



PULMONARY HYPERTENSION
ASSOCIATION OF CANADA

L'ASSOCIATION D'HYPERTENSION
PULMONAIRE DU CANADA

Outline for meetings with elected officials

1. **Introduce yourself:** Explain who you are and that you're there on behalf of Pulmonary Hypertension Association of Canada (PHA Canada) – a national charitable organization committed to empowering the Canadian pulmonary hypertension community through support, education, advocacy, awareness, and research – and la Fondation HTAPQ (Hypertension artérielle pulmonaire du Québec), a charitable organization recognized in Quebec as the province's leading support organization for people with pulmonary hypertension and their families.
2. **Purpose:** Explain that you are there to discuss the need for publicly funded access to sotatercept (Winrevair™) – an important treatment for pulmonary arterial hypertension (PAH).
3. **Key messages:**
 - i. PAH is a rare, progressive, and life-threatening disease characterized by high blood pressure in the lungs. As it progresses, it can weaken the heart and lead to complications, including heart failure. Left untreated, PAH may result in death in two to three years after diagnosis. It is estimated that more than 2,000 Canadians have been diagnosed with PAH, but as many as 4,000 may be affected. If appropriate, share some more facts about PAH from the [fact sheet](#).
 - ii. Tell your local elected official your brief personal story and connection to PAH.
 - iii. While treatment options have improved in recent years, the prognosis remains grim for many, as existing therapies often fail to stop the progression of this disease.
 - iv. An important new treatment option—sotatercept (Winrevair™)—was recently approved by Health Canada and recommended for public funding by Canada's Drug Agency. In Québec, for cost reasons, INESSS recommended against public funding for sotatercept despite recognizing its therapeutic benefit.
4. **Ask:** “I would appreciate it very much if you could contact the health minister to encourage him to expedite the pCPA negotiations for the price of sotatercept, as that is the only way to improve its cost-effectiveness, and to add sotatercept to the list of medications reimbursed by Quebec as soon as an agreement has been reached with the pCPA. To support this request, I have prepared a draft letter on your behalf.” Share the letter and remember to



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ask to be copied on the letter. [A draft letter is here](#). Let them know you'll follow up with an electronic copy so they can easily customize it.

5. **Conclusion:**

- Thank your elected official for their time and for agreeing to write the letter. Let them know you will follow up in the coming days and weeks.
- Be sure to **take a picture of you with your elected official** – ask permission to share it on social media.
- You can post the photo yourself or you can send it to PHA Canada at info@phacanada.ca for us to post.
- If you'd like to post yourself, here's a suggested message: *Thank you [@PoliticalOfficial] for the opportunity to discuss the challenges experienced by Quebeckers affected by #PAH and how to accelerate access to new treatments and quality care! #TimeMattersPAH @PHACanada #HTAPQ*

6. **Report back:** Let PHA Canada know about your meeting – when it happened, who attended, what happened, next steps, etc. Let us know how we can help you follow up with your local elected official, including sending additional information about PAH and/or treatment options. You can reach us at 1-877-774-2226 or info@phacanada.ca.

7. **Follow up:** Send an email thanking your elected representative for meeting with you. [A draft thank-you letter is here](#). Also, attach a copy of the draft letter from the elected representative to the health minister.

8. **Accept our congratulations** on your advocacy efforts!