

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

*Sponsored by Children's Hospital of Pittsburgh of UPMC  
(Draft Agenda)*

## **THURSDAY AUGUST 13, 2009**

**5:00 – 6:30PM**      **Early bird Meet & Greet**      *Holiday Inn Select*  
*For those who arrive early, meet*      *100 Lytton Avenue*  
*& Greet, Dinner on your own*      *Pittsburgh, (Oakland) PA 15213*

## **FRIDAY AUGUST 14, 2009**

**10:00 – 12:00 PM**      **HEA Board of Directors Pre-Conference Meetings**      *Wyndham Hotel*

**12:30 – 2:00 PM**      **Leadership Networking Lunch**      *Wyndham Pittsburgh University Place*  
*Hosted by: Barbara Ward, ABC President*      *3454 Forbes Ave*  
*Chris Arnold, HEA President*      *Pittsburgh (Oakland) PA 15213*

**2:30 – 4:00 PM**      **HEA Board of Directors Pre-Conference Meetings**      *Wyndham Hotel*

### **Children's Hospital of Pittsburgh of UPMC – Conference Center**

**5:00 – 8:00 PM**      **Conference Registration**      *Conference Center Lobby*

**5:30 – 6:00 PM**      **Opening Ceremonies'**      *Auditorium*

**6:00 – 7:00 PM**      **Bladder Exstrophy:  
Survival Guide "Live"**      *Auditorium*

*Geoffrey Neizgoda, William Reiner MD*  
*& Cast Members (Add one additional cast member from HEA)*  
- *5-6 minute promotional video*  
- *Brittney Godfrey Freedman (Speech 5-7 minutes)*  
- *Cameron Kohlman (Speech 5-7 minutes)*  
- *Panel Members:*      *Alyse Barth*  
                                 *Ariel Christensian*  
                                 *Madeline Smith*  
                                 *Emily Broeren*  
                                 *David Foulds*

**6:00 – 7:00 PM**      **Dating & Sex a Candid Discussion**      *Conference Room B & C*  
*Howard Devore, MD*

**7:00 – 7:45 PM**      **Motivational Speakers  
Adult Patients**      *Auditorium*  
*Cara Larson Wadman RN*  
*(Hypospadias motivation speaker TBA)*

**7:00 -7:45 PM**      **Hypospadias Treatment & Reconstruction Options**      *Conference Room B & C*  
*Ricardo Alvarez, MD*

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

*Sponsored by Children's Hospital of Pittsburgh of UPMC  
(Draft Agenda)*

|                       |  |  |
|-----------------------|--|--|
| <b>7:45 – 8:15 PM</b> | <b>Breakout Sessions</b><br><i>Parents<br/>Adults Bladder &amp; cloacal exstrophy<br/>Adults Hypospadias<br/>Teenagers</i> | <i>Auditorium<br/>Conference Room A<br/>Conference Room B &amp; C<br/>Conference Rooms E &amp; F</i> |
| <b>8:15 – 8:45 PM</b> | <b>Movie “The Night Before”</b><br><i>James Cole</i>   | <i>Auditorium</i>  |
| <b>9:00 PM - ?</b>    | <b>Adult Dinner at “Del’s Restaurant”</b><br><i>Hosted by: Ginger Keller-Ferguson of ABC<br/>&amp; Billy Deegan of HEA</i> | <i>Del’s Bar &amp; Restaurant DelPizzo<br/>4428 Liberty Avenue<br/>Pittsburgh (Bloomfield) PA</i>    |

## **SATURDAY AUGUST 15, 2009**

### **Children’s Hospital of Pittsburgh of UPMC – Conference Center**

|                         |  |                                   |
|-------------------------|--|-----------------------------------|
| <b>7:45 – 12:00 PM</b>  | <b>Conference Registration</b>   | <i>Conference Center Lobby</i>    |
| <b>7:45 – 8:00 AM</b>   | <b>Children’s Program Registration</b>   | <i>TBA</i>                        |
| <b>8:00 – 8:15 AM</b>   | <b>Morning Welcome</b>   | <i>Auditorium</i>                 |
| <b>8:15 – 8:45 AM</b>   | <b>What is Bladder Exstrophy,<br/>Epispadias &amp; Hypospadias?</b><br><i>CHP Urologist</i>                                      | <i>Auditorium</i>                 |
| <b>8:45 – 9:30 AM</b>   | <b>Psychosocial/sexual development</b><br><i>William Reiner MD</i>   | <i>Auditorium</i>                 |
| <b>9:30 – 9:45 AM</b>   | <b>Adult Patient from the UK</b><br><i>Margret Lloyd</i>   | <i>Auditorium</i>                 |
| <b>9:45 – 10:00 AM</b>  | <b>Break</b>   |                                   |
| <b>10:00- 10:45 AM</b>  | <b>Post-op Management Protocol for<br/>Newborn Exstrophy Children &amp;<br/>Cloacal Parent Video</b><br><i>Bradley Kropp, MD</i> | <i>Auditorium</i>                 |
| <b>10:00 - 11:00 AM</b> | <b>Informed Consent &amp; medical Privacy</b><br><i>Ann Tamar-Mattis &amp; Arlene Baratz MD</i>                                  | <i>Conference Rooms B &amp; C</i> |
| <b>10:45 – 11:30 PM</b> | <b>Failed Closure/Continent Procedures/<br/>Bladder Augmentation (or Topic TBA)</b><br><i>John Gearhart, MD</i>                  | <i>Auditorium</i>                 |
| <b>10:45 – 11:30 PM</b> | <b>Intermittent Catheterization</b>  |                                   |

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

*Sponsored by Children's Hospital of Pittsburgh of UPMC  
(Draft Agenda)*

|                        |   |                                     |
|------------------------|---|-------------------------------------|
|                        | <b>Techniques and Bladder Irrigations<br/>in Exstrophy Patients</b><br><i>Jake Klein, RN</i>  | <i>Conference Rooms A</i>           |
| <b>11:00 – 1:00 PM</b> | <b>LUNCH TIME (On your own)</b>   | <i>Cafeteria</i>                    |
| <b>12:00 – 1:00 PM</b> | <b>Medical Issues with Epispadias</b><br><i>TBA</i>   | <i>Conference Rooms B &amp; C</i>   |
| <b>1:00 – 2:30 PM</b>  | <b>Webcast:<br/>Stone Prevention/Stone Management</b><br><i>Michael Ost, MD</i>   | <i>Auditorium</i>                   |
|                        | <b>Minimal Invasive Surgery in Urology</b><br><i>Steven Docimo, MD</i>  | <i>Auditorium</i>                   |
| <b>1:00 – 1:45 PM</b>  | <b>Infections, Fistulas and Strictures<br/>in Hypospadias Patients</b><br><i>William Kennedy, MD</i>  | <i>Conference Rooms B &amp; C</i>   |
| <b>1:45 – 2:30 PM</b>  | <b>Talking about genital differences:<br/>Breaking the Silence</b><br><i>Howard Devore, MD</i>  | <i>Conference Rooms B &amp; C</i>   |
| <b>2:30 – 3:15 PM</b>  | <b>Environmental Exposures on the<br/>Developing Genito-urinary s\System,<br/>with a Focus on Recent Data<br/>Regarding Exstrophy.</b><br><i>Richard Grady, MD</i>      | <i>Auditorium</i>                   |
| <b>3:15 – 4:00 PM</b>  | <b>Barbara Neilson (Topic TBA)</b><br><i>Barbara Neilson</i>  | <i>Conference Rooms A,B &amp; C</i> |
| <b>3:15 – 4:00 PM</b>  | <b>Cloacal Exstrophy - Short Bowel</b><br><i>Rob Squires, MD</i>  | <i>Auditorium</i>                   |
|                        | <b>Cloacal Exstrophy – Intestinal<br/>Transplants</b><br><i>George Mazariegos, MD</i>   | <i>Auditorium</i>                   |
| <b>4:00 – 5:00 PM</b>  | <b>Cloacal Exstrophy Panel of Patients</b>  | <i>Conference Rooms A</i>           |
| <b>4:10 – 5:00 PM</b>  | <b>International Reports (5-10 minutes)</b><br>- <i>John Szua, Work in the Philippines</i><br>- <i>Australia</i><br>- <i>German Exstrophy Group</i><br>- <i>Nigeria</i> | <i>Auditorium</i>                   |

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

*Sponsored by Children's Hospital of Pittsburgh of UPMC  
(Draft Agenda)*

- UK
- Italy
- Other

|                        |                                  |  |
|------------------------|----------------------------------|--|
| <b>4:00 – 5:00 PM</b>  | <b>Children's Program Pickup</b> | <i>TBA</i>   |
| <b>6:30 - 10:00 PM</b> | <b>Banquet (7 PM Dinner)</b>     | <i>St Nicholas Greek Orthodox Cathedral<br/>Cathedral Hall<br/>419 South Dithridge St.<br/>Pittsburgh (Oakland) PA</i> |

## **SUNDAY AUGUST 16, 2009**

### **Children's Hospital of Pittsburgh of UPMC – Conference Center**

|                         |   |                                  |
|-------------------------|---|----------------------------------|
| <b>8:15 – 8:30 AM</b>   | <b>Morning Welcome</b>  | <i>Auditorium</i>                |
| <b>8:30 – 9:00 AM</b>   | <b>International Reports</b> <ul style="list-style-type: none"><li>- Youth Rally Committee, April Gimlen (20 minutes)</li><li>- Germany</li><li>- Canadian Ostomy Camp, Neilson (5 Minutes)</li></ul> | <i>Auditorium</i>                |
| <b>9:15 – 9:45 AM</b>   | <b>Adult Female Patient:<br/>Cloacal Exstrophy</b><br><i>Misty Blue Foster</i>  | <i>Auditorium</i>                |
| <b>9:00 – 9:45 AM</b>   | <b>School Issues &amp; Strategies</b><br><i>Alana Sullivan, Christine Sylva of BEECHAC</i>  | <i>Conference Room B &amp; C</i> |
| <b>9:00 – 9:45 AM</b>   | <b>Father's Rolls</b><br><i>Genevieve Kilman</i>  | <i>Conference Room A</i>         |
| <b>9:45 - 10:15 AM</b>  | <b>Questions with Dr Kennedy?</b><br><i>William Kennedy, MD</i>   | <i>Conference Room B &amp; C</i> |
| <b>9:45 – 10:15 AM</b>  | <b>How to talk to your kids about<br/>Upcoming Medical Procedures</b><br><i>Child Specialist from Toronto Sick Kids</i>   | <i>Auditorium</i>                |
| <b>10:30 – 11:25 AM</b> | <b>Coping Measures for Dealing with<br/>DSD</b><br><i>Billy Deagen, LSW</i>   | <i>Auditorium</i>                |
| <b>10:30 – 11:25 AM</b> | <b>Female Fertility &amp; other issues</b><br><i>Discussion Group, Cara Larson Wadman RN &amp; MD???</i>  | <i>Conference Room A</i>         |

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

*Sponsored by Children's Hospital of Pittsburgh of UPMC  
(Draft Agenda)*

|                         |   |   |
|-------------------------|---|---|
| <b>11:30 - 12:00 PM</b> | <b>Breakout sessions:</b><br><b>Adults:</b> <i>TBA</i><br><b>Teens:</b> <i>William Reiner, MD</i><br><b>Parents:</b> <i>TBA</i> | <i>Conference Room B &amp; C<br/>Conference Room A<br/>Auditorium</i> |
| <b>12:05 - 12:30 PM</b> | <b>Annual Meetings:</b><br><b>ABC:</b> <i>Barb Ward, President</i><br><b>HEA:</b> <i>Chris Arnold, President</i>                | <i>Auditorium<br/>Conference Room A, B &amp; C</i>                    |
| <b>12:30 - 1:00 PM</b>  | <b>Conference Evaluations</b><br><b>ABC:</b> <i>Barb Ward, President</i><br><b>HEA:</b> <i>Chris Arnold, President</i>          | <i>Auditorium<br/>Conference Room A, B &amp; C</i>                    |
| <b>1:00 - 1:30 PM</b>   | <b>Closing Ceremonies</b>   | <i>Auditorium</i>   |