

Guidance for Bone Marrow Failure Patients to Protect Against Coronavirus (COVID-19)

Frequently Asked Questions

*(Transcribed from the AAMDSIF webinar on March 13, 2020
with Dr. Mikkel Sekeres and Dr. Isabel Schuermeyer with the Cleveland Clinic,
edited for clarity and brevity)*

Summary FAQ from Expert Presentation

Q: What is the fatality rate of COVID-19? How many people are going to die?

A: This is a bit of a moving target because we don't know how many people have it in the world. Our best estimate so far is that probably close to one percent of people who get the virus will die. This is far more likely in susceptible populations. To put it in context, if about one percent of people who get the COVID-19 virus die, about .1% of people who get the flu die.

Q: What is the impact of COVID-19 on bone marrow failure patients who are getting active treatment? What should they do?

A: If you have a scheduled treatment, don't skip that treatment. You still need to get treated for your bone marrow condition. If it's an every six month follow-up or every three month follow-up, call your doctor's office and see if the appointment is really necessary or if it can be rescheduled until the active infection cycle has passed. Your medical center may allow you to participate in a virtual visit from your home.

Q: What about medications?

A: Make sure that you have a three month supply of your medication available, and possibly arrange mail order delivery of your medications.

Q: How can I manage stress and anxiety during the pandemic?

A: Human beings like certainty: we like knowing what's going on, we like knowing what's coming up next. We don't like feeling out of control so we can control how we respond to uncertainty and how we choose to handle it. One of the big myths is that we control our feelings. We don't control our feelings. Our amygdala controls our feelings, that's that fear center again in our brain. We do control how we respond to our feelings. We also control our health behaviors. It's critically important not letting people who have any symptoms of the COVID-19 infection or really any cold getting close to you. You can also reduce anxiety by doing things that will help make you feel a sense of safety, whether it's having a specific type of hand sanitizer in your car or purse or using a particular kind of soap. Another really

important way to cope with this is to go outdoors. Not saying you need to go out into a crowded area, in fact the opposite, we don't want people going into crowded areas.

Q: What about going outside?

A: A lot of times people when they start feeling anxious and stressed, they will self-quarantine and not want to go outside, and we know that going outside is critically important for your brain biochemistry, and overall for your health. So just go outside in nature, even it's just going out to your front porch or your balcony or whatever. The other thing is pick up a book, stay away from watching the news. The news is pretty scary and I've encouraged people to not focus on it as much.

Q: What else can we do to manage the stress?

A: Stay connected with your family and friends, virtually. Reach out to your health care team because they have resources available for you.

Questions from Webinar Participants

Q: What criteria should be used for determining who to test?

A: It is not consistent across the country. If you have a fever, and a cough and a sore throat and you've ruled out flu, allergies and colds, you should contact your health care team. Some centers have a helpline or an online screening process to use – it varies by community.

Q: What would be the most important thing for patients to let health care professionals know if they're not familiar with MDS regarding watch and wait if they were to contract COVID-19?

A: Sometimes we have to be the educators to folks who aren't used to treating patients with bone marrow failure disease. You should tell them that you have MDS or aplastic anemia or PNH and that your blood counts are always going to be very low and that your immune system does not function well. You should tell them that you are in a high risk group, even if you don't look like it.

Q: Is it known which blood cells will attack viruses in general and is this the same for the coronavirus?

A: Neutrophils are the subtypes of white blood cells that attack bacterial infections. The lymphocytes are the ones that attack viral infections, but they all work together. So to simply answer your question is it's the lymphocytes, the more complicated answer to your question is that all of our white blood cell elements work as a team to fight all sorts of infections.

Q: Will a daily dose of Prednisone make a patient higher risk since it's an immunosuppressant or lower it because it controls complement in those with extravascular hemolysis?

A: Prednisone is complicated. Prednisone suppresses the immune system. So that means you're more prone to infections like with the coronavirus. What it also can do is suppress symptoms that a person makes or may indicate an infection. It may suppress cough, it may suppress fever. So it's important to let people know that you're on a steroid like Prednisone because your symptoms won't be typical of other people's symptoms. The second aspect of that question talking about people who get really sick from coronavirus have a release of chemicals in their body called cytokines that may make the situation worse and may lead to some of the interstitial pneumonias you may have heard about that lands people in intensive care unit. So paradoxically, things like steroids maybe used to treat more serious infections to try to tamp down inflammation in some of those cytokines.

Q: Our next question is regarding kids coming home on spring break, flying to visit their parents, the question is should these students self-quarantine or just keep their distance from those who may be compromised and the other part was this person daughter is also coming to visit and uses that New York City subway, what is the best advice on how to handle this situation?

A: We don't really know the answer to this. In our own home, we're dealing with this and so we're trying to be sensible and self-quarantine. All you can do is your best, practice good hygiene and talk to your health care team.

Q: What are the initial symptoms of the virus? What would a case present like on the initial days of symptoms? Is it possible to have the virus without a fever?

A: Anything is possible. So the most common symptoms are fever, sore throat, and cough, but as I mentioned the virus can be transmitted without any symptoms at all for about five days. The one thing that doesn't seem to be as associated with it is all the kind of stuffy nose, sneezing, runny nose that we associate with a lot of other viruses. Doesn't mean it can't get that, it's just less common. So your suspicion for the coronavirus should be higher in the setting of fever, cough and sore throat.

Q: Do you have any recommendations for any type of special cleaning of fruits, vegetables, and other un-packaged foods from the grocery store?

A: Normal washing protocol for fruits and vegetables – a good rule here is the same 20 second minimum for hand washing.

Q: Are there any special precautions for PNH patients who are being treated with complement inhibitors being that they are more susceptible to infection or meningococcal disease?

A: There is nothing special for PNH patients vs other bone marrow failure disease. Practice social isolation, thorough cleaning of all surfaces, frequent hand washing and so forth. There are no special medicines that you can take to prevent this from infecting others.

Q: Should patients be wearing a mask if they plan to go out and they're going to be in groups of people?

A: The N95 mask is what healthcare professionals should be wearing to protect themselves while delivering healthcare. The flimsy masks you can buy at the pharmacy or online do not prevent transmission of the virus but they can help to keep the wearer from aerosolizing cough and cold germs.

Q: Is there a difference between the susceptibility for the coronavirus different between patients with bone marrow failure and those who do not have bone marrow failure?

A: Bone marrow failure patients are more susceptible to infections in general, however this has not been studied enough. We are focused so much on elders and people with compromised immune systems is that if they catch the virus, it can be much more serious because you don't have the defenses to get rid of it.

Q: Our father is 70, high risk MDS, and is due to start a course of EPO injections, are there any additional considerations that need to be given with the virus?

A: No more special considerations than trying to prevent getting infected with the virus. Ask how urgent it is to get started on treatment. If someone has higher risk MDS, it might be urgent to get that under control where someone with low risk MDS could wait for four weeks.

Q: This person had a transplant a few years ago and has normal blood values, would we still consider ourselves high risk or just take precautions as a healthy adult?

A: I would think transplant, even though you're out of the real danger period for when you're under super duper precautions, the first 100 days, the first six months, the first year post-transplant, I would still consider you high risk. I don't know enough about your personal situation to know if you have graft versus host disease or if you're still on some degree on MDS suppressants. So I would err on the side of caution, consider yourself high risk.

Q: Is it true women are more asymptomatic?

A: I hadn't heard that one. I have heard that kids are much less likely to get it.

Q: What treatment is available and would this just be for severe cases? And how would this impact bone marrow failure patients?

A: There are some treatments that are being tried, one of which is actually a protease inhibitor it's a drug that's used for HIV. Remember HIV is a virus just like this is a virus. It's been used in China, I've heard anecdotally some reports of successes, but it's really being reserved for people who are in intensive care units and on breathing machines. So the sickest of the sick.

Q: Are there contingency plans in place for treatments like Soliris and Ultomiris or other treatments for patients?

A: If you need to get a treatment, get a treatment. Facilities, if you are dependent on treatments to control your bone marrow disorder, then you should be getting your treatments. But that's more important than avoiding public place like a hospital.

Q: Is there a different risk for MDS, high risk versus low risk?

A: High risk tends in general to have a more comprised immune function than low risk, so I would think that it would be slightly higher risk, but I've seen low risk folks who have impaired immune function. I've seen high risk folks who have preserved immune function. So it kind of depends.

Q: Can the coronavirus be transmitted through a blood transfusion?

A: I don't know the answer to that. I heard no, but I don't have enough data... I want to answer you truthfully and I don't know have enough data to support that.

Update from AAMDSIF: *Please refer to this published statement from the Red Cross regarding the safety of the blood supply:* <https://www.redcross.org/about-us/news-and-events/press-release/2020/red-cross-media-statement-on-2019-novel-coronavirus.html>

Q: My husband is having a bone marrow transplant in the next few weeks. We are concerned about moving forward with the transplant. Do you have any suggestions on how to proceed and what types of questions we should ask before making the decision to move forward?

A: Check in with your transplant center and ask what they're doing about this virus and if they're screening patients beforehand. Many people can't wait for a bone marrow transplant. You have something that is severely compromising your bone marrow function, this represents a potential chance of cure, you've been waiting months to get to this point to finally get to the transplant and then this virus hits. So I think some transplants centers are formally testing people before they go through with the transplant, others are assessing your symptoms and if you don't have the symptoms, they're giving you the go ahead for transplant.

Q: If you are diagnosed with the coronavirus once, is it possible to get it again?

A: Just like any other virus, viruses can change over time. This is a pandemic and if the virus circles around the world and comes back, if it's the same virus, you should have immunity to it. If it's altered, you may not have as much immunity to it. With this virus, we don't have herd immunity like with the flu – a lot of people have had the flu before, they've had flu vaccines before so not everybody can pass it along.

Q: Would it be helpful in any way for patients to receive a pneumonia shot?

A: Yes, if you're due for one.

Q: Do you have any suggestions for patients who may be having difficulty trying to explain to family members or friends their concern about attending family functions or doing things normally? Is there a best way for patients to try to explain their in heightened fear right now of becoming affected by the virus?

A: I tell folks is to just be kind of upfront about it and say listen, I'm really concerned about my health. And this can be a really critically important time for me to keep my health my priority. And so I'm going to be limiting what I do and the situations that I'm in.

Q: Is there any change in patient protocol for when patients should be concerned about a fever?

A: There really isn't. If you have a fever and you have a bone marrow condition, you should be contacting your doctor's office and asking somebody whether or not your immune system is compromised enough that you need to go to the hospital and get antibiotics immediately. That's true at any time.

Q: Is there any danger of running out of blood supplies?

A: There is a danger of a shortage.

UPDATE FROM AAMDSIF: Please refer to this briefing from the Red Cross on the national blood shortage: <https://www.redcrossblood.org/local-homepage/news/article/critical-blood-shortage-3A-red-cross-urges-blood-and-platelet-donors-to-give-now-1.html>

Q: Do we know if this will follow influenza and have different strings annually?

A: We don't know yet.

Q: Could you please explain the relationship between lymphocytes and neutrophils relative to the virus?

A: Lymphocytes are predominately the subtypes of white blood cells that are responsible for fighting viral infections, neutrophils are more responsible for fighting bacterial infections. One special aspect of lymphocytes is that they can have memory. They're actually called memory T-cells, memory B-cells and those are the ones that when you're exposed to a vaccine remember what that vaccine looks like. So if you actually get an infection with something like measles, they get rid of it real fast.

Q: Are children less likely to be affected by the virus? And if so, does that mean that they are not carriers either?

A: Children are as likely to get infected with the virus, but not as likely to get sick with the virus. So they are carriers just like they're carriers of everything that makes us sick.

Q: There is a current clinical trial for PNH patients with Soliris. How does the pandemic affect current PNH patients?

A: Check with your local medical center to see how this is impacting clinical trial operations.

Q: Do we know if blood supplies are now being checked for the virus?

A: I don't know the answer to that. It's a great question.

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Q: Are labs taking the same precautions such as hospitals and what is the recommendation for that?

A: They should be, they should be practicing universal precautions. They should have some hand sanitizer that's available for you to use. The folks who are approaching you shouldn't be sick. They should be using sterile technique for drawing blood, so I say should, should, should, and hopefully they are at each one of these centers.

Q: Do you have any advice for newly diagnosed patients who maybe have not started treatment yet for MDS? Would it be safe for them to start treatment?

A: It depends on the treatment you're getting. If you have a lower risk myelodysplastic syndrome and you're starting treatment with an erythropoiesis-stimulating agent like Procrit or Aranesp, go ahead and start the treatment. This isn't going to affect it at all. If on the other hand, you're starting a treatment that may lower your white blood cell count, then I would check with your doctor about how important it is that you start that therapy right now as opposed to waiting a month or two.

Q: Most patients watch their white blood cell levels, how low should white blood levels be before patients start to self-quarantine?

A: We define Neutropenia as an immune system that's pretty significantly compromised with a neutrophil count less than 500. That's generally the point at which we start to think about putting patients on prophylactic antibiotics and ask them to start to initiate broader precautions. In this coronavirus era, all of us should be doing those same precautions. So I wouldn't look to a specific white blood count. Once the coronavirus threat has lessened, I don't think it's ever going to completely go away then we usually use a neutrophil count of about 500, but listen if your neutrophil count is 560, treat yourself to going on the same precautions, it's close enough.

Q: Do we know if the coronavirus can cause sepsis?

A: The coronavirus can infect the lungs and can cause a cytokine release that looks for all the worlds like sepsis. So I don't know if technically you would call that sepsis or gee it just looks a heck of a lot like sepsis, but it can get really serious.

Q: Are there any extra supplement that patients can use to boost their immune system?

A: No. That's a hard no.

Q: Are support groups helpful for patients during this time? Are there any other resources for connecting with patients for support?

A: I do think support groups can be helpful. Although, I would suggest that they be done virtually.

Q: Are there any specific instructions for patients if they feel they need to be tested, if they're going to their hospital, should they call ahead? Are there any those type of particulars that would be recommended for patients who think they'd been infected in going to be tested?

A: Some hospitals have identified specific areas where people who think they may have coronavirus should go to get tested so that they're separated out from the rest of the patient population who's there. Call ahead, see if there's a specific place that patients should go. Some hospitals are even doing mobile or drive-thru testing areas that may be more convenient for you.

Q: If a patient wants to get a second opinion about their bone marrow failure disease diagnosis in April and they are stable, should they reschedule?

A: Yes. Wait an extra month or two and see where things settle out.

Q: Would a wider use of GCSF be useful for MDS patients?

A: GCSF is a shot that increases the white blood cells in particular even neutrophils. There have not been large studies of this drug or its longer acting form (Neulasta) in MDS patients and therefore most of us don't recommend it for treatment of low immune systems in MDS.

Q: How long does the virus live on surfaces?

A: That's hotly debated right now. The initial reports came out and said it's up to eight hours and now there are people saying it depends on the surface and it could even be days. It's a moving target, I haven't seen something that's conclusive about that yet, but I've seen these huge ranges.

Q: What about patients who need or want to travel? What precautions should they take?

A: The bottom line is if you can avoid it, avoid it. But sometimes we can't avoid it. And if you can't avoid it and you have to go onto a plane I would bring some disinfectant wipes with me. I would touch nothing. I would wipe down everything I'm going to come in contact with on that plane. I would see if I can be seated in an area of the plane where there aren't a lot of other people and a lot of these planes these days are emptier than they usually are. That's all you can do. You can only do so much. And hopefully it will be okay.

Q: For an MDS patient who also has COPD, with the coronavirus, would there be a difference in the hit to the lung system?

A: Yeah. I think the answer to that is yes. And it's not that you're necessarily more susceptible to catching it, but if you get it, it can be much more serious.