

- Opening: Introduction Robert Sandhaus (pulmonologist at National Jewish Health) and Dr. Francis Glorieux (Chair of the OIF's Medical Advisory Council). Oi Staff Micheal Steward, Tracy Heart CEO OI Foundation.

Tracy : Hi everybody, thanks Michael. Thanks for getting us started and thanks for all of you for being here. I see all these familiar faces. This is a challenging time for all of us. During this time it is very important to share information, we share the best information that we have. And the OI Foundation is committed to doing that. Today we bring you two experts who will be talking to you about what we know right now about COVID-19. How it may affect people with OI, especially from a pulmonary/respiratory perspective, but also just in general: information that we know right now. With that I'm pleased to introduce to you two presenters today. Both look familiar to you. First: Dr. Francis Glorieux (Chair of the OIF's Medical Advisory Council) and Robert Sandhaus (pulmonologist at National Jewish Health). We're so pleased that they're here.

Glorieux: Thank you very much, Tracy. Hello to everyone. I understand very well that the "hello's" go well beyond the borders of North America. So we're very happy to be with you today. We are indeed going through trying times. Some people say that we are in a war. Just to put things in perspective. I'm old enough to remember the second WW, where people were told: "Today you have to go to war and take a gun to defend your land." That was not easy. Today we are in a war, but we are being said: "Stay home, on your sofa and look at what's going on." So, the situation is better int terms of perspective, but it is still a very trying time.

I don't have to explain the condition to you, you live with it. You live with OI in different levels. It is not easy everyday. The thing to remember in this perspective is that the major defect in your DNA, if you will, is linked to a molecule, which is colagen, which is present in bone and make all the problems that you know about bone brittleness and deformities. That molecule is also present in the lung, in it's integral part of the lung tissue itself. Any abnormality in that area affect also the lung tissue and it's possibility to fulfill it's function. That is why we have to consider that lung is a target of this mutation, and is an organ that we have to consider important in that perspective. That is what I wanted to say. I also wanted to say thank you to England from OIFE because

they're been working on preparing this as well in the usual very efficient way. The person who will be able to answer most of your questions is Dr Sandhaus, because he is a specialist of lung function and would be able to answer your questions, regarding this function and how it is affected, possible in the context of the COVID-19 infection. I will stay along for other questions if necessary.

Sandhaus: Thank you very much Francis and Tracy and Michael. I'll be referring to guidelines that we have in the US, that might be different than the guidelines that you have in your particular countries or localities. Please listen to what is local. What is local is often best. Just want to show a few slides. Primarily because there's a lot of words on them (insert). Francis addressed why we want to talk about this in OI populations over and above the general public and I will talk about that.  
— look at slides —

Please remember with all of the 10's of thousands of people who got infected, the total number of infected individuals who've died is a small fraction of those who were infected. We don't know the exact numbers of those who are infected, because here in the US the test for COVID-19 is still very much restricted. We expect that if there is universal availability of COVID-19 testing that we find 100 of thousands infected and that would make the death rate become much smaller. Having said that I don't want to diminish the risks should someone get infected and if there are ways to prevent infection, like the preventions that are taken it would be silly not to try to prevent getting infected. Even if you're a young individual, even if you don't have pulmonary symptoms, related to OI or other conditions. That's all I have in the way of the slides..

I think the most important thing at this point is to answer questions that have come forward. I do want to acknowledge the psychological impact of all the information that's pouring from TV screens, radio, news papers at all of us and the changes it's affected in our lives, workplace. The growing economic impact of this infection weighs on individuals greatly. It's really important to take a break sometimes from news channels, news papers. Try not to concentrate on it. Enjoy your time with family that you might have not had if you had to work. I'm doing that, because I'm a high risk group. In fact doctor Glorieux and I are both in the high risk group of being an 'elderly'. Tough to acknowledge that, but happy to be spending time with my wife at home, which is what I've been doing. And only going in if I have to see a patient as

flown in to see me at National Jewish. I reassure you that I'm not working in the ICU, but there is an amazing dedication going on with the high risk individuals, with the ICU doctors. In my institution the ICU doctors are doing 24 hour a day, 7 day shifts and then they get 14 days of to self-isolate at home to find out if they've been infected. If they have rested for a few days they come back and do 7 24 hour shifts again. They are asking retired doctors to come back to work and stuff like that. I know this has an affect on everyone who is listening to this tele-conference.

Tracy: Thank you very very much. Michael, will you be bringing in the questions?

Glorieux: Just a practical thing before I forget: something I do because I'm older. Take your temperature every morning. It's a very easy thing to do. Your temperature should be below 37.5 Celsius or 99.5 Fahrenheit. I do that after breakfast. If that is the case I'm comfortable that everything is ok. That is just a little thing that we have to add to our day to day activities to keep us as comfortable as possible.

Sandhaus: I second that!

Questions (read out by Micheal):

Q: What effects have been seen or affected for people with OI and are there other added difficulties treating COVID-19 with people with OI, compared to that of other people ?

A (Sandhaus): The first part of the question: As far as I know, I turn to Tracy to know if you'll be doing any tracking or will be doing tracking that have OI. The number of patients who've been identified, because of the restrictions on testing (in the US, at least) has been relatively low compared to the number we think are out there with infection. In most rare diseases there is not an effort at this point to find out if there are specific concerns or heightened infectivity for instance in people who have one of these rare diseases, like OI. In other words, we don't know - we assume that people with OI and other rare diseases aren't more likely to get infected, but we do think that they, if infected, they're more likely to get severe disease if their rare disease includes lung issues. And so that was the point of my last slide.

The second part of the question: the final treatment step that happens in patients that get severe disease is that they wind up on a respirator

or a ventilator. A tube in their lungs with a machine breathing for them. And that is always a risky proposition in people that have fragile ribs, fragile bones, things like that. So it's really important that should you were a relative find themselves in the ICU, that the physicians are aware of OI and the complications of OI and take special steps to reduce the pressures that a ventilator uses. Things along those lines. I'd be happy to speak to any physician that is caring for someone who is seriously ill with OI, just to review those things with them. Because I'm certain that there are many intensive care doctors who have never managed patients with OI.

Michael: I'll just put down our organization email. It's [bonelink@oif.org](mailto:bonelink@oif.org). If you want to contact us so that you can contact Dr, Sandhaus, please do.

Q: Can someone with a cold use an incentive spirometer or any spirometer?

A (Sandhaus): There's no reason to not use an incentive spirometer. I'm not sure what they mean by any spirometer. The term spirometer usually means a test to measure your lung function. An incentive spirometer is to help your respiratory muscles and your breathing capacity. There is no reason not to use an incentive spirometer unless it is an incentive spirometer you're sharing with other people, in which case I definitely would not use it.

Many pulmonary function labs have closed down in facilities that are seeing a lot of COVID-19 patients, because they found patients who were identified as having COVID-19 days or weeks after they had a lung function test at the facility. Our pulmonary function lab at Jewish National Hospital has closed down because of that.

Q: My daughter has OI and she's pregnant. What should she look out for?

A (Sandhaus): There have been people with COVID-19 who have been pregnant. Nr 1, the literature that is out there, and it's actually surprising how much is coming out from the experiences around the world. The information that is out there suggests that mothers with COVID-19 do not pass the infection on to their fetuses. They are not being born with COVID-19 and it is not a factor of their pregnancy beyond the effect of having either a complication from COVID-19 or respiratory issues from COVID-19. So there is no special issue as far as we know right now

regarding pregnancy. Except you's certainly think that pregnant woman should take extra special precautions, just as general OI patients should.

Q: If I didn't take a vaccin for the flu yet, should I risk going out again?

(32.00) A (Sandhaus): This is part of a series of questions I'm sure we're getting and always come up in these conversations. It's the risk-benefit analysis of going to get treatment. For instance often with '... '? inefficiency patients that I follow, which is another genetic condition get weekly infusions of their missing protein at infusion centers and the questions I get about that are: "should I skip my infusions, so that I'm not exposed to all the people who are at the hospitals or infusion centers I go to?" Really it is a tough question to answer. People need to weigh those decisions themselves. It is quite important to get a flu shot still if you haven't gotten one. Flu is still a much larger killer in the general population then COVID-19 is. Even in countries that have already been through major spikes in their COVID-19 infections like China and South-Korea. So getting the flu shot is important. I know that there are some pharmacies that will do that in a drive by setting in the US , where you just drive up, stick your arm out of the car and get your flu shot. I would think that in that situation that the benefit would out way the risk. Similarly with immunizations against pneumonia. Those things are all important to have right now, because the pneumonia that the pneumonia shot protects you against is the kind of pneumonia that can complicate a viral pneumonia. So, the answer to the question is: if you could find a way with minimum risk it would be a good idea to get those immunizations if you haven't had them yet..

Q: What about the kids? They say kids are less affected. Is an OI kid also less at risk? Should we maintain isolation? Right now we're home, but what about when is it time to go back to work?

A (Sandhaus): The two things about kids are: there is probably a higher rate of mild symptoms in kids and your adults than in older people, but it is not a guarantee that you would be outside of the complications of COVID-19 just by being young. The other thing is that kids who aren't demonstrating symptoms could well be infected. As you know, even adults who get infected are often asymptomatic for as long as two weeks before symptoms start and during that time can infect others. So I know that in our area even kids who don't have intrinsic lung disease, such as an the kind an OI individual, that kids are can being kept from

going on play dates, going on playgrounds and seeing their usual friends. This is a hard thing for kids and for parents who have cabin fever children in their homes. But still: kids can not only become infected, they can become a reservoir for other kids and adults.

Q: Recommendations for those in healthcare please? I'm type 4, moderate. 4-1, chest deformity. I'm a registered nurse, but not bedside in an office in hospital with a handful of other nurses. The hospital has yet any confirmed cases, but has several PUI's (Patient Under Investigation).

A (Sandhaus): PUI is a patient who is under investigation that has symptoms that can be consistent with COVID-19, but does not have the test results back, or cannot have a test. Just to clarify what was being asked.

Every healthcare provider that goes to work, whether they have OI or not, is making a risk-benefit assessment, because they are putting themselves at risk. As a type 4 OI individual the likelihood is that should you get infection, it will be more likely to have pulmonary complications than if you didn't have type 4 OI. So your decision making is your own. The first sign is that there is a growing case of individuals in your community who are testing positive that it would be reasonable to consider stepping back from your work or finding another job at the location where you work that doesn't have patient contact where you don't have direct contact. These things can often be impossible to arrange, but I think that you wouldn't be able to help anyone if you become ill and wind up being sick - sicker than your comrades in the healthcare setting you're working in.

Q: If we get infected with COVID-19 and fully recover, is our lung function forever diminished?

A: Well, the infection itself will not necessarily affect your lung function, once you've recovered. What I was probably not clear enough about: when I was talking about the persistent lung impairment: that was in patients in the ICU on ventilators, who developed what's called ARDS (Acute Respiratory Distress Syndrome), where fluid floods into lungs and it becomes very difficult to exchange oxygen in the lung tissue. If you simply have an infection and get a flu like illness some flu and get a fever, a cough, some increased shortness of breath and then it goes away it's not likely that it will affect your lung function at all once you've recovered.

Q: I was diagnosed with asthma. I assume that I should be self-isolating? And what about spouses? Should we be isolated from them if they continue to work outside of the home? I have severe asthma with other respiratory issues as well. Should I self-isolate? I'm 21.

A (Sandhaus): Some of it depends on how affective your asthma treatment is. If your asthma treatment normalizes your lung function then it's likely that you don't have any greater risks. One of the things that COVID-19 infection does especially when the infections/symptoms become severe is it causes a dramatic increase of inflammation in the airways. That can kick up someone's asthma. A simple COVID-19 infection without symptoms should not be a problem, related to your asthma. The sicker that you get with COVID-19, the more it can exacerbate your asthma and make it worse. If a physician knows about your asthma, they would probably intensify your asthma treatment. The tough questions about your spouse working and the general public and coming back: You and your spouse would have to decide on that. That is a decision that almost everyone in the country is making right now. If people are lucky enough to continue working, that's just something they have to decide. It is tough to live in a house with someone and be isolated from them, in reality. It may be that you simply make sure that your spouse makes sure that they are doing everything they can to avoid infection and even consider finding ways to work where they're not exposed to the general public for the benefit of your health.

Q: There's been a recent study about to be published about the virus being airborne. How can you protect yourself from that.

A (Sandhaus): There are very specific terms for how things are transmitted. The virus is not airborne, the virus is droplet borne. That makes a big difference. Airborne transmission can travel for miles. Droplet borne transmission only travels from 3 to 4 feet, which is why the recommendation is to keep at least 6 feet. The social distancing recommendation says to keep 6 feet from someone. Now, if a droplet lands on a surface, it can survive on that surface depending on what the surface is made of, from hours to a couple of days, which is why we are recommending disinfecting those surfaces that might have been coughed on or sneezed on. The droplet borne infections are very effectively prevented with the social distancing as well as with N95 masks. Ideally, when masks become readily available, it would be worthwhile considering wearing a mask when you're outside your

home, because they do work to prevent droplet borne transmission. The only reason that people are not recommending that now is because of the shortage of the masks and the decision that the current supplies would be used in the healthcare setting first, before people start using them outside of that setting. Presuming that there would be a big influx of mask production and that masks would be more readily available I would recommend people who are at risk would, like people with OI wear masks when outside their home.

Q: Regarding temperature: I normally have a higher body temperature. Does this impact that?

A(Sandhaus): It does impact it in the sense that you're not more susceptible to infection, but in terms of the impact of regarding recommendation s regarding taking your temperature: yes and no. Most people who have a higher resting body temperature should get different thermometers. Definitely, you're looking for a change in your baseline in your body temperature. You can add 1.5 degrees or 1 degree higher in Fahrenheit to your baseline body temperature to identify when you should be concerned. In that sense, yes.. You probably have to correct for that when looking for recommendations of when to be concerned. In our city, we're not asking people to come and get tested until their temperature reaches 100degrees Fahrenheit. That's partly because most people who have infection that's symptomatic have temperatures above 100/104. One of the things related to asthma or other underlying illnesses such as COPD is that the 3 things that are asked when you're doing a verbal screening for the likelihood that someone is infected is they ask: do you have a fever, do you increased shortness breath or do you have increased cough? Any patient that has chronic lung disease know that there are many times that when they're coming to visitation, because they have increased cough and shortness of breath, so a lot of patients who have frequent exacerbations are being told to keep finding to decide when you need to report to the medical setting is when they have a high temperature. High temperature is uncommon in exacerbations of asthma or exacerbations of COPD. Even though you should be concerned if your temperature starts to rise, true COVID-19 infection gives you pretty high fevers. It is not something subtle.

Q: Would it be safe to go to public parks. Staying in the house 24/7 is stressful, especially when having recovered from recent fractures.

A (Sandhaus): It's recommended to people who are in self-isolation to go outside to catch some sunshine, get some exercise, stretch your legs, get out from the house. You just have to avoid going to places where you're exposed to many other people. If you're going to the park, don't go to the playground: where you sit on a swing and you hold the chain or something like that that someone else has touched ten minutes before you did. Just take a nice walk to a beautiful location if you've got one near you. It will help everyday!

Q: I've heard that we should NOT be taking anti-inflammatory medications. Please verify.

A (Sandhaus): This is based on an anecdotal report from the French literature, in which they found that people who had more severe lung problems had a higher incidence of having taken non-steroidal anti-inflammatory medication like ibuprofen. There's a problem with that. People who are sicker are probably more likely to have taken anti-inflammatory medication. They probably had higher fevers, they probably took extra to get the fever down. People have told me that non-steroidal don't do a very good job of lowering the fever in COVID-19. It could be a self fulfilling story that people who were getting sicker take non- and therefore they are sicker so they wind up in the hospital and the ICU. The current recommendations that we're hearing both from local authorities and federal authorities who are asked this question is: don't take beyond the recommended dosages of non-steroidal. Take them to reduce your fever. There are a lot of aches and pains that are associated with COVID-19 infection. Take them if you need them, minimize the dose you take and never take more than the recommended dose.

Q: If we can maintain the social distancing standards, is it safe to swim? Or can the COVID-19 spread in a body of water?

A (Sandhaus): It is true that we know that chlorine, disinfectants are highly effective at killing the virus that causes COVID-19. I would think if you have a well regulated pool that uses chlorine stabilization of bacterial load in the pools that you could consider that. I have to say this is off the top of my head, based on knowing that chlorine and bleach are good at killing the virus. I have to say I've not seen any recommendations on that. I would think that swimming in the ocean is not an issue, with the changes that come with each wave.

Q:What is the identifier of recovery? The absence of symptoms? A negative test? Or both? Is it true that if someone tests positive, they will tests negative after recovery? What's your (?) on recovery? Is there any chance that you still could be contagious?

A (Sandhaus): The recommendations in the US vary from location to location. You do stop shedding the virus when your symptoms go away after you've had a COVID-19 infection. For instance: the recommendations at my institutions for when you're allowed to go back to work for if you've had a COVID-19 infection is that you have to be symptom free if you've had symptoms for a week and then you have to have two negative COVID-19 tests that are at least 24 hours apart. I know that in New York they require three tests that are negative that are at least 24 hours apart. I do want to get into the weeds a little: the COVID-19 testing that is currently done looks for the viral DNA. To say someone is negative means that they not only virus they don't have any viral DNA. You can be positive a week after all your symptoms are gone but have no active viral particles, because you're not measuring whether someone has an active infectious virus. We are measuring whether there is any DNA left that's from the virus in the back of your throat or in the back of the nose. The testing for those of you who don't know is a swab of nose or throat, looking for this DNA. It's a very strict rule. It also means that when people recover, they don't have virus anymore. The big question is: can someone get infected again after they've recovered from COVID-19? The exact answer is still not known entirely, but it appears that if you've recovered from COVID-19 you can not me re-infected by that version of the COVID-19 virus. On the other hand: the expectation is that the virus causing the virus will mutate over the months ahead. So it is possible that people get re-infected if the virus mutates enough that the immunity you've built up is not effective.

Glorieux: No, I heard the same as you. There is no evidence and it remains an open question.

Q: There's a severe blood shortage. I usually give blood. Should I risk going to do this?

A (Sandhaus): I think that you should call the donation centre and talk about the precautions that they're taking. I know that for most blood donation centers they are doing dramatic disinfecting protocols of the clean donors. One thing that is important to know is that there is absolutely no evidence that COVID-19 virus could be transmitted by

infusions or plasma products. For instance IVIG infusions. There is no evidence that plasma products derived from blood can transmit the virus. There is actually shortage of blood and they are recommending people to go. You should assess yourself the steps the blood bank is taking to protect the donors. I fully expect most of them are doing well. I have to say I have been disappointed by stories I collect from around the country about healthcare workers who've been blasé about doing the protective measures. I don't think that will happen in the blood bank, but certainly home nursing. I've had home nurses going to patients homes and act like they don't have to do any of the things that are recommended, because after all they're healthcare nurses and this isn't a big deal. They've dealt with viruses before. Now, these things stand out. It is certainly not the general practice of most healthcare professionals, but you really need to be the ones that evaluate what's being done to keep you safe when you are in a healthcare situation or a situation where you're donating blood.

Q: If you have and never had any lung issues are you still at higher risk than the general population? Are all OI patients considered high risk, even people with mild OI?

A (Sandhaus): I want to emphasize that all our warnings to OI patients are only based on our clinical opinions. We mask it by saying they are expert opinions, but really no-one is an expert yet on the lung issues in OI. Our opinions basically say that we know that there's deranged collagen in the lung of OI patients, we know that OI patients have abnormal lung function, even those with type 1 OI and we know that respiratory problems are the main killers of OI patient in general. Not just in times of viral infection. Putting those things together we are presuming that OI patients are likely to have an increased risk of things that focus on the lungs as COVID-19 does. A given individual, whose lung function test is normal and has never had a problem with their lungs in their life, can I say if that person is of increased risk? I can't. But discretion is the better part of valor. You probably want to at least consider that (protective measures).

The possibility that even healthy OI patients, healthy in terms of their lungs, could be at small increased risk compared to the general population.

Q: Would it help if people wear scarves or masks or bandanas over their nose when going outside? Can you confirm if facemasks are one time use?

A (Sandhaus): First of all, we're in an awkward situation, because the CDC is now recommending to healthcare workers wear scarves and bandanas if there aren't any face masks available. There is absolutely no evidence that scarves and bandanas are effective at preventing droplet transmitting diseases. Maybe some of those droplets will land on a strand of wool in a scarf and not get into your mouth. It would probably reduce a fraction of the risk, but not have the same type of beneficial effects like a surgical mask, or even better: an N95 mask will have.

In the setting of a plethora of availability of masks, it is always wise to wear them once and discard them. If you're wearing it to protect yourself, once you've been exposed to people who might have droplets the entire outside of the mask is presumably teeming with droplets that contain COVID-19 virus that have been stopped from being inhaled by you, so you'd prefer not to after use putting them on again. You certainly don't want to touch the front of the mask when you're taking it off. In times like this when masks are in short supply, the fact is the masks remain affective for several days of use before they get entirely saturated and they have a higher risk of not being effective in blocking those droplets. Remember, the mask is not preventing the viruses of being inhaled, it prevents the droplets that are containing the viruses from getting to your mucus membranes.

Q: Are there any other symptoms that we can be alert for, other than a high temperature, that we should be alert for that could indicate that we've contracted the virus?

A (Sandhaus): There are a couple of other symptoms that have become prominent when we talk about patients we've seen in the doctor's offices. Those include diarrhea and body aches and pains. There are some patients that have prominent GI symptoms, like diarrhea. It's not everyone, it's not the most prominent symptom, but it can happen. On the other hand, aches and pains like a flu-like illness are more common with diarrhea, but still not seen in everyone. There have been a fair number of people, since we often do respiratory viral screening in addition to the COVID-19 testing when we do the swabs, we have found people who have both influenza and COVID-19. So sometimes it's hard to separate the symptoms that are due to flu versus COVID-19.

Q: If you suspect you have the virus, should we immediately go to the hospital and treat it? Or should we attempt to treat it at home with medications our care provider may call in for us at a pharmacy?

A (Sandhaus): When you need to go to a hospital, you should not just go. You should call your doctor or the facility. This is not the same if it is an emergency situation, then you have to call an ambulance. But if you decide that it is the right time to go to the hospital, you should call first and they will question you about the symptoms, what you've done to alleviate them and decide it is worth the risk in case you don't have COVID-19 infection and find yourself picking it up there or whether it is something you can treat at home. The hospital emergency rooms are very good at recommending home remedies you might try to make yourself more comfortable as you live through the COVID-19 infection, because the majority of people who get COVID-19 just have a flu-like illness that's going to be self limiting and go away once you've produced enough anti-bodies against the virus. The first step is always to call the emergency or physician to find out if you need to come in. Again, emphasizing that if it is an emergency situation: yes, go to the hospital.

Q: If we were to fracture now, while at risk for COVID-19, how do we best handle going to emergency services?

A (Sandhaus): In large cities many of the hospitals are preventing patients from what they call elective surgery. For the vast majority that does not include broken bones. Many medical centers have developed areas of the hospital that they are trying to keep patients COVID-free from and have separate entrances for patients that are not treated for COVID-19 symptoms, but are treated for other emergencies. You should check with your local facility and find out the best way to manage these things. Many hospitals are setting bones- for non OI patients- in tents outside the hospital in an area where they don't allow people who are testing for COVID-19 to come. It's going to be location specific, about what's to be done. If you require some surgical procedure that is not elective the likelihood is that you have to do things, they might change you to another hospital. For instance the hospital in New York city is still doing orthopedic surgeries because that's all they're doing. They are referring all COVID-19 symptom patients to other locations and trying to keep that hospital as free as possible.

Glorieux: In Ontario they are doing it the same.

Q: What about zinc? Does that help reduce the severity of infection?

A (Sandhaus): I can't answer that question. I don't have any evidence that it would help. Zinc is used as a kind of over the counter medication that is supposed to reduce the risk of viral infections. But there is no evidence with respect to COVID-19.

Q: If very past due on infusion, would you recommend getting it even though you need to go to the children's hospital to get it?

A (Sandhaus): Every patient is making those decisions for themselves. Based on what the hospital tells them the risk is, and what they feel the risk is. It is specifically for bisphosphonate infusions. I would always turn to Dr Glorieux with these questions. For specific drugs have long half lives in terms of touching to the bone (1.09/34). It is beyond my respiratory knowledge.

Glorieux: You would have to do it case by case. Normally you don't want to interfere too much with the infusion rate, because it has a positive effect on the general wellbeing of the patient. I'm just facing that with two patients at the moment and we've decided to go ahead with the infusions and design in the hospital a specific area, well protected, where they will be admitted without being in contact with anything else, receive the infusion and go back. We have to weigh the plus and minuses of the situation, but overall I don't think it's appropriate to stop the infusion. We can play with the rate, but not stop the infusions, because they need it.

Sandhaus: That's good information, especially because I imagine you would come up against health care providers where they don't see a lot of OI patients, who would say "It's just bisfosfanate, you can miss it." I think that OI patients have to make sure that the person they're talking to understands this is not the usual use of bisphosfanates.

Glorieux: That's right. The rate of administration with Zoll, which is the one we use the most is "choose six months". That gives a little bit of leeway in terms of organizing the treatment. I don't see that as a major issue. But it has to be taken care of case by case.

Q: Would it be helpful to have some of the OI factsheets that are

available on the OIF's website printed out and ready to go in the event you need to go to the ER now? Would these be helpful for ER doctors or would something else be helpful?

Glorieux: I would say that all our patients do have that. They all have a card explaining their condition and telephone numbers to call and these are all forms to discuss the case in more detail. I think that is a fact that we've organized well in the past and is still appropriate.

For more information, go to:

[OIF.org/coronavirus2019/](https://oif.org/coronavirus2019/) (can also be found on [OIF.org](https://oif.org)).

If you want to reach the OIF directly (also if you want to reach Dr. Sandhaus): [BoneLink@oif.org](mailto:BoneLink@oif.org).

Or call: (301) 947-0083 or (844)889-7579 and leave a message.

[OIF.org/informationcentre](https://oif.org/informationcentre) for all medically verified factsheets.

Micheal: Please reach out to us. We want to be here for you. Thank you so much.

Tracy: Thank you Dr. Sandhaus, thank you Dr. Glorieux for all the wonderful information, for bringing our community together in this way. We will try to do more of these as we go along if we can, if we need to. Dr Sandhaus, Dr. Glorieux would you like to end this here with some final comments?

Glorieux: Yes, I would like to make one, which is linked to the psychological impact of that whole situation. I think that if you are isolated you don't have to keep it to yourself. We have social media and modern ways to communicate by FaceTime, Whatsapp, you know: social network. Keep that on and stay connected with the people around you, even if not physically, but at least in terms of keeping your spirits high.

Ingunn (OIFE): Thank you for allowing international participants on this call. It is also important to say that the virus is very different stages in different countries and it is very important if people are in doubt that

they should follow the guidelines and the restrictions from their local authorities and also there might be different rules on who can get testing, and who can get to the ER etc. So it's very important also to seek advice on your local authorities webpages.

Sandhaus: Thank you, that is very important. I'm so glad that you are on the call. I would like to just add that it's great to hear the kind of questions people are asking. As we learn more about this, you can turn to the OI foundation to find out the latest things that we've learned. Both from any OI patients that we might learn about or the general population. There are a bunch of studies going on with potential therapies against the COVID-19 virus infection as well as work on vaccines for the COVID-19. None of these are likely to be appearing in your drugstore shelf any time real soon, but at least know that this is going full speed ahead around the world to try to solve this issue.

Micheal: Again, I want to thank everyone and if you have questions for us, please reach out at [BoneLink@oif.org](mailto:BoneLink@oif.org). Thank you very much, stay healthy and see you very soon.