

WORLD CDG STATEMENT ON COVID-19 OUTBREAK

Document produced on 13th March 2020 (subject to updates)

WHAT DO WE KNOW?

Congenital disorders of glycosylation (CDG) are a family of **complex metabolic diseases**. Known CDG population is mostly **paediatric**. **COVID-19** is a newly identified **virus causing flu-like and respiratory infection** (and, in severe cases pneumonia) symptoms. Less frequently, gastrointestinal manifestations (e.g. diarrhoea) may occur. Although data is still scarce, some vulnerable ("**high risk**") populations have been identified, namely: **older adults**, patients with **lung, heart conditions** and/or **diabetes**.

A very recent update from the Centres for Disease Control (CDC) has stated that **NEUROLOGIC DISEASES** and **NEURODEVELOPMENTAL CONDITIONS** may have an **increased risk of having serious COVID-19 infection-related manifestations**. More information [HERE](#).

SYMPTOMS OF CORONAVIRUS (COVID-19)

Patients with COVID-19 have experienced mild to severe respiratory illness.

Symptoms can include:

If you have been in an area affected by COVID-19 or in close contact with someone with confirmed COVID-19 in the past two weeks and develop symptoms, call your doctor before going to a healthcare facility.



Symptoms may appear 2-14 days after exposure.



[CORONAVIRUS.DC.GOV](https://www.coronavirus.dc.gov)



DC **HEALTH**
GOVERNMENT OF THE DISTRICT OF COLUMBIA

GOVERNMENT OF THE DISTRICT OF COLUMBIA
MURIEL BOWSER, MAYOR

More information about COVID-19 [HERE](#).

WHAT ARE WE STILL UNSURE ABOUT?

Be aware that: 1) Since this is a new virus there is still **MUCH** that we **DO NOT KNOW**. We are learning more every day, so information contained in this recommendation may quickly become obsolete; 2) This is a **GLOBAL recommendation**. However, COVID-19 outbreak prevalence and response measures **vary across countries**.

Make sure you are well informed about your national/regional measures and situation.

To know more about COVID-19 prevalence in your country (and the world) visit [HERE](#)

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

WHAT CAN WE DO TO KEEP OUR CDG COMMUNITY SAFE?

1. Keep calm, but alert!

CDG patients/families SHOULD take extra care to prevent from getting this infection.

HOW?

First and foremost: There is still **no treatment** (or preventive measure like a vaccine) for COVID-19, so the best way to prevent illness is to avoid being exposed to this virus

a) Avoid close contact with people who are sick, and crowded places like movies, concerts, air travel, cruise travel, and the like, if possible.

b) Hygiene is your best ally! Every excuse is a good excuse to wash your hands (for at least 20 seconds). Water and soap are the best option, but you can also use alcohol-based hand sanitizer (with at least 60% alcohol). The World Health Organisation produced a short and informative video with 7 simple steps to protect yourself and those around you. Watch it [HERE](#) and share it among your contacts.

BUT, if you or a family member has flu-like symptoms, you are encouraged to reach out to your local healthcare provider ASAP and/or you may also request general advice from CDG clinical experts.

DO NOT GO TO THE HOSPITAL DIRECTLY *(only if strictly necessary)*

If available in your country, contact first your national health helpline

You should **avoid going to the hospital** because it can be a centre of transmission of infectious diseases and you risk exposure to COVID-19.

Also, in many cities, COVID-19 outbreak might:

1. Overcrowd hospitals resulting in lack of resources and equipment to fight it
2. Reduce the healthcare providers availability to treat other patients, and
3. Like previous experience with other infections, you know that your child (the CDG patient) may need to be admitted. This would put a greater strain on the hospital staff and meagre resources, preventing you from getting the best medical care possible.

With COVID-19 prevention is key, particularly if you are living with CDG!

Frequently Asked Questions (FAQs)

- Should my CDG child go to school?

If you are in an area of high prevalence you should take every precaution and adhere to local, regional and national recommendations (staying at home, teleconsultation, work from home, etc..).

Staying home from school is only beneficial if the entire family is avoiding contact with larger numbers of people, which may be difficult.

- What if I need to go the hospital?

- a) If you have a doctor's appointment scheduled and
 - a.1) You are in an **AREA OF HIGH COVID-19 INFECTION PREVALENCE**: Wait for your hospital/attending clinician to reach out to you and give you further instructions. In these areas, hospitals are already swamped.
 - a.2) You are in an **AREA OF LOW COVID-19 INFECTION PREVALENCE**: Call the hospital or your clinician **BEFOREHAND** to know if you should still go or postpone it.
- b) If you (your CDG child) starts having 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 minimise any risks and to make sure you receive the best care possible.
- c) If your child has other clinical issues that require medical attention and may require hospital admission, do NOT delay treatment. In **URGENT CASES**, you need to go to the hospital. Evaluate your situation carefully and contact your attending clinician/CDG expert.

- Should my CDG child get tested for COVID-19?

It is advised to adhere to local and national guidelines for testing. At this stage, it is not recommended to have CDG patients with no or very limited symptoms tested. Besides, some results might be "false negatives" and therefore, misleading.

- To use or to not use a mask?

Wearing masks do not effectively prevent infections, as they need to be frequently changed and adequately disposed. Also, the risk of contamination increases when adjusting a mask with your hands.



- Can I travel?

You should follow the recommendation of your local/regional authorities. Overall, it is recommended to avoid personals and work trips to minimize contacts and public crowds. If you do travel and suffer from acute respiratory illness before, during or after travel, please seek medical attention and share travel history with their health care provider as soon as possible.

- My children have questions. How should I address them?

A sense of fear, anxiety and restlessness caused by the high volume of news on media and altered family behaviour/routine can affect your children. Don't shy away from giving them some explanations (adapting to their level of understanding). Let them know why they need to be more careful and motivate them to take hygiene measures. Make these situations fun and educative!

For more tips, visit [HERE](#) (English), [HERE](#) (Spanish) and [HERE](#) (Portuguese).

Important information sources

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

CDC - Centres for Disease Control <https://www.cdc.gov/coronavirus/2019-ncov/index.html>

ENDORSED BY:

Reference Experts:

Dr. Eva Morava
Mayo Clinic, Rochester, USA

Dr. Rita Barone
University Hospital of Catania, Catania, Italy

Dr. Mercedes Serrano
Hospital Sant Joan de Dèu, Barcelona, Spain

Dr. Jaak Jaeken
University Hospitals Leuven, Leuven, Belgium

Dr David Coman
Australia

Dr. Ruqaiyah Altassan
Saudi Arabia

Dr. Laia Alsina
Hospital Sant Joan de Dèu, Barcelona, Spain

Dr Andrew Edmonson
Children's Hospital of Philadelphia, USA

Dr Christima Lam
University of Washington and Seattle Children's Hospital, USA

Dr Stephanie Grunewald
UK

Dr Erik Eklund
Skane University Hospital and Lund University, Sweden

Dr Marie-Ann Vals
Tartu University Hospital Children's Clinic, Tartu, Estonia

Dr Jolanta Sykut-Cegielska
The Institute of Mother and Child, Poland

Dr Bradley S. Miller
University of Minnesota Masonic Children's Hospital



Organisations:

Research networks

Frontiers in CDG Consortia (FCDGC)

CDG & Allies - Professionals and Patient associations International Network (CDG&Allies-PPAIN)

MetabERN – European Reference Network for Rare Metabolic Diseases

Mayo Clinic

National Institute of Children´s Diseases (*Národný Ústav Detských Chorôb*), Bratislava, Slovakia

Patient associations:

The Portuguese Association for CDG (APCDG)

CDG CARE

CDG UK

CDG Italia

CDG The Netherlands (VKS)

Asociación Española CDG (AESCDG)

Les P'tits CDG

Amour Fund