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Canadian PNH Network Position Statement on COVID-19 Vaccination

Disclaimer: *The recommendations expressed herein are general guidelines based on the available data at the time of writing. Application of these statements must be adapted to individual patients. The Canadian PNH Network assumes no responsibility or liability arising from error or omission, nor from the use of any information contained herein. This document should not serve as an alternative to specific medical advice from a physician or other treating healthcare practitioner.*

As COVID-19 vaccinations become available across Canada, patients with PNH and/or aplastic anemia (AA) will become eligible to receive them. Though the clinical trials performed did not include patients with PNH or AA, it is the position of the Canadian PNH Network that our patients receive the vaccination when invited unless there are specific reasons they are unable to do so. This is our position both for patients on specific treatments for PNH (e.g. eculizumab) and for those who are not.

After each vaccination, there is a small risk that symptoms of PNH may temporarily worsen (e.g. dark urine, abdominal pain, fatigue). If this happens, it would be important for patients to notify their hematologists.

There is a rare, severe adverse event associated with the adenoviral COVID-19 vaccines (AstraZeneca/COVISHIELD and Janssen/Johnson & Johnson) called vaccine-induced thrombotic thrombocytopenia (VITT). Though there is no clear increased risk in PNH patients, Health Canada has recommended that those with a history of cerebral sinus thrombosis with thrombocytopenia or previous heparin-induced thrombocytopenia (HIT) should receive alternate vaccines if available. Those patients who have already had their first dose of adenoviral vaccine without complications may receive the second dose, or whichever other vaccine is offered them in their jurisdiction.

The vaccines currently available are given as an intramuscular needle. Injections into the muscle can be associated with bleeding, so patients who have low platelet counts (<30 x 10⁹/L) should consult with their doctors before being vaccinated.

Patients who are taking blood thinners are encouraged to get vaccinated. There may be a small risk of bruising or bleeding at the injection site; however, putting pressure on the area for 3-5 minutes after the injection should help to minimize that risk.

If patients with AA who have received ATG within the last 6 months, vaccine response may be reduced, and patients should discuss this with their hematologist in advance of vaccination.

Regardless of vaccination status, it is important that everyone continue to follow the general practices of masking, hand hygiene, and physical distancing.

If patients are diagnosed with COVID-19, it is important that they notify their treating hematologist to discuss their condition and continuation of treatment for their PNH/AA.

As provincial and national guidance on COVID-19 vaccination changes, our guidance may also change as we learn more about the reactions experienced in the general population. Updated information, should it be required, will be posted here. For specific questions, PNH patients should discuss vaccination with their treating hematologist. General information about the vaccination program in Canada can be found at the following link:

<https://www.canada.ca/en/public-health/services/diseases/coronavirus-disease-covid-19/vaccines.html>