



AGENDA

JULY 22-25 | CHANDLER, ARIZONA

For complete session details, download the “debra Care Conference” mobile app onto your smart phone!

SUNDAY, JULY 22

TIME	SESSION	SPEAKER	LOCATION
1:00 - 5:00 PM	Attendee Check-In		Akimel O’otham 1/2
5:00 - 5:30 PM	Opening Remarks	Brett Kopelan	Pipai Kave Ballroom
5:30 - 7:00 PM	DINNER - followed by reception & music by Aaron White Duo (music from 6:30-8:30 PM with cash bar)		Akimel O’otham 3/4

MONDAY, JULY 23

7:45 - 9:00 AM	BREAKFAST		Akimel O’otham 3/4
9:00 - 9:45 AM	Anemia & Endocrine Issues in EB	Anne W. Lucky, MD	Pipai Kave Ballroom
	Break-Out Session: You’re No Good To Them if You Don’t Take Care of Yourself! Mental Health for Caregivers	Mark P. Popenhagen, PSYD	Quail
9:45 - 10:30 AM	Why Do I Need to Know My Mutations Causing EB?	Jouni Uitto, MD	Pipai Kave Ballroom
10:30 - 10:45 AM	BREAK		
10:45 - 11:30 AM	Understanding Clinical Research: What’s In It For Me?	Anna L. Bruckner, MD	Pipai Kave Ballroom
11:30 - 12:15 PM	Gene Therapy for Epidermolysis Bullosa	M. Peter Marinkovich, MD	Pipai Kave Ballroom
12:15 - 1:30 PM	LUNCH		Akimel O’otham 3/4
1:30 - 2:15 PM	Eye Care for EB Patients: Strategies to Prevent Blistering, Scarring, & Vision Loss	Vicki M. Chen, MD	Pipai Kave Ballroom
2:15 - 3:00 PM	Patient-Driven Treatment of Hand Contractures in EB	Roger Cornwall, MD	Pipai Kave Ballroom
3:00 - 3:15 PM	BREAK		
3:15 - 4:00 PM	Special Care Dentistry for Patients with Epidermolysis Bullosa	Mark Cannon, DDS	Pipai Kave Ballroom
	Break-Out Session: Dressing Changing Tips For Hands, Head and Other Hard-To-Dress Areas	Susan Maksomski, OTR/L, CHT & Jennifer Chan, OTR/L, CHT	Quail
4:00 - 4:45 PM	Government Affairs Update: Advocating on Behalf of the EB Community + Upcoming Opportunities	Brett Kopelan & Joe Murray, ESQ.	Pipai Kave Ballroom
4:45 - 5:30 PM	EB and Nutrition	Colleen Vicente, RD	Pipai Kave Ballroom
5:30 - 7:00 PM	DINNER		Akimel O’otham 3/4

TUESDAY, JULY 24

7:45 - 9:00 AM	BREAKFAST		Akimel O’otham 3/4
9:00 - 9:45 AM	What’s New in Cell Therapy for EB?	Jakub Tolar, MD, PhD	Pipai Kave Ballroom
9:45 - 10:15 AM	Sponsor Session: Krystal Biotech	Suma Krishnan	Pipai Kave Ballroom

TIME	SESSION	PRESENTER	LOCATION
10:15 - 10:30 AM	BREAK		
10:30 - 11:15 AM	Occupational & Physical Therapy Guidelines	Susan Maksomski, OTR/L, CHT & Amy Weisman, PT, DPT	Pipai Kave Ballroom
11:15 - 12:00 PM	Update in Management of EB Simplex	Joyce M.C. Teng, MD	Pipai Kave Ballroom
	Break-Out Session: Developmental Milestones Throughout the Lifespan	Alex King OTR/L, CCLS, CTRS	Quail
12:00 - 1:15 PM	LUNCH		Akimel O'otham 3/4
1:15 - 1:45 PM	Sponsor Session: Abeona Therapeutics, Inc.	Michelle Berg & Kaye Spratt, PhD	Pipai Kave Ballroom
1:45 - 2:30 PM	Multidisciplinary Care Overview	Harper Price, MD	Pipai Kave Ballroom
	Break-Out Session: Discussion for Young Adults (for teens & young adults with EB)	Community Member Michelle Hall & Mark P. Popenhagen, PSYD	Quail
2:30 - 3:00 PM	Sponsor Session: Castle Creek	Amir Tavakkol	Pipai Kave Ballroom
3:00 - 4:30 PM	FREE TIME		
4:30 - 5:30 PM	<i>Improv Mania: Family Friendly Improv Comedy Show! (Doors open at 4:15 PM)</i>		Pipai Kave Ballroom
5:30 - 7:00 PM	DINNER - followed by ice cream social & family-friendly DJ (music from 6:30-8:30 PM with cash bar)		Akimel O'otham 3/4

WEDNESDAY, JULY 25

7:45 - 9:00 AM	BREAKFAST		Akimel O'otham 3/4
9:00 - 9:45 AM	Non-Pharmaceutical Pain Management Techniques	Mark P. Popenhagen, PSYD	Pipai Kave Ballroom
9:45 - 10:30 AM	Wound Care Overview	Kimberly D. Morel, MD	Pipai Kave Ballroom
10:30 - 10:45 AM	BREAK		
10:45 - 11:30 AM	Gastrointestinal Issues in EB	Michael K. Farrell, MD	Pipai Kave Ballroom
	Break-Out Session: Puberty, Dating, and Everything That Follows: A Developmental Perspective on Sexuality with Specific Consideration for EB	Alex King OTR/L, CCLS, CTRS & Kellie Badger, RN	Quail
11:30 - 12:00 PM	Sponsor Session: Berg	Niven R. Narain	Pipai Kave Ballroom
12:00 - 12:45 PM	Gentamicin-mediated Readthrough Therapy for JEB and RDEB	Mei Chen, PhD	Pipai Kave Ballroom
12:45 - 2:00 PM	LUNCH		Akimel O'otham 3/4
2:00 - 2:45 PM	EB in Adulthood & Adult-Only Clinic Overview	Bahar Dasgeb, MD	Pipai Kave Ballroom
2:45 - 3:30 PM	Protections Under the Americans with Disabilities Act	David W. Knight	Pipai Kave Ballroom
	Break-Out Session: Squamous Cell Carcinoma and RDEB	Dr. Andrew South	Quail
3:30 - 3:45 PM	BREAK		
3:45 - 4:30 PM	Transitioning to Adult Care: Aging Out of Pediatrics	Kellie Badger, RN	Pipai Kave Ballroom
4:30 - 5:00 PM	Sponsor Session: Fibrocell	Alfred T. Lane, MD	Pipai Kave Ballroom
5:00 - 5:45 PM	Understanding the Genetics of EB	Dr. Andrew South	Pipai Kave Ballroom
5:45 - 6:00 PM	Closing Remarks	Brett Kopelan	Pipai Kave Ballroom
6:00 - 7:30 PM	DINNER		Akimel O'otham 3/4