NATIONAL KIDNEY FOUNDATION®

# NEWLY DIAGNOSED WITH IgAN: WHAT YOU NEED TO KNOW

## I received an IgAN diagnosis. Now what?

Receiving a new diagnosis can catch you off guard. It can feel overwhelming, especially if it is a condition that you may not have heard before, like **IgA Nephropathy (IgAN).** You should know that you are not alone. Understanding your condition, preparing for the next steps, and getting help are important ways to take control of your own health.

## What is IgAN?

**IgAN** is a kidney disease. It happens when a protein made by your immune system, called **IgA**, causes damage to the tiny filters in the kidneys, called **glomeruli.** When these filters are damaged, your kidneys may have trouble removing waste and extra fluid from your blood. IgAN is also called Berger's disease.

IgAN can look different from person to person, which is why follow-up testing and care based on your individual situation are so important.

### *What are the next steps?*

Here are some of the next steps you can take:

- **Schedule or confirm your next nephrology visit,** if you have not done so.
- **Schedule other medical appointments** as needed, including primary care or other specialists.
- **Don't be afraid to ask for help.** Ask a friend or loved one for help with managing your care, or if you need someone to go with you to appointments for emotional support. Ask your healthcare team for help and advice. You can also contact organizations like the National Kidney Foundation (855-NKF-CARES).
- **Learn your kidney numbers.** Ask about your urine albumin-to-creatinine ratio (UACR) or protein-to-creatinine ratio (UPCR). These tests check for excess protein in the urine, which is a sign of kidney damage. You should also ask about your estimated glomerular filtration rate (eGFR), which is a blood test that estimates how well your kidney's are filtering.
- **Check your blood pressure regularly.** High blood pressure can worsen kidney damage, and IgAN can also raise blood pressure.

## How to prepare for your next appointments

Being prepared helps you make the most of your time with your healthcare team and ensures all your questions and concerns are answered.

- Before the appointment gather your information, including ID and your health insurance card.
- Make a list of any other medical conditions you have.
- Bring exact names and dosages of every prescription drug, over-the-counter medication, vitamin, and herbal supplement you take. Be ready to review them with your healthcare team.
- Note if anyone in your family has a history of kidney disease.
- Write down any symptoms you've noticed (e.g., swelling in your face or legs, fatigue, foamy urine, or changes in how often you urinate).
- Bring a list of questions you might wish to ask.



## Questions to ask

Don't hesitate to bring a paper or notebook with your questions written down. Questions to consider asking can include the following:

### *Questions about testing*

- What is my current uPCR or UACR? How about my eGFR? What do they mean?
- How often should I have my UPCR/UACR and eGFR and checked?
- What can I do before blood and urine testing to ensure that my lab results are accurate?
- Which lab tests can help guide treatment decisions for my IgAN?
- What do my lab results mean?
- Can you please explain the results from my kidney biopsy?
- Will I need a repeat kidney biopsy?
- Should my family members be checked for IgAN?

### *Questions about treatment*

- Which signs and symptoms should prompt a call to my healthcare team?
- What blood pressure goal should I aim for?
- What lifestyle changes should I make to ensure the best outcomes with IgAN?
- What medicines may help protect my kidneys, and what side effects should I watch for?
- Are there medicines or supplements I should avoid?
- Should I consider a clinical trial?

### *Questions about support*

- Where can I find more information on IgAN that I can trust?
- Where can I find peer support groups or communities in person or online?
- What financial support programs are available for a person with IgAN?

## Remember

IgAN is a condition to check and manage over time. By learning your lab numbers, keeping up with appointments, asking questions, finding support, and working with your healthcare team, you can take meaningful control of your kidney health.



**For more information, contact the National Kidney Foundation**

Toll-free help line: 855.NKF.CARES or email: nkfcares@kidney.org

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