

Office of State Epidemiology (OSE) Rare Disease Program

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NEVADA DIVISION of PUBLIC
and BEHAVIORAL HEALTH

ALL IN GOOD HEALTH.

AGENDA

1. Office of State Epidemiology Overview
2. Rare Disease Program Overview
3. Sickle Cell Disease & Systemic Lupus Erythematosus Registries Overview



Office of State Epidemiology (OSE) Overview

- In July 2023, the Office of Public Health Investigations and Epidemiology (OPHIE) merged with the Office of State Epidemiology, retaining the OSE name.
- OSE many different programs including: Communicable Diseases, Healthcare Associated Infections, Environmental Health, Informatics, Rare Disease, and the Nevada Central Cancer Registry
- OSE conducts disease investigations, surveillance of different conditions, and epidemiological efforts in Nevada.

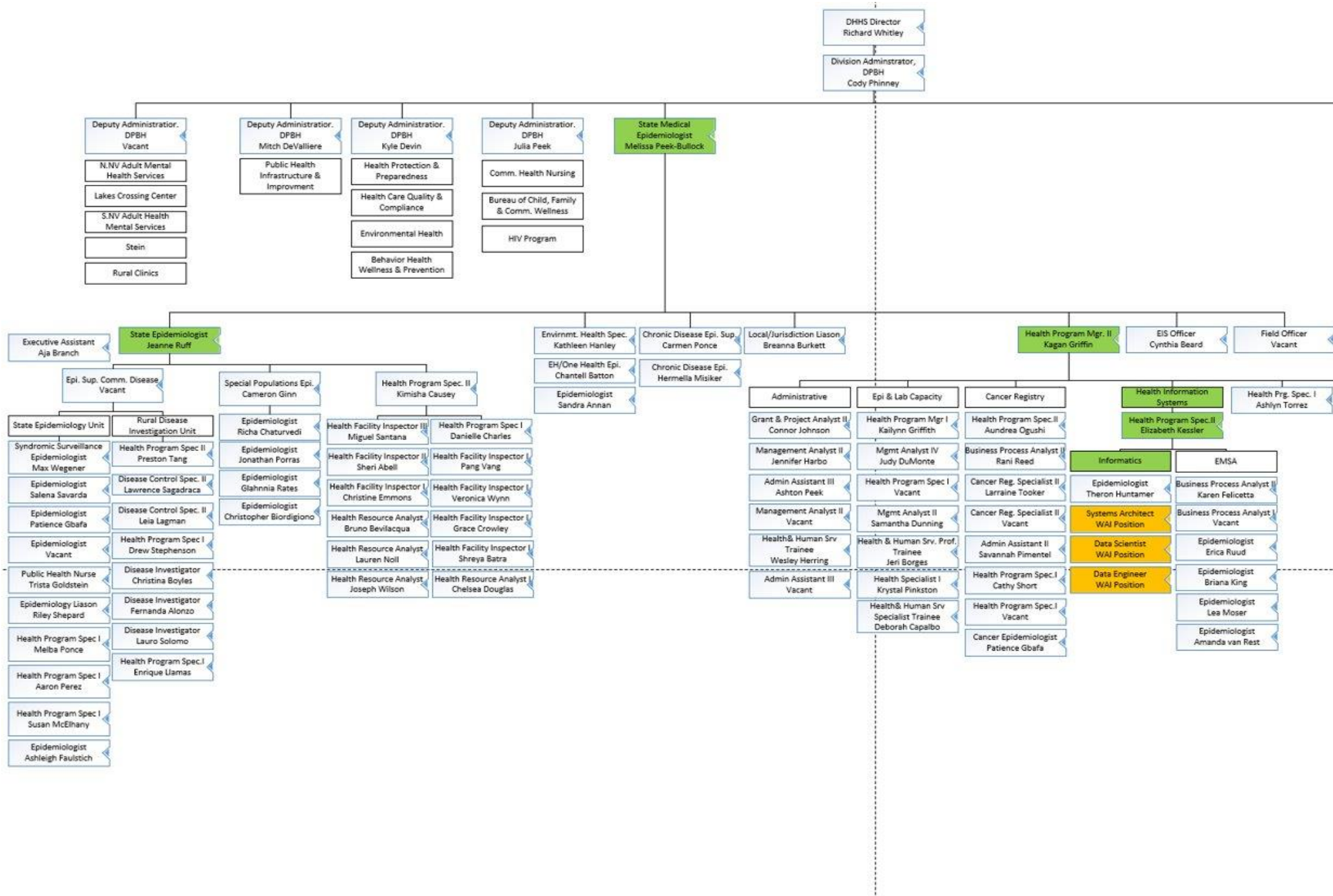


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THE OFFICE OF STATE
Epidemiology

The main goal of the Office of State Epidemiology is to prevent and respond to a variety of public health issues through disease surveillance, standardized data collection, meaningful interpretation, statewide standards, and centralized guidance in order to improve health outcomes for our communities.





Rare Disease Program Overview

- Created in 2022
- Developing and maintaining the sickle cell and lupus registries.
- Support staff for Nevada Rare Disease Advisory Council (RDAC).
- Will move under the Cancer Registry unit in OSE to form a new “Registries” unit.

Current Focuses:

- Actively searching and applying for grants to support rare disease surveillance.
- Establish and maintain a live data dashboard for SCD and SLE surveillance on the OSE webpage – nvose.org

SCD & SLE Registries Overview

Sickle Cell Disease Registry

- Legal Authority: [NRS 439.4921 – 4943](#)
- Passive surveillance system primarily focusing on incidence, prevalence, and mapping how the patient moves through the system.
- Created an SCD form for providers through the DPBH REDCap system.

Systemic Lupus Erythematosus Registry

- Legal Authority: [NRS 439.497 – 499](#)
- Passive surveillance system primarily focusing on incidence, prevalence, and mapping how the patient moves through the system.
- Created an SLE form for providers through the DPBH REDCap system.

QUESTIONS?



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CONTACT INFORMATION

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[OSE Rare Disease Webpage](#)

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ACRONYMS

OSE – Office of State Epidemiology

HPS I – Health Program Specialist I

NRS – Nevada Revised Statutes

HPM II – Health Program Manager II

SCD – Sickle Cell Disease

SLE- Systemic Lupus Erythematosus