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Author contributions

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Promotion of non-evidence-based therapeutics within patient-led Long COVID support groups

To the Editor — Long COVID support groups began as a patient-led movement, providing safe spaces for patients (including children and their parents and caregivers) to discuss the disease and collectively advocate for awareness, research and support. However, in many groups, individuals and organizations have been promoting experimental treatments, ongoing clinical trials and for-profit treatment plans (examples are included in Table 1). Given the current lack of understanding of the disease etiology of Long COVID and lack of any proven treatment options, patients are desperate for any offered hope. The net result can be an unethical situation that endangers patient health and wellbeing and decreases the integrity and effectiveness of the patient-led movement.

There is a clear and pressing need for treatment options for Long COVID. One of the most expedient options for new treatments is the repurposing of existing therapeutics and natural products. However, new treatment options need to be scientifically evaluated to ensure that they are safe and effective. There is currently no consensus understanding of the molecular mechanisms driving Long COVID, the diagnostic criteria needed to identify Long COVID disease, or whether

the diverse collection of symptoms seen reflect different disease processes that may not respond comparably to the same therapeutic. In addition, many Long COVID patients have symptoms that fluctuate in severity or improve over time, making causal associations with experimental therapeutics difficult. Thus, the evaluation of potential therapeutics needs to take place in carefully controlled clinical trials.

One therapeutic that is being consistently promoted within patient-led groups is ivermectin. Ivermectin is an affordable, widely used anti-parasitic drug that showed some early promise as a therapeutic to prevent or treat acute COVID-19. Based on these initial studies, larger clinical trials were launched to evaluate the drug's effectiveness. Recent meta-analyses have shown that ivermectin is not beneficial for the prevention or treatment of COVID-19¹. In addition, the largest clinical trial showing a benefit of ivermectin was recently withdrawn by the preprint organization that had posted it, due to discrepancies identified in individual patient data^{2,3}.

Unfortunately, the use of ivermectin has been widely promoted based on flawed data and without regard for the analyses of subsequent studies³. This is similar to the situation with hydroxychloroquine in 2020, in which the use of the drug was widely

promoted based on a limited number of small-scale studies showing a potential benefit in acute COVID-19 disease. Based on the early studies of hydroxychloroquine, full clinical trials were initiated that later proved that hydroxychloroquine had no beneficial effect, and could potentially worsen COVID-19 disease^{4,5}. Just as with hydroxychloroquine, misuse of ivermectin can have dangerous side effects and has been associated with illness and death, especially when patients resort to using readily available high-dose ivermectin designed for animals⁶. The use of ivermectin for protection against COVID-19 may also have contributed to infections, as some people reduced other precautions believing that they were protected from infection⁷. The promotion of ineffective therapeutics, such as ivermectin, is dangerous, and the promotion of such therapeutics within vulnerable patient support groups is unethical.

Long COVID support groups play an essential role in advocacy, patient support and research development. However, patient-led support groups are vulnerable to people joining the group who then use their access to promote experimental, unproven or ineffective therapeutics and treatments. The combination of potential adverse effects and the often false hope offered by these non-evidence-based therapeutics can be

Table 1 | Examples of the promotion of non-evidence-based therapeutics seen in Long COVID patient support groups

Type of person	Suggested action	Method
Administrator	Use of ivermectin to treat Long COVID	Promotion in online support groups and social media accounts.
Researcher	Use of a specific nutritional treatment plan (via for-profit company) to treat Long COVID	Promotion in online support groups and social media accounts. Marketing directly to group administrators to encourage secondary promotion.
Medical doctor	Use of a treatment plan including montelukast (via for-profit company) to treat Long COVID	Promotion in online support groups and marketing directly to patients and group members.
Pharmaceutical company representative	Use of montelukast to treat Long COVID	Promotion in online support groups and marketing directly to patients and group members.
Big data company representative	Sharing of patient data with a for-profit data company.	Promotion in online support groups and marketing directly to patients and group members.
An administrator and an anonymous member	Diagnostic test for Long COVID (via for-profit company)	Promotion on support group video call. Marketing directly to patients within the support group and to members of other support groups.
Anonymous member	Use of ivermectin to treat Long COVID	Specific promotion in online support groups in response to another member expressing a specific concern or symptom.
Anonymous member	Use of a treatment plan including ivermectin and therapeutics currently in clinical trials (via for-profit company) to treat Long COVID	Promotion in online support groups and social media accounts.
Anonymous member	Donation of funding to organizations promoting and running Long COVID treatment plans	Promotion in online support groups and social media accounts.

The promotion of these treatments, for which there is no peer-reviewed scientific evidence supporting use, is especially concerning, but the promotion of any treatment in a patient support group is inappropriate. Due to the nature of the online patient support groups, it is not possible to know whether the members in question are patients or represent outside interests, and so these are labeled 'anonymous member'.

damaging to patient health and wellbeing. The promotion of these therapeutics also suggests that there are existing treatment options for Long COVID patients, diminishing the ability of groups to advocate for new Long COVID research that may lead to actual evidence-based therapeutics.

The identification and evaluation of therapeutics for new diseases is unfortunately a slow process; however, this process is necessary for the ethical conduct of research and to ensure the health and safety of patients. Although there are no shortcuts, drug approval has been greatly accelerated during the pandemic. Long COVID patient support groups need to be aware that the promotion of non-evidence-based treatments is occurring within their groups and ensure the proper vetting and integrity of their membership. Sharing personal experiences is an important component

of many support groups. However, there needs to be a code of conduct in place to ensure clear divisions between the sharing of patient experiences and promotion of non-evidence-based therapies.

A code of conduct for Long COVID support groups should enable members to share their own experiences, including with treatments, but prohibit members suggesting or promoting treatments for others to use. For example, a member discussing their use of an experimental treatment could give valuable information to other members and researchers, but the discussion should include a disclaimer that this is an individual experience, not proof that this treatment would work similarly for others, and a suggestion to consult a doctor before using any treatments or therapeutics. In addition, the general promotion of treatments, the advertisement of commercial or fee-for-service programs

and the solicitation of donations for other groups or programs should be prohibited. The conduct of members should be moderated to ensure adherence to the code while also ensuring that any research and data posted within the group are drawn from reputable sources.

Long COVID support groups provide important and essential services, supporting patients and advocating for recognition and care. Through the establishment of an administrator-moderated code of conduct, it would be possible to eliminate dangerous misinformation and the promotion of non-evidence-based therapeutics, ensuring the safety and integrity of patient-led Long Covid support groups, as well as patient-led support groups for other medical conditions. □

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