



www.ewggd.com

ewggd2020@gmail.com

Notes from the EWGGD webinar on 1 April

Self-isolation:

Follow Ministry of Health guidelines for individual countries

Gaucher patients with co-morbidities and chronic illnesses have been advised to self-isolate

Patients with underlying lung disease or splenectomy or other high-risk factors and our GD 3 community have been advised to self-isolate completely (UK:12 weeks).

Pregnant Gaucher patients being told to self-isolate.

Gaucher treatment:

General consensus was that it was ok for patients to miss some infusions rather than visit hospitals for treatment where there was a higher risk of covid-19

In some countries home therapy has been given to those patients who usually went to hospital to protect them. In other regions, implementation of home therapy not immediately recommended because of geographic difficulties. The EWGGD believes home treatment should be strongly considered during this crisis

If a patient is on Cerdelga then they should inform clinicians before starting any new therapies to check for drug interactions. However, the safest approach is to stop Cerdelga for a short while that other treatments are necessary for covid-19 Hydroxychloroquine interferes with Eliglustat so shouldn't be taken together. One suggestion is to use MedScape's drug interaction checker

No problems are reported with supply chain if enzyme or Cerdelga.

Physicians should report any safety issues for their databases/registries

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Covid-19 disease course:

In general, admitted patients requiring ventilation have markers associated with macrophage activation.

So far, no reports of Gaucher patients with severe manifestations of covid-19

Data collection

The EWGGD board suggest capturing data relating to covid-19 in Gaucher patients in a standard way with the aim to answer two important question- are GD patients more susceptible to infection or complications?

Data will be collected locally according to local regulations but should not be shared unless there is ethical approval

- Gaucher related data
- Last lab before COVID 19
- COVID 19 related data
- Lab during COVID 19
- Situation of these patients at end of crisis: deceased, effects of loss of treatment, etc.

See enclosed documents

IGA:

IGA's aim is reach out to global community to let them know that we're here and that we are communicating with Health Care Providers who know and treat patients. It was important to communicate clear and consistent messages

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