

Explore  
your treatment  
options

P. 6

Keep your arms  
and legs strong  
—with yoga!

P. 16

# Health Monitor<sup>®</sup>

Living



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“I’m back  
to focusing  
on what  
matters  
most!”

## CIDP

After struggling with distressing symptoms, Katelyn Ratliff wound up in a wheelchair. Thankfully, finding the right neurologist led to a diagnosis of CIDP—and a treatment that’s got her back on her feet!



**8**  
“My family comes first—not CIDP!”

After struggling with distressing symptoms, Katelyn Ratliff wound up in a wheelchair. Thankfully, finding the right neurologist led to a diagnosis of CIDP—and a treatment that’s got her back on her feet!

**THE BASICS**

**3**  
Don’t let CIDP limit your life

Today there are more treatment options than ever—so getting the upper hand on symptoms is within reach

**YOU & YOUR CARE TEAM**

**7**  
The pros on your side

The medical professionals who can help diagnose and treat you

**15**  
How have you been feeling?

Share your answers with your healthcare team to help them better understand how CIDP is affecting you

**19**  
Q&A

Susan Shin, MD, answers your top questions about living with CIDP

**24**  
Questions to ask at your next exam

**TRUE INSPIRATION**

**16**  
“We’re focused on joy now!”

Anna and Rachael prove that while living with a chronic illness can be difficult, it doesn’t have to hold you back

**FEEL YOUR BEST**

**20**  
Reclaim your autonomy

These devices can help you navigate your home and beyond

**22**  
Stay strong—despite CIDP

Simple moves to boost circulation, improve muscle strength and more

**SPECIAL THANKS TO OUR MEDICAL REVIEWER**



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CED24

Cover photo by Scott Myers



# CIDP needn’t put limits on your life

Today there are more options to treat CIDP than ever before—so getting the upper hand on symptoms is within reach.



Chances are, when you were told you had chronic inflammatory demyelinating polyneuropathy (CIDP), your initial response was, “What is that?” Once the initial confusion wore off, your next reaction may have been fear, sadness or even anger. And while it’s perfectly natural to feel a wide range of emotions when

finding out you have a chronic, incurable autoimmune disease, it’s important to put the diagnosis in perspective and learn how you can prevent it from limiting your life.

If you need inspiration, look to Katelyn Ratliff (see her story on p. 8). After giving birth to her youngest daughter, she struggled with foot pain and numbness in her legs. When doctors initially couldn’t determine the cause of her symptoms, she wound up in a wheelchair. Today, thanks to find-



ing the right healthcare team, finally getting diagnosed with CIDP and starting an effective treatment, she's back on her feet and running after her three kids.

Or, look to Anna DiBlosi and Rachael Watson (see their stories starting on p. 16) who, despite living with CIDP for years, are determined not to let the condition hold them back.

Another key to becoming em-

powered? Being informed. So keep reading this guide to understand more about CIDP and the many options you have to help ensure you can maintain your mobility and independence.

**What is CIDP?**

Your body's immune system helps keep you safe from illness by creating antibodies that seek and destroy foreign invaders like

germs and viruses. But in an autoimmune disease, those antibodies mistakenly attack your own body. Here's what happens in CIDP: Normally, your brain communicates by sending electrical signals through the nerves. Each nerve is surrounded by a myelin sheath, a protective barrier that ensures electrical signals flow smoothly. But in CIDP, antibodies attack the myelin sheaths

around nerves that control your arms and legs—i.e., the peripheral nerves. Not only does this make it difficult for the brain to communicate with your nerves, but over time the nerves themselves can become damaged and die.

**What are the symptoms?**

There are CIDP variants—i.e., types (see sidebar, *below*)—and

each can cause slightly different symptoms, often making it a challenge for doctors to diagnose the condition.

However, the most common variant, called typical CIDP, causes muscle weakness and abnormal sensory sensations (like tingling or numbness) in the arms, hands, hips, legs and feet and affects both sides of the body.

If CIDP continues to progress, additional symptoms may include:

- Loss of muscle mass in arms and legs
- Trouble using arms, legs, hands or feet, including trouble walking
- Pain

In rare cases, CIDP may also cause:

- Difficulty breathing
- Difficulty swallowing
- Double vision
- Fatigue
- Hoarseness or voice changes
- Slurred speech
- Cardiovascular issues

These symptoms may change in severity over time. In some, they may come on slowly or rapidly and sometimes they may come and go—known as remittance and relapses. Regardless of which specific symptoms you experience, it's essential to see your healthcare provider as soon as possible. Early diagnosis and treatment are key to recovery.

**Who is at risk?**

CIDP can affect people of any age, race or gender; but those at higher risk include:

- **People assigned male at birth:** They are twice as likely as people assigned female at birth to develop CIDP. The reason for this is unknown, but it is noteworthy since most autoimmune diseases tend to affect those assigned female at birth at higher rates.
- **Age:** Risk increases with age, with 50 being the average age of onset.
- **Having diabetes:** While it's

**CIDP FAST FACTS**

**40,000**  
THE NUMBER OF PEOPLE IN THE U.S. DIAGNOSED WITH CIDP

**50**  
THE AVERAGE AGE MOST PEOPLE ARE DIAGNOSED

**2X**  
HOW MUCH MORE LIKELY PEOPLE ASSIGNED MALE AT BIRTH ARE TO DEVELOP CIDP

**40%**  
THE PERCENTAGE OF PEOPLE WITH CIDP WHO ARE ABLE TO ACHIEVE FULL REMISSION—A NUMBER THAT'S GROWING!



**THE CIDP TYPES—*explained***

**Typical CIDP:** The most common type, typical CIDP produces symmetrical (*affecting both sides of your body*) muscle weakness and sensory issues (*like tingling and numbness*).

**Multifocal motor neuropathy:** This causes muscle weakness and is usually asymmetrical, which means it affects only one side of the body.

**Lewis-Sumner syndrome (LSS):** This variant causes asymmetrical muscle weakness and sensory issues.

**Pure sensory CIDP:** This variant produces symmetrical sensory issues, balance problems and an abnormal gait (*walking pattern*).

**Pure motor CIDP:** This variant is marked by symmetrical muscle weakness.

Researchers are currently studying other variants of CIDP.

still being studied, research suggests that people with diabetes are at greater risk.

- **HIV infection:** Persons with HIV infection—particularly the mid-to-late stages of HIV—are more likely to develop CIDP.
- **Having other infections:** People with chronic inactive hepatitis B virus, chronic dysregulated Epstein-Barr virus and coronavirus (COVID-19) seem to be at a higher risk.

**How is it diagnosed?**

Your healthcare team may use these tests or procedures to diagnose CIDP:

- **Physical exam:** Your healthcare provider will check your vital signs with a focus on your nervous system and muscles.
- **Electromyography (EMG):** This test checks how well your nerves are communicating with your muscles.
- **Nerve conduction tests:** These

tests check how fast electrical signals are moving through your nerves.

- **Nerve biopsy:** This procedure will remove a small piece of a nerve for lab examination.
- **Spinal tap:** Also known as a lumbar puncture, this test checks the fluid that surrounds the brain and spinal cord for certain proteins that can signal CIDP.
- **MRI:** This scan may be used to look for physical signs of CIDP-induced nerve damage, including in the spine.
- **Blood tests:** Your doctor may draw blood to test for certain proteins and other indicators of CIDP.

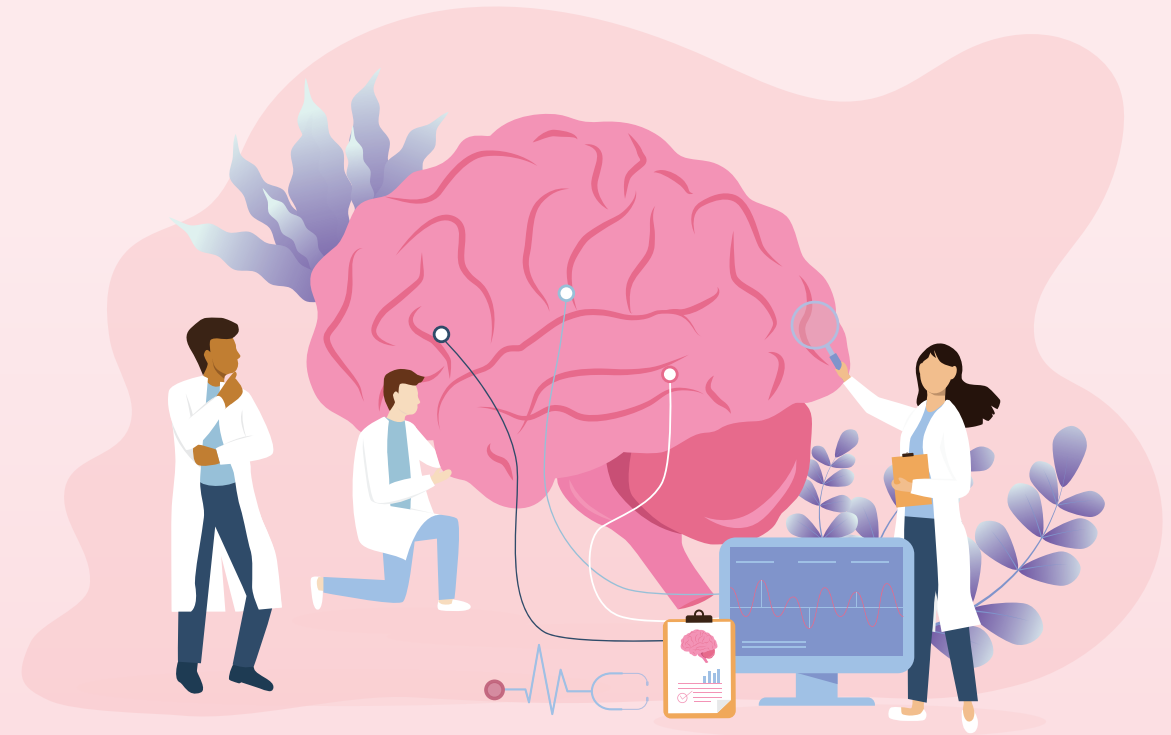
**How is it treated?**

Treatment options for CIDP depend upon the severity of your disease, but the goal is to stop your immune system from attacking your peripheral nerves. In some

cases, nerve damage can even be reversed and their function restored. In other cases, treatment may be more focused on preventing disease progression.

Treatment may include:

- **Corticosteroids:** These prescription medications can help calm an overactive immune system and lessen inflammation, thereby improving sensation in your limbs. Because corticosteroids can cause serious side effects, you may be able to use these medications only for a limited amount of time.
- **Immunosuppressants:** Typically used in combination with corticosteroids, these help slow or block your immune system, which also slows or blocks it from attacking your peripheral nerves.
- **Plasmapheresis:** Also known as plasma exchange, this treatment separates plasma from the blood, filters out the antibodies that are attacking your nerves, and then returns it to your body. You may need multiple treatments over time for this procedure to work.
- **Immunoglobulin treatment/immune globulins:** This involves the injection or infusion of healthy immunoglobulins into your body. They basically work by regulating your immune system—providing healthy antibodies that work as they should, while reducing the number of damaged antibodies that attack myelin.
- **Physical therapy:** This may be a suggested treatment option if you are experiencing difficulty with strength and/or mobility. ●



# The pros on your side

These medical professionals can help diagnose and treat chronic inflammatory demyelinating polyneuropathy (CIDP).

**Primary care provider (PCP):** an internist or family physician who manages and coordinates your overall care. Your PCP may have referred you to a neurologist for your CIDP care.

**Neurologist:** a physician who specializes in diseases involving the nervous system and who will create a treatment plan for you.

**Nurse/nurse practitioner/physician associate:** a medical professional who can answer questions, provide guidance and help you follow through with your treatment and self-care.

**Physiatrist:** a physician who can develop a care plan to address the physical effects of CIDP and boost your functional abilities.

**Physical therapist:** a licensed healthcare professional who can help you manage your CIDP symptoms through movement and exercise.

**Occupational therapist:** a licensed healthcare professional who can make recommendations to help you function your best while at home, work or out-and-about.

**Psychiatrist/psychologist/social worker:** a mental health professional who can provide counseling; psychiatrists can also prescribe medication.

**Dietitian:** a licensed nutrition professional who can help you eat well to feel your best. ●

# “My family comes first—*not CIDP!*”

After struggling with distressing symptoms following the birth of her daughter, Katelyn Ratliff wound up in a wheelchair. Thankfully, finding the right neurologist led to a diagnosis of CIDP—and a treatment that’s got her back on her feet!

—BY DANIELLE TUCKER

**T**

**hese days, 29-year-old Katelyn Ratliff is focused solely on the important stuff**—things like going bowling with her family, taking leisurely walks through the park and serving up wholesome family dinners for her three kids.

And while those may not sound like arduous activities, Katelyn is doing it all while battling chronic inflammatory demyelinating polyneuropathy (CIDP).

Katelyn’s health journey started more than two years ago during her last pregnancy. While in her third trimester, she was diagnosed with preeclampsia (dangerously high blood pressure that can occur during pregnancy). This led to a complicated birth, and her daughter spent more than three weeks in the NICU.

“I was there every day visiting her,” the Louisiana resident recalls. “My feet started to hurt, and I noticed that my legs felt heavy, but I just thought it was lingering effects of the epidural and being on my feet so much.” Rubbing her feet would alleviate the pain temporarily, but it would quickly return, and often with a vengeance.

One night, the pain was so severe Katelyn couldn’t get out of bed. After some time resting and taking a Tylenol, she could finally rise, but her feet continued to ache and burn. The night before her daughter’s discharge, Katelyn stayed with her in the hospital. “My feet were killing me, but I was so excited to bring her home!”

*Continued on next page* ▶





Several days later, Katelyn collapsed while trying to walk to the bathroom. “My aunt saw me and tried to help me up, but I immediately collapsed again.”

### “I needed answers!”

A trip to her primary care doctor revealed Katelyn still had high blood pressure but found no apparent reason for her foot pain. She left the appointment with a medication used to treat neuropathy. Within a week, Katelyn’s condition rapidly worsened. By the time she saw the doctor

for her follow-up appointment, she was in a wheelchair. Her next stop was a neurologist, but bloodwork still revealed nothing abnormal.

For the next eight months, Katelyn would go in and out of the hospital looking for answers. Shockingly, despite her young age, she suffered two heart attacks and a blood clot in her left lung—cardiac issues can be another, albeit rare, symptom of CIDP—while doctors still struggled to find answers.

“I ended up in the ICU twice. At one point I couldn’t walk, feed

or bathe myself.” A lumbar puncture eventually revealed there was excess protein in her cerebrospinal fluid, indicating a nervous system disorder, but they still weren’t sure which exact disorder she had. Still, they started Katelyn on intravenous immunoglobulin infusions (IVIG) to see if that would improve her symptoms, and it seemed to do the trick.

### “I finally found relief!”

Unfortunately, after being released from the ICU, she would return days

later with a fiery pain in her feet that felt like “thousands of bee stings.” This time Katelyn was in luck, however. She met with a new neurologist, Ebony McKinnies, MD, who reviewed her health history, ordered some more tests and finally diagnosed Katelyn with CIDP, a progressive condition in which the immune system attacks tissue called myelin that protects the body’s nerves—in the case of CIDP, it specifically targets the peripheral nervous system, which can impact the feet and legs. Another round of IVIG accompanied by blood thinners to help with her cardiovascular issues began to restore Katelyn’s strength.

These days, with the help of her care team, a new treatment regimen and the unwavering support of her family, Katelyn has made tremendous progress. “My last flare was in January 2023. I was in a wheelchair for seven months, but now I can walk on my own! I’ll never forget the expressions on my children’s faces when they saw me walk again for the first time. They yelled, ‘My momma can walk!’ They are my number one supporters.”

Katelyn continues physical and occupational therapy, and to prevent the relapse she had after her first IVIG treatment, she now uses regular maintenance immunoglobulin treatments that she can inject at home.

“My medication is keeping me stable. I still have periods where I lose feeling in my feet, but thanks to this treatment, I can still be an active mom. My life’s not 100% back to normal, but it’s close. I’ve even been able to work a desk job for the past year.”

Looking back on the early presentation of her symptoms, Katelyn regrets not seeking specialized medical care sooner. “Don’t ignore what your body is trying to tell you. I was being selfish trying *not* to be selfish. I wanted to be there for my kids. In the end, I missed eight months of my daughter’s firsts: her first word, first time holding a bottle, first time crawling. Sometimes I ask why God let this happen to me, but I’m convinced it was just a test of faith so I would rely on Him and come out stronger. It took a lot of help to get me here, and I’m grateful every day.” ●

Photos by Scott Myers



## Connect with others who understand!

For Katelyn, reaching out on social media made a big difference in helping her feel less isolated due to her CIDP. “These groups can offer advice, camaraderie and resources you won’t find in other places.” Here, some you can check out.

### GBS-CIDP Foundation International

([gbs-cidp.org](https://gbs-cidp.org)) is a global network that offers patient and family support, education, research and advocacy opportunities.

### Shining Through CIDP

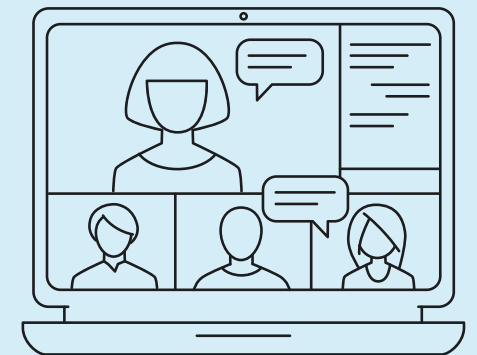
([shiningthroughcidp.com](https://shiningthroughcidp.com)) provides educational resources and a support phone line, and even shares inspirational stories and hosts events to raise awareness.

### The National Organization for Rare Disorders

([rarediseases.org](https://rarediseases.org)) provides care, support and resources for people living with a range of rare diseases, including CIDP.

### Facebook Groups

- GBS/CIDP Warriors
- GBS CIDP Fighters & Survivors



# Say **Hy** to HyQvia

A different way to get your CIDP treatment. HyQvia gives you choices.

HyQvia is used to treat CIDP in adults.

CIDP=chronic inflammatory demyelinating polyneuropathy.

**HyQvia**  
[Immune Globulin Infusion 10% (Human)  
with Recombinant Human Hyaluronidase]



Scan the QR code to  
learn more about HyQvia

**Up to once a month\***  
infusions in ~2 hours

\*Every 2, 3, or 4 weeks.



**Given just under  
the skin**

Not given into a vein.



**In center or at home**  
(including self-administration)

HyQvia can be infused at your doctor's office, in an infusion center, or at home after appropriate training. You and your doctor will decide what's best for you.

Ask your doctor if HyQvia could be right for you.

## What is HyQvia?

HyQvia is a liquid medicine that is given under the skin (subcutaneously) to treat chronic inflammatory demyelinating polyneuropathy (CIDP) in adults.

## IMPORTANT SAFETY INFORMATION

### What is the most important information that I should know about HyQvia?

- HyQvia can cause blood clots.
- Call your healthcare professional (HCP) if you have pain, swelling, warmth, redness, or a lump in your legs or arms, other than at the infusion site(s), unexplained shortness of breath, chest pain or discomfort that worsens on deep breathing, unexplained rapid pulse, numbness or weakness on one side of the body.
- Your HCP may perform blood tests regularly to check your IgG level.
- Do not infuse HyQvia into or around an infected or red swollen area because it can cause infection to spread.

## IMPORTANT SAFETY INFORMATION (continued)

### Who should not take HyQvia?

Do not take HyQvia if you:

- Are allergic to IgG, hyaluronidase, other blood products, or any ingredient in HyQvia.

### What should I avoid while taking HyQvia?

- HyQvia can make vaccines (like measles/mumps/rubella or chickenpox vaccines) not work as well for you. Before you get any vaccines, tell your HCP that you take HyQvia.

### What should I tell my HCP before I start using or while using HyQvia?

Tell your HCP if you:

- Have or had any kidney, liver, or heart problems or history of blood clots because HyQvia can make these problems worse.
- Have IgA deficiency or a history of severe allergic reactions to IgG or other blood products.
- Are pregnant, trying to become pregnant or are breast feeding. It is not known whether HyQvia can harm the unborn baby or breastfed infant.

### What are the possible or reasonably likely side effects of HyQvia?

**HyQvia can cause serious side effects. If any of the following problems occur after starting HyQvia, stop the infusion immediately and contact your HCP or call emergency services:**

- Hives, swelling in the mouth or throat, itching, trouble breathing, wheezing, fainting or dizziness. These could be signs of a serious allergic reaction.
- Bad headache with nausea, vomiting, stiff neck, fever, and sensitivity to light. These could be signs of irritation and swelling of the lining around your brain.
- Reduced urination, sudden weight gain, or swelling in your legs. These could be signs of a kidney problem.
- Pain, swelling, warmth, redness, or a lump in your legs or arms, other than at the infusion site(s). These could be signs of a blood clot.
- Brown or red urine, fast heart rate, yellow skin or eyes. These could be signs of a liver or blood problem.
- Chest pain or trouble breathing, blue lips or extremities. These could be signs of a serious heart or lung problem.
- Fever over 100°F. This could be a sign of an infection.

After HyQvia infusion a temporary, soft swelling may occur around the infusion site, which may last 1 to 3 days, due to the volume of fluid infused. The following possible side effects may occur at the site of infusion and generally go away within a few hours, and are less likely after the first few infusions.

- Mild or moderate pain
- Redness
- Swelling
- Itching

The most common side effects of HyQvia are:

- Headache
- Fatigue
- Nausea
- Fever
- Itching
- Redness
- Abdominal pain
- Back pain
- Pain in extremity

Antibodies to the hyaluronidase component of HyQvia were formed in some patients taking HyQvia. It is not known if there is any long-term effect. In theory, these antibodies could react with your body's own hyaluronidase (PH20). PH20 is present in the male reproductive tract. So far, these antibodies have not been associated with increased or new side-effects.

**These are not all the possible side effects. Talk to your HCP about any side effect that bothers you or that does not go away.**

**You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.**

**Please see the Important Facts about HyQvia on the next page and discuss with your HCP.**

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**IMPORTANT FACTS about HYQVIA (Hi-Q-via) [Immune Globulin Infusion 10% (Human) with Recombinant Human Hyaluronidase] Solution, for subcutaneous administration**

**What is the most important information I should know about HYQVIA?**

- HYQVIA can cause blood clots.
- Call your healthcare provider (HCP) if you have pain, swelling, warmth, redness, or a lump in your legs or arms, other than at the infusion site(s), unexplained shortness of breath, chest pain or discomfort that worsens on deep breathing, unexplained rapid pulse, numbness or weakness on one side of the body.
- Your HCP may perform blood tests regularly to check your IgG level.
- Do not infuse HYQVIA into or around an infected or red swollen area because it can cause infection to spread.

**What is HYQVIA?**

HYQVIA is a liquid medicine containing immune globulin and Recombinant Human Hyaluronidase. HYQVIA is given under the skin (subcutaneously) to treat primary immunodeficiency (PI) in people 2 years of age and older and chronic inflammatory demyelinating polyneuropathy (CIDP) in adults. HYQVIA contains IgG antibodies, collected from human plasma donated by healthy people.

- The antibodies help your body to fight off bacterial and viral infections. People who have CIDP are believed to have an autoimmune disease in which the body's immune system targets the nerves, leading to muscle weakness and numbness, usually in the arms and legs. IgG is thought to reduce the damage to the nerve and assist in defending the nerve from harm.
- The hyaluronidase is found in your body naturally. It's the first part of your two-part infusion. It temporarily opens the space under your skin (the subcutaneous space), allowing a larger amount of IgG to reach your subcutaneous tissue and be absorbed into your bloodstream.

**What should I tell my HCP before I start using or while using HYQVIA?**

- Tell your HCP if you:
- Have or had any kidney, liver, or heart problems or history of blood clots because HYQVIA can make these problems worse.
  - Have IgA deficiency or a history of severe allergic reactions to IgG or other blood products.
  - Are pregnant, trying to become pregnant, or are breastfeeding. It is not known whether HYQVIA can harm the unborn baby or breastfed infant.

**Who should not take HYQVIA?**

- Do not take HYQVIA if you are allergic to IgG, hyaluronidase, other blood products, or any ingredient in HYQVIA.

**How should I take HYQVIA?**

- HYQVIA is infused under the skin (subcutaneously) up to once every 4 weeks.
- You can get HYQVIA at your HCP's office, clinic, or hospital.
- You can use HYQVIA at home. You and your HCP will decide if home self-infusion is right for you.

**What are the possible or reasonably likely side effects of HYQVIA?**

After HYQVIA infusion a temporary, soft swelling may occur around the infusion site, which may last 1 to 3 days, due to the volume of fluid infused.

The following local reactions may occur at the site of infusion and generally go away in a few hours. Local reactions are less likely

- after the first few infusions.
- Mild or moderate pain
  - Redness
  - Swelling
  - Itching

The most common side effects of HYQVIA are: headache, vomiting fatigue, nausea, fever, itching, redness, abdominal pain, back pain, and pain in extremity.

Antibodies to the hyaluronidase component of HYQVIA were formed in some patients taking HYQVIA. It is not known if there is any long-term effect. In theory, these antibodies could react with your body's own PH20. PH20 is present in the male reproductive tract. So far, these antibodies have not been associated with increased or new side effects.

Call your HCP or go to your emergency department right away if you get:

- Hives, swelling in the mouth or throat, itching, trouble breathing, wheezing, fainting or dizziness. These could be signs of a serious allergic reaction.
- Bad headache with nausea, vomiting, stiff neck, fever, and sensitivity to light. These could be signs of irritation and swelling of the lining around your brain.
- Reduced urination, sudden weight gain, or swelling in your legs. These could be signs of a kidney problem.
- Pain, swelling, warmth, redness, or a lump in your legs or arms, other than at the infusion site(s). These could be signs of a blood clot.
- Brown or red urine, fast heart rate, yellow skin or eyes. These could be signs of a liver or blood problem.
- Chest pain or trouble breathing, blue lips or extremities. These could be signs of a serious heart or lung problem.

These are not all of the possible side effects for HYQVIA. You can ask your HCP for information that is provided to HCPs. Talk to your HCP about any side effects that bother you or that don't go away.

**How do I store HYQVIA?**

- Store HYQVIA refrigerated or at room temperature.
- You can store HYQVIA in the refrigerator (36°F to 46°F [2°C to 8°C]) for up to 36 months.
  - You can store HYQVIA at room temperature (up to 77°F [25°C]) for up to 3 months during the first 24 months from the date of manufacturing (Mfg Date) printed on the carton.
  - Do not return HYQVIA to the refrigerator if you take it out to room temperature.

Check the expiration date on the carton and vial label. Do not use HYQVIA after the expiration date.

Do not freeze.  
Protect from light. You can use the original HYQVIA containers to protect it from light.

**How do I get more information about HYQVIA?**

The risk information provided here is not comprehensive. To learn more, talk about HYQVIA with your HCP or pharmacist. The FDA-approved Full Prescribing Information, including Information for Patients, can be found at [www.HYQVIA.com](http://www.HYQVIA.com) or by calling 1-877-TAKEDA7 (1-877-825-3327).

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**YOU & YOUR CARE TEAM**

# How have you been feeling?

Living with chronic inflammatory demyelinating polyneuropathy (CIDP) not only affects you physically, but studies show it can also have an impact on all aspects of your health—from your sleep patterns to your stress levels.

Fill out the tool below to help your healthcare provider better understand how CIDP is affecting you and whether you may need to make some adjustments to your treatment plan.

PHYSICAL HEALTH	I deal with...	Never	A little	Somewhat	A lot	Almost always
	Numbness in my arms and hands					
	Numbness in my legs and feet					
	Tingling in my arms and hands					
	Tingling in my legs and feet					
	Muscle weakness in my arms and hands					
Muscle weakness in my legs and feet						

EVERYDAY LIFE	CIDP affects my ability to...	Never	A little	Somewhat	A lot	Almost always
	Sleep					
	Perform everyday tasks, like shower or cook					
	Do my favorite hobbies					
	Exercise					
	Be social/see or make friends					
	Date					
Perform my job						
Leave my house						

MENTAL HEALTH	In the past month, I have...	Never	A little	Somewhat	A lot	Almost always
	Had no appetite/skipped meals					
	Binge eaten ( <i>overeaten</i> )					
	Slept more than usual					
	Lost sleep or had difficulty sleeping					
	Declined social invitations					
	Cried more than usual					
	Stopped doing things I once enjoyed					
	Stopped caring about my appearance ( <i>my clothes, grooming</i> )					
	Argued with others more than usual					
Had trouble making decisions						
Had more aches ( <i>headache, stomachache or other</i> ) than usual						



# “Being chronically ill is hard, *yet we still find joy!*”

It took years for Anna and Rachael to receive diagnoses for their debilitating pain and loss of mobility. Read on to learn how they've stayed the course and found medal-worthy moments among the challenges. —BY DANIELLE TUCKER

## “Spread your knowledge”

ANNA DIBLOSI, 29  
LOS ANGELES

When Anna DiBlosi became sick on the last night of a trip to Tulum, Mexico, she blamed it on food poisoning and thought it would pass. Her stomachaches did improve, but two weeks later, she began experiencing knee pain after a visit to Dodger Stadium. “At first, I assumed I had tweaked my knee while walking to the elevated stadium, but screaming-level distress sent me to the ER.” During the wait to see an orthopedic specialist for a possible torn ligament, the intense pain spread. “It moved up and down my leg, and soon jumped to the other one. Within a month, the entire lower half of my body was involved.” Anna’s pain would puzzle doctors and lead her down a long road in search of answers.

### Trust your gut.

Pain, weakness and constant burning affected Anna’s body from her

jaw to the bottom of her feet. Probable diagnoses included fibromyalgia and reactive arthritis, but further testing would rule them out. “Nobody knew what was wrong. Neurologists would send me to rheumatologists. Rheumatologists would send me back to neurologists.” It took years to receive a concrete diagnosis —chronic inflammatory demyelinating polyneuropathy (CIDP), an acquired autoimmune disorder that attacks the peripheral nerves.

### Stay organized.

Anna’s quest for answers sent her all over the country. “I’ve seen dozens of doctors, including approximately fifteen to twenty rheumatologists. It’s important to know your medical history. I put all my records, imaging and lab reports in four-inch binders and created a medical summary outlining my



“My mom encouraged me to post about my CIDP journey online. It comforts me knowing there are others like me out there!”

symptoms, key tests and timeline. Having a complex history and being undiagnosed, you have to beg to see doctors. Don’t give up! And before you leave an appointment, schedule your next one.”

**Build a supportive team.** “Ninety-nine percent of my time

is spent in bed. I had to quit my tech advertising job and move in with my parents. I couldn’t do this without them and my boyfriend’s support.” Grateful for the support, Anna pays it forward: “My mom encouraged me to start posting about my CIDP journey online. She said if we weren’t getting help, oth-

ers weren’t either. It comforts me knowing there are others like me out there.” Anna’s Instagram page [@anna\\_diblosi](#) has over 16K followers. “I consider it my job now. The 20-30 minutes I spend answering direct messages gives me purpose. It shows I can be productive and move on.” ▶

Photo by Tamara Leigh



**“Dream big, and try hard!”**

**RACHAEL WATSON, 32**  
BRISBANE, AU

**Rachael Watson spent much of her young adult years searching for the root cause of increasing pain and discomfort.** In 2013, she was initially diagnosed with Guillain-Barre syndrome, an autoimmune disease that attacks the nerves, but her symptoms continued to worsen. It took almost a decade for Rachael to learn that the true culprit was CIDP. Today, she has partial function in her hands and arms but no use of her core or legs. She hasn't let a wheelchair hold her back, though: Hydrotherapy strengthened her body, gave her purpose and won her Paralympic gold.

**Seek multiple opinions.**

“I was misdiagnosed initially, and the doctor told me it was ‘all in my head.’ It took far too long to receive a proper diagnosis.” Rachael has a fantastic neurologist now and a robust treatment plan, but her outcome could have been different had interventions begun at the onset of symptoms. “Don't accept a single diagnosis as the only answer—push for a second or third opinion and more tests. You know your body and when something doesn't feel right.”

**Accomplish your “impossible.”**

Rachael added water therapy to her physiotherapy regimen. With help, she learned to swim again and progressed to swimming laps alone. She found a coach who helped her prepare for her first local competition. “Water allows me to move a lot easier, and I love it! I knew I wanted to compete more.” She trained with coaches, became fitter and faster, and swam a qualifying time for the 2016 Paralympics. Rachael won two Paralympic gold medals in Rio and Tokyo and two bronze in Paris. “Just because it hasn't been

done before doesn't mean it's impossible. Many people will tell you ‘it's too hard;’ that means you must have willpower and keep going forward if you have a dream.”

**Lean on the CIDP community.**

CIDP is rare, with only 5 to 7 confirmed cases per 100,000. As a result, there is a learning curve for everyone involved. “Family, friends, caregivers and medical professionals are all learning, too, and some will struggle more than others to accept the diagnosis and life changes. The network of people who live with CIDP and connect to support each other is gold—it is truly the only place you can go to, whether it be an online group or an in-person event, where people can give you the best knowledge on how to navigate day-to-day with this condition.” If you'd like to follow Rachael for more inspiration, check her Instagram [@rachaewatsonply](#).

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Photo by Rachael Watson



**Is maintenance mandatory? My doctor prescribed intravenous immunoglobulin (IVIG) treatments after I was diagnosed with CIDP. And the numbness in my arms and legs has noticeably improved! Now she says she wants to start me on a monthly maintenance therapy to prevent relapses. I don't understand—if the IVIG made the problem go away, why do I need monthly infusions? Aren't I cured?**

**Q**

**A**

*Answers to your questions about CIDP*

**A:** Unfortunately, there is no cure for CIDP because it is a chronic condition. IVIG is a treatment that is effective in removing inflammation, which slows the progression of the disease and allows the nerves to heal—this is why you had improved sensation in your arms and legs. But without maintenance therapy, IVIG's effect only lasts for a few weeks, after which most patients will quickly experience a renewed flare-up of symptoms. The bottom line is that maintenance therapy is essential for counteracting your immune system's attack on your peripheral nervous system and can help you feel your best much longer.

**FAMILY FEARS**

**Q:** *My father was recently diagnosed with CIDP, and now I'm worried—should I prepare for him to become disabled? Also, am I or my children now at risk for this condition?*

**A:** The good news is that CIDP is absolutely treatable, and a variety of effective therapies including IVIG, steroids and maintenance therapies, can help prevent its progression. In addition to medications, your father should investigate physical therapy, which can provide a wealth of exercises he can safely try out that can help bring back—and even build—strength. There are also assistive devices that your father can use to aid his mobility and daily routines to

keep him independent. CIDP is not a hereditary condition; however, if you experience any symptoms, be sure to let your doctor know your family history.

**IS ACTIVITY A-OK?**

**Q:** *Before I was diagnosed with CIDP I was very active: I loved hiking, cycling and swimming. Once I learned I had the condition, I stopped all three because I was so afraid of hurting myself. But I've been successfully treating my CIDP for years now. How do I know if it's safe to return to any of these activities, or is there another form of exercise that might be more appropriate?*

**A:** Exercise is very beneficial to CIDP because it can help improve muscle strength, endurance and balance. As long as your condition is being successfully treated, you should be able to go back to hiking, cycling and swimming. Other extremely beneficial exercises include walking, stretching and resistance training, all of which you can consider adding to your workout routine after checking with your healthcare provider. If you resume your activity and stay with it, in time you will find that you will be able to keep up with your friends and family the way that you did before your diagnosis.

**OUR EXPERT:**

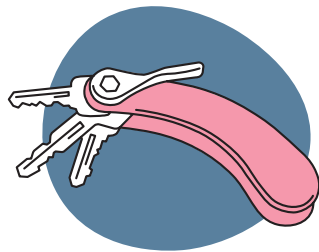
**Susan Shin, MD**, Associate Professor, Neurology, Mount Sinai Hospital; Program Director, Neuromuscular Medicine Fellowship; NY

# Reclaim *your* independence!

Embracing assistive devices can take the struggle out of ordinary activities.—BY SARA ROTONDI

When CIDP makes it difficult to use your arms and/or legs, not only can it make everyday tasks a challenge, but it can also take a toll on your mental well-being. To the rescue?

Assistive devices. “Anything that helps you regain your sense of independence can greatly improve your quality of life, sense of agency, self-esteem and confidence to be self-sufficient,” says clinical psychologist Fanny Ng, PhD, of Clarity Therapy in NYC, who specializes in helping people with chronic medical conditions. Best of all, today’s assistive devices go way beyond shower bars, canes and walkers—here’s a look at the inventive products out there that can help cut everyday tasks down to size.

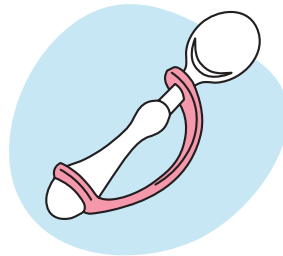


**Trouble locking your door?**

**Try a key grip.**

This device connects a large handle to your keys, making it much easier to turn them in a lock.

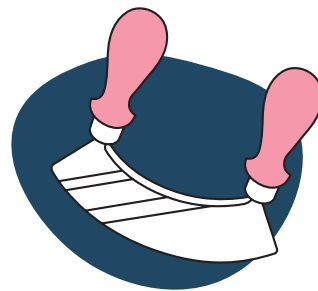
**Note:** If you have trouble grabbing your doorknob, consider switching to a lever-style handle, which can allow you to open and close doors without needing to grip or turn your wrist.



**Can’t grab utensils?**

**Invest in a silicone hand grip.**

This device can be attached to a variety of household items, including utensils, tools and your toothbrush. You slip your four top fingers through the grip, which allows you to hold the item without needing to curl your fingers to grasp it.

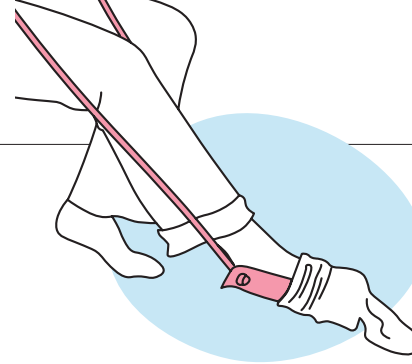


**Need meal prep assistance?**

**Consider a rolling knife.**

Also called a “mezzaluna knife,” it allows you to use both hands or even your palms to rock the knife back and forth to chop—no gripping or wrist dexterity required!

Illustrations by Juhee Kim



**Putting on socks and shoes a pain?**

**Try a sock assist and extra-long shoe horns.**

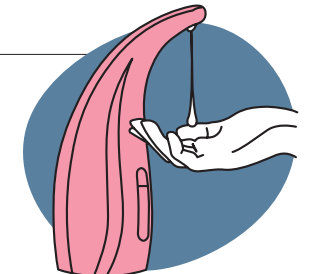
Sock assists hold the sock open—simply slip your foot in, then use the attached strings to pull the sock up and on. Extra-long shoe horns then allow you to slip on your favorite kicks so you’re ready to go!



**Tough getting dressed?**

**Consider zipper pulls and button hooks.**

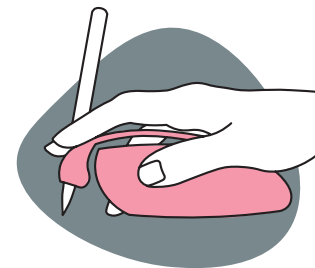
Nearly everyone has trouble zipping up a dress or top when it’s in the back, which is where zipper pulls can come in handy. Plus they also work on pants and front zippers if grabbing the tiny zipper head has become a near-herculean feat. Buttons more your problem? Hooks allow you to easily pull them through the hole.



**Has cleaning become cumbersome?**

**Consider touchless dispensers.**

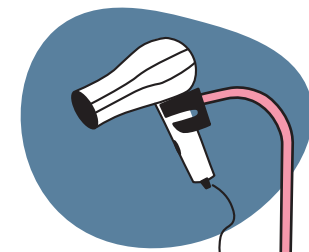
Laundry detergent and cleaning supplies often come in large, awkward containers that can be difficult to lift and pour. Ask someone to help you pour them into one of these touchless dispensers, and you just have to hold your cleaning rag or laundry cup under them and they will pour a small amount automatically.



**Struggling with pens and pencils?**

**Add an assistive writing tool.**

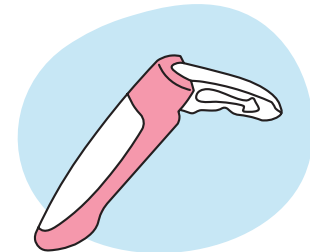
This allows your hand to be in a relaxed position, similar to moving a computer mouse, while writing or signing documents, and can be helpful for people with both hand and wrist dexterity issues.



**Hair-drying a hassle?**

**Get a dryer stand.**

When hand, wrist or arm issues make it practically impossible to wield a blow dryer, let this device do the holding for you. It can easily be manipulated to change angles, making it a breeze to style your locks.



**Hate getting in and out of the car?**

**Try a vehicle support handle!**

This item is small enough to fit in a purse or your car’s glove compartment; it hooks into the car door latch and provides a stable surface to help you push yourself up to get out or steady yourself as you sit down. ●

Most chain and local pharmacies carry assistive devices; you can also find many options at Walmart, Target and on Amazon.com.

# Help maintain flexibility—*with yoga!*

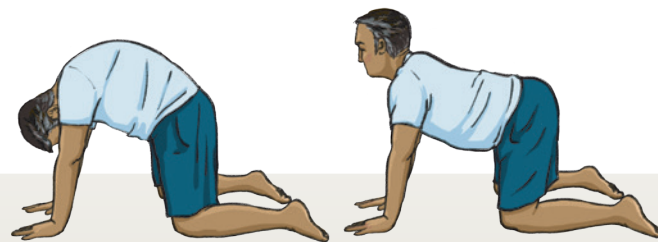
Simple moves to boost circulation, improve muscle strength and more.  
—BY RIKKI ECCLES

**W**hen it comes to neurological disorders like chronic inflammatory demyelinating polyneuropathy (CIDP), loss of sensation and responsiveness in the arms and legs can pose a daily challenge.

One method of exercise proven to help? Yoga, which multiple studies have shown can improve strength, balance and blood circulation to affected limbs. In fact, 84% of patients with demyelinating disorders similar to CIDP reported enhanced relaxation, reduced pain and spasms, improved balance and sleep and an increased sense of well-being after practicing yoga, according to a study in *Journal of Alternative and Complementary Medicine*.

That's why we asked Amanda Neufeld, a certified individual yoga therapist (C-IAYT) and experienced registered yoga teacher (E-RYT 500) who specializes in patients with multiple sclerosis and other neurological disorders for her favorite moves. "Yoga helps you redirect energy with intention, helps you get in tune with your body on a somatic level and has even been shown to boost gray matter in the brain," Neufeld adds. "This can help keep symptoms at bay because you can learn how to consciously relax muscle spasms as well as cope with things mentally and emotionally."

**Ready to get started?** Ask your healthcare provider if you can try any or all of the moves below, which are simple enough for beginners and can be performed anywhere!



## CAT-COW POSE

This pose helps stretch the spine and increases blood flow throughout the body. "It also strengthens the muscles of the back and neck, which can improve your gait and balance even while dealing with numbness," says Neufeld.

### To start:

1. Kneel on the floor and put your hands on the floor in front of you.
2. Keep your hands shoulder-width apart and your knees directly below your hips.
3. Inhale deeply and bring your abdomen in, arching your spine and bringing your head and pelvis down like a cat.
4. Exhale deeply while curving your lower back and bringing your head up, tilting your pelvis up like a cow.
5. Repeat 2-3 times.

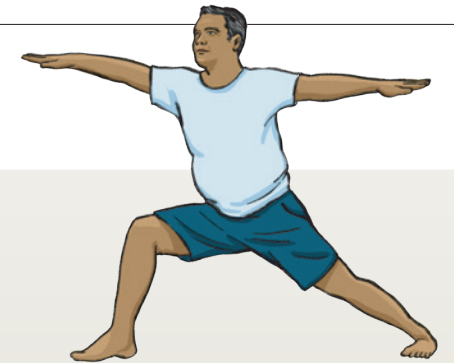


## CHILD'S POSE

"The rhythmic breathing and movements of the Child's Pose can create a mini-meditation that calms the mind while stretching many of the joints of the body," Neufeld says. "This creates a better environment in the body for improved nerve response in the limbs."

### To start:

1. Kneel on the floor and put your hands on the floor in front of you.
2. Spread your knees as wide as your shoulders, keeping the tops of your feet on the floor with the big toes touching.
3. Rest your belly between your thighs and root your forehead to the floor.
4. Relax the shoulders, jaw and eyes. If it is uncomfortable to place your forehead on the floor, rest it on a block or two stacked fists.
5. Stretch your arms in front of you with palms toward the floor or bring your arms back alongside your thighs with palms facing upwards. You can also stretch your arms forward with palms facing up for a shoulder release.
6. Stay in this position as long as you like, focusing on the steady inhales and exhales of your breath.



## WARRIOR II POSE

This pose improves leg strength and posture and stimulates the abdominal muscles, boosting power to your core to help with balance issues. Beyond that, Neufeld says the name is powerful in itself: "When you are in the Warrior II Pose, you tap into your inner strength. Remind yourself that you can do hard things and that your body can still accomplish so much."

### To start:

1. From a standing position, step your left foot back and turn it out 90 degrees.
2. Bend your right knee, keeping it directly over your ankle.
3. Extend your arms out to the sides, and gaze over your right hand.
4. Hold for 5-10 breaths.
5. Repeat on the other side.

## TREE POSE

This pose is great for practicing mindfulness, Neufeld says, which can help you "tap into your why and your intention behind your movements. Mindfulness is at the core of what helps you direct the energy in your body."

### To start:

1. Stand with your feet together and your knees slightly bent. Bring your hands to your hips or press your palms together in a prayer position in front of your heart.
2. Shift your weight onto your left foot and lift your right foot off the ground. Bend your right knee and open it to the right side.
3. Place the sole of your right foot against your left ankle, calf or upper thigh.
4. Focus on a single object or space in front of you. Keeping your eyes still can help you maintain balance and hold Tree Pose for a longer period of time.
5. Hold the pose for five breaths before switching sides.



Illustrations by Juhhee Kim

# Health Monitor Living



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## Questions to ask at today's exam

Do I have CIDP? What tests will I need to confirm this?



What treatments do you recommend for me and why do you think they would be a good fit?



How will we know if the treatment is working?



What side effects can I expect? Are there any side effects I should tell you about immediately?



Will I need maintenance treatment to prevent relapses?



Are there any lifestyle changes I can make to help improve my symptoms and prevent relapse?



Do you know of any support groups I can join?



### **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.