



Friday, 7 September 2018

	SCIENTIFIC PROGRAM	SOCIAL PROGRAM
	Grand Hotel Zermatterhof Matterhorn Saal	Zermatt
09:00	from 08:00 Registration	
09:10	Opening Session	
	Keynotes 1 Part 1	
10:30	Coffee break	
11:00	Keynotes 1 Part 2	
12:00	Lunch	
13:00	Keynotes 2 Part 1	
15:00	Coffee break	
15:30	Keynotes 2 Part 2	
16:30	Free Communication 1	
17:00		
18:00		Aperitif Matterhorn Museum
19:00		Traditional Swiss Cheese Fondue 1 st seating Grand Hotel Zermatterhof saycheese!
20:30		Traditional Swiss Cheese Fondue 2 nd 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	Prato Borni	Zermatt
08:30	Free Communication 2			
09:00	Keynotes 3			
10:15	Coffee break			
10:45	Keynotes 4			
12:00	Lunch Lobby			
13:00	Guided poster session			
13:30	Keynotes 5			
15:00	Coffee break			
15:30	Nutrition Forum	Sozial 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				Benefit Concert Luca Hänni Vernissage



Sunday, 9 September 2018

	Scientific program	Social program
	Grand Hotel Zermatterhof Matterhorn Saal	Zermatt
09:00	Documentary film	
10:00		
11:00		
		Annual Butterflychildren-Meeting of DEBRA Switzerland – other families with a butterflychild are welcome
16:00		

Friday, 7 September 2018

09:00 – 09:10	Opening Session
Matterhorn	Welcome Tanja Reusser (Belp CH)
09:10 – 10:30	Keynotes 1 – Research Part 1
Matterhorn	Chairs: Hagen Ott (Hannover DE), Elena Pope (Toronto CAN)
09:10 – 09:30	Research Activities John McGrath (London UK)
09:30 – 09:50	A new gene delivery system Lara Cutlar (Dublin IRL)
09:50 – 10:10	Gene therapy for recessive dystrophic epidermolysis bullosa Peter Marinkovich (Stanford USA)
10:10 – 10:30	News from EBS KLHL24 Agnes Schwieger-Briel (Zurich CH)
10:30 – 11:00	Coffee break in the industrial exhibition
11:00 – 12:00	Keynotes 1 – Research Part 2
Matterhorn	Chairs: Carolina Gouveia (Bern CH), John McGrath (London UK),
11:00 – 11:20	Replacement of the whole skin with genetically modified epidermal stem cells in a boy with junctional epidermolysis bullosa Norbert Teig (Bochum DE)
11:20 – 11:40	Itching for insight: Management of Pruritus in EB Hagen Ott (Hannover DE)
11:40 – 12:00	The valudation of iScorEB Elena Pope (Toronto CAN)
12:00 – 13:00	Lunch in the industrial exhibition


13:00 – 15:00 Keynotes 2 – Clinical Part 1

Matterhorn
Chairs: Agnes Schwieger-Briel (Zurich CH), Irene Lara Corrales (Toronto CAN)

13:00 – 13:20 We can influence the Pain! – pain treatment program for children (and their parents) with Epidermolysis bullosa

Michael Frosch (Datteln DE)

13:20 – 13:40 Herbal medicine - hope, opportunities and limitations

Anja Diem (Salzburg AT)

13:40 – 14:00 Growth in EB – what makes EB children big and strong?

Antonia Reimer (Freiburg DE)

14:00 – 14:20 Challenging wounds in EB

Jemima Mellerio (London UK)

14:20 – 14:40 Patient-Driven Treatment of Hand Contractures in Epidermolysis Bullosa

Roger Cornwall (Cincinnati USA)

14:40 – 15:00 Losartan treatment of recessive dystrophic EB: Where do we stand?

Leena Bruckner-Tuderman (Freiburg im Breisgau DE)

15:00 – 15:30 Coffee break in the industrial exhibition
15:30 – 16:30 Keynotes 2 – Clinical Part 2

Matterhorn
Chairs: Francis Palisson (Santiago CL), Leena Bruckner-Tuderman (Freiburg im Breisgau DE)

15:30 – 15:50 Struggling for Oral Health

Klaus Neuhaus (Bern CH)

15:50 – 16:10 CPG project - an overview

Judith Kristin Asche (Stavanger NO), Katty Mayre-Chilton (London UK)

16:10 – 16:30 Anaemia in EB

Irene Lara Corrales (Toronto CAN)

16:30 – 17:00 Free Communications 1

Matterhorn

Saturday, 8 September 2018
08:30 – 09:00 Free Communications 2

Matterhorn

09:00 – 10:15 Keynotes 3 – EB different experiences and multidisciplinary care

Matterhorn
Chairs: Agnes Schwieger-Briel (Zurich CH), Carolina Gouveia (Bern CH)

09:00 – 09:05 Welcoming

Carolina Gouveia (Bern CH), Agnes Schwieger-Briel (Zurich CH)

09:05 – 09:20 EB multidisciplinary care in Switzerland & Experiences of EB Nurses - bridging caretakers

Rosaria De Lorenzo (Bern CH), Carolina Gouveia (Bern CH)

09:20 – 09:35 Use of therapeutic contact lenses for the treatment of recurrent corneal erosio due to Epidermolysis Bullosa Dystrophica

Michael Bärtschi (Bern CH)

09:35 – 09:55 Multidisciplinary care in Singapore and South Asia

Mark Koh (Singapore SIN)

09:55 – 10:15 Inpatient Rehabilitation for Children with EB and their Families

Marion Küppers-Chinnow, Friederike Ufer (Sylt DE)

10:15 – 10:45 Coffee break in the industrial exhibition
10:45 – 12:00 Keynotes 4 – EB International

Matterhorn

Chairs: Rosaria De Lorenzo (Bern CH), Tanja Reusser (Belp CH)

10:45 – 11:00 Rare Recourcenet-Debra Croatia

Vlasta Zmazek (Zagreb HUN)

11:00 – 11:15 EB in Chile

Francis Palisson (Santiago CHI)

11:15 – 11:30 The role of DEBRA and regional associations in Brazil, a continental country

Jeanine Frantz (Blumenau BRA), Louisa Huber (Salvador BRA)

11:30 – 11:45 The voice of people with EB

Julia Cieplik (Iserlohn DE)

11:45 – 12:00 Above pain - on the wings of a butterfly

Michelle Zimmermann (Seedorf CH)

12:00 – 13:30 Lunch in the industrial exhibition
13:00 – 13:30 Poster Presentation



13:30 – 15:00 <i>Matterhorn</i>	Keynotes 5 – EB support – different experiences <i>Chairs: Anna-Barbara Schlüer (Zurich CH), Rosaria De Lorenzo (Bern CH)</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	Kindler syndrome, the fourth type of EB: Natural history and the propensity for skin cancer <i>Cristina Has (Freiburg DE)</i>
14:00 – 14:45	Chances and limitations of hypnosis <i>Nicole Wackernagel (Wil CH)</i>
14:45 – 15:00	EB without Borders <i>Lea Prujean (Vienna AT)</i>
15:00 – 15:30	Coffee break in the industrial exhibition
15:30 – 16:00 <i>Matterhorn</i>	Nutrition Forum <i>Rosie Jones (Birmingham UK), Lynne Hubbard (London UK), Markus Biedermann (Herzogenbuchsee CH)</i>
15:30 – 16:00 <i>Ruden</i>	Social Media Forum <i>Julia Cieplik (Iserlohn DE)</i>
16:00 – 17:00 <i>Matterhorn</i>	Nurse Forum: Daily tricks for live (open forum) <i>Natividad Romero (Marbella ES), Esther Dominguez (Marbella ES), Sylvia Kyprian (Hodrich CH), Jane Clapham (West Midlands UK)</i>
17:00 – 17:15 <i>Matterhorn</i>	Closing Session & Prize ceremony <i>Tanja Reusser (Belp CH)</i>
17:15 – 18:15 <i>Ruden</i>	Nurse Forum: Daily tricks for live (closed forum)
17:15 – 18:15	Annual General Meeting of DEBRA International

Sunday, 9 September 2018

09:00 – 10:00 <i>Matterhorn</i>	Documentary film
09:00 – 09:30	In Crystal Skin <i>Michaela O'Brien (Tulsa USA)</i>
09:30 – 10:00	The worst disease you've never heard of <i>Jack van Zijp (Den Haag NL)</i>