

Welcome to a C3G and primary  
IC-MPGN resource that's

# CENTERED ON YOU AND YOUR NEEDS

This resource is designed to offer you and  
your loved ones valuable information  
about C3G and primary IC-MPGN.

Find information on:

[Understanding C3G and primary IC-MPGN >](#)

[What causes C3G and primary IC-MPGN >](#)

[Navigating life with C3G or primary IC-MPGN >](#)

[Trusted resources and advocacy organizations >](#)

[Glossary of definitions >](#)



Actor portrayal.

Every person's experience with C3G/primary IC-MPGN is unique. The content in  
this brochure is provided for informational purposes only and does not contain  
individual treatment or medical advice. Always talk to your healthcare provider  
about questions you may have about the disease, its symptoms, and treatment.

C3G=C3 glomerulopathy; IC-MPGN=immune complex membranoproliferative  
glomerulonephritis.

## Understanding C3G and primary IC-MPGN



### The important role of your kidneys



Your kidneys are essential organs that filter your blood, helping to maintain a healthy balance of nutrients and electrolytes.



Your kidneys contain millions of tiny filters called **glomeruli**. These filters play a critical role in maintaining your body's health by removing and turning waste, toxins, and excess fluid in your blood into urine, and retaining essential proteins and nutrients.



In conditions like C3G or primary IC-MPGN, the glomeruli become targets of inflammation and damage. Over time, they are unable to filter blood effectively.

C3G and primary IC-MPGN are rare kidney diseases that can affect people of all ages. They can lead to serious kidney damage and impact how your kidneys work.

# The complement system is a critical part of the immune system

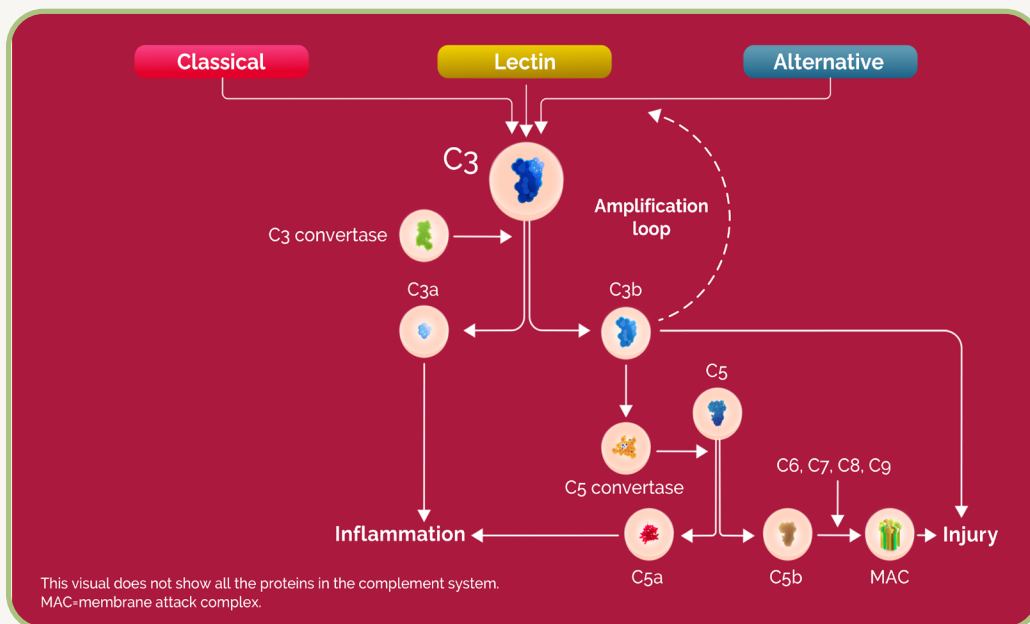


## Your complement system helps to:



- Fight infections
- Rid your body of infectious germs or damaged cells

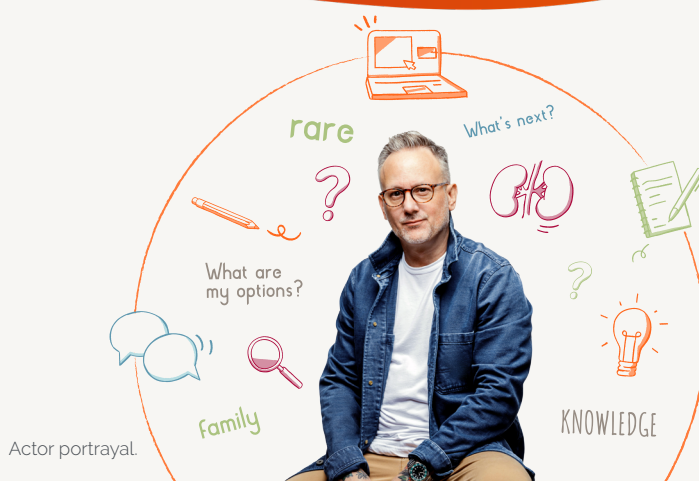
The complement system is made up of a network of proteins called complement proteins.



**Signals activate the system by causing a chain reaction:**  
One complement protein activates the next complement protein and continues down the network to protect the body from infections, clear out damaged cells, and promote inflammation to heal injuries.

**The complement system is always active to protect your body, but it's the overactivity that leads to kidney damage.**

## The impact of C3G or primary IC-MPGN on your body

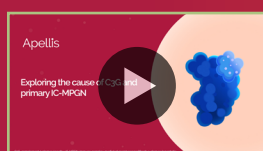


The complement system is part of your immune system and always active. C3G and primary IC-MPGN are caused when it is overactivated.

The **C3 protein** plays a central role in this process. When the complement system becomes overactivated, C3 is broken down excessively. In C3G, this leads to C3 breakdown fragments in the kidneys. In IC-MPGN, higher levels of immunoglobulins (antibodies) are also found in the kidneys. Both of these cause kidney damage.

**The overactivation of the complement system has a progressive, worsening effect on your kidneys**

As the complement system stays overactivated, kidney damage continues:



To see how your complement system works and the impact of its overactivation, watch the video on [RareKidneyAndYou.com](https://RareKidneyAndYou.com) >

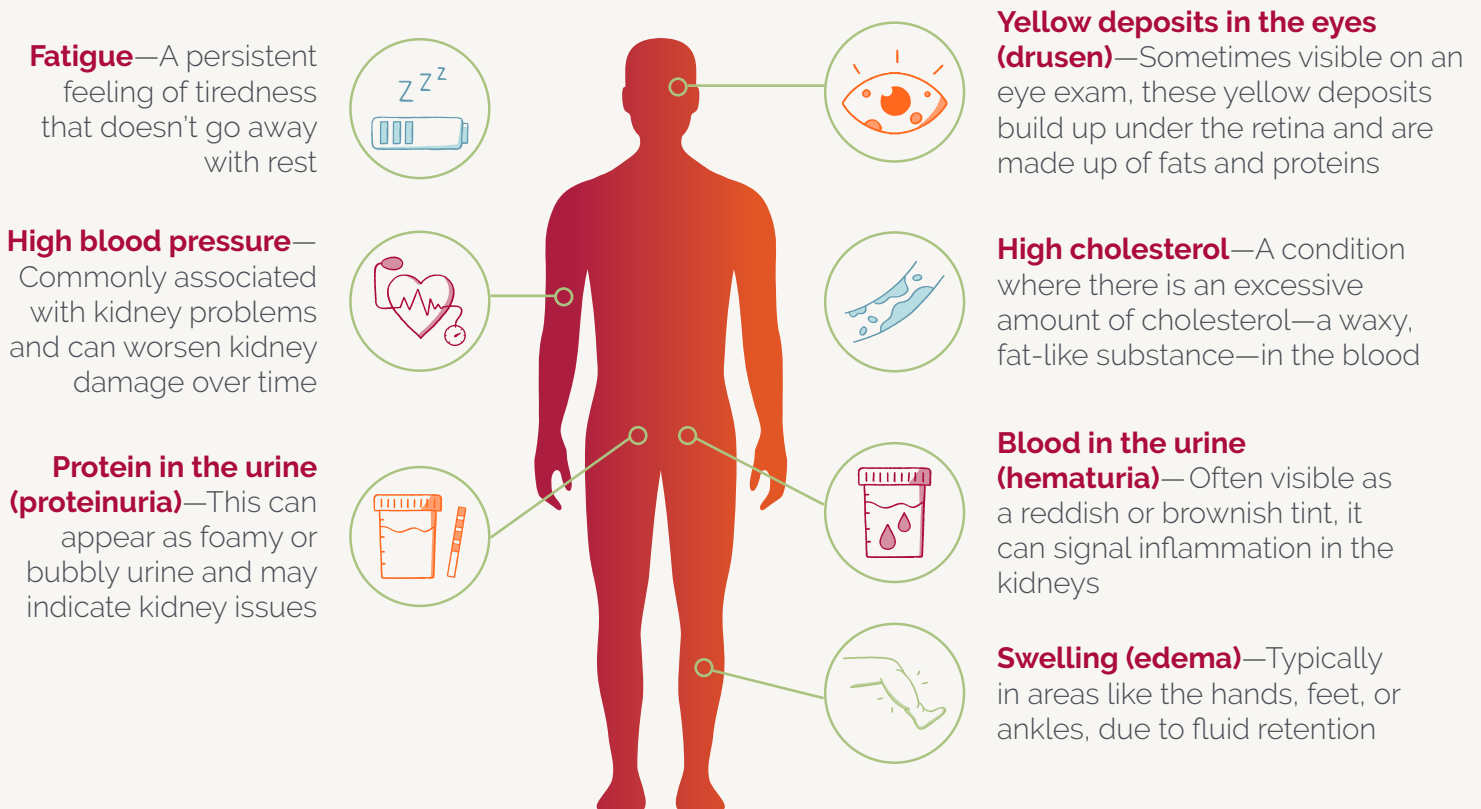


## Signs and symptoms of C3G or primary IC-MPGN

Actor portrayal.



Signs and symptoms of C3G and primary IC-MPGN vary but can include:



These symptoms may not always appear together, and they vary in severity from person to person.

While C3G and primary IC-MPGN progress in similar ways, their differences are important for diagnosis.

# Confirming a C3G or primary IC-MPGN diagnosis



## Initial testing

To understand how your kidneys are functioning and if they are impacted by C3G or primary IC-MPGN, your doctor will order tests for:

### Proteinuria

High levels of protein in the urine

Urine testing

### eGFR

How well your kidneys are functioning

Blood testing

### Others

Tests for levels of C3 in the blood

**Genetic testing and immunological testing**



### Getting a definitive diagnosis

To confirm a diagnosis of C3G or primary IC-MPGN, your doctor will perform a **kidney biopsy** to check for a buildup of C3 fragments and immunoglobulin deposits in kidney tissue as shown through imaging (known as staining).

eGFR=estimated glomerular filtration rate.

Confirming a C3G or primary IC-MPGN diagnosis will help your care team know what next steps to take.

## Navigating life with C3G or primary IC-MPGN

Actor portrayal.



### More treatment approaches are urgently needed to manage C3G and primary IC-MPGN effectively



Currently, management approaches are limited in the aspects of C3G and primary IC-MPGN they are able to address

- Some medications and dietary changes help manage symptoms of C3G and primary IC-MPGN. These include steroids, blood pressure medications, and reducing sodium in your diet
- Complement inhibitors vary and target different proteins or pathways in the complement system
- When these diseases are not adequately managed, they can lead to ongoing kidney inflammation and damage. This can cause kidney function to worsen over time, and potentially result in the need for dialysis and/or a kidney transplant

#### A kidney transplant can restore function, but it's not a cure

Almost 9 in 10 people with C3G see their disease return after a kidney transplant because the underlying cause—complement overactivation—remains.

- The complement system can stay overactivated and continue to create a buildup of C3 fragments, causing injury in the transplanted kidney

Because C3G and primary IC-MPGN are rare, complex, and affect people of all ages, it is clear that more research and work need to be done.

## You are not alone in this journey

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### Additional helpful resources

Staying connected with your care team and accessing reliable resources can help you manage C3G or primary IC-MPGN while staying informed about what the future holds.



AAKP is dedicated to improving the lives and long-term outcomes of kidney patients through education, advocacy, patient engagement, and the fostering of patient communities.

**[AAKP.org](https://aakp.org)** >



The American Kidney Fund (AKF) works on behalf of the 1 in 7 Americans living with kidney disease, and the millions more at risk, to support people wherever they are in their fight against kidney disease—from prevention through transplant.

**[KidneyFund.org](https://kidneyfund.org)** >



The Foundation aims to eliminate preventable kidney disease, improve the patient experience, and ensure equitable access to all aspects of quality kidney care, from diagnosis to transplantation.

**[Kidney.org](https://kidney.org)** >



NephCure's mission is to empower people with rare, protein-spilling kidney disease to take charge of their health while leading the revolution in research, new treatments, and care.

**[NephCure.org](https://nephcure.org)** >



The National Organization for Rare Disorders (NORD®) builds community and creates a lasting impact by improving the health and well-being of people with rare diseases by driving advances in care, research, and policy.

**[RareDiseases.org](https://rare diseases.org)** >

**Please note:** These resources are meant to be informational only and are not intended to replace medical advice. Always talk to your healthcare provider about any medical decisions.

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## Glossary of terms

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**C3 protein:** A protein that plays a central role in the complement system.

**C3G (C3 glomerulopathy):** A rare kidney disease caused by overactivation of the complement system, a part of the immune system that helps protect against infections. This disease is characterized by dominant C3 deposits with minimal or no immunoglobulin deposits on staining.

**Complement system:** Part of the immune system made up of a network of proteins that work together to help protect the body from infections, clear out damaged cells, and promote inflammation to heal injuries.

**eGFR (estimated glomerular filtration rate):** A measurement of how well your kidneys are filtering waste from your blood. It calculates this based on your blood creatinine levels, age, and gender.

**Genetic testing:** A blood test that involves analyzing a person's DNA to identify changes or mutations in genes, chromosomes, or proteins.

**Glomeruli:** Tiny, ball-shaped structures within the kidneys that act as the primary filtering units of the blood.

**Immunological testing:** A blood test that evaluates the functioning of the immune system by measuring the levels and activity of immune components, such as antibodies, complement proteins, or immune cells.

**Kidney biopsy:** A medical procedure in which a small sample of kidney tissue is removed and examined under a microscope or other imaging tools to diagnose or monitor kidney diseases.

**Primary IC-MPGN (immune complex membranoproliferative glomerulonephritis):** A rare kidney disease caused by overactivation of the complement system, a part of the immune system that helps protect against infections. This disease is characterized by dominant immunoglobulin deposits, or equal amounts of both immunoglobulin and C3 deposits on staining images.

**Proteinuria:** High levels of protein in urine that is detected through a urine test (dipstick test and/or urinalysis).

# Staying informed means staying empowered

Get connected to support and  
resources that are centered on you

You're not alone on your journey with  
**C3G or primary IC-MPGN**. Stay informed,  
supported, and connected to resources that  
can help you along the way.

Visit  
[RareKidneyAndYou.com](https://RareKidneyAndYou.com) >  
for more information,  
updates, and  
support resources.



Actor portrayal.

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