



**JULY 17-20, 2022**

For complete details, download our *debra Care Conference* mobile app!

**SUNDAY**

**1:00PM-5:00PM**  
Check-in

**5:00PM-6:00PM**  
Opening Remarks  
+

Keynote Speaker,  
Dr. Tolar  
+

Special Presentation:  
Stem Cell Based Medicine  
in EB

**6:00PM-7:15PM**  
Dinner

**7:00PM-8:30PM**  
Welcome Reception

**MONDAY**

**Breakfast - 8:00-9:00 AM**

**9:00AM**

ABC5+ stem cells in EB: Part 1  
(Rheacell)

**9:30AM**

Gene Therapy & EB

Skin Infections and EB

**10:15AM**

Oral Health Care for EB Patients and  
Caregivers

Treatment of EB with Nonsense  
Mutations

**11:00AM**

Medical Trauma Reactions in Youth

Squamous Cell Carcinoma  
and EB

**11:45AM**

Chronic Wound Care Mgmt.

Taking Control -  
Life's Transitions with EB

**Lunch - 12:30-1:45 PM**

**1:45PM**

Innovations in EB Research - Emerging  
Therapies

Thinking Outside the Tape -  
Hospital Visits

Teen Talk 1 (for young women)  
Teen Talk 2 (for young men)

**2:30PM**

Clinical Trials - Personal Experiences

Growing up with EB: Building Your  
Child's Self-Esteem

Crafting a Career/Passion

**3:15PM**

Peer-to-Peer Support Meet-Ups for:  
Individuals with EBS; Individuals with  
JEB + JEB Caregivers

ABC5+ stem cells in EB: Part 2 (for  
Clinicians and Researchers)

**3:30PM**

Advisory Board RDEB + DDEB (Krystal)

**Afternoon Break - 4:00-5:30 PM**  
**Dinner - 5:30-6:45 PM**

**6:30-8:30 PM**  
**COMMUNITY NIGHT!**  
**KARAOKE & OPEN MIC PARTY**

**TUESDAY**

**Breakfast - 8:00-9:00 AM**

**9:00AM**

Sponsored Session: Amryt

**9:30AM**

Occupational Therapy and Physical  
Therapy

Medical Trauma Reactions in  
Caregivers

**10:15AM**

Anesthesia Management and  
Outcomes in Patients with EB

Genetics of EB

**11:00AM**

Sponsor Session (Krystal Biotech)

Navigating Insurance/Benefits

**11:45AM**

Anemia and EB

Bandaging Techniques Workshop

**Lunch - 12:30-1:45 PM**

**1:45PM**

Eye Care and Research Update

Dress for Success - Practical Everyday  
Tools and Modifications

Siblings Talk

**2:30PM**

Relationships, Sexuality and EB

Family Guide to Coping with Chronic  
Illness

New Treatments for Skin and Ocular  
Lesions in EB (Eliksa)

**3:15PM**

Peer-to-Peer Support Meet-Ups for:  
Individuals with RDEB; RDEB  
Caregivers; Individuals with DDEB +  
Caregivers; EBS Caregivers

**4:00PM**

Advisory Board RDEB + JEB (Rheacell)

**Afternoon Break - 4:00-5:30 PM**  
**Dinner - 5:30-6:45 PM**

**6:30-8:30 PM**  
**RED CARPET MASQUERADE**  
**BALL**

**WEDNESDAY**

**Breakfast - 8:00-9:00 AM**

**9:00AM**

EB-101 Gene-Corrected Cell  
Therapy for RDEB (Abeona)

**9:30AM**

Gastrointestinal Issues & EB

Finding a Balance: Coping with Mental  
Health and EB

**10:15AM**

Your Cells, Our Science: Gene Therapy  
for DEB (Castle Creek)

Managing Finances + Planning Ahead

Navigating the School System -  
Elementary/High School

**11:00AM**

Pain and Itch Management

Navigating Schools - Higher Ed Edition

**11:45AM**

Pain and Itch - Everyday Strategies

Around the House - Practical Everyday  
Tools and Modifications

**Lunch - 12:30-1:45 PM**

**1:45PM**

Importance of Nutrition in EB

Employment Rights and Disability  
Insurance

**2:30PM**

Wound Care Panel - Practical  
Insights + Open Q&A

Jump Start Your Future Planning -  
Financial Planning (for Caregivers)

Exploration Session: Photography

**3:15PM**

Adaptive Sports and EB

Government Advocacy Efforts and  
Updates

**4:00-5:00PM- Camp Spirit Reception**

**5:00-6:45 PM**  
**CLOSING REMARKS AND**  
**DINNER**