



A Parent's Guide to Hospitalization for Bladder Exstrophy Closure



Welcome to Johns Hopkins Children's Center. You, your child, and your loved ones are about to begin a 6-8 week experience at our hospital. This book is to help prepare and guide you through this important step in the bladder exstrophy journey. Please remember that just as every person is unique, each child's hospital experience is different. This book was designed to give you an overview of what to expect, with some helpful hints from parents who have gone before you and staff that are eager to meet you.

We gratefully acknowledge the many physicians, nurses, and other hospital staff members who have contributed their time and expertise to the creation of this guide. In addition, we recognize that this resource would not have been possible without the input and review by numerous families who are a part of the Johns Hopkins' bladder exstrophy community. It was their desire to reflect back on their own experiences in order to help those following the same path that created the framework for this guide. Our sincerest thanks go to all who were involved.

In this guide we will cover:

- The Bladder Exstrophy Closure
- Healing in the Hospital
- Resources For You and Your Child

The Bladder Exstrophy Closure

On the day of your child's surgery, you will probably be expected to report to the pre-surgery center located on the 7th floor of the Children's Center (CMSC building) early in the morning. Your child will have his or her vital signs taken and sometimes are asked to change into our hospital pajamas.

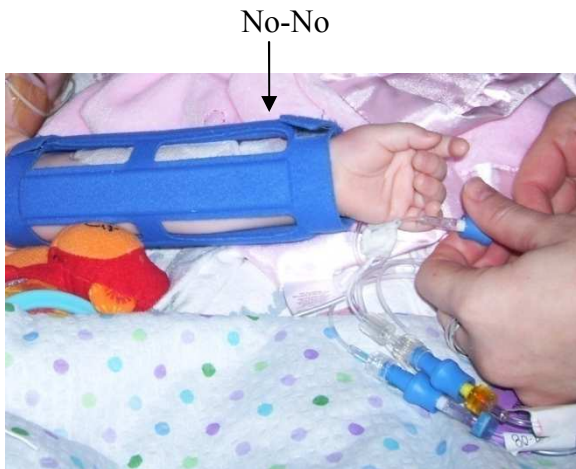
When it is time, one parent will be allowed to accompany your child back into the operating room and be present while he/she falls asleep. You will be asked to wear a gown, mask, and hair net if you wish to go back. You will also have the opportunity to meet the nurse that will stay with your child in the operating room. She will be the one who will call you about every two hours and let you know how things are going.



Hat, mask, and gown worn to the OR

Bladder exstrophy closure surgeries are typically 8 hours long. As a result, many parents have described the wait as tiring. Throughout your child's surgery, you will periodically be given updates from the operating room. There is a waiting room for families of patients in surgery. It is here that you will check in with the patient representative. He/She will take your cell phone number so that you can be updated if you decide to take a break. Some parents use the time while their child is in surgery to go for a walk, get a delicious lunch, or take a nap. You are also welcome to visit the Family Resource Library located on the third floor of the Children's Center, Room 301, to pick out books for your child, do a little research, or access the internet. It helps the time go by quicker!

After your child has drifted off to sleep and before the actual bladder closure begins, an IV line will be placed. Typically a PICC line (peripherally inserted central catheter) is placed in your child's arm. Or, if your child is smaller, an IJ (internal jugular line) may be placed in the neck. Usually, a PICC (or IJ) can stay in place the entire time your child is in the hospital and is used for administering many medicines. Most of the medicine received will be sedatives in order to keep your child as comfortable and still as possible, as well as antibiotics, to prevent any infections. Often times the PICC will have a No-No (fabric "splint") over it to help keep little hands from picking at or peeling off the dressing or pulling at the tubes.



When your child's surgery is finished, he/she may be taken to the Pediatric Intensive Care Unit (PICU). Many children will spend a couple days in the PICU before transfer to the 6th floor. In the PICU, your child will be able to receive the specialized care that many patients need immediately following surgery. Please check with your PICU nurse for visitation guidelines and overnight accommodations.

PICU entry and patient room (without bed)



When your child is ready to move out of the PICU, he/she will be transferred to the Intermediate Care Unit (IMC) on the 6th floor. The IMC is a room with six patient beds for children who need more nursing care. The 6th floor will become your new residence for the next few weeks. On the 6th floor, one parent is allowed to stay with your child at all times. There is a pull-out chair on which you can sleep if you choose to spend the night with your child.



IMC Unit on 6th floor



Healing in the Hospital

Since your child's bladder was on the outside of the body, the pelvis could not "close" in the front. The orthopedic surgeon will take small pieces (wedges) of bone from the pelvis and mold the two sides so that the pubic bone can be brought in front of the bladder. Your child will have an external fixator to hold the pelvic bones stable while they heal. Your child will also have skin traction on both legs. The traction holds your child's legs together and straight for optimal healing. Due to the traction, your child will be placed in a bed as opposed to a crib. There are weights at the end of the bed that help hold the legs in place. Your child will typically be in traction for about six weeks and will have to remain flat with very limited movement to have the best healing course possible. During this time your child will be given sedation medicines to help keep him/her comfortable and still.



External fixator



Traction attached to child's legs



Weights hanging from end of bed to stabilize child's legs

Your child will also have three tubes coming out of his/her new “belly button”. The biggest of the tubes is called the SP (supra pubic) tube and it goes into the bladder. The two smaller tubes are the stents. Each stent goes into the bladder and then up the ureters to a point just outside each kidney. Ureters are the tubes that connect the kidneys to the bladder. The stents allow the urine to drain properly while bypassing the bladder so it can heal.



Stents

SP tube

While your child is flat, eating may become difficult or the medication may affect his/her appetite. Some children also experience funny tastes in their mouths due to medicines they receive. As a result, a nasogastric tube (NG) may be placed. An NG is a tube that goes in the child's nose and down to the stomach. Formula can be given through the tube to replenish any needed calories and can also be delivered while your child is asleep. It is so important to get enough calories after surgery to promote healing!

NG tube



Approximately six weeks after the surgery, an x-ray will be taken to determine how well the pelvis is healing. If the x-ray shows good bony health, then the pins will be removed. The orthopedic team will come by to discuss this step and take the pins out. Some topical or oral medicine will be given to help with any pain. Pin removal is not usually painful but your child may be sore afterwards. Even though your child is out of traction, his or her legs will need to stay together for the next two weeks. Depending on the size of your child, either a single knee immobilizer or fabric covered splints (two No-Nos) will be put together on top of an ace bandage. When your child has reached this stage, he or she may be affectionately referred to as a mermaid or merman.



No-Nos wrapped together to immobilize patient's legs

When you first pick up your child, he or she will not have very good head control because of lying flat for so long. In addition, he or she will not want to bend at the hips right away. It often takes several days for your child to return to his or her old self. Your child may also be dizzy (i.e. a head rush) and nauseous when sitting up for the first time. Many parents find using a wagon available on the 6th floor to be helpful during this time. Since children are familiar with wagons, and they have enough space to recline comfortably, it can ease the transition to sitting as well as serve as a way to safely move about the hospital. You can take your child for a ride if the nurses allow and your child feels up to it.

About twenty-four hours after the pins come out the stents will be removed. The determining factor for stent removal is that the pin sites must be crusted over and no longer draining.



SP tube

Typically, within twenty-four hours of the stent removal, an ultrasound of the urinary system is performed. After the ultrasound is reviewed the SP tube will be capped. Residual urine in the tube will be monitored before the SP is removed completely.

Your child will have an appointment at the Urology Clinic a few days after discharge from the hospital. After this follow-up appointment, most families are able to leave the Baltimore area and return home.

Resources for You and Your Child

Housing:

For families traveling a long distance to reach Hopkins Children's, arrangements may be made to stay at The Children's House which is located across the street from the hospital or at the Ronald McDonald House which has shuttle service to and from the hospital. The staff at the Pediatric Urology Clinic can help make arrangements for you when they are scheduling your child's surgery.

To learn more about these facilities please visit their websites:

The Children's House www.thechildrenshouse.org

The Ronald McDonald House www.rmhbaltimore.com



The Children's House

Accommodations available on the 6th floor:

- Breast pump and breast milk refrigerator
- Formula and baby food
- Diapers and wipes
- Clothes washer and dryer
- Parent shower
- Parent refrigerator
- Bedside phone
- Wireless internet access

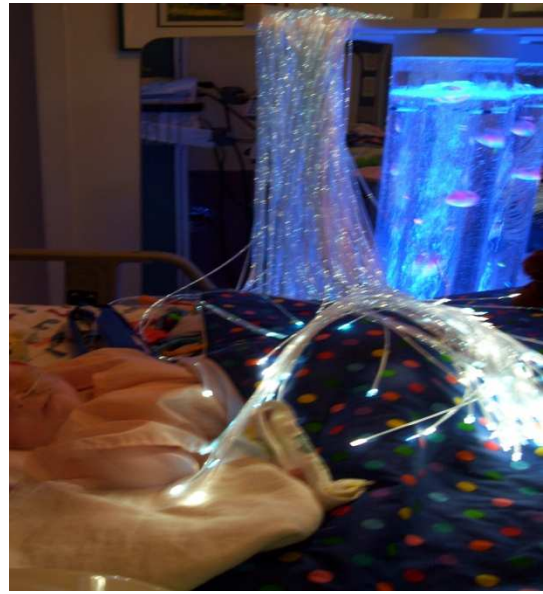
Helpful items to bring from home:

- Baby blankets washed in your own detergent
- A t-shirt you have worn that can be used to comfort your child
- Home videos/pictures of your child and other family members

While your child is healing, he/she may start to be awake for periods of time during which string mobiles, toys, or even photo collages will be hung from the ceiling. This will give your child something to look at during the many days he or she is lying flat on his or her back. Movies, books, and music are also used to help keep your child quietly entertained. Any favorite toys from home are welcomed to help make your child's stay a little easier. Child life specialists are available to help you with other ideas that can support your child's ongoing development and assist them in coping with traction.



Suspended mobile



VECTA machine

In order to help make the hospital experience more normal, most families will bring shirts for their child to wear rather than hospital pajamas. Short sleeve t-shirts, long sleeve shirts (not turtlenecks), and shirts that button down the front (but not onesies) are the best. Please remember that your child's legs will be wrapped so pants or shorts are not needed until your last few days here in the hospital.



T-shirts and blankets from home are familiar items in the strange hospital environment

Thank you for taking the time to learn more about what your family can expect during your child's bladder exstrophy closure. We look forward to serving and supporting you as you take the first steps of the bladder exstrophy journey.

If, after reading this booklet, you have any further questions regarding your upcoming experience at Johns Hopkins Children's Center please contact Amanda Moatz, Pediatric Urology Child Life Specialist at (410) 955-9652 or amoatz1@jhmi.edu.

Other helpful links and phone numbers:

Johns Hopkins Pediatric Urology	www.urology.jhu.edu/pediatric
Pediatric Urology Scheduling	(410) 955-6108
Pediatric Urology Nursing	(410) 614-6304
Johns Hopkins Child Life	www.hopkinschildrens.org/childlife

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Brought to you by the
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