NOVARTIS

Chronic Spontaneous Urticaria (CSU)

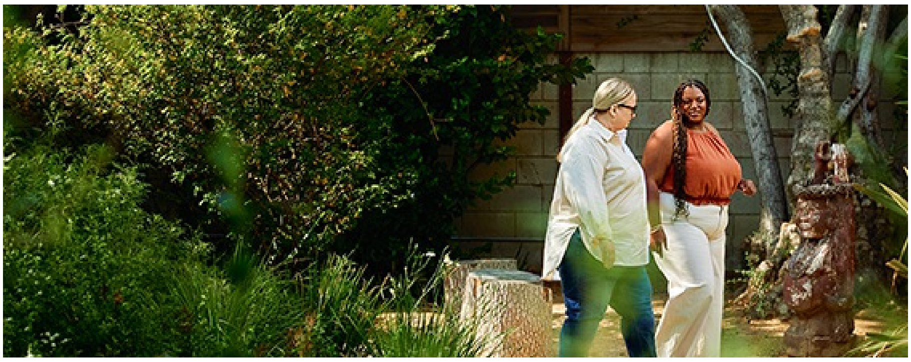
The Reality of Living with Chronic Spontaneous Urticaria

Chronic spontaneous urticaria (CSU) is a serious condition that affects approximately 1.7 million people in the United States and is characterized by itchy hives, deep tissue swelling (angioedema), or both for more than 6 weeks.[1,2,3] As an immune-related condition, CSU is driven by mast cells and other internal mechanisms rather than external factors such as triggers, which can make diagnosis and treatment challenging.[4,5,6]

Currently, antihistamines are the first-line treatment in CSU.[1] However, approximately 50% of people do not achieve complete control of their symptoms, which means that they continue to live with the distressing symptoms of the condition.[1]

The Impact of CSU

While patients are affected in different ways, the symptoms associated with CSU can have a significant impact on daily life.[7] According to one survey, approximately 70% of CSU patients reported mild to severe anxiety and depression. In another patient-reported survey, one out of five people with CSU reported missing at least one hour of work in the past seven days.[6,8]



The Tireless Search for an External Trigger That Isn't There

While it may be necessary to run tests to help rule out other conditions, there is no one biological marker for diagnosing CSU, so diagnosis relies primarily on physical examinations and tracking symptoms.[9]

By the time a patient has been diagnosed with CSU, they have likely gone through extensive testing and lifestyle changes in hopes of improving their symptoms without finding relief.[5] The exhaustive search for an external reason for their symptoms may be frustrating and tiring and can last for months or years.[4,10]

Addressing the Unmet Needs of the CSU Community

It’s not always apparent, but many patients with CSU are stuck in the relentless cycle of coping with symptoms and settling for good enough when it comes to treatment.[11] In fact, it can sometimes take around two years to get a diagnosis or treatment for CSU, and once diagnosed, approximately half of patients remain symptomatic despite taking increased doses of antihistamines.[4,12]

For those struggling with the burden of CSU, a patient community offers the opportunity for patients to feel seen and helps reduce feelings of isolation and embarrassment.

At Novartis, we are committed to raising awareness of CSU and working to address the unmet needs of this community, which is why we’ve created NeverJustHives.com – a resource for patients that provides information on CSU and tools to help patients navigate their condition and importantly, foster productive conversations with health care professionals. On the website you can also learn more about the CSU patient experience in the video series Spontaneous Connections

References:

1. Maurer M, Weller K, Bindslev-Jensen C, et al. *Allergy.* 2011;66:317-330. doi:10.1111/j.1398-9995.2010.02496.x.
2. The World Bank. Population, total. Accessed October 2024.

https://data.worldbank.org/indicator/SP.POP.TOTL

3. Maurer M, Costa C, Gimenez Arnau A, et al. *Clin Exp Allergy.* 2020;50:1166-1175. doi: 10.1111/cea.13716.
4. Kolkhir P, Gimenez-Arnau A, Kulthanan K, et al. *Nature.* 2022;8:61. doi:10.1038/s41572-022-00389-z.
5. AAAAI. Hives (Urticaria) Quiz. Accessed July 2024. https://www.aaaai.org/conditions-treatments/allergies/skin-allergy/hives-(urticaria)-quiz
6. Maurer M, Abuzakouk M, Bérard F, et al. *Allergy.* 2017;72(12):2005–2016. doi:10.1111/all.13209.
7. Balp M, Vietri J, Tian H, et al. *Patient.* 2015;8(6):551-8. doi:10.1007/s40271-015-0145-9.
8. Balp M-M, Krupsky K, Balkaran BL, et al. Oral presentation at: European Academy of Allergy and Clinical Immunology (EAACI) Hybrid Congress 2023; June 9–11, 2023; Hamburg, Germany.
9. Friedman A, Kwatra SG, Yosipovitch G. Dermatol Ther (Heidelb). 2024;14(6):1371-1387. doi: 10.1007/s13555-024-01173-5.
10. Goldstein S, Eftekhari S, Mitchell L, et al. *Acta Derm Venerol.* 2019;99(12):1097-8. doi: 10.2340/00015555-3282.
11. Johal K, Saini S. *Ann Allergy Asthma Immunol.* 2020;125:380-387. doi:10.1016/j.anai.2019.08.465.
12. Kaplan A, Lebwohl M, Giménez-Arnau AM, et al. *Allergy.* 2023;78: 389-401. doi:10.1111/all.15603.

Source URL: *https://prod1.novartis.com/us-en/patients-and-caregivers/diseases/chronic-spontaneous-urticaria-csu*

List of links present in page

1. https://prod1.novartis.com/us-en/us-en/patients-and-caregivers/diseases/chronic-spontaneous-urticaria-csu
2. https://www.neverjusthives.com/
3. https://www.neverjusthives.com/effect-of-chronic-hives/chronic-hives-stories
4. https://data.worldbank.org/indicator/SP.POP.TOTL
5. https://www.aaaai.org/conditions-treatments/allergies/skin-allergy/hives-(urticaria)-quiz