



In Their Own Voices

The Lived Experiences of IgG4-RD Patients



**Alliance for
Patient Access**

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Introduction

Most people have never heard of a rare and chronic autoimmune disease called IgG4-RD. Some even question whether it exists. But those who live with the disease see its impact in a range of symptoms that can turn their everyday lives upside down.

The condition can cause tumor-like masses or enlargement of multiple organs, as well as a range of complicated and challenging symptoms. Patients may have IgG4-RD with no signs or symptoms for months, or even years, before a diagnosis is made, allowing organ damage to occur before the patient is even aware of the disease.

If diagnosed before serious organ damage has occurred, IgG4-RD can respond well to medication. But the path to treatment is challenging.

To help illuminate the challenges IgG4-RD patients face, the Alliance for Patient Access virtually convened 18 patients from across the country to participate in two focus groups. This document shares their collective experiences.

Findings

Complex Symptoms Vary by Patient

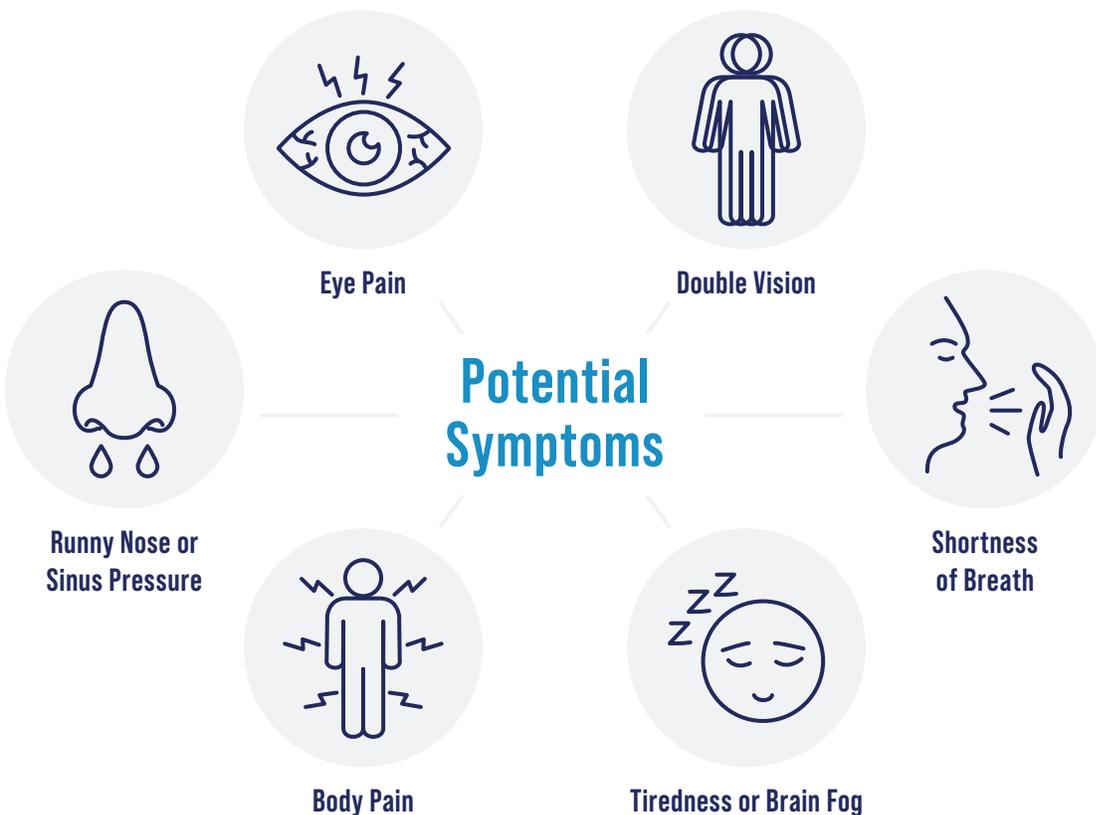
Patients' symptoms vary widely. Some patients described experiencing allergies such as sneezing, runny nose or sinus pressure. Other patients said they dealt with eye issues, such as eye pain, eye bulging or double vision.

Several more patients reported pain in other areas of the body, such as the feet, or experienced extreme weight loss. Patients described feeling tired, fighting brain fog or being short of breath as well.

Each patient had his or her own unique experience, but common symptoms were swelling of the face or other areas of the body, and eye discomfort.

“When I would lean down to tie my shoes, it felt like I was running a marathon. Turned out, my heart was enlarged and the size of a 300-pound man’s.”

- Patient from South Carolina



Difficult Diagnosis Process Frustrates Patients & Delays Treatment

The path to an IgG4-RD diagnosis is long and difficult, patients reported. For the vast majority of patients, it took several years to put a name to their symptoms. For others, it took several decades and multiple specialists to finally receive an accurate diagnosis.

Patients sought care from several different types of specialists, though rheumatologists were overwhelmingly the providers who diagnosed IgG4-RD patients. Patients also saw:



- Emergency medical specialists
- Gastroenterologists
- Nephrologists
- Neurologists
- Ophthalmologists
- Pathologists

Coupled by the frustration of being in pain, many patients experienced traumatizing misdiagnoses along the way. Because IgG4-RD manifests as tumors in the organs, some patients were told they had cancer, rather than IgG4-RD. Several patients even underwent painful chemotherapy treatments. Other patients received misdiagnoses of bronchitis, asthma, Sjogren's, thyroid eye disease, Lyme disease, Graves' disease or MS.

One patient, who was diagnosed in 2016, emphasized that a strong physician-patient relationship can make or break care for IgG4-RD patients. She described past encounters with some of her providers as “condescending.”

“I was called a hypochondriac countless times.”

-Patient from Washington

Similarly, patients reported that getting in to a see a provider or specialist proved difficult. “I had to wait five months. No doctors want you,” said a patient from California.

Several patients noted that, even when they did find a specialist or rheumatologist who would see them, providers often lacked the specific knowledge to treat IgG4-RD. One patient recalled her provider telling her, “I do not know how to care for you.”

Another patient from Columbus, Ohio reiterated, “If it doesn't fit the doctor's silo, they are not eager to work on a case that causes questions. I have had to break down the silos.”

Lack of Treatment Options and Access Undermines Patient Health

There is no cure for IgG4-RD, but some patients have found relief, or even reached remission, with different medications.

Prednisone, rituximab and injectables are common treatments for people living with IgG4-RD, but side effects can, in some cases, limit their use. Accessing those medications can be yet another challenge for patients.

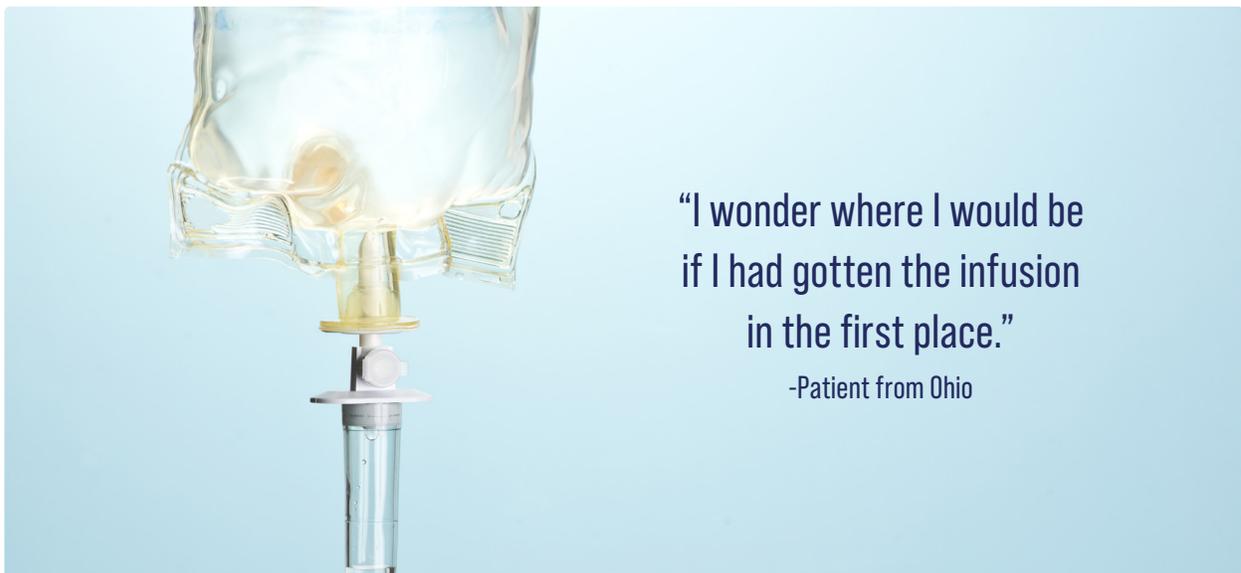
One patient was denied access to a prescribed medication by her insurer and was required to spend a year on a drug that did little to address her IgG4-RD. And after only one infusion of the prescribed medication, her IgG4-RD levels returned to normal.

Some patients have been able to afford the infusions with the help of co-pay

assistance programs or through the drug's manufacturer. But other patients said they still owed thousands of dollars in medical bills.

Moreover, most patients experienced some type of adverse side effect from their treatment. One patient described losing battles with her mental health while on prednisone. "I would be institutionalized if I was still on that," she said. Some patients put on a significant amount of weight while on the steroid. Another patient said the prednisone did more damage to her body for the year she was on it than the IgG4-RD did.

The patients overwhelmingly agreed there's a need for more treatment options.





Patients' Quality of Life Suffers

IgG4-RD changes the reality of everyday life, patients reported. One patient had undergone two open-heart surgeries in four days and lost both of her ovaries from tumors. Several patients had to leave their jobs or retire early because of IgG4-RD. Other patients said they had to stop traveling or stop participating in beloved hobbies. IgG4-RD was overtaking their bodies and disrupting their lives.

Instead of going to work or school, some patients spent multiple days a week visiting doctors and specialists. This was especially true when patients were first seeking a diagnosis and trying to understand the symptoms they were experiencing.

For others, IgG4-RD symptoms changed the rhythms of daily life permanently. "I live with my parents, I use a cane and I see a doctor every day," one patient explained. "No one knows if IgG4-RD is causing my symptoms, exacerbating them, or if it's the IgG4-RD treatment itself that's wreaking havoc," she concluded.

"My ability to complete daily activities is nonexistent."

-Patient from Montana

Another patient described similar challenges. "I can barely function at age 32. My work doesn't understand. I have considered filing for disability," she explained.

Patients Need Additional Support and Resources Moving Forward

Facebook support groups have been helpful for sharing lived experiences, asking questions and passing along educational resources, stated patients. Caregivers, family and friends also help however they can, but there is still a great unmet need for support in the IgG4-RD community, according to patients.

The burden of IgG4-RD weighs heavily on patients and those who serve as their caregivers. Patients expressed gratitude toward parents and partners who play a significant role in caregiving. Some patients said their employers have also been accommodating and supportive as they navigate life with IgG4-RD. Other patients, however, said their employers lack the understanding of the disease's

impact on quality of life and have been less accommodating.

The biggest takeaway was finding a trusted provider, others affirmed. Most patients ultimately found their diagnosis with a rheumatologist. One patient said of his provider, "The biggest lesson is that the doctor treats me like a human being."

Patients are positive there is hope on the horizon. More and more people will become aware of IgG4-RD and learn how to better care for the people living with it, one patient explained, and new treatment options are coming down the pike. Several patients echoed the sentiment and said they help increase awareness through word of mouth.

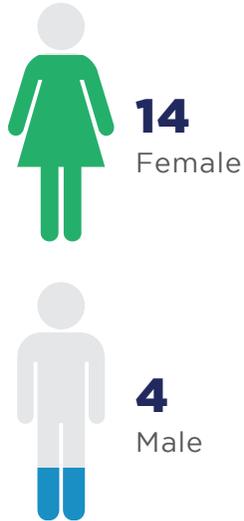
How Patients Describe IgG4-RD



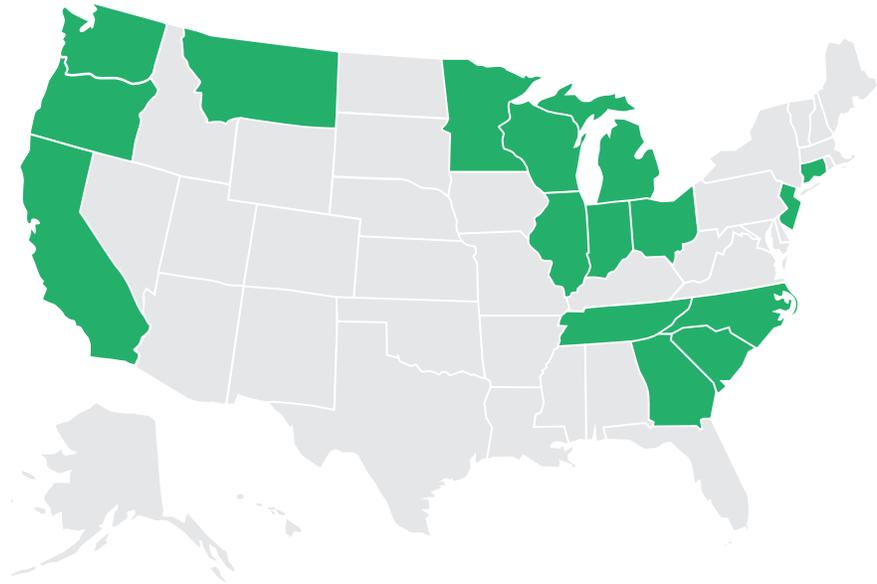
About the Alliance for Patient Access Focus Groups

Patients from across the country came together virtually on November 9 and 10, 2021 for two focus groups hosted by the Alliance for Patient Access.

Gender



State of Residence



**Alliance for
Patient Access**

The Alliance for Patient Access is a national network of policy-minded health care providers advocating for patient-centered care.

www.allianceforpatientaccess.org