

2012 Patient Care Conference Schedule

July 30th – August 1st, 2012

All Sessions held in the Orange Blossom Ballroom



TIME SCHEDULE	MONDAY, JULY 30
12:00pm - 4:30pm	Check-In
5:00pm - 5:30pm	Welcome and Opening Remarks Brett Kopelan, Executive Director debra of America
5:30pm – 5:50pm	Is Camp for You? Kaycie Artus, Danielle Malchano
5:50pm - 6:50pm	Stem Cell Transplantation for Severe Epidermolysis Bullosa Dr. John E. Wagner
7:00pm - 9:00pm	Welcome Reception

TIME SCHEDULE	TUESDAY, JULY 31
9:00am - 9:25am	What are the Odds? Genetic counseling for EB Dr. Amy Paller
9:25am - 9:40am	Update on Genetics and Stem Cell Therapies Dr. Angela M. Christiano
9:40am - 10:00am	Prenatal Diagnosis of Epidermolysis Bullosa Dr. Sharon A. Glick
10:00am - 10:10am	DNA Q&A with Dr. Angela M. Christiano, Dr. Sharon A. Glick, Dr. Amy Paller
10:10am - 10:30am	Break
10:30am - 11:25am	Surgical Management of Epidermolysis Bullosa Dr. Peter J. Stern
11:25am – 11:55am	Personalized Induced Pluripotent Stem Cells for Optimizing EB Treatment Dr. Jakub Tolar
11:55am – 12:30pm	Medical Complications of EB Worth Knowing About: Anemia and Low Bone Mass Dr. Anna Bruckner
12:30pm – 1:30 pm	Lunch Sponsored by Edgepark
1:30pm - 2:00pm	Anesthesia for Your Child with Epidermolysis Bullosa Dr. Eric Wittkugel
2:00pm - 2:30pm	Interdisciplinary EB Care Dr. Anne Lucky
2:30pm - 3:25pm	Physical and Occupational Therapy Panel Dr. Faye Dilgen, Marita Black, Susan Maksomski, Carrie Shotwell, John T. Smith, Moderator: Kristy Steinau
3:25pm – 4:30pm	Teen Roundtable and Ice Cream Social sponsored by befriend EB <i>concurrent running session for teens (14-19 yrs. old)</i>
3:25pm - 3:40pm	Break
3:40pm - 4:30pm	Medical and Integrative Approaches to the Management of Pain and Itch in EB Dr. John Saroyan, Dr. Traci Stein
4:30pm – 5:10pm	Common Gastrointestinal Problems in Patients with EB Dr. Michael Farrell Nutritional Challenges in EB: people with EB and clinicians working together Dr. Lynne D. Hubbard
5:10pm - 5:40pm	Oral Health and Epidermolysis Bullosa Dr. J. Timothy Wright
5:40pm – 6:10pm	A Family's Guide to Coping with Chronic Illness: What Works and What Doesn't Dr. Mark P. Popenhagen
6:30pm - 8:30pm	Dinner Sponsored by Coloplast

TIME SCHEDULE		WEDNESDAY, AUGUST 1	
9:00am – 9:20am	Protein Replacement Therapy for Dystrophic Epidermolysis Bullosa Dr. Mei Chen		
9:20am – 9:40am	Development of Systemic Protein Replacement Therapy for Dystrophic EB Dr. Mark de Souza		
9:40am – 9:50am	Protein Q&A with Dr. Mei Chen, Dr. Mark de Souza		
9:45am – 10:15am	Your Questions on Pain and Itch in EB with Dr. John Saroyan <i>concurrent running session open to all attendees</i>		
9:50am – 10:25am	Involvement of the Airway in Patients with EB Dr. Ravindhra Elluru		
10:25am – 10:45am	Break		
10:45am – 11:15am	A Consensus Approach to Wound Care Dr. Elena Pope		
11:15am – 11:45am	Cell Therapy for Epidermolysis Bullosa Dr. Alfred Lane		
11:45am – 12:15pm	Management of Esophageal Strictures in Epidermolysis Bullosa Patients Dr. Richard G. Azizkhan		
12:15pm - 1:15pm	Lunch Sponsored by National Rehab		
1:15pm – 1:45pm	Ocular Surface Rehabilitation in Dystrophic EB Dr. Arturo Kantor		
1:45pm – 2:15pm	Insurance Advocacy Michelle Graham		
2:15pm - 2:30pm	Closing Remarks Brett Kopelan, Executive Director debra of America		
3:30pm - 8:30pm	Family Field Trip to Downtown Disney Sponsored by Hollister		
4:30pm – 5:30pm	Dinner: Planet Hollywood		
6:00pm – 7:30pm	Show: Cirque du Soleil's La Nouba		

THIS AGENDA IS SUBJECT TO CHANGE.