NEVADA DIVISION of PUBLIC and BEHAVIORAL HEALTH

STATE OF NEVADA SYSTEMIC LUPUS ERYTHEMATOSUS (SLE) 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

SLE Patient Data

Date of Diagnosis	Primary Rheumatologist Provider Name (First and Last) _____

SLE Variant

☐ Systemic Lupus Erythematosus ☐ Lupus of the skin ☐ Drug-induced Lupus Erythematosus ☐ Neonatal Lupus Erythematosus ☐ Unknown

☐ Expanded Lupus Variant: _____

Lupus of the Skin (if checked above)

☐ Acute Cutaneous Lupus ☐ Chronic Cutaneous Lupus Erythematosus (Discord Lupus Erythematosus)

☐ Subacute Cutaneous Lupus Erythematosus ☐ Unknown ☐ Not Applicable

☐ Expanded Lupus of the Skin: _____

Drug-Induced Lupus (if checked above)

☐ Hydralazine ☐ Procainamide ☐ Isoniazid ☐ Minocycline ☐ Anti-TNF ☐ Not Applicable ☐ Unknown

☐ Expanded Drug-Induced Lupus: _____

In the last 12 months has the patient come in for treatment for a lupus flare?

☐ Yes

☐ No

☐ Unknown

If yes, how often has the patient come in for treatment for a lupus flare?

_____ (number of visits in the last 12 months)

☐ Unknown

Patient history of any of the following conditions?

☐ Unknown ☐ Not Applicable

☐ Asthma

☐ Hypertension

☐ Atherosclerosis

☐ Pericarditis

☐ Angina

☐ Kidney disease

☐ Type II Diabetes

☐ Fibromyalgia

☐ Cancer (blood, gastrointestinal, and lung)

☐ Osteoporosis

☐ Depression

☐ Anxiety

☐ Lupus or aseptic meningitis

☐ Eye disease

☐ Psychosis

☐ Antiphospholipid antibody syndrome

☐ Celiac disease

☐ Myasthenia gravis

☐ Rheumatoid arthritis

☐ Lupus arthritis

☐ Scleroderma

☐ Sjogren's syndrome

☐ Other: _____

Intentionally left blank

Treatment Data

Treatment Type: (select all that apply)

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

☐ Antimalarials

☐ Steroids

☐ Non-Steroidal anti-inflammatories (NSAIDs)

☐ Immunosuppressives

☐ Anticoagulants

☐ Monoclonal antibodies (mAbs)

☐ Acthar Gel (repository corticotropin)

☐ Opioids

☐ Non-pharmaceutical therapies

☐ Unknown

☐ Other: _____

Referred to another physician for this instance of SLE?

☐ 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 page 4-5

STATE OF NEVADA LUPUS REPORTING FORM INSTRUCTIONS

Pursuant to NRS 439.4976, 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.

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:

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
: Attaching a patient face sheet to this report is an acceptable method of providing the patient demographic information. If the patient is under 18 years of age, please provide parent/guardian Name, DOB, and zip code

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

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

Phone
: The home phone of the patient

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.

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

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

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

SLE Patient Data

Date of Diagnosis

Date patient was diagnosed

Primary Rheumatologist Provider Name

If you are not the primary rheumatologist, please provide the name of the primary rheumatologist this patient uses

SLE Variant

Lupus variant diagnosed

Lupus of the skin

If 'Lupus of the Skin' was checked specify which type. If 'Lupus of the skin' was not checked, check Not Applicable

Drug-induced lupus

If 'Drug-Induced Lupus was checked specify which type. If 'Drug-Induced Lupus' was not checked, check Not Applicable

Frequency patient has been seen for a lupus flare

State if the patient has been seen for a lupus flare, and state the number of times in the last 12 months

Patient History

Select all that apply if the patient has a history of the listed conditions

Treatment Data

Treatment type

Select all that apply for the type of treatment the patient is currently taking for this instance of SLE

Referred to another physician for this instance of SLE

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 useful in the investigation 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.