Rare Disease Registry Act

Legislative Request
Establish a Delaware Rare Disease Registry within the Division of Public Health to collect, analyze, and promulgate data on rare disease diagnoses and treatments to improve healthcare planning, resource allocation, and patient outcomes across the state

Executive Summary
Rare diseases affect an estimated 30 million people in the United States, including thousands of Delaware residents who are difficult to quantify due to a lack of centralized data. Delaware lacks an effective system for understanding the prevalence and impact of these conditions, a key requirement for creating policies to identify gaps in care and efficiently allocate resources. Creating a Delaware Rare Disease Registry would provide the data necessary to support evidence-based policy decisions, strengthen research efforts, and improve healthcare services for the patients, families, researchers, and providers affected by this issue.

Rationale
Delaware's lack of rare disease data prevents state leaders from fully understanding how many residents are affected by rare diseases or where significant healthcare gaps exist. Creating effective policy to address this issue will depend on accurate data. Delaware already maintains a reporting system for cancer and diagnosed tumors, which has greatly aided the Department of Health and Human services in stewarding healthcare throughout the state. A rare disease registry would create similarly positive infrastructure to inform key planning and decision-making.

Without effective policy changes, rare disorders will continue to impact a large proportion of Delawareans with long diagnostic journeys, disproportionate obstacles to care, and economic hurdles for families. The proposed registry will be an essential first step for efforts to support research initiatives, identify key gaps in legislation, and evaluate the effectiveness of future initiatives.

Proposed Action
The Delaware Division of Public Health should establish and maintain a Rare Disease Registry that:

- Collects information on diagnosed rare diseases using the National Organization for Rare Disorders definition.
- Receives reports from healthcare providers, hospitals, and diagnostic laboratories.
- Protects patient privacy through HIPAA-compliant reporting and data management practices.
- Publishes annual reports summarizing statewide trends, prevalence, and healthcare needs.
- Provides de-identified data for approved research and public health planning purposes.

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