



A ROADMAP TO  
BETTER CARE FOR  
**GOUT**

# ABOUT GOUT



**More than 9 million Americans live with gout, a chronic disease that leads to swollen joints and sudden, intensely painful attacks that can be debilitating. More than 50% of gout attacks start in the big toe, but gout can occur in any joint.<sup>1</sup>**

Gout occurs due to a buildup of uric acid in the body. Excess uric acid accumulates and can form deposits around the joints. If gout goes untreated, uric acid crystals will compound under the skin and in the affected joint, possibly eating away at the bone and compressing nerves. This can lead to limited movement or even permanent disability. Severe cases may require surgery.

Although gout is not curable, early treatment can improve outcomes. In addition to oral medication options, biologics are available that offer hope.

For many patients, living with gout is not only physically limiting, but also isolating. The disease can cause them to feel awkward around friends

and family, who may not understand what they're going through. Misconceptions about the condition may make people reluctant to talk about their experiences.

**Gout is a serious medical condition that, left untreated, can result in more frequent or enduring attacks.**

It can also increase patients' risk for other serious medical conditions, such as cardiovascular disease, kidney disease, diabetes and stroke.

Several key steps could help improve diagnosis, treatment and support for people living with gout.

## PIECES TO THE POLICY PUZZLE



1.

**TIMELY  
DIAGNOSIS**



2.

**IMPROVED  
TREATMENT  
GUIDANCE**



3.

**EXPANDED  
TESTING**



4.

**EDUCATION &  
AWARENESS**



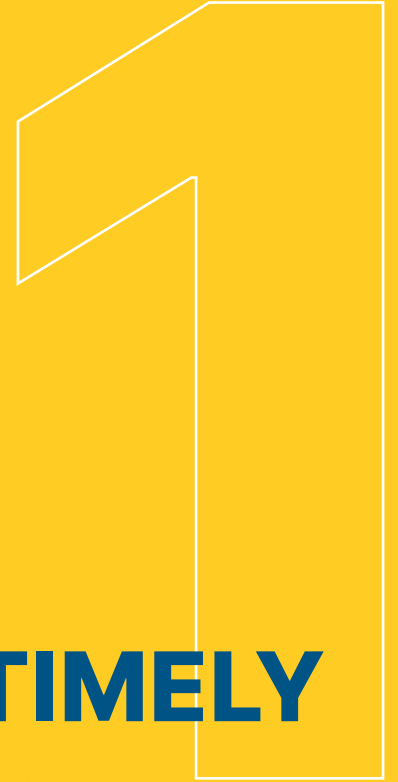
5.

**INCREASED  
ACCESS**



**STEP 1**

**FACILITATE TIMELY  
DIAGNOSIS**



## STEP 1: FACILITATE TIMELY DIAGNOSIS

**Gout is often managed by primary care providers, who may lack an understanding of gout treatment and the long-term effects gout can have on a patient.** Primary care providers may focus on diet and lifestyle changes, which are valuable tools in the treatment of gout but are not enough to manage this chronic disease successfully. Most people with gout need long-term treatment regimens to manage their condition; however, many primary care providers may not proactively discuss these innovative medication options.

Likewise, emergency room providers often lack education on gout, and their objective is to stabilize patients and treat acute symptoms such as the pain of a gout flare. They are simply not set up to offer treatment plans for long-term conditions. While patients may receive a gout diagnosis in the ER setting, they often do not receive follow-up, a specialist referral or education about the importance of proactively treating the disease. In fact, patients with gout are often misdiagnosed or sent home with prescriptions for opioids, which treat pain but not inflammation. This is particularly concerning given a recent study reporting a 26.8% increase in ER visits among U.S. patients living with gout.<sup>2</sup>

More gout patients than ever are seeking care directly from rheumatology providers, generally

considered to be the specialists with the most expert knowledge in this condition. Other providers who treat gout include nephrologists and podiatrists. The overall shortage of providers, however, limits their capacity to treat gout patients. The American Medical Association has estimated that by 2034, there will be a shortage of between 21,000 and 77,100 non-primary care physicians, making it even more imperative that health care providers and patients have the tools necessary to facilitate timely diagnosis.<sup>3</sup>

Simple but effective approaches like providing up-to-date resources for health care providers and facilitating connections with specialists can help more gout patients obtain a timely diagnosis.

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STEP 2

**IMPROVED  
TREATMENT  
GUIDANCE**



## STEP 2: IMPROVED TREATMENT GUIDANCE

**Current gout recommendations offered by the most reputable medical, scientific, and academic research institutions and professional organizations convey a wide range of treatment options and priorities.** Providers need clearer, more consistent guidelines that emphasize timely long-term treatment as well as acute treatment for pain.

There are two broad approaches to treating gout.



**1. Controlling Joint Pain.** This is the most common approach preferred by primary care providers, who typically prescribe anti-inflammatory drugs or corticosteroids to relieve patient pain.

While effective in the short term, the approach is akin to “treating the symptom, not the disease.” Many providers also simultaneously encourage broad, long-term lifestyle changes, which are beneficial but typically not enough to manage the disease alone.



**2. Urate-Lowering Therapy.** The second approach involves a few different strategies to decrease the amount of uric acid in the blood. Lowering uric acid levels in the blood is critical to preventing or lessening painful attacks and reducing the risk of gout complications such as kidney stones and the development of uric acid crystals called tophi.

FDA-approved medications are available to drive uric acid levels down to safe targets. However, some guidelines discourage the initiation of urate-lowering medications right away. This guidance has led to many primary care providers not initiating treatment as early as they could, or patients not pursuing long-term gout treatment and management.

Uric acid accumulates over time. The key to better outcomes overall, therefore, is not limiting long-term urate-lowering medication to patients who suffer from frequent attacks. Even patients with a single attack can accumulate high levels of uric acid and might benefit from a proactive and long-term approach to treatment. Providing clear guidance through medical guidelines or treatment recommendations is critical to supporting health care providers and ensuring gout patients receive the best possible care.





**STEP 3**

# **EXPAND TESTING**



## STEP 3: EXPAND TESTING

**More frequent and earlier testing, including of the general population, could help patients identify and address their gout early on.** Testing can be expanded effectively and affordably by raising awareness of available testing options, improving guidance around testing and ensuring coverage for simple diagnostic tests.



**Uric Acid Tests.** Gout can be diagnosed with a simple, relatively inexpensive blood test to determine a patient's uric acid level. However, this measure is not on a standard blood panel, meaning the health care provider or patient needs to request that their uric acid levels be tested. Improving access to this type of test is critical to improving gout care.

Uric acid blood tests, in many cases, should not be used as the sole tool to diagnose gout. Some people with high uric acid will never get gout, while others with low uric acid get gout anyway. Health care providers often use the results of other tests together with the uric acid test results to confirm the presence of gout.



**Synovial Fluid Tests.** Synovial fluid is a liquid found in the body's joints. This test looks at whether a person has urate crystals in the joint fluid, which could indicate the presence of gout. This is considered the most accurate test for diagnosing gout, and it takes a few minutes to complete.

Although synovial fluid analysis has been a tool used to diagnose gout, it is often difficult to perform in primary care and even rheumatologic settings. The procedure can be painful, and the patient may require anesthesia. This test can be used in combination with uric acid tests.



**X-Rays and Other Exams.** Traditional X-ray exams or ultrasound scans can be used to determine if a patient has sustained joint damage due to a gout attack.

In addition, an emerging technology called dual-energy computed tomography scanning uses two types of X-rays to take pictures of the inside of your body. This scan can find urate crystals that other tests cannot. This test is useful when the other tests are inconclusive.

More widespread and proactive awareness and use of these tests and exams can enhance providers' and patients' ability to detect, diagnose and treat gout.







STEP 4

# EDUCATION & AWARENESS



## STEP 4: EDUCATION & AWARENESS

**Because of misperceptions about gout, the disease has been frequently stigmatized.** This stigma persists today, with 26% of gout patients fearing stigmatization by friends or family members and 14% by health care workers. The fear of stigma is particularly severe in young patients.<sup>4</sup>

Many people also feel embarrassed, and patients with chronic illnesses in general often suffer from a decline in mental health after a diagnosis. Research shows that treating depression and chronic illness together can help people better manage both conditions.

Information on the chronic nature of gout is important. Both patients and the general public need to better understand that gout is a lifelong condition that typically can be managed only with medication. Early testing, diagnosis and long-term treatment can improve long-term outcomes, but only if both providers and patients have an informed and contemporary outlook on gout. Beyond resources for providers and patients, such as printed materials and workshops, a serious education campaign with funding for online and broadcast advertising or public service announcements could move the needle over time.

It is also important to increase awareness around communities disproportionately impacted by gout. This includes creating culturally appropriate educational materials and working within impacted communities to learn about specific access issues they may encounter.

Keys to providing meaningful peer support for patients with chronic illnesses and evidence for its success are becoming clear, including the importance of both person- and community-centered implementation, proactive offering of services, and attention to emotional support. Peer support plays a dual role—research has proven that it enhances both prevention and care while also humanizing health care more broadly.<sup>5</sup>



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**STEP 5**

**INCREASE ACCESS**

5

## STEP 5: INCREASE ACCESS

### Insurance coverage is one of the biggest obstacles to gout treatment.

Older drugs like allopurinol are low cost, while newer, more innovative drugs have higher price tags. The discrepancy impacts both access and affordability, with health plans using a variety of approaches to keep their own costs low—sometimes at the expense of gout patients' health.

#### COVERAGE BARRIERS



**Prior Authorization.** The prior authorization process is intended to ensure that medical treatments and services are necessary and that resources are being used efficiently. Yet prior authorization is often a barrier to treatment, especially when it limits or delays patient access by requiring health care providers to justify the care they prescribe. This can negatively impact patient health, quality of life and wellbeing.



**Cost Sharing.** Many insurance policies implement “copay accumulator programs,” which prohibit manufacturer payments from counting toward patients' deductible or annual out-of-pocket expenses. This creates barriers for patients by restricting the benefits that copay coupons can provide. When faced with this challenge, patients may be forced to ration their medication or stop treatment altogether, which can exacerbate their symptoms and condition.

Reforms at the health plan, state and federal levels can limit health plans' ability to dictate patient care and can improve patient access. Meanwhile, insurers should prioritize policies that will allow patients to treat gout proactively.

#### DISPARITIES & OTHER CONSIDERATIONS



**Socioeconomic & Geographic Factors.** Studies show that the absence of culturally appropriate care can lead to preventable mistakes and adverse events in health care settings. Clear communication, especially for non-native English speakers, is critical to health care providers' approach to care. It also encourages active dialogues in which patients and providers can ask questions, correct misunderstandings and build trust.<sup>6</sup>

Geographic barriers, such as patients living in rural or low-income areas, or other areas with provider shortages, can be mitigated through offerings such as telehealth.



**Communities of Color.** While all can feel gout's physical, financial and emotional hardships, some communities are more affected by gout than others. Communities disproportionately impacted by gout include Black Americans, Native Hawaiians, Asian Americans, Asian Pacific Islanders and the Hmong population. Appropriate access to timely treatment within these communities is critical to ensure people can live pain-free from gout.

# CONCLUSION

**Every day, gout is becoming more and more manageable thanks to breakthroughs in research and new treatment options.**

Connecting patients with optimal care and support requires certain steps forward, including policy reforms and funding that support timely diagnoses, improved treatment guidelines, expanded testing, heightened awareness and increased access to treatment.

These steps comprise a roadmap to optimal and improved treatment for the millions of Americans living with gout.



# REFERENCES

1. Alliance for Gout Awareness. What is Gout? <https://goutalliance.org/what-is-gout/>
2. Mithal A, Singh G. Emergency department visits for gout: a dramatic increase in the past decade. *Annals of the Rheumatic Diseases*. 2018; 77:141-142. [https://ard.bmj.com/content/77/Suppl\\_2/141.2](https://ard.bmj.com/content/77/Suppl_2/141.2)
3. American Medical Association. Doctor shortages are here—and they'll get worse if we don't act fast. 2022 April 13. <https://www.ama-assn.org/practice-management/sustainability/doctor-shortages-are-here-and-they-ll-get-worse-if-we-don-t-act>
4. Kleinstäuber M, Wolf L, Jones ASK, Dalbeth N, Petrie KJ. Internalized and Anticipated Stigmatization in Patients with Gout. *ACR Open Rheumatol*. 2020 Jan; 2(1):11-17. doi: 10.1002/acr2.11095. Epub 2019 Nov 11. PMID: 31943969; PMCID: PMC6957912. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6957912/#:~:text=Internalized%20and%20anticipated%20stigma%20are,nonadherence%20to%20urate%E2%80%90lowering%20medication.>
5. Fisher E, Ayala G, Ibarra L, et al. Contributions of Peer Support to Health, Health Care, and Prevention: Papers from Peers for Progress. *The Annals of Family Medicine*. Aug 2015, 13 (Suppl 1) S2-S8; DOI: 10.1370/afm.1852. [https://www.annfammed.org/content/13/Suppl\\_1/S2](https://www.annfammed.org/content/13/Suppl_1/S2)
6. Tulane University. How to Improve Cultural Competence in Health Care. 2021 March 1. <https://publichealth.tulane.edu/blog/cultural-competence-in-health-care/#:~:text=Cultural%20competence%20improves%20communication%2C%20which,correct%20misunderstandings%2C%20and%20build%20trust.>

## ALLIANCE FOR Gout Awareness

The Alliance for Gout Awareness works to reduce stigma and empower patients by improving public understanding of gout.

To learn more visit [goutalliance.org](https://goutalliance.org)

### OUR MEMBERS

