



April 2020

To patients with Gaucher disease and their caregivers:

In light of the recent COVID19 pandemic, many concerns have been raised regarding special management consideration in patients with Gaucher disease.

Having Gaucher disease may place an individual at higher risk for serious illness and complications should they contract COVID19. Currently, it is not known how patients will respond to the infection. Given the highly contagious nature of COVID19, we suggest that patients remain home during this time to minimize exposure to infection. In addition, all members of the patient's household should remain home or practice careful social distancing, adhering to recommendations issued by the Centers for Disease Control.

Although there are many unknown and unanswerable questions at this time, we recommend the following:

1. Patients should maintain close communication with a specialist familiar with Gaucher disease as assessment of disease status will be critical when making decisions with regards to continuation or implementation of Gaucher therapies. These will differ depending on geographical location, accessibility to infusions, and other treatment related needs. This is particularly important for patients who test positive for, or are suspected of having COVID19.
2. We recommend continuation of treatment/therapy, if possible, during this period. If treatment interruption is unavoidable, this should be discussed with the specialist managing Gaucher disease who can make management suggestions.
3. For patients on eliglustat therapy, it is important to know that drug interactions with agents currently used experimentally to treat COVID19 can interact with eliglustat. This should be discussed with his/her Gaucher disease specialist, as drug-drug interactions may be serious and/or fatal.
4. In patients with Gaucher disease infected with SARS CoV2, there are no contraindications to aggressive COVID19 management if needed, other than paying close attention to drug-drug interactions, as most patients with Gaucher disease, especially type 1 Gaucher disease, have a normal life expectancy. However, close communication with the patient's Gaucher specialist is strongly recommended due to special circumstances that may be present in a patient with Gaucher disease, such as a history of splenectomy, liver function test abnormalities, pulmonary dysfunction, altered immunity and certain hematological abnormalities/malignancies. These conditions may need special consideration when treating COVID19 and its complications. Some patients with Gaucher disease always have abnormal blood counts, liver function tests, ferritin levels and enlarged organs, so these results should not be used to make COVID19 management decisions.
5. Patients participating in clinical trials should maintain close communication with their study designated contact for further recommendations with regard to study drug changes or interactions with experimental COVID19 treatment options.
6. There may be further considerations in patients with type 2 or type 3 Gaucher disease, where interruptions to therapy should be avoided, and other complications may occur. These patients should be in close contact with their managing physicians.

If you need to be evaluated at the Emergency Department due to symptoms related to possible SARS-CoV-2 infection, please bring a copy of this letter and provide the following additional information:

1. Current Medications including dosages. Please include any supplements/herbal/over-the-counter medications):
2. Other medical diagnosis (such as hypertension, diabetes, pulmonary diagnosis, malignancies, Parkinson disease, stroke, seizures, etc.)
3. Surgical interventions and approximate year of such intervention (such as splenectomy, cardiac intervention, etc.)
4. Gaucher Disease specialist contact information
 - a. Dr. _____
 - b. Office phone:
 - c. Fax number:
 - d. Email address:
5. Clinical study contact information
 - a. Clinical study:
 - b. Study contact person: Dr. _____
 - c. Contact number:
 - d. Fax number:

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