

## COVID-19 and CDG - FAQs

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We are alert to new developments regarding COVID-19 on the World Health Organization (WHO) and in the Centers for Disease Control (CDC) websites and monitoring for any specific recommendations pertinent to the CDG population.

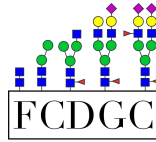
Below is a list of FAQs regarding COVID-19 and CDG. We consulted experts in our community for answers to the questions we have received over the last few days.

Please remember that some of your questions may have been already answered in the STATEMENT ABOUT COVID-19 – [www.worldcdg.org/covid-19](http://www.worldcdg.org/covid-19)

### Are there any reports of CDG patients infected with COVID-19? What were the complications?

To our knowledge, so far there are no reports of CDG patients infected with COVID-19. If you want to report/share a case of COVID-19 infection in a CDG patient, please [contact us](#).

CDG children and adults have extremely varied presentations of their CDG disease. While some patients have very mild phenotypes, others have severe phenotypes with involvement of several organs and systems (e.g. neurologic, cardiovascular, immune system, among others). Even though the binding of the new coronavirus to the host (us!) receptor needs proper glycosylation and theoretically CDG could be beneficial to prevent infection, CDG patients also frequently have an immune compromise,



therefore **we can't hypothesize that CDG patients are "not-vulnerable" to COVID-19 disease.**

Currently, there is no data pointing to whether ALL CDG patients are at higher risk of more severe disease from COVID-19. However, because most CDG patients have complex medical conditions, COVID-19 infection may trigger other clinical complications or present a more severe course in CDG patients.

You should always contact your CDG medical specialist or attending clinician about the specificities of your/the CDG patient's condition and about any specific clinical problems.

### Are children and adults with CDG more vulnerable to COVID-19 than other people?

Currently there is no evidence that CDG patients are more vulnerable to COVID-19 than other people. However, and although data is still scarce, some vulnerable ("**high risk**") populations have been identified, namely, older adults and with some medical conditions:

#### Underlying medical conditions identified by CDC that may increase the risk of serious COVID-19 for individuals of any age:

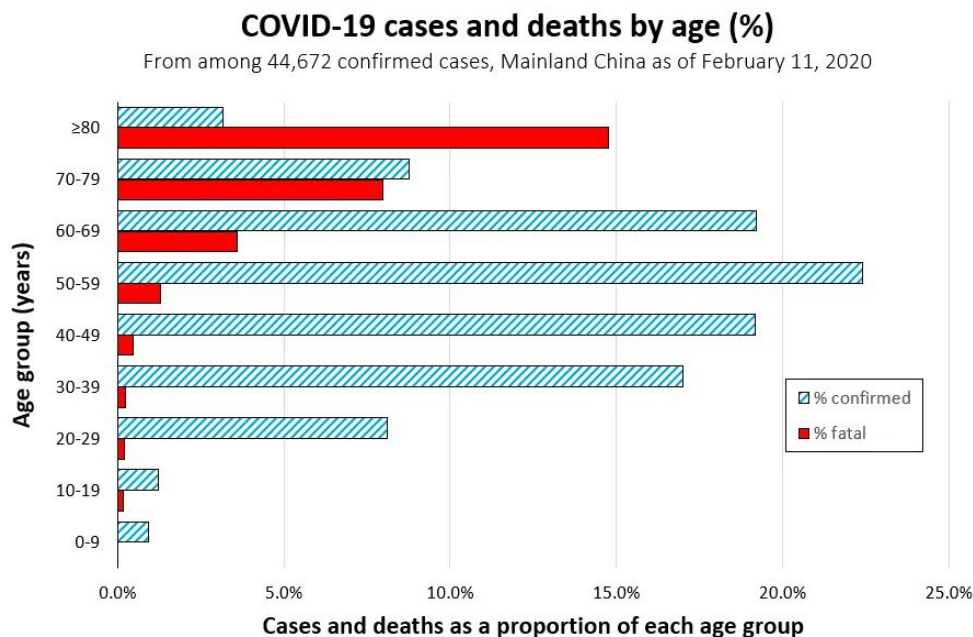
- **Blood disorders** (e.g., sickle cell disease or on blood thinners)
- **Chronic kidney disease** as defined by your doctor such that patients have been told to avoid or reduce the dose of medications because kidney disease, or is under treatment for kidney disease, including receiving dialysis
- **Chronic liver disease** as defined by your doctor (e.g., cirrhosis, chronic hepatitis), such that patients have been told to avoid or reduce the dose of medications because of liver disease or are under treatment for liver disease.
- **Compromised immune system** (immunosuppression) (e.g., seeing a doctor for cancer and treatment such as chemotherapy or radiation, received an organ or bone marrow transplant, taking high doses of corticosteroids or other immunosuppressant medications, HIV or AIDS)
- Current or recent **pregnancy** in the last two weeks
- **Endocrine disorders** (e.g., diabetes mellitus)
- **Metabolic disorders** (such as inherited metabolic disorders and mitochondrial disorders, this could also include CDG)
- **Heart disease** (such as congenital heart disease, congestive heart failure and coronary artery disease)
- **Lung disease** including asthma or chronic obstructive pulmonary disease (chronic bronchitis or emphysema) or other chronic conditions associated with impaired lung function or that require home oxygen.
- **Neurological and neurologic and neurodevelopment conditions** [including disorders of the brain, spinal cord, peripheral nerve, and muscle such as cerebral palsy, epilepsy (seizure disorders), stroke, intellectual disability, moderate to severe developmental delay, muscular dystrophy, or spinal cord injury].

<https://www.cdc.gov/coronavirus/2019-ncov/downloads/community-mitigation-strategy.pdf>

Therefore, CDG patients with any of these characteristics/conditions should take all recommended measures to prevent COVID-19 infection. Also, there might be cases where the overall clinical presentation can cause **underlying respiratory/pulmonary/lung problems**. Nevertheless, particularly in CDG, each case is different. For that reason, you should consult with your doctor about the specificities of your/the CDG patient condition for tailored advice.

### Is it true that children are not affected by COVID-19? What about CDG children?

COVID-19 can infect people of all ages with or without other medical conditions. However, in older people and people with other medical conditions (for instance, heart disease, diabetes, asthma, immunocompromised) COVID-19 can cause them to become severely ill, increasing mortality (see figure below). Therefore, all people, including CDG families, should protect themselves and their children from the virus by practicing good hand and respiratory hygiene as well as regularly cleaning/disinfecting surfaces at home. More information [HERE](#).



Data from Novel Coronavirus Pneumonia Emergency Response Epidemiology Team  
The Epidemiological Characteristics of an Outbreak of 2019 Novel Coronavirus Diseases (COVID-19) — China, 2020  
China CDC Weekly Vol.2  
Prepared by Ian M Mackay, virologydownunder.com  
Data up to: 11FEB2020  
Last update: 25FEB2020 AEST

### How does COVID-19 affect vulnerable children?

Very limited data about how COVID-19 manifests in children is available. Four children that developed pneumonia with laboratory-confirmed COVID-19, showed mild

pulmonary involvement with a focal ground-glass opacity (partial filling of the air spaces in the lungs with fluids and/or cells) or consolidation (when a region of lung tissue has filled with liquid instead of air). Reference [HERE](#).

If a CDG patient is infected with COVID-19, what measures should be taken when the first symptoms appear? What if we have to go to the emergency room?

Answer:

In case a CDG patient gets infected, you should contact your doctor and follow the instructions provided. If:

- a patient gets mildly ill, it is better to stay at home to avoid contaminating other people. In this case, you might want to have some management medical supplies at home like paracetamol for fever. Before taking any medication, consult with and follow the directives given by your physician. If the patient does not get better in 7 days, discuss next steps with your physician.
- a patient's condition is worsening (for example, if you have difficulty breathing), seek medical care right away. You should follow the recommendations of your local health authorities. Find a list of helpful links of country-specific health authorities [HERE](#). They will tell you what to do. If possible, call ahead to determine appropriate arrival procedures. Let your CDG physician know so they can help to direct care, if needed.

In case of suspicion or confirmation of infection, when should we go to the doctor/emergency?

Symptoms that may indicate COVID-19 infection are cough, fever and shortness of breath. If these symptoms are mild, it is recommended to stay at home to avoid contaminating other people.

Nevertheless, you should follow the recommendations of your local health authorities. Be sure to get care if you feel worse or you think it is an emergency.

Emergency warning signs for COVID-19 to get medical attention include:

- Difficulty breathing or shortness of breath
- Persistent pain or pressure in the chest
- New confusion or inability to arouse
- Bluish lips or face

I have a doctor's appointment scheduled, should I go to the hospital?

Most of all, you should always follow your governmental and health authorities' instructions. Nevertheless, if possible, cancel or postpone non-emergent appointments. You should discuss with your doctors the best solution for you or an alternative plan, such as therapies you can do from home.

Do not stress if your appointment has been postponed. Urgent appointments and essential examinations are being maintained. However, if your child has other clinical issues that require medical attention and may require hospital admission, do NOT delay treatment. In **EMERGENT CASES**, you need to go to the hospital. Evaluate your situation carefully and contact your attending clinician/CDG expert.

In case your CDG child starts having **serious symptoms indicative of COVID-19 you SHOULD NOT DELAY EVALUATION OR TREATMENT** and you may need to go to the hospital. BUT, before you do, PLEASE call your attending clinician/CDG Experts/your contact at the hospital (choose the best option for your case). They will advise you on what to do to minimize any risks and to make sure you receive the best care possible.

### My CDG child got a coronavirus infection before. Can he/she get it again?

There are several types of Coronavirus. After an infection with a certain type of virus, normally our body develops immunity against it, at least in the short term. However, that does not mean that we get immunized against all types of Coronavirus, but only to that specific type. Because COVID-19 is a new type of Coronavirus, nobody has immunity against it, and that is why it is infecting so many people at present.

Nevertheless, it will also depend on the immunological function of each patient and on the ability to generate specific antibodies to fight the virus.

It is also important to consider that after an infection with coronavirus or other viruses some diagnostic techniques may yield a negative result (false negative) while some other (more sensitive, like PCR) may be still positive. This is why there was a misinterpretation in some patients that were negative (false negative) but were in fact still infected.

### How scared should I be while we are an inpatient in the hospital?

**You should not be scared. You should be extra careful!**

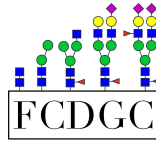
Each hospital has put in place a strategy to deal with the COVID-19 outbreak. This strategy may vary greatly from hospital to hospital. Make sure you are well aware and informed about the contingency plan adopted by your hospital. Also, keep in mind that visitors may be a potential virus carrier. So, you should adopt strict prevention and hygiene measures as well as disinfect carefully and constantly.

### How does COVID-19 affect the liver?

This virus does not affect the liver in and of itself. However, in PMM2-CDG, other viral infections have been reported to increase transaminases. Furthermore, in case of chronic liver disease.

### How does COVID-19 affect the immune system?

The new coronavirus does not inhibit the immune system. When infected, our immune system activates its mechanism to fight the virus. However, if a patient is immunocompromised and the immune system does not work well, the elimination of



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the virus is going to be more difficult and the patient might present with more severe symptoms of COVID-19.

If you/the CDG patient is on steroids/immunosuppressed, you should follow all hygiene and social distancing guidelines rigorously. Guidelines and best practice continue to be developed as this unfolds.

### Does COVID-19 affect more patients with clotting problems?

According to the CDC, patients with Blood disorders (e.g., sickle cell disease or on blood thinners) may be at higher risk of developing serious COVID-19. In the pediatric high-risk group, only patients with drepanocytosis (Sickle cell disease) are included but not with clotting problems.

### Should I avoid giving Ibuprofen to a CDG child or adult to treat fever?

According to the WHO, the Food and Drug Administration (FDA) and the European Medicines Agency (EMA), there is no evidence of any negative effects of taking Ibuprofen to treat fever during COVID-19 infection.

Note: If your doctor had previously recommended not taking Ibuprofen due to other complications (e.g. bleeding disorders), other medications are advised to manage fever. You should always consult with your doctor before changing any medication.

### Is there a vaccine or other prophylactic treatment that can prevent COVID-19 infection?

Up until now, there is not any vaccine specific for COVID-19 but several efforts are being made to develop one.

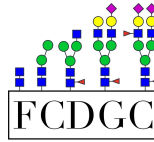
Other vaccines directed to other viruses or bacteria that infect the lungs (causing pneumonia for instance) will not protect against COVID-19 infection. However, WHO advises vaccination against respiratory illnesses to protect your/your child's health. If you have questions about which vaccines you or your child took or should take (if any), please contact your doctor.

### How is COVID-19 infection different from a flu?

Symptomatically, the two viruses are similar but the amount of people with severe and critical symptoms is higher in COVID-19 than in Influenza. It is important to remember that fever is the natural way of our body to fight against bacteria and viruses. Although fever is devastating for a patient and can be managed, it helps to fight against the virus. It is therefore a sign of normality of the immune system. One important difference between COVID-19 and Influenza is the speed of transmission from one person to another. Typically, Influenza spreads faster than COVID-19 and COVID-19 can go undetected in a person for longer. More information [HERE](#).

### What are the standard procedures to clean and disinfect the household?

General public should often clean and disinfect frequently touched surfaces (e.g. tables, doorknobs, light switches, handles, desks, toilets, faucets, sinks, among other)



with regular household cleaners and adequate disinfectants. If surfaces are dirty, they should be cleaned with soap and water prior to disinfection. Disinfectant solutions that contain more than 60% ethanol or 70% isopropanol will also inactivate the virus. To clean dirty laundry, a normal detergent can be used in the warmest temperature possible according to the specifications. Please have in mind that **you should always follow the manufacturer's instructions and precautions**. If you are caring for someone with COVID-19 in your household, stricter measures should be adopted as described [HERE](#).

### Do we know how many rare children have been affected?

We are not aware of any rare disease patient affected by COVID-19. As a case study, there are NO PATIENTS hospitalized in Hospital Sant Joan de Dèu, Barcelona, which is the greatest complexity pediatric Hospital in Spain and one of the four greatest complexity pediatric Hospital in Europe. Of the 12,000 patients with rare diseases, no one has been hospitalized to date. It is highly likely that rare disease patients, families and caregivers are particularly cautious following the directives and guidelines regarding COVID-19.

### Important Warning:

EMA is urging the public not to buy medicines from unauthorized websites and other vendors during the ongoing pandemic of COVID-19.

Vendors may claim that their products can treat or prevent COVID-19 or may appear to provide easy access to authentic medicines that are otherwise not available. Such products are likely to be falsified unauthorized medicines. These may contain the wrong or no active ingredient or the right ingredient in the wrong amount. They may also contain very harmful substances or lead to severe health problems or a worsening of your condition.

Therefore, **protect yourself from fraudulent vendors** by buying medicines from a local pharmacy or retailer or from an online pharmacy that is registered with the national competent authorities. More information [HERE](#).

### Important information sources

WHO - World Health Organization

<https://www.who.int/news-room/q-a-detail/q-a-coronaviruses>

CDC - Centers for Disease Control

<https://www.cdc.gov/coronavirus/2019-ncov/index.html>

You may also find other answers to rumors you heard about [HERE](#).