



National
PKU
Alliance

**We Thought You
Should Know**



The National PKU Alliance is aware of social media posts circulating about PKU and COVID-19. Please see the below information from **Dr. Cary O. Harding**, the Chair of our Scientific Advisory Board and Professor of Molecular and Medical Genetics and Pediatrics at Oregon and Health Science University:

Thank you for your question about COVID-19 infection and risks for patients with PKU. I do not anticipate that individuals with PKU will suffer any greater risk of being infected with COVID-19 virus than anyone else, and importantly if they do become infected, I do not think that having PKU will cause them to have any more complications or worse symptoms from the virus than anyone else who does not have PKU.



The Centers for Disease Control (CDC) has published guidance stating that individuals with inborn errors of metabolism might be at greater risk from COVID-19 than other individuals. This really would apply to those inborn errors of metabolism that are commonly life-threatening which is **not** the case for PKU.

That being said, COVID-19 is a serious disease. Everyone should obey whatever restrictions and guidelines are being recommended where they live. The most important things are to wash your hands frequently and if ill, particularly with fever, cough, vomiting, or diarrhea, isolate oneself at home and contact your primary care physician (not your PKU providers) about how to be evaluated clinically and tested for COVID-19. If you're feeling more severely ill, such as shortness of breath, then contact 911.

The most important thing to do with regards to PKU and the system disruptions that are likely to occur in the next few weeks is to make certain that you have ordered and obtained at least one month's supply of medical food or medication.

The NPKUA has also received detailed information from BioMarin, Cambrooke Therapeutics, Nutricia, and Vitaflo on their responses to COVID-19 and their plans to ensure they have adequate supply of medications and medical foods to treat PKU. In summary:

BioMarin works with a broad supplier base located in 25 countries around the world. They reviewed their supply chain and source only a small amount of raw materials from the affected outbreak areas and can source those materials elsewhere if necessary. You can contact your specialty pharmacy to see if you are able to get a 90 day supply of your medication based on your prescription and drug coverage.

Cambrooke routinely carries several months of inventory of the raw materials needed for their products and keeps several weeks of finished product on-hand at their distribution outlets in North America. They have increased production schedules and raw materials inventory to ensure they have what is needed for medical food formula and their most popular low protein food items.

Nutricia carries several months' work of products in the US. Their products are manufactured in the US, UK and the European Union. There have been no disruptions in their goods and while travel may be restricted, this does not apply to the free flow of commerce and goods.

Vitaflo plants in the US are operating as normal. They are in regular dialogue with co-manufacturers and raw material suppliers so they are in the best possible position to respond quickly. They have asked customers to continue to prescribe their products in their usual quantities.

The NPKUA will continue to update you on information as it is received from medical professionals and our industry partners as it becomes available. We are living in an unprecedented time. It is our responsibility to you, our PKU community, to give you reliable and scientifically based information during this time of uncertainty when it can be difficult to know what sources are reliable and most relevant to PKU.

We encourage members of our community to take appropriate precautions and to stay informed on COVID-19 through the [Centers for Disease Control and Prevention resource page](#).
