

Explore
your treatment
options

P. 6

Keep your
kidneys strong
with these
simple diet
tricks

P. 22

Health Monitor[®]

Living



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**“Kidney
disease can’t
keep me
grounded!”**

Immunoglobulin A Nephropathy

Samantha Schweisthal struggled for months with what she thought were chronic UTIs. When she found out the real culprit was immunoglobulin A nephropathy, she was devastated. Yet today she’s beating the odds—and keeping her kidneys strong—with help from chemotherapy and a targeted steroid.

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Samantha Schweisthal was devastated to learn she had immunoglobulin A nephropathy (IgAN). Today, she’s beating the odds—and keeping her kidneys strong—with help from chemotherapy and a targeted steroid.

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SPECIAL THANKS TO OUR MEDICAL REVIEWER



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Cover photo by London Mahogany

THE BASICS **m**



Setting the stage for a happy, healthy future!

While there’s still no cure for immunoglobulin A nephropathy (IgAN), today’s treatment options mean you have more ways to manage it than ever—and more reason to stay hopeful about the years ahead.

Ronald P. went to his annual physical expecting the usual—maybe some comments from his doctor about the smoking habit he couldn’t seem to kick. And he knew he needed to exercise more. But at 32 years old, all previous visits had resulted in a clean bill of health.

“I had just gotten over a terrible cold, upper respiratory infection and all, but I was finally feeling better, which I told my doctor, and he didn’t seem too concerned.”

While Ronald left that visit without any fanfare, a call from his doctor a few days later revealed cause for concern.

“He said they had found traces of blood and protein in my urine sample, and I had to go back in for more testing.” After follow-up tests and scans, including a kidney biopsy, Ronald learned he had an autoimmune disease called immunoglobulin A nephropathy (IgAN). In IgAN, the immune system overproduces IgA antibodies,

**IgAN
FAST FACT****2.5**

The number of cases of IgAN diagnosed per every 100,000 people worldwide, ranking it as a rare disease.

Source:
igan.stada/en

which normally fight off germs and other invaders, but in this case wind up clogging the kidneys' filtration system. Left unchecked, IgAN can lead to complications such as kidney failure.

Although there's still no cure for IgAN, available treatments can help slow the progression of the disease—and the sooner started on them, the better. In addition, some key lifestyle steps can also make a difference.

First on Ronald's list: quitting smoking. His doctor recommended he try the nicotine patch along with visiting a local support group for other smokers trying to quit. Ronald also made a commitment to walk at least 30 minutes a day and revamp his diet so he could drop some excess pounds.

"My doctor said all that would go a long way toward helping the overall health of my kidneys."

Ronald also got a prescription for a targeted-release

steroid that would lower the amount of IgA his body made and help his kidneys recover. "Follow-up tests showed the medication was doing its job. My doctor said if I stayed committed to my new healthier lifestyle, I had every reason to believe I could steer clear of complications and live symptom-free for the foreseeable future—who could ask for more motivation than that?"

IgAN and you

Whether you were recently diagnosed with IgAN or you have been coping with it for a while, it's important to know that new treatment breakthroughs are happening all the time that can help you live your life fully. To meet the challenges of facing this condition, start by spending some time with this guide and get inspired by others who, like Ronald, are living well despite kidney disease. First up, a refresher on the condition.

What is IgAN?

IgAN, also known as Berger's disease, occurs when immunoglobulin A (IgA), an antibody blood protein that normally works to fight against germs and infections, builds up in the glomeruli in your kidneys. Glomeruli are where your kidney normally filters toxins, proteins and waste from your blood. But when those filters get clogged, the result can be inflammation and damage to the kidneys.

While the exact cause of IgAN is not well understood, research has suggested that it may be caused by a combination of genetic and environmental factors. What we do know is that IgAN is a progressive disease and one of the leading causes of kidney failure. In fact, up to 30% of people with IgAN will develop end-stage renal disease within 20 to 25 years of the first onset of the disease.

Who is at risk?

Although anyone can develop IgAN, it is typically more common in people with a family history of the disease or with IgA vasculitis, which is when IgA collects in small blood vessels.

Additional factors include:

- Celiac disease or gluten allergy
- Inflammatory bowel disease (*Crohn's or ulcerative colitis*)
- Hepatitis (*liver inflammation*)
- Cirrhosis (*liver failure*)
- Human immunodeficiency virus (*HIV*)

There is also a higher prevalence of IgAN in people between the ages of 16 and 35 years old and those of Asian, Pacific Islander or White European ethnicity. Those assigned male at birth are also twice as likely as those assigned female to be diagnosed with IgAN.

What are the symptoms?

In the early stages of IgAN, most people don't experience any

symptoms. However, as the disease progresses, patients may experience some or all of the following:

- **Foamy urine**
- **Blood in urine (*hematuria*)**
- **Changes in the color of urine (*pink, dark brown or cola-colored urine*)**
- **Back pain**
- **Swelling of the legs, ankles, feet, belly/abdomen, or face**
- **High blood pressure**
- **Fatigue**

The first signs and symptoms are typically noticed after a cold, sore throat or respiratory infection.

How is it diagnosed?

Diagnosing IgAN is a multi-step process. First, your doctor will review your symptoms and conduct a physical examination. They will also request lab tests such as:

- **Urinalysis:** A urine sample will be collected to check for protein or blood in your urine.

- **Urine albumin-creatinine ratio (*uACR*):** This test measures the level of albumin (protein) and creatinine in your urine.
- **Estimated glomerular filtration rate (*eGFR*):** This is a blood test that will estimate how well your kidneys are removing waste products from your blood.

If lab tests indicate you have kidney damage, your healthcare provider will likely need to perform a kidney biopsy to officially confirm IgAN. This requires a minimally invasive surgical procedure where tiny pieces of your kidney are removed and then studied under a microscope by a pathologist. ►

**Are you Asian? Be alert!**

People of Asian descent are at the highest genetic risk for IgAN and are the most likely group to progress to kidney failure if diagnosed. If you are Asian and have any of the symptoms listed on p. 5—or have a blood relative who was diagnosed with kidney disease—it's important to tell your healthcare provider right away.



**IgAN
FAST FACTS**

2x
MEN ARE NEARLY
TWICE AS LIKELY
AS WOMEN TO BE
DIAGNOSED

16-35
THE AGE RANGE
WHEN IGAN IS
MOST LIKELY TO
BE DIAGNOSED

Source:
igan.stada/en

How is it treated?

While IgAN is still not able to be cured, the good news is it *is* treatable. Your healthcare provider will take several things into account when trying to determine the best option for you, including your current state of health and other conditions you may have.

Medicines to treat IgAN can include:

- **Immunosuppressants**, including corticosteroids, which can lower the amount of IgA proteins being made by your immune system. Corticosteroids are particularly beneficial when it comes to reducing inflammation and protecting kidney function. There are also targeted-release versions that specifically work to lower IgA proteins rather than suppress the entire immune system.
- **Endothelin receptor antagonists (ERAs)**, which relax the blood vessels in your kidneys and reduce the amount of protein in urine.
- **SGLT2 inhibitors**, which lower the amount of protein in urine and can also help lower blood sugar levels in people with diabetes, another condition that can impair kidney health.
- **Angiotensin-converting enzyme (ACE) inhibitors and angiotensin receptor blockers (ARBs)**, which help lower blood pressure. Because the kidneys help your body regulate your blood pressure, IgA can sometimes cause it to spike—this, in turn, can further damage your kidneys.
- **Statins**, which help lower LDL (aka “bad”) cholesterol. If your cholesterol levels are high, fatty deposits can build up in the vessels surrounding your kidneys, making it hard-

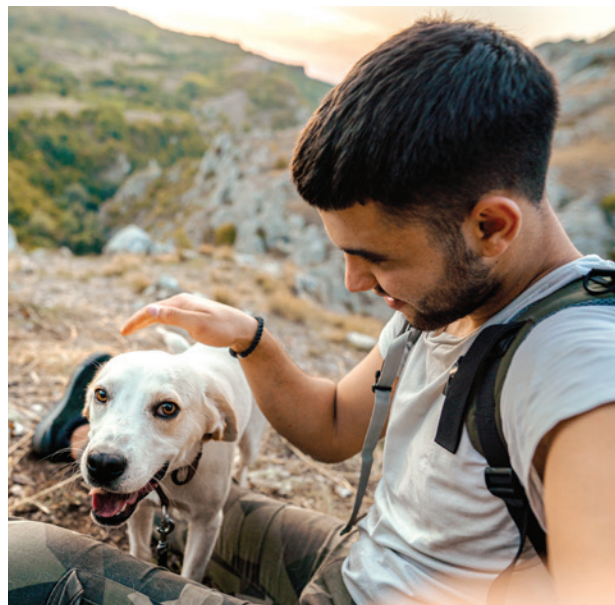
er for them to do their job.

- **Diuretics**, which can be used to reduce the swelling (edema) that may be present in your hands and/or feet as a result of kidney disease.
- **Supplements, including omega-3 fatty acids and vitamin E**, both of which have been shown to improve kidney health and function. Talk to your healthcare provider before taking any new vitamins or supplements.

What you can do

In addition to medication, lifestyle changes can also make an impact on how quickly IgAN progresses. Sticking to a low-sodium (around 1,500 mg daily, which is equal to about $\frac{3}{4}$ of a teaspoon of salt), low saturated-fat diet can help keep your blood vessels in top shape and improve the health of your kidneys. Getting the American Heart Association recommended 150 minutes per week of physical exercise has also been shown to help, as has maintaining a healthy weight. Quitting smoking and staying away from alcohol can be beneficial, too. (To learn more, see p. 20.)

But most important, stay hopeful—today’s treatments are helping many people with IgAN live active, symptom-free lives. And with so many new options currently being studied, there’s every reason to believe that if one treatment stops working for you, you’ll have plenty of different options to choose from in the future. ●



YOU & YOUR CARE TEAM



The pros on your side

These medical professionals can help diagnose and treat immunoglobulin A nephropathy (IgAN).

Primary care provider:

Specializes in internal or family medicine; may diagnose and treat various health conditions, including IgAN, and may refer you to specialists.

Nephrologist:

Specializes in diseases related to the kidneys, such as IgAN and chronic kidney disease.

Endocrinologist:

Specializes in diseases related to hormones and organs of the endocrine system, such as diabetes, metabolic disease and obesity.

Cardiologist:

Specializes in heart and blood vessel disease, including high cholesterol and high blood pressure.

Pathologist:

Specializes in studying biopsies to diagnose conditions, as well as their severity.

Nurse practitioner/Physician associate:

Healthcare professional who can monitor your IgAN and other conditions, prescribe medication and provide ongoing care.

Pharmacist:

A healthcare professional who can answer questions about your medicine, help you find affordable medicine options and send refill reminders so you stay on course.

Registered dietitian:

A healthcare professional who specializes in helping you adjust your eating patterns to improve your health. ●

Are your symptoms under control?

Fill in the answers below and share with your healthcare provider—it will help them understand how limmunoglobulin A nephropathy (IgAN) is impacting your life and whether you could benefit from an updated treatment plan.

In the last three months, how often have you experienced...

Swelling	Not at all	Sometimes	Frequently	Almost Always
In your legs/ankles/feet				
In your torso				
In your face				

Pain	Not at all	Sometimes	Frequently	Almost Always
Around your sides or lower back				
Other pain or discomfort (specify):				

Urinary symptoms	Not at all	Sometimes	Frequently	Almost Always
Foamy urine				
Pink in color				
Dark brown in color				
Increased urination				
Decreased urination				

General health and well-being	Not at all	Sometimes	Frequently	Almost Always
Fatigue				
Nausea				
Loss of appetite				
Headache				
High blood pressure				

Write down how your symptoms are affecting your mental health and your social life.
(e.g., Are you feeling drained? Turning down invitations? Sleeping too much or not enough?):

List any current medications you're taking, including OTC:

List any supplements you're taking:

Track your levels

Monitoring certain biomarkers, including various protein levels in your blood and urine, and your blood pressure can help assess how well your IgAN treatment plan is working. Use this worksheet each time you have a test done, and review it with your healthcare provider.

Kidney function

Your healthcare provider will likely order regular blood and urine tests to see how well your kidneys are functioning. Fill in the results below to keep track. (See the sidebar for more about each test.)

Date	Serum creatinine	Blood urea nitrogen (BUN)	Urine albumin-creatinine ratio (uACR)	Estimated glomerular filtration rate (eGFR)

Normal levels:
Serum creatinine: 0.6 - 1.2 g/dL Urine albumin-creatinine ratio: <30 mg/g per day
Blood urea nitrogen: 6 - 24 mg/dL Estimated glomerular filtration rate: >90 mL/min/1.73 m²

Blood pressure

The kidneys help to regulate blood pressure, so when you have IgAN, you may be at risk for high blood pressure. For patients with IgAN, maintaining blood pressure below 120/80 mm Hg is often recommended to minimize kidney damage and slow disease progression.

Date	Systolic Pressure (mm Hg)	Diastolic Pressure (mm Hg)

Blood pressure levels:
Normal: <120 mm Hg/<80 mm Hg
Elevated: 120-129 mm Hg/<80 mm Hg
High (stage 1): 130-139 mm Hg/80-89 mm Hg
High (stage 2): >140 mm Hg/>90mm Hg
Hypertensive crisis (consult your healthcare provider immediately): >180 mm Hg/>120 mm Hg



TESTS YOU MAY NEED

Your healthcare team may recommend the following tests to diagnose, monitor and evaluate your treatment for IgAN.

Serum creatinine test

Done either via a blood test or urinalysis, this test looks for elevated levels of creatinine—a waste product created when you use your muscles—which should be filtered by the kidney.

Blood urea nitrogen (BUN)

This blood test measures levels of urea nitrogen—a waste product made during digestion that is filtered through the kidneys.

Urine albumin-creatinine ratio (uACR)

This test looks for albumin (a type of protein) in your urine. When kidneys are functioning properly, very little to no albumin should be detected. Higher levels can indicate kidney damage even in someone whose eGFR (see below) results are above 60.

Estimated glomerular filtration rate (eGFR)

This test considers the results of the tests above as well as your age, weight and gender to determine the overall stage of your kidney disease. A result of 90 or higher indicates stage 1, or normal kidney function. An eGFR below 60 for three months or more, or an eGFR above 60 with high levels of albumin in your urine, indicates stage 3 kidney disease. Less than 15 indicates stage 5, or kidney failure.

“IgAN can’t keep *me* grounded!”

Samantha Schweisthal struggled for months with what she thought were chronic UTIs. When she found out the real culprit was immunoglobulin A nephropathy (IgAN), she was devastated. Yet today, she’s keeping her kidneys strong with help from chemotherapy and a targeted steroid.

—BY BETH SHAPOURI

Earlier this year, Samantha Schweisthal and her husband, Anthony, hiked Peru’s Machu Picchu—something the outdoor enthusiast had long dreamed about. Not only was the scenery amazing, but the climb held a special meaning for her: It proved that she was still strong and capable.

That meant everything to the Alabama resident who, just a few years earlier, was told her hiking days might be over for good.

Samantha’s health journey began in January 2020, when she kept getting bouts of what she calls “cola-colored urine” along with a slight fever. Believing they were recurrent UTIs, she figured they were tied to stress. After all, her military husband was in the midst of back-to-back deployments, and she was overloaded with coursework while pursuing a major in natural resources at Auburn University.

Yet even with over-the-counter meds and antibiotics, she couldn’t seem to shake the strange symptoms—and her doctor was having trouble figuring out the cause.

In fact, it wasn’t until Samantha mentioned something she considered completely unrelated—the fact that she is of Japanese descent—that the puzzle pieces came together.

“When I said that, my doctor snapped her fingers. She said, ‘I think you have IgA nephropathy [IgAN].’” (The autoimmune disease has higher incidents in Asia—particularly Japan.)

“I didn’t know where to start”

After various tests and a biopsy, Samantha found out that not only did she have IgAN, she has the type with crescentic formations—i.e., the inflammation is more severe, leading to a faster disease progression and poorer prognosis.

“To say I was devastated is an understatement,” Samantha recalls. She was also stunned to learn there is no cure. “I didn’t know where I was even supposed to start.”

Luckily, her kidney specialist had a plan—she’d be put on a combination of chemotherapy and a targeted

steroid immediately. These medications would work in tandem to tamp down the antibodies that were clogging her kidneys. The only downside?

“My doctor leveled with me that this was a serious treatment for a serious condition,” she recalls. “And at least while I was on the chemotherapy, I’d have to take it easy so my body could heal. That meant no hiking or any other physical activity.” Samantha even wound up taking time off from school so she could focus on getting well.

“I searched for an IgAN community”

While Samantha began treatment, she realized she wanted to find others going through what she was. She didn’t know anyone with the condition, so she went searching for other patients online. That’s when she found the IgA Nephropathy Foundation. Just six months after her diagnosis, she attended the foundation’s annual SPARK conference for patients and caregivers.



“Beating this disease every day is a hard thing, so imagine all the other hard things you can do!”

“The fact I was able to attend that the year I was diagnosed was key to how I view this disease,” she says. “It’s so important to have friends who know how big of a deal it is when I am able to go grocery shopping and wash my car and go to work on the same day because that is a big win for those of us with chronic kidney disease!”

Encouraged, she left with a renewed sense of purpose. Even better? She finished the course of chemotherapy, and thanks to that and the steroid, the results of her eGFR screening—a blood test

that measures kidney damage—showed that her kidney function has stabilized.

“I feel free to live my life again!”

With the good news, Samantha was able to return to school, where she graduated cum laude this past December, and she’s planning to start pursuing her Master’s of Science in forestry in the fall.

She’s also become a patient ambassador for the state of Alabama for the IgA Nephropathy Foundation, where she focuses on giving others hope. “I

tell them, ‘Beating this disease every day is a hard thing, so imagine all the other hard things you can do!’”

Overall, Samantha is feeling positive about the future. “These treatments gave me faith that I’ll be able to maintain my stability and pursue my career despite it being relatively labor-intensive and not typically common for people with chronic kidney disease. And who knows what might be on the horizon? There’s nothing to do but be hopeful!”

See Samantha’s tips on p. 15 ►

Help preserve your kidney function with **TARPEYO**

First FDA-approved treatment proven to reduce the loss of kidney function in adult patients with IgA Nephropathy (IgAN)

Cathrin, *actual* TARPEYO patient.
Cathrin was compensated for her time.



What if you could change the course of your IgAN?



Lasting results

Proven results over 2 years in both kidney function and proteinuria*†



Designed to target a source of IgAN in the gut‡



9-month course

4 capsules taken once a day



No FDA-mandated tests required

*At 2 years, there was a >50% difference in kidney function as measured by eGFR: -5.3 mL/min/1.73 m² in patients who received TARPEYO + blood pressure medication vs -11.2 mL/min/1.73 m² in those who received blood pressure medication alone.

†At 2 years, there was an average 34% reduction from baseline in UPCR in patients who received TARPEYO + blood pressure medication vs 4% in those who received blood pressure medication alone.

‡It has not been established to what extent the efficacy of TARPEYO is from local effects (in the gut) vs systemic effects (in circulation).



TARPEYO Touchpoints offers programs to help you access and afford your medication.

Phone: 1-833-444-8277



Ask your doctor today if TARPEYO is right for you.

Scan to learn more at [TARPEYO.com](https://www.TARPEYO.com)

Important Safety Information (cont'd)

What should I avoid while taking TARPEYO?

Do not eat grapefruit or drink grapefruit juice during your treatment with TARPEYO. Eating grapefruit or drinking grapefruit juice can increase the level of TARPEYO in your blood.

What are the possible side effects of TARPEYO?

TARPEYO may cause serious side effects, including:

• **Effects of having too much corticosteroid medicine in your blood (hypercorticism).** Long-time use of TARPEYO can cause you to have signs and symptoms of too much cortisol, a stress hormone in your blood. Tell your healthcare provider if you have any of the following signs and symptoms of hypercorticism:

- acne
- bruise easily
- rounding of your face (moon face)
- ankle swelling
- thicker or more hair on your body and face
- a fatty pad or hump between your shoulders (buffalo hump)
- pink or purple stretch marks on the skin of your abdomen, thighs, breasts, or arms

• **Adrenal suppression.** When TARPEYO is taken for a long period of time (chronic use), adrenal suppression can happen. This is a condition in which the adrenal glands do not make enough steroid hormones. Symptoms of adrenal suppression include:

- tiredness
- weakness
- nausea and vomiting
- low blood pressure

Tell your healthcare provider if you are under stress or have any symptoms of adrenal suppression during treatment with TARPEYO.

• **Risk of immunosuppression.** TARPEYO weakens your immune system. Taking medicines that weaken your immune system makes you more likely to get infections. Avoid contact with people who have contagious diseases, such as chickenpox or measles, during treatment with TARPEYO. Tell your healthcare provider right away if you come in contact with anyone who has chickenpox or measles. Consult with your healthcare provider regarding appropriate vaccination scheduling.

• Tell your healthcare provider if you develop any symptoms of infection during treatment with TARPEYO, including:

- fever
- feeling tired
- chills
- aches
- pain
- nausea and vomiting

The most common side effects of TARPEYO include:

- swelling of the lower legs, ankles, and feet
- high blood pressure
- muscle spasms
- acne
- headache
- upper respiratory tract infection
- swelling of the face
- weight increase
- indigestion
- irritation or inflammation of the skin
- joint pain
- increased white blood cell count

These are not all the possible side effects of TARPEYO.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

Please additional Important Safety Information in the accompanying Brief Summary.

Indication

What is TARPEYO?

TARPEYO is a prescription medicine used to reduce the loss of kidney function in adults with a kidney disease called primary immunoglobulin A nephropathy (IgAN) who are at risk for their disease getting worse. It is not known if TARPEYO is safe and effective in children.

Important Safety Information

Do not take TARPEYO if you are allergic to budesonide or any of the ingredients in TARPEYO. See the accompanying page brief summary for the complete list of ingredients in TARPEYO.

This brief summary highlights the most important information about TARPEYO. Please read it carefully before using TARPEYO and each time you get a refill, as there may be new information. This brief summary does not take the place of talking with your healthcare provider about your medical condition or your treatment. If you have any questions after reading this, ask your healthcare provider. For more information, go to www.TARPEYO.com.

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Before taking TARPEYO, tell your healthcare provider about all of your medical conditions, including if you:

- have liver problems.
- plan to have surgery.
- have chickenpox or measles or have recently been near anyone with chickenpox or measles.
- have an infection.
- have high blood sugar levels (prediabetes or diabetes).
- have glaucoma or cataracts.
- have a family history of diabetes or glaucoma.
- have or have had tuberculosis.
- have high blood pressure (hypertension).
- have decreased bone mineral density (osteoporosis).
- have stomach ulcers.
- are pregnant or plan to become pregnant. TARPEYO may harm your unborn baby. Talk to your healthcare provider about the possible risk to your unborn baby if you take TARPEYO when you are pregnant.
- are breastfeeding or plan to breastfeed. It is not known if TARPEYO passes into your breast milk or if it will affect your baby. Talk to your healthcare provider about the best way to feed your baby during treatment with TARPEYO.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. TARPEYO and other medicines may affect each other causing side effects.

How should I take TARPEYO?

- Take TARPEYO exactly as your healthcare provider tells you.
- Your healthcare provider will decide how long you should take TARPEYO. Do not stop taking TARPEYO without first talking with your healthcare provider.
- Take your prescribed dose of TARPEYO 1 time each day in the morning, at least 1 hour before a meal.
- Swallow TARPEYO capsules whole. **Do not** open, chew, crush, or break TARPEYO capsules before swallowing.
- If you miss a dose of TARPEYO, take your prescribed dose at your next scheduled time. **Do not** take two doses of TARPEYO at the same time.
- If you take too much TARPEYO, call your healthcare provider right away or go to the nearest hospital emergency room.

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- nausea and vomiting
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Tell your healthcare provider if you are under stress or have any symptoms of adrenal suppression during treatment with TARPEYO.

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- joint pain
- increased white blood cell count

These are not all the possible side effects of TARPEYO.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store TARPEYO?

- Store TARPEYO at room temperature between 68°F to 77°F (20°C to 25°C).
- Keep TARPEYO in a tightly closed container.
- Protect from moisture.

Keep TARPEYO and all medicines out of the reach of children.

General information about the safe and effective use of TARPEYO.

Medicines are sometimes prescribed for purposes other than those listed in a Patient Information leaflet. Do not use TARPEYO for a condition for which it was not prescribed. Do not give TARPEYO to other people, even if they have the same symptoms you have. It may harm them. You can ask your pharmacist or healthcare provider for information about TARPEYO that is written for health professionals.

What are the ingredients in TARPEYO?

Active ingredient: budesonide

Inactive ingredients: sugar spheres (sucrose and starch), hypromellose, polyethylene glycol, citric acid monohydrate, ethyl cellulose, medium chain triglycerides and oleic acid.

The capsules contain: hypromellose and titanium oxide (E171).

The printing ink on the capsules contain: shellac, propylene glycol and black iron oxide (E172).

The enteric coating on the capsules contain: methacrylic acid and methacrylate copolymer, talc and dibutyl sebacate.

Manufactured for and distributed by: Calliditas Therapeutics AB, Stockholm, Sweden

This brief summary is based on the TARPEYO Prescribing Information (December 2023).

calliditas
THERAPEUTICS

TARPEYO®
(budesonide) delayed release capsules • 4 mg

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Photos by London Mahogany

SAMANTHA'S TIPS FOR STAYING ON THE TRAIL TO SUCCESS

GET OUT AND ABOUT (WHEN YOU CAN).

When she needs rest, she takes it, but on the days she feels up to it, Samantha makes sure to get out of the house. “Even if it’s just going and cruising the racks at TJ Maxx,” she insists. She says it’s easy to want to stay in with kidney disease, but getting out in the world helps her from “sinking inward in a doom-and-gloom kind of way.”

SET GOALS BIG AND SMALL.

“I always give myself something to work for and to stay positive about,” she says. “It can be small, like taking my medication every day or making sure that this basket of laundry is folded.” Having things she can cross off her list makes her feel productive.

TRY YOUR OWN SPICE COMBOS.

Living with IgAN means following a very low-sodium diet. To help with that, Samantha has begun making her own spice blends. “I’ll just look up stuff on Pinterest, or I’ll Google something like ‘salt-free taco spice.’ ” She keeps the blends in tiny jars in the kitchen. “My cabinet is full of them!”

Looking to learn more or connect with others with IgAN?



VISIT THE INF!

The IgA Nephropathy Foundation is a patient-run organization founded in 2004 by Bonnie Schneider after her son, Eddie, was diagnosed with IgAN at age 13. Along with connecting patients and caregivers throughout the year and hosting its in-person SPARK events to build a community around the condition, it also funds research into finding a cure (to date, they’ve awarded over \$1,000,000 in fellowship grants to Columbia University and University of Alabama at Birmingham).

To learn more, visit IgAN.org



“We’re *not* letting IgAN slow us down!”

From transplants to making major diet changes, Courtney and Judy offer the personal strategies that are keeping them focused on the future despite chronic kidney disease. —BY WHITNEY HARRIS

“Don’t lose hope!”

COURTNEY WALKER
KANSAS CITY, KS

Courtney Walker is no stranger to living with a chronic health condition—after all, she was diagnosed with Crohn’s disease in 1996. And despite that, she was able to manage her condition with dietary changes and medication while still working as a swim instructor and leading industrial safety programs for businesses.

So when she started experiencing fatigue and repeated UTIs, she assumed it was either stress or some new side effect of her Crohn’s. But when another UTI hit and her doctor did a urinalysis, results revealed Courtney’s kidneys weren’t working properly. She was referred to a nephrologist who performed a biopsy and diagnosed her with immunoglobulin A nephropathy (IgAN). At the time, her kidney function was at 37% and she was diagnosed with stage 3b (i.e., “moderate”) chronic kidney disease.

“I felt shock and fear of the unknown,” Courtney remembers. “I was already past the early stages of the disease and left wondering, *How long until I’m on dialysis?*”

A few years later, Courtney was recommended for the kidney transplant list after repeated *C. diff* (*Clostridium difficile*) infections—a complication of her Crohn’s—worsened the IgAN.

“I started a campaign to find a living donor,” she says, reaching out to family and friends and casting as wide a net as possible on social media. And it worked. This past summer, Courtney celebrated her one year “transplantversary.”

While her kidney function has improved dramatically thanks to the transplant, Courtney still has IgAN and continues to follow her treatment plan to keep her new kidney healthy. Here, she shares the methods she still uses to thrive.

“One upside of living with a chronic condition: I see things as richer and more special because of what I’m dealing with.”



Be patient—and research!

“For me it took about a year to figure out how to live with IgAN. It’s up to you to learn as much as you can so you can understand your labs and bloodwork and learn to speak the same language as the doctors. My most recommended resources are the National Kidney Foundation (kidney.org), the IgAN Foundation (IgAN.org) and Neph-Cure (nephcure.org).”

Focus on food.

“Finding a dietitian who has experience working with people with kidney disease can be a huge benefit. I try to follow a diet low in animal protein, sodium and potassium. My dietitian helped me find things like the plant-based protein drinks by Kate Farms, as well as Bragg Liquid Aminos, which I use as a lower-sodium alternative to soy sauce.”

Celebrate the small things.

“Take time to reflect on what’s going well. I’m feeling more energy since my transplant, so I’m phasing out my daytime nap. I have feet to walk on. I still have the ability to laugh, meditate and write in my journal. I see things as richer and more special because of what I’m dealing with. I’m a water person, so getting to swim in the ocean, go fishing, or scuba dive is all wonderful. It’s important to be grateful every day!” ►

Photos by Elaine D. Cochran



“Be your own advocate!”

JUDY AKIN
OAHU, HI

After Judy Akin gave birth to her son in 2013, she found herself always exhausted, unable to lose weight and constantly getting sick with colds that wouldn't quit. She figured it was all due to the stress of being a full-time mom and working a demanding management job.

Finally, after getting hit with a case of shingles, Judy went to her family doctor for blood tests “just to make sure everything was really okay.” Results showed evidence of kidney disease; a biopsy confirmed IgAN—already at stage 3, with her kidney function at just 44%.

“There was nobody in my family with any known history of kidney disease,” Judy remembers. “I was totally shocked.”

Today, with the help of high blood pressure and cholesterol medication,

as well as a dedication to dietary changes, Judy is sharing her story in the hopes it will help others living with IgAN.

Be open to the information.

“When I was diagnosed, I had no idea what IgAN was; I hadn't even heard of it. Because it's a rare disease, your doctor may not have seen it in any of their patients. So try to connect with the IgAN community through organizations like the IgAN Foundation (IgAN.org). They're pulling all the current info into one place. You can read other people's stories and find specialists, articles, blogs and clinical trials.”

Listen to your body.

“You know what's going on with your body better than anyone else, so if something doesn't feel right, don't give up until you get answers. Be prepared to ask the uncomfortable questions! If a doctor doesn't give you answers then demand they listen to you. And don't be afraid to find a new doctor if you don't feel like your current one is hearing you.”

Talk to a therapist.

“My primary care physician highly recommended therapy for me. You're constantly dealing with different stages of grief while living with chronic illness—whether it's a new diagnosis, bad lab report or feeling weak. Nobody around you truly understands, and talking to a therapist can help.” ●

Health **m** Monitor

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Photo by waaltzhawaii



NEW OPTIONS I've been living with IgAN for a few years and have mostly been on blood pressure medication to help manage it. I recently heard there might be new treatment options available—how will I know if I should consider switching or adding medications?

Q
A

Answers to your top questions about IgAN

A: Yes, there are a number of emerging therapies that offer patients and their providers new possibilities for managing IgAN, including immunosuppressants, targeted-release steroids, endothelin receptor antagonists and SGLT2 inhibitors. Your decision to make any changes should be made with your nephrologist. If a change in therapy is appropriate, the two of you should discuss the goals of treatment, potential risks and benefits and plans for long-term follow-up.

TAKING VITAMINS

Q: I've been looking into supplements to help with my energy levels, but I'm concerned for my kidney health. Are there supplements I should avoid taking due to having IgAN?

A: First, changes in your “energy levels” could suggest a need for improved IgAN symptom management or a need to search for a new health issue. Second, you shouldn't add any prescription or over-the-counter medications or supplements—or otherwise change your treatment plan—without first consulting with your IgAN health-care provider. Some supplements can interact with certain medications or act another way in the body you may not want, so it's always best to double-check and ensure there's nothing else going on with your health.

CAN I STAY ACTIVE?

Q: I'm 23 and very active, including cycling, swim-

ming and running up to 40 miles a week. Last year I trained for an Iron Man. I was just diagnosed with IgAN—will this change the way I can work out?

A: There are no specific physical activity restrictions for patients with IgAN, but fatigue can be a side effect. You may also need to take it easy after certain types of treatments, but this is typically temporary. In general, nephrologists recommend regular physical activity for patients with all forms of chronic kidney disease to improve their overall health—particularly your cardiovascular health, blood pressure levels and maintenance of a healthy weight. While each individual's experience with IgAN will be unique, physical activity can benefit your overall well-being. ●

OUR EXPERT:

Gentzon Hall, MD, PhD, FASN, Assistant Professor of Medicine in Nephrology; Vice Chief of Diversity, Equity and Inclusion for the Division of Nephrology, Duke University; Director of the GlomCon Foundation HBCU Outreach and Workforce Development Department



Making healthy habits *stick!*

While immunoglobulin A nephropathy (IgAN) cannot be cured, taking steps toward a healthier lifestyle not only can support your kidney health, but can also help you manage symptoms and, in some cases, can even help slow the progression of the disease. Here, some of the best changes you can make—and how to stick with them for the long-haul. —BY SARA ROTONDI



Kick the butts

Smoking has been shown to worsen protein levels in the urine of people with IgAN, according to a study by the National Kidney Foundation. That's because it causes blood vessels to constrict—and when that happens in your kidneys, it makes it more challenging for the organ to filter your blood. Since IgAN is already increasing the burden on your kidneys' ability to do their job, smoking only worsens the impact.

The best way?

Combining medication, such as nicotine replacements (the patch, lozenge, gum, oral inhaler, or nasal spray) or oral medicines (varenicline or bupropion), with addiction counseling, according to the Tobacco Research and Treatment Program at MD Anderson Cancer Center. You can also find resources and other tips to help you at [SmokeFree.gov](https://www.smokefree.gov).



Dial back your alcohol intake

Much like smoking impacts more than the lungs, drinking excess alcohol can increase health risks to more than just your liver. That's because alcohol—whether beer, wine or liquor—causes dehydration, which makes it tougher for the kidneys to filter your blood. It also increases blood pressure and produces toxins your kidney has to work overtime to filter.

The best way?

Indulge wisely. Lowering your alcohol-related risk does not always mean giving up happy hour completely. You should always keep the amounts you drink within the recommended levels (that's two drinks or less in a day for men and one drink or less in a day for women, as per the CDC), and make sure to ask your kidney care team what levels are safe for you. And to make the transition easier, try replacing your usual drink with a “mocktail” made from sparkling water and fruit juices—that way you can still partake in the fun without the negative side effects.



Stay active

You probably already know the American Heart Association recommends 150 minutes a week of physical activity to keep your ticker in top shape, but this recommendation extends to kidney disease patients, as well. A study in the journal *Sports* found that kidney disease patients who maintained regular physical activity had a profoundly improved outcome—getting moving not only slowed disease progression and helped stave off the need for dialysis and kidney transplant, but it also lowered anxiety and depression. The bottom line? Staying active can significantly improve your mood and help your kidneys stay healthier for longer.

The best way?

First, choose something that seems genuinely fun to you. You don't need to train for a marathon; studies show that a range of activities—everything from yoga and walking to strength training—provide benefits to people with kidney disease. Second, invite someone to join you—a workout buddy can not only make the time spent exercising go by faster, but can also motivate you to show up, since someone else is counting on you. ●



Looking to overhaul your eating plan?

See the next page for tips on how to make an IgAN-friendly menu a part of your daily diet!



How to eat to *help* your kidneys

Since being diagnosed with immunoglobulin A nephropathy (IgAN), you've probably learned about the importance of modifying your diet to improve kidney function. If you're wondering exactly how to go about that, don't stress: We've turned to dietitians and other experts for their top tips. —BY JOANA MANGUNE

Go low-sodium

One of the first nutrition tips typically suggested to people with IgAN is to monitor their daily sodium intake. That's because consuming too much can cause fluid retention and increase blood pressure, two issues already worsened by IgAN's impact on the kidneys. Try to...

Focus on one meal at a time.

"Generally, a low sodium diet includes less than 2,000 mg a day, and someone with kidney disease may need to aim even lower," explains Brandy Winfree Root, MBA, RDN, CSR, LDN (brandywinfreerdn.com), co-chair of the Florida Council on Renal Nutrition. "Keeping your numbers low can seem daunting, but focusing on a meal-by-meal basis can make it easier. Aim for less than 600 mg of sodium per meal and less than 200 mg of sodium per snack (if 2,000 mg is your goal). It's much easier to make changes when you aim for smaller, more achievable goals."

Swap salt for herbs and seasonings.

Herbs and spices can not only add flavor to food without needing to sprinkle on extra salt, but many also contain vitamins and antioxidants that can improve kidney function. "For great all-purpose spice mixes, I love the Mrs. Dash line," says Winfree Root. "It's low in sodium and adds so much flavor you won't even miss the salt."

Mix in low-sodium options.

"If you have a favorite salty snack that you need to have, that's totally fine," says Melanie Betz MS, RD, CSR, FNKF, FAND, registered dietitian and researcher in kidney nutrition (thekidneydietitian.org). "Just make sure it fits within your daily sodium budget by 'stretching' it. For example, if you love salted almonds, make a mix including half unsalted ones. That way you're still satisfying your craving, but you've halved the total salt you're consuming."

Manage your protein intake

As your body breaks down protein, it creates a waste product called urea that's filtered out through the kidneys. But because IgAN damages your kidney's filtration power, protein can build up in your urine and urea can build up in your blood, both of which cause fatigue and appetite loss. Of course, protein is an essential nutrient, so you can't just cut it from your diet. Ask your healthcare team how much you should include in your daily diet, and in the meantime, try to...

Pick plants over animals.

"Protein isn't just found in beef and chicken; plants can be a great source, too," explains Betz. "And plant proteins produce less waste, so they're easier for your kidneys to handle." Some options include mushrooms, seeds, lentils, quinoa, tofu, soy and seitan.

Bulk up with healthy carbs and fats.

Most major diet plans still make protein the core of every meal, but when you have kidney disease, it may be best to treat it as more of a side dish. Filling $\frac{3}{4}$ of your plate with whole-grain options like brown rice, barley and whole-wheat pasta alongside lots of vegetables and/or fruits can help you still feel full and get a wide variety of vitamins and nutrients without depriving yourself.

Get choosy with fats

Like protein, fat is a macronutrient that makes up the core part of a healthy diet, but too much of the wrong type can cause inflammation and lead to high cholesterol, which can worsen IgAN. You can separate fats into three categories: the "good," i.e., unsaturated fats; the "bad," i.e., saturated fats; and the "ugly," i.e., trans fats. Aim for 20% to 35% of your total daily calories to come from unsaturated fats and no more than 5% to 6% of daily calories from saturated fat. Trans fats—labeled as anything "partially hydrogenated" on ingredient lists—should be cut entirely. To help you achieve this, try to...

Replace—don't remove!

"Cutting out foods you love doesn't work," explains Steven Winiarski, DO, clinical lipidologist and founder of The Cholesterol Doctors telemedicine practice (cholesteroldoctors.com). In fact, *Psychology Today* reports that diets where people are told not to eat certain foods increases overeating of that food by 133%! Instead, Dr. Winiarski recommends substituting high-saturated fat ingredients in your food with healthier swaps—i.e., olive oil instead of butter or lard or a reduced-fat cheese instead of the full-fat variety.

Stock up on nuts.

Nuts are a top source of healthy omega-3 fatty acids and other polyunsaturated fats (PUFAs)—and one study in the *American Journal of Kidney Diseases* found that consuming higher levels of PUFAs can help prevent kidney disease. "Omega-3 fatty acids help fight inflammation prevalent in IgAN," explains Winfree Root. "Peanuts, pecans and walnuts are all high in omega-3s and are great snack options, since they also contain plant proteins—just stick to low-salt or unsalted mixes," says Winfree Root. Not a nut fan? Other sources include avocados, olives and fish like salmon, tuna and sardines.



Supporting kidney health with supplements

Here are some supplements recommended by the National Kidney Foundation. Before taking any new supplement, be sure to discuss it with your healthcare provider.

VITAMIN D:

Can help prevent weak bones and reduce the risk for fractures for people with kidney disease

• You can also find it in: mushrooms, tofu, fortified plant milks

VITAMIN C:

Can help speed up healing in damaged kidneys

• You can also find it in: citrus fruits, peppers, broccoli

IRON:

Can help prevent anemia, a common issue in people with kidney disease

• You can also find it in: lentils, pumpkin seeds, spinach



Health Monitor Living

Questions to ask at today's exam



Scan this QR code for a free digital copy or home delivery

What is the severity of my immunoglobulin A nephropathy (IgAN)? How will we know this?



What treatments do you recommend?



Do you know of any support groups I could join to find others living with IgAN or other kidney diseases?



What lifestyle changes should I make to help care for my kidney health?



How will we know if my treatment is working? What tests and other monitoring will I need and how often?



What are the side effects I can expect with this treatment? Are there any side effects I should call you about right away?



On treatment and need help covering the cost?

Ask your healthcare provider about patient assistance programs or call the manufacturer of the treatment you have been prescribed. Many pharmaceutical companies offer copay assistance programs that can make treatment more affordable.