**SUPPLEMENT**

Effects of the COVID-19 pandemic on patients with NMO spectrum disorders and MOG-antibody associated diseases (COPANMO(G)-Study)

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**eQuestionnaire:**

Please find below the English version of the original questionnaire for the survey of effects of the COVID-19 pandemic on patients with NMO spectrum disorders and MOG-antibody associated diseases from the *COPANMO(G) Study*.

Clinical data on disease onset, severity, duration, serostatus, and immunotherapy were retrieved or cross-checked from the NEMOS database in which all centers prospectively update the information of every individual patient. Any patient-reported onset or relapse of MOGAD / NMOSD in temporal association to vaccination against or infection with SARS-CoV-2 was evaluated by contacting the treating NEMOS center and contacting the respective patient by telephone (for details see the methods section of the main manuscript).

**The questionnaire is protected by copyright.** Unauthorized use is not permitted. If you are interested in usage, please send a qualified request to huemmert.martin@mh-hannover.de. The use of the EuroQoL Group Five Dimension Five Level Scale (EQ-5D-5L) must be registered separately (https://euroqol.org/) and is not part of this supplement for copyright reasons.



**Questionnaire about the effects of the COVID-19 pandemic**

**on patients with NMOSD and MOGAD**

Today´s date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**With which gender do you identify?**

* female
* male
* non-binary

**How old are you?** \_\_\_\_\_\_\_ years

**What is your height and weight?** Height: \_\_\_\_\_\_\_ cm Weight: \_\_\_\_\_\_\_ kg

**What disease have you been diagnosed with?**

* Neuromyelitis optica spectrum disorder (NMOSD)
* MOG-antibody associated disease (MOGAD)

**How long have you had NMOSD/MOGAD (time since first symptoms)?**

\_\_\_\_\_\_\_ years

**Have you been diagnosed with any of the following diseases aside from NMOSD/MOGAD?** *You can select multiple appropriate answers.*

* None
* Stroke
* Chronic respiratory disease (COPD, sleep apnea, bronchial asthma)
* Diabetes
* High blood pressure (Hypertension)
* Coronary artery disease (CAD, coronary heart disease)
* PAD (peripheral arterial disease, mostly of the legs)
* Chronic kidney disease
* Chronic liver disease
* Inflammatory bowel disease
* Rheumatic disease
(e. g. Rheumatoid arthritis, Lupus erythematodes, Ankylosing spondylitis, Sjögren´s syndrome)
* Psoriasis
* I have or have had a malignant disease / cancer
* Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Which immunotherapy are you currently receiving for treatment of NMOSD/MOGAD?***You can select multiple appropriate answers.*

* Prednisolone or other oral steroids
* Rituximab
* Azathioprine
* Mycophenolate-Mofetil (common trade name: CellCept)
* Methotrexate
* Eculizumab
* Tocilizumab
* Satralizumab
* Inebilizumab
* Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

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| **Effects of the COVID-19 pandemic** |

**Has your immunotherapy for NMOSD/MOGAD been changed because of the COVID-19 pandemic?**

* No change
* Stopped
* Paused
* Dosing change
* Treatment interval change
* Change to a different drug, namely: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

In case of change, please describe:

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

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**In case of change of immunotherapy for NMOSD/MOGAD: Was this change made by your neurologist?**

* By myself
* By my neurlogist
* By NEMOS center
* Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Have your other therapies changed because of the COVID-19 pandemic?**

**Physiotherapy?**

* Yes
* If yes, reason: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* No

**Speech therapie?**

* Yes
* If yes, reason: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* No

**Other?:** \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

* Yes
* If yes, reason: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* No

**Did you keep up your doctor’s appointments as usual?**

* Yes
* No
* If no, reason: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Overall, how would you rate your personal risk of suffering from COVID-19?**

* Low
* Medium
* High
* Very high

**How satisfied are you in general with your health care during the COVID-19 pandemic?**

* Very satisfied
* Rather satisfied
* Rather dissatisfied
* Very dissatisfied

**What improvements do you think are needed for health care during the COVID-19 pandemic?**

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**May we contact you in case of queries (voluntary information!)**

⬜ Yes You can reach me under the following phone number: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

⬜ No

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| **COVID-19 infection** |

**Have you had COVID-19, and if so, how was the course of the disease?**

* No
* Yes, I had an infection without symptoms.
* Yes, I had an infection with mild symptoms.
* Yes, I needed to be admitted to the hospital.
* Yes, I was admitted to the hospital and needed supplemental oxygen.
* Yes, I needed ICU treatment.
* Yes, I needed mechanical ventilation.

**If you have not had COVID-19 before, you can proceed directly to the questions on page 6 (Vaccination against COVID-19).**

**In case of COVID-19 infection:**

Date:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ *(Please state month and year, e. g. October 2020)*

**Was the infection confirmed by laboratory testing?**

* No
* Yes:

**With a COVID-19 swab and PCR test:**

* Yes
* No

If yes:

Date \_\_\_\_\_\_\_\_\_\_\_\_ Result: ⬜ positive ⬜ negative

Date \_\_\_\_\_\_\_\_\_\_\_\_ Result: ⬜ positive ⬜ negative

Date \_\_\_\_\_\_\_\_\_\_\_\_ Result: ⬜ positive ⬜ negative

**With a COVID-19 swab and rapid antigen test:**

* Yes
* No

If yes:

Date \_\_\_\_\_\_\_\_\_\_\_\_ Result: ⬜ positive ⬜ negative

Date \_\_\_\_\_\_\_\_\_\_\_\_ Result: ⬜ positive ⬜ negative

Date \_\_\_\_\_\_\_\_\_\_\_\_ Result: ⬜ positive ⬜ negative

**By detecting COVID-19 antibodies in the blood:**

* Yes
* No

If yes:

Date \_\_\_\_\_\_\_\_\_\_\_\_ Result: ⬜ positive ⬜ negative

Date \_\_\_\_\_\_\_\_\_\_\_\_ Result: ⬜ positive ⬜ negative

Date \_\_\_\_\_\_\_\_\_\_\_\_ Result: ⬜ positive ⬜ negative

**What symptoms did you experience during your COVID-19 infection?**
*You can select multiple appropriate answers.*

* Cough
* Dyspnea
* Fatigue
* Joint pain
* Muscle pain
* Rhinitis (cold)
* Sore throat
* Headache
* Loss of smell
* Loss of taste
* Fever
* Other symptoms: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**If you have had COVID-19, are you still experiencing any symptoms?**

If yes, please sprecify:

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**If you have had COVID-19, did you experience a worsening / relapse of your NMOSD / MOGAD?**

* Yes
* No

If yes, when:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ *(Please state month and year, e. g. October 2020)*

**If you have had COVID-19, did your immunotherapy which you received for your NMOSD/MOGAD get changed because of COVID-19?**

* No change
* Stopped
* Paused
* Dosing change
* Treatment interval change
* Change to a different drug, namely: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

In case of change, please specify:

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

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| **Vaccination against COVID-19** |

**Different vaccines against COVID-19 (SARS-CoV-2) have been approved in Europe. Are you planning on getting vaccinated?**

* I’ve already been vaccinated against COVID19.
* Yes, as soon as possible.
* I am still waiting out of concern of possible unknown side effects.
* In principle yes, but only with a viral vector-based vaccine
(e. g. AstraZeneca, Johnson&Johnson).
* In principle yes, but only with an mRNA-vaccine
(e. g. BioNTech/Pfizer, Moderna).
* No
* Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**In case you wish to get vaccinated, which kind of doctor would you prefer to perform your vaccination, if you could choose?**

* Vaccination center
* NEMOS center
* General practitioner
* Outpatient neurologist
* Other / I don’t know

**In case you don’t wish to get vaccinated, what is your decision based on?**

*You can select multiple appropriate answers.*

* Vaccination side effects in general.
* Vaccination side effects influencing your NMOSD / MOGAD.
* I refuse vaccinations in general.
* I don´t see the need to for COVID-19 vaccination.
* I have already suffered from COVID-19.
* SARS-CoV-2 antibodies have been detected in my blood.
* Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**I’ve made my decision on vaccination...** *(You can select multiple appropriate answers)*

* … after consulting my NEMOS center.
* … after consulting my general practitioner.
* … after consulting my relatives.
* … based on the recommendations of patients' organizations.
* … based entirely on my own opinion.

**In case you have already been vaccinated, have you had a relapse / an attack of your NMOSD / MOGAD in temporal association with vaccination?**

* Yes, \_\_\_\_\_\_\_\_weeks after vaccination, symptoms:

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

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* No