

## Coronavirus Disease 2019 (COVID-19) Statement to the Community

*March 13, 2020 (updated March 26)*

IPWSO is grateful to the PWSA (USA) for permission to adapt, for an international audience, the statement on COVID-19 that PWSA (USA) had previously prepared. The Chair of the IPWSO Clinical and Scientific Advisory Committee has agreed this adapted statement. If important new information becomes available we will change or add to this statement.

IPWSO is aware that the threat of illness, such as COVID-19, is always a potential danger to those with PWS, their families and their communities. How people in different countries can reduce this threat will depend upon their individual circumstances, their financial resources, and the extent to which they have access to health advice and medical services. We advise our families across the world to be extra vigilant in their efforts to prevent the spread of viral illness especially at this time when COVID-19 is likely to be present in or will spread to all communities at some point. For information on this particularly infectious virus we advise you to only use trusted websites for information or speak to informed health professionals or access information being provided by Government Health agencies in your country. Where such advice may not be available below are links to the World Health Organization and USA Centers for Disease Control (CDC) websites where you can get the facts and answers to many of your questions.

<https://www.who.int/emergencies/diseases/novel-coronavirus-2019/advice-for-public>

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

Symptoms of a COVID-19 infection can include fever, cough, myalgia (muscle aches) and fatigue (tiredness). Some individuals with a COVID-19 infection develop shortness of breath. This is a serious progression of the disease and can lead to respiratory failure. **Such breathing difficulties are a concern and require urgent medical attention.**

Many of the symptoms of a COVID-19 infection can be similar to other viral illnesses including the flu. Testing using a mouth swab can diagnose a COVID-19 infection, but testing ability in many countries is limited at the current time. Hopefully this will improve in the near future. It should also be noted that some individuals, especially children, can be asymptomatic with a COVID-19 infection, but they can still pass the infection on to others.

Factors that can increase the risk of COVID-19 becoming a serious infection are the presence of additional conditions like high blood pressure (hypertension), diabetes mellitus, heart and blood vessel (cardio-vascular) disease, chronic respiratory infections, obesity, and being over 60 years old. Many of these are common in people with PWS.

**Additional considerations for people with PWS:** Many individuals with PWS have temperature dysregulation so they might not manifest with a fever when they have an infection. Underlying respiratory conditions are also a problem in many people with PWS. Remember: ***Breathing difficulties warrant urgent medical attention.*** A high pain threshold is something also to keep in mind when medically evaluating a person with PWS. They may not complain of pain even though they are very unwell.

It is also important to remember that persons with PWS do not always present with typical symptoms when ill, and they may be at risk for a delay in identification of illness because of this. Apparent arbitrary things, such as subtle changes in behavior or in sleeping patterns or increase in anxiety can indicate an impending illness. You should have a high level of suspicion if any symptoms that indicates a possible infection are observed.

Remember to have your Medical Alert Booklet with you when seeking medical care in any setting. The Medical Alert Booklet is available in 16 languages at this link

<https://www.ipwso.org/medical-alerts-booklet>

More medical information on PWS can be found at:

<https://www.ipwso.org/a-z-of-medical-issues> and

<https://www.pwsausa.org/medical-issues-a-z/>

## **What can you do right now?**

**Access to specialist advice and care may vary across countries. However, it is important for you to remember that there is a lot that you can do to help prevent the spread of the virus and reduce the risks if a person becomes ill.**

Avoid large gatherings of people and crowded places.

Avoid, if possible, travel on crowded public transport.

Avoid close contact with others.

Avoid non-essential travel such as airline travel.

People with a COVID-19 infection, even if asymptomatic, should self-quarantine for 14 days.

## **Practice everyday preventive actions now:**

- Remind everyone in your household of the importance of practicing everyday preventive actions that can help prevent the spread of COVID-19.

**Practice good personal health habits and plan for home-based actions:**

- Avoid close contact with people who are sick.
- Stay home when you are sick, except to get medical care.
- Cover your coughs and sneezes with a tissue.
- Clean frequently touched surfaces and objects daily (e.g., tables, countertops, light switches, doorknobs, and cabinet handles) using a regular household detergent and water.
- If surfaces are dirty, they should be cleaned using a detergent and water prior to disinfection. Always follow the manufacturer's instructions for all cleaning and disinfection products.
- Wash your hands often with soap and water for at least 20 seconds, especially after going to the bathroom; before eating; and after blowing your nose, coughing, or sneezing. If soap and water are not readily available, where possible use a hand sanitizer that contains at least 60% alcohol. Always wash your hands with soap and water if your hands are visibly dirty.