INTERNATIONAL EXSTROPHY CONFERENCE
SUMMER 2015 | SEATTLE

Saturday, August 1
7am to 5pm

CONFERENCE PROGRAM
Welcome

ON BEHALF OF SEATTLE CHILDREN’S HOSPITAL, and especially the Division of Urology, I extend a very warm welcome to the presenters, families, volunteers, and sponsors who have made possible the 2015 International Exstrophy Conference.

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

We are grateful for your participation and hope you look forward to an educational, fun, and inspiring day.

All the best,

PAUL A. MERGUERIAN, MD, MS
Division Chief, Urology; The Dr. Michael Mithcell Endowed Chair in Pediatric Urology
ON BEHALF OF A-BE-C AND THE ENTIRE ORGANIZING COMMITTEE, welcome to Seattle for the 2015 International Exstrophy Conference. We have been working hard to provide you and your family with the opportunity to learn more about bladder exstrophy. You also will be able to meet and mingle with others affected by these anomalies, and the professionals who care for them.

This conference will feature professional medical speakers, presentations from the bladder exstrophy community, a personal testimonial from a young adult living with bladder exstrophy and stories and tips from three parents of children with bladder exstrophy.

We have planned a busy agenda with something for everyone. But there will also be plenty of time for you to ask questions of our speakers and connect with other people who can truly understand your experiences. We have a great afternoon planned at Meridian Park, not far from the conference site at Seattle Children’s Hospital. We are looking forward to seeing you all for some good fellowship, conversation, and a whole lot of fun.

We would like to thank the staff at Children’s Hospital, the many volunteers who have donated their time, and the individual donors and sponsors who generously contributed to help make this conference a success.

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,

PAMELA BLOCK
President & Executive Director, Association for the Bladder Exstrophy Community

Conference Committee

- Paul A. Merguerian, MD, MS - Division Chief, Urology; The Dr. Michael Mitchell Endowed Chair in Pediatric Urology, Seattle Children’s
- Richard Grady, M.D. - Director, Pediatric Urology Fellowship Seattle Children’s & A-BE-C’s Medical Advisory Board Chair
- Pamela Block, Executive Director, Association for the Bladder Exstrophy Community
- Ginger Thomas, CPRN – Bladder Exstrophy Coordinator, Seattle Children’s
- De ‘Angela Chase, Administrative Assistant III | Urology Seattle Children's
- Megan Dew, Administrative Assistant, Urology & General Surgery | Surgical Services, Seattle Children's Hospital
- Leah Hullinger, Parent, Advocate, Fundraiser, Mick’s Art Show
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<tr>
<th>Time</th>
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<td>7:00 - 7:45 am</td>
<td>Registration and Continental Breakfast</td>
<td>Hosted by Coloplast</td>
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<td>8:00 – 8:10 am</td>
<td>Welcome and A-BE-C</td>
<td>Pamela Block</td>
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<td>Executive Director, Association for the Bladder Exstrophy Community</td>
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<td>8:10 – 8:30 am</td>
<td>Lessons Learned &amp; Improvements in the Treatment of Bladder Exstrophy</td>
<td>Michael Mitchell, MD</td>
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<td>Pediatric Urologist, Children's Hospital of Wisconsin</td>
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<td>8:30 – 8:45 am</td>
<td>The Role of Child Life in Exstrophy Patients</td>
<td>Lauren Peeples, MBA, CCLS, CIMI</td>
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<td>8:45 - 9:00 am</td>
<td>Understanding Sexual Function of Patients with Bladder Exstrophy</td>
<td>Dr. William Reiner, MD</td>
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<td>Director of the Psychosexual Development Clinic, University of Oklahoma's Department of Urology</td>
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<td>9:00 – 9:10 am</td>
<td>A Teenagers View of Bladder Exstrophy</td>
<td>Rachel Fisher</td>
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<td>9:10 – 9:30 am</td>
<td>Sexuality and Fertility in Exstrophy Patients</td>
<td>Barry Duel, MD, FAAP, FACS</td>
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<td>Director, Division of Pediatric Urology, SSM Cardinal Glennon Children's Medical Center</td>
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<td>9:30 - 9:50 am</td>
<td>Patient and Family Centered Care</td>
<td>Richard Grady, MD</td>
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<td>Director, Division of Urology's Pediatric Fellowship Program</td>
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<td>Seattle Children's Hospital</td>
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<td>9:50 - 10:00 am</td>
<td>Parent Roundtable BREAK</td>
<td>Amber, Robin, Amy, Tom</td>
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<td>10:10 – 10:40 am</td>
<td>Parent/Patient Roundtable</td>
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<td>10:40 – 11:40 am</td>
<td>Panel Discussion</td>
<td>Pramod Reddy, MD</td>
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<td>Initial Evaluation and management</td>
<td>Director of the Division of Pediatric Urology Cincinnati Children's</td>
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<td>Paul Merguerian, MD, MS</td>
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<td>Long-term Outcomes, Continence and Renal Function</td>
<td>Division Chief of Urology, Seattle Children's</td>
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<td>Continent Diversion, Types and Outcomes</td>
<td>Richard Grady, MD</td>
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<td>Director, Division of Urology's Pediatric Fellowship Program, Seattle Children's Hospital</td>
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<td>11:40 am – 12:00 pm</td>
<td>International Exstrophy – A Story of Hope</td>
<td>Richard Grady, MD &amp; International Team</td>
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<td>12:00 – 12:15 pm</td>
<td>Looking Forward and Closing Remarks</td>
<td>Pamela Block</td>
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<td>12:30 pm</td>
<td>Depart to Meridian Park</td>
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Sessions for Kids and Teens

Morning Kids and Teens Sessions

- Childcare will be available for the younger children, ages 6 months – 7 years, will be held in the childcare room and will be staffed by from 7:45 – 12:30. Parents will need to bring ID and check their children in and out. Parents, also be sure to bring your cell phone and provide the number so the care providers can reach you if needed. Please bring plenty of diapers, pull-ups, bottles, formula and other needed supplies for your child as appropriate. **Note: if your child caths and needs assistance, the care providers are not able to assist.**

- For children ages 8-11, we will have a Game Truck located outside the River Entrance. Children will need to be signed in and out.

- Dr. Reiner will be facilitating a special breakout session for children ages 9-17 with bladder extrophy. Children will gather in the main auditorium and will leave with Dr. Reiner after his presentation in the main auditorium.

Afternoon Sessions

- Dr Reiner would like to invite families with children between the ages of 6-9 to join him in the park for an informal meet and great and joint parent/child session.

Afternoon Activities - 1-5pm

The conference continues in the afternoon at Meridian Park, just a short drive from Children’s. All speakers encourage you to attend and bring your questions and they will continue the topic discussions in this informal setting. Also, plan to enjoy a complimentary catered lunch while you’re there.

Directions to Meridian Park – 4649 Sunnyside Avenue North, Seattle, WA 98103

- From Seattle Children’s Hospital Parking lot 1, exit lot and take a right.
- Turn left at the light onto Sandpoint Way NE/WA-513
- Continue to follow WA-513
- Stay straight to go onto NE 45th Street
- Turn right onto Meridian Avenue
- Meridian Park will be on your right
- Please find street parking along Meridian Avenue. Wheelchair access is available at both Meridian Park entrances.
Speaker Bios

**Pamela Block** As a mother by choice of a child with exstrophy, Pamela Block has a passion for and an understanding of this rare medical condition. In 2009, Pamela adopted her 4-year-old daughter from China who was born with bladder exstrophy. Since bringing her daughter home, Pamela has dealt with the many hurdles of raising a child with exstrophy including her daughter’s complete primary repair after a late and failed initial closure while in a Chinese orphanage.

As President and Executive Director of A-BE-C, Pamela’s leadership goals are to forge partnerships with patients, their families, and the medical community to enhance the care and clinical outcomes, provide value and improve the quality of life for the children born with this condition. Together we will serve as advocates for the children with bladder exstrophy throughout the world.

Pamela brings to A-BE-C over twenty years of business and nonprofit experience, including significant roles in management, program and organizational development, strategic and business planning and business development. Before joining A-BE-C, she served as Vice President of the consulting division of Comprehensive Health Education Foundation (C.H.E.F.) that helps health and human service nonprofits become stronger and more sustainable in their efforts to eliminate health inequities. She has been actively involved as a volunteer with nonprofits, most notably for her ongoing fundraising and advocacy efforts on behalf of Chinese orphans living with special needs. Pamela attended the University of Tennessee as a business major and received her Certificate in Nonprofit Management from Duke University.

**Dr. Barry Duel** is Director of Pediatric Urology at Cardinal Glennon Children’s Hospital and St. Louis University, where he moved in 2013. Prior to that, he was an Associate Professor of Urology and Pediatrics at the University of California, Irvine, followed by five years in practice at Cedar-Sinai in Los Angeles.

Dr. Duel has conducted innovative research in pediatric incontinence and urologic reconstruction, which has been published in numerous professional journals and presented widely nationally and internationally. Dr. Duel's areas of clinical interest include robotic and minimally invasive surgery and the treatment of children with urinary incontinence.

Dr. Duel is a Fellow of both the American College of Surgeons and the American Academy of Pediatrics, and is board certified in Urology and has earned a Certificate of Added Qualification in Pediatric Urology from the American Board of Urology. He is a member of numerous professional and academic organizations, including the Society for Fetal Urology and the Society for Pediatric Urology.

After receiving his medical degree from Harvard Medical School in Boston, Massachusetts, he completed a residency in urologic surgery at the Harvard Program in Urology, which included extensive research and clinical experience at Boston Children's Hospital. Dr. Duel went on to complete a pediatric urology fellowship at Children's Hospital of Michigan in Detroit before joining the teaching faculty at the University of California, Irvine.
Tom Exler III was born in Pittsburgh with bladder exstrophy. He has been an active member of A-BE-C since 1994. 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.

Tom is the current Vice President of the Association for the Bladder Exstrophy Community and Chairman and Founder of Courage to Shine. He is also the Board Secretary of Jamie Dream Team which is based in Pittsburgh PA. He currently lives in Pittsburgh, PA and works at Children's Hospital of Pittsburgh of UPMC. This year he received the 2015 Jefferson Award for Public Service, and has been nominate for the Global Genes 2015 RARE Champion of Hope - Advocacy. In 2012 he was honor was the UroMed Hometown Heroes."

Rachel Fisher was born in eastern NC in 1992 with classic bladder exstrophy. After an initial failed closure she underwent a successful closure followed by bladder neck reconstruction but developed blockages in both ureters by age four. Consequently she underwent a surgery to create a neobladder and Mitrofanoff resulting in an abdominal continent catheterizable stoma.

Rachel played competitive soccer in high school and recently graduated from UNCW with a psychology degree. She is now residing in Houston for a yearlong internship and would like to bring the Johns Hopkins annual picnic concept, which was an invaluable resource in her life, to the Houston BE community. She is also very interested in the international efforts of the BE community.

Dr. Richard Grady is a pediatric urologist and a world-renowned expert in pediatric bladder reconstruction at Seattle Children’s Hospital. For the past seven years, Dr. Richard Grady has brought together a world class team of physicians from the United States and India to better the lives of exstrophy patients in Gujarat. Each year, Dr. Grady and his colleague, Dr. Shukla assemble their team of international experts in bladder exstrophy in the cities Nadiad and Ahmedabad to conduct over a dozen major reconstructive exstrophy surgeries on children over an eight-day period. In the developing world, unrepaired bladder exstrophy leave these children and young adults shunned and at the risk of further severe medical conditions. By performing these much needed surgeries, the international exstrophy team have not only saved lives, they have transformed them.

In 2010, The US House of Representatives commended Dr. Richard Grady and Dr. Aseem Shukla for their medical work in India. In addition to his annual trips to India, Dr. Grady has also travelled to the Gaza strip 8 times to perform surgeries on patients with bladder exstrophy and other complex urological conditions.

Dr. Grady is the Director, Pediatric Urology Fellowship and has built a Center of Excellence for bladder exstrophy at Seattle Children’s. His program is known worldwide for their skill and research in caring for children with this condition. He has received many awards including Seattle Top Doctor 2014, 2013, 2012 and 2010 and US News Top Doctor in 2012.
Dr. Paul Merguerian is the Division Chief of Urology at Seattle Children’s and Professor of Urology at the University of Washington.

Dr. Merguerian is an accomplished scholar, a committed teacher and mentor, and surgeon. His area of academic focus has been on complex reconstruction, transplantation, and more recently safety, efficiency, and cost within the field of pediatric urology.

He received his medical degree from Hadassah Medical School in Jerusalem and completed his Residency in Urology at the University of Rochester. He then went on to complete a Fellowship in Pediatric Urology at the Hospital for Sick Children in Toronto. He received his Masters in Science from the Dartmouth Institute of Health Policy and Clinical Practice, and has received Lean Six Sigma training at the Dartmouth School of Engineering.

Dr. Merguerian has held appointments at Stanford, the University of Toronto, and most recently at Dartmouth where he was the director of the Children’s Hospital at Dartmouth. In addition to his extensive work in process improvement and quality assurance, Dr. Merguerian has served as a key faculty mentor for Pediatric Urology Fellows at the University of Washington; as a clinic teacher and preceptor for Urology residents; and as a supervisor/teacher for residents during their research year. Urology, disorders of sex development, developmental pediatrics, reconstructive pelvic medicine. In addition, Dr. Merguerian has volunteered his time treating children with extrophy in India and Armenia.

Dr. Michael E. Mitchell is a specialist in pediatric urology at the Children’s Hospital of Wisconsin. His work focuses on issues related to pediatric urology, including urethral valves, bladder dysfunction, bladder extrophy, and urologic reconstruction. He is known internationally throughout the urology community for his efforts to manage children with extrophy and has written or co-written numerous articles on this topic.

Dr. Mitchell received his undergraduate degree from Princeton University, his medical degree from Harvard Medical School, and surgical, urology, and research training at Peter Bent Brigham Hospital, Boston Children’s Hospital, Massachusetts General Hospital, and the National Institute of Child Health and Development.

When Dr. Mitchell was Chief of Pediatric Urology at Riley Children’s Hospital in Indianapolis, he developed a Division of Pediatric Urology and a strong interest in urologic reconstruction, particularly the management of children with urethral valves and bladder extrophy. He has developed surgical techniques to correct the most complex urologic malformations in children and has pioneered surgical techniques for patients diagnosed with bladder extrophy and the complete primary repair of bladder extrophy. Dr. Mitchell has furthered understanding of the pathophysiology of the bladder of children with posterior urethral valves and coined the term “valve bladder.” He emphasized the important role of early bladder cycling and the primary valve ablation approach for almost all patients with valves.

Lauren Peeples, MBA, CCLS, CIMI, obtained her bachelor’s degree in family studies and human development from the University of Arizona and her master’s degree in Business Administration with an emphasis on Health Systems Management from Grand Canyon University. Currently she works a child life specialist at Seattle Children’s, providing care to patients and families in the Emergency Department.

She has over 10 years of experience in the field of Child Life, having previously worked at Phoenix Children’s Hospital, Nationwide Children's Hospital (formerly Columbus Children’s) and held part time and per diem roles at two community based hospitals in Phoenix. Her primary areas of interest are optimizing procedural pain management and developing educational tools that utilize mobile technology to teach patients and families in the hospital.
Dr. Pramod P. Reddy is Director of the Division of Pediatric Urology at Cincinnati Children’s Hospital and Professor of Clinical Surgery at the University of Cincinnati’s College of Medicine.

In addition to maintaining a busy clinical practice, Dr. Reddy conducts research into the normal development of the urinary bladder and its innervation, the role of tissue-engineered substitutes for bladder replacement, and bladder dysfunction.

Dr. Reddy received his medical degree from Nagarjuna University in Guntur, India and completed a residency at Albany, New York’s Albany Medical Center, and a fellowship at Toronto’s Hospital for Sick Children. He has been recognized with numerous awards for his contributions to pediatric urology. He was named both a Pfizer Urological Scholar and an American Urological Association Scholar. As a member of the Fetal Care Center of Cincinnati, he is actively involved in managing congenital conditions that involve the genitourinary tract of the fetus; his involvement ranges from diagnosis and counseling to in-utero intervention.

Dr. Reddy is committed to advancing the science to improve the outcomes of prenatally diagnosed urological conditions, while at the same time ensuring that the ethical considerations keep pace with the technological and medical advances.

Dr. William G. Reiner is Professor of Pediatric Urology, Adjunct Professor of Child and Adolescent Psychiatry, and Director of the Psychosexual Development Clinic at the University of Oklahoma’s Department of Urology. His research interests span the areas of child development in children and adolescents with classical bladder extrophy, cloacal extrophy, hypospadias, absence of female or male genitals, and other major pediatric genital birth defects.

Dr. Reiner received his medical degree from the University of California-Irvine. He completed his residency at Johns Hopkins Hospital. He is board-certified from the American Board of Psychiatry and Neurology, Child and Adolescent Psychiatry; the American Board of Urology; and the National Board of Medical Examiners.

Dr. Reiner’s research has been focused in the following areas:

- Gender identity
- The impact of genital function and appearance on children’s development as well as on their parents
- Urinary incontinence and function and its impact on the children’s development as well as on their parents
- Anxiety about peer and social relations, sexual development, and romantic relationships
- The effect of genital and urinary tract surgeries on children’s development and parent effectiveness
Parent Panelists – Background

Robin
My name is Robin Kimbro. I live in Moses Lake, in Central Washington with my husband of almost 25 years and our 3 children. Our journey began just over 15 years ago when our son, Spencer, was diagnosed with Spina Bifida during our 5-month ultrasound. We were sent to see an OB specialist in Spokane and after almost 3 months of every two-week appointments, to monitor growth and his stress level, Spencer arrived on June 21, 2000, 7 ½ weeks early, by C-section to avoid damaging any tumors/growths. Spokane doctors looked over Spencer and decided they could “try” to “fix” him. Lucky for us, a Pediatric Urologist in Spokane looked at Spencer and told us she knew what he had and knew who could help us. The next morning Spencer was flown across the state to Seattle Children’s Hospital to see Dr. Mitchell and Dr. Grady. He was diagnosed with Bladder Exstrophy, atypical Cloacal Exstrophy, Spina Bifida, Congenital Scoliosis, Omphalocele, paraplegia and skeletal deformities.

Over the last 15 years Spencer has had 20+ surgeries and procedures. He has endured Myelocystocele repair, complete primary closure with the creation of his colostomy, bladder closure at 6 months, hernia repair, removal of his large intestines in 2010 with creation of ileostomy and many others. Dr. Grady and I had many talks about the next steps to gaining continence, and in his wisdom he told me that Spencer would let us know when he was ready. We tried several deflux injections, which worked for only a short time. In 2012 Spencer decided that he was ready to give up the pull-ups and try cathing. After consulting with Dr. Grady, Spencer decided on another surgery, Mitrofanoff and bladder augmentation using his stomach tissue. The surgery went without any problems and follow-up care was minimal. He has been doing great maintaining his Mitrofanoff. He is independently cathing and lives a typical teenage life.

Through all of these medical procedures and surgeries, our family has refused to stop being active. We continue to camp, hunt and fish. Spencer has always wanted to participate in sports and wasn’t about to allow a wheelchair to slow him down. We found a parasport team in Spokane, ParaSport Spokane, where Spencer could play Wheelchair basketball and Wheelchair racing. Spencer has excelled in these activities. His junior basketball team has gone to nationals the last four years and is currently ranked 11th in the nation. Spencer participated in his high school cross country and track teams. This last spring Spencer won state in all four of his track events, the 100m, 200m, 400m and 800m. He went on to national and international track and field events. He placed second in two of his races at the US Paralympic National Track and Field Championship in June. He represented the United States junior track team and won 4 gold medals at the International Wheelchair and Ambulatory sports meet in the Netherlands in July. The most important achievement to this point for Spencer is fulfilling his goal of making the U.S. Paralympic Track and Field Team. He will be representing the United States in Toronto for the Para PanAm games August 7-15, 2015. Go TEAM USA! This has been an amazing journey.

Amber
My name is Amber Metcalfe. I live about an hour north of Seattle in the town of Arlington with my husband and four children.

My story with BE started about thirteen years ago when I was pregnant with my oldest son Aaron. I enjoyed a blissful pregnancy until my seventh month of pregnancy. I was ordered a routine ultrasound because I was measuring a bit big for where I was in my pregnancy and my midwife wanted to check out dates and make sure everything looked okay. I remember being so excited for this appointment. I was going to get a first peak at my baby, and my husband and I had decided that we wanted to find out the gender at that time too. I remember being in awe as the screen showed his brain and his face and his profile. Everything was doing well until the tech traveled further down his body to start capturing images of his abdomen. The room suddenly went quiet and the look of concern could not be hidden. I remember asking if everything was ok, only to be told that he needed to talk to someone outside our room, and would be back shortly. My heart sank. I knew something was terribly
wrong. The radiologist came in to confirm that there was indeed something not right but they couldn’t tell me exactly what it was. They needed us to be transferred to a larger hospital for more in-depth ultrasounds and consultations. It was an agonizing weekend waiting for those next appointments. We finally met with a set of doctors who did indeed diagnosis my son with BE, but the text books that they pulled out were very outdated, and we were presented with a very archaic approach to dealing with my baby’s abnormalities. We were heart broken and left that appointment with little hope of a positive outcome.

Two weeks later a friend of a friend was doing some networking for us and happened upon the name of Dr Mitchell. We couldn’t believe that a leading world specialist in BE was so close right in Seattle. We immediately set up an appointment. I remember walking into the room and being met with such gentleness and most of all, hope. Dr Mitchell was so calm in explaining everything to us, and reassured us that everything was going to be okay. There was such a huge difference in speaking with someone who knew what they were talking about. He put our minds at ease, and he told me to enjoy the last month of my pregnancy, and he would see us after our baby was born.

Four weeks later I was induced at Swedish Hospital and two days after birth Aaron underwent a twelve-hour surgery to complete his osteotomy and primary closure. He healed up well and was an easy-going baby. We didn’t have another surgery until he was nine months old and at that time we went in to re-implant the ureters.

I remember Ginger telling me to enjoy the baby years because those were the golden years with BE. I didn’t understand at the time what she meant but as the years have gone by I now understand her all too well.

When Aaron was four our care transferred over to Dr. Grady.

Aaron went into preschool wearing pull-ups. It wasn’t a big deal at the time, but as he went into kindergarten and first grade it became a bigger issue. We tried deflux and botox injections several times but didn’t find success with either. Aaron was becoming frustrated and aware of the difference with his peers, and after encountering teasing he was becoming even more self-conscious about the odor that came with wearing pull ups full time. We knew if was time to do something bigger to attempt to be dry. At age seven we went in for a mitt surgery. The initial healing went well, but it was very disappointing to not achieve continence with the surgery. We were then stuck with the same leaking as before but on top of that we were also having to cath. This was the beginning of some really rough years for Aaron. He had a very sensitive bladder and cathing caused a lot of nerve pain and bladder spasms. It was a lot to handle at his age, and he really wasn’t handling it well. We tried many surgical procedures trying to correct things, only to be met with reoccurring failure. Aaron was dealing with intense anxiety and was acting out in some really concerning ways. Coming to the hospital triggered panic attacks, and we even have experienced him running away from the hospital. It was a really scary time for us, and we were starting to feel kind of desperate. We also had entered a two year cycle of dealing with monthly kidney infections. Aaron had lost a lot of weight and was not in a healthy place. He was sick almost all the time and missed out on a lot of fun events due to illness and hospital stays.

We finally decided that cathing was causing too much trauma for him and his kidneys were under too much pressure. We opted to go the route of a full time urostomy bag. In March of 2014 he had the bladder augmentation and his stoma was opened wider to allow the urine flow to be much freer, giving his kidneys a break. We had one-year infection free, and during that time Aaron’s overall health improved greatly and his spirits started to rebound. We found a really good therapist that he sees on a regular basis, and he is able to handle stress so much better now than a couple years ago. It is so rewarding to me to see his confidence growing and see him enjoying life again. The urostomy bags come with their own set of challenges but Aaron is happy again, and that is really what matters most. Aaron is an amazing kid and I am so proud of him.

**Amy**

We live in a suburb of Kansas City. My pregnancy with our third child was uncomplicated. My husband, our 2 sons and I anxiously awaited the arrival of our baby girl! Prenatal anatomy ultrasounds looked great! Her type of bladder extrophy was “covered”, so nothing was seen projecting from the abdominal wall. (However, looking back on the videos of the prenatal ultrasounds, a normal distended bladder was never identified.)
The actual delivery went well after a successful induction at 39 weeks. She was a healthy baby with excellent Apgar scores. The nurses quickly put a diaper on her. Shortly after, they said the pediatrician was at the hospital and he would evaluate her. We didn’t think this was atypical as they examine all newborns within 24 hours. It seemed to be taking a while for her to be brought back to our room, so my husband went down the hall to check on her. Looking through the window of the newborn nursery, he saw the doctor and nurses examining our daughter with an open medical textbook nearby. He knew immediately this wasn’t a good sign. Soon, the pediatrician came into our room to tell us something was wrong with our baby, but he didn’t know what it was. She was then taken to our local children’s hospital where she was diagnosed with female epispadias. We were discharged home with a follow-up appointment with the pediatric urologist in 1 month.

At the follow-up appointment, we found out how extensive the surgery would be and we also learned failure rates are high. As we left the children’s hospital, our research on this rare birth defect began.

Our journey took us to Baltimore to see Dr. Gearhart at Johns Hopkins. Later, from Dr. Kropp, we learned about the complete primary repair for exstrophy and we subsequently scheduled a consultation with him in Oklahoma City. While attempting to make the overwhelming decision regarding which surgical method we should pursue and the timing of the surgery, we spoke with Dr. Reiner, Dr. Grady and Dr. Mitchell over the phone. Ultimately, our daughter had a complete primary repair including bilateral iliac osteotomies by Drs. Mitchell, Groth and Balcomo at Children’s Hospital of Wisconsin on December 16, 2011 at 3.5 months of age. Since surgery, she has done very well without any complications. She is a happy, healthy little girl who loves princesses and anything pink! She also loves to be outside and does her best to keep up with her older brothers! Our daughter will turn 4-years-old in couple of months. Other than our yearly follow-up appointments and renal ultrasounds, we have been “coasting” with no issues or big decisions to be made in regards to bladder exstrophy. We know we will have challenges ahead, but we have enjoyed these relatively carefree toddler years.

We are forever grateful to these surgeons who took the time to educate us about bladder exstrophy and to calm our fears. The knowledge they shared and the compassion they showed to our family will never be forgotten!
2015 Sponsors
Thank you to our sponsors for their generous contributions towards making this conference a success. Representatives from each organization have been invited to attend the morning sessions and they have tables set up during the afternoon. Please introduce yourselves and learn more about their products.

Coloplast
Coloplast develops products and services to make life easier for people with deeply personal and private medical conditions. The more intimate the condition, the greater the requirement to come closer to customers, understand their world and develop solutions that are sensitive to their special needs. We call this Intimate Healthcare. It's one of the most rewarding feelings - knowing you've made a real difference to another person’s quality of life. At Coloplast we share a passion to make this difference and we’re committed to achieving it”.

Cure Medical
Cure Medical manufactures catheters and is the first and only company to manufacture all of its products without DEHP, latex and BPA. Cure Medical donates 10% of its net profits to scientific research, seeking to develop treatments for spinal cord injuries and related neurological disorders. Simply by choosing to use Cure products, you are contributing to a more promising future by supporting research for finding a cure.

Wellspect Healthcare
Wellspect HealthCare is a leading global provider of innovative urological products and services. We listen and learn from the people who use and work with our products to develop new solutions, tailored to their needs. LoFric® catheters are an example of that approach, proving that a Good Life, with improved long-term outcomes, is achieved from a Good Start, by using the most documented catheter from the beginning. As part of our commitment to improve quality of life for users and healthcare professionals worldwide, we passionately strive to make a real difference every day to everyone who needs our products and services.

ABC Medical
ABC Medical is a national leader in providing urological and other medical supplies, delivered directly to customers’ homes. ABC Medical offers an unmatched combination of personalized service, quality medical supplies, education and outreach to its customers. ABC stands for Adapt. Believe. Compete., representing the Company’s mission of providing people with disabilities unparalleled support to adapt to their situation, believe in themselves and compete every day. As the exclusive medical supply sponsor of many of the largest adaptive sports organization in the U.S., ABC Medical supports and attends over 200 adaptive sports events every year.

IDEAS
The North American Intestinal Disease Education and Awareness Society is a non-profit that raises awareness of intestinal diseases through education and public awareness campaigns. IDEAS provides quality of life enhancing programs for children and young adults afflicted with intestinal diseases and their families. IDEAS conducts advocacy programs on behalf of all people living with intestinal diseases. We provide support to all individuals living with various diversionary surgeries and hope to encourage everyone to live life to the fullest. Please visit our website for more information at www.weneedideas.ca.