



This morning as I brought my 10-year-old over to the bus, I gave him the news that he'd been dreading: there were now COVID-19 cases in our home state of Maryland. He doesn't have a PI, but he knows all about [my condition](#), so he was deadly serious when he told me that he was going to lock me in the house to keep me safe.

What we're living through now is unsettling to some, and downright scary to others – especially those who are newer to our community. I know some people are hoping to be given some special instructions, but honestly? The guidelines that the CDC and others are promoting do, by and large, apply to us as well.

Fear is natural. In my son's case, he was scared for my health. But after we talked for a while, he eventually backed off of his threat to lock me away. I couldn't tell him exactly how this particular situation will unfold, but I was able to tell him that there's a lot that we do know about public health and that if we're vigilant about the basics – especially hand washing – we'll weather the storm together.

What I said to him, I'll also say to you. But since we don't get to go on car-rides together, know that the team here at IDF will keep you updated about where we are, situations that may be more problematic for those affected by PI, and what we can do to help each other.

Below is a list of resources that might be helpful. Know that as we monitor the situation, we'll continue to [provide updates](#) on the IDF website. Other resources include:

- [IDF COVID-19 update page](#)
- [IDF COVID-19 video update](#)
- [Centers for Disease Control \(CDC\)](#) resource page
- [Plasma Protein Safety Announcement](#)

Testing for COVID-19: The Fever Issue

As you may know, many individuals with a primary immunodeficiency (PI) report that they don't run a fever even when they have contracted a serious viral infection. Because fever is one of the primary criteria for determining testing for COVID-19, this is a serious concern for many in our community. Yesterday we started receiving reports from members of our community who, even though their doctors wanted it, have been denied testing because they did not have a fever that met the testing standard. This issue is one that's tailor-made for IDF and our community, so we're working behind the scenes to raise awareness of this issue and to encourage adjustments to the testing criteria. If you have a history of a fever-response that masks your clinical presentation, you may want to talk with **your medical team directly about how best to document or communicate that to others.**

Managing the influx of questions

"Ask IDF" has received a great number of questions about coronavirus, as you can imagine. While we are able to answer basic questions that affect the IDF community at large, there were questions that are specific to individual situations. We want to help, but many of the questions that we receive are ones that are so specific to an individual's diagnosis, clinical presentation, or personal situation that they are outside of the areas where we can provide guidance. As with any healthcare issue, neither IDF nor the Internet at large is going to provide you with the answers that you need. You should always **address these questions with your physician first.**

How you can help

- If you have a question about general concerns as a member of the IDF community, continue to utilize [Ask IDF](#) when you need an answer to a question.
- If you have an experience that you want/need to share that our team needs to know about, please email stories@primaryimmune.org. It's the best way for us to monitor what's happening in other locations.
- If you have a specific question related to your unique circumstance, contact your physician directly.
- **You are the best possible advocate and educator – for yourself, for your family, and for the PI community. Continue to share [information about IDF and PI](#) with those you know.**

One last thought

Those of us affected by PI are used to risk-management. We're used to thinking about germ surfaces and how to navigate people around us who might be sick. Now? Others are getting a taste for what our lives are often like. Eventually, the threat of COVID-19 will pass, and they'll want to default to their less-concerned state. Let's not let that happen. Let's use this as an opportunity to keep pathogen transmission on everyone's mind. To help them to remember how scary it can be to feel vulnerable when a virus is going around. And to maybe make some lasting changes, such as trying other greetings instead of germ handshakes.



Live Long and Prosper.

John G. Boyle, President & CEO