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 ☐Other _____	☐Private Office ☐ Childhood Cancer and Rare Disease Center (PT 20-699) ☐Other _____	☐Emergency Room ☐Laboratory ☐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	Parent or Guardian DOB	Parent or Guardian Zip Code

Patient Medical Record Number	Patient Occupation/Employer/School	Patient on disability? ☐ Yes ☐ No ☐ Unknown

Incarcerated ☐No ☐ Yes	Has the patient died of this condition? ☐ Yes ☐ No Date: _____	Marital Status ☐Single ☐ Married ☐ Widowed ☐ Separated ☐ Divorced ☐Unknown

Intentionally Left Blank

Sickle Cell Disease (SCD) Patient Data

Date of Diagnosis	Primary Hematologist Provider Name (first and last) _____

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: _____

Patient history of any of the following conditions?

☐ Unknown ☐ Not Applicable

☐ Acute chest syndrome
☐ Vaso-Occlusive Crises
☐ Acute renal disease
☐ Chronic renal disease
☐ Priapism
☐ Anemia
☐ Sickle hepatopathy
☐ Avascular osteonecrosis
☐ Pneumonia
☐ Hypertension
☐ Pulmonary hypertension
☐ Chronic pain
☐ Leg ulcers
☐ Osteomyelitis
☐ Kidney disease
☐ Cholecystitis
☐ Cholelithiasis
☐ Diastolic heart dysfunctions
☐ Splenic sequestration
☐ Stroke
☐ Asthma
☐ Jaundice
☐ Gall Bladder disease
☐ Type II Diabetes
☐ Septic arthritis
☐ Sepsis
☐ Meningitis
☐ Upper and/lower respiratory tract infection
☐ Urinary tract infections
☐ Malaria
☐ Tuberculosis
☐ HIV
☐ Other: _____

In the last 12 months, how often has the patient been in sickle cell disease crisis (SCC)?

SCC main clinical feature is "acute painful crisis," and primarily characterized by severe acute pain and impaired end-organ function.

_____ Number of times patient was in SCC in the last 12 months

If the patient has not been in SCC in the last 12 months, put zero (0).

☐ Unknown

In the last 12 months, has the patient come in for IV pain management?

☐ Yes

☐ No

☐ Unknown

If yes, how often has the patient come in for IV pain management?

_____ (number of visits in the last 12 months)

If unknown, please leave blank.

In the last 12 months, has the patient required hospitalization for pain management?

☐ Yes

☐ No

☐ Unknown

If yes, how often has the patient been hospitalized for pain management?

_____ (number of visits in the last 12 months)

If unknown, please leave blank.

Intentionally Left Blank

Treatment Data

Is there a pain management plan?

☐ Yes

☐ No

☐ Unknown

What type of pain management plan is the patient on?

Non-pharmaceutical therapies include but are not limited to yoga, massages, transcutaneous electrical nerve stimulation (TENS), virtual reality, and guided audiovisual relaxation

☐ Pharmaceutical therapies

☐ Non-pharmaceutical therapies

☐ Unknown

☐ Other: _____

Has the patient received any of the following treatment options?

☐ Sickle cell disease specific pharmaceuticals
☐ Blood transfusion
☐ Bone marrow or stem cell transplant
☐ Folic acid
☐ Gene therapies
☐ Opioids
☐ Non-steroid anti-inflammatory drugs (NSAIDs)
☐ Unknown
☐ Other: _____

SCD Specific Pharmaceuticals:

☐ Hydroxyurea

☐ L-glutamine Oral Powder

☐ Crizanlizumab

☐ Voxelotor

☐ Other: _____

Please specify which gene therapies the patient is taking:

☐ Exagamglogene autotemcel or CASGEVY
☐ Lovotibeglogene autotemcel or LYFGENIA
☐ Unknown

☐ Other: _____

Is opioid use consistent with pain management plan?

☐ Yes

☐ No

☐ Unknown

Referred to another physician for this instance of SCD?

☐ Yes ☐ No

Facility Name

Facility Address (Street Name and Number)

Facility City	Facility State	Facility Zip Code

Physician Name	Physician Phone Number

Barriers to Care

Did the patient report any barriers to access of care?

☐ Transportation ☐ Language ☐ Culture ☐ Not Applicable

☐ Insurance/Coverage ☐ Religion ☐ Cost/financial ☐ Unknown/Did not ask

☐ Other: _____

Health care access and quality includes key issues, such as access to health care, access to primary care, health insurance coverage, and health literacy. These issues can make it difficult or impossible for people to prepare for and respond to an emergency to their full potential.

If you checked any of the boxes, please provide details on the patient's reported barrier to accessing care:

Comment Section

Additional Comments:

*Reporting form instructions are on pages 4-6.

STATE OF NEVADA SCD REPORTING FORM INSTRUCTIONS

Pursuant to NRS 439.4929, the State of Nevada has established a system of reporting for SCD and its variants to conduct comprehensive epidemiologic surveys and to evaluate the appropriateness of measures for the treatment of SCD and its variants.

Hospitals, medical laboratories, and other facilities providing screening, diagnostic or therapeutic services to patients with respect to SCD and its variants shall report the information pursuant to NRS 439.4931 and each report must include:

1. The name, address, age, and ethnicity of the patient.
2. The variant of SCD 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 SCD 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
: Attaching a patient face sheet to this report is an acceptable method of providing the patient demographic information. If the patient is a newborn, please provide the parent/guardian Name, DOB, and zip code

Address/County/City/State/Zip
: The home address of the patient, including the county

Home Phone/Cell Phone
: The home phone and the cell phone of the patient

Date of Birth (DOB) / Age
: The patient's date of birth or age if birthdate is unknown.

Gender / Sex Assigned at Birth
: The current gender of the patient and the sex assigned at birth

Race / Ethnicity
: Race and ethnicity categories have been chosen to match those used by the Centers for Disease Control and Prevention

Parent or Guardian Name/DOB/Zip Code
: For patients under the age of 18, the name of the person(s) responsible for the patient. Put the name, DOB, and zip code. This data is primarily needed if the patient is a newborn

Occupation / Employer / School
: The occupation or employer of the patient, or the name of the school attended for students

Medical Record Number
: A patient identifier unique to the facility or office

Patient on disability
: The disability status of the patient. If the patient has been on disability, please put the timeframe in the comments

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

Marital Status
: The marital status of the patient.

Sickle Cell Disease (SCD) Patient Data

Date of Diagnosis
: Date patient was diagnosed.

Primary Hematologist Provider Name
: If you are not the primary hematologist, please provide the name of the primary hematologist this patient uses

Sickle Cell Disease Variant
: Sickle Cell Disease variant diagnosed

HBB Pathogenic Variant
: State if the patient has HBB pathogenic variant. If so, list the type of HBB pathogenic variant

Patient History
: Mark all that apply if the patient has a history of the listed conditions

Frequency patient has been in sickle cell crisis
: State if the patient has been in sickle cell crisis in the last 12 months, and state the number of times in the last 12 months

Frequency patient has been seen for IV pain management
: State if the patient has been seen for IV pain management and state the number of times in the last 12 months

Frequency patient has been hospitalized for pain management
: State if the patient has been hospitalized for pain management and state the number of times in the last 12 months

Treatment Data

Pain Management Plan
: State if the patient is currently on a pain management plan

Pain Management Plan Type
: State the type of pain management plan the patient is currently using

Treatment Options
: Select all that apply for the type of treatment the patient is currently taking for this instance of SCD

SCD Specific Pharmaceuticals
: If the patient is taking SCD specific pharmaceuticals, state which pharmaceuticals the patient is currently on

Gene Therapies
: If the patient is on a gene therapy, specify which one the patient is on

Opioid use with pain management plan
: State whether the patient's opioid use is consistent with the pain plan

Referral given to this patient for their sickle cell disease

State whether the patient has been referred to another facility or physician and provide the facility or attending physician to be able to track this patient

Barriers to Care

Patient reported any barriers to care

If the patient reported any barriers to care, please specify which barrier they encountered, and provide any additional details in the following box

Comment Section

Provide any additional information that may be helpful or to explain answers given elsewhere on this form

Reporting requirements include fully completing this reporting form. 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 at atorrez@health.nv.gov.