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Congressman Peters
US House of Representatives
Rayburn House Office Building, 2338,
Washington, DC 20515

Congressman Shimkus
US House of Representatives
Rayburn House Office Building, 2217,
Washington, DC 20515

Dear Congressmen Peters and Shimkus,

We are writing to thank you for introducing H.R.4144, the "Ending the Diagnostic Odyssey Act." For me, this is very personal, and a long time coming. My daughter and son were diagnosed in 1994 with a rare genetic condition after a long diagnostic odyssey. They were five and seven years old, and I had been trying to discovery what was wrong with them for years. There was no option for affordable whole genome sequencing in those days. A diagnosis means a great deal to a family, as I am sure you know. Just having that information empowers us as parents. In my case, it allowed me to establish a patient advocacy foundation, build a research coalition, and eventually become CEO of Genetic Alliance to do the same for all diseases. I have a strong passion to see that all children receive a diagnosis in a timely manner.

As you know, nearly 80% of all rare diseases have a genetic cause, and half of rare disease cases impact children. The average diagnostic odyssey can last from anywhere from five to seven years. You can imagine the anguish of parents watching their children suffer, watching them endure one test after another. The toll this takes on the family, emotionally and financially, is a great travesty in an age where comprehensive genetic screening available and affordable. Whole Genome Sequencing will alleviate an enormous part of a huge burden these families carry.

Knowing the genetic cause of a disease can mean an actionable diagnosis – leading to changes in treatment and management of the condition, prevent additional unnecessary testing, and help families find a support structure via other families and organizations. This has utility and benefits for the child, the family, and society at large. And when there is no treatment at the ready, just having multiple kids diagnosed early on, with the hope of gathering data on their condition and those of other kids like them, accelerates treatment development.

The "Ending the Diagnostic Odyssey Act" would allow states to conduct a pilot program to increase the Federal Medical Assistance Percentage rate (FMAP) to provide Whole Genome Sequencing clinical services for children on Medicaid with a disease that is suspected to have a

genetic cause. We are eager to see this bill signed into law so this first-line test can be offered to families, regardless of income.

This legislation has the potential to build upon the promises of the "21st Century Cures Act," furthering the emerging field of precision medicine, and lowering health care costs by facilitating better diagnoses, and the consideration of preventive measures.

Thank you again for your leadership on this important legislation.

Sincerely,

Sharon F. Terry
President and CEO