

A photograph of two women sitting and talking. The woman on the left is Black with her hair in a bun, wearing a yellow shirt and a colorful headband. The woman on the right is white with blonde hair and glasses, wearing a red and white striped shirt. They are in a casual indoor setting with a plant in the background.

In Their Own Voices

The Lived Experiences of IgG4-RD Patients

Report Update

Following the success of the November 2021 focus groups for IgG4-RD patients, the Alliance for Patience Access hosted another focus group to capture additional insights. Patients from across the country met virtually on July 20, 2022 to discuss their experiences living with the rare condition.

September 2022



Findings

Patients Struggle with the Condition's Burdensome Symptoms

Patients described a wide range of symptoms, such as severe pain and gallbladder failure, as well as dry eyes, mouth and skin. Many patients said the symptoms have significantly worsened their quality of life, making it difficult to go to work or spend time with loved ones.

With such varied symptoms, it can be difficult to diagnose the condition.

"I just stopped going [to the doctor] because they couldn't figure it out."

-Patient from California

Managing Symptoms Effectively Proves Challenging

Even after an IgG4-RD diagnosis, symptoms remain a challenge for most patients. There are some treatments frequently used off-label for patients with IgG4-RD, but no treatment has been approved to specifically treat this condition.

The treatments that do exist aren't always accessible. Patients may face high costs for treatment or be met with resistance for coverage from their insurance company.

On top of access barriers, one patient cited an allergy that prevented her from receiving one of the more common treatments. Other patients explained that the treatments were just as draining as the symptoms they were battling.

"I'm a mom of three little ones so I'm tired already, but this is a whole new level."

-Patient from Tennessee

Difficult Diagnosis Process Frustrates Patients & Delays Treatment

Throughout the discussion, patients identified three gaps that must be addressed for the IgG4-RD patient community.

Limited Access to Clinical Trials

One opportunity that patients largely agreed upon was a desire to participate in clinical trials. When asked whether they were interested in participating in trials, patients enthusiastically expressed interest. Confusion about which trial might be appropriate and how to learn more were common refrains, however.

And while some patients are aware of clinical trials, they may not be located near the trial center or have the resources necessary for the related travel. One patient expressed interest but noted, “I live in a pretty small town, 4+ hours from big cities.”

Increased awareness is critical not only for quick and correct diagnoses, but also for enrollment in clinical trials that may lead to advancements in treatment for patients.

Lack of Patient Connection

While there are some patient connection opportunities available to IgG4-RD

patients, like groups on social media platforms, participants all agreed that they wanted to engage with other patients more. Several patients explained that, while their diagnosis provided clarity, it also felt isolating. Given the condition’s rarity, relatively new recognition and the severity of its symptoms, it is difficult to connect with others who have a similar experience.

“I would really like to reach out to others who are similarly affected.”

-Patient from California

Few Patient Educational Resources

Patients also wanted more educational resources. For many patients, an IgG4-RD diagnosis felt confusing. Most materials are directed at provider education, rather than patient education. One patient who has been diagnosed since 2013 explained that he still struggles to understand his condition.

Infographics and content that explain the disease in simple terms would be ideal for both recently diagnosed patients and those who have been diagnosed for years.

How Patients Describe IgG4-RD

Participants used a number of words to describe their experience with IgG4-RD:

“Chaos”

“Unknown”

“Rare”

“Complicated”

