CONGRESSMAN
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Fifteenth District of California

Committee on Energy and Commerce
Subcommittee on Health
Member Day
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Thank you, Madam Chair.

In 2015, when I was the head of Future Forum, a group of young Democratic Members of the House of Representatives who are focused on issues and opportunities for millennial Americans, I had the honor of meeting Dr. J Craig Venter, a key figure in the Human Genome Project. Dr. Venter has dedicated his life to genomics research and is known for leading the first draft sequence of the human genome. After meeting with several stakeholders passionate about genomics, I gained a greater appreciation of how critical these technologies can be in diagnosing and preventing severe diseases. I decided that legislative action was needed to promote access to genetic and genomic testing.

Genetic testing has the potential to further the emerging field of precision medicine. Today, there are currently 75,000 different genetic tests that represent approximately 10,000 unique test types and cover more than 4,600 disorders. Precision medicine is healthcare based on the individual variability in medical history, genes, environment, and lifestyle for each person. This tailored treatment can cut healthcare costs by facilitating better diagnosis and the consideration of certain preventive measures.

However, many of these tests are not covered by insurance providers and the Centers for Medicare and Medicaid Services (CMS) has not made coverage determinations for many genetic tests. Instead, CMS allows Medical Administrative Contractors (MACs) and state Medicaid agencies to make their own coverage determinations. Many believe genetic testing will help realize a brighter future of healthcare, especially for children and younger Americans, but the realization of this future will be limited without increasing access to testing through insurance coverage.

Since genetic tests are considered an optional benefit through the Medicaid program, state Medicaid agencies can choose whether or not to cover them with requirements varying from

state to state. For example, 35 states cover BRCA testing, which can help determine a patient's risk for developing breast and ovarian cancer, for qualifying individuals based on their personal and family history of cancer. Even if a patient's state Medicaid agency covers such a test, barriers like pre-approval and a lack of access to genetic counseling still prevent many from receiving and understanding their own genetic testing results.

Last Congress, I introduced the *Advancing Access to Precision Medicine Act*, along with 22 members of Congress, both Democrats and Republicans. This bill would address some of the problems I just mentioned by directing the Department of Health and Human Services to enter into an agreement with the National Academy of Medicine to develop recommendations on how the federal government may reduce barriers to the utilization of genetic and genomic testing. The bill would also allow states to apply for an exception to the federal medical assistance percentage rate (FMAP), thereby providing them with more money, to provide whole genome sequencing clinical services for certain children on Medicaid who have an unresolved disease that is suspected to have a genetic cause. The purpose is to provide data regarding whether such services help settle a child's diagnostic odyssey, improve clinical outcomes, and ultimately reduce program expenditures. I believe that these actions will help support the transformation of our health care system to better focus on the uniqueness of each and every patient in the future.

I am currently working on a revised version of this bill to better encourage coverage of genetic testing. I look forward to re-introducing this bill in the coming weeks with my fellow colleagues and working with the Energy and Commerce Committee on it.

Thank you for allowing me to speak to you today and I would be happy to answer any questions you may have.