NEVADA DIVISION of PUBLIC and BEHAVIORAL HEALTH

STATE OF NEVADA SICKLE CELL DISEASE (SCD) REPORTING FORM*

Source

Provider Name	Provider Telephone #	Report Date
Facility/Organization (Name)		
Facility/Organization (Address)		

Facility Type

Inpatient:	Outpatient:	Other Facility:
☐Hospital	☐Private Office	☐Emergency Room ☐Laboratory
☐Other ________________	☐Other ______________________	☐Corrections ☐Other_______________

Patient Demographic Data

Patient Name (Last)	(First) (MI)	DOB	Age	Sex assigned at birth ☐Male ☐ Female

Patient Address	(City)	(State)	(Zip)	Current Gender ☐Female ☐M to F Transgender ☐Male ☐F to M Transgender ☐Unknown ☐ Refused to answer ☐Additional gender identity (specify): ______________________________
County of Residence	Home Phone	Cell Phone		

Race(s)	Ethnicity
☐White ☐Black ☐Asian ☐American Indian ☐ Pacific Islander ☐Other ☐Unknown ☐Expanded Race: __________________________	☐Hispanic/Latino ☐Non-Hispanic/Latino ☐Unknown ☐Expanded Ethnicity: ____________________________

Parent or Guardian Name	Birth Country and Arrival Date	Primary Language Spoken
Social Security Number	Occupation/Employer/School	Medical Records Number

Incarcerated	Patient Died of this Condition:	Marital Status
☐No ☐ Yes	☐ Yes ☐ No Date: ______________	☐Single ☐ Married ☐ Widowed ☐ Separated ☐ Divorced ☐Unknown

Intentionally Left Blank

Sickle Cell Disease (SCD) Patient Data

Date of Diagnosis	Sickle Cell Disease without crisis	Blood Reference Value
Date of Last Contact	☐ Yes ☐ No ☐ Unknown	

Sickle Cell Disease Variant:

☐ Sickle Cell Anemia (HbSS) ☐ Sickle Hemoglobin-C Disease (HbSC) ☐ Sickle Hemoglobin Beta-thalassemia (HbS) ☐ Sickle Beta-Zero Thalassemia ☐ Unknown

☐ Expanded SCD Variant: ____________________

HBB Pathogenic Variant

☐ Yes ☐ Not Applicable

☐ No ☐ Unknown

Type: ____________________

Other Diseases Suffered by Patient

☐ Asthma ☐ Gall Bladder Disease ☐ Diabetes ☐ Pneumonia ☐ Unknown ☐ Not Applicable

☐ Other: ____________________

Treatment Data

Given Treatment: ☐ Yes ☐ No ☐ Unknown	☐ Hydroxyurea ☐ L-glutamine Oral Powder ☐ Crizanlizumab ☐ Voxelotor ☐ Other: ____________________	Date Started Date Ended
Prescribed Opioids: ☐ Yes ☐ No ☐ Unknown	Does the patient have adequate access to that opioid? ☐ Yes ☐ No ☐ Unknown	Date Started Date Ended

Referred to Hospital or another Physician for this lupus? ☐ Yes ☐ No	Hospital Name Physician Name and Phone #

Comment Section

*Reporting form instructions are on page 3 and 4.

STATE OF NEVADA LUPUS REPORTING FORM INSTRUCTIONS

Pursuant to NRS 439.4976, establishment of a system of reporting information on lupus and its variants. The State of Nevada has established a system of reporting for lupus and its variants to conduct comprehensive epidemiologic surveys and to evaluate the appropriateness of measures for the treatment of lupus and its variants within the state of Nevada.

Hospitals, medical laboratories, and other facilities provide screening, diagnostic or therapeutic services to patients with respect to lupus and its variants shall report the information pursuant to NRS 439.4978 each report must include, without limitation:

1. The name, address, age, and ethnicity of the patient.
2. The variant of lupus with which the person has been diagnosed.
3. The method of treatment, including, without limitation, any opioid prescribed for the patient has adequate access to that opioid.
4. Any other diseases from which the patient suffers.
5. If a patient diagnosed with lupus and its variants dies, his or her age of death.

Source Information

Provider Name/Phone Number

The physician primarily responsible for the care of this patient

Person Reporting/Phone/Fax

Provide if different than attending physician

Facility/Organization

List the locations for facilities with multiple locations.

Report Date

The date that this report is submitted

Patient Demographic Data

Sufficient information must be provided to allow the patient to be contacted. If insufficient information is provided, you will be contacted to provide that information. Attaching a patient face sheet to this report is an acceptable method of providing the patient demographic information.

Address/County/City/State/Zip

The home address of the patient, including the county.

Date of Birth / Age

The patient's date of birth or age if birthdate is unknown.

Parent or Guardian Name

For patients under the age of 18, the name of the person(s) responsible for the patient.

Phone

The home phone of the patient.

Occupation / Employer / School

The occupation or employer of the patient, or the name of the school attended for students.

Social Security Number

This information greatly assists in the investigation of cases, allowing easier access to laboratory and medical records.

Medical Record Number

A patient identifier unique to the facility or office.

Gender / Sex Assigned at Birth
The current gender of the patient and the sex assigned at birth.
Marital Status
The marital status of the patient.
Race / Ethnicity
Race and ethnicity categories have been chosen to match those used by the Centers for Disease Control and Prevention.
Primary Language Spoken
Providing this information makes it easier to contact non-English-speaking patients and arrange for translators.
Birth Country and Arrival Date
If the patient was not born in the United States, provide the patient's country of origin and date of arrival in the US.
Incarcerated
The incarceration status of the patient. If the patient is currently incarcerated, list the facility in the comments section.
Deceased / Date of Death
If the patient has died, list the date of death. If known, list the cause of death under comments.

Sickle Cell Disease (SCD) Patient Data

Date of Diagnosis
Date patient was diagnosed.
Date of last contact
Date last contacted the patient.
Sickle cell disease without crisis
State if this is sickle cell disease without or with crisis.
Blood Reference Value
State the blood reference value of the patient.
Sickle Cell Disease Variant
Sickle Cell Disease variant diagnosed.
HBB Pathogenic Variant
State if the patient has HBB pathogenic variant. If so listed the type of HBB pathogenic variant.
Other Diseases Suffered by Patient
Mark all that apply and specify all other diseases suffered by the patient.

Treatment Data

Given treatment
List all treatment that has been prescribed as it relates to sickle cell disease and its variants and provide the date prescribed treatment.
Prescribed Opioids
State whether the patient has been prescribed opioids as it relates to sickle cell disease, and if the patient has adequate access to opioids. Provide the date opioids have been prescribed and ended.
Referred to Hospital or another Physician for this sickle cell disease
State whether the patient has been referred to another facility or physician and provide the hospital or attending physician to be able to track this patient.

Comment Section

Provide any additional information that may be useful in the investigation or to explain answers given elsewhere on this form.

Reporting requirements include fully completing reporting forms. The completed reporting form can be sent through a secure email to dpbhrdr@health.nv.gov or faxed to 775-684-5999.

The reporting form can be found on the Rare Disease Registries Webpage or obtained by contacting the Lupus and Other Rare Diseases Project Coordinator, Ashlyn Torrez by emailing at atorrez@health.nv.gov.