

# Henoch-Schönlein Purpura (HSP)

This leaflet provides information about Henoch-Schönlein Purpura (HSP pronounced "hen-awk shern-line purr-purr-ah"). If you have any further questions or concerns, please speak to the staff member in charge of your care.

## What is Henoch-Schönlein Purpura (HSP) and why have I got it?

Henoch-Schönlein Purpura (HSP) is a condition where the small blood vessels in the body become inflamed – also known as a vasculitis. The inflamed blood vessels bleed into the skin causing a characteristic rash. Small blood vessels occur throughout the body, so other organs such as joints, the gut and kidneys can be involved. We would not expect extra bleeding from normal cuts and scrapes

The cause is unknown but it is thought that a trigger (often a virus such as a cold) causes an abnormal reaction in the body's immune system. It is not inherited or contagious. It is a rare condition affecting fewer than 1 in 5,000 children in the UK, and 9 out of 10 cases occurs in children aged 2-10 years.

## What are the signs and symptoms?

As small blood vessels occur throughout the body, several organs can be involved:

**SKIN**: In all cases rash occurs. It is bruise-like (purpura) or reddish purple spots (petechiae) that are non-blanching (do not disappear when pressed). It is most often on the legs, buttocks and elbows.

**GUT:** Abdominal (tummy) pain is very common and can be severe. The inflamed blood vessels in the bowel can cause blood in the stool and in rare cases, an abnormal folding of the bowel can occur called intussuception. This causes blockage and may require surgery. **JOINTS:** Three quarters of cases will develop inflammation in their joints, particularly the knees and ankles which can become swollen, tender, warm and painful. This can lead to difficulties in walking. The inflammation will gradually clear over time and there is no lasting damage to the joints.

**KIDNEYS**: Approximately half of children with HSP will have kidney involvement. The inflammation of the kidney (called nephritis) causes blood and protein to leak into the urine and can be associated with high blood pressure. This usually settles on its own but in a very small number (approximately 3%), serious kidney problems can develop. This can develop for up to six months after onset, so it is necessary to monitor all children with HSP during this period. **TESTICLES**: 3 in 10 boys experience orchitis (inflammation of the testicles) causing scrotal swelling, pain and redness. This can predispose to twisting of the testis (testicular torsion) with sudden severe pain requiring urgent medical attention.

OTHER: Other parts can be affected. These are rare but can be serious.

HSP is often mild with most recovering after 4-6 weeks without any problems. However, it can last several months with symptoms flaring and reducing in this time. Approx one third has relapse within 4-6 months of the initial episode. Very rarely, longer term serious kidney problems can develop for up to six months.

#### Do I need any tests to confirm the diagnosis?

There are no specific tests for HSP and the diagnosis is made on the typical symptoms. However, there are tests the doctor may want to do to exclude other diagnoses and check the effect of the inflammation on the kidneys. These will include blood tests, urine dipstick test and a blood pressure test. The doctor may suggest investigations for specific symptoms as required.

#### What treatments are available?

There are no specific treatments for HSP and in most cases it will resolve after 4-6 weeks. Therefore, treatment is based on controlling symptoms. This can include resting and painkillers, such as paracetamol. Ibuprofen can also help but should be avoided in anyone who has suspected kidney complications or gut bleeding. If the joint or abdominal pains are severe, steroid medication may be helpful.

All children with HSP require follow up for a minimum of six months for screening for potential kidney disease. In most cases, this involves a urine dipstick and blood pressure check at 1 month, 3 months and 6 months post diagnosis.

## What happens if I do not get treatment?

For most people, HSP self resolves by 4-6 weeks. However, the complications can be serious if left untreated. Severe testicular or abdominal pain that does not settle with simple painkillers or blood in the stool needs urgent review as may require surgical intervention.

Severe kidney disease, although rare, could lead to renal failure if unmanaged.

## Is there anything I can do to help myself?

Please make appointments with your GP at 1 month, 3 months and 6 months for your child's blood pressure and urine checks even if your child is well. You can use the patient record below to keep track of the follow required and results. Please bring this to all medical appointments during the HSP follow up.

Height:

95<sup>th</sup> Centile for BP:

Weight:

Cuff size:

# **GP** Letter for Follow up

Dear Colleague,

Please will you continue to follow up this patient with Henoch-Schönlein Purpura (HSP), they are normotensive and their urinalysis has been negative.

All children with HSP require follow up to at least six months for HSP nephritis. We advise that children who do not show evidence of proteinuria at one week have their blood pressure checked and urine dipped three times in the next five months at 1 month, 3 months and 6 months after initial presentation.

Therefore, we would be very grateful if you could perform continuing reviews of this patient as per the table below and refer to the general paediatric team at St George's if any signs of nephritis are present.

Thank you

The St George's Paediatric Team

	Assessment	Outcome	
1 month post diagnosis	Urine dip negative and BP normal	Follow up in 2 months	
	Haematuria present	<b>Refer to General Paediatric team</b> Paediatric Hot Phone via switchboard	
	Proteinuria ≥ 1+		
	BP > 95 centile on 3 readings		
3 Months post diagnosis	Urine dip negative and BP normal	Follow up in 3 months	
	Haematuria present	Refer to General Paediatric team Paediatric Hot Phone via switchboard	
	Proteinuria ≥ 1+		
	BP > 95 centile on 3 readings		
6 months post diagnosis	Urine dip negative and BP normal	NO further follow up required	
	Haematuria present	Refer to General Paediatric team	
		Paediatric Hot Phone via switchboard	

Date of review	Months post diagnosis	Urine dipstick (Protein)	Urine dipstick (Blood)	BP (mmHg)	Comment

## **Useful sources of information**

NHS UK: Henoch-Schönlein Purpura (HSP) https://www.nhs.uk/conditions/henoch-schonlein-purpura-hsp/ Henoch-Schönlein Purpura Support Group. c/o Contact a Family Email: <u>hsp.help@inbox.com</u> Website: www.cafamily.org.uk

#### **Contact us**

If you have any questions or concerns regarding HSP, please contact the paediatric medical secretaries on email <u>children.secretariesC@stgeorges.nhs.uk</u> or 020 8725 2931 (Monday to Friday 9am to 4.30pm.) If possible, please give the name of the doctor you saw. Out of hours, please leave a voice message

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

#### Additional services

#### Patient Advice and Liaison Service (PALS)

PALS can offer you advice and information when you have comments or concerns about our services or care. You can contact the PALS team on the advisory telephone line Monday, Tuesday, Thursday and Friday from 2pm to 5pm.

A Walk-in service is available: Monday, Tuesday and Thursday between 10am and 4pm Friday between 10am and 2pm.

The Walk-in and Advisory telephone services are closed on Wednesdays. Please contact PALS in advance to check if there are any changes to opening times.

PALS is based within the hospital in the ground floor main corridor between Grosvenor and Lanesborough wings.

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

#### **NHS UK**

The NHS 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 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.



Reference: PAE\_HSP\_01 Published: February 2025 Review date: February 2027