



## Highlights from the IG Living Teleconference, June 24, 2014

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### Topic: **Why Common Variable Immunodeficiency Disease (CVID) Takes So Long to Diagnose**

Guest expert: *Marc Riedl, MD, MS, board-certified in allergy/immunology and an associate professor of medicine in the division of rheumatology, allergy and immunology at the University of California, San Diego, was the guest expert at the **IG Living Readers Teleconference held June 24** during which he discussed the major challenges of diagnosing CVID.*

Historically, it has been a challenge to get the proper testing for diagnosing CVID, which is an uncommon condition. According to the latest data, it takes somewhere between four and seven years to diagnose CVID, which is an improvement because it used to take a decade or longer.

There has been a lot of effort to raise awareness about primary immunodeficiencies (PIs) over the years, and awareness has improved. But, in the big picture of medicine, CVID is still a very rare condition. So, one reason it takes so long to diagnose is because it remains quite uncommon in the general population. Most physicians and healthcare practitioners are either not familiar with the disease, or they may have heard about it in their training, but have forgotten about it. Therefore, CVID is not on the radar screen of most general practitioners; it's not something they're thinking about or testing for.

Another reason CVID can take long to diagnose is that there is a perception that PIs are a pediatric problem — something that is diagnosed when born or early in life. So, many adults have to battle the myth that it doesn't happen to adults or that they would have been diagnosed already.

In addition, in today's world of modern medicine, doctors get sidelined into their own specialties, and through no fault of their own, they don't connect the dots to look at the big picture. As such, individuals have to run into the right specialist or seek out the right one who will look at the big picture and who will conduct the appropriate testing.

Yet another reason diagnosis takes so long is that while infection is the hallmark of CVID, there are also many other symptoms and complications. Therefore, if the

primary symptom is gastrointestinal problems or granuloma disease, physicians don't equate that to an immune deficiency, and CVID gets overlooked.

Even when physicians think of CVID as a possible diagnosis, they often don't know what tests to conduct or how to interpret those tests. This is a particular challenge, so we're trying to encourage physicians who are not familiar with CVID to refer patients to someone who is familiar with the disease.

Finally, finding the right doctor to diagnose CVID can be a challenge. The symptoms of CVID can be very common: sinus infections, bronchiectasis, bowel issues, etc. These are conditions that a lot of physicians see as run of the mill, but they're not if they keep recurring. It takes a certain healthcare practitioner to know that this is not normal. Unfortunately, there is a lack of specialists who have a lot of interest in this kind of immunology.