



HEA



2009 ABC/HEA International Exstrophy, Epispadias, and Hypospadias Conference

**August 14–16, 2009
Pittsburgh, Pennsylvania**

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Welcome



ON BEHALF OF CHILDREN'S HOSPITAL OF PITTSBURGH OF UPMC, and especially the Division of Urology, I extend a welcome to the presenters, families, volunteers, and visitors who have made possible the 2009 ABC/HEA International Exstrophy, Epispadias, and Hypospadias Conference.

This is a unique opportunity for physicians, families, and researchers to learn from one another about the medical, social, emotional, and practical aspects of living with exstrophy, epispadias, and hypospadias.

Everyone in the Children's family hopes you enjoy your visit to our new campus, which opened this May. We're very proud of our new home, which combines state-of-the-art technology with an environment dedicated to healing.

All the best,

A handwritten signature in blue ink, appearing to read 'Steven G. Docimo'. The signature is stylized and fluid, with a large initial 'S' and 'D'.

Steven G. Docimo, MD

Vice President of Medical Affairs and
Chief, Division of Urology, Children's Hospital of Pittsburgh of UPMC
Professor of Urology, University of Pittsburgh School of Medicine



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ON BEHALF OF THE ENTIRE ORGANIZING COMMITTEE, we would like to welcome you to Pittsburgh for the 2009 ABC/HEA International Exstrophy, Epispadias, and Hypospadias Conference. We have been working hard to provide you and your family with the opportunity to learn more about the bladder exstrophy, epispadias, and hypospadias conditions. You also will be able to meet and mingle with others affected by these anomalies, and the professionals who care for them.

This year our conference will span three days and include professional medical speakers, presentations from our members, as well as personal testimonies from four adults living with bladder exstrophy and one person living with hypospadias. We have planned a busy agenda with something for everyone. But even with that busy agenda, there will be plenty of time for you to ask questions of our speakers and connect with other people who can truly understand your experiences.

We also have a great dinner and dance planned for Saturday, Aug. 15, from 7 to 11 p.m. at St. Nicholas Greek Orthodox Cathedral in Pittsburgh's Oakland neighborhood, not far from the conference site at Children's Hospital of Pittsburgh of UPMC. We are looking forward to seeing you all for some good fellowship, conversation, and a whole lot of fun.

We sincerely hope that this conference will be educational and meaningful to you. This is a great opportunity to develop greater understanding, strengthen your support network, and make new friends. Always remember that you are not alone.

Sincerely,

Association for the Bladder Exstrophy Community

Barb Ward, president
Thomas Exler III, vice president
Cindy Buckley, executive director

Hypospadias & Epispadias Association

Chris Arnold, president
Franci Newhouse, vice president
William Deegan, executive director

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Agenda

Friday, Aug. 14

Conference presentations will be held beginning Friday at 5:30 p.m. at:
Children's Hospital of Pittsburgh of UPMC, 4401 Penn Avenue, Lawrenceville
in the Conference Center at the John G. Rangos Sr. Research Center

5 – 8 p.m.	Conference Registration	Conference Center Lobby
5:30 – 6 p.m.	Welcome <i>Barbara Ward, ABC; Chris Arnold, HEA</i>	Auditorium
6 – 7 p.m.	Bladder Exstrophy: Survival Guide "Live" <i>Geoffrey Neizgoda, MD; William Reiner, MD & Cast Members</i> 5–6 minute video Panel Members: <i>Alyse Barth Emily Broeren Ariel Christensen David Foulds Madeline Smith Misty Blue Foster Thomas Exler III</i>	Auditorium
6 – 7 p.m.	Dating and Sex: A Survival Guide <i>Tiger Devore, PhD</i>	Conference Rooms B & C
7 – 7:45 p.m.	Motivational Speakers Adult Patients <i>Cara Larson Wadman, RN Paul Kerensa Young</i>	Auditorium
7 – 7:45 p.m.	Hypospadias Treatment & Reconstruction Options <i>Ricardo Alvarez, MD</i>	Conference Rooms B & C

Friday, Aug. 14 (continued)

7:45 – 8:15 p.m.	Breakout Sessions <i>Parents</i> <i>Adults with Exstrophy and Hypospadias</i> <i>Teens and Kids Meet & Greet</i>	Auditorium Room A Rooms B & C
8:15 – 9 p.m.	Teens & Kids Meet & Greet	Rooms B & C
8:15 – 9 p.m.	Movie — <i>The Night Before</i> <i>James Cole, Director</i>	Auditorium



The Night Before explores the physical and emotional effects of exstrophy and epispadias. Based on the childhood experiences of writer James Cole, this short film follows three boys sharing a hospital room in the hours before surgery, showing how human compassion can conquer childhood fears. Directed by Jay Holben, the film was awarded the International Cinematographers Guild Showcase Award in 2003 and the Audience Award for Best Dramatic Short at the Valley Film Festival in 2006.

9 p.m.	Adult Meet & Greet at Del's Restaurant 4428 Liberty Avenue	Hosted by: Alice Ambrose of ABC Billy Deegan of HEA
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Saturday, Aug. 15

Children's Hospital of Pittsburgh of UPMC
in the Conference Center at the John G. Rangos Sr. Research Center

7:30 a.m. – 8 a.m.	Conference and Teens & Kids Program Registration	Main Hospital Waiting Area, Floor 3
8 – 8:15 a.m.	Welcome	Auditorium
8:15 – 8:45 a.m.	What are Hypospadias, Epispadias, Bladder Exstrophy, and Cloacal Exstrophy? <i>Francis Schneck, MD</i>	Auditorium
8:45 – 9:30 a.m.	Psychosocial Aspects of Child Development in Exstrophy <i>William Reiner, MD</i>	Auditorium
9:30 – 9:45 a.m.	Adult Bladder Exstrophy Patient From the UK <i>Margaret Lloyd</i>	Auditorium
9:30 – 9:45 a.m.	Demonstration: How to Participate in the Online Chat Rooms <i>Doug Jasper & Ed Weaver, Jr., HEA Chat Room leaders</i>	Conference Rooms B & C
9:45 – 10 a.m.	Break	
10 – 10:45 a.m.	Post-op Management Protocol for Newborn Exstrophy Children and Cloacal Parent Video <i>Bradley Kropp, MD</i>	Auditorium

10 – 11 a.m.	Informed Consent and Medical Privacy <i>Ann Tamar-Mattis, JD, & Arlene Baratz, MD</i>	Rooms B & C
10:45 – 11:30 p.m.	Preparing Your Child for Bladder Neck Reconstruction <i>John Gearhart, MD & Arlene Gerson, PhD</i>	Auditorium
11 a.m. – 1 p.m.	Lunch (<i>On your own — presentations do not stop</i>)	Cafeteria
Noon – 1 p.m.	Epispadias: Medical Issues <i>John Gearhart, MD</i>	Auditorium
1 – 2:30 p.m.	Stone Prevention/Stone Management <i>Steven Docimo, MD</i>	Auditorium
	Minimally Invasive Surgery in Urology <i>Steven Docimo, MD</i>	Auditorium
1 – 1:45 p.m.	Infections, Fistulas, and Strictures in Hypospadias Patients <i>William Kennedy, MD</i>	Rooms B & C
1:45 – 2:30 p.m.	Talking About Genital Differences <i>Tiger Devore, PhD</i>	Rooms B & C
2:30 – 2:45 p.m.	Break	
2:45 – 3:30 p.m.	Environmental Exposures: Effects on the Developing Genitourinary System <i>Richard Grady, MD</i>	Auditorium
2:45 – 3:30 p.m.	Hypospadias, Epispadias, and Exstrophy: Classroom and School Considerations <i>Alana Sullivan & Betty Engel</i>	Rooms B & C
3:30 – 4:15 p.m.	Exstrophy — Short Bowel <i>Robert Squires, MD</i>	Auditorium
	Cloacal Exstrophy — Intestinal Transplants <i>George Mazariegos, MD</i>	Auditorium
3:30 – 4:15 p.m.	Topic TBA <i>Barbara Neilson, MSW, RSW</i>	Rooms B & C
4:15 – 5:15 p.m.	Cloacal Exstrophy Patient Panel	Room A
4:15 – 5:15 p.m.	Intermittent Catheterization Techniques and Bladder Irrigations in Exstrophy Patients <i>Jake Klein, RN</i>	Rooms B & C
4:15 – 5:15 p.m.	International Reports Philippines Australia Nigeria United Kingdom Colombia	Auditorium
4 – 5 p.m.	Teens & Kids Program Pick Up	Main Hospital Waiting Area, Floor 3 See the kids agenda, page 7.
6:30 – 10 p.m.	Banquet (Dinner begins at 7 p.m.)	St. Nicholas Greek Orthodox Cathedral 419 South Dithridge St.

Sunday, Aug. 16

Children's Hospital of Pittsburgh of UPMC
in the Conference Center at the John G. Rangos Sr. Research Center

7:30 – 8 a.m.	Teens and Kids Program Drop Off	Conference Center Lobby
8 – 8:40 a.m.	Welcome and Continuation of International Reports <i>Youth Rally Committee</i> <i>Germany</i> <i>Canadian Ostomy Camp</i>	Auditorium
8:40 – 9 a.m.	Motivational Speaker <i>Ed Weaver, Jr.</i>	Auditorium
9 – 9:45 a.m.	Adult Female Patient: Cloacal Exstrophy <i>Misty Blue Foster</i>	Auditorium
9 – 9:45 a.m.	Fathers' Roles <i>Genevieve Kilman, CCLS</i>	Rooms B & C
9:45 – 10:15 a.m.	Questions and Answer Session <i>William Kennedy, MD</i>	Rooms B & C
9:45 – 10:15 a.m.	How to Talk to Your Kids About Upcoming Medical Procedures <i>Genevieve Kilman, CCLS</i>	Auditorium
10:15 – 10:30 a.m.	Break	
10:30 – 11:30 a.m.	Coping Measures for Dealing with DSDs <i>Billy Deegen, LMSW, CASAC</i>	Auditorium
10:30 – 11:30 a.m.	Female Issues <i>Discussion Group: Cara Larson Wadman RN</i>	Rooms B & C
10:30 – 11:30 a.m.	Live from Pittsburgh: Online HEA Chatroom	Room A
11:30 a.m. – noon	Breakout sessions: Adults <i>Billy Deegan & Cara Larson Wadman</i> Teens <i>Doug Jasper & Tom Exler III</i> Parents <i>Barbara Neilson & Genevieve Kilman</i>	Rooms B & C Room A Auditorium
Noon – 12:30 p.m.	Annual Membership Meetings ABC <i>Barb Ward, president</i> HEA <i>Chris Arnold, president</i>	Auditorium Rooms A, B & C
12:30 – 1 p.m.	Conference Evaluations and Summary ABC <i>Barb Ward, president</i> HEA <i>Chris Arnold, president</i>	Auditorium Rooms A, B & C
1 – 1:30 p.m.	Slide Show and Closing Remarks <i>Barb Ward & Chris Arnold</i>	Auditorium
1:30 p.m.	Teens & Kids Program Pick Up	Main Hospital Waiting Area, Floor 3

Teens and Kids Activities

Please Note:

- Any items you provide should be clearly labeled with your child's name.
- Please provide a blanket/pillow for children that require naps.
- Provide bottles, formula, diapers, and wipes if applicable.
- Children ages 1–8 and those not attending the field trip will have lunch with their parents.
Please sign your child in/out of childcare.

Friday, Aug. 14

6 – 7 p.m.	Bladder Exstrophy: Survival Guide “Live”	Auditorium
7:45 – 8:15 p.m.	Teen/Child Meet & Greet	Conference Rooms B & C
7:45 – 8:45 p.m.	Teens/Kids Meet & Greet	Conference Rooms B & C

Saturday, Aug. 15

7:30 – 8 a.m.	Teens/Kids Registration and Drop Off	Main Hospital Waiting Area, Floor 3
8 – 11:30 a.m.	Activities & Crafts for Kids in Child Care	Main Hospital Waiting Area, Floor 3
8:30 a.m. – 1:30 p.m.	Pittsburgh Zoo & PPG Aquarium Field Trip <i>(ages 9–17 — lunch provided)</i>	
11 a.m. – 1 p.m.	Lunch (kids ages 1–8 eat with parents)	Cafeteria, Main Hospital, Floor 3
12:30 – 5 p.m.	Activities & Crafts for Kids in Childcare	Main Hospital Waiting Area, Floor 3
2 – 3 p.m.	SIB Chat <i>(for ages 8–17)</i>	Main Hospital Waiting Area, Floor 3
2 – 3 p.m.	Rap with Dr Reiner <i>(for ages 7–11)</i>	Main Hospital Waiting Area, Floor 3
3:15 – 4:15 p.m.	Teen Rap with Dr Reiner <i>(for ages 12–19)</i>	Main Hospital Waiting Area, Floor 3
5 – 5:15 p.m.	Parents pick up from teens & kids programs	Main Hospital Waiting Area, Floor 3

Sunday, Aug. 16

7:45 – 8:15 a.m.	Drop off	Main Hospital Waiting Area, Floor 3
8:30 – 9:15 a.m.	Catheterizing Workshop with Jake Klein, MS, CPNP	Conference Room A
9:15 – 10:15 a.m.	Bladder Exstrophy Kids Chat with Dr Docimo <i>for ages 7–11 — discussion will focus on surgical options; parents are encouraged to attend</i>	Main Hospital Waiting Area, Floor 3
10:15 – 11:15 a.m.	Bladder Exstrophy Girl Rap with an adult	Conference Room A
10:15 – 11:15 a.m.	Exstrophy/Epispadias/Hypospadias Boy Rap with an adult	Conference Room A
11:15 – 11:45 a.m.	Film: <i>The Night Before</i> <i>(for ages 9 and up with parental permission)</i>	Main Hospital Waiting Area, Floor 3
1:30 p.m.	Pick-up from Teens & Kids Program	Main Hospital Waiting Area, Floor 3

Participants' Bios

Ricardo Alvarez, MD

Ricardo Alvarez, MD, completed his medical training in Colombia and his residency and pediatric oncology training in Costa Rica, and served an international observership in pediatric urology at Miami Children's Hospital. Dr. Alvarez is a member of the international urologic volunteers group IVUmed, and Physicians for Peace. He is the director and founder of the recently-developed Institute for Hypospadias in the Caribbean, which is committed to reducing the complication rates in hypospadias surgery and fostering research into hypospadias and related pathologies for the benefit of the patients throughout the Caribbean.

Chris Arnold

Chris Arnold is the president of Hypospadias & Epispadias Association (HEA). He lives in the beautiful temperate rainforests of northwestern British Columbia, Canada, just south of the Alaskan boarder. He is a behavioral consultant, teacher, author, and businessman whose most recent endeavor is running an old-fashioned ice cream parlor. He lives with his wife, six large exotic parrots, and two Dobermans. When not working, he and his wife love to travel to interesting places and have decided Costa Rica is the place they eventually want to be.



Cindy Buckley

Cindy Buckley is executive director of the ABC. She and her husband, David, were introduced to the world of bladder exstrophy when their son, Max, was born in 1998 with classic exstrophy. To raise funds for patients to travel for treatment, she started the Wings of Hope Program with the ABC and has flown more than 100 families from all corners of the globe to exstrophy experts. She took on the executive director position in 2006 after serving as vice president since 2000.



James Cole

James Cole was born in 1966 with cloacal exstrophy, a severe variation of exstrophy that required numerous corrective surgeries through age 16. Childhood interests in drawing and writing led to creating his first film in fifth grade. Author of many scripts and teleplays, he also has written for many print and online publications, including *The New York Times* and the *Los Angeles Times*. He is an active participant in both the Association for Bladder Exstrophy Community and adult exstrophy forums, and spoken at the ABC Conference in Milwaukee in 2003 and the HEA Conference in New York City in 2006.



Billy Deegan, LMSW, CASAC

Billy Deegan is executive director for HEA. He has had a private counseling practice in New York City, focusing on addictions and post-traumatic stress. He became involved in HEA in 2002, working to make educational and supportive information available to adults and families living with genital differences, with the goal of bringing all Disorders of Sexual Development (DSD) advocacy groups together under one large, financially solvent, and politically savvy umbrella group to ensure that DSDs be treated by multidisciplinary teams in centers of excellence.



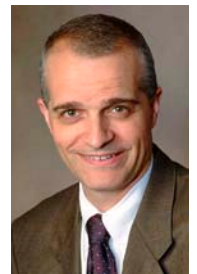
Tiger H. Devore, PhD

Tiger Devore, PhD is an intersexed person, psychologist and certified sex therapist. He studied at UCLA's Neuropsychiatric Institute with neurobiologist Roger Gorski, PhD, and served as a research intern at the Johns Hopkins Psychohormonal Research Unit. He is an activist and advocate for sexually different people, appearing as a guest expert on "Oprah" and many other news and information shows, in addition to magazine and radio interviews.



Steven G. Docimo, MD

Steven G. Docimo, MD is the vice president of medical affairs and chief medical officer at Children's Hospital of Pittsburgh of UPMC. In this capacity, he has the primary responsibility for oversight of quality improvement and patient safety and serves as the hospital's spokesperson on medical issues. Dr. Docimo is an internationally recognized leader in minimally invasive surgery. He is an experienced educator, and is professor and director of pediatric urology and vice chair of the Department of Urology at the University of Pittsburgh School of Medicine. Dr. Docimo also maintains an active clinical practice.



Before coming to Children's in 2000, Dr. Docimo spent seven years at The Johns Hopkins Hospital, where he was professor of urology and director of pediatric endourology. He earlier served in the U.S. Navy as lieutenant commander and worked for three years as an attending urologist at the Naval Medical Center in Portsmouth, Va. He has published more than 250 scientific articles, abstracts, and book chapters, as well as editing four major textbooks. Dr. Docimo received his medical degree from The Johns Hopkins University School of Medicine in 1984 and completed his residency in urology with the Harvard Program, Brigham and Women's Hospital in Boston. His education included a fellowship in pediatric urology at Johns Hopkins and a research fellowship at Children's Hospital Boston sponsored by the National Kidney Foundation and the American Foundation for Urologic Diseases.

Tom Exler III

ABC vice president Tom Exler III was born in Pittsburgh with bladder exstrophy. He has been a member of ABC since 1994 and vice president since 2006. He is an inventory coordinator in the materials management department at Children's Hospital of Pittsburgh of UPMC. In the early 1970s, his mother and surgeon founded a support group for parents of children with ostomy and intestinal or urinary diversions. He made his first speech about living with exstrophy in 1976 at the age of 10. Since then, he has given many speeches and volunteered with organizations, including as a camp counselor at the United Ostomy Association Youth Rally. He founded the United Ostomy Association Young Adult Network in 2002. He has been active in sports, including playing goalie for the Pittsburgh St. Colm Crusaders Gaelic Football Club in the early 1990s.



Richard W. Grady, MD

Richard W. Grady, MD, is an attending physician at Seattle Children's Hospital, where he is interim chief, fellowship program director and director of clinical research in the Division of Urology. He also is associate professor of urology at the University of Washington School of Medicine. Dr. Grady received his MD from the University of Michigan and completed a urology residency at the Cleveland Clinic Foundation. His training includes a research scholarship at the National Institutes of Health in cell-mediated immunity and a fellowship in pediatric urology at Seattle Children's. Dr. Grady's research and clinical research interests include urinary tract infections, complex congenital anomalies such as exstrophy, neurogenic bladder conditions, and disorders of sex differentiation. Current projects include a study of quality of life for patients with spina bifida and clinical research trials studying methods to treat urinary tract infections in children. Dr. Grady has been a visiting professor overseas, in addition to participating in medical missions to India.



Misty Blue Foster

Misty Blue Foster was born three months premature at Stanford Hospital in California. She was diagnosed at birth with Cloacal Exstrophy and Spina Bifida. At age 5, Misty was placed in foster care for 14 difficult years after her mother was incarcerated, and later died of complications related to drug addiction. She has had multiple surgeries at the Lucile Packard Children's Hospital, including failed bladder closures and failed bladder neck repair. She ultimately got the Mitroffanoff procedure with bladder augmentation using intestine at age 10. She had a spinal fusion with Harrington Rod placement at age 16 to correct her scoliosis. She also has an ilieostomy. Now 24, she is married, working as an LVN in the Cardiology Department at the Palo Alto Veterans Hospital, and studying for her BSN degree.



William Kennedy, MD

William Kennedy, MD, is the associate chief of Pediatric Urology at the Lucile Packard Children's Hospital, and associate professor at the Stanford University School of Medicine. Dr. Kennedy completed his fellowship in pediatric urology in 1997 at The Children's Hospital of Philadelphia. He has been a featured presenter at a number of HEA conferences.

Genevieve Kilman, CCLS

Genevieve Kilman is a certified child life specialist who has been at the Toronto Hospital for Sick Children Urology Clinic since 2006. After completing a child life program at Wheelock College in Boston, she interned at Boston Floating Hospital, The Children's Hospital of Philadelphia, and Boston Trauma and Recovery Center for Children. She worked for several years at the Children's Hospital of Philadelphia with urology patients recovering from hypospadias repairs.

John Gearhart, MD

John Gearhart, MD, is professor of pediatric urology and director of the James Buchanan Brady Urological Institute at The Johns Hopkins Hospital. He is a graduate of the University of Louisville School of Medicine and had post-graduate training at the University of Liverpool in England. Dr. Gearhart has been on the faculty of The Johns Hopkins Hospital for 25 years and was recently awarded an honorary fellowship in the Royal College of Surgeons in Great Britain for his contribution to pediatric surgery in the field of bladder exstrophy. He has authored more than 265 scientific papers, authored or edited two books and has been a guest professor at more than 25 institutions in the United States and abroad.



Jason “Jake” C. Klein, CPNP, ARNP

Jason “Jake” C. Klein is a certified pediatric nurse practitioner who specializes in pediatric urology, focusing on health promotion and disease prevention. He is a full-time provider for the Pediatric Urology Clinic at the Children’s Hospital at Oklahoma University Medical Center in Oklahoma City. He earned a bachelor’s of science in degree in nursing in 1992 at Oklahoma University College of Nursing and worked for the next 10 years in surgical settings. He graduated from the school’s pediatric nurse practitioner program in 2002, and has since served a fellowship with Dr. Bradley Kropp, who is also presenting at the conference. He sees patients with all conditions associated with pediatric urology, as well doing post-operative urinary reconstruction, intermittent catheterization, bladder irrigation, and bowel teaching. He also interprets and performs video urodynamic evaluations, and is pursuing further specialization in dysfunction elimination syndrome.

Bradley P. Kropp, MD

Bradley P. Kropp, MD, is chief of the Pediatric Urology Service at the Children’s Hospital of Oklahoma and professor and vice-chair of the Department of Urology at the Oklahoma University Health Sciences Center in Oklahoma City. He obtained his MD at the Medical College of Ohio in Toledo; served a urology residency at the Indiana University Department of Urology; and a pediatric urology fellowship at James Whitcomb Riley Children’s Hospital at Indiana University. He is certified as a pediatric renal transplant surgeon. Dr. Kropp is director of a basic science research laboratory housed at Presbyterian Health Foundation Research Park, working in tissue engineering and the use of intestinal submucosa in regenerative bladder augmentation. His major clinical focus is in the reconstruction of exstrophy and neurogenic bladders, as well as bladder physiology and contractility, compliance studies of the urinary bladder, tissue engineering techniques in bladder regeneration and stem cell research.



Margaret Lloyd

Margaret Lloyd was born in 1954 with classic bladder exstrophy and underwent a ureterosigmoidostomy at the age of 9 months. Living what she describes as a “fit and healthy” life, she is an assistant head teacher in a large primary school in the north east of England. She has been married for 34 years to her husband, David, and has two grown sons and two grandsons, ages 4 and 2. In addition to spending as much time as she can with her grandsons, she enjoys traveling and socializing.



George V. Mazariegos, MD

George V. Mazariegos, MD, is the director of Pediatric Transplantation at Children’s Hospital of Pittsburgh of UPMC and at the Thomas E. Starzl Transplantation Institute. He is a professor at the University of Pittsburgh School of Medicine in the departments of Surgery, Anesthesiology and Critical Care Medicine, and holds the Jamie Lee Curtis Chair in Pediatric Transplantation Surgery. Dr. Mazariegos specializes in the treatment of pediatric patients who have liver and/or intestinal disease that require transplantation. He also cares for children who develop acute liver failure and who may require specialized liver support therapies until they recover or until donor organs are available. Dr. Mazariegos directs all clinical activities for children requiring liver and/or intestine transplants. He is active in supervising operative procedure, and pre- and post-operative care, including long term follow-up. His research interests include transplantation tolerance and withdrawal of immunosuppression, as well as the development of immune monitoring tools to allow individualization of patient immunosuppression.



Barbara Neilson, MSW, RSW

Barbara Neilson, MSW, RSW is academic and clinical specialist and educational coordinator in the Department of Social Work/Division of Urology at the Hospital for Sick Children (SickKids) in Toronto, Canada, where she has worked for 19 years. Her practice concentrates on patients and families with disorders of sex development (DSD), including bladder exstrophy, cloacal exstrophy and epispadias, and she also leads online support groups for exstrophy patients and families. She is on the medical advisory board of the Intersex Society of North America and participated in the development of clinical guidelines for practitioners and families for the care of DSD patients.



Jeffrey A. Niezgod, MD

Jeffrey A. Niezgod, MD, the founder and president emeritus of the Association ABC. He is the medical director of the Center for Comprehensive Wound Care and Hyperbaric Oxygen Therapy at Aurora St. Luke’s Medical Center in Milwaukee, Wisconsin, and is president of Hyperbaric & Wound Care Associates, a physician specialty group serving southeastern Wisconsin and northern Illinois. Following the 1989 birth of their son, Geoffrey, who was born with exstrophy, Dr. Niezgod and his wife, Kathleen, established the ABC with the hope of empowering and reaching out to other families with children with exstrophy. Since its inception, the ABC has grown from a group of 70 families to several hundred, with membership spanning the world. Dr. Niezgod and his wife continue to actively participate in the ABC providing guidance and philanthropic support.



William G. Reiner, MD

William G. Reiner, MD, is professor and director of the Psychosexual Development Clinic at the University of Oklahoma Health Sciences Center in Oklahoma City and part-time faculty member at the Johns Hopkins Medical Institutions in Baltimore. His main interests are in the issues of longitudinal development in children born with major congenital birth defects of the genito-urinary system, including the bladder exstrophy-epispadias condition, anomalous genitalia, and other disorders. While his clinical and research interests focus on the psychosocial and psychosexual growth and development of these children at all ages and stages in their development into young adulthood, he also studies the long term effects on parents and siblings. He is board-certified in urology, psychiatry, and child and adolescent psychiatry. He is part of a team of investigators that includes Drs. Brad Kropp and John Gearhart, who also are speaking at the conference.



Jimmy Simons

Jimmy Simons, originally from Colorado, was born with a bladder exstrophy that prompted an immediate flight to Philadelphia for the first of many surgeries. Still not fully continent as an active adult, he chose to undergo more surgeries after college. He is now healthy after surgeries for a continent stoma and an enlarged bladder. He now works in Washington, DC as a systems engineer for Cisco Systems, plays rugby, and is an amateur comedian in the DC comic scene. Each summer, he works as a counselor to the Youth Rally and also volunteers teaching computer skills in a library.



Robert H. Squires Jr., MD

Robert H. Squires Jr., MD is clinical director of the Division of Gastroenterology and co-director of the Intestinal Care and Rehabilitation (ICARE) program at Children's Hospital of Pittsburgh of UPMC, and professor of pediatrics at the University of Pittsburgh School of Medicine. Dr. Squires is the Principal Investigator for two consortia sponsored by the National Institutes of Health (NIH), the Pediatric Acute Liver Failure Study Group and the Pediatric Intestinal Failure Consortium (PIFCon). In addition, he serves as a site investigator for two other NIH-sponsored consortia, the Biliary Atresia Research Consortium (BARC) and Cholestatic Liver Consortium (CLiC). Other research interests include medical aspects of liver and intestinal transplantation and hepatocyte transplantation.



Dr. Squires received a bachelor's degree from Austin College in Sherman, Texas and his earned his MD degree at the University of Texas Medical Branch in Galveston. Following an internship, residency, and a year as chief resident at St. Louis Children's Hospital and Washington University School of Medicine, he completed a fellowship in pediatric gastroenterology and nutrition at St. Louis Children's Hospital in 1982.

Heiko Reutter, MD

Heiko M. Reutter, MD, is the ABC liaison officer in Europe. He is a pediatric and genetic researcher and clinician at the University Hospital Bonn, Germany, concentrating on children born with the bladder exstrophy-epispadias complex. Dr. Reutter's clinical interests focus on the secondary complications occurring after exstrophy repair, such as epididymitis or uterine prolaps among exstrophy patients. He is further interested in the evaluation of the psychosocial outcome of exstrophy patients. Studying the epidemiology and genetics of the bladder-exstrophy-epispadias complex, his lab group has conducted the largest reported epidemiological survey on the bladder exstrophy epispadias complex. His group further has carried out the first genome wide linkage analysis on familial cases of the bladder exstrophy epispadias complex, yielding genetic regions likely to harbor genes causing this condition.



Alana Sullivan

Alana Sullivan is president of Bladder Exstrophy, Epispadias, Cloacal Exstrophy, Hypospadias, Australian Community (BEECHAC). Alana is a single parent of four children, including Nicholas, age 15, who was born with classic bladder exstrophy, and has supported him during more than 30 procedures in Australia, and Johns Hopkins in Baltimore. She has gained funding for his surgeries, advocated with his schools for quality facilities and to encourage dignity and respect for him as a person, and has helped set up a charity for his ongoing financial and medical needs.



Francis X. Schneck, MD

Francis X. Schneck, MD is clinical director for the Division of Pediatric Urology as well as the program director for the Pediatric Urology Residency Program at Children's Hospital of Pittsburgh of UPMC. He also is associate professor of urology at the University of Pittsburgh School of Medicine. Dr. Schneck has been a member of Children's Hospital's medical staff since 1995. He attended the Georgetown University School of Medicine, completed a urology residency at the University of Pittsburgh School of Medicine, and a pediatric urology fellowship at The Children's Hospital in Boston. His accolades have included the Basic Science Research Prize from the Section on Urology of the American Academy of Pediatrics, and perennial recognition for quality of care and patient satisfaction within the Children's Hospital community. His responsibilities include oversight of urology consultation services, surgical services, and service standards.



Anne Tamar-Mattis, JD

Anne Tamar-Mattis, JD, is the founder and executive director of Advocates for Informed Choice, the first organization in the country focusing on legal advocacy for the civil and human rights of children born with DSDs. She is a graduate of University of California Berkley Law, and has returned there as a lecturer. She is a former director of the LYRIC Youth Talkline and former program director of the San Francisco LGBT Community Center. Her partner, Suegee Tamar-Mattis, MD, is among the first physicians in the country open about being a person with a DSD.

Barb Ward

Barb Ward is president of the ABC. She has been involved with the association for seven years and has served as president since 2002. Barb is a graduate of the University of Toronto with a bachelor's degree in psychology and biology. She has been instrumental in expanding the ABC's web presence.



Paul Young

Paul Young was born in Britain in 1979 with classic bladder exstrophy. He had an epispadias repair at 18 months and an array of surgeries during his early years, including a colocystoplasty at age 5. Now 30 and recently married, he has been a comedy writer and stand-up comedian for nearly a decade in the UK, and uses his hospital experiences (and proud bellybuttonlessness) in his set. He will share hints and tips he's picked up while intermittently catheterizing for 22 years, and address practical problems and emotional dilemmas one can face in relationships, socializing, and everyday life.



The ABC and HEA would like to thank all of the speakers, facilitators, and volunteers who made possible the 2009 ABC/HEA International Exstrophy, Epispadias, and Hypospadias Conference.

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