



## AGENDA SNAPSHOT

debra Care Conference (DCC)  
Omni Hotel at Centennial Park | Atlanta, GA  
July 28-31, 2024

We look forward to welcoming you to the 2024 debra Care Conference in Atlanta! Get ready for an unforgettable four days as we discover insights from EB experts, explore the latest research advancements, and make connections within the community through peer-led sessions and discussion groups. From family-friendly activities to exciting social events, dive into our agenda snapshot to preview what awaits you.

# Conference Day 1

Sunday, July 28

1:00	<b>Check-In</b> Kick-off the conference by picking-up your welcome packet and name badges at our conference headquarters, starting at 1:00PM. Stick around to chat with our exhibitors and fellow attendees! <b>Reminder: Hotel check-in is 4:00PM EST.</b>
5:00	<b>Opening Remarks</b> Brett Kopelan, Executive Director, debra of America
5:30	<b>Dinner</b>
6:30	<b>A Warm Welcome: Relax and Connect with Your DCC Family (Welcome Reception)</b>

DCC Mobile App Forthcoming! Schedule is subject to change.



# Conference Day 2

Foundational Insights and Integrative Approaches  
Fundamental Breakthroughs in Therapies & Research  
Peer-to-Peer Meet-ups

Monday, July 29

8:00	<b>Breakfast</b>
9:00	Room 1: Clinical Strategies for EB Pain and Itch Management Room 2: Understanding the Genetics of EB
9:45	Room 1: Natural Progression of EB Wounds: Foundational Insights Room 2: Emerging Therapies for EB: Exploring Types and What They Offer
10:30	<b>Break</b>
10:45	Room 1: Wound Care Best Practices: A Look Across EB Subtypes Room 2: Interdisciplinary & Preventive Care Models for Comprehensive EB Health
11:30	Room 1: Identification and Treatment of Infections in EB Room 2: Stigma Study + Psychosocial Burden of EB (60 minutes)
12:15	<b>Break</b>
12:30	Room 1: Chiesi Update - U.S. FDA Approved Treatment for DEB & JEB Room 2: The Complexities of Care for EB Simplex
1:15	<b>Lunch</b>
2:30	Room 1: Why COL7A1 Is Important for Wound Healing & Real-World Experience (Krystal Biotech Update) Room 2: EB Simplex: Advancements in Therapy Room 3: JEB Research Updates
3:15	Room 1: Coping with Your Child's Chronic Illness Room 2: Taking Control: Building the Foundation for Life's Transitions Room 3: Cannabinoids for Symptom Management in EB
4:00	Peer Get Togethers + Peer-to-Peer Support Meet-ups by Age
4:45	<b>Break</b>
5:00	Keynote Conversation with FDA Leadership: Lola Fashoyin-Aje, MD, MPH, Director of the Office of Clinical Evaluation & Brett Kopelan, Executive Director, debra of America
5:45	<b>Dinner</b>
7:00	<b>Community Night: Karaoke!</b>



# Conference Day 3

Targeted Care Approaches and Strategies  
Therapies in the Pipeline: Innovation and Advancements  
Peer-to-Peer Meet-ups

Tuesday, July 30

8:00	<b>Breakfast</b>
9:00	Room 1: Addressing Important Gastrointestinal Problems in EB Room 2: Worth the Leap? Understanding Clinical Trials & Making Decisions Room 3: Grief Support and Discussion: Navigating the Many Faces of Loss
9:45	Room 1: Oral Healthcare for EB Room 2: Squamous Cell Carcinoma Cancer in EB Room 3: Women with EB: Pregnancy Outcomes, Management and Open Discussion
10:30	<b>Break</b>
10:45	Room 1: Happy Feet: Managing Foot Challenges of EB Room 2: Your Cells, Our Science: Gene Therapy for Dystrophic Epidermolysis Bullosa Room 3: Family Planning: Exploring Options for Growing Your Family
11:30	Room 1: Eye Care and EB Room 2: Dupilumab for Itch: Clinical Trial Update (for all EB Types) Room 3: Intimacy & Wellness in Relationships for Individuals Affected by EB
12:15	<b>Break</b>
12:30	Room 1: Demystifying Palliative Care: Optimizing Quality of Life Room 2: Paradigm Therapeutics Research Update (for all EB Types)
1:15	<b>Lunch + Room 1: LUNCH &amp; LEARN: Navigating Life's Changes - Discussion Forum</b>
2:30	Room 1: Nutrition and Wound Healing + The Role of Diet & Vitamin C Room 2: Unlocking the Potential of Extracellular Vesicles: Aegle's New Clinical Trial
3:15	Room 1: Dismissed No More: Navigating the World with EB, Seen or Unseen Room 2: Abeona Pz-cel Research Update (for RDEB) (3:00 to 3:30)
4:00	<b>Break</b>
4:15	Room 1: Living and Thriving with EB: Personal Experiences & Occupational Therapy Room 2: Anemia and EB
5:00	Peer-to-Peer Support Meet-ups by EB Types
5:45	<b>Break</b>
6:30	<b>DCC Celebration of Champions: Dinner &amp; Dance Party</b>



# Conference Day 4

Advocacy and Wellness - Navigating Challenges, Cultivating Strength  
 Progress in Research & Future Directions  
 Workshops & Peer-to-Peer Meet-ups

Wednesday, July 31

8:00	<b>Breakfast</b>
9:00	Room 1: Navigating Insurance, Disability, and Employment Room 2: Advocating for EB Health: Using Assertiveness in Medical Settings
9:45	Room 1: Transitions to Adults Providers - Insights from Clinical Practice Room 2: Navigating School/School Systems (Elementary and High School)
10:30	<b>Break</b>
10:45	Room 1: Financial Independence - Managing Finance and Planning Ahead Room 2: Aging with EB - Discussion with Dermatologists Room 3: Fostering Family Strength: Techniques for Cultivating Well-Being
11:30	Room 1: TWiB Clinical Trial Overview for EB Simplex Room 2: Allogenic ABCB5-positive dermal mesenchymal stem cells (ABCB5+ MSCs) for the treatment RDEB (RHEACELL Update) Room 3: Guided Meditation - Strength Within
12:00	<b>Break</b>
12:15	Room 1: Self-Care for Adults Living with EB: Body and Mind Wellness Room 2: Self-Care for Caregivers: Health Outcomes for Caregivers Room 3: Venture Philanthropy
1:00	<b>Lunch + Room 1: LUNCH &amp; LEARN: Intimacy Part II: A Supportive Discussion Forum</b>
2:15	Peer-to-Peer Support Meet-ups by EB Types (Continued Conversations) & Hands-On Drop-In Learning Stations: Hospital/Emergency Care Mgmt.; Bandaging Techniques; Adaptive Equipment; Resource Hub
4:00	<b>Break</b>
4:15	Government Advocacy Update and Discussion
5:00	Closing Remarks
5:30	<b>Dinner</b>