

# 2016 debra CARE CONFERENCE

July 24 – July 27, 2016

## SUNDAY, JULY 24

1:00pm – 5:30pm	Registration
5:30pm – 6:00pm	The Power of A Wish A special presentation by Make-A-Wish America 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

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

## TUESDAY, JULY 26

9:00am – 9:45am	Do No Harm: BMT for Severe Generalized EB Jakub Tolar, MD, PhD	Practical Interventions and Therapeutic Guidelines Q&A with Occupational and Physical Therapists 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 Roger Cornwall, MD	
10:30am – 10:45am	Break	
10:45am – 11:30am	The Psychology of Pain: What Everyone Needs to Know Mark Popenhagen, PSYD	
11:30am – 1:00pm	Brunch	

1:00pm – 1:30pm	Sponsor Session: Fibrocell	Sibs Speak: Open Conversation for Siblings (ages 13-17) Mark Popenhagen, PsyD
1:30pm – 2:15pm	Advocacy 101: Tools to Becoming a Successful EB Advocate Jennifer Bernstein, Brett Kopelan, Joe Murray, Andrew Tavani	
2:15pm – 2:45pm	Amicus SD-101 Clinical Development Program Update 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 Jennifer M. Phillips, MS, RD, LD	Session Focus: Family Planning Led by members of the EB Community
9:45am – 10:30am	Wound Care Town Hall Sandra Oehlke, APRN, CPNP-PC, DCNP, CCM, CCRP, CWOCN Jean Whalen, RNIII, BSN, CPN	
10:30am -10:45am	Break	
10:45am-11:30am	EB Simplex Research Updates Sharon A. Glick, MD	
11:30am-11:45am	Closing Remarks	
11:45am-1:00pm	Brunch	

## 2016 debra Care Conference Speakers

### **JOHANN BAUER, MD, MBA HCM**

**Head of the University Clinic for Dermatology  
SALK/Paracelsus Medical University**

Dr. Johann Bauer is a Professor of Dermatology and the Chairman at the Department of Dermatology, University Clinic of the Paracelsus Medical University in Salzburg, Austria. He is the CEO of EB House Austria, and co-founder of Procomcure, Inc. and Diaderm, llc. Dr. Bauer has worked extensively within academic settings such as Thomas Jefferson University, Emory University School of Medicine, University of Innsbruck and the Austrian Academy of Sciences.



### **JENNIFER BERNSTEIN**

**Executive Vice President  
Horizon Government Affairs**

Jennifer joined Horizon Government Affairs in December 2008, where she serves as Executive Vice President, focusing on legislative and regulatory developments within the pharmaceutical and biotechnology sectors. Prior to joining HGA, Jennifer spent several years on Capitol Hill as a staff member for former Pennsylvania Congressman James Greenwood. Jennifer has worked closely with the rare disease community for many years, and with Rare Disease Legislative Advocates and the Congressional Rare Disease Caucus since they were both established in 2010. She lives in Falls Church, Virginia with her husband and three children.



**ANNA L. BRUCKNER, MD**

**Associate Professor of Dermatology and Pediatrics**

**University of Colorado School of Medicine and Children's Hospital Colorado**

Dr. Bruckner is the director of pediatric dermatologist at Children's Hospital Colorado (CHCO) and a faculty member of the University of Colorado School of Medicine. She has been committed to EB since her dermatology residency and was the former director of the EB clinic at Stanford University. She currently co-directs the EB clinic at CHCO and is the lead investigator for the EB Clinical Research Consortium, a collaborative multisite network devoted to clinical research about EB. Her research on EB includes complications and outcomes of EB, clinical trials, and the development and validation of an outcomes measure for EB.



**VERONICA CARULLO, MD**

**Director of Pediatric Pain Management**

**Montefiore Medical Center in Bronx, NY**

Dr. Veronica Carullo is currently the Director of Pediatric Pain Management at Montefiore Medical Center in Bronx, NY. She is board-certified in General Pediatrics and Anesthesiology with subspecialty certifications in Pain Management, Pediatric Anesthesiology, and Hospice & Palliative Medicine. Dr. Carullo obtained her medical degree from the University of Miami School of Medicine. She completed residencies in General Pediatrics and Anesthesiology at New York Presbyterian Hospital-Weill Cornell Medical Center in New York, NY followed by a combined Adult and Pediatric Pain Fellowship at Children's Hospital Boston, Beth Israel Deaconess Medical Center, and Brigham & Women's Hospital in Boston, MA.



**MARK L. CANNON, DDS, MS**

**Professor, Division of Dentistry**

**Department of Otolaryngology, Feinberg School of Medicine**

**Northwestern University –Ann and Robert Lurie Children’s Hospital**

Dr. Cannon received his Doctorate of Dental Surgery from the University of Nebraska and then attended Northwestern University for his Masters of Pediatric Dentistry. He completed his residency at Children’s Memorial Hospital and received his Diplomate status by the American Board of Pediatric Dentistry. He is a past president of the Illinois Society of Dentistry for Children, a Professor of Otolaryngology, Division of Dentistry at Northwestern University, Feinberg School of Medicine, and a member of the International Association of Pediatric Dentistry. In addition to maintaining a large private practice in the suburbs of Chicago, he is the Research Coordinator of the residency program at Ann and Robert Lurie Children’s Hospital, Chicago, Illinois. Dr. Cannon has presented guest lectures at the University of Athens, Greece, Sao Paulista State University, UNESP, Aracatuba, Brazil, University of Texas- Houston, University of Alabama-Birmingham, and at the University of Illinois, Chicago, Department of Pediatric Dentistry. He has had presentations to the following organizations; I.A.D.R./A.A.D.R., the American Academy of Pediatric Dentistry, the American Society of Dentistry for Children, Academy of Dental Materials, World Congress of Biological Materials, International Association of Pediatric Dentistry, Pediatric Dental Association of Asia, Australasian Academy of Pediatric Dentistry, World Congress of Preventive Dentistry, Mexican Association of Pediatric Dentistry and the European Association of Pediatric Dentistry.



**JENNIFER CHAN**

**Pediatric Occupational Therapist and Certified Hand Therapist**

**Lucile Packard Children’s Hospital**

Jennifer Chan is a pediatric occupational therapist and certified hand therapist at Lucile Packard Children’s Hospital in Palo Alto, California. She has worked as a pediatric OT for over 30 years. The last 8 years Jennifer has specialized in pediatric hand therapy and participates in clinics for brachial plexus palsy and a monthly Epidermolysis Bullosa clinic at LPCH. Her work as part of the EB clinic team has inspired an interest to develop resources for occupational therapists working with EB patients and their families. In addition, she is conducting a research study of patients with RDEB comparing self-reported quality of life and independence in activities of daily living.



**ROGER CORNWALL, MD**  
**Surgical Director, Epidermolysis Bullosa Center**  
**Cincinnati Children's Hospital Medical Center**

Dr. Cornwall has been a full time pediatric hand surgeon for 12 years, after completing his education and training at Stanford University, Columbia University, Mount Sinai Hospital, Harvard University, and the Children's Hospital of Philadelphia. However, the vast majority of Dr. Cornwall's education in the care of EB comes from the children and families he has encountered since joining the Cincinnati Children's Epidermolysis Bullosa Center 7 years ago. Dr. Cornwall has recently become the Surgical Director of the Epidermolysis Bullosa Center, and his EB research focuses on the impact of hand surgery on patient-reported outcomes and quality of life.



**SHARON A. GLICK, MD**  
**Director, Pediatric Dermatology**  
**SUNY Downstate Medical Center**

Dr. Sharon A. Glick is an Associate Clinical Professor of Dermatology and Pediatrics at the State University of New York (SUNY) Downstate Medical Center at Brooklyn, NY. She is a board-certified dermatologist and pediatric dermatologist, and a fellow of the American Academy of Dermatology and the American Academy of Pediatrics. Dr. Glick received her MD from Albert Einstein College of Medicine and completed residencies in dermatology and pediatrics at Yale New Haven Hospital. She earned an MS degree in human genetics from Sarah Lawrence College. Her clinical and research interests include Epidermolysis Bullosa, infantile hemangiomas, acne, atopic dermatitis and the genodermatoses. She currently serves on the Scientific Advisory Board of debra.



**ANNE W. LUCKY, MD**  
**Medical Director, Cincinnati Children's EB Center**  
**Cincinnati Children's Hospital**

Dr. Lucky is the Medical Director of the Cincinnati Children's Epidermolysis Bullosa Center in Cincinnati, OH. She has had over 30 years of experience caring for children and adults with EB. Her training has been in Pediatrics and Pediatric Dermatology at the Yale University School of Medicine, New Haven CT and the Boston Children's Hospital, Boston, MA. She is author of over 200 peer reviewed scientific papers. She is currently an Adjunct Professor of Dermatology and Pediatrics at the University of Cincinnati College of Medicine.



**SUSAN MAKSOMSKI, OTR/L, CHT**  
**Head Occupational Therapist**  
**Morgan Stanley Children's Hospital of New York**

Susan Maksomski has been working as an Occupational Therapist/Certified Hand Therapist at the New York Presbyterian Hospital for 19 years. She has worked with children suffering from Epidermolysis Bullosa for eight years in an interdisciplinary setting, as well as, individually. Susan has been certified as a hand therapist for thirteen years specializing in upper extremity rehabilitation for both adults and children. She has attended the DEBRA Patient Care Conference previously and has gained significant knowledge from patients and families dealing with Epidermolysis Bullosa. She has also experienced working with families in the home environment dealing with the day to day struggles of patient care. Susan has been a lab instructor in splinting at Columbia University for the past fifteen years. She recently obtained a Master's of Science in Organizational Leadership at Quinnipiac University.



**M. PETER MARINKOVICH, MD**  
**Director, Blistering Disease Clinic**  
**Stanford University School of Medicine**

Dr. Marinkovich received his dermatology training at Oregon Health Sciences University, and his research training in the laboratory of Dr. Robert Burgeson, who discovered type VII collagen. Dr. Marinkovich's early work led to the characterization of several key basement membrane components involved in epidermolysis bullosa, including laminin-332 and laminin-311. He later joined the faculty at Stanford University and served as an attending in the National EB Registry at Stanford University and currently directs the Stanford Blistering Disease Clinic. Dr. Marinkovich's NIH funded laboratory has had a longstanding focus on the development of molecular therapy for various subtypes of epidermolysis bullosa.



**JOE MURRAY**  
**Director of Government & Legal Affairs**  
**debra of America**

Joe is debra of America's Director of Government and Legal Affairs. Before joining debra in April of last year, he served in a wide array of legislative policy and leadership roles on Capitol Hill in Washington, DC in both the United States House of Representatives and United States Senate with an emphasis in health care, entitlement, and educational areas. Joe has served in a leadership position in a number of civic and political organizations including local, state, and national political campaigns, his local civic association, as well as a neighborhood organization organized for snow removal parking regulation reform efforts. For the last three years, he has served as a Deacon in his local church and a Sunday school teacher to Fourth Grade boys. He is a licensed attorney in Virginia, having earned his law degree from the Catholic University of America Columbus School of Law in Washington, DC and his BA in Politics (Economics minor) from Rutgers University in New Brunswick, New Jersey. He and his wife, Katie, reside in the suburbs of Washington, DC in northern Virginia while raising their two young children, Ella (9 year RDEB) and AJ (2 years old).





**SANDRA OEHLKE, APRN CPNP-PC DCNP CCM CCRP CWOCN**  
**Skin Integrity Nurse Practitioner**  
**Childrens Hospital of Minnesota**

Sandra Oehlke has been the Skin Integrity nurse practitioner at Children's Hospitals and Clinics of Minnesota for the past 8 years. She consults on inpatients as well as outpatients. She is a pediatric nurse practitioner certified in dermatology, case management, research as well as wound ostomy and continence care. Prior to her position at Children's she graduated from Winona State University with her BSN in 1982 and did her clinical training in Rochester MN at Mayo Clinic facilities. She has worked as a pediatric nurse at Vanderbilt University Hospital and the University of Minnesota Hospital. She was a catastrophic case manager and transplant coordination for United Health Care Corporation. She has served as an adjunct clinical professor at the College of St. Catherine's AD program. In 2002, she received Master of Arts in Nursing at the College of St. Catherine. She continues to mentor students from the Emory WOCNEP, University of MN DNP program and St. Catherine's University's nurse practitioner program. She has won awards and presented posters, and lectures in her areas of specialty.



**JENNIFER PHILLIPS, MS, RD, LD, CNSC**  
**Registered Dietitian**  
**Cincinnati Children's Hospital Medical Center**

Jennifer Phillips is a Pediatric Clinical Dietitian at Cincinnati Children's Hospital Medical Center. She has 12 years of clinical pediatric experience. Jennifer is currently practicing in the Pediatric Intensive Care Unit and Epidermolysis Bullosa Center. She has been an EB Center dietitian for the last 9 years. Jennifer Phillips received her Bachelor of Science and Master of Science degrees from Marshall University. Jennifer is also a Certified Nutrition Support Clinician.

**AMY S. PALLER, MD**

**Chair, Department of Dermatology**

**Northwestern University Feinberg School of Medicine**

Amy Paller, MS, MD is the Walter J. Hamlin Chair and Professor of Dermatology, Professor of Pediatrics, and Principal Investigator of the NIH-funded Skin Disease Research Center at Northwestern University's Feinberg School of Medicine. She received her undergraduate and graduate degrees from Brown University and her medical degree from Stanford University. Dr. Paller completed residency training in both Pediatrics and Dermatology at Northwestern University and her postdoctoral research fellowship at the University of North Carolina. She served as Chief of Pediatric Dermatology at Northwestern's Children's Hospital beginning in 1988 and became Chair of Dermatology in 2004. She has been President of the Society for Pediatric Dermatology, Society for Investigative Dermatology, and Women's Dermatologic Society. Dr. Paller is an NIH-funded investigator who has served on the NIH Board of Scientific Counselors (NIAMS). Her clinical interests focus on genetic disorders of the skin, including epidermolysis bullosa, and cutaneous immunologic disorders in children. Her laboratory work includes research on the topical delivery of siRNA-nanoparticle gene suppression as therapy for skin disorders; she has shown this technology to dramatically reduce the abnormal keratin 14 in EB simplex Dowling-Meara in cultured cells. Dr. Paller has also directed the Pediatric Dermatology Clinical Trials Unit at Northwestern since the early 1990's, and has been the lead investigator on EB trials. She is the author of several leading textbooks of dermatology and is an Associate Editor of the Journal of Investigative Dermatology. Dr. Paller is currently Co-chair of the Pediatric Dermatology Research Alliance (PeDRA), Chair of the SAB of the National Eczema Association, Vice President of the International Society for Atopic Dermatitis, and serves/ has served on the Medical and Scientific Advisory Boards of the DebRA, FIRST, International Psoriasis Council, National Psoriasis Foundation, and the Pachyonychia Congenita Project



**MARK P. POPENHAGEN, PSYD**

**Psychology Director**

**PCH Complex Chronic Pain Program**

**Phoenix Children's Hospital**

Mark P. Popenhagen, PsyD, is a psychologist with clinical specialization in Pediatric Psychology, Pain Management, and Palliative Care. He received his doctoral degree at the Minnesota School of Professional Psychology in Egan, Minnesota. After completing his fellowship in Pediatric Psychology at St. Jude Children's Research Hospital in Memphis, Tennessee, he continued on as their pain psychologist and later went on to pursue further pain management and palliative care opportunities at the University of Colorado/Children's Hospital of Denver and Loyola University Medical Center/Ronald McDonald Children's Hospital in Maywood, Illinois.

Dr. Popenhagen joined the Pain Management Service and the Psychology Department at Phoenix Children's Hospital in early 2013. He serves as the head of mental health services for the Pain Management Service and focuses his efforts on inpatient and outpatient nonpharmacologic treatment of acute and chronic pain for a variety of conditions such as cancer, migraine headaches, fibromyalgia, complex regional pain syndrome, hyperalgesias, cystic fibrosis, and epidermolysis bullosa. Dr.

Popenhagen has co-authored several book chapters and journal articles on pain and is a frequent invited lecturer on the topics of pediatric pain management and coping with chronic illness.



**ANDREW TAVANI**  
**Vice President, National Sales**  
**Aristotle**

Andrew Tavani serves as Aristotle's Vice President of National Sales. Andrew has been with Aristotle for 21 years, working as a Political Technology Specialist and National Sales Manager until 2002 when he was promoted to the position of Vice President of National Sales. Over the past several years, he has advised many national, state, and local organizations, campaigns, consultants, and PAC's on the uses of voter files, micro-targeting, analytics and political technology. He has extensive knowledge in the area of electoral politics and campaign strategy, and is a member of the American Association of Political Consultants. Andrew regularly speaks on voter file and micro-targeting panels for Winning Campaigns Magazine, AAPC, and Campaign and Elections magazine. Andrew holds a Master of Arts degree in Political Science from Georgia State University and a Bachelor of Arts degree in Political Science from the University of Hartford.

He is married to his wife Shawn and they have a daughter Ellie and a son Max. Andrew and his wife Shawn have raised over \$250,000 for research and programs for debra of America for the past 10 years. They co-chair Butterfly Wishes for Ellie which raises money and awareness for Epidermolysis Bullosa on behalf of debra of America. Andrew has also run three marathons for research on behalf of the EB community. Andrew is a member of the Board of Directors for debra of America and also serves as Vice Chair on its Executive Committee.



**JAKUB TOLAR, MD, PHD**  
**Professor and Director, Stem Cell Institute**  
**University of Minnesota**

Dr. Jakub Tolar is currently a practicing physician, professor in Pediatric Blood and Marrow Transplantation, and the Director of Stem Cell Institute at the University of Minnesota. Dr. Tolar combines his passion for patient care with his laboratory research in a search for better, safer treatments. He is currently pursuing the possibility of curing genetic disorders by removing, correcting, and reintroducing patients' cells in the hope that these cells will provide an effective treatment without the negative effects of unrelated donor transplantation.



**AMY WEISMAN**  
**Pediatric Physical Therapist**  
**Lucile Packard Children's Hospital at Stanford University**

Amy has been a pediatric physical therapist for 12 years and over nine of them in the inpatient and outpatient settings with Lucile Packard Children's Hospital at Stanford. Amy joined the EB Clinic in 2014, and truly enjoys working with all the wonderful patients, their amazing families and dedicated providers in the EB Clinic. Amy is very interested in developing a physical therapy clinical practice guideline for EB patients.



**JEAN WHALEN**  
**RNIII, BSN, CPN**

**Cincinnati Children's Hospital Epidermolysis Bullosa Center**

Jean Whalen has 37 years' experience as a Pediatric Nurse at Cincinnati Children's Hospital with 20 of those years in outpatient Dermatology and Epidermolysis Bullosa. Jean works as a member of an interdisciplinary provider team including three RNs, an Advanced Practice Nurse and a Medical Assistant who provide clinical care, care management, education and support to this complex population. CCHMC's EB center treats patients from a wide geographical area who require ongoing management and care coordination during their visit, in the interim between visits, and with the patient's local providers. She provides patients and families education regarding their/ their child's skin disorder as well as wound care strategies product information, and information regarding resources and supports.

