

Inpatient Rehabilitation for Children with EB and their Families



International DEBRA Congress 2018
Zermatt, Switzerland

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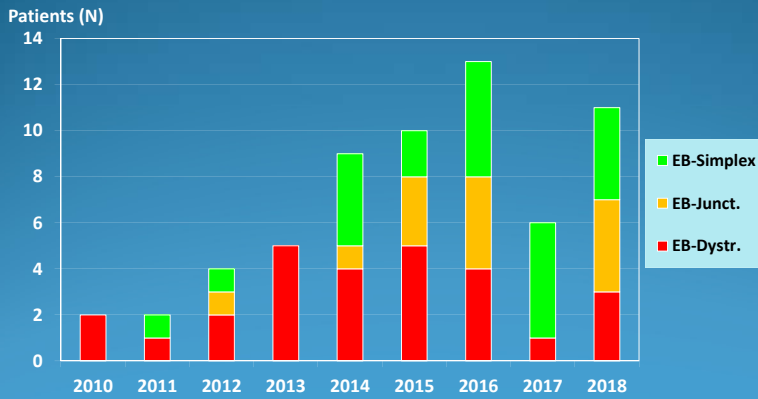
4-week interventions with children and adolescents age 0 to 18 years

Indications:

- Asthma bronchiale
- Atopic dermatitis
- Obesity
- Diabetes mellitus
- Psoriasis

→ Epidermolysis bullosa, Ichthyosis

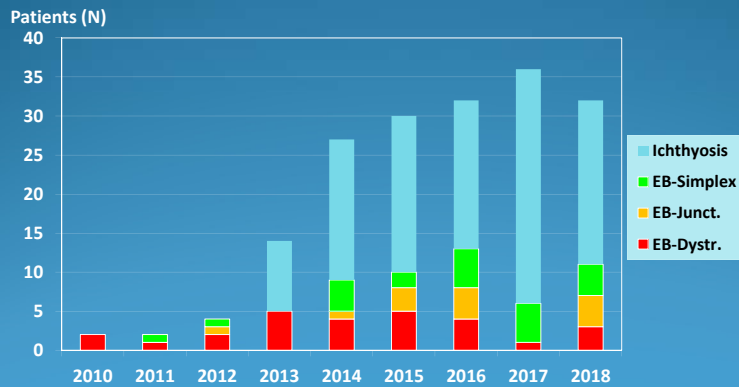
Development of Number of Patients with 'Epidermolysis bullosa' 2010 - 2018



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Development of Number of Patients with 'Rare Skin Diseases' 2010 - 2018



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Rehabilitation of Children in Germany

- Patients with chronic diseases and participatory deficit
- Legal entitlement of health benefits by health insurance or government
- Inpatient rehabilitation adds to ambulatory therapy
- Therapeutic and educational intervention in an interdisciplinary and multiprofessional setting

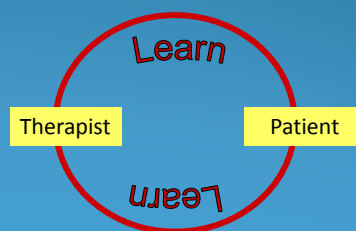
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Our Philosophy



- The human being in the centre
- Salutogenesis, holistic approach
- Individualised empowerment
- Looking forward
- Learning - training – apply
- Fun!



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Projekt ResHa - Rehabilitation of Rare Skin diseases in Children and Adolescents

Aim of the study:



- ResHa 1:
Development of a concept for the Rehabilitation of Rare Skin Diseases in children and adolescents (2014-2015)
- ResHa 2:
Evaluation of the developed concept implemented in Fachklinik Sylt (2016-2019)

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Rehab-Modules

Movement

Medicine

Nutrition

Medical Care

Education

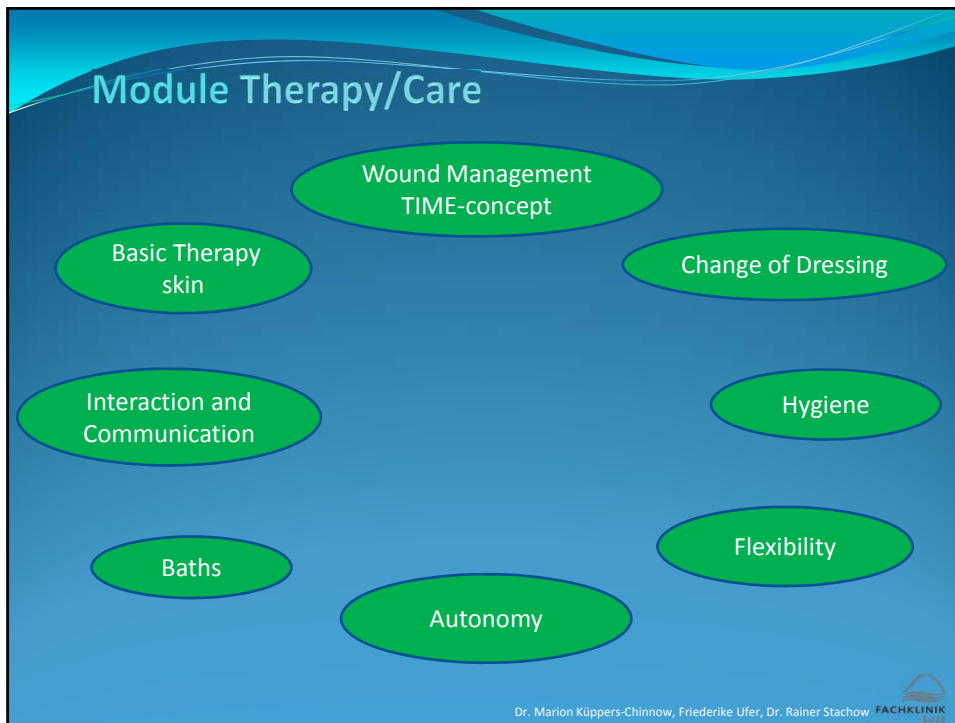
Psychology

Social work

Future

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Change of dressings

Module Therapy/Care

- Involvement of parents – supervision by EB nurse/doctor
- Try something ‚New‘
- Wound management - TIME-concept
- Lotions (basis therapy skin and wound margins)
- Interaction/Supervision

‚Dressing is part of daily routine and life‘



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Patient S., 12 years old, dystrophic EB

1. June admission



26. June discharge



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Baths



- Full- or partial baths with sea water
- Aqua therapy in the indoor pool
- Baths for disinfection, cleaning and removal of dressings
- Bath additives according to skin condition

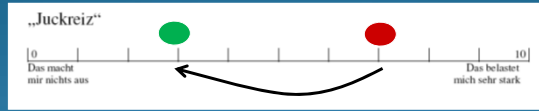


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Itch and Pain

Module Therapy – Care



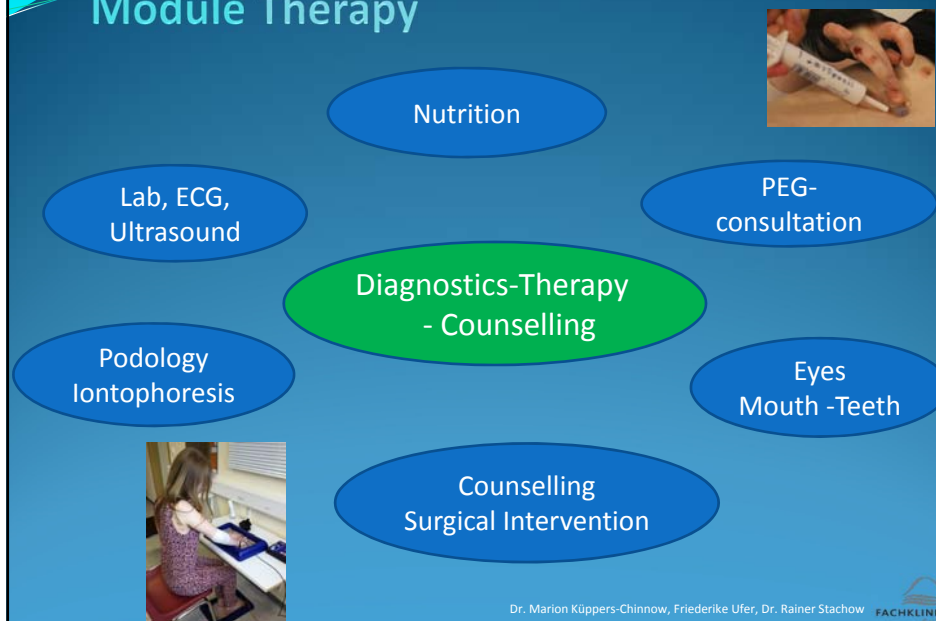
- Perception
- Quality of life
- Therapeutic options
 - medication: WHO-stepwise-approach
 - non medication techniques



→ train in rehab routine



Module Therapy



Module Psychology

„EB is a disease of the entire family and system“

Body Image
Self Recognition

Stigmatisation,
Reclusion, Depression

Stress
Pain Itch

Interaction
Communication

Ressources
Future Perspectives

Fear
Guilt

Supervision

Passivity vs. Autonomy

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Module Movement: Sport - Swimming - Physiotherapy

„Movement is the most important aspect for prognosis and quality of life in EB“

- Sport:
 - Gym, swimmingpool, beach
- Physiotherapy
- Ergotherapy
- Hippo therapy



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Modul Movement

Boost of positive body perception

- Relaxation
- Snoezelen
- Lotion massage
- Qi-gong



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EB - Training

EB-
Pathophysiology

Woundmanagement
TIME-Concept

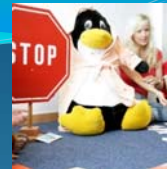
Future Therapeutic
Options

Nutrition

Pain and Itch

Psychosocial Aspects
in EB

Future perspectives:
School, Employment



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L., 12 years, EBD

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Take Home Message

- Inpatient rehabilitation procedures are an important addition to the ambulatory care
- Holistic, interdisciplinary, multiprofessional
- Prevention, future perspective
- Individually relevant

„Goal is to foster a positive life with participation and autonomy“

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Thank you for your attention!

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