



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

ABCb+ 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

Exploration Series 1: Careers

3:15PM

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

ABCb+ 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 Series 2: 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