

INTERNATIONAL DEBRA CONGRESS 2018

PROGRAM

7-9 SEPTEMBER 2018
ZERMATT, SWITZERLAND

CONFERENCE VENUE

Grand Hotel Zermatterhof
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WELCOME

Ladies and Gentlemen,

A rare disease like Epidermolysis bullosa affects not only individuals, but also their families and their environment. Younger patients, also known as ‘Butterfly Children’, are now able to live to adulthood thanks to medical progress. However, in order to survive with their extremely fragile skin they must cope with numerous difficulties over the course of their lives, difficulties that are also shared by their relatives.

The Federal Council wants to improve the quality of life of people with rare diseases. Therefore he adopted the ‘National Rare Disease Policy’ in 2014, at the end of 2017 he has extended its implementation by two years. What is needed are rapid diagnoses, good care, support in everyday life, better research and good international cooperation.

The patient organisation DEBRA has tremendous merit. First and foremost, DEBRA pools knowledge, including patient expertise. The national DEBRA group network is based on people and organisations on a national and international level. This information is used by those directly affected and their relatives, but also by medical and non-medical personnel. In fact, DEBRA plays a pioneering role.

I congratulate DEBRA Switzerland on its twentieth birthday, and wish all participants a stimulating and insightful congress.



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Alain Berset

President of the Swiss Confederation | Head of the Federal Department of Home Affairs

Organising committee

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Urs Höltschi

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Tanja Reusser

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Head of paediatric dermatology
Bern University Hospital

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Head of EB-clinic
Staff Dermatologist and Pediatrician
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University Children’s Hospital Zurich

Rosaria De Lorenzo

Nurse specialist for epidermolysis bullosa,
University clinic for dermatology
Bern University Hospital

Dr. Anna-Barbara Schlüer

Nurse specialist APN wound- and stoma care, PhD, MScN, RN,
University Children’s Hospital



Friday, 7 September 2018

	SCIENTIFIC PROGRAM	SOCIAL PROGRAM
	Grand Hotel Zermatterhof Matterhorn Saal	Zermatt
	from 08:00 Registration	
09:00	Opening session	
09:10	Keynotes 1	
10:30	Coffee break	
11:00	Keynotes 2	
12:00	Lunch	
13:00	Keynotes 3	
15:00	Coffee break	
15:30	Keynotes 4	
16:45	Free Communication 1	
17:15	Video presentation	
18:00		Aperitif Matterhorn Museum
19:00		Traditional Swiss Cheese Fondue 1st seating Grand Hotel Zermatterhof saycheese!
20:30		Traditional Swiss Cheese Fondue 2nd seating Grand Hotel Zermatterhof saycheese!
22:00		Dancing & Networking Hotel Post, Broken Bar

Saturday, 8 September 2018

	SCIENTIFIC PROGRAM		SOCIAL PROGRAM
	Matterhorn Saal	Grand Hotel Zermatterhof Salon Ruden	Zermatt
			Prato Borni
08:00			
08:30	Free Communication 2	Symposium	
09:00	Keynotes 5		
10:15	Coffee break		
10:45	Keynotes 6		
12:00	Lunch Lobby		
13:00	Guided poster session		
13:30	Keynotes 7		
14:45	Coffee break		
15:30	Nutrition Forum	Social Media Forum	
16:00		Nurse Forum (open)	
17:00		Closing session	
17:15		Nurse Forum (closed)	General Meeting of DEBRA International
18:15			
18:30			Gala Dinner 20 Years of DEBRA Switzerland Grand Hotel Zermatterhof Matterhorn Saal
22:30			Charity Concert Luca Hänni Vernissage



Friday, 7 September 2018

09:00 – 09:10	Opening Session <i>Matterhorn</i>
	Welcome <i>Tanja Reusser (Belp CH)</i>
09:10 – 10:30	Keynotes 1 – Research <i>Matterhorn</i>
	<i>Chairs: Hagen Ott (Hannover DE), Elena Pope (Toronto CAN)</i>
09:10 – 09:30	Research activities <i>John McGrath (London UK)</i>
09:30 – 09:50	A new gene delivery system <i>Lara Cutlar (Dublin IRL)</i>
09:50 – 10:10	Gene therapy for recessive dystrophic Epidermolysis bullosa <i>Peter Marinkovich (Stanford USA)</i>
10:10 – 10:30	News from EBS KLHL24 <i>Agnes Schwieger-Briel (Zurich CH)</i>
10:30 – 11:00	Coffee break in the industrial exhibition
11:00 – 12:00	Keynotes 2 – Research & Clinical <i>Matterhorn</i>
	<i>Chairs: Carolina Gouveia (Bern CH), John McGrath (London UK)</i>
11:00 – 11:20	Replacement of the whole skin with genetically modified epidermal stem cells in a boy with junctional epidermolysis bullosa <i>Norbert Teig (Bochum DE)</i>
11:20 – 11:40	We can influence the pain! – pain treatment program for children (and their parents) with Epidermolysis bullosa <i>Michael Frosch (Datteln DE)</i>
11:40 – 12:00	The validation of iScorEB <i>Elena Pope (Toronto CAN)</i>
12:00 – 13:00	Lunch in the industrial exhibition
13:00 – 15:00	Keynotes 3 – Clinical <i>Matterhorn</i>
	<i>Chairs: Agnes Schwieger-Briel (Zurich CH), Irene Lara Corrales (Toronto CAN)</i>
13:00 – 13:20	Itching for insight: Management of pruritus in EB <i>Hagen Ott (Hannover DE)</i>
13:20 – 13:40	Herbal medicine - hope, opportunities and limitations <i>Anja Diem (Salzburg AT)</i>
13:40 – 14:00	Growth in EB – what makes EB children big and strong? <i>Antonia Reimer (Freiburg DE)</i>
14:00 – 14:20	Challenging wounds in EB <i>Jemima Mellerio (London UK)</i>

Friday, 7 September 2018

14:20 – 14:40	Patient-driven treatment of hand contractures in epidermolysis bullosa <i>Roger Cornwall (Cincinnati USA)</i>
14:40 – 15:00	Losartan treatment of recessive dystrophic EB: Where do we stand? <i>Leena Bruckner-Tuderman (Freiburg im Breisgau DE)</i>
15:00 – 15:30	Coffee break in the industrial exhibition
15:30 – 16:45	Keynotes 4 – Clinical <i>Matterhorn</i>
	<i>Chairs: Francis Palisson (Santiago CL), Leena Bruckner-Tuderman (Freiburg im Breisgau DE)</i>
15:30 – 15:50	Struggling for oral health <i>Klaus Neuhaus (Bern CH)</i>
15:50 – 16:10	CPG project - an overview <i>Judith Kristin Asche (Stavanger NO), Kattya Mayre-Chilton (London UK)</i>
16:10 – 16:30	Anaemia in EB <i>Irene Lara Corrales (Toronto CAN)</i>
16:30 – 16:45	Kindler syndrome, the fourth type of EB: Natural history and the propensity for skin cancer <i>Cristina Has (Freiburg DE)</i>
16:45 – 17:15	Free Communications 1 <i>Matterhorn</i>
	<i>Chairs: Carolina Gouveia (Bern CH), Jemima Mellerio (London UK)</i>
FM 1.1	The use of hydrotherapy for children with Epidermolysis bullosa <i>M. Wood, A. Martinez, C. McDonald (London UK)</i>
FM 1.2	GLOVE 1 Generation and evaluation of hand therapy devices for Epidermolysis bullosa – Findings from the dressing glove proof of concept study <i>R. Box, P. Grocott, T. Graham, S. Sooriah (London UK)</i>
FM 1.3	Identifying the optimum role and function of an Epidermolysis bullosa outreach nurse <i>S. Kearny, A. Donohoe, E. McAuliffe (Dublin IRL)</i>
17:15 – 17:20	Video Presentation <i>Matterhorn</i>
	Rehabilitation of butterfly children in a health resort <i>Tatyana Volgunova (Moscow RU), Natalia Maricheva (Moscow RU)</i>
08:00 – 09:00	Symposium Amryt Pharma <i>Ruden</i>
	'EASE' Phase 3 Pivotal Trial Update <i>Janet Boylan, Mark Sumeray (Dublin IRL)</i>

Saturday, 8 September 2018

08:00 – 09:00	Symposium Amryt Pharma <i>Ruden</i>
	'EASE' Phase 3 Pivotal Trial Update <i>Janet Boylan, Mark Sumeray (Dublin IRL)</i>



Saturday, 8 September 2018

08:30 – 09:00	Free Communications 2 <i>Matterhorn</i>	<i>Chairs: Peter Marinkovich (Stanford USA), Cristina Has (Freiburg DE)</i>
FM 2.1	Implementation plan for the development of telemedicine (TM) in the adult Epidermolysis bullosa (EB) service in London <i>A. Downe (London UK)</i>	
FM 2.2	Comprehensive care in Epidermolysis bullosa - an experience from resource poor settings <i>R. Hiremagalore, P. Kantheti, G. Barakka (Bangalore IND)</i>	
FM 2.3	Systemically administered flightless I neutralising antibodies home to skin wounds leading to improved healing and survival of recessive dystrophic Epidermolysis bullosa mice <i>N. Stevens¹, J. Uitto², Z. Kopecki¹, A. Cowin¹(¹Adelaide AUS, ²Philadelphia USA)</i>	
09:00 – 10:15	Keynotes 5 – EB different experiences and multidisciplinary care <i>Matterhorn</i>	<i>Chairs: Carolina Gouveia (Bern CH), Agnes Schwiieger-Briel (Zurich CH)</i>
09:00 – 09:20	EB multidisciplinary care in Switzerland & experiences of EB Nurses - bridging caretakers <i>Rosaria De Lorenzo (Bern CH), Carolina Gouveia (Bern CH)</i>	
09:20 – 09:35	Use of therapeutic contact lenses for the treatment of recurrent corneal erosions due to Epidermolysis bullosa dystrophica <i>Michael Bärtschi (Bern CH)</i>	
09:35 – 09:55	Multidisciplinary care in Singapore and South Asia <i>Mark Koh (Singapore SIN)</i>	
09:55 – 10:15	Inpatient rehabilitation for children with EB and their families <i>Marion Küppers-Chinnow, Friederike Ufer (Sylt DE)</i>	
10:15 – 10:45	Coffee break in the industrial exhibition	
10:45 – 12:00	Keynotes 6 – EB International <i>Matterhorn</i>	<i>Chairs: Rosaria De Lorenzo (Bern CH), Tanja Reusser (Belp CH)</i>
10:45 – 11:00	Rare Recourcenet-Debra Croatia <i>Vlasta Zmazek (Zagreb HUN)</i>	
11:00 – 11:15	EB in Chile <i>Francis Palisso (Santiago CHI)</i>	
11:15 – 11:30	The role of DEBRA and regional associations in Brazil, a continental country <i>Jeanine Frantz (Blumenau BRA), Louisa Huber (Salvador BRA)</i>	
11:30 – 11:45	The voice of people with EB <i>Julia Cieplik (Iserlohn DE)</i>	
11:45 – 12:00	Above pain - on the wings of a butterfly <i>Michelle Zimmermann (Seedorf CH)</i>	

Saturday, 8 September 2018

12:00 – 13:30	Lunch in the industrial exhibition	
13:00 – 13:30	Poster presentation	
13:30 – 14:45	Keynotes 7 – EB support – different experiences <i>Matterhorn</i>	<i>Chairs: Rosaria De Lorenzo (Bern CH), Mark Koh (Singapore SIN)</i>
13:30 – 13:45	International EB psychosocial guidelines: support for the individual, family and professionals <i>Kate Martin (Warwickshire UK)</i>	
13:45 – 14:00	Chances and limitations of hypnosis <i>Nicole Wackernagel (Wil CH)</i>	
14:00 – 14:45	EB without borders <i>Lea Prujean (Vienna AT)</i>	
14:45 – 15:30	Coffee break in the industrial exhibition	
15:30 – 16:00	Nutrition Forum <i>Matterhorn</i>	<i>Rosie Jones (Birmingham UK), Lynne Hubbard (London UK), Markus Biedermann (Herzogenbuchsee CH)</i>
15:30 – 16:00	Social Media Forum <i>Ruden</i>	<i>Julia Cieplik (Iserlohn DE)</i>
16:00 – 17:00	Nurse Forum: Daily tricks for live (open forum) <i>Ruden</i>	<i>Jane Clapham (West Mildands UK), Lynne Hubbard (London UK), Rosie Jones (Birmingham UK), Bettina Hafner (Zurich CH), Miriam Villa (Marbella ES), Esther Dominguez (Marbella ES)</i>
17:00 – 17:15	Closing Session <i>Ruden</i>	<i>Tanja Reusser (Belp CH)</i>
17:15 – 18:15	Nurse Forum: Daily tricks for live (closed forum) <i>Ruden</i>	<i>Jane Clapham (West Mildands UK), Lynne Hubbard (London UK), Rosie Jones (Birmingham UK), Bettina Hafner (Zurich CH), Miriam Villa (Marbella ES), Esther Dominguez (Marbella ES)</i>
17:15 – 18:15	General Meeting of DEBRA International <i>Prato Borni</i>	



Sunday, 9 September 2018

09:00 – 10:00	Documentary film
	<i>Matterhorn</i>
09:00 – 09:30	In Crystal Skin <i>Michaela O'Brien (Tulsa USA)</i>
09:30 – 10:00	The worst disease you've ever heard of <i>Jack van Zijp (Den Haag NL)</i>

SOCIAL PROGRAMM

Friday, 7 September 2018

Aperitif at the Matterhorn Museum

Time: 17:30 - 19:00

Fondue dinner at the restaurant „saycheese“ Grand Hotel Zermatterhof

Time: 19:00 - 20:30 1st seating
20:30 - 22:00 2nd seating

Dancing & Networking at „Broken Bar“ Unique Hotel Post

Time: 22:00 - open end

Saturday, 8 September 2018

Gala dinner & celebration 20 years of DEBRA Schweiz at Grand Hotel Zermatterhof

Time: 19:00 - 22:00

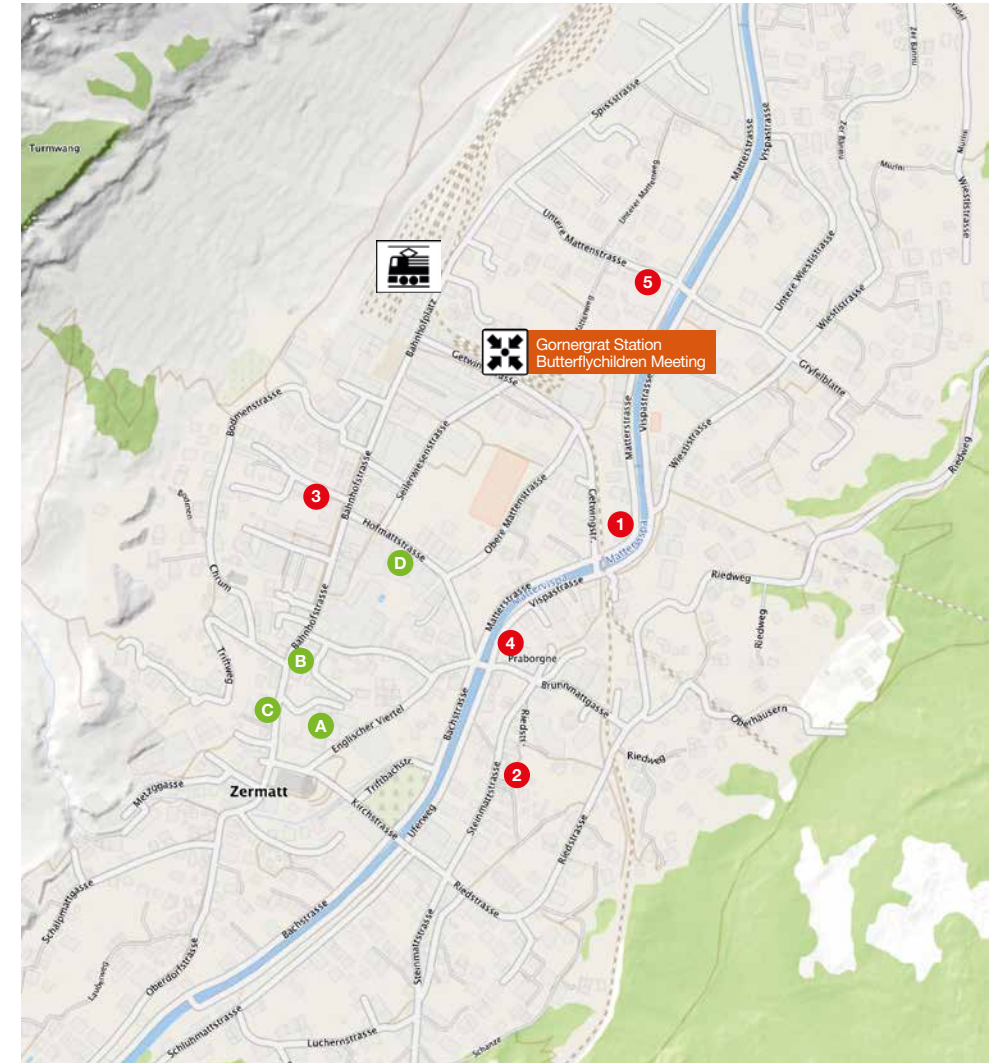
Charity concert at "Vernissage" at the Backstage Boutique SPA Hotel – with Luca Hännli

Time: 22:00 - open end

Sunday, 9 September 2018

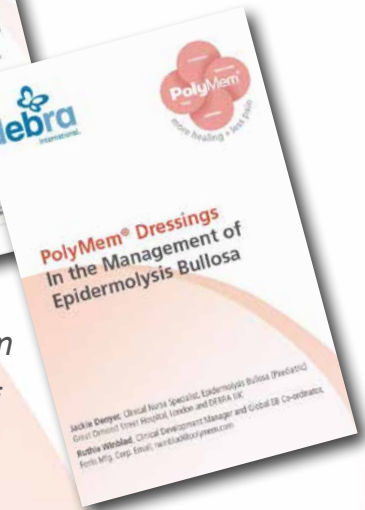
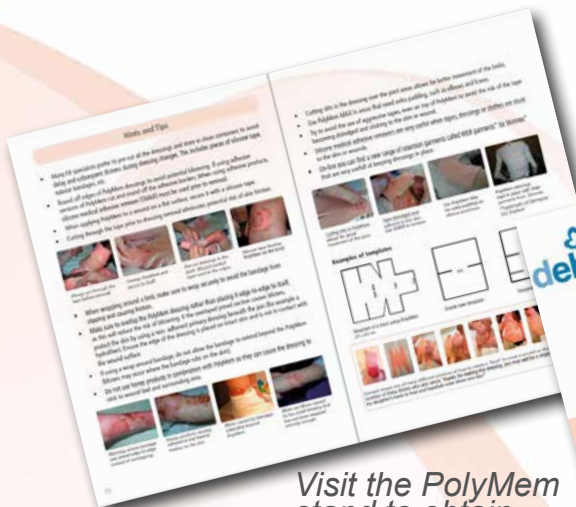
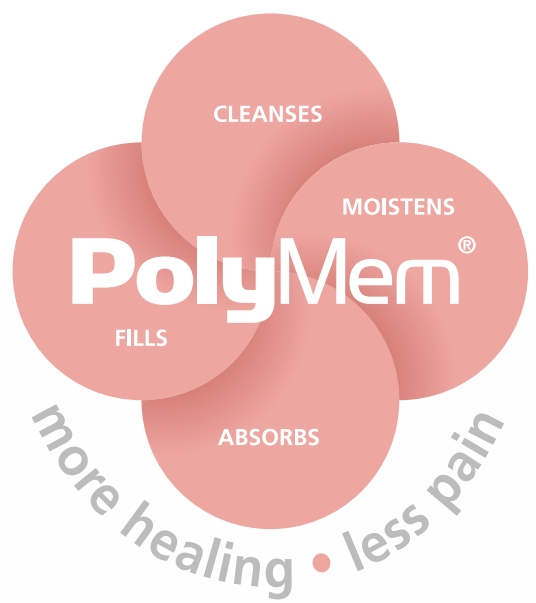
Annual Butterflychildren-Meeting of DEBRA Switzerland on the Gornergrat

Time: 11:00 - 16:00



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|----------------------------------------------------------------------|----------------------------|
| A Grand Hotel Zermatterhof, Congress Location | 1 Hotel Admiral |
| B Hotel Post, Broken Bar
Dancing & Networking | 2 Hotel Aristella |
| C Matterhorn Museum | 3 Hotel Continental |
| D Backstage Boutique SPA Hotel, Vernissage
Benefit Concert | 4 Hotel Parnass |
| | 5 Hotel Sunstar |

PolyMem has been used with great success in the treatment of EB wounds around the world. Let us share our experience with you.



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