



Rare Diseases Working Group IgG4-RD Initiative

2026 MEETING SUMMARY

The Alliance for Patient Access hosted its annual meeting of the IgG4-RD Initiative of the Rare Diseases Working Group on August 14-15, 2026, in Washington, DC. Clinicians convened to discuss barriers to treatment and the importance of IgG4-RD education.

DIAGNOSTIC ODYSSEY

Diagnosing IgG4-RD involves a complex, multi-step process of scans and testing which can contribute to delays in diagnosis. Patients often move from specialist-to-specialist, receiving misdiagnoses before confirming an IgG4-RD diagnosis. Meeting participants found that the most common misdiagnosis is cancer. One clinician said, "IgG4-RD is a slow-moving disease and erodes things slowly, making it harder to identify and diagnose." Clinicians emphasized a need for standardized testing to improve timely diagnosis.

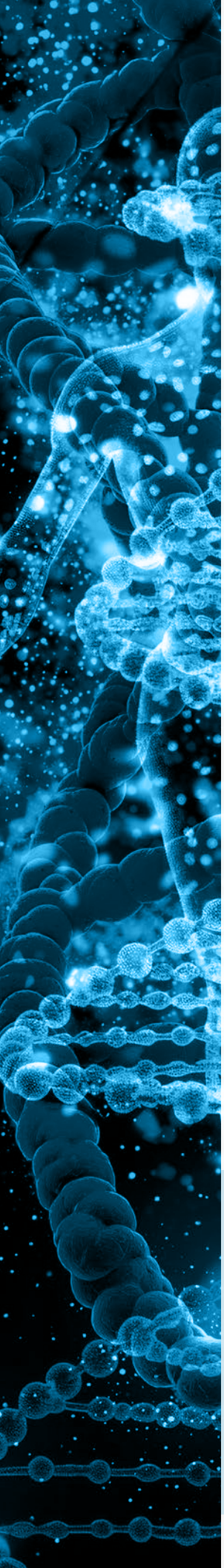
ACCESS TO TREATMENT

Patient access to appropriate IgG4-RD treatment was a priority among clinicians. Although awareness of IgG4-RD is growing, clinicians noted that the shortage of specialists remains a barrier for patients to receive timely care. One clinician said, "We are not taking full advantage of telehealth." While telehealth access expanded during the COVID-19 pandemic, restrictions related to state licensures for clinicians and health plan coverage still limit patients' ability to access care. In addition to medication access, clinicians agreed that providing patients with support as they navigate a multidisciplinary care team is essential to ensure they can access innovative therapies.

UTILIZATION MANAGEMENT

Prior Authorization

Prior authorization remains a barrier to timely access to IgG4-RD treatment. Clinicians discussed the challenges of communicating with insurers to explain clinical rationale for treatment options and address medication coverage. These administrative requirements take time away from patient care and can contribute to delays in patients receiving necessary testing and treatments. For patients with IgG4-RD, clinicians agreed that these delays allow symptoms to worsen and require more complex treatment plans.



Step Therapy

Clinicians expressed the ongoing challenge with step therapy making treatment options more complex. This delay can contribute to worsening symptoms and increased side effects for their patients with IgG4-RD. This practice delays access to treatments that patients need by requiring trial and failure of insurer-preferred medications before gaining access to newer, innovative options. Clinicians discussed developing legislation that emphasizes how step therapy negatively impacts patient health. One clinician said, “Health plans place a wedge between clinicians and their patients.”

MENTAL HEALTH CONSIDERATIONS

Clinicians agreed that challenges navigating the diagnostic odyssey negatively impacted patients’ mental health. A clinician said, “It is important to acknowledge the exhaustion of patients undergoing testing, procedures, clinical visits and costs of care.” Ensuring that patients receive support from their clinical teams and caregivers is essential.

WRAPAROUND CARE FOR PATIENTS

Clinicians emphasized the need for wraparound care, emphasizing patient support from symptom onset to diagnosis and treatment. Connecting patients with the appropriate support networks can reduce the burden and confusion of managing a complex rare disease. These resources can help answer patient questions, inform decision making, and direct them to communities of other patients and caregivers.

NEXT STEPS

Meeting participants agreed that educating clinicians and policymakers about IgG4-RD and potential treatment options is necessary to improve care. Ensuring educational resources are available to improve advocacy efforts about reducing patient barriers to care was also expressed as a priority.

GET INVOLVED

To learn more about AfPA’s Rare Diseases Working Group and IgG4-RD Initiative, visit **AllianceForPatientAccess.Org** or contact Megan Vogt
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