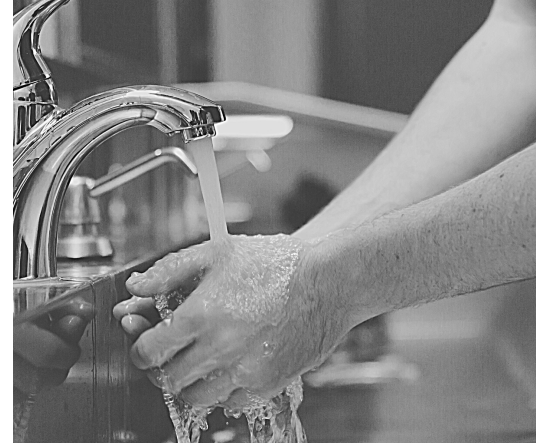




Association for the Bladder Exstrophy Community

## SUPPORTING CHILDREN WITH BLADDER EXSTROPHY IN SCHOOL



We expect children with bladder exstrophy to thrive in all areas of the school setting, including academics, sports, clubs, social activities, and management of their healthcare needs. We offer areas to consider in developing best approaches. Toileting, continence care, missed class time due to hospitalizations or clinic appointments as well as peer considerations can be challenging without a careful plan in place.

School nurses, teachers, counselors, and other school staff can be great allies in helping a child with bladder exstrophy manage their toileting needs and be successful in all areas of school.

### IMPLICATIONS

- Frequent bathroom use
- Use of pullups or pads
- Urinary accidents
- Urine smell
- Missed school for medical needs
- Storage for bathroom supplies/change of clothes

### WHAT IS BLADDER EXSTROPHY?

Bladder Exstrophy (BE) is a rare congenital disability affecting 1 in 50,000 children born per year that causes the bladder to form improperly during gestation. A child with bladder exstrophy is born with their bladder 'inside out' and positioned on the abdomen. Imagine a balloon or ball that has been cut in two and opened up so that the inside is visible.

Bladder exstrophy may occur in varying degrees and usually involves several systems within the body including the urinary tract, reproductive tract as well as pelvic skeletal muscles and bones. In Cloacal Exstrophy, intestinal tracts are also involved. Children with bladder exstrophy can be at particular risk for kidney reflux, urinary and bladder infections, chronic kidney disease, and bladder rupture.

Treatment for bladder exstrophy typically involves surgical bladder closure, repair of pelvic bones and urethra within the first few months of birth and can be followed by further reconstructive surgeries over several years. With good health care management, children with bladder exstrophy are expected to do well and achieve all their developmental milestones.



# How Schools Can Help

## BATHROOM PLANS

Frequent bathroom use and incontinence is common among children with bladder exstrophy. These students may need regularly scheduled and frequent breaks to use the restroom without asking permission. Their ability to wait until planned bathroom breaks may be medically impossible.

Younger children may need a regular, confidential and gentle reminders from the teacher to use a bathroom in the nurse's office or a different private bathroom. Students with bladder exstrophy may be assigned a seat near the classroom door for a quick exit. All bathrooms should be clean and ideally private for discrete storage of continence supplies and a change of clothes.



## SCHOOL PLANS

For children living in the USA, developing a plan with schools can typically be done through an Individual Health Plan (IHP), a 504 Plan, or an Individualized Education Program (IEP). The child's urology team or pediatrician can provide a letter outlining the child's medical needs to assist in creating accommodations the child will need to be successful academically, socially and medically.

## COUNSELING

Counseling can offer a confidential and safe place for a student to develop solutions to deal with a number of issues related to bladder exstrophy and to enhance resiliency and coping. Children with a chronic medical condition may be at higher-risk for mental health issues.

## PEER SUPPORT

Talking with other families or children with bladder exstrophy can be very helpful and important for a child to know they are not alone.

## UNUSUAL EVENTS

Careful planning in the event of substitute teachers, substitute nurses, field trips, or emergency events should be considered. Often, a second set of supplies may remain in the child's classroom or backpack.

## CONFIDENTIALITY

Many children choose to be very private and only share when they have identified a trusted friend. Other children are comfortable with being more open. School staff should partner with children and their families to develop a response regarding why a student may have preferential seating, miss class time frequently, go to the nurse often, have clothing changes, or use a catheter.

