

# 2012 Patient Care Conference Schedule

July 30<sup>th</sup> – August 1<sup>st</sup>, 2012

All Sessions held in the Orange Blossom Ballroom



TIME SCHEDULE	MONDAY, JULY 30
12:00pm - 4:30pm	Check-In
5:00pm - 5:30pm	Welcome and Opening Remarks Brett Kopelan, Executive Director <b>debra</b> of America
5:30pm – 5:50pm	Is Camp for You? Kaycie Artus, Danielle Malchano
5:50pm - 6:50pm	Stem Cell Transplantation for Severe Epidermolysis Bullosa Dr. John E. Wagner
7:00pm - 9:00pm	<b>Welcome Reception</b>

TIME SCHEDULE	TUESDAY, JULY 31
9:00am - 9:25am	What are the Odds? Genetic counseling for EB Dr. Amy Paller
9:25am - 9:40am	Update on Genetics and Stem Cell Therapies Dr. Angela M. Christiano
9:40am - 10:00am	Prenatal Diagnosis of Epidermolysis Bullosa Dr. Sharon A. Glick
10:00am - 10:10am	DNA Q&A with Dr. Angela M. Christiano, Dr. Sharon A. Glick, Dr. Amy Paller
10:10am - 10:30am	<b>Break</b>
10:30am - 11:25am	Surgical Management of Epidermolysis Bullosa Dr. Peter J. Stern
11:25am – 11:55am	Personalized Induced Pluripotent Stem Cells for Optimizing EB Treatment Dr. Jakub Tolar
11:55am – 12:30pm	Medical Complications of EB Worth Knowing About: Anemia and Low Bone Mass Dr. Anna Bruckner
12:30pm – 1:30 pm	<b>Lunch Sponsored by Edgepark</b>
1:30pm - 2:00pm	Anesthesia for Your Child with Epidermolysis Bullosa Dr. Eric Wittkugel
2:00pm - 2:30pm	Interdisciplinary EB Care Dr. Anne Lucky
2:30pm - 3:25pm	Physical and Occupational Therapy Panel Dr. Faye Dilgen, Marita Black, Susan Maksomski, Carrie Shotwell, John T. Smith, Moderator: Kristy Steinau
3:25pm – 4:30pm	Teen Roundtable and Ice Cream Social sponsored by <b>befriend EB</b> <i>concurrent running session for teens (14-19 yrs. old)</i>
3:25pm - 3:40pm	<b>Break</b>
3:40pm - 4:30pm	Medical and Integrative Approaches to the Management of Pain and Itch in EB Dr. John Saroyan, Dr. Traci Stein
4:30pm – 5:10pm	Common Gastrointestinal Problems in Patients with EB Dr. Michael Farrell Nutritional Challenges in EB: people with EB and clinicians working together Dr. Lynne D. Hubbard
5:10pm - 5:40pm	Oral Health and Epidermolysis Bullosa Dr. J. Timothy Wright
5:40pm – 6:10pm	A Family's Guide to Coping with Chronic Illness: What Works and What Doesn't Dr. Mark P. Popenhagen
6:30pm - 8:30pm	<b>Dinner Sponsored by Coloplast</b>

<b>TIME SCHEDULE</b>		<b>WEDNESDAY, AUGUST 1</b>	
9:00am – 9:20am	Protein Replacement Therapy for Dystrophic Epidermolysis Bullosa Dr. Mei Chen		
9:20am – 9:40am	Development of Systemic Protein Replacement Therapy for Dystrophic EB Dr. Mark de Souza		
9:40am – 9:50am	Protein Q&A with Dr. Mei Chen, Dr. Mark de Souza		
9:45am – 10:15am	Your Questions on Pain and Itch in EB with Dr. John Saroyan <i>concurrent running session open to all attendees</i>		
9:50am – 10:25am	Involvement of the Airway in Patients with EB Dr. Ravindhra Elluru		
10:25am – 10:45am	<b>Break</b>		
10:45am – 11:15am	A Consensus Approach to Wound Care Dr. Elena Pope		
11:15am – 11:45am	Cell Therapy for Epidermolysis Bullosa Dr. Alfred Lane		
11:45am – 12:15pm	Management of Esophageal Strictures in Epidermolysis Bullosa Patients Dr. Richard G. Azizkhan		
12:15pm - 1:15pm	<b>Lunch Sponsored by National Rehab</b>		
1:15pm – 1:45pm	Ocular Surface Rehabilitation in Dystrophic EB Dr. Arturo Kantor		
1:45pm – 2:15pm	Insurance Advocacy Michelle Graham		
2:15pm - 2:30pm	Closing Remarks Brett Kopelan, Executive Director debra of America		
3:30pm - 8:30pm	<b>Family Field Trip to Downtown Disney Sponsored by Hollister</b>		
4:30pm – 5:30pm	Dinner: Planet Hollywood		
6:00pm – 7:30pm	Show: Cirque du Soleil's La Nouba		

THIS AGENDA IS SUBJECT TO CHANGE.

## 2012 Patient Care Conference Speakers



**Kaycie Artus**  
Director  
Camp Spirit

Kaycie Artus has been a Physical Therapist at Children's Hospital Colorado for 30 years. She was Clinical Coordinator and specialized in Abnormal Development and Abnormal Biomechanics. She has been treating children with EB for over 30 years, starting at Denver Health prior to Children's Hospital Colorado. Kaycie has a special place in her heart for children with EB, and when Children's started a multi-specialty clinic for patients and families she became the Physical Therapy Specialist. In 2005 she started Camp Spirit, a Winter Adventure Camp for children with Recessive Dystrophic EB.



**Richard G. Azizkhan, MD, PhD**  
Co-Director of Epidermolysis Bullosa Center  
Cincinnati Children's Hospital

Dr. Richard Azizkhan is the Surgeon-in-Chief at the Cincinnati Children's Hospital Medical Center since 1998. He occupies the Lester W. Martin Chair in Pediatric Surgery and is also Professor of Surgery and Pediatrics at the University of Cincinnati, College of Medicine. He is founding Co-Director of the Cincinnati Children's Epidermolysis Bullosa Center. Dr. Azizkhan's innovations and contributions to the management of childhood cancer, neonatal anomalies, chest wall deformities, vascular malformations, EB and esophageal disorders and have led to international recognition and numerous awards. He is currently the President of the World Federation of Associations of Pediatric Surgeons. For 20 years, Dr. Azizkhan has been actively involved in International Medical Education and medical humanitarian activities throughout the world.



**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 NICU and treating outpatients, she also functions as the primary Physical Therapist for the Epidermolysis Bullosa Clinic at Columbia University Medical Center. Marita has eight years' experience as a Physical Therapist, including more than five 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.

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**Anna Bruckner, MD**  
**Associate Professor of Dermatology and Pediatrics**  
**Children's Hospital Colorado**

Dr. Anna Bruckner was born and raised in Colorado and then attended Northwestern University for her undergraduate education and medical school. She returned to Colorado for training in pediatrics and dermatology, and then completed a Pediatric Dermatology fellowship at the University of California, San Francisco. Dr. Bruckner was on the faculty in the Department of Dermatology at Stanford University from 2004-2011 before returning to Colorado. She currently directs the EB clinic at Children's Hospital Colorado. Her academic interests are improving clinical care and outcomes for patients with genetic skin disorders, particularly Epidermolysis Bullosa.



**Mei Chen, PhD**  
**Professor and Director of Research**  
**University of Southern California**

Dr. Chen obtained a Ph.D. in Cell Biology, Virology and Molecular Biology at Albert Einstein College of Medicine in New York. After postdoctoral training in Cell and Developmental Biology at Memorial Sloan-Kettering Cancer Center and Cornell University Medical College, Dr. Chen joined the faculty of the Dermatology at Northwestern University Medical School and then the University of Southern California where she is currently Professor and Director of USC Laboratories for Investigative Dermatology. Dr. Chen's research has focused on developing various therapeutic approaches including cell therapy, protein therapy and gene therapy for Dystrophic Epidermolysis Bullosa. Her research programs have been continuously supported by NIH grants for the last twenty years.



**Angela M. Christiano, PhD**  
**Professor of Dermatology and Genetics & Development**  
**Columbia University**

Dr. Angela M. Christiano obtained her BA in Biology from Rutgers University, and her MS and PhD in Microbiology and Molecular Genetics at Rutgers University/UMDNJ. Her postdoctoral training was in the Department of Dermatology at Jefferson Medical College. She joined the Faculty of Dermatology at Columbia University in 1995, and is currently the Richard and Mildred Rhodebeck Professor of Dermatology and Genetics & Development and Vice-Chair for Basic Science Research in Dermatology. She is the Director of the Center for Human Genetics and Co-Director of the Center for Skin and Mucosal Biology in the School of Dental Medicine. Dr. Christiano was instrumental in defining the molecular basis of epidermolysis bullosa. Her lab is now pursuing the use of bone marrow derived cells to treat skin disorders, and is carrying out translational research in collaboration with Dr. Mitchell Cairo at Columbia University.



**Mark de Souza, PhD**

**President and CEO**

**Lotus Tissue Repair, Inc.**

Mark is a founder of Lotus Tissue Repair and serves as its President and Chief Executive Officer. Prior to founding Lotus, he was Vice President of Business Development at Dyax Corp, a biopharmaceutical company which discovered, developed and commercializes KALBITOR®, its lead product in hereditary angioedema, an orphan genetic disease. He joined Dyax in 2001. Since 2003, he led the business development team, which was responsible for licensing Dyax's phage display technology and products, generating >\$200 million from 50+ licensing transactions. Prior to joining Dyax, he led an academic research lab at the University of California, Berkeley.



**Faye Dilgen, PT**

**Doctor of Physical Therapy, PT Supervisor**

**Harkness Center for Dance Injuries**

Dr. Dilgen is the Supervisor of Dance Physical Therapy at the Harkness Center for Dance Injuries, NYU Hospital for Joint Diseases. She received her graduate PT education and DPT from Long Island University, where she served on the faculty as Adjunct Professor of Cardiopulmonary Function. Dr. Dilgen has also served on the faculty at College of Staten Island. In addition, Dr. Dilgen is the mom of 9 year old John Hudson, who has RDEB. When John Hudson was born, she along with Cathy Twible and Michele Disco started a support group in NY for families affected by EB.



**Ravindra Elluru, MD, PhD**

**Associate Professor**

**Cincinnati Children's Hospital**

Dr. Elluru is a Pediatric Otolaryngologist at Cincinnati Children's Hospital. In addition to treating general ears, nose, and throat diseases, he specializes in the treatment of disorders of the larynx and trachea. He has worked with the EB Center at Cincinnati Children's Hospital to treat children with airway involvement. He is sincerely and passionately interested in helping children with EB and their families enjoy the best quality of life possible.



**Michael K. Farrell, MD**

**Chief of Staff**

**Cincinnati Children's Hospital**

Dr. Michael Farrell graduated from Jefferson Medical College, and served in Navy for 3 years. He completed a Residency and Fellowship at Cincinnati Children's Hospital. Currently, he is Professor of Pediatrics UC College of Medicine and Chief of Staff at Cincinnati Children's Hospital. His interests are general pediatric gastroenterology and nutritional issues in chronic disease. Dr. Farrell has worked with EB patients last ten years.



**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.



**Michelle Graham**  
**Insurance Consultant**  
**National Rehab (NR)**

Michelle Graham has served as the NR EB Advocate Team's insurance expert for six years. She has 15 years' experience navigating the complex health insurance landscape. She works tirelessly to help find answers to even the most difficult insurance questions. Michelle first learned about EB while assisting one of the first children to undergo BMT. Michelle understands the importance of having wound care supplies covered by insurance. Prior to NR, she helped people who have hemophilia obtain much needed medication through their insurance.



**Lynne D. Hubbard**  
**Specialist Dietitian in Epidermolysis Bullosa**  
**St. Thomas' Hospital, London**

Lynne Hubbard began her dietetic career in 1985 and spent 19 years caring for adults and children with burn injury at the Regional Burns Unit in Birmingham. She completed her MPhil in 2005 on causes of faltering growth in children after burn injury. Lynne Hubbard joined the adult EB team at St. Thomas' Hospital, London in 2005 and has been able to use her past experience in burn injury to work with people who have EB and their families, helping them maintain good nutrition and enjoy food as a positive part of life.



**Arturo Kantor, MD**  
**Director, Cornea Service**  
**Fundación Oftalmológica Los Andes (Andes**  
**Ophthalmological Foundation)**

Dr. Arturo Kantor is the Director of Cornea Service at Fundación Oftalmológica Los Andes (Andes Ophthalmological Foundation) in Santiago, Chile. In 1995, he received the award for Best Graduate Training Program in Ophthalmology from the Chilean Society of Ophthalmology and Alcon Laboratories. He has taught at Universidad de Chile, Universidad de los Andes, the University of Iowa, and taught graduate courses in the Chilean Society of Ophthalmology. He has presented at international congresses, both in Chile and abroad. He was the first physician to perform a successful Keratoprosthesis (replacing damaged/diseased cornea with an artificial one) in a child with EB.



**Alfred Lane, MD, MA**

**Professor of Dermatology and Pediatrics  
Stanford University Medical School.**

Dr. Alfred T. Lane is a Professor of Dermatology and Pediatrics at Stanford University Medical School. He joined the faculty in 1990, and was Chair of the Department of Dermatology from 1995 till 2010. His clinical practice is limited to pediatric dermatology. He currently works with a Stanford research team focusing on developing protein therapy, gene therapy, and stem cell therapy for EB and other genetic skin diseases. In the process of preparing for gene therapy clinical trials, he completed a Masters of Arts in Religious Studies (Spirituality) at Santa Clara University. He has tried to focus his education in the areas of moral decision-making in medical care, specifically on genetic research on children with severe life threatening diseases.



**Anne Lucky, MD**

**Pediatric Dermatologist  
Cincinnati Children's Hospital**

Dr. Anne Lucky practices Pediatric Dermatology at Cincinnati Children's Hospital and at Dermatology Associates of Cincinnati. She received her AB degree from Brown University in 1966 and MD degree from the Yale University School of Medicine in 1970. She completed training in Pediatrics at Boston Children's Hospital, Human Genetics at Yale, Endocrinology at the National Institutes of Health, and Dermatology at Yale. Anne is a member of the Society for Pediatric Dermatology and served for 10 years on the American Board of Dermatology, being past-president of both organizations. She is one of the founders and serves as a Co-Director of Cincinnati Children's Epidermolysis Bullosa Center.



**Susan Maksomski, ORT/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 14 years. She has worked with children suffering from Epidermolysis Bullosa for over four years in an interdisciplinary setting, as well as individually. Susan attended the DebRA Patient Care Conference in 2008 and 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 eleven years.



**Danielle Malchano RN, BSN, WCC**  
**Specialty Account Manager**  
**National Rehab (NR)**

Danielle Malchano has been a nurse for 29 years, and in 2010, obtained her wound care certification. She has worked at NR for 11 years, the last five as a member of NR's dedicated EB Advocate Team. She meets with physicians to make them aware of NR's ability to provide wound care products directly to their EB patients, provides wound care education to dermatology residency programs and educational programs to healthcare providers to increase their EB awareness and also volunteers at camps for people with skin conditions. Prior to NR, she served as a clinical consult for Highmark BCBS.



**Amy Paller, MD**  
**Professor and Chair of Dermatology, Professor of Pediatrics**  
**Northwestern University**

Dr. Paller is the Walter J. Hamlin Chair and Professor of Dermatology and Professor of Pediatrics at Northwestern University. She did graduate work in genetics at Brown, medical school at Stanford, postdoctoral fellowship in EB at University of N. Carolina, and residencies in Pediatrics and Dermatology at Northwestern. Her clinical work focuses on genetic skin disorders. An author of more than 350 original publications, Dr. Paller has several grants from the National Institutes of Health, including one to develop a gene therapy approach that could be applied to EB simplex. Dr. Paller is on the Scientific Advisory Board of DEBRA.

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**Elena Pope, MD, FRCPC**

**Associate Professor, University of Toronto  
Head, Dermatology, Hospital for Sick Children**

Dr. Elena Pope is an Associate Professor of Paediatrics, University of Toronto and Director, Section of Dermatology, Hospital for Sick Children. Her main areas of clinical focus are Epidermolysis Bullosa, Cutaneous T-cell lymphomas and vascular tumours. She is an academic-clinician and is involved in many aspects of teaching, educational development and evaluation.



**Mark P. Popenhagen, Psy.D.**

**Pediatric Psychologist  
Dreyer Medical Clinic**

Dr. Mark Popenhagen is a Pediatric Psychologist specializing in issues related to pain and chronic illnesses. In 2001, he earned his doctorate at Minnesota School of Professional Psychology. After completing a postdoctoral fellowship at St. Jude Children's Research Hospital, he continued as their Pain Psychologist before joining the Pediatric Pain Team at the University of Colorado Health Sciences Center. Dr. Popenhagen then co-developed the pain and palliative care teams at Loyola University Medical System/Ronald McDonald Children's Hospital before moving to his current position at Dreyer Medical Clinic in Aurora, Illinois.



**John Saroyan, MD, FAAP**

**Assistant Professor of Pediatric Pain Management and Palliative Care in Anesthesiology  
Assistant Professor of Pediatrics, College of Physicians and Surgeons  
Columbia University**

Dr. John Saroyan is an Assistant Professor of Pediatric Pain Management and Palliative Care in Anesthesiology, and Assistant Professor of Pediatrics, as well as Program Director for the Hospice and Palliative Medicine Fellowship at the Columbia University College of Physicians and Surgeons. He is Medical Director of the Pediatric Advanced Care Team at New York-Presbyterian Morgan Stanley Children's Hospital. Dr. Saroyan's clinical practice includes inpatient and outpatient settings and his patients range in age from neonates to young adults. His research has included measuring pediatric pain management knowledge of resident trainees, communication of pain and symptoms in seriously ill children, and opioid prescribing practices of pediatric clinicians. He is and has been the pain, symptom management and palliative care pediatrician for approximately thirty patients with Epidermolysis Bullosa.



**Carrie Shotwell**

**Occupational Therapist II  
Cincinnati Children's Medical Center**

Carrie Shotwell is a Pediatric Occupational Therapist, and has worked at Cincinnati Children's Medical Center for the past 7 years. She has been an Occupational Therapist in the EB Center for 4 years. In 2010, Carrie Shotwell presented "The Occupational Therapist's Role in Managing EB" to the Occupational Therapy Regional Meeting in Cincinnati. She co-presented "OT & PT for Children with EB" at the 2010 Debra Regional Meeting in Cincinnati. Carrie also co-presented "Introduction to Pediatric Splinting" to Occupational Therapy students at Xavier University, Cincinnati in 2010, 2011, and 2012.



**John T Smith, MA,OTR**  
**Occupational Therapist**  
**Mt. Sinai Hospital**

John T Smith was introduced to occupational therapy by a relative receiving OT for severe, disfiguring burns. Inspired by OT's focus on function and adaptation, John received an MA in OT from NYU in 1991. John's work focus evolved into pediatrics, development and feeding. He received certifications in NOMAS, an infant feeding assessment tool and Dr. Brazelton's NBAS, an infant neuro-behavioral assessment tool. John began working with Epidermolysis Bullosa while working at New York Presbyterian/ Morgan Stanley's Children Hospital of New York's NICU and clinic. He continued his work with EB in home care where he learned a new meaning of adaptation and function. Presently he works at Mt Sinai Hospital, New York, NY in Pediatrics. He is continually inspired by EB children and families.



**Traci Stein, PhD, MPH**  
**Clinical Health Psychologist**

Dr. Traci Stein is a clinical health psychologist who received her PhD, MS, and MPhil degrees in clinical psychology from Columbia University, and an MPH in community health education from New York University. She is fellowship-trained in pain management psychology and works with children and adults presenting with a wide range of medical and psychological issues. Dr. Stein has expertise in a variety of complementary approaches, including hypnotherapy and guided imagery, biofeedback, and mindfulness training. She is also the former director of integrative medicine at Columbia University. Dr. Stein currently has a private practice in Manhattan, is a clinical supervisor at Teachers College, Columbia University, and the Complementary & Alternative Medicine topic expert at [GoodTherapy.org](http://GoodTherapy.org).



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

Kristy Steinau has over fifteen years of experience as a pediatric physical therapist. During this time, she has spent at least fourteen years treating and working with patients who have Epidermolysis Bullosa. She has been a member of the EB Center team since its induction in 2003. In 2008, she presented on EB and hydrotherapy, both sedated and non-sedated, for DEBRA Chile. Additionally, she presented at the 2010 Patient Care Conference on general physical therapy needs. Kristy continues to work with patients who have EB and learn from them and their families.



**Peter J. Stern, MD**  
**Chairman and Professor**  
**University of Cincinnati**

Dr. Peter J. Stern received his Orthopaedic specialty education at the Harvard Combined Program and completed a hand surgery fellowship with Dr. Harold E. Kleinert. In 1992, he was appointed Chairman of the University of Cincinnati, Department of Orthopaedic Surgery, and is the Norman S. and Elizabeth C.A. Hill Professor of Orthopaedic Surgery. He has served as the President of the American Society for Surgery of the Hand in 2000, the American Board of Orthopaedic Surgery, and the American Orthopaedic Association. He has served on the Board of Trustees of the Orthopaedic Research and Education Foundation. Dr. Stern has trained 40 fellows and over 100 orthopaedic residents.



**Jakub Tolar, MD, PhD**  
**Associate Professor**  
**University of Minnesota**

Dr. Tolar received his medical education in Prague, and came from the Czech Republic in 1992 to complete his PhD in Molecular, Cellular & Developmental Biology and Genetics at the University of Minnesota. He is currently an associate professor in Pediatric Blood and Marrow Transplantation and the Director of Stem Cell/Gene Therapies at UMN. Dr. Tolar focuses on clinical protocols using hematopoietic stem cell transplant as a treatment for RDEB, JEB, Hurler syndrome, Fanconi anemia, dyskeratosis congenita, and severe aplastic anemia. He combines his passion for patient care with his laboratory research in a search for better, safer treatments.



**John Wagner, MD**  
**Director of Blood and Marrow Transplant**  
**University of Minnesota**

Dr. John Wagner is a Professor in the Department of Pediatrics, Director of the Blood and Marrow Transplant Program, and Co-Director of the Center for Translational Medicine and Scientific Director of Clinical Research for the Stem Cell Institute at the University of Minnesota. He holds two endowed chairs – Children's Cancer Research Fund/Hageboeck Family Chair in Childhood Cancer Research, and the University of Minnesota McKnight-Residential Chair. Dr. Wagner received his M.D. at Jefferson Medical College, completed his internship and residency in Pediatrics at Duke University School of Medicine in 1984, and a postdoctoral fellowship in Hematology-Oncology at the Johns Hopkins School of Medicine in 1987 where he remained until joining the faculty at the University of Minnesota in 1991. Dr. Wagner is board certified in Pediatrics and Pediatric Hematology/Oncology. He is recognized for pioneering the use of umbilical cord blood transplantation, use of embryo selection to insure an HLA matched, healthy child ('savior sibling') for couples at high risk for a genetic disease, and use of stem cell populations to repair the skin in severely affected children with EB.



**Eric Wittkugel, MD**  
**Associate Professor, Clinical Anesthesia and Pediatrics**  
**Cincinnati Children's Hospital**

Dr. Eric Wittkugel is a pediatric anesthesiologist at Cincinnati Children's Hospital where he is an anesthesiology consultant to the Epidermolysis Bullosa Center. He completed his pediatric residency at the Children's Hospital of Philadelphia, anesthesiology residency at the University of Pennsylvania and a fellowship in pediatric anesthesiology at the Children's Hospital of Philadelphia. During the last 20 years, he has cared for many children with EB undergoing a wide variety of surgical procedures. He has written and spoken widely about anesthesia for children with EB. He is delighted to discuss essential information about anesthesia for your child with EB.



**J. Timothy Wright, DDS, MS**  
**Bawden Distinguished Professor and Chair**  
**University of North Carolina**

Dr. J. Timothy Wright received his DDS degree from West Virginia University and Pediatric Dentistry training at the University of Alabama at Birmingham. Dr. Wright is the James Bawden Distinguished Professor and Chair in the Department of Pediatric Dentistry at the University of North Carolina. His research involves characterizing and treating developmental defects of teeth and bone and he has completed extensive research on the oral manifestations and treatment of Epidermolysis Bullosa. His research has been funded by the National Institutes of Health since 1987 and has over 170 scientific publications.

## **DEBRA OF AMERICA HOLDS 6<sup>th</sup> BIENNIAL PATIENT CARE CONFERENCE FOR EPIDERMOLYSIS BULLOSA PATIENTS AND MEDICAL EXPERTS FROM JULY 30 TO AUGUST 1 IN ORLANDO, FLORIDA**

### **Three Day Conference For Rare Genetic Disorder Includes Family Field Trip To Downtown Disney's Planet Hollywood And Cirque du Soleil's La Nouba**

**New York, NY (July 26, 2012)** — [DeBRA of America, Inc.](#) will be holding the biennial [DeBRA Patient Care Conference](#) (PCC) for the children and families affected by Epidermolysis Bullosa (EB) from July 30 through August 1 at the Gaylord Palms Resort and Convention Center in Orlando/Kissimmee, Florida. EB is a rare, debilitating and fatal genetic condition that affects 1 out of every 50,000 live births.

The [DeBRA](#) PCC will bring together EB patients, their families, 40 leading medical experts, sponsors and exhibitors from all over the world. This year is the PCC's largest in history, with almost 400 people in attendance. Sponsors include; *Mölnlycke Health Care, Hollister Wound Care, National Rehab, Coloplast* and *Edgepark Medical Supplies*. [DeBRA's](#) Nurse Educator, Geri Kelly from Cincinnati Children's Hospital Medical Center, will be on hand to assist and answer questions.

The most prominent symptom patients with EB live with is skin so fragile that even the slightest friction can cause severe blistering and sores; inside and outside their bodies. Caused by a mutation on a gene, EB has a long list of manifestations and secondary complications that require multiple interventions from a range of medical specialists. Every racial and ethnic group, as well as both genders, are affected equally by EB. There is no cure or treatment. Pain management, wound care and preventative bandaging are the only treatment options. [DeBRA](#) of America is the only national not-for-profit that supports research for a cure or treatments for, while providing services and programs to those who suffer from EB - *the worst disease you never heard of*.

The children with EB will enjoy many fun filled activities over the three day conference, including three separate Kids Rooms with arts and crafts, books, movies and video games, as well as a Teen Roundtable & Ice Cream Social. The Gaylord Palms Resort and Convention Center has also arranged a private meet and greet with popular DreamWorks Animation characters. On August 1, marking the last night of the PCC, [DeBRA](#) will bring the EB children and their families on the Family Field Trip to Downtown Disney for dinner at Planet Hollywood and to see Cirque du Soleil's La Nouba.

Brett Kopelan, [DeBRA's](#) Executive Director and father to Rafi, a five-year-old EB girl, says "we are looking forward to seeing all the EB families at the PCC this year. I am confident that everyone will learn a tremendous amount from the esteemed group of speakers, but more importantly it's my sincere hope that everyone goes home after the PCC having had a great time - because the kids deserve it."

#### **About [DeBRA](#) of America, Inc.**

The Dystrophic Epidermolysis Bullosa Research Association of America, Inc. ([DeBRA](#)) founded over 30 years ago is headquartered in New York City, and is the only national not-for-profit that supports the research for treatments and a cure, while providing services and programs to those who suffer from, Epidermolysis Bullosa (EB). [DeBRA's](#) [14<sup>th</sup> Annual Mats Wilander Tennis & Golf Benefit](#) will be October 1 at Quaker Ridge Golf Club in Scarsdale, NY. [www.debra.org](http://www.debra.org).

# # #

#### **For media coverage of the PCC, please contact:**

Casey Fitzpatrick, Communications & Events Director: 212-868-1573 x105, [casey@debra.org](mailto:casey@debra.org)

Brett Kopelan, Executive Director: 212-868-1573 x110, [brett@debra.org](mailto:brett@debra.org)