-MehMD-TAKE CONTROL

CHRONIC SPONTANEOUS URTICARIA

GOOD TO KNOW

Advocating for yourself

CARING FOR YOU

Taking care of your mental health

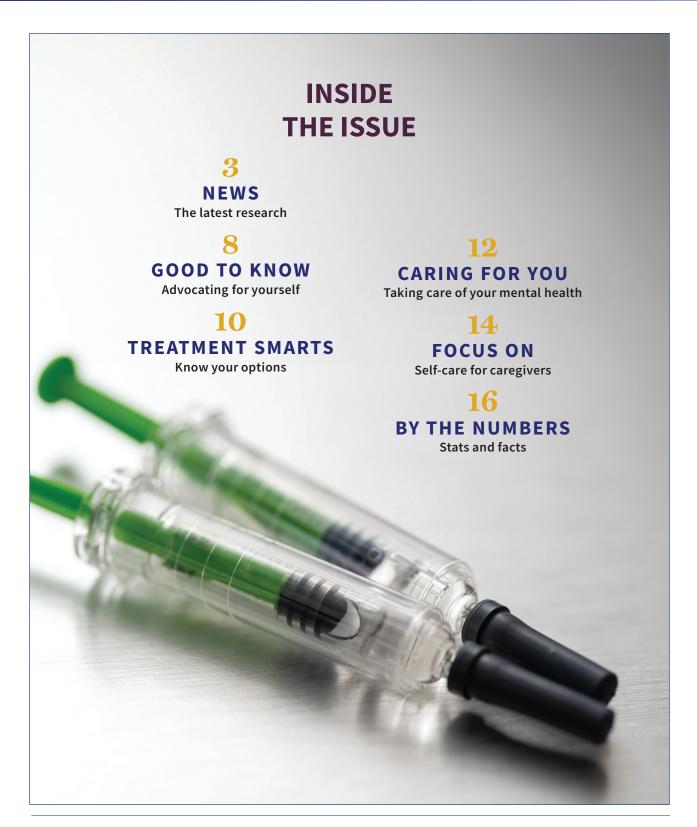
BY THE NUMBERS

Stats and facts
page 16



SCAN ME
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THE LATEST ON

GET A LITTLE CLOSER

Does your CSU keep you from being intimate with your partner? A recent survey found that both men and women with CSU reported substantially higher rates of sexual dysfunction and erectile dysfunction than people who don't have this condition. Sexual function is a major contributor to quality of life. If your CSU is taking a toll on your sex life and overall quality of life, it might be time to talk to your doctor about a more effective treatment.

SOURCE: Dermatology Practical & Conceptual

How many more women aet CSU

SOURCE: National Library of Medicine

Number of people who have CSUboth in the U.S. and worldwide.

SOURCE: National Library of Medicine

CHOOSING THE BEST TREATMENT FOR YOU

For many people with CSU, it's a long road to diagnosis and another long haul to a treatment that works. What if there were a test to see whether a certain drug might work for you before you tried it? Researchers recently discovered that patients who get the best results from biologic medications for CSU seem to have high numbers of immune cells called myeloid progenitors. People with lower levels of these cells either didn't get much benefit from the medication or it just took longer for them to see the effects. One day, doctors could test your blood to look for these cells before making treatment recommendations.

SOURCE: Allergy

HAVE YOU HAD YOUR THYROID CHECKED?

CSU often goes hand in hand with other autoimmune diseases, including autoimmune thyroid diseases. New research shows thyroid problems might be even more common in people with CSU than previously believed. The study found that more than 1 in 4 people with CSU have hypothyroidism. People with CSU also have high levels of specific hormones and proteins that can promote thyroid diseases. If you haven't already, ask your doctor if you need to have your thyroid checked.

SOURCE: Diagnostics



HELP INTERRUPT THE CYCLE OF ITCH AND HIVES FROM CSU WITH ONCE-MONTHLY XOLAIR





SCAN TO GO TO OUR HOME PAGE

For people 12 years of age and older with chronic spontaneous urticaria (CSU) not controlled by H1 antihistamines.

What is XOLAIR?

XOLAIR® (omalizumab) for subcutaneous use is an injectable prescription medicine used to treat chronic spontaneous urticaria (CSU, previously referred to as chronic idiopathic urticaria (CIU), chronic hives without a known cause) in people 12 years of age and older who continue to have hives that are not controlled with H1 antihistamine treatment. It is not known if XOLAIR is safe and effective in people with CSU under 12 years of age.

XOLAIR is not used to treat other forms of hives.

IMPORTANT SAFETY INFORMATION

What is the most important information I should know about XOLAIR?

Severe allergic reaction. A severe allergic reaction called anaphylaxis can happen when you receive XOLAIR. The reaction can occur after the first dose, or after many doses. It may also occur right after a XOLAIR injection or days later. Anaphylaxis is a life-threatening condition and can lead to death. Go to the nearest emergency room right away if you have any of these symptoms of an allergic reaction:

- wheezing, shortness of breath, cough, chest tightness, or trouble breathing
- low blood pressure, dizziness, fainting, rapid or weak heartbeat, anxiety, or feeling of "impending doom"
- flushing, itching, hives, or feeling warm
- swelling of the throat or tongue, throat tightness, hoarse voice, or trouble swallowing

Your healthcare provider will monitor you closely for symptoms of an allergic reaction while you are receiving XOLAIR and for a period of time after treatment is initiated. Your healthcare provider should talk to you about getting medical treatment if you have symptoms of an allergic reaction.

Do not receive and use XOLAIR if you are allergic to omalizumab or any of the ingredients in XOLAIR.

Before receiving XOLAIR, tell your healthcare provider about all of your medical conditions, including if you:

- have a latex allergy or any other allergies (such as food allergy or seasonal allergies). The needle cap on the XOLAIR prefilled syringe contains a type of natural rubber latex
- have ever had a severe allergic reaction called anaphylaxis
- have or have had a parasitic infection
- have or have had cancer
- are pregnant or plan to become pregnant. It is not known if XOLAIR may harm your unborn baby.
- are breastfeeding or plan to breastfeed. It is not known
 if XOLAIR passes into your breast milk. Talk with your
 healthcare provider about the best way to feed your
 baby while you receive and use XOLAIR.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

How should I receive and use XOLAIR?

- When starting treatment, XOLAIR should be given by your healthcare provider in a healthcare setting.
- Do not try to inject XOLAIR until you have been shown the right way to give XOLAIR prefilled syringe or autoinjector injections by a healthcare provider. Use XOLAIR exactly as prescribed by your healthcare provider.
- The XOLAIR autoinjector (all doses) is intended for use only in adults and adolescents aged 12 years and older. For children 12 years of age and older, XOLAIR prefilled syringe or autoinjector may be self-injected under adult supervision.
- See the detailed Instructions for Use that comes with XOLAIR for information on the right way to prepare and inject XOLAIR.
- XOLAIR is given in 1 or more injections under the skin (subcutaneous), 1 time every 4 weeks.
- In people with chronic hives, a blood test is not necessary to determine the dose or dosing frequency.
- Do not decrease or stop taking any of your other hive medicine unless your healthcare providers tell you to.
- You may not see improvement in your symptoms right away after XOLAIR treatment.
- If you inject more XOLAIR than prescribed, call your healthcare provider right away.

What are the possible side effects of XOLAIR? XOLAIR may cause serious side effects, including:

- Cancer. Cases of cancer were observed in some people who received XOLAIR.
- Fever, muscle aches, and rash. Some people get these symptoms 1 to 5 days after receiving a XOLAIR

- injection. If you have any of these symptoms, tell your healthcare provider.
- Parasitic infection. Some people who are at a high risk for parasite (worm) infections, get a parasite infection after receiving XOLAIR. Your healthcare provider can test your stool to check if you have a parasite infection.
- Heart and circulation problems. Some people who
 receive XOLAIR have had chest pain, heart attack,
 blood clots in the lungs or legs, or temporary symptoms
 of weakness on one side of the body, slurred speech, or
 altered vision. It is not known whether these are caused
 by XOLAIR.

The most common side effects of XOLAIR in people with chronic spontaneous urticaria: nausea, headaches, swelling of the inside of your nose, throat or sinuses, cough, joint pain, and upper respiratory tract infection.

These are not all the possible side effects of XOLAIR. Call your doctor for medical advice about side effects.

You may report side effects to the FDA at (800) FDA-1088 or www.fda.gov/medwatch. You may also report side effects to Genentech at (888) 835-2555 or Novartis Pharmaceuticals Corporation at (888) 669-6682.

Please see Consumer Brief Summary on the following page.

Genentech



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CONSUMER BRIEF SUMMARY

The risk information provided here is not comprehensive. This information does not take the place of talking with your doctor about your medical condition or treatment. To learn more about XOLAIR® (omalizumab), talk to your doctor or pharmacist. For more information and to obtain the FDA-approved product labeling, visit xolair.com/csu.

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Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

How should I receive and use XOLAIR?

- When starting treatment, XOLAIR should be given by your healthcare provider in a healthcare setting.
- If your healthcare provider decides that you or a caregiver may be able to give your own XOLAIR prefilled syringe or autoinjector injections, you should receive training on the right way to prepare and inject XOLAIR.
- Do not try to inject XOLAIR until you have been shown the right way to give XOLAIR prefilled syringe or autoinjector injections by a healthcare provider. Use XOLAIR exactly as prescribed by your healthcare provider.
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 Some people who receive XOLAIR have had chest pain, heart attack, blood clots in the lungs or legs, or temporary symptoms of weakness on one side of the body, slurred speech, or altered vision. It is not known whether these are caused by XOLAIR.

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You may report side effects to the FDA at (800) FDA-1088 or www.fda.gov/medwatch. You may also report side effects to Genentech at (888) 835-2555 or Novartis Pharmaceuticals Corporation at (888) 669-6682.

General information about the safe and effective use of XOLAIR.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use XOLAIR for a condition for which it was not prescribed. Do not give XOLAIR to other people, even if they have the same symptoms that you have. It may harm them.

For more information, go to www.xolair.com/csu or call 1-866-4XOLAIR (1-866-496-5247).

What are the ingredients in XOLAIR?
Active ingredient: omalizumab
Inactive ingredients: Prefilled syringe
or Autoinjector: arginine hydrochloride,
histidine, L-histidine hydrochloride
monohydrate, and polysorbate 20
Vial: histidine, L-histidine hydrochloride
monohydrate, polysorbate 20 and
sucrose

Manufactured by: Genentech, Inc., A Member of the Roche Group, 1 DNA Way, South San Francisco, CA 94080-4990 U.S. License No.: 1048

Jointly Marketed by: Genentech USA, Inc., A Member of the Roche Group, 1 DNA Way, South San Francisco, CA 94080-4990

Novartis Pharmaceuticals Corporation, One Health Plaza, East Hanover, NJ 07936-1080

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M-US-00012100(v3.0) Printed in USA 03/24

WHAT XOLAIR PATIENTS WITH CSU ARE SAYING



"

Everyone's different, but **XOLAIR** worked for me when nothing else would.

Jamika, an actual XOLAIR patient —

Jamika is a real patient with CSU, chronic spontaneous urticaria. She was compensated for her time and expenses to share her personal experience. Individual results may vary.



I go to the doctor **once** a **month**. I get my injection and then I get on with my day.

Kristen, an actual XOLAIR patient

Kristen is a real patient with CSU, chronic spontaneous urticaria.

She was compensated for her time and expenses to share her personal experience. Individual results may vary.





Please see Consumer Brief Summary

on the adjacent page.

HEAR MORE FROM THE XOLAIR COMMUNITY



Scan the QR code to watch real patients like you share their experiences living with chronic hives with no known trigger or visit XOLAIR.com/CSUpatientstories.

ADVOCATING FOR YOURSELF

Get quality care for your CSU

By Rachel Reiff Ellis Reviewed by Neha Pathak, MD, WebMD Chief Physician Editor

hronic spontaneous urticaria (CSU) is a condition that causes raised, itchy areas of skin on your body. You most commonly hear it called hives. When your hives crop up over and over again, they're chronic. If it's not clear why they're suddenly coming on, that's called spontaneous or idiopathic.

Hives can be pink, red, or dark. These hives can show up anywhere on the body and might come and go quickly over time. Dealing with them can be frustrating, especially because you don't know why they're happening. But they are a sign your body is protecting itself.

"It can be helpful to think of it as the body's defense system or immune system overreacting and causing the skin to swell and itch," says Nicole Negbenebor, MD, a dermatologist at University of Iowa Health Care in Iowa City.

BEST PRACTICES

As you work with your dermatologist to stop your itching and manage your rash, there are things you can do to make sure you're being heard.

First, find a dermatologist you feel comfortable with and can talk to openly and honestly. You'll work closely together, so having a good relationship helps you both. Keep up with your visits so your relationship and care—is most effective.

"Consistent appointments and good communication allow for timely adjustments to the care plan,"



STRENGTH IN NUMBERS

Find support and advocacy advice through online groups such as:

Hives Support Group (dailystrength.org/group/hives)

Chronic-Hives.com Community Hub (chronic-hives.com/community)

Chronic Idiopathic Urticaria (Facebook group)



ASK YOUR DOCTOR

Nicole Negbenebor, MD, lists questions to bring with you to your appointment.

- + What might be triggering my CSU?
- + What treatment options are available?
- + Why am I on the medication I'm on?
- + How can I track my symptoms and triggers?
- + What should I do if I have a flare-up?
- + How often should I schedule follow-up appointments for my condition?

Negbenebor says. Ask questions to better understand your condition, she says. Staying informed gives you a solid foundation for navigating the ups and downs of your condition.

KNOW YOUR SYMPTOMS

One valuable tool for better communication and advocacy for yourself as you manage CSU is a symptom diary. Keeping a diary of your symptoms helps both to identify triggers and see patterns in your flares.

Even better, take pictures when your hives show up and include those in your symptom diary.

"This is important, because CSU symptoms are fleeting, so by the time you get to your doctor's appointment, your wheals, or welts, are already gone," says Mary P. Smith, MD, a dermatologist at Sutter Health in Sacramento, CA. "Pictures can help us see what you're dealing with."

With a fuller view of what your symptoms look like and when they happen, your doctor can suggest the most effective lifestyle changes and treatments for you.

KNOW YOUR OPTIONS

Strategies for managing your condition

By Rachel Reiff Ellis

Reviewed by Neha Pathak, MD, WebMD Chief Physician Editor

hronic spontaneous urticaria (CSU) causes raised, itchy skin blotches (hives) that come and go over a period of more than six weeks. The word "chronic" means they often continue happening for months or even years, and the word "spontaneous" means you don't know what's causing them.

Living with CSU can be uncomfortable and get in the way of your everyday activities, and even prevent restful sleep. But there are medications and practices you can follow to help ease your symptoms.

AVOID TRIGGERS

Even though you may not know the exact cause for your hives, there are certain things that may make symptoms worse. The first step in symptom management is looking into what those factors might be, says Anna Chacon, MD, a dermatologist and founder of Miami Derm in Coral Gables, FL.

"Lab testing can rule out an autoimmune condition or chronic infection and help to find a resolution for the consistent outbreaks," Chacon says.

It can be easy to miss or forget things that could be affecting you, so Chacon recommends keeping a journal to record details of your life when you have an outbreak.

"Diet, medications, natural exposures, or even outside emotional factors like stress could be to blame and easily missed without thorough observation," Chacon says.





MEDICATION THAT HELPS

While corticosteroid creams you spread on your skin can help mild patches that don't cover much of your body, typically your doctor will start you on over-thecounter anti-itch medications vou take by mouth called antihistamines. Histamines are chemicals your body releases when it thinks it's under threat (like from an allergen). Antihistamines block these chemicals, so you don't get the hive response.

Chacon recommends newer, "secondgeneration" options over "first-generation" medications, which can cause drowsiness and other side effects. Look for a nondrowsy label for antihistamine choices in the second-generation category.

Sometimes doctors prescribe a short course of oral corticosteroids for a bad flare of hives, but it's not a long-term option, says Isabela Jones, MD, a dermatologist and founder of Virginia Square Dermatology in Arlington.

"Since these medications go through your whole body, they can cause some unpleasant side effects," Jones says.

Some cases of CSU may not respond to first-line treatments and need more advanced prescription options.

Prescription injection medications such as leukotriene receptor antagonists and monoclonal antibodies calm your immune system to reduce inflammation and swelling. Your doctor may have you take this in addition to your antihistamine.

Certain tricyclic antidepressant medications you take by mouth have antihistamine-like properties and can reduce hives. These typically make you drowsy.

TAKING CARE OF YOUR MENTAL HEALTH

Steps to take when stubborn and itchy skin symptoms are causing you distress

By Kendall K. Morgan Reviewed by Neha Pathak, MD, WebMD Chief Physician Editor

hile chronic hives may be skin deep and aren't life-threatening, they can affect every aspect of your life. CSU puts you at more risk for depression and reduces your general sense of well-being.

"Although it is usually not anything dangerous, CSU can be very stubborn and refractory to treatment requiring multiple agents to get it under control," says Purvi Parikh, MD, an allergist and immunologist at Allergy & Asthma Associates of Murray Hill in New York City and spokesperson for the Allergy & Asthma Network. "Symptoms come daily, and it can be debilitating to be constantly itchy."

FACING UNPREDICTABLE, **DEBILITATING, AND VISIBLE SYMPTOMS**

Sonali P. Majmudar, MD, an allergist at Majmudar Allergy in Hoffman Estates and Algonquin, IL, who is a spokesperson for the American College of Allergy, Asthma, & Immunology,

> MENTAL HEALTH DISORDERS AND CSU

One study showed mental disorders often occurring in people with CSU include:

- + Depression
- + Anxiety

+ ADHD

- + PTSD
- + Personality disorder
- + OCD

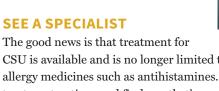
says the inability to predict CSU symptoms or understand what triggers them can make this condition especially frustrating. It's not uncommon to have faced years of misdiagnoses and treatments that don't work as CSU can mimic other health conditions.

"My patients often come to me saying they have seen multiple doctors and have tried many treatments without significant relief," Majmudar says. "Impaired sleep quality is another common issue. I think this is why this disease can cause high emotional and physical burden that negatively affects quality of life. Especially when severe, these patients are living with a highly symptomatic and visible skin disease. which can lead to additional mental health challenges."

SEE A SPECIALIST

CSU is available and is no longer limited to standard allergy medicines such as antihistamines. To explore your treatment options and find one that's more likely to bring relief, Parikh recommends seeing a board-certified allergist. Even though CSU is rarely linked to any allergies, an experienced allergist or immunologist can guide treatment for your CSU with the latest medicines in ways your primary care doctor can't.

"We have many biologic medications that have been





game changers in the world of hives and many new ones on the horizon, which can get them under control faster than traditional treatments," Parikh says.

SHARE YOUR EXPERIENCES

Majmudar encourages sharing with your doctor just how much the condition is affecting you. She says it's not uncommon for doctors to underestimate symptom severity and the emotional toll it's taking. Let them know if the medicines you're on aren't

working well enough to relieve your skin symptoms and the mental health struggles that come with them.

"For patients struggling with CSU and their mental health, know that you are not alone. As with all chronic diseases, it's a long journey," Majmudar says. "Talk to your doctors—they are there to support you."

If you're experiencing significant anxiety, depression, or overwhelming stress that interferes with daily life, she says, seek counseling from a mental health professional, too.

SELF-CARE FOR CAREGIVERS OF THOSE WITH CSU

Work as a team and take time for yourself

By Kendall K. Morgan Reviewed by Neha Pathak, MD, WebMD Chief Physician Editor

hronic spontaneous urticaria (CSU) can be debilitating. As a result, it's a challenging condition for those with CSU and for caregivers alike, says Kristen Willard, executive director of We CU, a nonprofit organization dedicated to improving the lives of people with chronic urticaria, who also has CSU.

"Chronic urticaria can affect every aspect of life, from daily tasks like cooking and cleaning to financial and social well-being," says Willard, who is also vice president of education at Global Allergy & Airways Patient Platform (GAAPP.org) in Washington, DC. "Because the condition often demands the full attention of those affected, their loved ones may need to take on additional responsibilities. This can include managing household chores during flare-ups, providing emotional support, or even assisting with financial and medical needs. The demands of caregiving span all areas of life, making it physically and emotionally taxing for the entire family."

PRIORITIZE YOURSELF

Willard recommends working together with your loved one as a team. But don't forget to focus on yourself.

"It's easy for caregivers to put their own needs aside as they devote their time, energy, and focus to their loved one's condition," Willard says. "However, prioritizing your well-being is essential. Whenever possible, get enough rest, eat well, seek support, and take time for yourself. Allow yourself to acknowledge feelings of sadness, frustration, or exhaustion rather than suppressing them. Openly discuss with your loved one the possibility of involving additional caregivers to share the responsibility and provide relief for both of you."

CAREGIVER RESOURCES

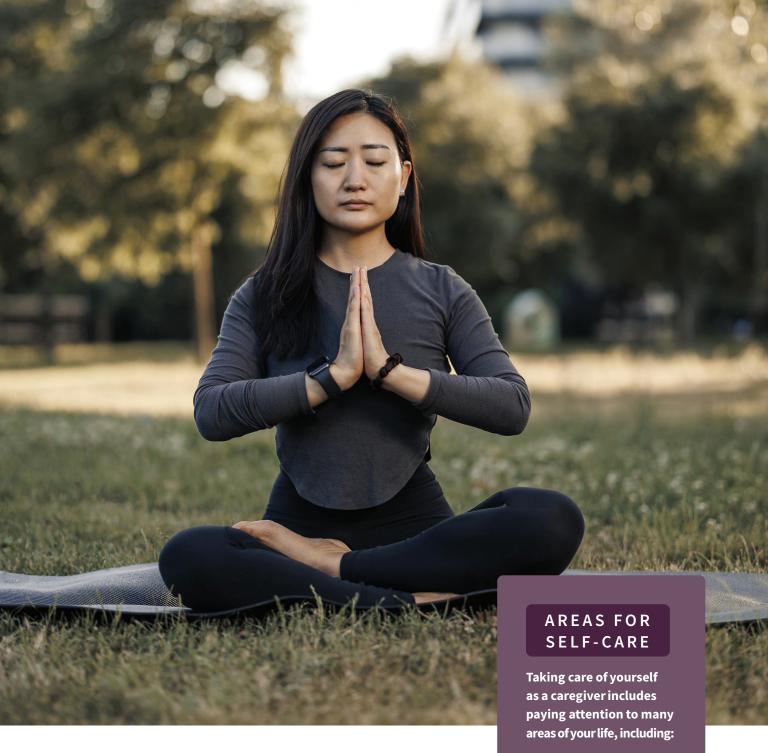
For more information and support to help in your CSU caregiving journey, see:

- + Family Caregiver Alliance https://www.caregiver.org
- + Global Allergy & Airways Patient Platform Urticaria **Shared Decision-Making Aid** https://gaapp.org/urticaria-shared-decision-making
- + We CU https://chronic-urticaria.org

BEING SELF-AWARE

Avoiding caregiver burnout requires self-awareness, says Susanne White, an experienced caregiver in Port St. Lucie, FL, and author of the book Self-Care for Caregivers. She stresses the importance of recognizing your own feelings and needs.

"Self-care is not all bubble baths and yoga because it's difficult," White says. "I think we have to be self-aware, and we have to get to know ourselves and know when we need to take a



break or take a breather, maybe walk outside for five minutes and allow ourselves permission to take those breaks and feel like we deserve it. That's the big issue is that caregivers don't feel they deserve to take a break or they don't deserve self-care, and self-care is not a luxury. It's critical in the caregiving journey."

Try scheduling time for self-care, she suggests. Reach out to a friend or find other caregivers for support.

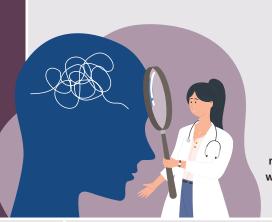
It should be encouraging for you as a caregiver to know there's hope for treating CSU, Willard says. Existing treatments can help you both get back to the life you deserve. If your loved one with CSU is suffering with uncontrolled symptoms, consider going with them to an allergist to explore any new treatment options or alternatives.

+ Being active

- + Eating well
- + Prioritizing sleep
- + Lowering stress
- + Taking breaks
- + Caring for your health
- + Reaching out for help



Reviewed by Neha Pathak, MD, WebMD Chief Physician Editor



Amount of people with CSU whose quality of life—including family relationships and emotional well-being-is badly affected,

based on an online survey.



Amount of people in the **U.S.** affected by chronic spontaneous urticaria (CSU).

Number of months it takes for a person in the U.S. to receive a CSU diagnosis after their first visit to a doctor.

20 to **40**



Age group in which CSU is most common in the U.S.

How many more women have CSU

Amount of people with **CSU** whose symptoms remained uncontrolled despite receiving

treatment, leading to higher health care costs, based on a U.S. study.

Amount of people who have autoallergic CSU, a subtype of the skin condition where the body acts like it is allergic to itself.



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