



## COVID-19: Focus on High Risk MDS and Secondary AML

# Webinar Summary

*(transcribed from the AAMDSIF webinar on March 31, 2020 with Dr. Gail Roboz with New York Presbyterian Hospital, edited for clarity and brevity)*

**Q: What do we know about COVID-19 now that we may not have known previously?**

A: There are really no parts of the world that are being spared from COVID-19. It's highly infectious and it's transmitted through coughs and sneezes. It's transmitted through droplets and the virus is not sparing any one group of people – it's affecting young and old, healthy and ill patients alike. Information about the virus continues to change over time – things that we thought a few weeks ago are not true today and will be wrong next month. Things are changing rapidly and that there are enormous regional differences. This is a great example of why we need personalized medicine!

**Q: What's the most important thing you can tell patients about COVID-19?**

A: Stay home. Stay home. Stay home. Try really, really hard not to go out, especially if you are already a patient or a caregiver. You have to assume that anyone you run into outside of your home already has the virus.

**Q: What else can we do to avoid contracting COVID-19?**

A: Try really hard to stop touching your face. Wash your hands frequently with warm, soapy water for at least 20 seconds. Try to get yourself hand sanitizer and use it often. If you have to go out to a medical appointment or you're an essential worker, don't touch doorknobs or elevator buttons. Use your elbow or your knee and then keep your hands away from your face until you can thoroughly wash them. Cover your mouth with a tissue or handkerchief if you cough or sneeze and then wash your hands after coughing or sneezing.

**Q: Should we wear masks?**

A: Guidance on this is evolving and is based on availability as well as science. Most people are wearing masks incorrectly or around their necks (instead of over their mouths) and that doesn't do any good. You probably should wear a mask if only to keep you from touching your face and spreading around germs. Generally available masks don't protect you from COVID-19 but you're a little bit protected and it can also protect others from you coughing or sneezing on them.

**Q: What about interactions with colleagues, neighbors and family members?**

A: Avoid close contact with anyone if you can avoid it. Avoid people who are sick and discourage anyone from visiting you at home. Social isolation means that you don't go out to dinner or hang out with people. There are folks who are asymptomatic carries of COVID-19 and so you need to maintain that distance to protect yourself. Avoid gatherings of people if at all possible. Remember that this varies by parts of the country and my advice is coming from fighting this virus in New York City – we're just a few weeks behind Italy. I hope it doesn't happen in your community but it might. I hope some of you will be spared from seeing a lot of this but don't count on it.

**Q: What practices should I use when cleaning my home?**

A: Clean frequently touched objects with household cleaning or wipes including tables, doorknobs, light switches, handles, toilets, faucets, laptops, keyboards and cell phones. Leave the doors open inside your house so you don't have to keep touching doorknobs.

**Q: Can I travel?**

A: Travel is to be avoided. Many of us are under full travel bans. Depending on where you live and how you get places, you may be able to drive your car from home to the doctor's office or to the grocery store. In larger areas like Manhattan, we use public transit and they are begging people not to use it. That said, crossing state lines or getting on airplanes to go somewhere is to be avoided. Some states are limiting if people can leave/enter the state. So if at all possible, don't travel.

**Q: What else should we avoid?**

A: Elevator buttons, door handles, touch screens, handrails and flat surfaces in public areas. In some places, stores are still open and in others, almost everything is shut down so it depends. You should talk to your physician about making any necessary trips away from home during these times.

**Q: If I think I have a (mild case) of COVID-19 as a bone marrow failure disease patient, should I get tested?**

A: Testing is still challenging because you can't just go out and get it in some parts of the country. If you are feeling sick and have a cough, a cold, the most important thing isn't to run out and try to get a test – you should stay home and isolate and try not to cough on anyone. There may be specific reasons why someone should get tested and many hospitals can do rapid testing, it's best to stay home if your symptoms are mild.

**Q: What if I really think I need to be tested or at least seen by a doctor? Should I just go in?**

A: No. If your symptoms are mild, depending on where you live, you should call your doctor's office and schedule a telemedicine or phone/video appointment. That way, you stay safely at home and don't expose yourself and others.

**Q: I have a regular appointment coming up with my treating hematologist/oncologist. Should I keep it?**

A: Check with your doctor's office. They may have different protocols for your appointments, they may be doing only telemedicine or phone/video appointments or they may not be seeing patients. Reach out and talk to someone at the office before you go to your regular appointment. If you are a critically ill patient who needs close monitoring and/or treatment, you're going to want to have a good phone conversation with your health team because you have some very careful decisions to make about upcoming appointments, treatments and hospitalizations. For patients undergoing chemotherapy, you may get an immediate test for COVID-19 and there are new protocols for this, depending on individual circumstances. We know that this is really hard on patients and for those who are hospitalized, you are going to be quite alone – no visitors. We are thinking very carefully about hospitalizing patients because it makes a stressful situation even harder, especially over prolonged periods.

For those patients where we don't have a choice, we're using FaceTime and other technology to try and bring families into rooms as much as possible.

**Q: Should I follow a neutropenic diet right now?**

A: In general, most patients (even with acute leukemia) are not specifically on neutropenic diets. That said, if you are neutropenic, you should avoid raw foods and unwashed vegetables. You have to be very careful with things that are unpasteurized. You don't want to risk getting hospitalized right now so be mindful of what you're eating. If you're following a diet that works for you, stick with it.

**Q: How should I handle getting prescriptions refilled?**

A: If you can, try to get three months supply of medications through a mail order or delivery service. Handle your delivery carefully and wipe down everything in a plastic bottle with a Clorox wipe and be sure to wash your hands carefully after opening up any packages. Be prepared to self-quarantine for 14 days. You will want to talk to your own physician but if you are symptomatic, we need to keep you away from others and if we have to get you into the office, you need to let everyone know that you may have COVID-19.

**Q: Where should we look for information about COVID-19?**

A: The CDC website is a good resource and we also recommend the FDA and NIH websites. You can also check the AAMDSIF website for links to these resources.

**Q: Does taking Revlimid as an MDS patient affect the COVID-19 virus?**

A: Revlimid has immune system modulating properties and our current recommendation for patients who are on treatments like Revlimid, if you're stable with good blood counts, don't make a change to your treatment. We don't have any specific information that there

would be a higher chance of infection or having complications. If you stop taking a medication that's working for you, that has potential risks. The last thing we want during this dangerous situation is for you to have an increase in transfusion requirements which would require you to go into the office more often. There are also potential shortages of blood and platelets so if you're on therapy and it's going well, stay on it.

**Q: If a patient with MDS were diagnosed with COVID-19, what is most important to share with a medical team unfamiliar with MDS?**

A: Right now, we're broadly cautious about patients with underlying health conditions and COVID-19 but most medical teams may not know what MDS is and no one knows what happens when an MDS patient has COVID-19. Tell them that MDS is a bone marrow failure problem and about your own blood counts – explain if you run low neutrophils or low hemoglobin or low platelets or all three. That said, it's not clear if the underlying diagnosis (in this case, MDS) is going to change what they do related to COVID-19. ERs have protocols in place for what to do with oxygenation levels, breathing issues, high fevers – there are algorithms about whether to admit or not to admit to hospital and different hospitals have different protocols. They need to know what medications you're on given that many hospitals are treating with hydroxychloroquine and there could be a potential interaction with MDS medications. If you get COVID-19 and are not hospitalized, you'll want to talk with your MDS doctor every day or every other day by video or phone, just to see how you're doing – how your symptoms are evolving if they are mild.

**Q: If a patient is in complete remission from AML and they require monthly labs for monitoring, should they continue to get blood draws or should they hold for a bit and wait it out?**

A: If the patient's previous blood tests were looking absolutely perfect and the patient is tolerating the treatment regime well and there's a track record of good lab tests over time, I would be willing to recommend skipping a regular blood draw. That said, it's really important to discuss this individually with the treating physician because it varies based on where you are in the country. In some places, you can still go in for lab work safely or use an alternative lab that isn't part of a hospital (so you won't have as high of an exposure risk) but in other places like New York, it's just better to wait it out.

**Q: Can the COVID-19 virus be transmitted through a blood transfusion?**

A: We believe not. This is being actively investigated but we believe that we have safe blood, platelet and blood product transfusions however things can change in a few weeks. As the testing and monitoring of the virus becomes more advanced, we may find that we can detect it more easily but for right now, we believe not. That said, now is a good time to reevaluate where patients are with transfusion frequency and the threshold when you go in for a transfusion. For example, you might normally get a transfusion at 7.5 but during the COVID-19 pandemic, you might wait another week and see what happens. This is an

individual decision between a patient and their doctor because there is no magic number for every patient.

**Q: Are patients with MDS or related conditions more likely to contract COVID-19?**

A: We don't officially know the answer to that question because testing (especially in the US) has been challenging. We don't really know yet how many people have COVID-19 much less how many people with MDS have COVID-19 who are feeling fine (asymptomatic). We believe though, that cancer patients in general (including MDS and AML) have a higher likelihood of getting COVID-19 and of getting complications if infected. All I can tell you is that from the front lines of this in NYC, we have seen some weird situations – from the patient who we wouldn't have thought would have any significant symptoms who does and the patient who we thought would be hospitalized with serious problems who isn't. COVID-19 isn't behaving in a manner that's predictable so operate under the assumption that there's a risk and do all of the things possible to protect yourself.

**Q: Can COVID-19 be transmitted by ways other than saliva and mucus?**

A: At the moment, it looks like saliva and droplet transmission through coughs and sneezes are the primary way of transmission. We think transmission through other bodily fluids is very, very limited but testing has not been completed. We don't think it can be transmitted through urine or fecal matter.

People are understandably concerned about surfaces including cardboard and plastic. It looks like the virus can hang out on these surfaces but we don't think this is the major way of transmission. We are still wiping everything down a lot but you can go too far. You should be worried enough to be careful with your behavior but don't scrub the skin off your hands so they are bleeding and you have cuts. That's not going to help.

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

A: This is a really important question, especially for neutropenic patients. In general, we are worried about COVID-19 no matter what. If you are running a fever, you are going to be talking to your doctor anyway. If you are neutropenic and running a fever, neutropenic fevers have to be evaluated, especially in patients with hematologic malignancies and we don't want to delay but your evaluation in the ER is going to be different than usual because you'll be assessed for COVID-19 too. So if you have a neutropenic fever and you don't feel too badly (no shaking, no chills), call your doctor and they can evaluate you over the phone. They may send you to their office but if it's a bad fever, they might want you to go to the ER.

**Q: Would a wider use of GCSF be useful at this time for MDS patients?**

A: In general, a broad application of GCSF is not being advised. (GCSF growth factors are designed to improve white blood cell counts.) We have no idea if it's going to mitigate risk for infection or complications. For patients who are undergoing therapy for MDS and AML, we

have been a little bit quicker to use growth factors and if we think we can get a 48 – 72 hour jump on bringing up very low WBC count, we think about it. Keep in mind though, that just because you get a GCSF injection doesn't mean your neutrophils will go up in 5 seconds. For most patients, you're shortening the neutropenia by 48 – 72 hours and if the leukemia is under control and your bone marrow is recovering, adding GCSF will only improve things by a day or two at the most.

For MDS patients, it can be tricky because we can get a boost in neutrophils with drugs like GCSF but then you go all the way back down again, two days later. If you're hospitalized with neutropenic fever and being assessed for COVID-19, then yes, we are thinking about GCSF because a few days might matter there.

**Q: Do you have any recommendations on special cleaning of fruits and vegetables and other unpackaged foods from the grocery store? Are there safety recommendations for when you're bringing in these items from the grocery store?**

A: This is a difficult area because it's very tough to put together data that makes sense. What we're trying to recommend is that if you are having things delivered is to get them out of their containers, dump the food out into another dish and get rid of the original container. Many of us are opening things outside the door, trying not to bring the delivery bags into the house or wiping down containers (like peanut butter jars) when you bring it inside. After you've brought everything in, wash your hands very carefully and then wash your fresh produce but you don't need to use bleach and accidentally poison yourself! Some people are opting only for fruits and vegetables that can be peeled.

We have to be very clear that we don't know if this works – it's just what we're doing to try our very best in a rapidly changing situation.

**Q: If a patient were to come down with a fever, okay, should they be taking ibuprofen or is Tylenol recommended?**

A: There are concerns about using ibuprofen in the COVID-19 setting but they are difficult to sort out because we don't have any type of control data. We do know that patients with COVID-19 on NSAIDs are doing worse. It's sufficiently concerning from anecdotal reports that we are not recommending drugs like ibuprofen, Advil, Aleve, NSAIDs for fever control. We are recommending Tylenol.

**Q: If an MDS patient were to contract COVID-19, would it change the progression of the disease?**

A: We do not know that.

**Q: Do you know if there are currently any clinical trials looking into potential treatments for COVID-19?**

A: Great question. Absolutely yes. (Clinical trials in the United States are listed at [www.clinicaltrials.gov](http://www.clinicaltrials.gov) and the listings are searchable.) This is a bittersweet time for those of us who run clinical trials for MDS and AML. As someone who runs 15 – 20 MDS and AML trials at once, it's been difficult to shut down clinical trial enrollment. A lot of centers have had to shut down or significantly slow down enrollment because we are so overrun with COVID-19 patients. The good news is that our clinical trial centers have fantastic data, regulatory and nursing staff – clinical trial management is complex and we're working tirelessly to get COVID-19 trials up and running.

**Q: If a High Risk MDS patient is planning to go to transplant, what should they consider in moving forward?**

A: There are going to be different answers depending on where you are. Transplant centers across the world are in constant communication with one another and what we know is that all of the ICUs, infectious disease doctors, pulmonary specialists and other supportive specialists who are critical for getting patients through transplant are very occupied with COVID-19 patients at the moment. Many transplants are being delayed because we need to get you through the procedure safely and that the backup we need is 100% available.

However, there are some situations where people might proceed depending on the COVID-19 situation, the availability of supportive services and everything else. This has to be a conversation with the treating physician and the transplant team. If you really, really have to get a transplant done in the next month, I have concern that the underlying disease is so severe that the transplant might not be curative. A short-term delay of a few weeks or months can be temporarily treated with a small number of doses of a hypomethylating agent or something to keep you in remission.

You need to have a serious conversation with your doctor about the process of transplant including the isolation from family and the post-transplant monitoring and the potential post-transplant complications. You would have to be in and out of the center frequently which would increase exposure risk to COVID-19. So if there's any chance of delaying, that may be a good idea.

**Q: What is the latest information on higher temperature (weather) in battling the virus?**

A: While I think we all would love for the weather to just get warm and for everything to go away and that it was being hoped for a while that the warmer weather would have an effect on the virus, warmer parts of the world are getting the virus and patients are still getting infected. There are some concerns that in the fall it could surge again and we could have a second peak. We are hoping to be much more ready for a second wave.

**Q: If patients have an outside cleaning company that comes into the home, is there anything that patients can do to make sure that the cleaning company staff is safe or should they suspend cleaning services until the crisis is over?**

A: It's really hard especially for some patients who are frail and need the help. Cleaning is really hard, doing laundry is hard and there might be circumstances where it's just not feasible to cancel. If you can't cancel, I would try to have the cleaning staff stay as far away as possible from the patient and make sure that they have a mask and gloves to wear while in the home.

**Q: If I have more questions about COVID-19 and bone marrow failure disease?**

A: You do have resources. You can reach out to AAMDSIF, you can reach out to your doctor, your cancer center, to my own hospital (New York Presbyterian). We are trying really, really hard to keep every patient as safe as possible. You need to keep hope and optimism but you also have to have some fear and caution. Take this seriously, be worried enough to take precautions and we'll get you through this.