



## COVID-19: Focus on Aplastic Anemia and PNH

# Frequently Asked Questions

*(transcribed from the AAMDSIF webinar on March 20, 2020 with Dr. Carlos De Castro at Duke University Medical Center, edited for clarity and brevity)*

**Q: Are aplastic anemia and PNH patients more susceptible to COVID-19?**

A: We don't have direct answers because there's just not enough data out there yet. Everyone is susceptible because we don't have any immunity to this virus. There's nothing in PNH to suggest that patients would be more susceptible to the infection. For aplastic anemia and MDS and even a few PNH patients who might be on cyclosporine, which does suppress the T-cells, there could be the theoretical concern that they may be more susceptible, but there's no data to prove that right now.

**Q: If PNH patients get COVID-19, what's going to happen to us?**

A: The big issue with coronavirus (not proven with COVID-19, but highly likely) is that it probably will activate complement. When we had the SARS virus, there was a lot of scientific evidence that the complement was activated, especially in the lungs. For a PNH patient who contracts COVID-19, there is a high likelihood that they could overwhelm whatever complement-inhibitor they are on and see a flare in hemolysis. If that happens, the patient should reach out to their treating hematologist/oncologist to get another dose of whatever inhibitor they are using.

**Q: Is there any evidence that any of the current PNH treatments (Soliris, Ultomiris) could help with the infection?**

A: We don't know for sure but if you're on a complement-inhibitor, there's some evidence that theoretically it may help. There is one clinical trial looking at this now.

**Q: Should we be concerned about the drug supply?**

A: The manufacturer (Alexion) has issued a statement that they are committed to getting the drugs to patients. We hope there will be no drop in supply but we'll have to see.

**Q: Is it safe for aplastic anemia and PNH patients to enjoy outdoor activities such as golf?**

A: As far as we know, I don't think there's going to be any issues with playing golf alone. You have to be careful with whom you associate so golf, hiking or running alone should be fine.

**Q: Are there higher risks (including complications from COVID-19) for PNH patients over 70 who are taking Ultomiris that would require transfusions?**

A: The greater risk for elder patients is just their age. There is nothing from being on Ultomiris or having PNH that would lead to a greater risk for problems if they get COVID-19. If they have comorbidities (other chronic health conditions), those would be a factor. The only reason a PNH patient (on Ultomiris) would need a blood transfusion is if the virus activates complement and overwhelms the Ultomiris. The patient would start hemolyzing and would then need a transfusion.

**Q: If a patient has classic PNH including extreme vascular hemolysis and takes 15mg Prednisone daily, does this increase their risk of getting COVID-19?**

A: Theoretically yes, but there isn't any evidence that any of the large number of people who take Prednisone are at higher risk. Prednisone does suppress the immune system so it could happen.

**Q: If a pediatric patient has been taking Cyclosporine for the last six years, should their parent take them to the ER if they begin to show symptoms of COVID-19? Should he continue to take his medication?**

A: If the patient starts to show symptoms, they should call their treating hematologist/oncologist to find out where they can be screened. We are not recommending that patients go to the ER because they are getting overwhelmed and it's a risky environment for our patients.

**Q: Does taking Prednisone make you more susceptible to COVID-19?**

A: Prednisone is a little bit of an immunosuppressant so theoretically it could but we haven't seen any data to suggest this yet.

**Q: Are you aware of any research efforts that patients could participate in related to COVID-19?**

A: There are all sorts of trials going on, looking at hydroxychloroquine and an anti-retroviral that was developed for Ebola. (You can find more about clinical trials at [www.clinicaltrials.gov](http://www.clinicaltrials.gov).)

**Q: If a patient were to become infected with COVID-19, would there be a reason to ask for an emergency introduction of one of the other complement therapies to be added to the patient's current treatment regime?**

A: If the patient's disease is well controlled, they should just continue doing that unless the virus overwhelms the treatment and hemolysis begins. They wouldn't necessarily need to switch or add on a new treatment, but work with their treating hematologist/oncologist to adjust dosing and schedules.

**Q: If a patient is doing well on Soliris, would this be a good time to switch to Ultomiris to reduce the frequencies of infusions?**

A: Sure, it would be great to not have to travel to the infusion center so often. This is a difficult question to answer for specific patients so please speak to your treating hematologist/oncologist.

**Q: How long after recovery from aplastic anemia is a patient less susceptible to contracting the virus?**

A: I don't think we know the answer to that one. Even if you had aplastic anemia or if you're still on Cyclosporine, you're still a little susceptible, but there's no data that if you are on no immune suppressants that you'd have anything different than anybody else.

**Q: If a PNH patient is forced to miss an Ultomiris treatment, what could be the potential repercussions?**

A: If you miss a treatment, you could start hemolyzing again as the level of the drug in your system falls lower and lower. What we found with Soliris (Eculizumab) but we don't know for sure yet with Ultomiris, is that missing one dose usually does not cause serious hemolyzing again - it comes on slow. Patients notice some fatigue. It's not recommended, of course. Some patients can go right back on the treatment but others need to start over with a loading dose.

**Q: In addition to the question regarding susceptibility for patients who are taking Cyclosporine, are there any additional concerns with patients who are taking blood thinners for PNH?**

A: No, not that I'm aware of. Not in terms of COVID-19.

**Q: How long should aplastic anemia and PNH patients and family members isolate from the public?**

A: The less contact you have with others, the better. We don't know how long this virus is going to last for, so try to reduce your risk as much as possible.

**Q: Should aplastic anemia and PNH patients wear masks? If so, what kind?**

A: Any kind of mask is good but the best kind are N95. Right now those are in short supply and are needed by healthcare workers.

**Q: If a PNH patient had a coronavirus a few years ago, are they immune to this one?**

A: We don't think there's cross immunity. This is a novel virus - a whole new type of coronavirus.

**Q: Is a patient taking APL2 (a treatment for PNH in clinical trials) at higher risk for COVID-19?**

A: No. Their risk is the same as everybody else. There is maybe an inflammatory inhibiting effect for the lungs but that's not yet proven.

**Q: A PNH patient with ongoing immunosuppressant treatment after a full response to ATG with regular blood counts - are they more susceptible than non-immunocompromised people?**

A: We don't know for sure. If you are still on Cyclosporine, your T-cells are suppressed a little bit and those T-cells are part of your anti-viral immunity system. There's no data yet.

**Q: Should PNH patients follow the regular guidelines for going to the ER in the event of a fever?**

A: The guidelines are going to have to change. Speak to your treating hematologist/oncologist first.

**Q: Does Cyclosporine provide any protection against COVID-19? There's some evidence that it helped for the SARS and MERS outbreaks.**

A: It certainly is possible. The response in the lungs is acute respiratory distress syndrome and anything that can dampen down the immune system may help but we just don't know that.

**Q: Is it safe for patients to receive medications through the mail?**

A: There is some evidence that the virus can live for 24 hours on the package surface so you could put the package somewhere for a day and then it would be safe to open.

**Q: Should patients take ibuprofen?**

A: If you are on blood thinners (common for PNH patients), you should avoid NSAIDs. There is a lot of controversy on this and we just don't know for sure right now.

**Q: If a PNH patient on Soliris or Ultomiris screens positive for COVID-19, what should be communicated to their healthcare team?**

A: The patient should follow the quarantine protocol, assuming they are not hospitalized. They should make sure their treating hematologist/oncologist is aware. If the patient needs to be hospitalized due to the severity of the infection, the patient may begin hemolyzing and the patient may need an additional dose of their medication.

**Q: Should an aplastic anemia or PNH patient take Cyclosporine or another antiviral medication? Will it have any effect on COVID-19?**

A: We don't know what antivirals are going to work on COVID-19 right now. It is unlikely that any of them will work but everything is being looked at.

**Q: If a patient contracts COVID-19, other than hemolysis, what other complications might a PNH patient experience?**

A: We don't think there's going to be anything that would affect patient recovery other than hemolysis.

**Q: Will a PNH patient see an increased clone size if they contract COVID-19?**

A: No. It shouldn't affect clone size at all.

**Q: Would it be beneficial for a PNH patient taking Ultomiris to have a factor D inhibitor added to their regimen or is it too early to tell?**

A: Way too early to tell, unfortunately.

**Q: Are there any anti-inflammatory medications that are recommended for PNH patients on Soliris?**

A: Any of them are fine unless you're on a blood thinner or have renal dysfunction.

**Q: Does kissing your partner put you at higher risk for contracting COVID-19?**

A: Only if your partner has COVID-19.

**Q: Should patients take their temperature every day as part of self-screening?**

A: I don't know if you need to take it daily. If you get a fever, most people know it's a fever and take their temperature then.

**Q: If a PNH patient is on penicillin, does this help reduce their risk of contracting COVID-19?**

A: No. This is a virus that has nothing to do with penicillin.

**Q: If an aplastic anemia patient has been through ATG/Cyclosporine successfully, are they at higher risk than a normal person?**

A: Cyclosporine can put people at a slightly higher risk but it also could be helpful if a patient gets COVID-19 and it might protect the lungs.

**Q: A pediatric (now young adult) patient with classic PNH has never required medication, however when they got the swine flu, it created serious hemolysis and they were in the ICU for several days. The patient has 60% PNH clones but have avoided going on treatment due to lack of symptoms. Are they at higher risk for COVID-19?**

A: They have the same risk of getting the virus as anyone but they also have the same chance of getting a big hemolytic response as previously.

**Q: If an aplastic anemia patient gets the pneumonia shot and then gets COVID-19, would that help prevent an acute inflammatory response?**

A: The pneumonia shot prevents bacterial pneumonia and doesn't have anything to do with COVID-19.

**Q: If a patient was treated with Campath (chemotherapy) in 2004 for aplastic anemia and has normal ANC but their lymphocytes are very low, is six feet of social distancing enough?**

A: They should be much more conservative.

**Q: If a grandparent has a bone marrow failure disease, how should families handle socializing? They want to keep everyone safe but they also want the grandchildren to see their family.**

A: Unfortunately, there's no magic pill to keep everyone safe so right now, you have to try and keep away, wash your hands a lot and practice social distancing.

**Q: If college students are returning home because campuses are closed, how do families with an aplastic anemia or PNH patient in the home treat the returning student?**

A: We recommend that the student self-quarantine for 14 days.

**Q: If patients need to travel for work, are there any recommendations for them?**

A: Not right now, although there are going to be travel restrictions for everyone.

**Q: A stable PNH patient with a very low clone and not on treatment is wondering if they should just go ahead and start treatment now or if they get the virus, just treat those symptoms?**

A: Treat the virus symptoms if they get COVID-19.

**Q: If a severe aplastic anemia patient has a very low white cell count, how do they distinguish between COVID-19 and other respiratory symptoms?**

A: Part of the screening for COVID-19 includes ruling out all of the other virus and bacterial infections. It would be incredibly rare to have the flu and COVID-19 at the same time.

**Q: If a PNH patient had a bone marrow transplant (BMT) two years ago, are they at additional risk for contracting COVID-19?**

A: Two years out is probably not a huge increased risk.