

Gout is a form of arthritis that occurs when too much uric acid builds up in the joints. Symptoms most commonly present in the large toe, but can be present in other joints, and include a sudden onset of severe pain, redness, and swelling. Gout attacks often happen at night, as the body's temperature lowers allowing uric acid to more quickly crystallize in the joints to cause the onset of an attack. With proper treatment, gout and its painful attacks can be successfully managed<sup>1</sup>.

TREND is a community-powered digital analytics company that turns the conversations of rare and chronic disease communities into actionable insights that spark broader understanding and therapeutic progress. We have been partnering with GSGA for this important work. The purpose of this research is to better understand people who first experienced symptoms of gout between the ages of 18-34 years old. A survey was fielded from January 1 to February 29, 2024, in the Gout Support Group of America, an online group on Facebook.

## Survey Respondent Data

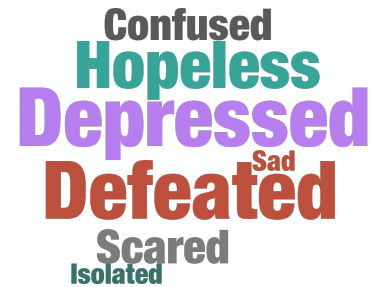
<b>Total Respondents</b> N=6	
Age range when diagnosed: 23 to 31 years	
<b>Racial Identity</b>	<b>Gender Identity:</b>
Asian: 2 (33%)	Male: 6 (100%)
White: 4 (67%)	Female: 0 (0%)

## Initial Experiences

All of the survey respondents saw a doctor when their symptoms first appeared. Five (83%) saw a primary care physician and one (17%) met with a rheumatologist.

*"First doctor from urgent care said it was an injury."*

*"I informed the doctor that gout runs in my family and described the pain I was experiencing. He told me that I was too young to have gout and that I must have somehow injured myself."*



## Challenges Shared

For these respondents, being diagnosed with gout led to mental, physical, and emotional challenges. The pain associated with gout was described as unimaginable, unbearable, relentless, piercing, and excruciating. As seen in the word cloud, the mental health impacts are considerable as well; many spoke of being depressed, feeling defeated, and feeling hopeless upon diagnosis and even afterwards.

## Initial Conversations and Resulting Thoughts

The survey respondents were asked to think back to the initial conversations with their doctor and rate the following statements from strongly disagree to strongly agree. A lack of understanding and assumptions by others along with worries about the long term impact were common experiences.

Statement	Top 2 Box Agreement (N=6)
I often feel embarrassed to discuss my gout condition with others.	33%
I believe my peers do not fully understand what it's like to live with gout at a young age.	83%
I have avoided social activities due to my gout symptoms.	67%
I worry about the long-term impact of gout on my health and lifestyle.	83%
I feel that my gout symptoms have been dismissed or not taken seriously by healthcare professionals due to my age.	67%
I have faced negative judgments or assumptions about my lifestyle because of my gout.	67%
The stigma associated with gout has impacted my mental health.	0%

## CONCLUSION



Receiving a diagnosis of gout while under 35 years of age presented various challenges for this group of survey respondents. They experienced skepticism from clinicians and a lack of understanding from others. The impacts of the diagnosis range from very negative emotions to avoidance of social situations to feeling judged. This work highlights the importance of generating awareness about living with gout, regardless of one's age, to help manage not only the symptoms but also the resulting emotional, physical, and social challenges.

## Quality of Life Impacts

When asked about the impact of gout on their lives, the respondents shared social, familial, and physical issues.

*"It affected my ability to socialize with friends and co-workers. At times I felt like an outcast."*

*"Don't like my children seeing me bedridden, weak, & unproductive."*

*"I'm unable to do strenuous exercise without pain."*

*"I spend so much time researching how to fix myself that I don't get to put time into relationships."*