Rheumatology COVID-19 Registry

Introduction

Thank you for agreeing to take part in this important effort on behalf of the global rheumatology community. Our hope is that information you and others provide will help us understand how the novel COVID-19 virus impacts patients with rheumatologic conditions or those taking immunosuppressive drugs. We hope to better understand their risk of infection, track outcomes, and use this data to inform treatment.

Please note, this survey is for health care professionals caring for adult rheumatology patients. Surveys for pediatric patient reports or for patients to report their own symptoms are available on the COVID-19 Global Rheumatology Alliance website.

The case report form should take about 5-7 minutes to complete. Patients identifiers such as name or date of birth will not be collected. All information will be kept strictly confidential and will only be shared with researchers compiling information. Information and updates will be shared via the COVID-19 Global Rheumatology Alliance website: https://rheum-covid.org.

The success of this collaborative effort depends on active participation by our rheumatology community to obtain accurate and reliable information. We ask that you share this site with your colleagues and encourage them to report any cases of COVID-19 in rheumatology patients.

The COVID-19 Global Rheumatology Alliance

Rheum COVID-19 Provider Information

Family name/last name of reporting provider ________________________________

Given name/first name of reporting provider ________________________________

Email address: __________________________________
(Institutional email preferred)

Role of reporting provider (e.g., physician, nurse, etc.) ________________________________

Specialty of reporting provider ________________________________

Hospital or clinic name ________________________________

City of hospital/clinic ________________________________

State or province of hospital/clinic ________________________________

Country of hospital/clinic ________________________________

Note: This form is for reference only, please do not use it to provide data to the registry

For reference only. To add data to the registry, please go to https://rheum-covid.org
Rheum COVID-19 Patient Information

Unique Patient Identifier: (automated)____________________

Patient age
___________________________ (19-99 years)

This registry is for adult patients only.

Patient sex at birth
Female
Male
Other or not known

COVID-19 information

COVID-19 Diagnosis: Date
___________________________ (If day is unknown, enter 15. )

COVID-19 Diagnosis: location
  o Home or standalone testing (e.g., mobile testing site)
  o Nursing home or assisted living facility
  o Outpatient facility
  o Emergency department
  o Inpatient/hospital
  o Unknown
  o Other ___________________________

COVID-19 Diagnosis: How was the COVID-19 diagnosis made?
(Check all that apply)
  o Presumptive diagnosis based on symptoms only
  o PCR
  o Antibody
  o Metagenomic testing
  o CT scan
  o Laboratory assay, type unknown
  o Unknown
  o Other ___________________________
Has this patient ever had symptoms of COVID-19 infection?

- Yes
- No
- Unknown

COVID-19: If yes, Clinical symptoms during course of infection (Check all that apply)

- Fever
- Headache
- Sore throat
- Cough
- Shortness of breath
- Arthralgia
- Myalgia
- Chest pain
- Abdominal pain
- Diarrhea, vomiting or nausea
- Rhinorrhea
- Irritability/confusion
- Malaise
- Anosmia
- Dysgeusia
- Other

COVID-19 other clinical symptoms, please specify:

__________________________________________________________________________

COVID-19: Treatment (Only include medications given as treatment for this infection. Treatment for underlying rheumatic disease listed in next section).

(Check all that apply)

- No treatment except supportive care
- Remdesivir
- Lopinavir/ritonavir
- Anti-malarials (e.g. chloroquine, hydroxychloroquine)
- IL-6 inhibitors (e.g. tocilizumab, sarilumab, siltuximab)
- Bevacizumab
- JAK inhibitors (e.g. tofacitinib, baricitinib, upadacitinib)
- Serpin inhibitors
- Ciclosporine
- Glucocorticoids
- IVIG
- Plasma from recovered patients
- Other

COVID-19: Treatment, additional notes/other:

__________________________________________________________________________

Is the patient deceased?

- Yes, deceased
- Not deceased or vital status not known at this time.

If deceased, Approximate number of days from COVID19 symptom onset to death:__________
If not deceased, Have the patient's COVID19 symptoms resolved at the time of this report?

- Yes
- No
- Unknown

If yes, patient's symptoms resolved: Approximate number of days from COVID19 symptom onset to resolution.

(# days)

If deceased or symptoms resolved: Was the patient hospitalized during the illness?

- Yes
- No
- Unknown

If not hospitalized: Did the patient require any medical interventions? (e.g., supplemental oxygen)

- Yes
- No
- Unknown

If hospitalized: What was the maximum level of care required during the illness?

- Did not require supplemental oxygen
- Required supplemental oxygen
- Required non-invasive ventilation or high flow oxygen devices
- Required invasive mechanical ventilation or ECMO
- Ventilation required, but type unknown
- Interventions unknown

If symptoms not resolved: Approximate number of days since COVID19 symptom onset (until today).

(# days)

If symptoms not resolved: Has the patient been hospitalized during the illness?

- Yes
- No
- Unknown

If symptoms not resolved & not hospitalized: Has the patient required any medical interventions so far? (e.g., supplemental oxygen)

- Yes
- No
- Unknown
If symptoms not resolved & hospitalized: What is the maximum level of care required during the patient's illness so far?

- Did not require supplemental oxygen
- Required supplemental oxygen
- Required non-invasive ventilation or high flow oxygen devices
- Required invasive mechanical ventilation or ECMO
- Ventilation required, but type unknown
- Interventions unknown

COVID-19: Complications
(check all that apply)

- No known complications
- Acute Respiratory Distress Syndrome or ARDS
- Sepsis
- Myocarditis or new heart failure
- Concomitant or secondary infection (e.g. Influenza)
- Other serious complication

COVID-19 Complications: please specify secondary or concomitant infection.

__________________________________

COVID-19 complications: please specify other serious complications.

__________________________________

Infection Acquisition: In the 14 days before onset of illness did the patient have any of the following?
(Check all that apply)

- History of travel to an area with documented cases of COVID-19 infection
- Close contact with a confirmed or probable case of COVID-19 infection
- Presence in a healthcare facility where COVID-19 infections have been managed
- None of the above (community acquired)
- Unknown
- Other

COVID-19 other infection acquisition, please specify:

__________________________________
# Rheumatic or Autoimmune Disease and Treatment

Primary rheumatic/autoimmune diagnosis(es)
(Please check only primary diagnosis.)

- ANCA-associated vasculitis (e.g., GPA, EGPA)
- Other vasculitis including Kawasaki disease
- Anti-phospholipid antibody syndrome
- Autoinflammatory syndrome (including TRAPS, CAPS, FMF)
- Axial spondyloarthritis (including ankylosing spondylitis)
- Other spondyloarthritis (including reactive arthritis)
- Behcet’s
- Chronic recurrent multifocal osteomyelitis
- Giant cell arteritis
- IgG4-related disease
- Inflammatory myopathy (e.g. dermatomyositis, polymyositis)
- Juvenile idiopathic arthritis, not systemic
- Systemic juvenile idiopathic arthritis
- Mixed connective tissue disease
- Ocular inflammation
- Polymyalgia rheumatica
- Psoriatic arthritis
- Rheumatoid arthritis
- Other inflammatory arthritis
- Sarcoidosis
- Sjogren’s syndrome
- Systemic lupus erythematosus
- Systemic sclerosis
- Undifferentiated connective tissue disease
- Other

Inflammatory ocular diagnosis, please specify:

- Uveitis, Anterior
- Uveitis, Intermediate
- Uveitis, Posterior
- Panuveitis
- Scleritis
- Retinal vasculitis
- Other

Rheumatic/autoimmune diagnosis other, please specify

_________________________________________________________________

Rheumatic/autoimmune disease activity at the time of COVID-19 symptom onset (or at COVID-19 diagnosis if asymptomatic):

- Remission
- Minimal or low disease activity
- Moderate disease activity
- Severe or high disease activity
- Unknown

For reference only. To add data to the registry, please go to https://rheum-covid.org
# Treatments for underlying rheumatic/autoimmune disease

Glucocorticoids (including prednisone, methylprednisolone) at time of COVID-19 symptom onset (or at COVID-19 diagnosis if asymptomatic):

- [ ] Yes
- [ ] No
- [ ] Unknown

If taking glucocorticoids, then dose (prednisone equivalent) at the time of COVID-19 symptom onset (or at COVID-19 diagnosis if asymptomatic):

__________________________________  (mg/day)

Was the glucocorticoid stopped or continued after COVID-19 diagnosis?

- [ ] Stopped
- [ ] Continued at same dose
- [ ] Tapered dose
- [ ] Increased dosage
- [ ] Unknown

Immune modulating medications immediately prior to the time of COVID-19 symptom onset (or at COVID-19 diagnosis if asymptomatic):

(up to 5 medications can be selected)

- [ ] None
- [ ] Abatacept
- [ ] Antifibrotics (pirfenidone, nitedinib)
- [ ] Antimalarials (including hydroxychloroquine, chloroquine)
- [ ] Apremilast
- [ ] Azathioprine / 6-MP
- [ ] Belimumab
- [ ] CD-20 inhibitors (including rituximab, ofatumumab)
- [ ] Cyclophosphamide
- [ ] Cyclosporine
- [ ] Denosumab
- [ ] IL-1 inhibitors (including anakinra, canakinumab, rilonacept)
- [ ] IL-6 inhibitors (including tocilizumab, sarilumab)
- [ ] IL-12/23 inhibitors (including ustekinumab, guselkumab)
- [ ] IL-17 inhibitors (including secukinumab, ixekizumab)
- [ ] IVIG
- [ ] JAK inhibitors (including tofacitinib, baricitinib, upadacitinib)
- [ ] Leflunomide
- [ ] Methotrexate
- [ ] Mycophenolate mofetil / mycophenolic acid
- [ ] Sulfasalazine
- [ ] Tacrolimus
- [ ] Thalidomide / lenalidomide
- [ ] TNF-inhibitors (including infliximab, etanercept, adalimumab, golimumab, certolizumab, and biosimilars)
- [ ] Steroid eye drops
- [ ] Unknown
- [ ] Other ____________________________________________

For each medication listed:

Was the medication stopped or continued after COVID-19 diagnosis?

- [ ] Stopped
- [ ] Continued
- [ ] Unknown

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**At the time of COVID-19 symptom onset (or diagnosis if asymptomatic), was the patient taking any of the following medications?**

<table>
<thead>
<tr>
<th>Medication</th>
<th>Yes and medication continued</th>
<th>Yes and medication stopped</th>
<th>No</th>
<th>unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACE inhibitor</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Angiotensin receptor blocker</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Nonsteroidal anti-inflammatory (NSAID)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>PD5 inhibitor (e.g., sildenafil)</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

**Comorbidity and Pregnancy**

(Check all that apply)

- None
- Interstitial lung disease (e.g. NSIP, UIP, IPF)
- Obstructive lung disease (COPD/asthma)
- Other lung disease
- Diabetes
- Morbid obesity (BMI 40+)
- Hypertension
- Cardiovascular disease (coronary artery disease, congestive heart failure)
- Pulmonary hypertension
- Chronic renal insufficiency or end stage renal disease
- Cancer
- Organ transplant recipient
- Immunodeficiency
- Inflammatory bowel disease
- Liver disease
- Chronic neurological or neuromuscular disease
- Trisomy 21
- Psychiatric condition (e.g., schizophrenia, bipolar disorder)
- Pregnancy
- Post-partum (< 6 weeks)
- Unknown

If ILD selected: Which choice best characterizes this patient's interstitial lung disease: (check all that apply)

- Idiopathic Pulmonary Fibrosis
- Connective tissue disease, specify CTD: ____________________________
- Hypersensitivity pneumonitis
- Sarcoidosis
- Unknown
- Other ILD: ____________________________
COVID-19 Patient Information

Race/ethnic origin
(Check all that apply)

☐ Arab
☐ Black
☐ East Asian
☐ South Asian
☐ West Asian / Middle Eastern
☐ Pacific Islander
☐ Latin American
☐ White
☐ Native American / Aboriginal / 1st Nations
☐ Other
☐ Unknown or prefer not to answer

Race: other, please specify:

__________________________________

Smoking Status

☐ Current smoker
☐ Former smoker
☐ Never smoked
☐ Unknown smoking status

Does the patient currently use e-cigarettes or vape?

☐ Yes
☐ No
☐ Unknown

Laboratory Test Results

Are there any laboratory test results available related to this patient's COVID-19 infection?

Yes (see next page)

No (go to end)
### Pathogen Tests

<table>
<thead>
<tr>
<th></th>
<th>Positive</th>
<th>Negative</th>
<th>Not Assessed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Influenza A</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Influenza B</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>NON COVID-19 Coronavirus</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>RSV</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Adenovirus</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Bacteria</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Other Respiratory Infection (e.g. fungal)</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

### Other laboratory test results

<table>
<thead>
<tr>
<th>Test Description</th>
<th>Yes</th>
<th>No</th>
<th>Not Assessed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anemia (hemoglobin &lt; 9.2 g/dL) D-dimer &gt; upper limit of normal (ULN)</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Ferritin &gt;2000 ng/mL</td>
<td>○</td>
<td>○</td>
<td>○</td>
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<tr>
<td>IL-6 levels &gt; ULN</td>
<td>○</td>
<td>○</td>
<td>○</td>
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<tr>
<td>sIL2R &gt; ULN</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Fibrinogen &lt; 250 mg/dL</td>
<td>○</td>
<td>○</td>
<td>○</td>
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<tr>
<td>Leukopenia (WBC &lt; 5,000/mm3)</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>AST OR ALT (SGOT or SGPT) &gt; ULN</td>
<td>○</td>
<td>○</td>
<td>○</td>
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<tr>
<td>Absolute Lymphocyte Count &lt; 1,500/mm3</td>
<td>○</td>
<td>○</td>
<td>○</td>
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<tr>
<td>Platelets &lt; 110,000/mm3</td>
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<td>○</td>
<td>○</td>
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<tr>
<td>Triglyceride &gt;133 mg/dL</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Known splenomegaly or hepatomegaly</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

### Follow-up/Notes

May we contact you to get more information about the outcomes of this case?  
○ Yes  ○ No

Would you like to share any lessons or other aspects from this case?

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Thank you!