior authorisation (E112/S2)
- **Problem with 1 Belgian sickfund:** refuses to deliver S2 for more than the 1 day of the consultation

Casus: why is it the problem ?

Incompatible different NHS systems in terms of reimbursement:

The Netherlands	Belgium
Reimbursement based on a DBC: “diagnose-behandelings-combinatie”	Reimbursement based on a specific nomenclature and per act
 does not want to pay if the patient doesn't follow the full DBC → asks for a 1 year S2	 Belgian sickfund does not want to give a S2 for more than the single consultation → delivers 1 day only S2

- ✓ Check with sickfund (CM): no answer, refuses to change attitude
- ✓ Check with EB-team in B: cannot help
 - ➔ **Solution:** problem was solved by EB-team in Groningen with **European Health Insurance Card (EHIC)**

Any improvement with the directive ?

- In the context of the transposition of the EU Directive in Belgium, this issue has been raised at the National Institute for Sickness and Invalidity Insurance (INAMI) and we were answered:

“ the problem is well known, but the directive won’t change anything. Both countries are not willing to harmonised their systems”

Thank you for your attention!

More info on Debra belgium:

www.debra-belgium.org



RaDiOrg.be
Rare Diseases Organisation

**EURORDIS Membership Meeting
2012, Brussels, 23 May**

Cross border HC

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**A national RD patient
organisation perspective**

Jonathan Ventura
RaDiOrg.be coordinator



1. WHY should a national alliance advocate?

- **At a diseases-specific PO level**, positive results of advocacy works only benefit to an individual patient or a limited group of RD patients. It provides answers to individual issues without any (or with a limited) impact on the system in itself



- **A a national PO organisation level**, the objective is to work towards a system that would give benefits to the whole rare diseases community via an adapted system to their needs and expectations.



2. HOW should a national alliance advocate?

- ✓ **Understanding the new EU directive and how it could help patients to go abroad for HC**
 - *Very important role of EURORDIS*

- ✓ **Understanding the current national situation from a “community perspective” :**
 - RaDiOrg.be is conducting a survey which trends to date show that:
 - 28% of respondents have already gone abroad for HC
 - 27% of respondents have already considered doing so but 75% of them never heard about the new EU directive!
 - Lots of positive/negative experiences!

- ✓ **Relaying patients’ concerns and suggestions**
 - Identifying the key people to advocate to and meet them to explain the current situation and seek for solutions (= partnership)
 - Maintaining a collaborative climate



Thank you for your listening!

Further info:

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