Posterior Urethral Valves (PUV) Newborn Services

This leaflet offers more information about Posterior Urethral Valves. If you have any further questions or concerns, please speak to the staff member in charge of your care.

What are posterior urethral valves (PUV)?

PUV is a condition found only in boys that affects the urethra (the tube which runs from the bladder to the outside of the body, down the inside of the penis).

Incidence

1 in every 8,000 births will have PUV. The urinary system consists of the kidneys, the bladder and ureters. The kidneys filter the blood to remove waste products and form urine. The urine flows from the kidneys down through the ureters to the bladder and is passed through the urethra into the nappy.

Abnormal extra membranes in the posterior urethra cause a narrowing of this passage between the bladder and the tip of the penis. This narrowing is near the bladder. This makes it difficult for your baby to pass urine and the bladder becomes bigger and causes pressure, which may result in urine being pushed back into the ureters and kidneys. This is known as reflux. Your baby will need to take low dose antibiotics (prophylactic antibiotics) in case the bladder becomes enlarged and there is reflux, which can lead to kidney damage.

What causes posterior urethral valves?

This condition is not inherited in any recognised way and seems to happen in the early stages of pregnancy when the organs, muscle and other tissue start to form. It is not due to anything a mother did or ate during pregnancy.

What are the signs and symptoms of PUV?

There are various symptoms associated with PUV, but they may not affect every child in the same way. The degree of blockage affects the severity of the symptoms.

Some symptoms include:

- an enlarged bladder, which can be felt through the abdomen as a lump
- urinary tract infections (UTIs)
- difficulty urinating

- a weak stream of urine
- unusually frequent urination
- bed wetting after toilet training has been successful
- poor weight gain.

However, these symptoms can resemble those of other conditions, so you should always check with your doctor.

How is PUV diagnosed?

PUV can be diagnosed by a routine ultrasound scan during pregnancy, which will show if the bladder, ureters or kidneys are swollen. It can also be diagnosed in a newborn baby if the bladder is swollen and urine dribbles constantly.

If the blockage was not severe before or just after birth, the condition can remain undetected until the child has symptoms as above.

What is the treatment?

This depends on the symptoms and how ill your baby is when diagnosed. Sometimes other treatments may need to be carried out first if there has been oligohydramnios (shallow pool of fluid surrounding your baby in pregnancy). When your baby is born they will be admitted to the neonatal unit. There are several options for treatment, depending on how severely the symptoms are affecting your baby.

First, a urinary catheter (thin, plastic tube) is passed into the bladder to drain away the urine and your baby's urine output and some blood test values will be monitored closely. Your baby will need intravenous fluids (a drip), which are delivered directly into a vein. Also your baby will need to be on antibiotics. Within the first few days after birth, your baby will need a renal tract ultrasound scan and a micturating cystourethrogram (MCUG).

Renal Tract Ultrasound – this is very similar to the ultrasound scan that you had during pregnancy. It creates a picture of the organs inside the body and shows how well they are working.

Micturating cystourethrogram – this test shows the blockage that is present in the urethra and can show urine passing from the bladder to the urethra. It will also show if the urine is flowing backwards up the ureters and towards the kidneys.

When your baby is stable, a surgical procedure will be required to remove the membrane which has been causing the obstruction. This procedure is called an ablation or resection. This procedure is carried out in an operating theatre under a general anaesthetic. There is no need to cut the skin and it is usually carried out using a cystoscope (a tiny camera with an instrument to cut the membrane).

Can I feed my baby?

Most babies will need intravenous fluids to start with (a drip). Staff will show you how to express milk for your baby if you wish to do this. However, providing your baby is well, we encourage normal feeding either by breast or bottle as soon as possible.

What happens after the operation?

Your baby will need to continue taking antibiotics and will be closely monitored by the urology team to check if there are any long term problems. He will need another renal tract ultrasound at six weeks and an outpatient appointment to discuss the ultrasound results, which usually take place at St George's Hospital. He will also be followed up to adulthood by the paediatric urology team.

Potential problems

- Continued reflux of urine from the bladder into the upper renal tract, resulting in infection and increasing damage to the kidneys.
- Difficulties in emptying the bladder fully
- High Pressure bladders
- Floppy weak bladders
- Reduced kidney function.

If St George's Hospital is not your local hospital

When your baby has had surgery and made a good recovery, i.e. when their specialist medical and nursing requirements are less, the baby will be transferred back to the care of your local hospital. This transfer is a sign of progress and will not occur until the baby is ready. It will allow you to be closer to home and become familiar with your local healthcare professionals.

Useful sources of information

NHS pregnancy and baby advice

http://www.nhs.uk/conditions/pregnancy-and-baby/

BLISS

Bliss is a support group which is able to offer support and advice to families with babies with a range of conditions.

Fourth Floor Maya House 134-138 Borough High Street London SE1 1LB Enquiries: 020 7378 1122 Email: <u>hello@bliss.org.uk</u> Website: <u>www.bliss.org.uk</u> Use your smartphone to scan the QR code (you may need to download a QR code scanning app).



For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.stgeorges.nhs.uk

Additional services

Patient Advice and Liaison Service (PALS)

PALS can offer you on-the-spot advice and information when you have comments or concerns about our services or the care you have received. You can visit the PALS office between 9.30am and 4.30pm, Monday to Friday in the main corridor between Grosvenor and Lanesborough wings (near the lift foyer).

Tel: 020 8725 2453 Email: pals@stgeorges.nhs.uk

NHS Choices

NHS Choices provides online information and guidance on all aspects of health and healthcare, to help you make decisions about your health. Web: www.nhs.uk

NHS 111

You can call 111 when you need medical help fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones.

Tel: 111

AccessAble

You can download accessibility guides for all of our services by searching 'St George's Hospital' on the AccessAble website (www.accessable.co.uk). The guides are designed to ensure everyone – including those with accessibility needs – can access our hospital and community sites with confidence.



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