

Genomic Answers for Children's Health Act

Reps. Scott Peters (CA-50) & Gus Bilirakis (FL-12)

Problem: Research shows that it too often takes children with rare diseases years and visits to many different doctors to get a correct diagnosis. During this “diagnostic odyssey”, children with rare diseases often undergo unnecessary tests and procedures, receive incorrect diagnoses, and experience delays in getting effective care. This long timeline means that many children with rare diseases experience irreversible damage as the disease progresses. Further, most state Medicaid programs do not cover important genomic sequencing, often leading to hassles and delays in getting access to the genomic sequencing they need.

The bill would: guarantee Medicaid coverage for whole genome and whole exome sequencing for children under age 21 when clinically necessary; specifically, it:

- Adds genomic sequencing services (including whole genome sequencing and whole exome sequencing) as a covered Medicaid service under “early and period screening, diagnostic, and treatment services” for children with certain clinical criteria, aligning with American Academy of Pediatrics and American College of Genetics and Genomics recommendations;
- Directs CMS to conduct activities to spread awareness of coverage for genomic sequencing; and
- Directs GAO to issue a report on implementation of coverage and outstanding barriers to access for genomic sequencing;
- Requires that state Medicaid programs must provide a payment separate from the bundled inpatient rate for genomic sequencing performed in the inpatient setting.

Goals of the legislation:

- Facilitate faster and more accurate diagnoses for children, thereby removing unnecessary testing and treatments for the patient; and
- Ensuring that any child on Medicaid has access to whatever genomic sequencing the child needs – regardless of the child’s location or type of disease

To learn more about or to cosponsor the Genomic Answers for Children's Health Act, please contact Dillon Cooke (Rep. Peters) at Dillon.Cooke2@mail.house.gov.