

2014 Patient Care Conference Speakers



Kaycie Artus
Physical Therapist
Director, Camp Spirit Colorado

Kaycie Artus has worked with children with Epidermolysis Bullosa for over 30 years. She has a special place in her heart for this population. She was the physical therapist in the Children's Hospital Colorado EB Multi-specialty Clinic until her retirement in 2012. She continues to run the EB Winter Adventure Camp for Children with Recessive Dystrophic EB.



Marita Black, PT, DPT, PCS
Assistant Head Physical Therapist
Morgan Stanley Children's Hospital of New York

Marita Black is the Assistant Head Physical Therapist at Morgan Stanley Children's Hospital of New York. Along with working in the Neonatal Intensive Care Unit and treating outpatients, she also functions as the primary Physical Therapist for the Epidermolysis Bullosa (EB) clinic at Columbia University Medical Center. Marita has ten years of experience as a Physical Therapist, including more than seven years in pediatrics. She has worked with children of all ages who are diagnosed with EB and has been involved in research after bone marrow transplants. Marita is a Pediatric Certified Specialist. She received her Transitional Doctorate of Physical Therapy from Temple University, a Physical Therapy Master's degree from Boston University, and a Bachelors of Science degree in Psychobiology from Binghamton University.



John C. Browning, MD
Assistant Professor of Pediatrics and Dermatology
Baylor College of Medicine and Children's Hospital of San Antonio

Dr. John Browning is an assistant professor at Baylor College of Medicine where he is Chief of Dermatology at the Children's Hospital of San Antonio. He directs the epidermolysis bullosa clinic at that site. Dr. Browning is chair of the American Academy of Dermatology's Camp Discovery Program, which provides summer camp free of charge for children with skin disorders. He is the founding dermatologist of Camp Dermadillo (Camp Discovery - Texas) where he continues to volunteer his time every summer.



Anna L. Bruckner, MD
Associate Professor of Dermatology and Pediatrics
Co-Director, Epidermolysis Bullosa Clinic
University of Colorado School of Medicine, Children's Hospital Colorado

Dr. Bruckner is a pediatric dermatologist at Children's Hospital Colorado and a faculty member of the University of Colorado School of Medicine. She has been committed to EB since her dermatology residency. In her former position at Stanford University, she directed the monthly multidisciplinary EB clinic, and she spearheaded the formation of the EB Clinical Research Consortium (EBCRC). She co-directs the EB clinic at Children's Hospital Colorado now. Her research on EB includes bone health in EB, clinical trials, using EBCRC data to study outcomes of EB, and the cooperative development and validation of an outcomes measure for EB.

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EXHIBITORS



Mark L. Cannon, DDS
Associate Professor Feinberg School of Medicine
Northwestern University

Dr. Mark L. Cannon received his Doctorate of Dental Surgery from the University of Nebraska, 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. After completing his hospital residency and obtaining his Masters in the specialty of Pediatric Dentistry, Dr. Cannon was asked to stay as a Faculty member of Northwestern University Dental School. He has kept up teaching as clinical Associate Professor of the Feinberg School of Medicine, and is the Research Coordinator for the Pediatric Dental Program at the Ann and Robert Lurie Children's Hospital of Chicago. Dr. Cannon has been involved in research for many years, developing new products and techniques for dentistry and obtaining patents. In addition to maintaining a large private practice in the suburbs of Chicago, he has lectured at many national and international meetings, often as the keynote speaker. He has presented to a number of state and local dental societies.



Roger Cornwall, MD
Director of Hand and Upper Extremity Center
Cincinnati Children's Hospital Medical Center

Dr. Cornwall has been a full time pediatric hand surgeon for 10 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 Clinic 5 years ago. In keeping with that perspective, Dr. Cornwall's research has been the first to study patient-reported measures of hand function in EB, as well as the impact of hand surgery on those measures.

Susan K. DeClercq
Assistant United States Attorney
United States Attorney's Office - Eastern District of Michigan

Susan K. DeClercq is an Assistant United States Attorney in Detroit, Michigan specializing in civil rights cases, including fair housing, police misconduct, equal employment, and disability law. Prior to joining the U.S. Attorney's Office in

2004, Ms. DeClercq was a litigation associate at the law firm of Skadden, Arps, Slate, Meagher, & Flom, LLP in Washington, DC and served as a law clerk to U.S. District Court Judge Avern Cohn.



Ravi Elluru MD, PhD

Associate Professor

Cincinnati Children's Hospital/ Division of Pediatric Otolaryngology; University of Cincinnati College of Medicine, Department of Otolaryngology

Dr. Elluru is a pediatric otolaryngologist at Cincinnati Children's Hospital, and has been in practice for 11 years. He completed medical school at UT Southwestern Medical Center in Dallas, Texas and a residency in otolaryngology head and neck surgery at Washington University School of Medicine in St. Louis, Missouri. He completed specialized training in pediatric Otolaryngology at Cincinnati Children's Hospital. Dr. Elluru has been part of the EB Center at Cincinnati Children's Hospital for the last 5 years, helping the EB team manage ENT issues in patients with EB. Of all the different children he sees in his daily work life, he is most passionate regarding the care he deliver to children with EB. Most of the "real" learning he has had on this disease processes has come from the parents of the children he treats. Dr. Elluru consider this opportunity to talk with them one of the biggest honors in his life.



Michael K. Farrell, MD

Chief of Staff - Cincinnati Children's Hospital Medical Center

Professor of Pediatrics - University of Cincinnati College of Medicine

Cincinnati Children's Hospital Medical Center

Dr. Farrell is a Pediatric Gastroenterologist with thirty-five years of experience. He completed his pediatric residency and fellowships at Cincinnati Children's. He is Chief of Staff at Cincinnati Children's and Professor of Pediatrics at the University of Cincinnati College of Medicine. He is a member of the multi-disciplinary EB team. His interests are general gastroenterology and clinical nutrition.



Kenneth R. Goldschneider, MD, FAAP

**Director, Cincinnati Children's Pain Management Center
Cincinnati Children's Hospital Medical Center**

Kenneth Goldschneider, MD, FAAP, is professor of Clinical Anesthesia and Pediatrics and is Director of the Pain Management Center and is a leading expert in treating complex chronic pain conditions in infants, children and young adults. He can be found mostly commonly at work, having fun adventures with his family, riding on the nearby bike trail or playing music (so a meeting in Music City is OK by him!)



John Lynn Jefferies, MD, MPH, FACC, FAHA
Director, Advanced Heart Failure and Cardiomyopathy
Cincinnati Children's Hospital Medical Center

Dr. Jefferies, an associate professor pediatric cardiology and adult cardiovascular diseases, is the Director of Advanced Heart Failure / Cardiomyopathy with The Heart Institute at Cincinnati Children's Hospital Medical Center. He completed

his combined pediatric and adult cardiology training at the Baylor College of Medicine in Houston, Texas at the Texas Children's Hospital and the Texas Heart Institute. He has authored or co-authored over 100 peer-reviewed manuscripts and book chapters on cardiomyopathy, cardiovascular genetics, and adults with congenital heart disease.



Al Lane, MD
Professor of Dermatology and Pediatrics, Emeritus
Stanford University

Dr. Alfred T. Lane is a Professor of Dermatology and Pediatrics (Emeritus) at Stanford University Medical School. Al joined the faculty of Stanford University Medical School in 1990 and in 1996 he was promoted to Professor of Dermatology and Pediatrics and became Chair of the Department of Dermatology until 2010. Al's clinical practice has been focused exclusively to clinical research since 2010. Al currently works with a Stanford research team focusing on developing protein therapy, gene therapy and stem cell therapy for Epidermolysis Bullosa and other genetic skin diseases. He has been concerned about ethical issues in treating children in clinical trials. In the process of preparing for gene therapy clinical trials, he completed a Masters of Arts in Religious Studies (Spirituality) at Santa Clara University in 2004 He has tried to focus his education in the areas of moral decision-making in medical care and specifically on genetic research on children with severe life threatening diseases. He currently is the Co-Chair of the Ethics Committee of Lucile Packard Children's Hospital.



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
Occupational Therapist/Certified Hand Therapist
New York Presbyterian Hospital

Susan Maksomski has been working as an Occupational Therapist/Certified Hand Therapist at the New York Presbyterian Hospital for over 16 years. She has worked with children suffering from EB for six years in an interdisciplinary setting, as well as individually. Susan has been certified as a hand therapist for ten years specializing in upper extremity rehabilitation for adults and children. She has attended the DEBRA PCC previously and gained significant knowledge from patients and families dealing with Epidermolysis Bullosa. She 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 thirteen years. Currently, she is enrolled in the Masters 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.



Sandra Oehlke, RN, CPNP-PC, DNC, DCNP, CCM, CCRP, CWOCN
Skin Integrity Nurse Practitioner
Children's Hospitals and Clinics of Minnesota

Sandra Oehlke has been the Skin Integrity nurse practitioner at Children's Hospitals and Clinics of Minnesota for the past 6 years. Prior to her position at Children's she graduated from Winona State University with her BSN in 1982 and did her clinical years in Rochester MN. She has worked as a pediatric nurse at Vanderbilt University Hospital, the U of M, and Ridgeview Medical Center in MN. She was a catastrophic case manager and transplant coordination for UHC as well 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 then became a dermatology nurse practitioner and clinical research professional at a pediatric dermatology Clinic. When she joined Children's in 2008 she did her WOCN training at the University of Texas, M.D. Anderson Cancer Research Center (WOCNEP). Sandra is involved in several professional organizations on the regional and national level. She is married with a son and daughter in college.

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EXHIBITORS





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. [Read More.](#)



Ellen G. Pfindner, PhD
Director, EBDx Program
GeneDx Inc. Gaithersburg MD

Ellen Pfindner received her BS from Simmons College and PhD from the University of Pennsylvania. After teaching at the University of Pennsylvania, she managed the Molecular Diagnosis Laboratory at the Hospital of the University of Pennsylvania. Dr. Pfindner has established CLIA certified molecular genetic testing laboratories at the Albert Einstein Medical Center and at Thomas Jefferson University where she developed the clinical genetic testing service with Dr. Jouni Uitto. For the last 9 years Dr. Pfindner has directed the EB genetic testing program at GeneDx. Dr. Pfindner has worked EB for 19 years and is the author of numerous scientific articles on the genetics of EB.

Jennifer Phillips, MS, RD, LD
Registered Dietitian
Cincinnati Children's Hospital Medical Center

Jennifer Phillips is a Clinical Dietitian at Cincinnati Children's Hospital Medical Center. She has 10 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 7 years. Jennifer Phillips received her Bachelor of Science and Master of Science degrees from Marshall University.



Mark P. Popenhagen, PsyD
Psychology Director
PCH Complex Chronic Pain Program
Phoenix Children's Hospital

Dr. Mark Popenhagen is a psychologist with clinical specializations in Pediatric Psychology, Pain Management, and Palliative Care. He received his doctoral degree at the Minnesota School of Professional Psychology. After completing his fellowship in Pediatric Psychology at St. Jude Children's Research Hospital in Memphis, Tennessee, he continued on as their pain psychologist. He 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. He joined Phoenix Children's Hospital in 2013, and is serving as the Program Director of the Complex Chronic Pain Program.



Carol Schober-Flores, RN, BSN, CWS
Children's Hospital Colorado EB Center

Carol Schober-Flores has worked in Dermatology for 25 years and started working with patients diagnosed with EB 20 years ago. She began working with the EB population at University Hospital, but moved with Dermatology to the Children's Hospital Colorado to maintain the continuity of care for these patients. Carol has her Bachelor's of Science in Nursing and is a Clinical Wound Specialist, but finds that her true passion lies in working with individuals diagnosed with EB and their family members. She has assisted in the education of EB both through formal and informal lectures and with publications. Her job as a wound care nurse for these families is to assist them with education regarding their child's skin disorder, teaching them wound care strategies, obtaining wound supplies and assisting with home care nursing support. She is also a liaison for them when questions or problems arise.



Carrie Shotwell
Occupational Therapist
Cincinnati Children's Hospital Medical Center

Carrie Shotwell is an occupational therapist and a member of the EB Center at Cincinnati Children's Hospital. She also has experience in pediatric hand therapy, development, and feeding disorders. She has presented on the subject of the role of therapy in children with EB at the debra Patient Care conferences in Cincinnati, Orlando, and Toronto.



Kristy Steinau, PT, DPT
Physical Therapist
Cincinnati Children's Hospital Medical Center

Kristy Steinau has over seventeen years of experience as a pediatric physical therapist at Cincinnati Children's Hospital Medical Center. During this time, she has spent sixteen years treating and working with patients who have EB. She was introduced to patients with EB by providing whirlpools and dressing changes. She has been a member of the EB center team since its induction. In 2008, she presented, "Epidermolysis Bullosa and hydrotherapy, both sedated and non-sedated" for DEBRA Chile. She has also presented nationally and internationally on Physical Therapy for patients with EB in Cincinnati, Orlando, and Toronto.



Lisa Taylor, RN, WCN

Pediatric Dermatology

Lucile Packard Children's Hospital at Stanford

Lisa Taylor has been passionate about pediatric dermatology for the past nine years. She is honored to work with the amazing families and dedicated physicians who are devoted to better skin treatments for Epidermolysis Bullosa. Lisa Taylor has a background in neonatal ICU and has spent 20 years working with pediatric oncology.



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.

The 2014 PCC Kids Room

Welcome to the Kid's Rooms

Arts, Crafts, Games, Toys,
Movies, Facepainting and more!

With Special Guests:

Thursday, July 31st

11:45am - Character Meet & Greet

Friday, Aug. 1st

12:00pm - Matthew Moon

3:30pm - Animal Tales

Saturday, August 2nd

11:00am - Super Science

3:30pm - Magic Show

Open during conference sessions

Presidential Chambers A & B Governor's Chamber E

The PCC Kids Room, sponsored by Hollister Wound Care, was filled with toys, books, games, music, movies, and arts & crafts. There was something for everyone. We were joined by several Special Guests who came to give performances, including **Animal Tales**, **Super Science**, **Matthew Moon** and more.

The PCC Kids Room is located close to conference sessions, and children must be signed in and out by a parent or guardian. Children under 5 years old must be accompanied by an adult.



2012 Patient Care Conference - Kids Room



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EXHIBITORS



DEBRA 2014 PATIENT CARE CONFERENCE

July 30 – August 2, 2014

GOVERNOR'S BALLROOM NORTH

WEDNESDAY, JULY 30	
12:00pm – 4:00pm	Registration
4:00pm – 4:15pm	Welcome and Opening Remarks Brett Kopelan, Executive Director <i>debra</i> of America
4:15pm – 5:00pm	Blood and Marrow Transplantation for Severe EB Jakub Tolar, MD, PhD
5:00pm – 5:30pm	Ears, Nose and Throat Ailments in Children with Epidermolysis Bullosa Ravi Elluru, MD, PhD
5:30pm – 8:00pm	Welcome Dinner Reception
THURSDAY, JULY 31	
8:00am – 9:30am	Breakfast
10:00am – 10:35am	Overview of EB Anne W. Lucky, MD
10:35am – 11:10am	Blenderized Foods by GT Jennifer Phillips, MS, RD, LD
11:10am – 11:45am	Anemia and bone health in EB Anna L. Bruckner, MD
11:45am – 12:00pm	Break
12:00pm – 12:35pm	Effectiveness of SD-101 in Treating Blisters and Lesions in Patients with Epidermolysis Bullosa - Results of a Phase 2b/3 Randomized Placebo Controlled Trial Robert Ryan, PhD
12:35pm – 1:00pm	<i>Free Time</i>
1:00pm – 5:30pm	Family Field Trip General Jackson Showboat
6:00pm – 7:30pm	Dinner
FRIDAY, AUGUST 1	
8:00am – 9:30am	Breakfast
10:00am – 10:45am	Genetics and Genetic Testing for Epidermolysis Bullosa Ellen G. Pfindner, PhD
10:45am – 11:45am	Wound Care Panel Panel Chair: Sandra Oehlke, RN, CPNP-PC, DNC, DCNP, CCM, CCRP, CWOCN Kim Hazelbaker, RNII, BSN, CPN; Carol Schober-Flores, RN, BSN, CWS; Lisa Taylor, RN, WCN; Jean Whalen, RNIII, BSN, CPN
11:45am – 12:00pm	Sponsor Session: National Rehab
12:00pm – 12:35pm	Principles of Biomedical Ethics Related to EB: Do Risks Outweigh Possible Rewards? Al Lane, MD
12:35pm – 1:10pm	Protections Afforded by the Americans with Disabilities Act Susan K. DeClercq
1:10pm – 2:10pm	Lunch
2:10pm – 2:30pm	<i>Free Time</i>
2:30pm – 3:00pm	Step by Step Through The Clinical Trial Process Lawrence Charnas, MD, PhD
3:00pm – 3:35pm	Gene therapy and micro needle based protein therapy for RDEB M. Peter Marinkovich, MD

3:35pm – 3:50pm	Break
3:50pm – 4:25pm	Oral Care for Patients with Epidermolysis Bullosa Mark L. Cannon, DDS
4:25pm – 5:00pm	Measuring and improving patient-reported hand function in epidermolysis bullosa Roger Cornwall, MD
5:00pm – 5:30pm	<i>Group Photo</i>
5:30pm – 7:00pm	Dinner
7:30pm – 9:00pm	Movie Screening <i>Butterfly Girl</i>
SATURDAY, AUGUST 2	
8:00am – 9:30am	Breakfast
9:30am – 10:00am	Research Updates on EB Simplex Sharon A. Glick, MD
10:00am – 10:35am	Development of a genetically modified autologous dermal fibroblast for the treatment of RDEB John Maslowski
10:35am – 11:10am	Treating Pain and Itch in EB Kenneth R. Goldschneider, MD, FAAP
11:10am – 11:45pm	But I Didn't Even Touch You Yet... Coping with Anticipatory Anxiety Mark P. Popenhagen, PsyD
11:45am – 12:00pm	Sponsor Session: Hollister
12:00pm – 12:35pm	Topicals Amy S. Paller, MD
12:35pm – 1:10pm	Guts and Butts – What the EB patient needs to know Jason Frischer, MD
1:10pm – 2:10pm	Lunch
2:10pm – 3:00pm	<i>Free Time</i>
3:00pm – 3:35pm	Development of recombinant collagen 7 for the treatment of DEB Marcia Sellos-Moura, PhD
3:35pm – 4:10pm	Cardiovascular Findings in RDEB John Lynn Jefferies, MD, MPH, FACC, FAHA
4:10pm – 4:45pm	The Ins and Outs of Gastrointestinal Issues in EB Michael K. Farrell, MD
4:45pm – 5:00pm	Break
5:00pm – 5:35pm	Insurance Advocacy Panel Brett Kopelan, Joseph Murray, Andrew Tavani
5:35pm – 5:45pm	Closing Remarks Brett Kopelan, Executive Director <i>debra</i> of America
6:00pm – 7:30pm	Dinner

BREAKOUT SESSIONS – PRESIDENTIAL BOARDROOM A

FRIDAY, AUGUST 1	
3:00pm – 4:00pm	Occupational Therapy and Physical Therapy for the patient with EB Panel Chair: Kristy Steinau, PT, DPT Kaycie Artus; Marita Black, PT, DPT, PCS; Susan Maksomski, OTR/L, CHT; Carrie Shotwell
SATURDAY, AUGUST 2	
10:00am – 10:35am	Camp Options for children with Epidermolysis Bullosa Kaycie Artus; John C. Browning, MD



Dystrophic Epidermolysis Bullosa Research Association of America

DEBRA OF AMERICA TO HOST 7TH BIENNIAL PATIENT CARE CONFERENCE FOR PEOPLE WITH EPIDERMOLYSIS BULLOSA AND MEDICAL EXPERTS FROM JULY 30 TO AUGUST 2 IN NASHVILLE, TENNESSEE

Four-Day Conference For People With Rare Genetic Disorder

NEW YORK, NY (April 14, 2014) — [debra of America](http://debra.org) will be hosting the biennial 2014 [debra Patient Care Conference](http://debra.org/PCC2014) (PCC) for children and families affected by Epidermolysis Bullosa (EB), a rare, debilitating, and fatal genetic connective tissue disorder that affects 1 out of every 20,000 live births in the United States. Because their skin is so fragile, they are often known as ‘Butterfly Children.’ The conference runs July 30 to August 2, 2014 at the Gaylord Opryland Resort and Convention Center in Nashville, Tennessee.

The *debra Patient Care Conference* will bring together people with Epidermolysis Bullosa, their families, caregivers, advocates, leading medical experts, sponsors, and exhibitors from across the United States. [debra](http://debra.org) of America’s EB Nurse Educator, Geri Kelly from Cincinnati Children’s Hospital Medical Center, will be available to meet and answer questions. The conference is currently at capacity, which sets a conference record with almost 500 people registered to attend. Sponsors include; Hollister Wound Care (Platinum), Mölnlycke Health Care (Gold), National Rehab (Gold), Scioderm (Silver), Edgemark Medical Supplies (Bronze), and Ferris Mfg. Corp. (Bronze). For sponsorship opportunities, exhibitor booth/signage, and more, visit: debra.org/PCC2014

Epidermolysis Bullosa (EB) is a rare genetic connective tissue disorder in which people do not produce a vital protein which allows their skin to adhere to itself. The most prominent symptom is skin so fragile that even the slightest friction can cause severe blistering and sores inside and outside their bodies. EB afflicts both genders and all racial and ethnic backgrounds equally. That means taking off a shirt or a hug from a loved one is incredibly painful and causes the skin to peel away. There is no cure or treatment for EB; pain management, wound care, and preventative bandaging are the only options.

For many families, the *debra Patient Care Conference* is their only opportunity to hear talks and meet with members of the medical profession who have developed expertise in particular areas of EB care and research. They can also speak with bandage manufacturers and distributors about new wound care products. Attendees will enjoy a variety of activities including, the Kids Room for younger guests, interactive sessions like the Teen Roundtable and EB on Social Media, time to socialize with new and old friends, and the exciting Family Field Trip.

Brett Kopelan, [debra](http://debra.org) of America’s Executive Director and father to Rafi, a six-year-old girl with EB says, *“The record attendance we are having this year clearly demonstrates how important our Patient Care Conference is to the families that live with EB. Not only will the conference provide an opportunity to hear about the tremendous progress researchers are making toward a treatment, but it will also allow for an opportunity to fun. The one hundred plus children attending will be able to socialize and play games in one of our three fully staffed playrooms, while their parents are able to meet face to face with the professional community dedicated to caring for those with EB and finding a cure for what we call, ‘the worst disease you’ve never heard of.’”*

ABOUT DEBRA OF AMERICA

The Dystrophic Epidermolysis Bullosa Research Association of America ([debra](http://debra.org) of America) founded in 1980, is headquartered in New York City, and is the only national nonprofit that supports the research for treatments and a cure, while providing services and programs to those who suffer from Epidermolysis Bullosa (EB). debra.org

#

FOR MEDIA COVERAGE

Casey Fitzpatrick, Communications & Events Director: 212-868-1573 x105, casey@debra.org

WHAT IS EB? Epidermolysis Bullosa (EB) is a rare genetic connective tissue disorder in which children do not produce a vital protein which allows their skin to adhere to itself. Because their skin is so fragile, they are often known as ‘Butterfly Children.’ EB afflicts both genders and all racial and ethnic backgrounds equally. The most well-known and prominent manifestation of EB is blistering or tearing of the skin from any friction. That means taking off a shirt or a hug is incredibly painful and causes the skin to peel away. Imagine your child suffering from a disease where more than 70% of their body is covered in open sores and blisters.

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