

Help Us Solve The Cruel Mystery **LUPUS**

March 26, 2020

To: State Boards of Pharmacy

To Whom It May Concern:

As organizations with extensive experience serving patients who for decades have relied on the antimalarial medications hydroxychloroquine (HCQ) and chloroquine (CQ), we are writing to urge you to take action to ensure people living with rheumatoid arthritis (RA) and lupus continue to have access to these medications. RA, lupus, and malaria are the only conditions for which these drugs are specifically approved by the FDA and they are the standard of care for tens of thousands of patients who depend on them to avoid disability, illness, and early death.

HCQ and chloroquine are being studied as potential treatments for COVID-19, which has exponentially increased the demand for the drugs and resulted in shortages and the implementation of policies that are limiting their availability to people with RA and lupus. In many cases, patients are forced to ration their medication or go without it altogether, placing them at risk for worsening disease. We request that you work with us to address the challenges patients are now facing, including the following:

- COVID-related restrictions: Patients across the country are reporting that they are unable to fill prescriptions for RA or lupus because the drugs are set aside only for use in COVID-19. In some cases, the medications are even being set aside for the *future* use for COVID-19. Similarly, patients are reporting that even if the medications are available for RA and lupus, they must first obtain approval from a third party certifying that they are eligible to receive the medication. This delays patient access to their medication and places an unnecessary administrative burden on rheumatology and other practices, which are already struggling to maintain their patient load amid this public health crisis. We strongly oppose these restrictions and urge states and other stakeholders not to impose them, and to rescind such policies that have already been implemented. Instead, we support polices that specifically ensure access to HCQ and CQ for FDA approved indications (or for off-label uses supported by the scientific literature), without requiring these patients to take additional steps to obtain their prescriptions.
- **Stockpiling:** There are reports of hospitals, health systems, health plans, and providers stockpiling large quantities of HCQ and chloroquine. In some cases, these stockpiles are for exclusive use for COVID-19 or even the potential use of the drugs for COVID-19. While we recognize the urgent global need to have treatments for COVID-19 like HCQ and CQ available for that use, we should not deny access to these medications for the people who already rely on them and for whom they are proven to work.
- Quantity limits: Increasingly HCQ prescriptions are being limited to 7 or 14 days, even for patients with lupus and RA. Not only does this place an additional barrier for people with chronic diseases to receive needed medications, but it also puts them at greater risk for exposure to COVID-19 by requiring them to travel outside their home more frequently to fill their prescriptions. Exceptions to quantity limits should be made for patients with chronic diseases who take HCQ as part of their regular course of care.

- Off-label restrictions: We support polices that restrict HCQ and chloroquine access to those who take it for FDA-approved indications. However, we encourage stakeholders to provide flexibility to allow for off-label use when those uses are supported by the scientific literature and when those medications are already part of a patient's treatment plan. For example, people with conditions like juvenile idiopathic arthritis, Sjogren's Syndrome, sarcoidosis, Q fever, and porphyria cutanea tarda are routinely prescribed HCQ as an effective treatment. Those patients should continue to have access to these medications.
- Inappropriate and unreasonable prescribing: Reports also indicate that physicians are selfprescribing HCQ and chloroquine or prescribing it for their friends and family. Moreover, in many parts of the country there are no restrictions limiting the prescribing of HCQ and chloroquine. For example, the drugs are being prescribed to prevent COVID-19 even though no studies show efficacy for this use. Such examples of unreasonable prescribing must be stopped in order to preserve the availability of the drug for currently approved uses, scientifically accepted uses and, potentially, for use to treat COVID-19.

We are committed to doing our part to prevent the spread of COVID-19 and to supporting the search for treatments. However, as you and other stakeholders work to advance these common goals, we urge you to take action that preserves the ability of people with RA and lupus to access the medications they need to fight their disease.

We look forward to continuing to work with you on these issues. Please contact Anna Hyde at <u>ahyde@arthritis.org</u> or Patrick Wildman at <u>wildman@lupus.org</u> if you have any questions or if we can assist you in any way.

Sincerely,

Ann M. Palmer

Ann M. Palmer President and CEO Arthritis Foundation

Tem Alber

Stevan W. Gibson President and CEO Lupus Foundation of America

cc: AHIP

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