For clinicians and patients, advances in clinical and genomic diagnostics in the last decade have occasioned a new era of hope in healthcare. As discoveries based on the human genome have yielded greater insights about the role of genetics in disease, new diagnostic tests have been developed that help clinicians accurately diagnose a disorder and get the patient on an effective treatment plan more quickly than ever before.

These diagnostic advances are especially critical in the field of neurology. Unlike many medical conditions that can often be diagnosed largely based on symptoms and signs, neurological disorders often elude clear diagnosis, because signs and symptoms overlap with other diseases. Moreover, most neurological disorders that are rare—afflicting about 200,000 or fewer people—are even more likely to escape diagnosis, because clinicians invariably have less experience diagnosing them. Research shows that it can take five or more years to get an accurate diagnosis for a patient’s rare condition. Advances in genomics and diagnostic technologies offer greater odds of a clear and timely diagnosis, which for many is the prelude to efficacious treatment.

But developing the right test to diagnose a condition is only half the battle. For many patients, financial constraints are another hurdle to surmount in accessing diagnostic test services. Because of the comparatively low volume of testing for rare neurological conditions, evidence-based information about clinical validity and patient outcomes is often less robust than for practice areas, such as oncology and cardiovascular disease, affecting large populations.

And in some cases, there is no cure or treatment for a disorder following diagnosis. Health plans may therefore be reluctant to reimburse for these testing services, leaving patients with the responsibility to pay for the test. Considering the sophisticated technology, knowledge, and expertise needed to develop and validate these services, the fees can range in the hundreds and even thousands of dollars. Lack of access to diagnostic tests is an excruciating position for the physician as well as the patient. As physicians, we want our patients to be able to access the best possible medical care. Patients with rare disorders are often dealing with baffling symptoms, not to mention acute confusion and fear, and these emotions inevitably cascade to their family members.

In order to surmount these challenges, our health care system needs to reconsider how it evaluates the medical necessity of genomic diagnostics for rare neurological disorders. Define a test’s value based on more than the availability of a treatment. In an ideal world, a clear diagnosis would lead to a treatment that alleviates or cures the condition. In the real world, rare neurological disorders, bereft of approved therapies, often progress to severe disability or even death.

But should the availability of a treatment really be the defining measure by which the value of a diagnostic is measured? Isn’t a clear diagnosis of great value to a patient otherwise groping in the dark, sometimes for years, for an answer to their health problem? Won’t this information help the patient, (Continued on page 15)
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working with her or his physician, predict the course of the disease, reach out to patient groups for support, and make difficult life planning decisions with family members? And what about the insights a diagnosis provides to family members about their risk or the chances they could pass a disorder to offspring?

Provide patients and physicians with guidance through the diagnostic process. It is not uncommon for a patient to consult with several physicians and undergo a battery of tests before a diagnosis is revealed. With each encounter, the patient must also reckon with their health plan and shoulder any patient responsibility for costs.

It is the physician—the lifeline and gatekeeper for patients who require diagnostic testing to facilitate an accurate diagnosis—who plays the critical role in advocating for his/her patient through this process. At Athena Diagnostics, we recently introduced the Athena Alliance Program to help physicians access specialized neurology testing for their patients, including assistance with test selection options to balance costs and clinical value. The program features a patient concierge service, matching patients requiring diagnostic testing services with an individual specialist to support their needs, and a financial assistance program to help cover the patient’s share of testing fees, available to eligible individuals.

Forward thinking diagnostic providers realize that simply offering a test is not enough in the case of highly sophisticated genomics for rare neurological conditions. They must facilitate access to the tests for physicians and their patients.

Create value pathways to help health plans appropriately reimburse for critical diagnostics. In the long-term, health economists, payers, diagnostic laboratories, researchers, and physicians need to collaborate on the development of evidence-based healthcare delivery “value pathways” that are sufficiently strong to inform payers making coverage and payment determinations. But until availability of neurological testing can be increased by clearly demonstrating how such testing improves health outcomes and reduces economic costs, we must ensure that cost and access is never a deterrent to patients who seek testing.

Joseph J. Higgins, MD, FAAN, is Medical Director of Neurology for Athena Diagnostics, a business of Quest Diagnostics, the world’s leading provider of diagnostic information services.

The Athena Alliance Program was created to expand patient access to a variety of diagnostic methodologies and testing, especially those with esoteric disorders. The Athena Alliance Program is focused on providing patient-centric customer service. Each patient has an individual specialist and a team of dedicated personnel to support them from the time of test ordering through to the test results.

See more at: http://www.athenadiagnostics.com/content/ordering/billing/alliance#sthash.5UgvZc5Z.dpuf