

SCHEDULE OF EVENTS: SUNDAY AND MONDAY

Sunday, July 28

1:00 - 4:45 PM	Check-In
5:00	Opening Remarks
5:30	Dinner
6:30	Welcome Reception

Monday, July 29

8:00 AM

Breakfast

9:00

Pain & Itch - Dr. Lavery & Dr. Brooks Peterson

9:00

Genetics of EB - Dr. South and Sarah Morill, OTR

9:45

Wounds: Foundational Insights - Dr. Jean Tang

9:45

Emerging Therapies - Dr. Marinkovich

10:30

Break

10:45

Wound Care Best Practices - Dr. Kim Morel, Kadee Troop

10:45

Interdisciplinary & Preventive Care - Dr. Anne Lucky

11:30

Infections in EB - Dr. Marissa Perman

11:30

Stigma Study and Psychosocial - Dr. A. Paller & L. Yang

11:30

JEB Overview - Dr. Bruckner and C. Doernbrack, CPNP-PC

12:15 PM

Break

12:30

Chiesi Global Rare Diseases Update

12:30

EB Simplex Care Mgmt. - Dr. Joyce Teng

1:15

Lunch

2:30

Krystal Biotech Update

2:30

Research Updates for EBS - Dr. Joyce Teng

2:30

Meet-up: Individuals with JEB + Caregivers

3:15

Your Child Has EB. Now What? - Dr. Popenhagen

3:15

Life's Transitions - Alex King, OTR, H. DeAngelis, Toni Roberts

3:15

Cannabinoids for Symptom Mgmt. - L. Yang & Dr. Paller

3:15

Meet-up: Siblings of those with EB

4:00

Break

4:15

Peer Get Togethers + Support Meet-Ups

5:00

Keynote w/ Dr. Lola Fashoyin-Aje, MD, MPH

5:45

Dinner

7:00

Community Night: Karaoke!

SCHEDULE OF EVENTS: TUESDAY

Tuesday, July 30

8:00 AM

Breakfast

9:00

Gastrointestinal Challenges - Dr. Brumbaugh

9:00

Understanding Clinical Trials - Dr. Gorel

9:00

Grief Support and Discussion -Dr. Davis & Toni Roberts

9:45

Oral Healthcare for EB - Dr. Cannon

9:45

Squamous Cell Carcinoma in EB - Dr. Nikbahkt +

9:45

Women with EB & Pregnancy - Emily Boros-Rausch, Ida Steinlein and Lynna Yang

10:30

Break

10:45

Managing Foot Challenges - Dr. Bruckner

10:45

Research Update: Castle Creek

10:45

Family Planning and Discussion - E. Boros-Rausch, M. Disco, MS, CGC & L. Dellicker, MSW, LCSW

11:30

Eye Care and EB - Dr. Azabari & Amora Matteson

11:30

Dupilumab for Itch - Dr. Amy Paller

11:30

Intimacy & Wellness - Alex King, OTR & Michelle Hall

12:15 PM

Break

12:30

Demystifying Palliative Care - Dr. Popenhagen

12:30

Paradigm Therapeutics Update

12:30

Teen Talk for Young Men (13+)

1:15

Lunch

1:15

Lunch & Learn: Life's Changes -Sarah Morrill, OTR & Armando Head McCurdy

2:30

EB & Nutrition - C. Cacioppo, MS, RD, CDE

2:30

Aegle Therapeutics Update

2:30

Teen Talk for Young Women (13+)

3:15

Abeona Therapeutics Update

3:15

EB, Seen and Unseen - Dr. Candela, Sarah Morrill, OTR and Aaron Sandoval

4:00

Break

4:15

Occupational Therapy, Living and Thriving

4:15

Anemia and EB

5:00

Peer-to-Peer Support Meet-Ups

5:45

Break

6:00

Dinner

7:00

DCC Celebration of Champions: Dance Party

SCHEDULE OF EVENTS: WEDNESDAY

Wednesday, July 31

8:00 AM

Breakfast

9:00

Insurance, Disability and Financial Planning - H. DeAngelis, M, Hall & L. Radar

9:00

Assertiveness in Medical Settings - Dr. Valentine and R. Russo

9:45

Navigating School Systems - Alex King, OTR, Catherine Doernbrack, Dr. Bodan

9:45

Transitioning to Adult Providers - Dr. Price

10:30

Break

10:45

Aging with EB - Dr. Gorel, Dr. Nikbahkt & Dr. Price

10:45

Fostering Family Strength - Desiree Joy Sparrow

11:30

TWi Biotechnology Update

11:30

RHEACELL Update

11:30

Guided Meditation - Desiree Joy Sparrow

12:00 PM

Break

12:15

Self-Care for Adults with EB - Toni Roberts

12:15

Self-Care for Caregivers - Dr. Valentine and Dr. Bodan

12:15

Venture Philanthropy - Ryan Fullmer

1:00

Lunch & Learn: Relationships Part II - A. King, OTR & M. Hall

2:15

Hands-on Learning Stations:

- Adaptive Equipment
- Bandaging Techniques
- Emergency Care Mgmt.
- Resource Hub

4:00

Break

4:15

Government Advocacy - Brett Kopelan

5:00

Closing Remarks - Brett Kopelan

5:30

Dinner



OVER 40 SESSIONS
RECORDED, VIEW NOW ON
EBCONNECT.ORG!

SPOTLIGHT: PEER-LED SUPPORT

We're excited to continue our peer-to-peer support groups and get together at the DCC! Led by community members, these meet-ups provide a space to listen, share experiences, and support one another. Each specific group has their own dedicated session. No sign-up required.

Monday, July 29

- Parents and their Littles (0-5)
- Parents of School-Aged Kids (6-11)
- Parents of Teens/Young Adults
- Siblings of Those with EB
- Families of Lost Loved Ones
- Kiddos in the Kids Room (6-11)
- Teens w/ EB (12-17)
- Young Adults w/ EB (18-35)
- Adults w/ EB (35+)
- Individuals with JEB + Caregivers

Tuesday, July 30

- Individuals with EB Simplex
- Caregivers of EB Simplex
- Individuals with RDEB
- Caregivers of RDEB
- Individuals DDEB + Caregivers
- Teen Talk for Young Men (13+)
- Teen Talk for Young Women (13+)

Wednesday, July 31

Drop-In Learning Stations:

- Adaptive Equipment
- Bandaging Techniques
- Emergency Care Mgmt.
- Resource Hub

Plus, Continued Conversations

NEW FOR 2024!

TIPS:

If you do not know your EB type, or feel you identify more with any other given group, you are welcome to join that group's session. Visit **debra HQ** in the Grand Ballroom (M4) for more info, and see the **DCC Mobile App** for exact timing and room locations. Many are in the late afternoon each day but not all, so please review carefully.

KIDS ROOMS HOURS & SPECIAL ACTIVITIES

DCC Kids Rooms are located on M3. Entrance is in the foyer.

Monday, July 29

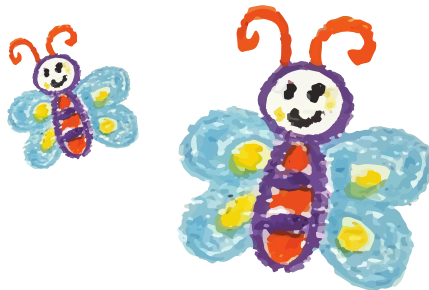
8:45 AM	Kids Rooms Open
10:00	Live Entertainment: Piccadilly Puppets
11:00	Creations Hour: Puppet Palooza
1:30-2:15 PM	Kids Rooms Closed for Lunch
3:00	Live Entertainment: Big Idea Bubbles Show
4:15-5:00 PM	Peer Group Meet-Up: Littles and Their Parents & Peer Group Meet-up: Kiddos 6-11
6:00	Kids Rooms Close

Tuesday, July 30

8:45 AM	Kids Rooms Open
10:30	Live Entertainment: Party Animals Reptile Show
12:00 PM	Crafting Magic: Mason Jar Lanterns
1:30-2:15	Kids Rooms Closed for Lunch
2:30	Live Entertainment: The Magic Man
4:00	Gold Medal Makers: Olympics Craft Hour
6:00	Kids Rooms Close

Wednesday, July 31

8:45 AM	Kids Rooms Open
9:30	Creative Keepsake: Decorated Door Hangers
11:00	Live Entertainment: Fun Weird Science
1:15-2:00 PM	Kids Rooms Closed for Lunch
2:30	Live Entertainment: Lego Master Model Builders
4:15	Kids Rooms Close



THANK YOU TO OUR SPONSORS

The debra Care Conference (DCC) is made possible by the generosity and support of our sponsors.
Visit them in the Exhibitor Hall in the Grand Ballroom!

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