

IgG4-RD and the Diagnostic Odyssey

Q&A WITH LEONARD CALABRESE, DO



Q. What is IgG4-RD?

IgG4-RD is a rare and complex immune disorder that was officially recognized as a disease only about two decades ago. It often looks like a range of other diseases, so it can take several years to diagnose properly. IgG4-RD can result in uncontrolled signs and symptoms, decreased quality of life, loss of vital organ function and even fatality.

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Q. What is your role in the process of diagnosing IgG4-RD?

I'm an immunologist, and we are well-versed in assessing and diagnosing complex multi-system disorders. We prescribe the medications that are used to treat the disease, which are called "immunomodulatory" drugs. We also work closely with rheumatologists and other clinicians to review data and research, so we are equipped to diagnose and treat patients.

Q. What are some barriers to receiving an accurate IgG4-RD diagnosis?

The biggest challenge is a lack of early recognition from many clinicians. For example, a clinician cannot diagnose something they are unaware of. And if they do, there's a lot of confusion surrounding next steps because they must identify how to understand the different facets of the disease and which specialist their patient needs. It's a complex disease that impacts multiple organ systems, so there's a lot to consider when diagnosing.



Q. What is the clinician's role in supporting patients through their diagnostic odyssey?

The clinician's role is to be the patient's best advocate and partner. They should not only understand what their complaints are regarding their symptoms but also take time to understand their concerns about their condition as a whole. Support goes a long way in easing the burden on patients who are already undergoing a strenuous journey to determine what their symptoms could mean.

Q. What can decisionmakers do to reduce barriers to diagnosis and help bridge knowledge gaps?

Decisionmakers can pour resources into awareness campaigns and educational initiatives for medical associations, many of whom have networks of clinicians that are ideal candidates to learn more about IgG4-RD. Awareness and understanding is the key to earlier diagnosis and a better prognosis for many rare diseases.

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ABOUT THE AUTHOR

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

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