

What Now?

What to Expect When IgAN Is Suspected



What is IgAN?

- IgAN is short for immunoglobulin A nephropathy. IgAN is a type of kidney disease.
- It is an uncommon disease. Approximately 200,000 people in the United States have IgAN.

What causes IgAN?

- Kidney experts think that 4 events, or “hits,” lead to IgAN.
 - **Hit 1:** For some reason, a person’s body makes more of an unusual type of antibody known as galactose-deficient IgA1 (gd-IgA1).
 - **Hit 2:** The person’s body recognizes gd-IgA1 as not normal, and it makes more antibodies, this time against gd-IgA1. This starts an immune response to get rid of the “strange” gd-IgA1 antibodies.
 - **Hit 3:** To help get rid of gd-IgA1, the new antibodies bind to it and form complexes.
 - **Hit 4:** The complexes—which are large clusters of antibody proteins—become stuck in the part of the kidney that filters what should leave the body away from what should stay. Unfortunately, this signals the body to attack the antibody clusters, and the kidney becomes damaged in the process. **This leads to a chronic kidney disease.**

Why me?

- Genetics may determine whether you develop IgAN. It runs in families.
- It may be triggered by an infection. As the body responds to the infection, it may make antibodies that mistakenly identify gd-IgA1 antibodies as part of an infection.

Why does my healthcare professional think I have IgAN?

- Your healthcare professional recognized signs and symptoms of kidney problems, such as swelling, sudden weight gain, blood in your urine, protein in your urine.
- If they cannot identify another more common cause, they may test for IgAN.

What type of testing will I need?

- To diagnose IgAN, your healthcare professional will take a small sample—a biopsy—of your kidney for microscopic examination.
- This is currently the only way to diagnose IgAN.
- **It is important to get a diagnosis because IgAN can progress to kidney failure. As many as one half of people with IgAN develop kidney failure within 20 years of diagnosis, IF IT GOES UNTREATED.**



What type of treatment will I need?

- Your healthcare professional will examine the sample from your kidney and run some other tests. They will use the test results to determine whether and how fast your IgAN might progress. Based on those results, they will come up with a treatment plan.
- **Important goals of treatment are to slow kidney damage and reduce the protein getting into your urine, which will also help slow kidney damage.**
- Treatments for this include: blood pressure control, use of medications known as ACE inhibitors or ARBs, lifestyle approaches such as diet, and cardiovascular health improvement.

Are there any other treatments?

- Research is finding new medications that can help stop the “4 hits” and slow IgAN progression. If you do not respond well to treatments listed in the previous section, your healthcare professional may use 1 or more of these or suggest that you enroll in a clinical trial.

Additional resources

- National Institute of Diabetes and Digestive and Kidney Disease:
niddk.nih.gov/health-information/kidney-disease/iga-nephropathy
- Kidney Disease: Improving Global Outcomes:
kdigo.org/wp-content/uploads/2024/12/KDIGO-IgAN-Infographics_2024.pdf



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