CONDITION

Focal segmental glomerulosclerosis

Focal segmental glomerulosclerosis is a pattern of kidney-filter scarring that can cause protein loss and reduced kidney function.

WHAT IT IS
Scarring affecting some parts of some kidney filters

BODY SYSTEM
Kidneys and urinary system

MAIN SYMPTOMS
Foamy urine, swelling, weight gain, tiredness

WHAT CAUSES IT
Immune, inherited, kidney stress, drugs, infections, or unknown

HOW IT IS DIAGNOSED
Kidney biopsy, supported by blood and urine tests

MAIN TREATMENT
Kidney-protective medicines and sometimes immune-suppressing treatment

CAN IT BE CURED?
Sometimes - remission or cause removal may stop damage

IS IT AN EMERGENCY?
Sometimes - severe breathlessness or very low urine output

LONG-TERM OUTLOOK
Remission is possible, but some develop kidney failure

Overview

Focal segmental glomerulosclerosis, or FSGS, is a pattern of scarring in the kidneys' filtering units, called glomeruli. These filters remove waste and extra water from the blood while keeping useful substances, such as protein, in the body.

"Focal" means only some glomeruli are affected. "Segmental" means only part of an affected glomerulus is scarred. "Glomerulosclerosis" means scarring of the kidney filters.

FSGS is better understood as a condition or biopsy pattern than as one disease. Different processes can produce the same scarring pattern, and finding the likely cause matters because immune-related, inherited, and stress-related forms are treated differently.

Damaged filters may allow protein, especially albumin, to leak into the urine. Heavy protein loss

with low blood albumin, swelling, and other features is called nephrotic syndrome. FSGS can also reduce kidney function. Some people enter remission, while others develop chronic kidney disease.

Symptoms

FSGS may cause no obvious symptoms at first. It is sometimes found after a urine test detects protein or a blood test shows reduced kidney function.

Possible symptoms include:

Foamy urine alone does not prove protein is present. Urine can look bubbly for harmless reasons, including a fast urine stream, so a urine test is needed.

Symptoms do not reliably show how much scarring is present. Some people feel well despite significant protein loss or reduced kidney function.

- Foamy or frothy urine caused by excess protein
- Swelling around the eyes, feet, ankles, legs, or abdomen
- Rapid weight gain from retained fluid
- Tiredness or reduced energy
- Reduced appetite
- Shortness of breath if fluid builds up
- High blood pressure

Causes and risk factors

FSGS can be grouped by the likely cause of kidney injury.

Primary FSGS is thought to involve a harmful process in the blood that directly injures filtering cells called podocytes. These cells help stop protein from leaking through the filters. The exact circulating factor has not been confirmed, so primary FSGS is diagnosed after other causes are considered.

Secondary or adaptive FSGS develops when kidney filters are placed under extra strain. This may occur with fewer functioning filters, severe obesity, structural kidney problems, another condition that increases pressure inside the glomeruli, or previous kidney damage.

Genetic FSGS is caused by a gene change affecting the filters. It may begin in childhood or adulthood and can occur without a known family history. Certain APOL1 variants increase risk

among people with recent African ancestry, although most people with these variants do not develop FSGS.

Some infections and medicines can also produce an FSGS pattern. Examples include HIV and certain drugs that injure podocytes. Treating or removing the trigger may help, although established scar tissue usually remains.

Sometimes the cause cannot be identified despite detailed assessment.

Diagnosis

Blood and urine tests show how the kidneys are affected, but a kidney biopsy usually confirms the FSGS pattern. During a biopsy, a thin needle removes a small tissue sample, usually with ultrasound guidance, for examination in a laboratory.

Because FSGS affects only some filters, a small biopsy can occasionally miss scarred areas. Findings must therefore be considered alongside symptoms, protein levels, kidney function, and possible causes.

Other parts of the assessment may include:

Genetic testing may be particularly useful with childhood or early-onset disease, a family history, treatment-resistant nephrotic syndrome, or other signs of an inherited condition. Results can affect treatment and discussions about relatives or kidney transplantation.

- A urine protein measurement, sometimes using a protein-to-creatinine ratio
- Blood creatinine and estimated glomerular filtration rate, or eGFR
- Blood albumin, cholesterol, and electrolyte tests
- Blood pressure measurement
- Tests for infections or immune conditions when relevant
- Kidney imaging to assess size and structure
- Genetic testing when an inherited form is possible

Treatment and management

Treatment aims to reduce protein loss, control swelling and blood pressure, protect kidney function, and address the cause when possible.

Many people receive kidney-protective treatment. Medicines that block the renin-angiotensin system, such as an ACE inhibitor or angiotensin receptor blocker, can lower blood pressure

and reduce protein leakage. Other kidney-protective medicines may also be appropriate. Monitoring is required because these treatments can affect kidney function, blood pressure, and potassium.

A lower-sodium diet may help with swelling and blood pressure. A dietitian can help avoid unnecessary protein restriction or nutritional risk. Diuretics, or water tablets like furosemide or hydrochlorothiazide , may remove excess fluid.

Primary FSGS may be treated with corticosteroids like prednisone or hydrocortisone to reduce immune activity. If these do not work, are not tolerated, or are unsuitable, another immune-suppressing medicine may be considered. These medicines can cause important side effects and require regular monitoring.

Immune-suppressing treatment is generally not expected to help adaptive or genetic FSGS unless there is another reason to use it. Management instead focuses on reducing strain and treating the cause, such as by managing weight, treating an infection, reviewing a suspected medicine, or addressing another kidney condition.

Success is often measured by how much urine protein falls. Complete remission means protein loss has returned close to normal. Partial remission means it has fallen substantially but remains above normal. Even partial remission may help preserve kidney function.

If kidney failure develops, options include dialysis or a kidney transplant. Primary FSGS can return in a transplanted kidney, sometimes soon after surgery. Genetic and secondary forms are generally less likely to recur, although individual circumstances differ.

Medicines commonly used for this include sparsentan . Which one suits you, if any, is a decision for you and your doctor.

Complications

Ongoing protein loss and scarring can cause chronic kidney disease. Kidney function may decline slowly, remain stable for long periods, or worsen more quickly. Some people eventually develop kidney failure.

Nephrotic syndrome can also increase the chance of:

These problems do not affect everyone. Regular urine, blood, and blood pressure checks can identify changes before they cause obvious symptoms.

- Significant fluid retention
- Blood clots

- Infections
- High cholesterol and related blood vessel risks
- Poor nutrition from prolonged protein loss
- Sudden worsening of kidney function

Prevention

FSGS cannot always be prevented. Primary and genetic forms are not known to result from ordinary lifestyle choices, and an inherited risk does not mean someone caused the condition.

Some secondary kidney stress may be reduced by controlling blood pressure, maintaining a sustainable weight, treating relevant infections, and avoiding non-prescribed drugs that can injure the kidneys.

Do not stop a prescribed medicine because of concern about FSGS without medical advice. If a medicine is suspected, its risks and benefits must be reviewed safely.

After diagnosis, taking treatment as agreed and attending monitoring appointments may reduce further damage. These steps cannot remove existing scars but may protect filters that still work.

Living with it and what to expect

The course of FSGS varies. Important factors include the cause, urine protein level, response to treatment, kidney function at diagnosis, genetic findings, and amount of scarring.

Over months, treatment may reduce swelling and urine protein. Full or partial remission can last, but relapses may occur. A relapse means protein leakage rises again after improvement. Swelling or urine changes may be clues, although laboratory testing is more reliable.

Over years, some people maintain stable kidney function and continue their usual work, education, exercise, and family life. Others need repeated nephrotic syndrome treatment or develop worsening chronic kidney disease. Existing scars are generally permanent, but progression is not inevitable.

Follow-up usually includes blood pressure checks and blood and urine tests to monitor kidney filtering, potassium, albumin, and protein loss. Checks may be more frequent after treatment changes, during a relapse, or when kidney function is unstable.

Daily weight checks may be recommended when swelling is a problem. A quick increase can

reflect fluid retention rather than body fat. Medication plans may need review during vomiting, diarrhoea, pregnancy, surgery, or another serious illness.

A kidney team, renal dietitian, pharmacist, social worker, or counsellor can help with practical and emotional concerns.

When to get medical help

Arrange routine medical review for persistent foamy urine, new ankle or facial swelling, unexplained fluid-related weight gain, or repeated high blood pressure readings. These symptoms have many causes, but urine and blood tests can check kidney health.

If you have diagnosed FSGS, contact your kidney team promptly about increasing swelling, reduced urine output, a clear weight rise over a short time, possible treatment side effects, or symptoms of relapse. Keep planned follow-up appointments even when you feel well.

Seek urgent medical help for:

Call emergency services for severe breathing difficulty, fainting, confusion, or chest pain with sweating or marked weakness. These symptoms require immediate assessment even if their cause is not FSGS.

- New or worsening shortness of breath
- Very little or no urine
- Painful swelling in one leg
- Sudden chest pain
- Coughing up blood
- Fever or signs of serious infection while taking immune-suppressing medicine

Common questions

Is FSGS cancer?

No. FSGS is scarring in the kidneys' filtering units, not cancer. "Focal" describes how the scarring is distributed and does not mean a tumour is present.

Is FSGS an autoimmune disease?

Sometimes an immune process is suspected, particularly in primary FSGS, but FSGS is not always autoimmune. It can also result from inherited changes, strain on kidney filters, infections, medicines, or an unidentified cause.

Can FSGS go away?

Protein leakage can enter complete or partial remission with treatment or after a reversible cause is addressed. Scarred tissue usually does not return to normal. Monitoring is needed because remission may not be permanent.

Will everyone with FSGS need dialysis?

No. Some people maintain useful kidney function for many years, especially when protein loss improves. Others develop kidney failure and need dialysis or transplantation. Urine protein, kidney function, cause, and treatment response help indicate risk but cannot predict an individual's course with certainty.

Can FSGS come back after a kidney transplant?

Primary FSGS can recur in a transplanted kidney. Recurrence is less typical in genetic or adaptive FSGS. Transplant teams consider the suspected cause, previous course, and genetic results when discussing risk.

Can FSGS run in families?

Some forms are inherited, but many are not. Genetic testing may be considered when FSGS starts young, affects relatives, resists standard treatment, or has other inherited features. A genetic counsellor can explain what results may mean for relatives.

Sources

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