How AVISE Testing Can Improve a Patient's Diagnosis Journey

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Autoimmune diseases, like rheumatoid arthritis, lupus, and multiple sclerosis (MS), affect <u>more</u> <u>than 24 million people</u> in the United States. Despite millions of Americans living with these long-term illnesses, there's still a lack of a cohesive diagnosing process that could save patients time and money. Lupus is one of the many autoimmune diseases that can take several years to diagnose, putting additional and unnecessary stress on patients and loved ones.

As a lupus warrior, I share a common diagnosis journey with the autoimmune disease community.

My diagnosis journey began once I noticed ringworm-like rashes develop on my arms and later to other body parts as a teenager. Initially, my family and I assumed I had bug bites. Then, over one year, the rashes became painful, and my face swelled. As I dealt with the pain and discomfort from the rashes, my family and I visited a pediatrician, dermatologists, rheumatologists, and several other specialists to find out what was wrong.

It wasn't until I got a biopsy, had several tests, and was examined by specialists at an out-oftown hospital that I was diagnosed with systemic lupus erythematosus (SLE) and Sjögren's syndrome.

It was a relief to finally get a diagnosis, but also frustrating that it took about two years to receive one. What if my healthcare team thoroughly examined my symptoms earlier on to speed up the diagnosis process?

I knew they had to run several tests and examinations to come to a lupus diagnosis. Still, a lot of ambiguity limited how much we could truly understand this diagnosis. Not having access to the knowledge and tools to learn about lupus kept us in the dark.

No one should have to wait several years to get an autoimmune disease diagnosis; this is where AVISE testing comes into play.

Here are some difficulties patients and their loved ones face during the diagnosis journey and how AVISE can improve this experience.

Getting Multiple Tests and Seeing Several Doctors

When healthcare providers are uncertain about a patient's reported symptoms, they run several screening tests to determine what condition(s) a patient may have. If the results are inconclusive, doctors may continue to run additional tests or refer the patient to a specialist. Often, the more specialists a patient sees, the more confused they become as they get a plethora of medical information thrown at them.

When I was examined by all those specialists towards the latter end of my diagnosis journey, I encountered several doctors whose specialties I was unaware of. How were these doctors helping my family and me find a diagnosis?

Also, in my experience, I was getting passed back and forth between a dermatologist and a rheumatologist for care and treatment. I knew that each time I went to a doctor's appointment, I had to submit a blood and urine test, but wasn't truly understanding how these tests played a role in my diagnosis and later management of my lupus.

The Costs of Testing Over Time

Unfortunately, patients can run into out-of-pocket expenses getting screening tests. Insurance companies cover a partial amount of the costs but still leave a hefty bill for the patient to pay. Or, in some situations, insurance companies won't cover any costs if they deem that the screening doesn't fall under the <u>preventive health service</u> category. Medical bills can be pretty hefty, so when insurance doesn't cover testing, it can leave patients and families with a financial burden as they find a diagnosis.

Getting screening tests for autoimmune diseases can involve costs outside medical care that patients and their families must cover. Transportation, hotel stays, and food are just a few expenses that patients are responsible for covering while getting autoimmune disease screenings.

Fortunately, my pediatric rheumatologist and dermatologist were only about an hour and a half from my hometown, so we never needed to stay overnight. In addition, we had excellent insurance coverage, so we didn't face any financial burdens. However, we still had to cover gas costs, parking tickets, and food for my appointments.

Organizations Advocating and Supporting Autoimmune Disease Patients

Over the past few years, several organizations have advocated for improved screening and testing for autoimmune diseases. These organizations understand how frustrated autoimmune disease patients and their families are with getting multiple screenings, visiting several doctors, and spending time and money finding a diagnosis. As a way to advocate for these patients, many organizations are creating or funding research efforts to accelerate the diagnosing process.

A few organizations advocating and providing support for patients and their families are:

- Autoimmune Families
- The Chronic Care Policy Alliance (CCPA)
- Chronic Illness Coalition (CIC)
- The EPIC Foundation
- American Chronic Pain Association

I'm sure several patients, including myself, appreciate these organizations pushing for a better patient experience.

How AVISE Testing Helps the Diagnosis Journey

As a lupus patient that spent several years waiting on a diagnosis, I wish the process would've been much faster. Thankfully, AVISE testing is making the diagnosis journey a less stressful experience. AVISE testing is revolutionizing the diagnosis, prognosis, and monitoring of autoimmune conditions like lupus.

Because autoimmune disorders can have overlapping symptoms, it's not uncommon for doctors to misdiagnosis these health conditions. With an understanding of the complexities of autoimmune diseases, AVISE offers testing to help clinicians help distinguish overlapping symptoms to provide a more definite and accurate diagnosis for patients.

The <u>AVISE CTD diagnostic tool</u> assists in the differential diagnosis of:

- SLE
- Rheumatoid arthritis (RA)
- Sjögren's syndrome
- Scleroderma
- Polymyositis and dermatomyositis (PM/DM)
- Antiphospholipid syndrome (APS)
- Autoimmune thyroid disease

Although getting a diagnosis can be one of the most challenging aspects for autoimmune disease patients, the next step in the care journey is understanding the prognosis. Many autoimmune diseases carry severe complications, like organ failure, heart disease, mood disorders, and nerve damage.

To help with the early detection of severe autoimmune disorder complications, there are a few AVISE prognostic tests designed for SLE and RA. <u>AVISE SLE Prognostic</u> assesses for potential organ involvement, and <u>AVISE PC4d</u> is a signal that has been associated with thrombotic events in patients living with lupus. The <u>AVISE Anti-CarP</u> is a lab test identifying the potential risk of joint damage for RA patients.

After diagnosing a patient and providing a prognosis, monitoring is the next step in caring for and treating autoimmune diseases. To ensure a patient's symptoms don't worsen and medications aren't causing adverse effects, many specialists monitor their condition through regular check-ups and blood testing.

I'm grateful to have a mild form of SLE, so with medication and lifestyle adjustments, my risk of severe complications is relatively low. Once I got over the hurdle of getting diagnosed, my care journey for lupus was quite simple.

AVISE has a few monitoring tests to assist doctors with assessing their patients' autoimmune conditions. <u>AVISE SLE Monitor</u> is an advanced blood test including six biomarkers to assess SLE patients. <u>AVISE MTX</u> allows doctors to examine a patient's exposure to methotrexate. <u>AVISE HCQ</u> is a therapeutic drug monitoring hydroxychloroquine in a patient's blood.

My lupus monitoring includes visiting a rheumatologist twice a year to monitor my lupus and an ophthalmologist once a year to ensure that my lupus medication, hydroxychloroquine, isn't affecting my eyesight.

All three testing types by AVISE make diagnosing, treating, and managing autoimmune disorders much quicker and easier for patients and their healthcare providers.

As a patient living with lupus for almost ten years, I didn't have access to AVISE testing during my diagnosis journey. Still, I hope more patients won't have to share the same experience as I did and can speed through the diagnosis process to start treatment.

I genuinely appreciate AVISE tests as they're using research to expedite the diagnosis of autoimmune disorders and advocating for patients and families who must endure this health journey.

When you go through such a tiresome diagnosis journey as I did, it not only delays diagnosis but can stress you and your loved ones. Many chronic illness warriors have had to advocate for themselves to get the diagnosis and treatment they deserve. And because of this, I think one of the most important aspects of being someone with a chronic condition is to have hope. Hope will ultimately get you through the diagnosis, treatment, and care of chronic illnesses.