

# 2018 DEBRA CARE CONFERENCE

JULY 22–25, 2018 | CHANDLER, AZ



GENERAL SESSIONSCHEDULE -SUBJECT TO CHANGE.

## SUNDAY, JULY 22

1:00 pm – 5:00 pm Attendee Check-in (note, hotel check-in time is 4 pm)

5:00 pm – 6:00 pm Opening Remarks and Reception

6:00 pm – 7:30 pm Dinner

## MONDAY, JULY 23

7:45 am – 9:00 am Breakfast

9:00 am – 9:45 am **Anemia and Endocrine Issues in EB** | Anne W. Lucky, MD

9:45 am – 10:30 am **Why Do I Need to Know My Mutations Causing EB?** | Jouni Uitto, MD

10:30 am – 10:45 am Break

10:45 am – 11:30 am **Understanding Clinical Research: What's in it for me** | Anna M. Bruckner, MD

11:30 am – 12:15 pm **Gene Therapy for Epidermolysis Bullosa** | M. Peter Marinkovich, MD

12:15 pm – 1:30 pm Lunch

1:30 pm – 2:15 pm **Eye Care for EB Patients: Strategies to prevent blistering, scarring and vision loss** | Vicki M. Chen, MD

2:15 pm – 3:00 pm **Patient-Driven Treatment of Hand Contractures in EB** | Roger Cornwall, MD

3:00 pm – 3:15 pm Break

3:15 pm – 4:00 pm **Special Care Dentistry for Patients with Epidermolysis Bullosa** | Mark Cannon, DDS

4:00 pm - 4:45 pm **Is Symptom Relief Research Important?** | Amy S. Paller, MD

4:45 pm – 5:30 pm **Session TBA**

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5:30 pm – 7:30 pm Dinner

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7:30 pm – 9:30 pm **Social Activity TBA**

## TUESDAY, JULY 24

7:45 am – 9:00 am Breakfast

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9:00 am – 9:45 am **What's New in Cell Therapy for EB?** | Jakub Tolar, MD, PhD

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9:45 am – 10:30 am **Session TBA**

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10:30 am – 10:45 am Break

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10:45 am – 11:30 am **Occupational and Physical Therapy Guidelines** | Susan Maksomski, OTR/L, CHT, Amy Weisman, PT, DPT

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11:30 am – 12:15 pm **Update in Management of Epidermolysis Bullosa Simplex** | Joyce M.C. Teng, MD

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12:15 pm – 1:30 pm Lunch

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1:30 pm – 2:15 pm **Multidisciplinary Care Overview** | Harper Price, MD

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2:15 pm – 3:00 pm **Government Affairs Update: Advocating on behalf of the EB Community and upcoming opportunities** | Brett Kopelan and Joe Murray, ESQ.

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3:00 pm – 5:30 pm **Social Activity TBA**

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5:30 pm – 7:30 pm Dinner

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7:30 pm – 9:30 pm **Social Activity TBA**

## WEDNESDAY, JULY 25

7:45 am – 9:00 am Breakfast

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9:00 am – 9:45 am **Non-Pharmaceutical Pain Management Techniques** | Mark P. Popenhagen, PSYD

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9:45 am – 10:30 am **Session TBA**

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10:30 am – 10:45 am Break

10:45 am – 11:30 am	<b>Gastrointestinal Issues in Epidermolysis Bullosa</b>   Michael K. Farrell, MD
11:30 am – 12:15 pm	<b>Gentamicin-mediated Readthrough Therapy for JEB and RDEB</b>   Mei Chen, PhD and Dr. David Woodley
12:15 pm – 1:30 pm	Lunch
1:30 pm – 2:15 pm	<b>EB in Adulthood &amp; Adult-Only Clinic Overview</b>   Bahar Dasgeb, MD
2:15 pm – 3:00 pm	<b>Protections Under the Americans with Disabilities Act</b>   David W. Knight
3:00 pm – 3:15 pm	Break
3:15 pm – 4:00 pm	<b>Transitioning to Adult Care-Aging out of Pediatrics</b>   Kellie Badger, RN
4:00 pm – 4:30 pm	<b><i>Session TBA</i></b>
4:30 pm – 5:15 pm	<b>Understanding the Genetics of EB</b>   Dr. Andrew South
5:15 pm – 5:30 pm	Closing Remarks
5:30 pm – 7:30 pm	Dinner

## BREAK-OUT SESSIONS, ROUNDTABLE DISCUSSIONS, AND SOCIAL ACTIVITIES TO COME!

### ***Additional planned sessions to be included:***

- Coping with Chronic Illness
- Diet & Nutrition
- Discussion for Young Adults with EB
- Discussion for Siblings of those with EB
- Government Affairs
- Pain Management Overview
- Squamous Cell Carcinoma and RDEB
- Wound Care
- and more!