



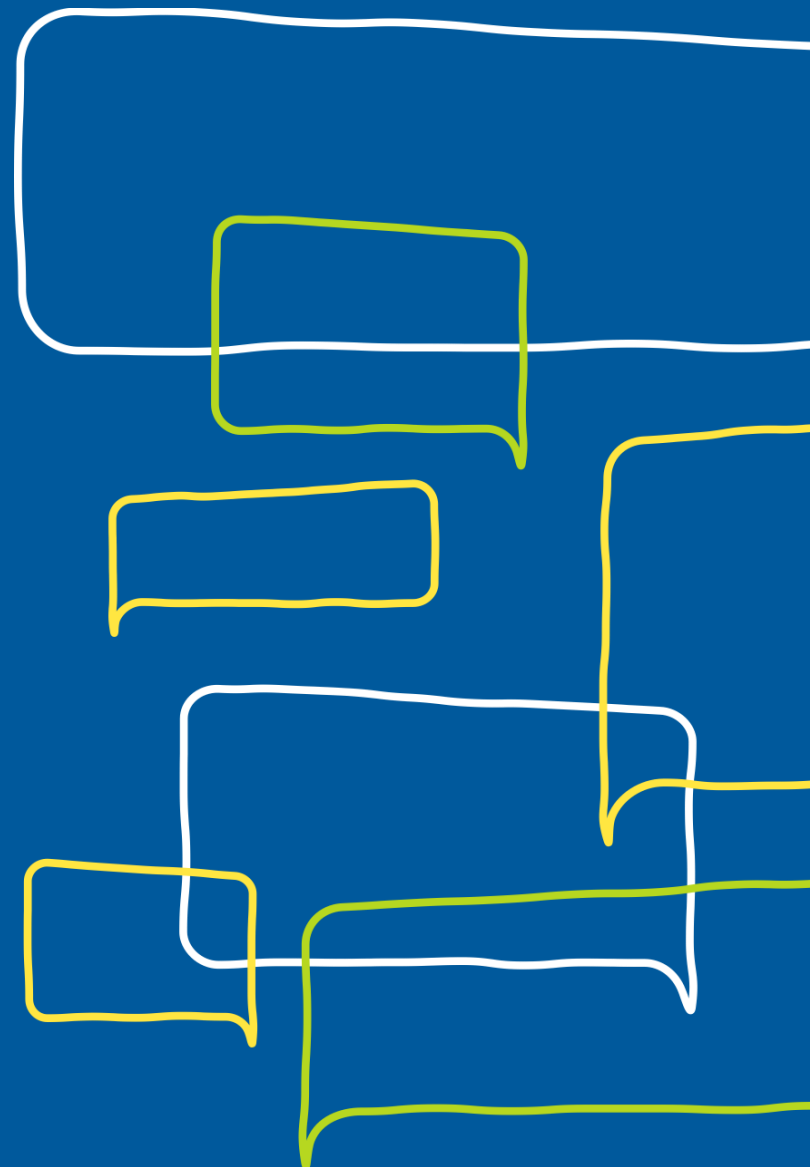
Focus on FSGS: What You Need to Know

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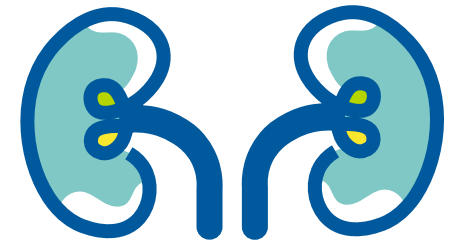
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FSGS Basics



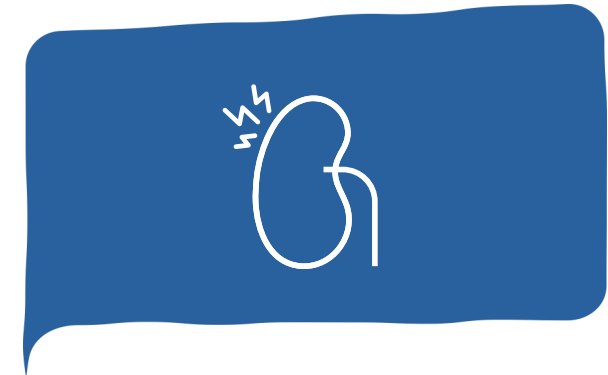
What is focal segmental glomerulosclerosis (FSGS)?

- FSGS is a **rare type of kidney disease** that causes scarring on the kidney's tiny filters (glomeruli).
- This scarring can make it harder for the kidneys to filter waste and water out of the body.
- The kidneys can become more damaged over time and eventually stop working.



FSGS and kidney failure

- When the kidneys stop working, it's called **kidney failure** or **end-stage kidney disease**.
- Over half of people with FSGS experience kidney failure.
- Finding and treating FSGS early can reduce the risk of kidney failure.



Who can develop FSGS?

- Anyone can develop FSGS, including children, teens and adults.
- FSGS is more common in:
 - Adults
 - Men
 - Black or African American people



Signs and symptoms of FSGS

- Common symptoms of FSGS include:
 - Urine (pee) that is foamy, bubbly or dark
 - Swelling in the legs, ankles, feet, hands or face (especially around the eyes)
 - Sudden weight gain
 - Feeling more tired than usual
- A person with FSGS may not notice any symptoms at first. Over time, they may have some or all of these symptoms.
- Tell a health care professional if you have any of these symptoms.



Signs and symptoms of FSGS (continued)

- Health care professionals may do tests to check for signs of FSGS that you can't see or feel, including:
 - High levels of protein in your urine
 - Low levels of protein in your blood
 - High blood pressure
 - High cholesterol

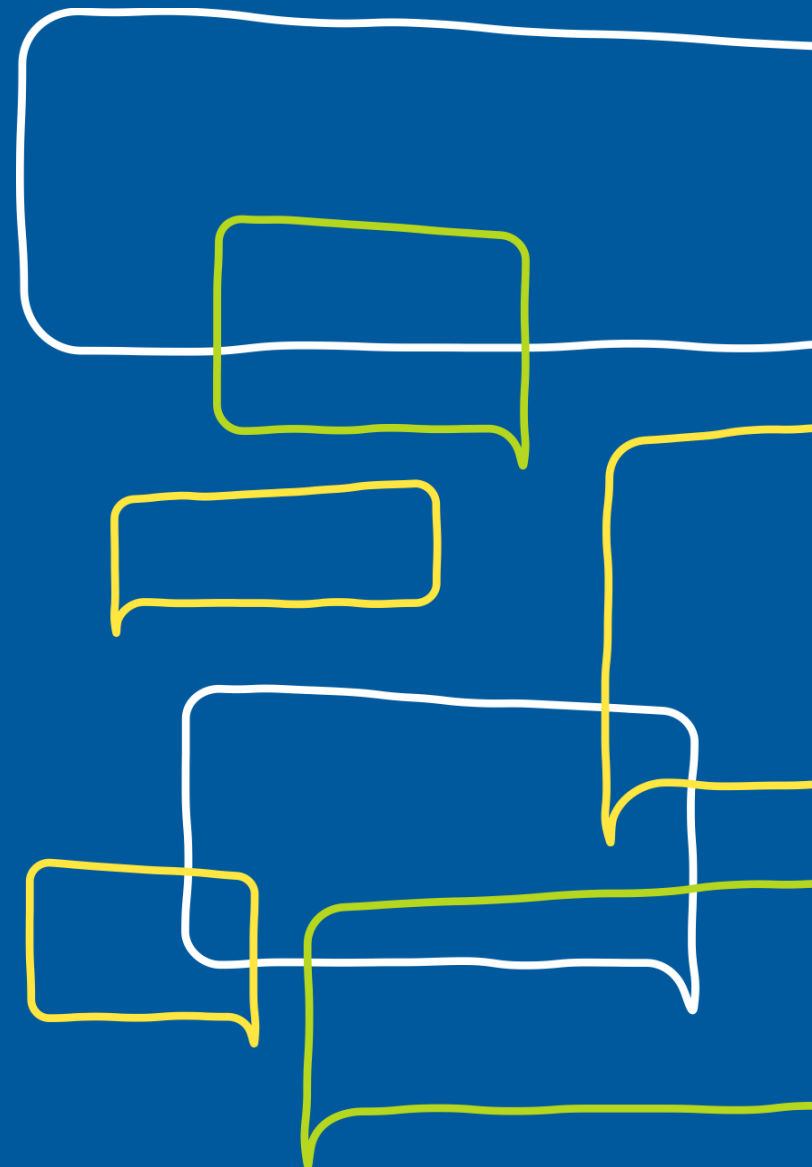
How is FSGS related to chronic kidney disease?

- **Chronic kidney disease** is damage to kidney structure or function that lasts for three months or more. This can include damage caused by FSGS.



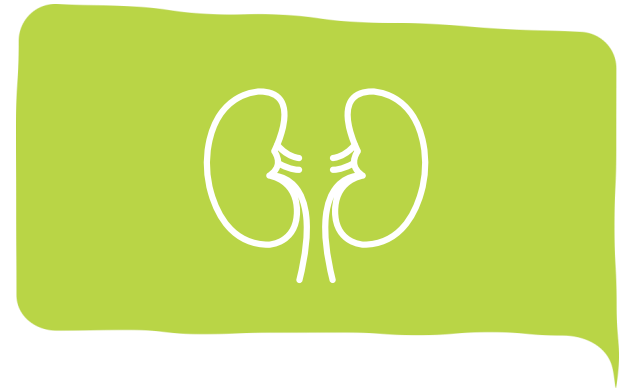
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Types of FSGS



Four Types of FSGS

- There are four types of FSGS:
 - Primary FSGS
 - Secondary FSGS
 - Genetic FSGS
 - Unknown FSGS



Primary FSGS

- **Primary FSGS** is when FSGS happens without a clear or known cause.
- Researchers think **primary FSGS** may happen when a person's immune system attacks their kidneys.



Secondary FSGS

- **Secondary FSGS** is when FSGS is caused by:
 - **Another health condition**, like high blood pressure, obesity or a viral infection
 - **Taking certain medicines**, like lithium, anti-cancer drugs or NSAIDs (non-steroidal anti-inflammatory drugs)
 - **Taking drugs that weren't prescribed by a professional**, like heroin or anabolic steroids



Genetic FSGS

- **Genetic FSGS** (also called familial FSGS) is when FSGS is caused by **mutations**, or changes, in certain genes.
- Some mutations run in the family. Others are random mutations with no known cause.
- If someone in your family has kidney disease, your health care professional may recommend **genetic testing**.
- A **genetic counselor** can help you explore your options.

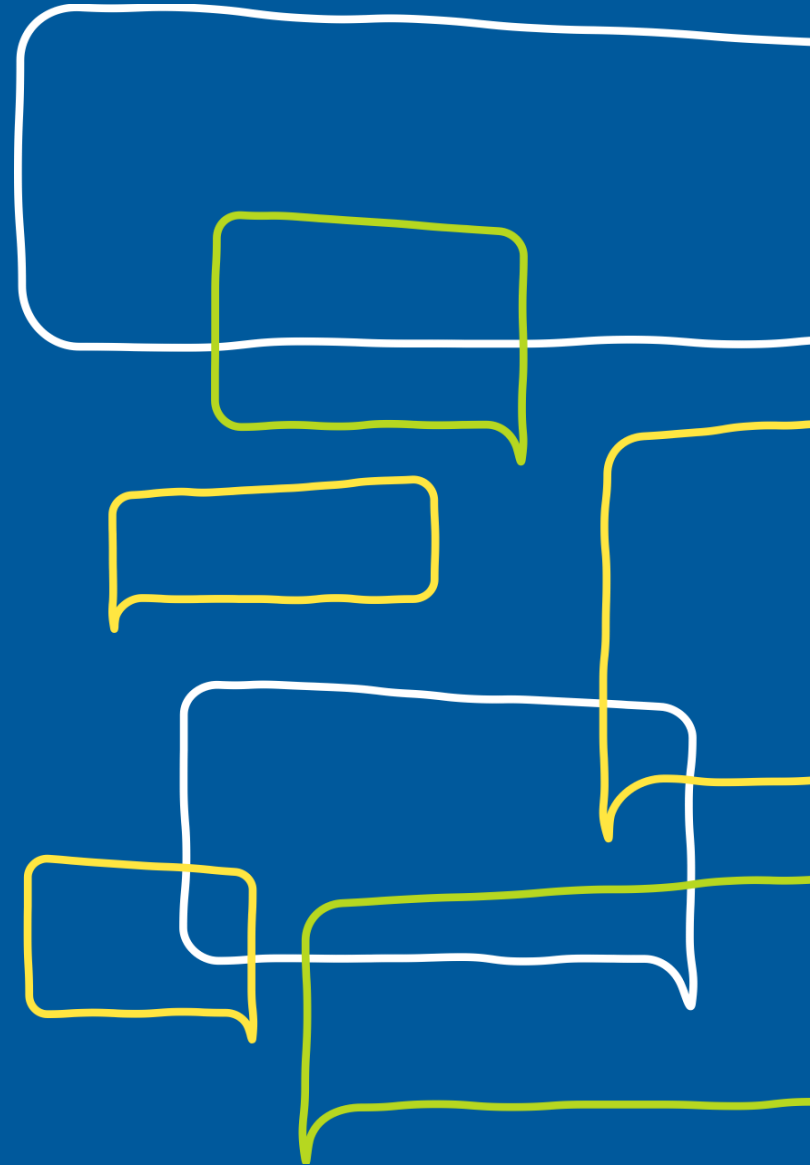


Unknown FSGS

- **Unknown FSGS** is when a person has FSGS but:
 - They don't have genetic mutations related to FSGS
 - Their FSGS is not caused by another health condition or a medicine or drug they've taken
 - They don't meet the criteria for primary FSGS

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FSGS Diagnosis



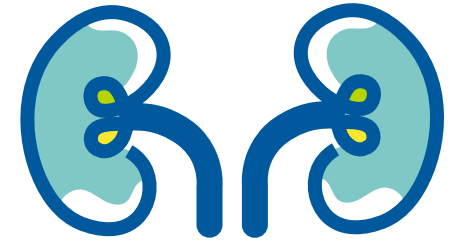
Benefits of early diagnosis

- Finding and treating FSGS early can slow down kidney damage and reduce the risk of kidney failure.
- If you have any FSGS symptoms, ask your health care professional about getting a **kidney biopsy**.



Kidney biopsy

- A **kidney biopsy** is the only way to tell for sure if a person has FSGS.
- Getting a biopsy will also help your health care professional figure out the best treatment plan.
- A professional will take a tiny piece of tissue from one of your kidneys. Then, a pathologist will look at the piece of tissue under a microscope.



Other tests used to diagnose FSGS

- In addition to a kidney biopsy, health care professionals may:
 - Do **urine tests** to check for high levels of protein in your urine
 - Do **blood tests** to check for other signs of FSGS, including low levels of protein and high cholesterol or fat levels in your blood
 - Recommend **genetic testing, serology testing or viral testing** to find out what type of FSGS you have



Understanding your test results

- Ask for a copy of your biopsy report and any other test results. Ask your health care professional to explain the results.
- Here are a few questions you may want to ask:
 - Does the biopsy show that I have FSGS?
 - What type of FSGS do I have?
 - How do my biopsy results affect my treatment plan?
 - Do I have too much protein in my urine?
 - What type of treatment do I need?
 - What are the goals of treatment based on my results?
 - How will we know if treatment is working?
 - How often will I need labs or follow-up visits?
 - Are there any lifestyle or medicine changes I should make?

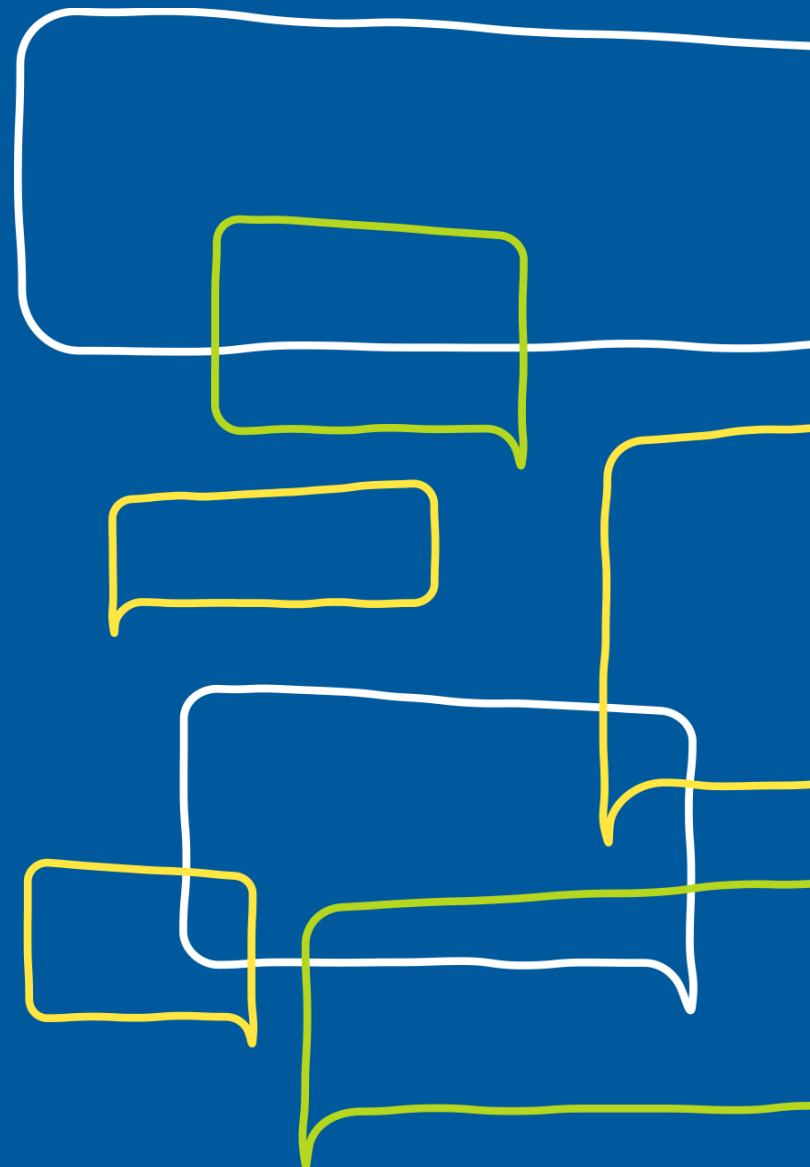
Advocating for your needs

- You have the right to understand your diagnosis, test results and treatment plan.
- If you have questions about your results, you can:
 - Ask your health care professional to contact the pathologist listed in your report
 - Ask for another pathologist to review your report
- If a health care professional isn't listening or addressing your questions, you can get a second opinion—or switch to another professional.



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FSGS Treatments



Treatments for FSGS

- FSGS treatment is tailored to each patient's needs.
- There are three main goals of treatment:
 - Protect the kidney filters (glomeruli)
 - Reduce protein in the urine
 - Improve your quality of life by reducing FSGS symptoms

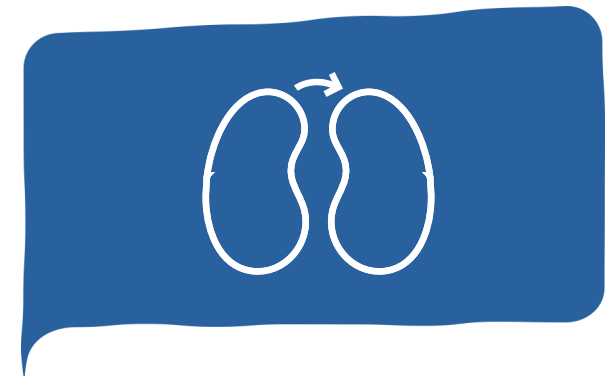


Medicines used to treat FSGS

- People with FSGS may need to take some or all of these medicines:
 - **Immunosuppressants**, including steroids or calcineurin inhibitors, to weaken the immune system and reduce inflammation
 - **Blood pressure medicines** called ACE inhibitors or ARBs
 - **SGLT2 inhibitors** to reduce the amount of sugar and sodium in the blood
- Researchers are developing new medicines to treat FSGS—and one new medicine has been approved by the FDA.
- Ask your health care professional what medicines are right for you.

Treatments for kidney failure

- People with FSGS who experience kidney failure may need:
 - **Dialysis:** A treatment to clean your blood when your kidneys are not able to
 - **Kidney transplant:** A surgery to give a person with kidney failure a healthy kidney from someone else



Treatments for recurrent FSGS

- When FSGS comes back after a kidney transplant, it's called **recurrent FSGS**.
- People with recurrent FSGS may need **plasmapheresis**, also called **plasma exchange (PLEX)**—a treatment to reduce the amount of protein in the urine.
- Some people with recurrent or hard-to-treat FSGS may receive **Liposorber**—a treatment that removes certain types of cholesterol from the blood.
- People with recurrent FSGS may also take **immunosuppressants**.



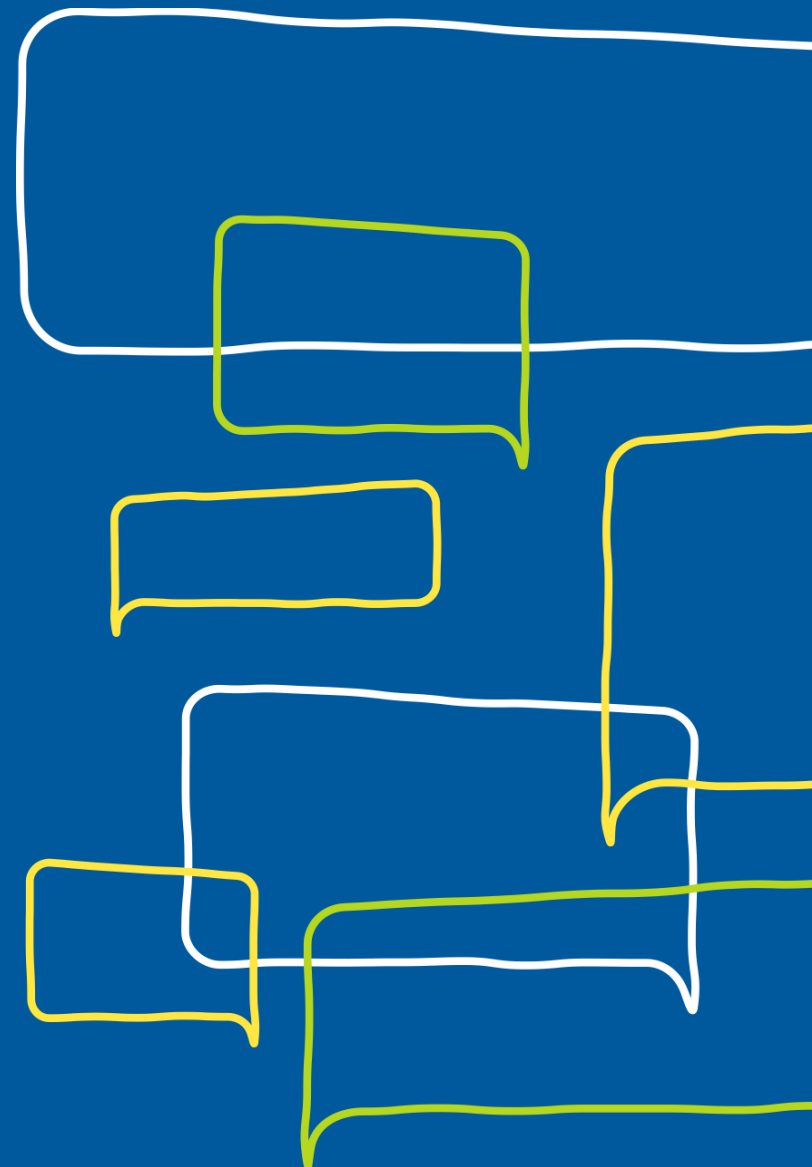
Clinical trials

- In **clinical trials**, researchers study new treatments to make sure they are safe and find out how well they work.
- By participating in a clinical trial, you can help researchers learn about FSGS and find new and better treatments.
- You may be able to try a new treatment—but there's no guarantee it will help your FSGS symptoms.
- To learn more about participating in a clinical trial, talk to your health care professional.



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FSGS Management



Ways to protect kidney health

- If you have FSGS, you can protect your kidney health by:
 - Following a kidney-friendly eating plan
 - Staying active
 - Working with a team of health care professionals
 - Taking medicines as directed
 - Watching for changes in your body



Eat kidney-friendly foods

- Eat foods that support kidney health, including:
 - Foods low in sodium (salt), phosphorous and potassium
 - Whole grains
 - Fresh fruits and vegetables
- Limit sugary drinks.
- Limit protein and fluid intake if your doctor recommends it.
- Check out AKF's Kidney Kitchen[®] at kitchen.kidneyfund.org.



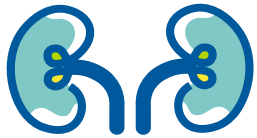
Stay active

- Stay physically active—for example, by:
 - Walking or running
 - Dancing
 - Swimming
 - Playing sports
 - Practicing yoga
 - Playing with kids, grandkids or pets
 - Doing chores around the house
- If you have an injury, disability or other challenges that make it hard to get moving, ask your health care professional for recommendations.



Build a team of trusted health care professionals

- People with FSGS usually need a team of health care professionals, including specialists like these:



Nephrologist

Kidney doctor



Cardiologist

Heart doctor

Work together with your care team

- Check in with your care team regularly so they can adjust your treatment plan as needed.
- Here are some tips to help you get the best care:
 - Make a list of your health care professionals and share it with everyone on your care team.
 - Tell each professional about all medicines you're taking.
 - Ask a caregiver or loved one to join you for appointments.
 - Write down questions and updates before each appointment.
 - Ask follow-up questions.
 - Remember that it's okay to get a second opinion or switch to a new professional.

Take medicines as directed

- Take medicines consistently as directed by your care team.
- If you notice any side effects or have questions about your medicines, reach out to your care team.



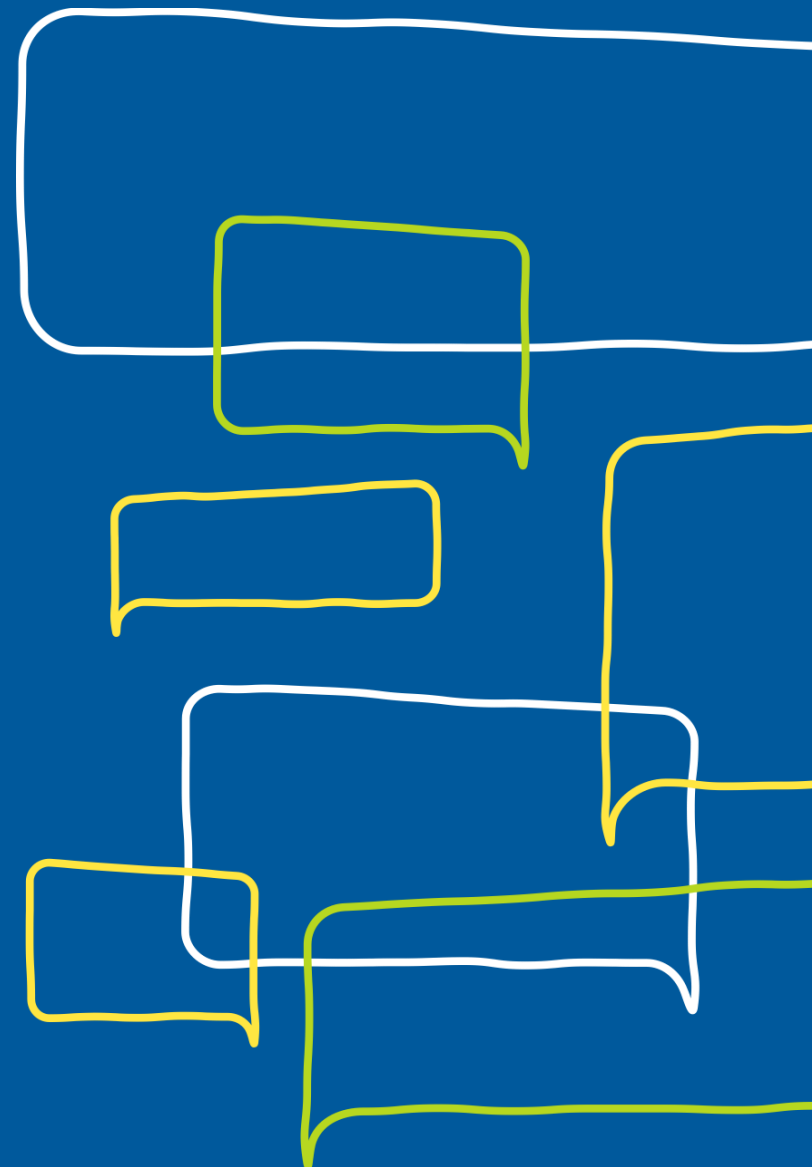
Watch for changes

- Watch for changes in your body, including:
 - Sudden weight gain
 - Foamy urine
 - Increased swelling in your legs, ankles, feet, hands or face (especially around your eyes)
 - High blood pressure (130/80 or higher)
- These changes can mean that fluid is building up in your body.
- If you notice these changes, tell your care team right away.



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Wrap-Up



Key takeaways

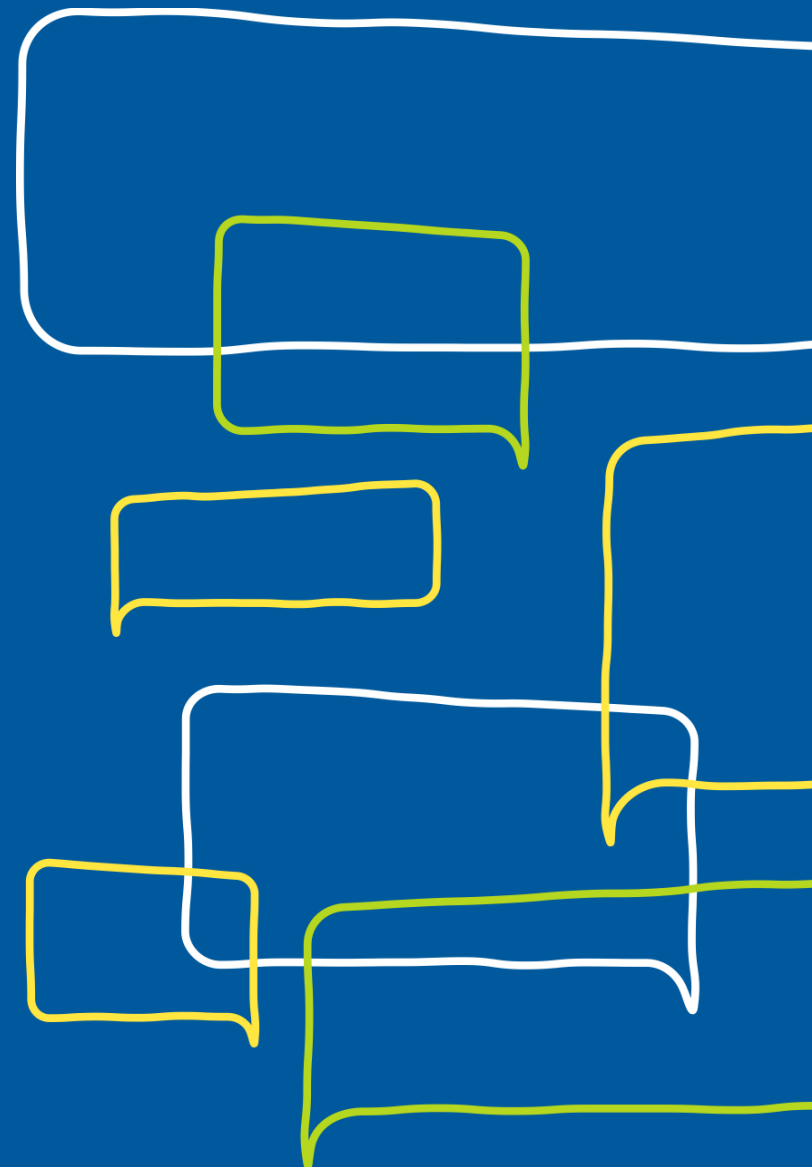
- FSGS is a **rare type of kidney disease** that causes scarring on the kidney's tiny filters. Over time, FSGS can lead to **kidney failure**.
- If you notice changes in your urine, new or increased swelling, sudden weight gain or you're feeling more tired than usual, ask your health care professional about getting a **kidney biopsy**.

Key takeaways (continued)

- If you're diagnosed with FSGS, your care team will create a **personal treatment plan** tailored to your needs.
- If you have FSGS, you can **protect your kidney health** by:
 - Following a kidney-friendly eating plan
 - Staying active
 - Working together with your care team
 - Taking medicines as directed
 - Watching for changes in your body



Questions?



Learn more about FSGS

Check out these resources from the American Kidney Fund to learn more:

- [FSGS webpage](#)
- [FSGS guide](#)
- [Kidney biopsy webpage](#)
- [Kidney biopsy guide](#)

Want to talk? Get in touch!

- [KHC Name]
 - Email:
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