

# 2016 debra CARE CONFERENCE

July 24 – July 27, 2016

## SUNDAY, JULY 24

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|-----------------|--|
| 1:00pm – 5:30pm | Registration   |
| 5:30pm – 6:00pm | The Power of A Wish<br>A special presentation by Make-A-Wish America<br>Sandra K. Ring, M.S., CCLS, Senior Manager, Medical Eligibility and Outreach |
| 6:00pm – 7:30pm | Free Time  |
| 7:30pm – 9:00pm | Social Hour...and a half!  |

## MONDAY, JULY 25

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|-------------------|--|--|
| 9:00am – 9:45am   | Update on Genetic Classification of EB & Interdisciplinary Care<br>Anne W. Lucky, MD   |  |
| 9:45am – 10:30am  | Clinical Trials of Gene Therapy for RDEB<br>M. Peter Marinkovich, MD   |  |
| 10:30am – 10:45am | Break  |  |
| 10:45am – 11:30am | Clinical Trials: What You Should Know<br>Amy S. Paller, MD   | Teen Talk: Open Conversation for Teens with EB (ages 13-17)<br>Mark Popenhagen, PsyD   |
| 11:30am – 1:00pm  | Brunch   |  |
| 1:00pm – 1:45pm   | Pain Management in EB<br>Veronica Carullo, MD  |  |
| 1:45pm – 2:30pm   | Oral Health Care for EB<br>Mark Cannon, DDS  |  |
| 2:30pm – 3:15pm   | Weeping Wounds! How can I tell if a wound is infected?<br>Anna M. Bruckner, MD   |  |
| 3:15pm – 3:30pm   | Break  |  |
| 3:30pm – 4:15pm   | A Study of Effectiveness of Diacerein in Prevention of Blister Formation in EBS-DM<br>Johann Bauer, MD, MBA, HCM   | A Family's Guide to Coping with Chronic Illness (first-time attendees encouraged to attend - all are welcome)<br>Mark Popenhagen, PsyD |
| 4:15pm - 5:00pm   | Occupational Therapy and Physical Therapy Tips for Children and Adults with EB<br>Susan Maksomski, OTR/L, CHT, Amy Weisman, PT, DPT, Jennifer Chan, OTR/L, CHT         |  |
| 5:00pm – 5:30pm   | Keynote: A Father's Journey<br>John Crowley, National Chairman, Make-A-Wish of America<br>Chairman & CEO, Amicus Therapeutics Inc.<br>Father of two with Pompe Disease |  |
| 5:30pm – 7:30pm   | Dinner   |  |
| 7:30pm – 9:30pm   | Movie Viewing: Extraordinary Measures  |  |

## TUESDAY, JULY 26

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|-------------------|--|--|
| 9:00am – 9:45am   | Do No Harm: BMT for Severe Generalized EB<br>Jakub Tolar, MD, PhD            | Practical Interventions and Therapeutic Guidelines Q&A with Occupational and Physical Therapists<br>Susan Maksomski, OTR/L, CHT, Amy Weisman, PT, DPT, Jennifer Chan, OTR/L, CHT |
| 9:45am – 10:30am  | Balancing Risks and Benefits in Hand Surgery for EB<br>Roger Cornwall, MD    |  |
| 10:30am – 10:45am | Break  |  |
| 10:45am – 11:30am | The Psychology of Pain: What Everyone Needs to Know<br>Mark Popenhagen, PSYD |  |
| 11:30am – 1:00pm  | Brunch   |  |

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| 1:00pm – 1:30pm           | Sponsor Session: Fibrocell   | Sibs Speak: Open Conversation for Siblings (ages 13-17)<br>Mark Popenhagen, PsyD |
| 1:30pm – 2:15pm           | Advocacy 101: Tools to Becoming a Successful EB Advocate<br>Jennifer Bernstein, Brett Kopelan, Joe Murray, Andrew Tavani               |  |
| 2:15pm – 2:45pm           | Amicus SD-101 Clinical Development Program Update<br>Eric Cantor, MD, Vice President Global Medical Affairs, Amicus Therapeutics, Inc. |  |
| 2:45pm – 3:00pm           | Break  |  |
| 3:00pm – 5:00pm           | Canvas Painting Party  |  |
| 5:00pm – 5:30pm           | Group Photo  |  |
| 5:30pm – 7:30pm           | Dinner   |  |
| 7:30pm – 9:30pm           | Evening Social   |  |
| <b>WEDNESDAY, JULY 27</b> |  |  |
| 9:00am – 9:45am           | Nutrition in EB<br>Jennifer M. Phillips, MS, RD, LD  | Session Focus: Family Planning<br>Led by members of the EB Community             |
| 9:45am – 10:30am          | Wound Care Town Hall<br>Sandra Oehlke, APRN, CPNP-PC, DCNP, CCM, CCRP, CWOCN<br>Jean Whalen, RNIII, BSN, CPN                           |  |
| 10:30am -10:45am          | Break  |  |
| 10:45am-11:30am           | EB Simplex Research Updates<br>Sharon A. Glick, MD   |  |
| 11:30am-11:45am           | Closing Remarks  |  |
| 11:45am-1:00pm            | Brunch   |  |