



Joint statement on the current epidemics of new Coronavirus

SARS-CoV-2 — COVID-19

From IPOPI, ESID, INGID, APSID, ARAPID, ASID, CIS, LASID, SEAPID

(Original statement, as of 2020, 13th February,

1st update, as of 2020, 11th March).

Coronavirus - what is it?

In December 2019, a cluster of pneumonia cases was reported in Wuhan, Hubei Province, China, linked to be caused by a novel coronavirus (SARS-CoV-2, leading to COVID-19 disease).¹ Coronaviruses are common in many different animal species and it is rare that they infect people and spread between them, but it happens. Recent examples include Severe Acute Respiratory Syndrome (SARS-CoV—Cov, for coronavirus), and Middle-East Respiratory Syndrome (MERS-CoV). The SARS-CoV-2 is distinct from the previous two coronaviruses and causes COVID-19 disease.²

Is COVID-19 worse than seasonal flu?

Every year the World Health Organization (WHO) estimates about 3-5 million severe cases of seasonal flu worldwide with 250,000 – 650,000 deaths. Data on the epidemiology of COVID-19 remains scarce. Coronaviruses belong to a different family of viruses than the flu viruses. Another apparent difference with seasonal flu is that COVID-19 seems to be spreading quicker than the seasonal flu. In significant outbreaks, this can lead to overwhelmed local medical care institutions and generate the emergency situation that is now reflected in the news. A better picture of the similarities and the differences between seasonal flu and COVID-19 is likely to be available in the near future.

What is the current situation regarding COVID-19?

The situation is changing all the time and we advise you to monitor for the latest advice applicable to your area.

As of 2020 11th March, close to 120,000 cases of COVID-19 have been reported worldwide (118 countries). The majority are in mainland China and in other countries in Asia, but now cases have also been reported in Europe, America and Oceania and to a lesser extent in Africa.³ Excluding China, the countries with the highest number of reported cases are Italy, Iran, South Korea, France, Spain, Germany, the United States and Japan.⁴

¹ European Centre for Disease Prevention and Control. Infection prevention and control for the care of patients with 2019-nCoV in healthcare settings. ECDC: Stockholm; 2020. Available at: <https://www.ecdc.europa.eu/sites/default/files/documents/nove-coronavirus-infection-prevention-control-patients-healthcare-settings.pdf> [Accessed 04-03-2020]

² Centers for Disease Control and Prevention. 2019 Novel Coronavirus, situation summary. 02-02-2020. Available at: <https://www.cdc.gov/coronavirus/index.html> [Accessed 11-03-2020].

³ European Centre for Disease Prevention and Control. Situation update worldwide, 11 March 2020. Available at: <https://www.ecdc.europa.eu/en/geographical-distribution-2019-ncov-cases> [Accessed 11-03-2020].

⁴ Ibid.



A comprehensive response from the public health sector, depending on the severeness of the viral disease and its spread highlights the fact that the recent COVID-19 outbreak should be taken seriously. However, it should also be contrasted with the seasonal flu that can also pose a significant threat to patients with a primary immunodeficiency (PID).

How does it spread?

The transmission mode of COVID-19 is similar to the previous coronavirus outbreaks, and seasonal flu, spreading from person to person through:

- Respiratory droplets spreading when coughing or sneezing
- Close personal contact with an infected person (shaking hands or touching)
- Touching contaminated surfaces and then touching eyes, nose or mouth with unwashed hands.⁵

Clinical symptoms due to COVID-19 infection

Human coronaviruses commonly cause mild to moderate illness in the general population. So far, the main clinical signs and symptoms reported in this outbreak include *fever, tiredness, fatigue, dry cough and running nose*. Some patients also experience *aches and pains, nasal congestion, sore throat and/or diarrhoea*. These symptoms are usually mild and begin gradually. Some people become infected but don't develop any symptoms and don't feel unwell. Approximately 80% of the affected people recover from the disease without needing special treatment.⁶

Should PID patients get systematically tested for COVID-19?

The situation is changing all the time and we advise you to monitor for the latest advice applicable to your area.

The test usually consists in a nasal swab, that is sent to a dedicated microbiology laboratory for detection of this virus (by polymerase chain reaction (PCR) method, within a few hours).

However, in light of shortage of manpower and availability of PCR, most national guidelines do not include or manage patients with chronic diseases including PID different to other patients. At this stage, it is not recommended to have PID patients with no, or very limited, symptoms tested. Furthermore, in some cases, a negative PCR does not rule out infection (“false negative”).

Hence, it is advised to adhere to local and national guidelines for testing.

⁵ The World Health Organization. Q&A on coronaviruses (COVID-19). 9 March 2020. Available at: <https://www.who.int/news-room/q-a-detail/q-a-coronaviruses> [Accessed 11-03-2020].

⁶ Ibid.



Precautions

Any respiratory virus that can be spread from person-to-person may be a risk for PID patients. Therefore, PID patients should be cautious and keep track of developments of COVID-19 in their region. Whilst immunoglobulin (Ig) replacement therapy provides protection against a wide range of infections, it does not guarantee immunity against coronavirus. The World Health Organization's (WHO)⁷ and the Centers for Disease Control and Prevention's (CDC)⁸ recommendations to reduce exposure to and transmission of COVID-19 include, but are not limited to, the list below.

- **The MOST IMPORTANT means to prevent infection are:**
 - Wash hands frequently (every hour) by using alcohol-based hand rub or soap and water (20 seconds), especially after direct contact with ill people or their environment
 - Avoid touching eyes, nose and mouth
 - Avoid close contact (1 meter) with people suffering from acute respiratory infections
 - Avoid close contact (1 meter) with anyone who has fever and cough
 - Avoid greeting people by shaking hands or kissing
- People with symptoms of acute respiratory infection should practice cough etiquette (maintain distance, cover coughs and sneezes with disposable tissues or clothing, and wash hands) and wear a respiratory mask if instructed by their local health care provider.
- If you feel unwell and experience symptoms such as fever, cough and/or difficulty breathing, seek prompt medical assistance from your health care provider

Should I wear a mask?

Masks are generally not effective for preventing infection. Most people do not have the appropriate training for a good fitting mask. Masks need to be replaced regularly and there is likely a greater risk of contaminating your face from your hands adjusting a mask than the benefit from wearing one. The exception to this is in a healthcare setting when you are given a mask, shown how to wear it and how to dispose of it appropriately.

Can my child go to school?

The situation is changing all the time and we advise you to monitor for the latest advice applicable to your area.

School attendance depends on the local epidemiological situation and the underlying PID and needs to be discussed by the PID expert physician.

Can I travel?

The situation is changing all the time and we advise you to monitor for the latest advice applicable to your area.

⁷ Ibid.

⁸ Centers for Disease Control and Prevention. Prevention & Treatment. 10-03-2020. Available at: <https://www.cdc.gov/coronavirus/2019-ncov/about/prevention-treatment.html> [Accessed 11-03-2020].



Travelers who suffer from acute respiratory illness before, during or after travel, are encouraged to seek medical attention and share travel history with their health care provider as soon as possible. Overall, it is recommended to postpone personal and professional trips as much as possible.

Is there a vaccine?

There is currently no vaccine available for COVID-19. However, updating seasonal influenza vaccination where applicable, to assist in preventing seasonal flu (a disease with similar symptoms to SARS-CoV-2), should be discussed with your PID expert.

Our recommendations for PID patients

There is currently no data pointing to whether PID patients are actually at higher risk of more severe disease from COVID-19 (as per the WHO, CDCs and PID expert healthcare professionals and NMO representatives along with patients themselves).

However, it is believed that PID patients might be at higher risk for this infection or a more severe course of the disease. Thus, patients with PID need to take extra care to prevent from getting this infection.

Patients with PID living in areas of high prevalence should take every precautions and adhere to local, regional and national recommendations (staying at home, teleconsultation, work from home, etc..).

However, for PID patients, beyond the precautions mentioned above, we advise prompt phone contact with a doctor if an infection is suspected (should it be your PID expert, or your GP who should let your PID expert know about your condition in order to provide the best advice for each PID patient's specific condition). Patients should always keep the details of their PID diagnosis and medical charts, medications, PID expert doctor and next of kin at hand, in case urgent medical care is needed.

PID patients with lung and/or heart complications, solid organ transplants' recipients, recent recipients of hematopoietic stem cell transplantation or gene therapy, PID patients undergoing treatment for a cancer (malignancy), as well as patients under immunosuppressive or immunomodulatory drugs (for autoimmune or inflammatory or autoinflammatory complicating the PID course) should remain on their specific therapy until recommended otherwise by their PID expert physician. Immunosuppressive drugs (in particular corticosteroids), might limit signs of infections (fever and other clinical symptoms). It is this recommended to contact your PID expert physician in case of unexplained change in clinical status including your well-being.

PID patients with significant respiratory issues (severe asthma, bronchiectasis or chronic respiratory failure) should receive special attention (as for any risk of respiratory infection).

Keep in mind that it is always essential to regularly continue to take the treatment for your PID.

Plasma Derived Medicinal Products (PDMPs), such as immunoglobulins (IVIG or SCIG) are safe and will protect you from many other infections.

For everyone, including PID patients, we strongly recommend you to keep aware of the latest information on the COVID-19 outbreak in your region, for example provided by [the World Health Organization](#) (WHO), [the European Centre for Disease Prevention and Control](#) (ECDC) and by your national and local public health authorities.



Plasma Derived Medicinal Products (PDMPs), including Immunoglobulins

According to a statement from Plasma Protein Therapeutics Association (PPTA) there is no risk of transmission of SARS-CoV-2 by **PDMPs**.⁹

For PID patients who are on Ig replacement therapy, there is no evidence to date that more frequent dosing of Ig will offer more protection. Whilst Ig replacement therapy provides protection against a range of infections, it does not guarantee immunity against coronavirus.

For PID patients whose condition does not require to be under regular Ig replacement therapy, there is no need to start Ig replacement therapy since no antibodies targeting COVID-19 is expected to be contained in the existing preparations.

There is no recommendation to give immunoglobulins to the general population to protect or treat people against COVID-19.

National guidelines provided by your national health authorities should be followed (the epidemiological situation and the management might differ from one country to another).

We should stress the fact that only your PID expert would know best what to recommend to you.

⁹ The Plasma Protein Therapeutics Association. New Coronavirus (SARS-CoV-2) and Plasma Protein Therapies. Updated February 17, 2020. Available at: <https://www.pptaglobal.org/media-and-information/ppta-statements/1055-2019-novel-coronavirus-2019-ncov-and-plasma-protein-therapies> [Accessed 11-03-2020].



About IPOPI

IPOPI is the leading advocate for primary immunodeficiencies' patients worldwide working in collaboration with patients, doctors, politicians, regulators, pharmaceutical industry and other relevant stakeholders. IPOPI is the Association of national PID patient organisations currently representing 68 countries. More info: www.ipopi.org, [Facebook](#), [Twitter](#)

About ESID

The European Society for Immunodeficiencies (ESID) is a non-profit organization whose main objectives are to facilitate the exchange of ideas and information among doctors, nurses, biomedical investigators, patients and their families concerned with primary immunodeficiency diseases and also to promote research on causes, mechanisms and treatment of these disorders. ESID was established as an informal group in 1983 and became a society in 1994. More information: www.esid.org, www.twitter.com/ESIDSociety

About INGID

The aims of INGID are to improve and extend the quality of nursing care of patients with primary immune deficiencies, and to increase the awareness and understanding of primary immunodeficiencies amongst nurses. More info: www.ingid.org

About APSID

The Asia Pacific Society for Immunodeficiencies (APSID) works to provide PID care, education and research for PID patients, through collaborative infrastructure and various APSID Working Parties. A group of over 60 Asian paediatricians and scientists interested in Primary Immunodeficiency met in Osaka, April 2015 and pledged to establish APSID with the following missions: To care and cure patients with primary immunodeficiency (PID), To share PID experience so as to promote collaboration & education, To improve PID management through understanding its genetics & pathogenesis and To advocate and advance the care of PID patients through engaging governments, patient organizations & industry.

About ARAPID

ARAPID is the Arab Society for PID. Its purpose is to bring together the English-speaking east region of the Arab world, closer to the French-speaking west region, to better serve PID patients from the Arab world who are united by consanguinity, etiological profile of PIDs and culture (awareness).

About ASID

The African Society for Immunodeficiency (ASID) is a PID focused scientific society. Its main objectives are to improve PID awareness and care within Africa and has been working on addressing continental African PID peculiarities. ASID strives to support African patients through collaborating with national and international patient groups and works with national societies and other relevant authorities to achieve its objectives. ASID also collaborates with international PID societies and alliances, and the industry to promote better PID care and research. Please visit website: www.asid-africa.org



About CIS

The Clinical Immunology Society (CIS) is based in the United States but has members from around the globe. The mission of CIS is to facilitate education, translational research and novel approaches to therapy in clinical immunology and to promote excellence in the care of patients with immunologic/inflammatory disorders.

About LASID

The Latin American Society for Immunodeficiencies (LASID) is a vibrant and inclusive international society. This is the home of all professionals dedicated to the field of Primary Immunodeficiencies aiming to develop and perfect the education, scientific research, and health care within this medical specialty. LASID's mission comprises the following: To increase awareness in Primary Immunodeficiency Diseases (PID) at all levels all over the continent, to develop diagnostic capabilities to reach as many as possible patients and to favor the development of centers providing appropriate treatments for PID patients.

About SEAPID

South East Asia Primary Immunodeficiency Network or "SEAPID" is a regional NGO - the South East Asian network of Primary Immunodeficiency Experts. It was established in Bangkok, Thailand on 26th January 2015, following an accord reached by experts from the six South East Asian founding countries, namely, Indonesia, Malaysia, the Philippines, Singapore, Thailand and Vietnam.

More resources:

2 short videos done by Prof. Kate Sullivan, member of the medical board of the Immune Deficiency Foundation (IDF)

<https://youtu.be/ydk-Q959RJY> (posted on 2020, March 3rd)

<https://youtu.be/3DUKPxgYaYc> (posted on 2020, March 10th)

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