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Department of Health and Human Services

Rare Diseases in Nevada: The Implementation of SB315

Division of Public and Behavioral Health

Presented by Julia Peek, MHA, CPM

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Helping people. It's who we are and what we do.

Agenda

1. Rare Disease Facts
2. SB315 – Basics
    1. Status
    2. Challenges
    3. Pathways Forward
3. Questions

Rare Disease Facts

- In the United States, a disease is considered rare if it affects fewer than 1 in 200,000 people
- 1 in 10 people are affected by rare disease – this translates to 25-30 million Americans
- Globally, 400 million people suffer from a rare disease
- 50% of those affected by rare diseases are children and 30% of children with a rare disease will not live to the age of 5
- Rare Diseases impact more people than Cancer and AIDS combined

Rare Disease Facts continued:

- There are approximately 7,000 known rare diseases
- There are more than 500 types of rare cancer
- ALL pediatric cancers are rare
- Most rare diseases are genetic or have a genetic component
- More than 90% of rare diseases do not have any FDA-approved treatment or associated research
- 50% of rare diseases do not have a foundation or support group

SB315

Creation of a Rare Disease Advisory Council (NRS 439.5075 – 439.5077)

Nevada is the 10th state to enact a Rare Disease Advisory Council (early adopters)

Only 9 other states have councils

Rare Disease Advisory Council (RDAC) Membership

- Not more than three physicians who practice in the area of cardiology, emergency care, neurology, oncology, orthopedics, pediatrics or primary care and provide care to patients with rare diseases
- Two registered nurses who provide care to patients with rare diseases
- Not more than two administrators of hospitals that provide care to patients with rare diseases or their designees
- One representative of the Division who provides education concerning rare diseases or the management of chronic conditions
- The employee of the Division who is responsible for epidemiology services
- Two persons over 18 years of age who have suffered from or currently suffer from a rare disease
- Two parents or guardians who each have experience caring for a child with a rare disease
- One representative of an organization dedicated to providing services to patients suffering from rare diseases in northern Nevada
- One representative of an organization dedicated to providing services to patients suffering from rare diseases in southern Nevada

RDAC Duties

- Perform a statistical and qualitative examination of the incidence, causes and economic burden of rare diseases in Nevada
- Receive and consider reports and testimony concerning rare diseases from persons, the Division, community-based organizations, providers of health care and other local and national organizations whose work relates to rare diseases
- Increase awareness of the burden caused by rare diseases in Nevada
- Identify evidence-based strategies to prevent and control rare diseases
- Determine the effect of delayed or inappropriate treatment on the quality of life for patients suffering from rare diseases and the economy of Nevada
- Study the effect of early treatment for rare disease on the quality of life for patients suffering from rare diseases, the provision of services to such patients and reimbursement for such services

RDAC Duties continued:

- Increase awareness among providers of health care of the symptoms of and care for patients with rare diseases
- Evaluate the systems for delivery of treatment for rare diseases in place in Nevada and develop recommendations to increase the survival rates and quality of life of patients with rare diseases
- Determine effective methods of collecting data concerning case of rare diseases in Nevada for the purpose of conducting epidemiological studies of rare diseases
- Establish a comprehensive plan for the management of rare diseases in Nevada, which must include recommendations for the state and local health authorities, public and private organizations, businesses and potential sources of funding, and update the comprehensive plan as necessary

RDAC Deliverables

- *Develop a registry of rare diseases diagnosed in Nevada to determine the genetic and environmental factors that contribute to such rare diseases**
- Compile an annual report that includes a summary of the council's activities and any recommendations of the council for legislation or other policies.

SB315 RDAC Status

- RDAC members chosen and council includes all mandated member types
- First RDAC meeting scheduled and Agenda posted
- Draft Bylaws created

SB315 RDAC Challenges

- Length of time necessary to procure willing council members from all statutorily required groups
- "Pause" in efforts due to focus on COVID-19
- Many rare diseases have their own "patient-powered" registries/data repositories, but these are few and data is subjective
- *The establishment of a "rare disease registry" is not currently feasible due to paucity of available data, non-standardized definitions of specific diseases (i.e. lack of ICD10 codes), large numbers of specific types of diseases

SB315 RDAC Pathways Forward

- Prioritize certain rare diseases for first and second years of RDAC implementation and then add as able
  - Pediatric cancers
  - Sickle Cell Disease and its variants
- Further priorities as established by the RDAC
- Funding available through the sale of special license plate: Cure Childhood Cancer
  - Amount generated per plate sold: $25/$20 (Initial/Renewal)
  - Promote license plate on website and through social media platforms

Nevada Cure Childhood Cancer License Plate

Questions?

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Acronyms

- RDAC: Rare Disease Advisory Council
- SB315: Senate Bill 315 (2019 Legislative Session)