

Survey: Impact of COVID-19 Pandemic on Rare Disease Patients in Canada

Question		HORIZON
1.	At this time, to the best of your knowledge, what is the most likely impact of COVID-19 on (adequate) supply of your company's drugs to Canadian patients? If the answer varies by drug, please provide either specific drug information or respond in general across all drugs.	At this time Horizon has an adequate supply of all three of our rare disease medicines (RAVICTI® for Urea Cycle Disorders, PROCYSBI® for nephropathic cystinosis & QUINSAIR® for pseudomonas infections in adult CF patients) to last through 2020.
2.	If interruption or shortage in drug supply were anticipated or took place, where could Canadian patients find information about the situation and any plans for addressing or mitigating the impact? Is there a website, information line, or contact person?	Any patients with concerns, can reach out directly to our TranscendRare program. Contact: 1-844-823-4226 Email: transcendrare@innomar-strategies.com
3.	This question addresses any clinical trials that your company has at this time that includes Canadian sites or Canadian patients in other countries. At this time, to the best of your knowledge, have you experienced or do you anticipate any interruptions, delays, or modifications in the conduct of these trials due to COVID-19? Please describe any modifications or other adjustments.	Horizon currently has no clinical trials running in Canada.
4.	To the best of your knowledge, are there any clinical trials that will not take place or will be delayed as a result of COVID-19? Please describe.	No
5.	Where can patients find information about any increased risk of getting COVID-19 or increased impact of COVID-19 due to any medications provided by your company?	There are no increased risk with our medicines. Additionally, all of our medicines can be shipped directly to the patient's home so there should not be additional risks in obtaining medicines.
6.	To the best of your knowledge, are there any changes in patient support programs that are anticipated or planned, related to issues due to COVID-19? Please describe.	We have actually enhanced our patient support program to add home delivery to those patients who currently were not receiving. All programs including compassionate program and financial assistance will continue to be available to patients through the TranscendRare program.

7.	How can patients or patient organizations find updated information about your company's policies, plans, or actions related to COVID-19? How will you communicate with patients or patient groups?	Individual patients or caregivers can reach out to the TranscendRare program as above. Any patient group can reach out to our Horizon team directly via connect@horizontherapeutics.com and follow Horizon's social media channels for regular company updates.
8.	Is there any other information that you wish to communicate share at this time?	It is Horizon's main focus to make sure there are no interruptions in patient's medicine supply during this time. We are taking extra precaution to monitor our manufacturing, distributing and delivery vendors. At this point we don't anticipate any delays. If we anticipate delays our team will do everything in our power to come up with solutions to overcome the hurdles and get medication to the patients.