



# Chronic Urticaria in the Black Community: More than Hives

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Virtual Conference  
**May 1st**  
**4:00 PM ET**

# Chronic Urticaria in the Black Community: More than Hives

Presented by: Allergy & Asthma Network

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**Thank you, Genentech and  
Novartis for providing funding  
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Moderator  
**Sherrina Gibson**



Physician Speaker  
**Dr. Nicole Negbenebor**



Patient Speaker  
**Emmeka "Meka" Hawkins**

# Patient Story



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# Navigating Chronic Urticaria: Empowering Patients and Caregivers

**Nicole Negbenebor, MD, FAAD**

May 1, 2025

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# Welcome to Our Chronic Urticaria (CU) Community



Wollina, U., Verma, S. B., & Ashique, K. T. (2018). Urticaria and Angioedema in Skin of Color. In *Pigmented Ethnic Skin and Imported Dermatoses: A Text-Atlas* (pp. 271-277). Cham: Springer International Publishing.

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# Agenda

The Need for Better CU Resources

Addressing Educational Gaps and  
Misinformation

Building a Trusted Community

Exploring Root Causes and Lifestyle  
Factors

# The Need for Better CU resources

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# Bridging the Gap: The Need for Reliable CU Information

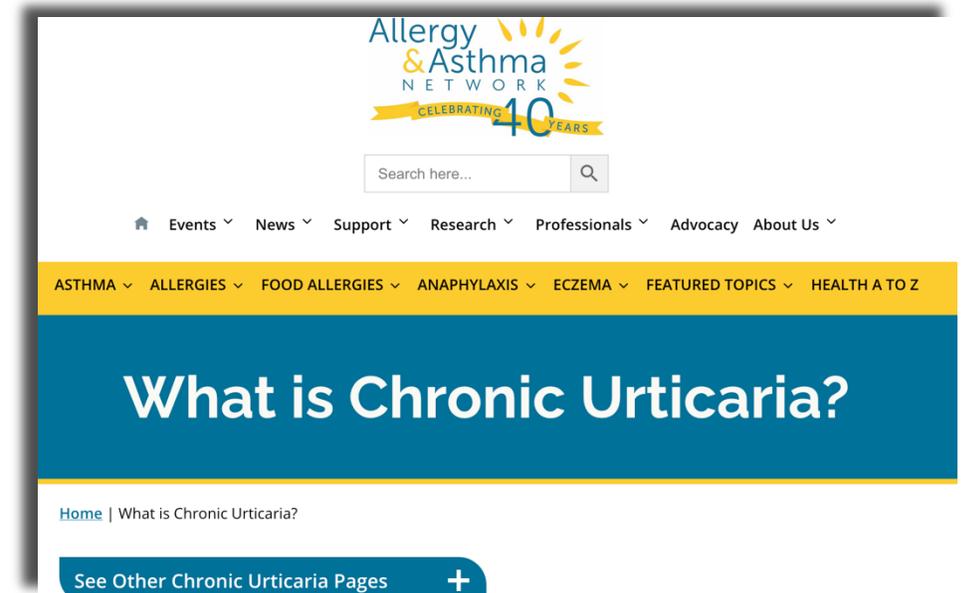
- Many CU websites and materials don't show people of different races, skin tones, and backgrounds
- CU can look different on darker skin – but photos often only show lighter skin examples
- Under representation may lead to delayed diagnosis and worse disease
- Everyone deserves to see themselves reflected in healthcare



<https://images.app.goo.gl/ds9A3ANF7NhBDA7R7>

# Bridging the Gap: The Need for Reliable CU Information

- We need a dedicated, trustworthy space specifically focused on CU
- Centralized, credible support improves care
- A trusted resource can help reduce confusion and anxiety
- Our aim is to work towards creating more inclusive and centralized resources for the CU community



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# What Inclusive Resources Should Offer

- **Images** of CU on **all skin tones** and in different body types, ages, and genders
- **Real stories** from people living with CU
- **Culturally sensitive advice** on skincare, diet, and treatment preferences
- **Easy-to-read guides** explaining symptoms, diagnosis, treatment, and living with CU from experts
- **Accessible** materials available in multiple languages and for different abilities (e.g., vision impairments)

# Educational Gaps and Misinformation

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# Educational Gaps and Misinformation

## Common patient challenges:

- *What is CU? Is it an allergy? A skin infection? Can I give this to other people?*
- *Why are doctors sometimes confused too?*
- *Why do treatments work for some and not others?*

## These challenges lead to...

- Misdiagnosis (e.g., mistaking CU for eczema, lupus, or allergies)
- Patients wasted time and money on the wrong treatments
- Emotional distress when the correct care is delayed



Reddit · r/urticaria

260+ comments · 1 year ago

## To those of you whose chronic urticaria resolved, did ...

I'm on month 5 of this rollercoaster. 5 months ago I randomly woke up with welts covering up my entire body and every day since I've been ...



Reddit · r/ChronicIllness

10+ comments · 1 year ago

## chronic spontaneous urticaria : r/ChronicIllness

Chronic Urticaria is the medical term for **hives that recur**, like mine that I've had since my earliest memories. Mine is also connected to my ...



Reddit · r/urticaria

10+ comments · 1 year ago

## Can someone explain HOW chronic urticaria works?

I have spent the last couple of weeks in and out of doctors only to be told I have **Chronic Urticaria**. I

don't understand how I get this

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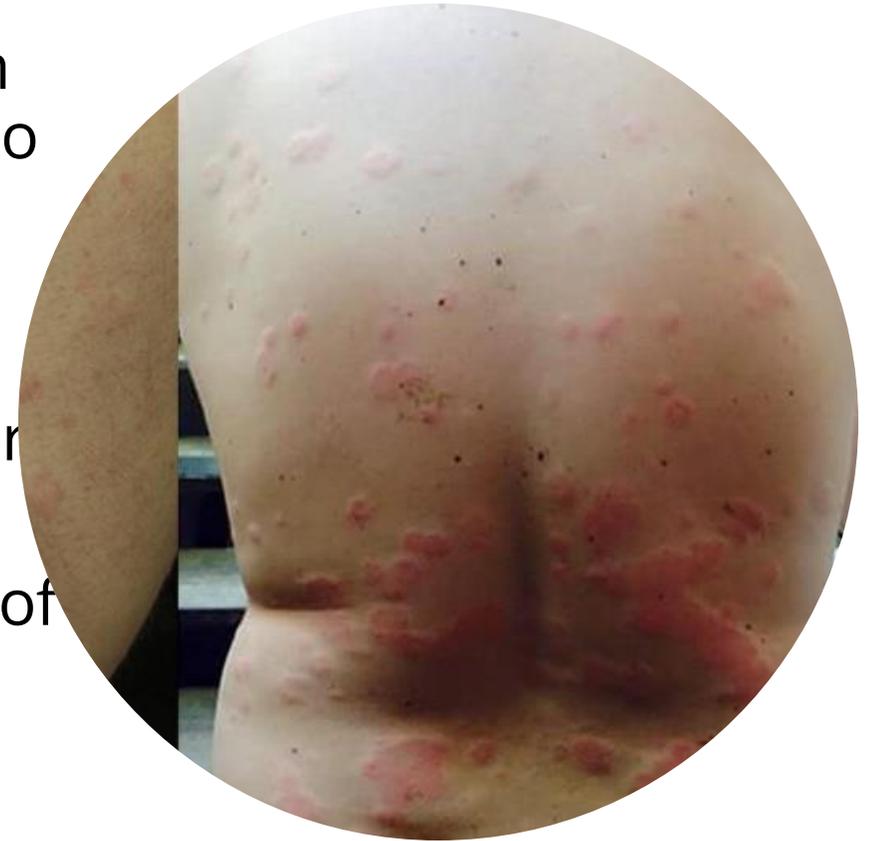
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# Educational Gaps and Misinformation

The exact cause of chronic urticaria (CU) is often unknown, which is why it's sometimes referred to as chronic idiopathic urticaria (CIU) or chronic spontaneous urticaria (CSU)

This can be frustrating for patients and caregivers

The welts of urticaria are caused by the release of immune system chemicals, such as histamine, from mast cells in the skin —> itching, swelling, and possible redness



Kanani, A., Betschel, S.D. & Warrington, R. Urticaria and angioedema. Allergy Asthma Clin Immunol 14 (Suppl 2), 59 (2018). <https://doi.org/10.1186/s13223-018-0288-z>

# Common Misunderstandings Around CU

**CU** is **not** always caused by allergies

**It can sometimes be autoimmune**, meaning the immune system mistakenly attacks healthy tissue

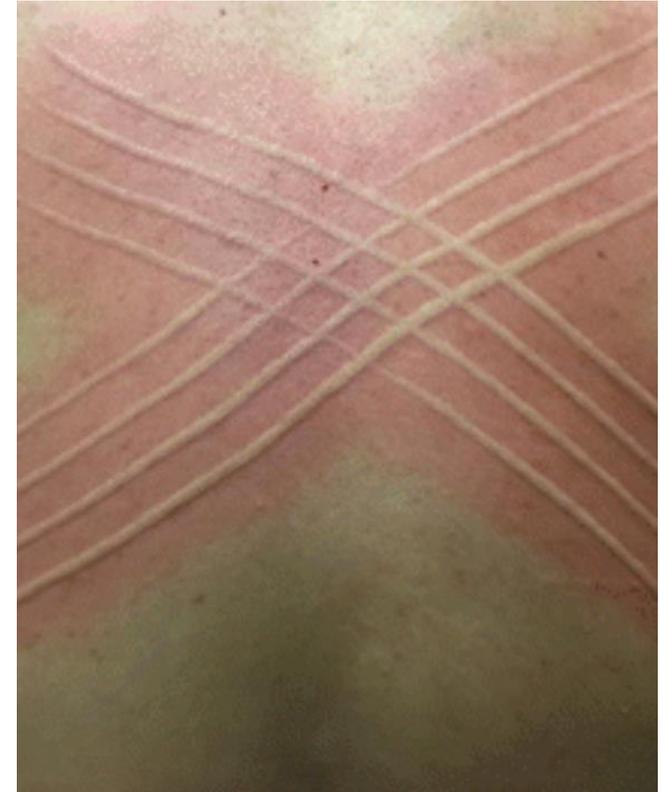
- Associated with thyroid disease, lupus, celiac, type 1 diabetes, Sjogren's, rheumatoid, etc

**Physical** triggers can cause Chronic Inducible Urticaria

- Dermographism from scratching, cold, heat, pressure, exercise, solar, vibratory, aquagenic

**Certain factors may play a role in triggering or exacerbating CU**

- Hormones, stress, foods, additives, medications, infections



Radonjic-Hoesli, S., Hofmeier, K. S., Micaletto, S., Schmid-Grendelmeier, P., Bircher, A., & Simon, D. (2018). Urticaria and angioedema: an update on classification and pathogenesis. *Clinical reviews in allergy & immunology*, 54, 88-101.

# Common Misunderstandings Around CU

- Antihistamines: These are the first-line treatment, but dosing and expectations vary
  - Ex: Cetirizine, loratadine, fexofenadine
  - May increase to up to 4x the usual dose
- Steroids: Should only be used for short bursts, not daily long-term

# Common Misunderstandings Around CU

- **Omalizumab** (Xolair): **biologic** (a monoclonal antibody) blocks immunoglobulin E (IgE), an antibody involved in allergic reactions
  - Injection once a month
- **Dupilumab** (Dupixent): **biologic block interaction** between interleukin-4 (IL-4) and interleukin-13 (IL-13)
  - Patients aged 12 years and older with CSU
- **Symptom control** is important – but uncovering root causes matters too

# Building a Trusted Community

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# Building Better Education

## What patients need:

- **Clear definitions** of CU, different types (spontaneous vs. inducible)
- **Step-by-step guides** on how to work with your doctor
- **Simple explanations** of medicines: how and when to use them safely
- **Practical tips** for managing flares at home
- **Video workshops** and **interactive webinars** to learn in a supportive environment



Identifying and Treating Hives on Black Skin: What You Need to Know. Medically reviewed by [Bukky Aremu, APRN](#) – Written by [Alysa Hullett](#) – Updated on August 6, 2024

# Desire for Community and Support

## Why community matters:

- Living with CU can feel isolating and frustrating
- Support groups online and social media are often unregulated
  - Harmful advice spreads
- People crave real, evidence-based support where they can also share their feelings and struggles

## Key needs:

- Trusted online forums moderated by healthcare experts
- Small coaching groups led by trained CU mentors
- In-person meetups and virtual support events

# What a Supportive CU Community Should Look Like

- **Safe spaces** free from judgment and false "cures"
- **Trained peer coaches** who know how to listen and guide
- **Groups organized by interests:** medication support, managing daily life, emotional health, caregiver groups
- **Events that offer real help:** workshops on skincare, mental health check-ins, Q&A with doctors



# Root Causes and Lifestyle Factors

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# Focusing on Root Causes, Not Just Symptoms

## Patients are asking:

- "Why is this happening to me?"
- "What is triggering my flares?"

## The missing piece:

- Most treatments today only manage **symptoms** — not the **underlying reasons** why the immune system is acting up
- We need **research and education** on root causes like autoimmune conditions, infections, stress, hormones, and more

# Lifestyle Factors That May Impact CU



**Skincare:** Use gentle cleansers and moisturizers; avoid fragrances and harsh chemicals



**Haircare:** Look for sulfate-free shampoos and avoid dyes/relaxers during flares



**Clothing:** Choose soft, breathable fabrics like cotton and bamboo; avoid rough or synthetic materials

# Lifestyle Factors That May Impact CU

**Diet and Environment:** For some, certain foods, temperature changes, or allergens may be triggers

**Stress Management:** Chronic stress can worsen symptoms. Mindfulness, yoga, therapy, and sleep hygiene help



# Moving Towards Whole-Person Care

CU isn't just a skin condition — it affects mental health, daily life, and emotional wellbeing

## Whole-person care involves:

- Finding root triggers
- Empowering patients with knowledge
- Offering emotional support
- Respecting each person's unique journey



# Our Shared Vision

- A diverse, empowered CU community
- A world where CU patients see themselves reflected in every resource
- Trusted education for all
- Real support that goes beyond symptom control
- Hope and healing through connection and understanding
- **True hope** through understanding and empowerment – not just "living with it," but thriving

# How You Can Get Involved



**Join** upcoming workshops and webinars

**Join** patient panels and feedback groups

**Share** your CU story to help others feel less alone

**Support** the building of inclusive, evidence-based CU resources

**Volunteer** as a peer supporter

**Advocate** for CU awareness in your local healthcare systems

**You are not alone. We are here to support each other.**

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# Questions & Answers Section

# Closing Remarks & Thank You!