

Secure COVID-19 SCD

Reporting of COVID-19 cases in SCD globally

This form is to be completed by a health care professional caring for a patient with sickle cell disease and documented coronavirus (COVID 19).

Please report only confirmed COVID-19 cases, and report after sufficient time has passed to observe the disease course through resolution of acute illness and/or death.

Fields marked with a red asterisk (*) are required.

If you have any questions, please contact us at: covid.sicklecell@mcw.edu.

Reporter Information

Name of reporter *

Email address of reporter *

Name of physician providing care for Sickle Cell disease *

Name of center/practice providing care for Sickle Cell disease *

Patient Information

Age, in years *

Country of residence

- Not in this country list ---
- Åland Islands
- Afghanistan
- Albania
- Algeria
- Andorra
- Angola
- Anguilla
- Antarctica
- Antigua and Barbuda
- Argentina
- Armenia
- Aruba
- Australia
- Austria
- Azerbaijan
- Bahamas
- Bahrain
- Bangladesh
- Barbados
- Belarus
- Belgium
- Belize
- Benin
- Bermuda
- Bhutan
- Bolivia, Plurinational State of
- Bosnia and Herzegovina
- Botswana
- Bouvet Island
- Brazil
- British Indian Ocean Territory
- Brunei Darussalam
- Bulgaria
- Burkina Faso
- Burundi
- Côte d'Ivoire
- Cambodia
- Cameroon
- Canada
- Cape Verde
- Cayman Islands
- Central African Republic
- Chad
- Chile
- China
- Christmas Island
- Cocos (Keeling) Islands
- Colombia
- Comoros
- Congo
- Congo, the Democratic Republic of the
- Cook Islands
- Costa Rica
- Croatia
- Cuba
- Cyprus
- Czech Republic
- Denmark
- Djibouti
- Dominica
- Dominican Republic
- Ecuador
- Egypt
- El Salvador
- Equatorial Guinea
- Eritrea
- Estonia
- Ethiopia

- Falkland Islands (Malvinas)
- Faroe Islands
- Fiji
- Finland
- France
- French Guiana
- French Polynesia
- French Southern Territories
- Gabon
- Gambia
- Georgia
- Germany
- Ghana
- Gibraltar
- Greece
- Greenland
- Grenada
- Guadeloupe
- Guatemala
- Guernsey
- Guinea
- Guinea-Bissau
- Guyana
- Haiti
- Heard Island and McDonald Islands
- Holy See (Vatican City State)
- Honduras
- Hong Kong
- Hungary
- Iceland
- India
- Indonesia
- Iran, Islamic Republic of
- Iraq
- Ireland
- Isle of Man
- Israel
- Italy
- Jamaica
- Japan
- Jersey
- Jordan
- Kazakhstan
- Kenya
- Kiribati
- Korea, Democratic Peoples Republic of
- Korea, Republic of
- Kuwait
- Kyrgyzstan
- Lao Peoples Democratic Republic
- Latvia
- Lebanon
- Lesotho
- Liberia
- Libyan Arab Jamahiriya
- Liechtenstein
- Lithuania
- Luxembourg
- Macao
- Macedonia, the former Yugoslav Republic of
- Madagascar
- Malawi
- Malaysia
- Maldives
- Mali
- Malta
- Marshall Islands
- Martinique
- Mauritania
- Mauritius
- Mayotte

- Mexico
- Micronesia, Federated States of
- Moldova, Republic of
- Monaco
- Mongolia
- Montenegro
- Montserrat
- Morocco
- Mozambique
- Myanmar
- Namibia
- Nauru
- Nepal
- Netherlands
- Netherlands Antilles
- New Caledonia
- New Zealand
- Nicaragua
- Niger
- Nigeria
- Niue
- Norfolk Island
- Northern Mariana Islands
- Norway
- Oman
- Pakistan
- Palau
- Palestinian Territory, Occupied
- Panama
- Papua New Guinea
- Paraguay
- Peru
- Philippines
- Pitcairn
- Poland
- Portugal
- Qatar
- Ré union
- Romania
- Russian Federation
- Rwanda
- Saint Barthélemy
- Saint Helena, Ascension and Tristan da Cunha
- Saint Kitts and Nevis
- Saint Lucia
- Saint Martin (French part)
- Saint Pierre and Miquelon
- Saint Vincent and the Grenadines
- Samoa
- San Marino
- Sao Tome and Principe
- Saudi Arabia
- Senegal
- Serbia
- Seychelles
- Sierra Leone
- Singapore
- Slovakia
- Slovenia
- Solomon Islands
- Somalia
- South Africa
- South Georgia and the South Sandwich Islands
- Spain
- Sri Lanka
- Sudan
- Suriname
- Svalbard and Jan Mayen
- Swaziland
- Sweden
- Switzerland

- Syrian Arab Republic
- Taiwan, Province of China
- Tajikistan
- Tanzania, United Republic of
- Thailand
- Timor-Leste
- Togo
- Tokelau
- Tonga
- Trinidad and Tobago
- Tunisia
- Turkey
- Turkmenistan
- Turks and Caicos Islands
- Tuvalu
- Uganda
- Ukraine
- United Arab Emirates
- United Kingdom
- United States
- Uruguay
- Uzbekistan
- Vanuatu
- Venezuela, Bolivarian Republic of
- Vietnam
- Virgin Islands, British
- Wallis and Futuna
- Western Sahara
- Yemen
- Zambia
- Zimbabwe

State of residence (if applicable)

- ALABAMA ALASKA
 AMERICAN SAMOA ARIZONA
 ARKANSAS CALIFORNIA
 COLORADO CONNECTICUT
 DELAWARE DISTRICT OF COLUMBIA
 FLORIDA GEORGIA
 GUAM HAWAII IDAHO
 ILLINOIS INDIANA
 IOWA KANSAS KENTUCKY
 LOUISIANA MAINE
 MARYLAND MASSACHUSETTS
 MICHIGAN MINNESOTA
 MISSISSIPPI MISSOURI
 MONTANA NEBRASKA
 NEVADA NEW HAMPSHIRE
 NEW JERSEY NEW MEXICO
 NEW YORK NORTH CAROLINA
 NORTH DAKOTA OHIO
 OKLAHOMA OREGON
 PENNSYLVANIA PUERTO RICO
 RHODE ISLAND SOUTH CAROLINA
 SOUTH DAKOTA TENNESSEE
 TEXAS UTAH VERMONT
 VIRGIN ISLANDS VIRGINIA
 WASHINGTON WEST VIRGINIA
 WISCONSIN WYOMING

Gender

- Female
 Male
 Other

Race (may check more than one)

- White
 Black or African American
 American Indian / Native Alaskan
 Asian
 Native Hawaiian / Pacific Islander
 Other

Please specify other race

Ethnicity

- Hispanic/Latino
 Not Hispanic/Latino
 Unknown / Chose not to answer

Disease factors Sickle Cell genotype:

- Hemoglobin SS disease
 Hemoglobin S beta zero thalassemia
 Hemoglobin SC disease
 Hemoglobin S beta + thalassemia
 Other

Please specify genotype

Patient weight (kg)

Home SCD Medications

Home SCD medications at time of COVID diagnosis (please include medications stopped within two weeks of time of diagnosis). (check all that apply)

- Hydroxyurea
 Penicillin
 Crizanlizumab
 Voxelotor
 Glutamine

Chronic red blood cell transfusions

- Yes
 No

Most recent Hemoglobin S level in relationship to covid testing day

of weeks since last transfusion prior to illness

Clinical reasons for receiving chronic red blood cell transfusions?

- Overt stroke
 Silent stroke
 High TCD result (Transcranial Doppler)
 Pain
 Splenic sequestration
 Other

Other Reason for transfusion

Is patient receiving chelation therapy?

- Yes
 No

At the time of COVID diagnosis, was the patient taking an ACE inhibitor (angiotensin converting enzyme inhibitors) or an ARB (angiotensin-receptor blockers)?

- Yes
 No

If patient is receiving other treatment, please describe

Did the patient take any NSAIDS during the COVID19 infection?

- Yes
 No

Were any of the SCD medications stopped due to COVID19?

- Yes
 No

Home SCD medications stopped due to COVID19. (check all that apply)

- Hydroxyurea
 Penicillin
 Crizanlizumab
 Voxelotor
 Glutamin

Specify other medication that was stopped due to COVID19

Sickle cell disease-related history:

Pain: Number of times hospitalized for pain in the last 3 years

If this is unknown please enter "999"; if the patient has never experienced this enter "0"

Pain: Number of treat and release emergency department visits for pain requiring IV opioids in last 3 years

If this is unknown please enter "999"; if the patient has never experienced this enter "0"

Acute chest syndrome: Number of episodes in last 3 years

If this is unknown please enter "999"; if the patient has never experienced this enter "0"

Priapism: Number of episodes in last 3 years

If this is unknown please enter "999"; if the patient has never experienced this enter "0"

	Yes	No
Brain: Overt Stroke history	<input type="radio"/>	<input type="radio"/>
Brain: Silent Stroke History	<input type="radio"/>	<input type="radio"/>
Brain: Known CNS vasculopathy	<input type="radio"/>	<input type="radio"/>
Brain: High TCD result (Transcranial Doppler)	<input type="radio"/>	<input type="radio"/>
Heart/Lung: Pulmonary hypertension	<input type="radio"/>	<input type="radio"/>
Kidney disease: Albuminuria	<input type="radio"/>	<input type="radio"/>
Kidney disease: Decreased Renal function	<input type="radio"/>	<input type="radio"/>
Kidney disease: Sickle cell disease nephropathy	<input type="radio"/>	<input type="radio"/>
Splenic Sequestration	<input type="radio"/>	<input type="radio"/>

Does the patient have any of the following comorbidities?

Does the patient have any of the following comorbidities (check all that apply)?

- Cardiovascular disease (coronary artery disease, heart failure, arrhythmia, etc))
- Diabetes
- Asthma
- COPD
- Other Chronic Lung Disease (NOT asthma/COPD)
- Hypertension
- Cancer
- Chronic liver disease (PSC, NAFLD, cirrhosis, etc.)
- Current cigarette smoker
- Current user of other tobacco products other than cigarettes (vaping, etc.)

Does the patient have any of the following comorbidities (check all that apply)?

- Anxiety, depression, and/or behavioral problems
- Asthma
- Attention deficit/hyperactivity disorder
- Celiac disease
- Developmental delay or learning disability
- Diabetes
- Headaches
- Kidney Disease
- Obesity
- Seizure disorder
- Sleep disturbances
- Stroke
- Thyroid disease
- Current cigarette smoker
- Current user of other tobacco products other than cigarettes (vaping, etc.)

COVID 19 Questions

Year of diagnosis of COVID 19

- | | | |
|----------------------------|----------------------------|----------------------------|
| <input type="radio"/> 2019 | <input type="radio"/> 2020 | <input type="radio"/> 2021 |
| <input type="radio"/> 2022 | <input type="radio"/> 2023 | <input type="radio"/> 2024 |
| <input type="radio"/> 2025 | <input type="radio"/> 2026 | <input type="radio"/> 2027 |
| <input type="radio"/> 2028 | <input type="radio"/> 2029 | <input type="radio"/> 2030 |
| <input type="radio"/> 2031 | <input type="radio"/> 2032 | <input type="radio"/> 2033 |
| <input type="radio"/> 2034 | <input type="radio"/> 2035 | <input type="radio"/> 2036 |
| <input type="radio"/> 2037 | <input type="radio"/> 2038 | <input type="radio"/> 2039 |
| <input type="radio"/> 2040 | | |

Specify approximate number of days of symptoms from COVID 19 (if known)

Please choose a severity of COVID-19

- Asymptomatic-no clinical signs or symptoms during the positive COVID-19 period.
- Mild- symptoms of acute upper respiratory tract infection, including fever, fatigue, myalgia, cough, sore throat, runny nose, and sneezing or gastrointestinal symptoms or digestive symptoms such as nausea, vomiting, abdominal pain and diarrhea.
- Moderate-pneumonia, with or without clinical symptoms, no hypoxia
- Severe-early respiratory symptoms or gastrointestinal symptoms followed by dyspnea and hypoxia (O2 saturations less than 92%)
- Critical-ARDS, respiratory failure, encephalopathy, shock, coagulopathy, multi-organ impairment (lung, heart, kidney, brain) that may be life threatening

Have patient's symptoms resolved at the time of this report?

- Yes
- No
- Unknown
- Patient never developed symptoms (just tested positive)

Did patient develop any of these sickle cell disease symptoms at the time of COVID 19 infection?

	Yes	No
Stroke	<input type="radio"/>	<input type="radio"/>
Acute chest syndrome/pneumonia	<input type="radio"/>	<input type="radio"/>
Pain	<input type="radio"/>	<input type="radio"/>
Priapism	<input type="radio"/>	<input type="radio"/>
Splenic sequestration	<input type="radio"/>	<input type="radio"/>
Aplastic crisis	<input type="radio"/>	<input type="radio"/>
Pulmonary hypertension	<input type="radio"/>	<input type="radio"/>
Heart arrhythmias	<input type="radio"/>	<input type="radio"/>
Heart failure	<input type="radio"/>	<input type="radio"/>
Venous Clot	<input type="radio"/>	<input type="radio"/>
Pulmonary Embolus	<input type="radio"/>	<input type="radio"/>
Arterial Clot	<input type="radio"/>	<input type="radio"/>
Kidney failure	<input type="radio"/>	<input type="radio"/>
Was Dialysis required?	<input type="radio"/>	<input type="radio"/>
Did the patient recover kidney function?	<input type="radio"/>	<input type="radio"/>
Bacterial infection	<input type="radio"/>	<input type="radio"/>

What organism if known

COVID 19 Treatment Medications

	Yes	No
Did the patient receive Hydroxychloroquine for treatment of the COVID-19 infection?	<input type="radio"/>	<input type="radio"/>
Azithromycin?	<input type="radio"/>	<input type="radio"/>
Convalescent plasma infusion?	<input type="radio"/>	<input type="radio"/>
Corticosteroids?	<input type="radio"/>	<input type="radio"/>
Tocilizumab (anti-IL6) ?	<input type="radio"/>	<input type="radio"/>
Remdesivir?	<input type="radio"/>	<input type="radio"/>
Lopinavir/Ritonavir?	<input type="radio"/>	<input type="radio"/>
Heparin (any form) ?	<input type="radio"/>	<input type="radio"/>

What type of dose was given

- Therapeutic dose
 Preventative dose

COVID 19 Treatment Course

	Yes	No	Unknown
Did patient die of COVID 19 or other complications caused by or contributed to by COVID 19?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Was patient evaluated in a hospital ER?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Has the patient been hospitalized?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Length of stay (days)

Did patient require a ventilator?

- Yes
 No
 Unknown

Did the patient receive blood transfusion?

- Yes
 No

Did the patient receive the transfusion as:

- Simple transfusion
 Exchange transfusion

Did patient require admission to an intensive care unit (including step-down units)?

- Yes
 No
 Unknown