

# **GLOMERULAR DISEASE:**

## ***What You Need To Know***



National  
Kidney  
Foundation™

[www.kidney.org](http://www.kidney.org)

## **National Kidney Foundation's Kidney Disease Outcomes Quality Initiative**

**The National Kidney Foundation's Kidney Disease Outcomes Quality Initiative (NKF-KDOQI™) develops guidelines that help your doctor and healthcare team make important decisions about your treatment plan. The information in this brochure is based on the NKF-KDOQI recommended guidelines for glomerular disease.**

# GLOMERULAR DISEASE: WHAT YOU NEED TO KNOW

- Ask your doctor for the name of your disease.
- Read about your disease on the pages that have its name and matching color. For example, if you have lupus nephritis, read the pages that have a red tab.
- All patients and their families should read the pages with an orange tab.

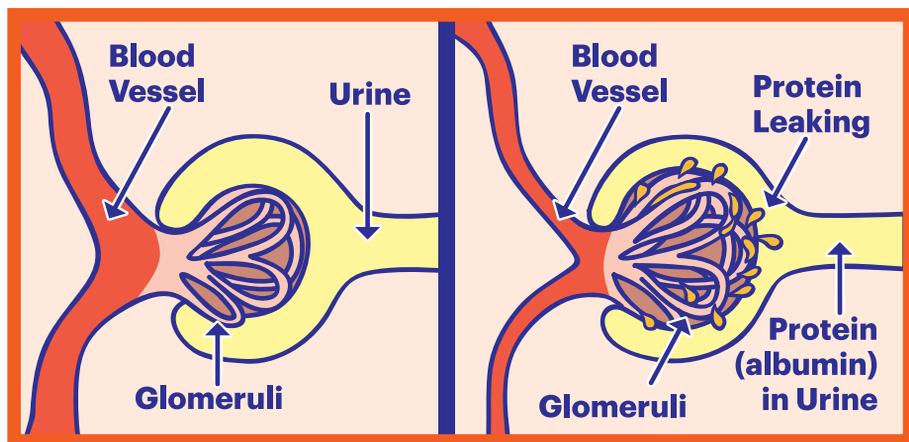
## TABLE OF CONTENTS

<b>■ ALL</b>	Information for ALL Patients and Families . . . . .	4, 26
<b>■ FSGS</b>	Focal Segmental Glomerulosclerosis. . . . .	6
<b>■ IgAN</b>	ImmunoGlobulin A Nephropathy . . . . .	9
<b>■ LN</b>	Lupus Nephritis . . . . .	11
<b>■ MCD</b>	Minimal Change Disease. . . . .	16
<b>■ MN</b>	Membranous Nephropathy . . . . .	19
<b>■ MPGN</b>	Membranoproliferative Glomerulonephritis . . . . .	23

## ALL Patients and Families

### What is glomerular disease?

- Your kidneys have about one million tiny filters called **nephrons**. Each nephron has a **glomerulus**, which you can see in the picture below. A glomerulus is a ball of tiny blood vessels that filter your blood. More than one glomerulus is called **glomeruli**. Glomeruli work like the strainers used in cooking. While blood moves through them, they let waste and extra water pass into the nephrons' tubes to make urine. But at the same time, they hold back the protein and blood that your body needs.
- Glomerular disease can cause your glomeruli to leak blood or protein into your urine. Your urine may look pink or light brown from blood, or it may be foamy from protein.



NEPHRON

- A high level of protein in the urine is called **proteinuria**.
- Some people with glomerular disease have **nephrotic syndrome**, which includes **edema**, or swelling, usually of the ankles, **nephrotic-range proteinuria** (high level of protein in the urine of 3.5 grams per day or more), **hypoalbuminemia**, a low-level of the protein albumin in the blood, and high cholesterol. Other problems caused by nephrotic syndrome include high blood pressure, increased risk for getting infections, and blood that clots more than normal.

Other people may not have nephrotic syndrome, but still have some signs of it, such as protein in their urine, edema, and high blood pressure. They may also have other signs that are not part of nephrotic syndrome, such as blood in the urine, inflamed glomeruli, and lower kidney function because of kidney damage. If you have all of these extra signs, then you have **nephritic syndrome**.

- Over time, glomerular disease may stop the kidneys from getting rid of wastes in your blood. When this goes on for a long time, waste builds up in your blood, and you may have **chronic kidney disease** (kidney disease for 3 or more months). This can then progress to **kidney failure** (the kidneys stop working).
- All of the diseases described here are diagnosed by a kidney biopsy, in which a tiny piece of kidney is examined under a microscope.
- ***There are treatments for glomerular disease.***
- ***The sooner you start treatment, the better!***

## Focal Segmental Glomerulosclerosis (FSGS)

### What is focal segmental glomerulosclerosis?

Focal segmental glomerulosclerosis (FSGS) causes scarring (sclerosis) in different spots throughout the kidney. It usually only affects one section of a glomerulus and only a small number of glomeruli within the spots that are scarred.

- **Primary FSGS** starts in the kidney and is not caused by another disease or drug. It comes from **genes** you are born with (like the genes that determine your eye color, you can also be born with genes that determine if you will have kidney disease). Doctors have found some of the genes that cause FSGS. They are using this knowledge to study new treatments for FSGS.
- FSGS can have a **secondary** cause, which means it is caused by another disease or a drug. Examples include: viruses such as HIV or drugs such as the anabolic steroids abused by some athletes (these steroids are different from the type of steroids that you may get as part of your treatment).
- FSGS can also be secondary to another type of glomerular disease that you had already before you got FSGS.
- Other cases of FSGS are **idiopathic**, which means that their cause is not known.
- Both children and adults can get FSGS. The number of people who have FSGS is growing in the United States.
- Proteinuria is one of the main signs of FSGS.

## What tests are done to find out if you have FSGS?

- **Urine test** to find protein and blood
- **Blood test** to find levels of protein, cholesterol, and wastes
- **Glomerular filtration rate (GFR)**, a blood test to know how well the kidneys are filtering
- **Kidney biopsy** to look at a tiny piece of the kidney under a microscope, in order to diagnose FSGS
- **Genetic testing** may be done to see if you were born with genes that caused your kidney disease. This information may help your doctor decide what type of treatment is best for you.

## What are the treatments for FSGS?

- The type of treatment you get depends on the cause of your FSGS. Everyone is different and your doctor will make a treatment plan that is right for your type of FSGS.
- If your FSGS is caused by another disease and you get treated for it, then your FSGS may go away.
- If a certain drug has caused your FSGS and you stop taking it, then your FSGS may go away.
- Primary or idiopathic FSGS may be treated with a drug called a **corticosteroid**, usually **prednisone**. It reduces the inflammation in your kidneys caused by the body's defense system. This defense system is known as your **immune system**, which is "turned on" by glomerular disease. Corticosteroids do have side effects, and not all patients will benefit from this type of treatment. You need to discuss the benefits versus

the risks of this treatment with your doctor. Genetic testing may help you know if your type of FSGS will respond to this treatment or not.

- If you cannot take prednisone, then your doctor may suggest another type of drug called a **calcineurin inhibitor (CNI)**, which stops your body's defense system from causing inflammation in your kidneys.
- If you do not have nephrotic-range proteinuria, and you respond well to **supportive care** (treatments that have fewer risks), then you may not need prednisone. Your kidney biopsy results will also help your doctor decide if you need prednisone.
- For other options see page 29.
- Supportive care includes using a blood pressure drug known as an **ACE inhibitor** or an **ARB**. These two types of drugs can control high blood pressure and reduce the amount of protein in the urine. Pills that remove extra fluid from your body, called **diuretics**, and a low-salt diet may help reduce edema.



## Immunoglobulin A Nephropathy (IgAN)

### What is immunoglobulin A nephropathy?

- Immunoglobulin A nephropathy is called **IgAN** for short.
- **Immunoglobulin A (IgA)** is a protein that helps the body fight infections.
- IgAN is a kidney disease that occurs when IgA stays stuck in the glomeruli.
- When IgA stays in the glomeruli for many years, it can cause the kidneys to leak blood and protein into the urine.
- **Primary IgAN** starts in the kidney and is not caused by another disease or drug, and is the most common type of IgAN.
- **Secondary IgAN** is caused by other diseases such as celiac disease, and is not common.
- Other less common types of IgAN are called **atypical forms of IgAN**.
- Each person may have a different set of signs and symptoms from IgAN, from some blood in the urine to all of the others already mentioned, including nephrotic syndrome (see section “All Patients and Families” on p. 5).

### What tests are done to find out if you have IgAN?

- **Urine test** to find protein and blood
- **Blood test** to find levels of protein, cholesterol, and wastes
- **Glomerular filtration rate (GFR)**, a blood test to know how well the kidneys are filtering
- **Kidney biopsy** to look at a tiny piece of the kidney under a microscope in order to diagnose IgAN

## What are the treatments for IgAN?

- When the protein level in your urine or your blood pressure is too high, your doctor will recommend an **ACE inhibitor** or an **ARB**. These two types of drugs can control high blood pressure and reduce the amount of protein in the urine. Pills that remove extra fluid from your body, called **diuretics**, and a low-salt diet may reduce edema. These types of treatment are called **supportive care** because they have few risks.
- If you still have too much protein in your urine after getting supportive care for 3 to 6 months, then your doctor may recommend a drug called a **corticosteroid**, usually **prednisone**. It reduces the inflammation in your kidneys caused by the body's defense system. This defense system is known as your **immune system**, which is "turned on" by glomerular disease. Corticosteroids do have side effects, so you need to discuss the benefits versus the risks of this treatment with your doctor. You will only get prednisone if you still have good kidney function. If your kidney function is poor, then prednisone will not help.
- If protein in the urine stays too high after 3 to 6 months of supportive care, experts suggest that you also use fish oil. *But first check with your healthcare team to make sure that it is safe for you.* They will recommend a reliable brand and the correct amount you should take.
- Atypical forms of IgAN may need other medications.
- For other options see page 29.

## Lupus Nephritis (LN)

### What is lupus nephritis?

- Lupus nephritis (LN) is an inflammation of the kidneys caused by the disease **systemic lupus erythematosus (SLE)**, or **lupus** for short.
- Lupus is an **autoimmune disease** in which the body's defense system (**immune system**) does not work right and attacks the body's own cells and organs, rather than defending them. Lupus causes inflammation of the small blood vessels and sometimes the kidneys by attacking them like they would attack a disease.
- LN is divided into 6 classes, based on the type of damage the disease has caused. For example, class 1 causes less damage than class 3.
- Some signs of LN include foamy urine, edema, and high blood pressure.

### What tests are done to find out if you have LN?

- **Urine test** to find protein and blood
- **Blood test** to find levels of protein, cholesterol, and wastes
- **Glomerular filtration rate (GFR)**, a blood test to know how well the kidneys are filtering
- **Kidney biopsy** to look at a tiny piece of the kidney under a microscope in order to diagnose LN
- **Blood test** for **antiphospholipid antibodies** at least once during your disease. If you have these antibodies, you might have an increased risk for getting blood clots. Our immune system makes **antibodies** to defend our bodies

from harmful diseases and substances. But sometimes these antibodies do not work right and they attack the body itself.

## What are the treatments for LN?

- The type of treatment you get depends on what class of disease you have.
- **Class 1 and 2** (if the level of protein in the urine is not very high) require the standard treatment for lupus. In other words, no extra treatment for kidney disease.
- **Class 2** with a *high* amount of protein in the urine is treated with either a drug called a **corticosteroid**, usually **prednisone**, or a **calcineurin inhibitor (CNI)**. Prednisone reduces the inflammation in your kidneys caused by the body's defense system. This defense system is known as your **immune system**, which is "turned on" by glomerular disease. A **calcineurin inhibitor (CNI)** also stops your immune system from causing inflammation in your kidneys. These medications have side effects, so you need to discuss the benefits versus the risks of these treatments with your doctor.
- **Class 3 and 4** require two phases of treatment, **initial** and **maintenance**. Initial treatment includes a stronger dose of drugs in order to quickly decrease inflammation in the kidneys. These drugs include prednisone, along with either **cyclophosphamide** or **mycophenolate mofetil (MMF)**, both of which decrease your immune system's response to glomerular disease. You would take these drugs for 3 to 6 months. During this phase, you may or may not go into **remission** (the disease is not active and you do not have signs of the disease, such as proteinuria).

- The maintenance phase includes lower doses of prednisone, along with either **azathioprine** or MMF, both of which decrease your immune system's response to glomerular disease. A CNI may be used for people who cannot take azathioprine or MMF. After you are in complete remission, you will get maintenance therapy for at least 1 year before starting to decrease and finally ending therapy.
- If you are going to get cyclophosphamide, discuss with your doctor the benefits of intravenous therapy (getting the drug through a vein) instead of taking it as a pill. In LN, intravenous cyclophosphamide is usually preferred. When you get cyclophosphamide, you should also get **mesna**, a drug that protects your bladder during treatment.
- You should discuss with your doctor the effect of treatment on your chances of having children. There are ways to make sure that treatment is less harmful to this process.
- You should always discuss the risks versus the benefits of any of the treatments you receive, considering your overall health and the health of your kidneys. There are times when the side effects of certain treatments are not worth the risk to your health. Likewise, if your kidney function or overall health is too poor, treatment may do more harm than good.
- **Class 5** patients with normal kidney function and only a small amount of protein in the urine should only get **supportive care** (treatments that have little or no risks, like following a healthy diet to protect your kidneys). They should get prednisone and other drugs to treat lupus symptoms that only affect other parts of the body, and not the kidneys. But if these patients have nephrotic-

range proteinuria that does not go away, then they should get prednisone plus one of these drugs that weaken the immune system: cyclophosphamide, a CNI, azathioprine, or MMF, depending on the special needs of each patient.

- **Class 6** patients should only receive prednisone and other drugs to treat the symptoms of lupus found in other parts of the body, and not in the kidney. For this class, these drugs will not help the kidneys.
- Experts suggest that all patients with LN of any class be treated with **hydroxychloroquine** in order to reduce lupus flare ups. Hydroxychloroquine stops your immune system from causing damage to your body.
- Experts suggest that all patients with LN of any class take blood pressure pills called **ACE inhibitors** or **ARBs** in order to protect their kidneys. *Both of these drugs can cause birth defects, so you should also be on birth control.* If you are pregnant, or want to become pregnant, discuss which drugs to use instead with your doctor.
- Relapse is usually treated by using the same treatment plan that brought you into remission the first time. You should discuss with your doctor if it would be better to use a drug other than cyclophosphamide for your relapse so that your lifetime dose of this drug is kept at a safe level.
- **Resistant disease** does not respond to the usual treatments and there are other drugs that your doctor may think are helpful. These drugs include **rituximab**, **immunoglobulin**, or a CNI, all of which stop the immune system from causing damage to the kidneys.
- Children usually receive the same treatment as adults, but drug doses are based on their size and level of kidney function.

- It is recommended that women not become pregnant until they have a complete remission of LN. If you do become pregnant and are not in remission, your doctor will want you to stay on certain drugs. Even if you are in remission, it is recommended that you continue taking hydroxychloroquine. It has been found to be safe during pregnancy and prevents flare ups of both lupus and LN. You should discuss with your doctor the need to stop cyclophosphamide, MMF, ACE inhibitors, and ARBs because all these drugs can cause birth defects. Your doctor may also recommend that you take low dose aspirin because it may help protect the fetus. Azathioprine and prednisone are safe during pregnancy. Blood pressure control is very important during pregnancy, but use the preferred drugs **labetalol** and/or **nifedipine**.
- For other options see page 29.



## Minimal Change Disease (MCD)

### What is minimal change disease?

- Minimal change disease (MCD) is one of the most common causes of nephrotic syndrome, especially in children.
- MCD causes the signs and symptoms of nephrotic syndrome to happen much quicker than they would with other glomerular diseases. For example, you could have a large amount of swelling in your ankles within one day rather than it building up over many days.
- The glomeruli of people with MCD look normal under an ordinary microscope. But under a high power microscope, the “minimal changes” in the glomeruli can be seen.
- The kidneys’ ability to clean wastes from the blood is usually not damaged, especially in children
- MCD can be **secondary** if it caused by another disease or drug, but this is rare. MCD is usually **primary**, which means that it starts in the kidney for unknown reasons.
- MCD is the most common cause of the nephrotic syndrome in children.

### What tests are done to find out if you have MCD?

- **Urine test** to find protein and blood
- **Blood test** to find levels of protein, cholesterol, and wastes
- **Glomerular filtration rate (GFR)**, a blood test to know how well the kidneys are filtering
- **Kidney biopsy** to look at a tiny piece of the kidney under a microscope in order to diagnose MCD. Because MCD

is the most common cause of the nephrotic syndrome in children, they first get treated for MCD before getting a biopsy. Only if treatment does not improve their symptoms right away, is a biopsy done to see if there is another cause of their symptoms

## What are the treatments for MCD?

- MCD is usually easier to treat than other glomerular diseases, especially in children.
- The treatment plan for the nephrotic syndrome in children with MCD is usually **prednisone** (a drug that is a type of **corticosteroid**) for at least 12 weeks. It is very important to not stop treatment earlier than this, even if your child starts getting better very quickly. By sticking to the full treatment plan, your child will be less likely to relapse. Fewer relapses will mean better health and fewer side effects from drugs in the long term. If a child has relapses, then the doses and times for taking prednisone are changed, depending on how often the child relapses. If side effects from prednisone are a problem, then other drugs may be used, including **cyclophosphamide**, **chlorambucil**, **levamisole**, a **calcineurin inhibitor (CNI)**, and **mycophenolate mofetil (MMF)**. All of these drugs, including prednisone, stop your body's defense system from damaging the kidneys. Your body's defense system is known as your **immune system**, which is "turned on" by glomerular disease.
- For children who do not respond to prednisone alone (**steroid-resistant nephrotic syndrome**, or **SRNS** for short), a CNI combined with low-dose prednisone is tried first. If that does not work, then MMF or high-dose prednisone is used, or a combination of the two may also be tried. It is recommended that children with SRNS also take an **ACE inhibitor** or **ARB**. These two drugs can

control high blood pressure and reduce the amount of protein in the urine.

- The treatment plan for the nephrotic syndrome in adults with MCD usually starts with prednisone. Most patients start getting better within 8 weeks or less. The length of treatment will also depend on how bad the side effects from prednisone may be. If you have a lot of relapses or have become dependent on prednisone to keep the disease under control, then you may need cyclophosphamide. If that is not effective, then you may need a CNI (especially if you want to be able to have children because cyclophosphamide may cause problems with this process). If you are not able to take any of these drugs, then you may be given MMF.
- For other options see page 29.

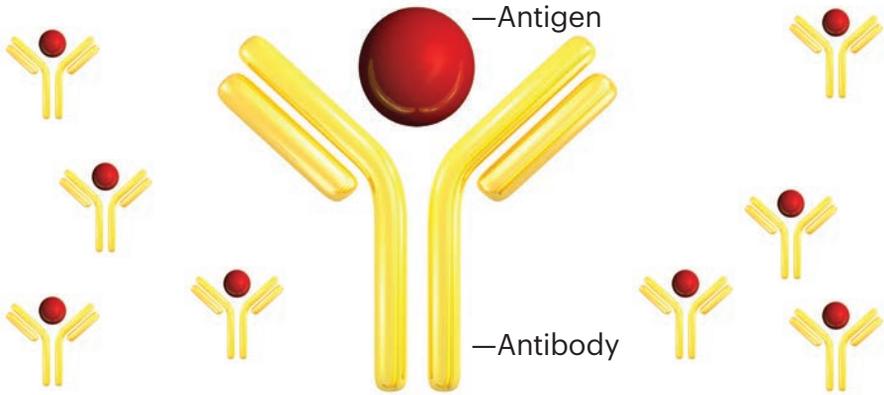


## Membranous Nephropathy (MN)

### What is membranous nephropathy?

- Membranous nephropathy (MN) is an **autoimmune disease**, which is caused when your defense system turns against you and harms your body rather than protecting it. Your defense system is known as your **immune system**, which is “turned on” by glomerular kidney disease.
- MN usually causes nephrotic syndrome and may cause kidney failure over time.
- There are two kinds of MN: **idiopathic MN**, of which the cause is unknown, is more common than **secondary MN**, which is caused by another disease or drug. The most common causes of secondary MN are hepatitis B virus, non-steroidal anti-inflammatory drugs or NSAIDs, systemic lupus erythematosus (lupus for short), and cancer. Other diseases and infections can also be causes.
- MN causes the walls of the glomeruli to become thick when **immune complexes** get stuck inside them. (See the picture.) Immune complexes are formed in the kidney when **antibodies** from the body’s defense system attack dangerous substances called **antigens** formed by disease.
- Some people with MN go into **spontaneous remission**, which means it suddenly goes away without treatment. Some remain stable, and others progress to kidney failure.

## *Immune Complexes that Get Stuck in Glomeruli*



### **What tests are done to find out if I have MN?**

- **Urine test** to find protein and blood
- **Blood test** to find levels of protein, cholesterol, and wastes
- **Glomerular filtration rate (GFR)**, a blood test to know how well the kidneys are filtering
- **Kidney biopsy** to look at a tiny piece of the kidney under a microscope in order to diagnose MN. The kidney biopsy may show if you have a certain type of antibody that your body usually makes when you have MN, and this may help your doctors decide the best treatment.

### **What are the treatments for MN?**

- After it is confirmed that you have MN, your doctor will follow up with you very closely for 6 months. This waiting period allows time to see if you go into **remission** (the disease stops being active) without being exposed to strong drugs. During this waiting time, you will be given **supportive care** (treatments that have little or no risk).

This type of care may include an **ACE inhibitor or an ARB**, drugs that reduce high blood pressure and proteinuria. Pills that remove extra fluid from your body (**diuretics**) and a low-salt diet may be used to reduce edema.

- If MN does not improve after 6 months and you have very bad symptoms, then you will get a **corticosteroid**, usually **prednisone** and **cyclophosphamide** (these drugs stop the immune system from causing damage to your kidneys), on a special schedule over 6 months. After this treatment, your doctor will follow up closely with you for another 6 months while you get supportive care. If you relapse, you may get the same treatment you got the first time you went into remission.
- Other treatment plans include a **calcineurin inhibitor (CNI)**, another drug that stops the immune system from hurting your kidneys, but it may take a longer time on this treatment to achieve remission.
- Children usually get the same type of treatments as adults. It is very rare for a child to have MN, so it is important to check for anything that might be causing the disease, especially lupus. In very young children it is also important to check for **BSA-related MN** (a very rare type of MN cause by **bovine serum albumin**, a protein found mainly in cow's milk and beef products) so that your child's diet can be changed.
- Because of the side effects from cyclophosphamide, it is very important to discuss with your doctor how much of the drug is safe for you to take over the course of your life. It can also affect your chances of having children.

- If you have nephrotic syndrome, hypoalbuminemia, and other risks for getting blood clots, then your doctor may give you a blood-thinning drug to prevent blood clots, called an **anticoagulant**.
- For other options see page 29.



## Membranoproliferative Glomerulonephritis (MPGN)

### What is membranoproliferative glomerulonephritis?

Membranoproliferative glomerulonephritis (**MPGN**) is usually caused by other diseases, such as lupus, hepatitis B or C, and cancer. MPGN that is **idiopathic** (the cause of a disease is not known) is very rare.

- Patients often have nephrotic syndrome, high blood pressure, blood in the urine, and lowered kidney function that usually gets worse
- There are different classes of MPGN and doctors are still working on how to describe each of them. For now, doctors refer to 3 different types of MPGN, based on how the immune system hurts the kidneys and which parts of the glomerulus become damaged
- **Type 1** MPGN is caused when **immune complexes** get stuck in the walls of the glomeruli. Our body's defense system (**immune system**) makes **antibodies** to attack substances in our bodies that they see as harmful. These harmful substances are called **antigens**, and they combine with antibodies to make immune complexes. (See picture.) These complexes harm the kidneys.
- In **Types 1** and **3**, the immune system attack is the same, but the immune complexes get stuck in different parts of the glomerulus. **Type 3** also causes holes to form in the glomerulus.
- **Type 2** is also called **C3 glomerulopathy** and has two sub-types, **dense deposit disease (DDD)** and **C3 glomerulonephropathy (C3GN)**.

## What tests are done to find out if I have MPGN?

- **Urine test** to find protein and blood
- **Blood test** to find levels of protein, cholesterol, and wastes
- **Glomerular filtration rate (GFR)**, a blood test to know how well the kidneys are filtering
- **Kidney biopsy** to look at a tiny piece of the kidney under a microscope and to diagnose MPGN. Because MPGN is so rare, and because knowing the class of your disease can help your doctor decide on the best treatment, it is very important that the person looking at your biopsy is an expert in glomerular diseases. You or your doctor may need to contact a large research center to find such an expert.

## What are the treatments for MPGN?

- Before a treatment plan is made, the doctor must be sure that all possible causes of MPGN have been ruled out. If MPGN is not caused by another disease, such as hepatitis C, the treatment plan will be different.
- For both adults and children, the general treatment is the same. If you have nephrotic syndrome, or have it along with other symptoms, then you will get **cyclophosphamide** or **mycophenolate mofetil (MMF)**, plus low-dose **prednisone** for less than 6 months. All of these drugs stop the immune system from harming the kidneys. For children, your doctor may decide to start with prednisone only, depending on the class of MPGN. The treatment must be carefully planned for each patient.

- Patients who do not respond to prednisone may take a **calcineurin inhibitor (CNI)**, another type of drug that stops the immune system from harming the kidneys, in addition to **MMF**.
- People with normal kidney function and who do not have nephrotic-range proteinuria can get **supportive care** (treatments that have little or no side effects, like following a healthy diet). But your doctor will need to follow up closely with you.
- When kidney disease is too severe or if the disease is not active, then treatment won't help and could only do more harm.
- Type 2 MPGN (DDD and C3GN) may respond to the drug **eculizumab**, another type of drug that stops the immune system from harming the kidneys.
- For other options see page 29.



## ALL Patients and Families

### Along with treatment for your glomerular disease, what else can you do to protect your kidneys and your overall health?

- If you are overweight, it is helpful to lose weight. Obesity may cause glomerular disease. It is also a cause of high blood pressure and diabetes, both of which hurt the kidneys.
- Avoid non-steroidal anti-inflammatory drugs (NSAIDs) such as aspirin, ibuprofen, and naproxen.
- Before taking any over-the-counter drug, vitamin, mineral, weight loss or sports supplement, ask your doctor which is safe.
- It is recommended that you do not take herbal supplements. Many herbal products are toxic to the kidneys or have harmful substances not listed on bottle labels.
- Do not smoke.
- Exercise often.
- Avoid alcohol.
- Follow a healthy diet low in salt. You should meet with a registered dietitian who knows the best diet for you or your child.
- Control your blood pressure and blood sugar.
- Make sure that your vaccines or those of your child are up to date. But before getting a vaccine, make sure you discuss glomerular disease with your healthcare provider. There are special rules for getting vaccines when you or your child is taking drugs like prednisone. It is especially important to follow these rules for children's vaccines.

- Take all medicine as instructed by your doctor. As soon as you have any problems, let your doctor know.
- If you need a test with contrast dye (for example, a CAT scan or MRI), make sure your doctor measures your kidney function first.

## How do you and your doctor know how well you are doing?

- Changes in test results, such as the amount of protein in your urine and albumin in your blood
- Changes in the signs and symptoms of your disease, such as edema and high blood pressure
- Changes in biopsy results, which show if your disease is still active or not, or if it is getting better or worse. The biopsy can also show if your kidneys are being hurt by the drugs you are taking.
- How well you follow your treatment plan
- How well you keep appointments



## Key points to remember:

- Each patient is different, so your treatment plan will be made just for you.
- Understand the risks and benefits of a treatment. Sometimes the risks of a treatment may be too great for it to really be helpful. *Some drugs are very strong and it may be important to limit how often you take them during your lifetime.*
- It is very important to follow up with your doctor exactly as instructed. Many of the drugs discussed in this brochure must always be at the right level in your blood. Your doctor may need to change the amount of a drug you take in order to keep the right level in your blood.
- Prevent obesity in both children and adults. It can cause kidney disease.
- Discuss birth control and pregnancy with your doctor. It is important to plan a pregnancy based on remission status, symptoms, and your treatment plan. If you are a woman, the drugs you take may need to be changed so you will not hurt the fetus. Whether you are a man or a woman, sometimes the drugs you take need to be changed so you will not harm your chances of having children. This is especially true for cyclophosphamide and chlorambucil.
- Other drugs and treatments may be helpful to you if the first-choice options discussed in this brochure do not work for you. The websites on page 30 may be helpful for you and your doctor to learn about them. It may be possible for you or your child to be part of a study that uses a new treatment.

- Two new treatments approved by the Food and Drug Administration (FDA) for glomerular disease include:
  - Adrenocorticotrophic hormone (ACTH) to reduce proteinuria in nephrotic syndrome for all glomerular diseases discussed in this brochure.
  - Liposorber Apheresis System for pediatric FSGS, either before kidney transplant or after kidney transplant if FSGS comes back.



## Resources:

- Research studies for glomerular disease and nephrotic syndrome:
  - List of research studies from around the world that use human participants: **[www.ClinicalTrials.gov](http://www.ClinicalTrials.gov)**
  - Nephrotic Syndrome Study Network:  
**<https://rarediseasesnetwork.epi.usf.edu/NEPTUNE>**
- Information for patients with glomerular disease and nephrotic syndrome:
  - **National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC)**  
3 Information Way  
Bethesda, MD 20892-3580  
Phone, in English and Español:  
800.891.5390  
TTY: 866.569.1162  
**[www.kidney.niddk.nih.gov](http://www.kidney.niddk.nih.gov)**
  - **NephCure Foundation**  
15 Waterloo Ave  
Berwyn, PA 19312  
Phone: 866.637.4287  
**[www.nephcure.org](http://www.nephcure.org)**
  - **Lupus Foundation of America**  
2000 L Street, N.W., Suite 410  
Washington, DC 20036  
Phone: 202.349.1155  
In English and Español:  
800.866.0121  
**[www.lupus.org](http://www.lupus.org)**

- Call the **NKF Cares Patient Help Line** toll-free at **800.855.NKF.Cares (855.653.2273)** or email **nkfcares@kidney.org**
- Learn more at **www.kidney.org**

## TREATMENT TRACKER

Dates	/ /	/ /	/ /	/ /
Appointments				
Doctor's Name and Phone	Time/Day		Time/Day	
Dr: Phone:				
Dr: Phone:				
Dr: Phone:				

### MEDICATIONS

Name	Doses/Times	Changes	Changes	Changes	Changes

### TEST RESULTS

Urine protein				
Serum albumin				
eGFR				
Blood pressure				
Weight				
Cholesterol				
Other				

## TREATMENT TRACKER

/ /	/ /	/ /	/ /
Time/Day	Time/Day	Time/Day	Time/Day

### MEDICATIONS

Changes	Changes	Changes	Changes	Changes	Changes






The **National Kidney Foundation** is the leading organization in the U.S. dedicated to the awareness, prevention, and treatment of kidney disease for hundreds of thousands of healthcare professionals, millions of patients and their families, and tens of millions of Americans at risk.

Help fight kidney disease.

Learn more at **[www.kidney.org](http://www.kidney.org)**



National  
Kidney  
Foundation™

30 East 33rd Street  
New York, NY 10016  
800.622.9010

Awareness. Prevention. Treatment.

This educational resource  
supported by



QUESTCOR®  
PHARMACEUTICALS, INC.



**Mixed Sources**

Product group from well-managed  
forests, controlled sources and  
recycled wood or fiber  
[www.fsc.org](http://www.fsc.org) Cert no. XXX-XXX-XXXX  
© 1996 Forest Stewardship Council