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Please acknowledge receipt of this correspondence

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Cc: Pascale M. Abie, Administrative Assistant to the Office of the Director-
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From: xxxx

Subject: Removal of code for Congenital Lyme & other ICD11 Transparency
Issues

I am sending this letter to you at the request of members of my constituency, many of whom are in rural communities, and who are being affected by tickborne infections. These include men, women, and children, and indeed the unborn child, who are being infected with these tickborne infections, often unrecognised by patient and the medical community alike.

Globally, countries have committed to the vision of leaving no one behind in the context of the Sustainable Development Goals. In addition, countries are committing to the strategies of Universal Health Coverage to enable all who need health care will receive the appropriate health when they need it.

As member states of the World Health Organization (WHO), we trust WHO to be transparent in all actions and so I believe there should be a review of a process which questions WHO's reputation on transparency and I strongly believe you will also agree with my request for a review.

I request WHO reinstate 1C1G.2 Congenital Lyme borreliosis into the ICD11 and ensure all Lyme codes presented in the June 18, 2018 ICD11 release remain visible and accessible to future ICD11 users. This includes the life-threatening conditions of 6D85.Y Dementia due to Lyme Disease and 8A45.0Y Central Nervous System demyelination due to Lyme borreliosis. I also urge WHO demonstrate its stated commitments to transparency and stakeholder engagement.

1C1G.2 Congenital Lyme borreliosis was removed in a very non-transparent manner from the ICD11 on December 17, 2018. This action, to remove this condition, was taken six months after the release of WHO's 'stable' ICD11 Report.

Correspondence from a member of the ICD11 Medical and Scientific Advisory Committee (MSAC) stated, *"This was in response to a request for the removal of Congenital Lyme borreliosis by the Public Health Agency of Canada (PHAC)..."*

The concern relates to the removal of the ICD-11 codes for congenital Lyme disease. They were present in June 2018 and they disappeared by December 2018. There has been no clear evidence based explanation provided for these actions that has been made public. By the removal of this codes, mothers with Lyme Disease and their children are being left out of the counting at national and global level: we are leaving them behind. The opportunities for documenting the syndromes and spectrum of pathologies associated with vertical transmission of Lyme Disease will be lost, unless you re-instate this very important IC1G.2 Congenital Lyme code.

I seek your office to work with your technical team to review the process leading to this decision, to get other sources of data and allow the voices of the patient groups and the community to be heard. I can provide to you the names of scientists and patient advocate groups who are willing to accompany the process of revisiting the position of congenital Lyme Disease in the ICD11 codes.

Transparency and accountability of this process is lacking.

We ask the following responses from the WHO:

Why was the code removed?

What was the process that led to this removal?

We have been informed that an 'external group' was appointed who made this decision. Who are the members of this group?

Detailed scientific data was provided to get Congenital Lyme accepted as a code. What scientific data was reviewed to subsequently re-review this 'inclusion' decision, and what was the difference from the initial scientific data and subsequent scientific data that lead to reversal of the decision, to have the code 'excluded'?

Other congenital infections have been identified by ICD codes: both viral and bacterial infections. We want clarification as to what was the criteria for acceptance was for these other conditions, and where Congenital Lyme failed to meet the same criteria, in the re-review of the data that was provided by this 'unidentified' external review group.

We are additionally concerned that other ICD11 codes for Lyme Borreliosis are under threat; and would like re-assurance that this will not happen. And that the same lack of transparency that has occurred with Congenital Lyme will not occur again.

All Lyme codes presented in the June 18, 2018 ICD11 release remain visible and accessible to future ICD11 users. They are as follows:

ICD11

1C1G Lyme borreliosis
1C1G.0 Early cutaneous Lyme borreliosis
1C1G.1 Disseminated Lyme borreliosis
1C1G.10 Lyme Neuroborreliosis
1C1G.11 Lyme Carditis
1C1G.12 Ophthalmic Lyme borreliosis
1C1G.13 Lyme arthritis
1C1G.14 Late cutaneous Lyme borreliosis
1C1G.1Y Other specified disseminated Lyme borreliosis
1C1G.1Z Disseminated Lyme borreliosis, unspecified
1C1G.2 Congenital Lyme borreliosis (now removed)
1C1GY Other specified Lyme borreliosis
6D85.Y Dementia due to other specified diseases classified elsewhere; Dementia due to Lyme Disease
9C20.1 Infectious panuveitis; Infectious panuveitis in Lyme disease
9B66.1 Infectious intermediate Choroiditis; Infectious intermediate uveitis in Lyme disease
8A45.0Y Other Specified white matter disorders due to infections; Central Nervous System demyelination due to Lyme borreliosis

On behalf of our constituency, we ask for immediate re-instatement of Congenital Lyme to the ICD 11 codes. And we ask a guarantee that you preserve current codes, ensuring they not be tampered with, as has occurred with Congenital Lyme.

I therefore would also urge the WHO to demonstrate its stated commitments to transparency and stakeholder engagement by hosting a meeting with patient stakeholder and with doctors, scientists, lawyers, human right experts and elected officials who champion their cause.

Thank you.

Name etc.