COVID-19 Q&A with the OIF: March 19, 2020

One hundred and six, okay, fantastic! okay so now we're rapidly rising above I want to just reintroduce myself very quickly. My name is Michael Stewart I work at the OI Foundation as the regional program services manager. I want to thank you all for joining us today. A quick note on some of the rules and procedures we're gonna try and follow in this call so like many of you the OIF now is practicing good social distancing policies so we're working from home so you're all getting a lovely view of my living room right now but I can imagine looking into many of your living rooms as well but we want to let people know that for this call because this would be a lot of microphones a lot of people on this call. We are at 121 (people) right now and it could probably keep climbing for a while. Please mute your microphones throughout the call unless you're specifically called on to speak by one
of the speakers here we just want to

0:00:54.960,0:00:58.980
make sure there's not background noise
so that we can't hear the speakers. As

0:00:58.980,0:01:03.239
you all know dogs will bark doors will
slam babies will cry and that's totally

0:01:03.239,0:01:06.990
fine but we just want to be able to hear
that we're well I would make sure that

0:01:06.990,0:01:11.670
we're hearing the information from our
speakers as many of you have already

0:01:11.670,0:01:16.200
started I see that you are typing
questions into the chat feature. We

0:01:16.200,0:01:19.740
appreciate that. When the speakers are
going we can ask that if you have

0:01:19.740,0:01:23.369
questions for them please put your
questions into that chapter and in a

0:01:23.369,0:01:27.180
timely way when they're done we're going
to try to answer as many of them as we

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can in the time allotted I do see that
people are asking about transcription

0:01:32.790,0:01:38.670
options unfortunately so we don't have
we charter understanding again we are

0:01:38.670,0:01:42.600
sort of also learning about zoom and
video conferencing on the fly like many

0:01:42.600,0:01:46.500
of you we're gonna try to get this
transcribed as soon as possible once

0:01:46.500,0:01:52.200
it's recorded so that the recording we
send out has descriptions as well but we
appreciate your patience and if you have
any questions feel free to pacifically a
message I'm oh I F staff my name is
Michael Stewart so with that being said
I'm going to bring it over to Tracy Hart
who is the CEO of the OI Foundation.
(Tracy) Hi everybody! Thanks Michael thanks so
much for for
going us started and thanks to all of
you for being here. I see so many
familiar faces
I'm loving connecting with everyone here
in the US and Canada and all over the
world so so glad you're here today!
So this is a challenging time for all of
us. We all know that and as a community I
think it's so important that we share the
information and we share the best
information that we have. The OI
Foundation is committed to doing that
know right now about Covid-19 and how it may
affect people with OI, especially from
a pulmonary and respiratory perspective
but also just in general information
that we we know right now. So with that, I
am pleased to introduce our to our two

0:03:05.819,0:03:11.280
presenters today they both probably look
very familiar to you. Dr. Francis Glorieux

0:03:11.280,0:03:16.650
from Shriners Hospital for Children in
Montreal. He is the chair of the OIF

0:03:16.650,0:03:22.200
Medical Advisory Council and then Dr.
sandy Sandhaus, who many of you know is

0:03:22.200,0:03:28.500
a pulmonologist from National Jewish
Health in Denver Colorado and he is also

0:03:28.500,0:03:34.049
a member of the OIF Medical Advisory
Council and a former member of the board

0:03:34.049,0:03:38.549
of directors of the OIF as well so we're
still pleased that they're here and dr.

0:03:38.549,0:03:45.299
Gloria I'm going to turn it over to you.
(Dr. Glorieux) Thank you very much Tracy

0:03:45.299,0:03:52.350
and hello to everyone and I understand
that the hello goes well beyond the

0:03:52.350,0:03:59.549
borders of North America so we're very
happy to to be with you today

0:03:59.549,0:04:08.130
we indeed go into trying times some
people say that Oh in a war just to make

0:04:08.130,0:04:14.310
thing in two perspectives I'm old enough
to remember the Second World War where

0:04:14.310,0:04:21.150
people were said we're told today you
have to go to war and take again to

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defend your land and that was not easy.
Today we are in a war

but what we have said stay home in your sofa and say and look at

what's going on so the situation is a little better in terms of perspective

but it's still you know away trying times. OI, I don't have to introduce the condition to you, you live with it and at different levels and certainly it's not easy every day 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 collagen which is present in bone and make all the problems that you know about bone brittleness and deformities with that molecules is also present in the lung and it's integral part of the lung tissue itself so any abnormality in the it structure will affect also the structure of the bone of the lung tissue and it's a possibility to fill fulfill its function so that's why we have to consider that lung is a target of those mutation and neither is an organ that we have to consider important in that
perspective. So that's that's really what

0:06:06.990,0:06:17.100
I wanted to say I want to say also thank
you to Ingunn from OIFE because she's

0:06:17.100,0:06:25.080
been working on preparing this as well
in a usual very efficient way and and

0:06:25.080,0:06:31.360
that's very important for us
the person who really be able to answer

0:06:31.360,0:06:32.880
most of your question is Dr. Sandhaus

0:06:32.880,0:06:37.719
because he is a specialist of lung

0:06:37.719,0:06:45.669
function and is or expert in the biology
and he will be able to answer your

0:06:45.669,0:06:52.419
questions regarding the dysfunction and
how it's affected possibly in the

0:06:52.419,0:07:02.139
context of the coronavirus infection so
Sandy I leave it to you and I will stay

0:07:02.139,0:07:08.680
around for other question if necessary.
( Dr. Sandhaus) Great, thank you very much Francis

0:07:08.680,0:07:15.789
and Tracy and Michael. I wanted
to thank you for inviting me and I have

0:07:15.789,0:07:23.339
done a number of these presentations for
a number of patient populations and I

0:07:23.339,0:07:27.819
thank you also for reminding me that
there are international participants

0:07:27.819,0:07:34.180
from outside the US and I'll be
referring to guidelines that we have
here in the US that might be different than the guidelines that you have in your particular countries or even localities, so please listen to what's local what's local is often best. I'm gonna just show a few slides primarily because I just thing we get this going because there's a lot of words on them and sometimes helps to see them as well as hear them. I think the first thing we need to do is talk about some of the terms that you've heard from your newscasts and and the like. We refer to the disease caused by this novel coronavirus as Covid-19. Covid-19 and the virus itself is either called novel coronavirus or SARS-CoV-2 because it says ninety percent similarity with the SARS virus that caused some deaths around the world several years ago which is also a corona virus. So I'll refer through this mostly as COVID-19 because it's the easiest to say and Francis addressed why we'd want to
talk about this in OI populations over
and above the general public and I'll

kind of talk about that. In terms of
general recommendations the best source

for specific recommendations and answers
to your questions is going to be your

own local physician or medical center
because they really know what's going on

in your neighborhood. There are big
differences between urban areas and

rural areas in terms of numbers of
people identified things like that and

each locality is pretty much putting
forward its own (please mute your

microphones if they're not muted) you can
stay informed in the US by visiting the

CDC website. They just updated their
website yesterday to have a much more

user-friendly approach to finding
information and this link that you see

on the slide will be available to you
beyond this talk so don't bother writing

it down now. You that will be provided to
you that's the general recommendations

for everyone not just people with OI
in the U.S. are listed on these two
slides. First, is the concept of social distancing which I'm sure you've heard a lot about this includes when in public or even when visitors come to your home they attempt to stay at least six feet away from other people in your immediate area. Try not to shake hands or touch the skin of other individuals if you do that reflexively you should really wash your hands using the directions that we'll go over in a little while. And the current recommendations from the CDC are to avoid groups of more than 10 people even if you think that time of you can stay six feet apart from each other there are specific recommendations to avoid pretty much all except non-essential air travel. You can make up whatever you want for "non-essential." We certainly recommend against going on cruise ships because of the closed environment it's an incubator for infections to be passed to one another. And in areas of high prevalence most localities that have major public transportation systems are
suggesting that people avoid public transportation unless necessary for everyone and please avoid close contact with people who have respiratory illnesses especially acute respiratory illnesses, not chronic disease, but respiratory illnesses that have started within the last four weeks or so. If you become sick whether it's the flu, a cold, or the corona virus please limit your contact with others as much as possible stay home if you're sick, we call this "self isolation." Family members who live with you should follow exactly the same restrictions that you do the presumption is if you're sick family members who live in the same house or have been exposed. Other general recommendations:

some localities have adopted, especially in the west coast of the United States, a shelter-in-place directive in these areas individuals whether infected or not are asked not to leave their homes except for exceptions that are kind of outlined at each locality for instance going to get a prescription, getting food,
delivering food things, like that are
listening it's exceptions to the to the

recommended nation that you not leave
your home.

Important for protecting those around
you: cover your nose and mouth when you
cough or sneeze. This is independent of
whether you have symptoms or not it's
best to cover your mouth and nose with a tissue. Immediately discard the
tissue and then wash your hands
avoid touching your eyes nose and mouth

with unwashed hands and that's a that's
the main mode of entry of this novel
coronavirus into the body is through the
eyes, nose, mouth. Clean and disinfect
surfaces and objects that may be
contaminated with germs.

Coronavirus can spread by cough and
the virus can live on solid surfaces for
many hours if not days depending on the
type of surface if it's not disinfected

obviously there's some shortage of
disinfectant wipes and things like that.
You can go to the CDC website and see
how to make your own disinfectant wipe
form isopropyl alcohol peroxide and
glycerin. Most important of all wash your
hands often with soap and water for at
least 20 seconds.
You've probably heard - if you sing
Happy Birthday twice while you're
washing your hands that's a pretty good
estimate if for washing your hands for
at least 20 seconds I've got my happy
birthdays down to eighteen seconds so I
do a couple of extra wipes
if soap and water aren't available use
alcohol-based hand rubs with at least
60% alcohol that 60% figure is specific
for this coronavirus and other
coronaviruses that it the alcohol
content needs to be at least 60% in
order to kill the virus and don't forget
to scrub all parts of your hand and
continue scrubbing until your hands and
fingers are dry
when using the alcohol hand rubs.
Try to maintain a two-week supply of
food and water at your home if possible,
and if possible maintain an extra supply
of your prescription medications at your
home so you don't have to visit

0:15:17.429,0:15:22.709
the pharmacy as often. If you do have to
visit a pharmacy many pharmacies have

0:15:22.709,0:15:29.099
drive through prescription pickup or
delivery of prescriptions. Now please

0:15:29.099,0:15:39.149
explore the local options in your... in
your area. What about things that are

0:15:39.149,0:15:46.139
specific to OI?
Dr. Glorieux gave an excellent description

0:15:46.139,0:15:53.729
of why there might be things that are
specific to OI. In general, I would

0:15:53.729,0:16:03.149
consider OI to be in a high-risk group
for getting serious symptoms and

0:16:03.149,0:16:08.269
complications should they get infected
and that's because of the known

0:16:08.269,0:16:14.329
pulmonary impairment, some mild, some
severe, that virtually all OI

0:16:14.329,0:16:23.669
individuals have because of the collagen
abnormalities due to the genes

0:16:23.669,0:16:30.299
that you've inherited. So how does
that change knowing that you're more

0:16:30.299,0:16:35.220
susceptible? Well, basically you should
take the recommendations more seriously

0:16:35.220,0:16:40.709
than the general population. In general,
the general population that doesn't know

0:16:40.709,0:16:46.259
anyone who's infected believes that they
are that they won't get infected and

they don't necessarily have to follow things strictly. In general, younger

individuals have the somewhat mistaken impression that they... that the younger

you are the less likely you are to even have symptoms from Covid-19. Recent data

from the US that's based that... that impression of young people being

essentially immune to the ill effects of Covid-19 infection.

That's primarily from research done in China. But research

in the United States has started to show individuals with severe complications

from Covid-19 who were under 10 who are

teenagers and who are millennial adults. So the fact is that everyone

should be following these things and individuals with OI should be following

these recommendations strictly because of the presumed increased risk of

serious complications should you get infected now some of this is dependent

on how severe the lung disease is a big factor in whether you get severe
complications is your age, the older you are the more, likely you are this

will be a simple flu-like illness and that will actually affect things more seriously. What do we mean by more seriously? Well, the major complication that individuals who wind up getting admitted to the hospital have is viral pneumonia.

And that viral pneumonia is both sides of the lung basically it affects all the lobes of the lung and in patients who have survived severe viral pneumonia due to Covid-19, there those individuals have been left with some scarring and fibrosis in their lung after they've recovered.

Now we know from other diseases that cause this type of pneumonia and what's called a RDS, acute respiratory distress syndrome, we know that that fibrosis and impaired lung function after recovery can actually ...the lung function can actually improve over the months following such a an infection and a pneumonia. We don't know if that's going to happen in Covid-19 but it seems likely
because the similarities of pneumonia we're seeing versus the pneumonia that we know from other viral infections even corona virus infections going on to recover. So the main cause of death is respiratory failure and organ failure, multiple organ failure if someone gets ARDS and gets a bacterial infection on top of the viral infection, but please remember it's with all of the thousands and thousands and tens of thousands of people that have been infected, the total number of infected individuals who've actually died from these infections is a small fraction of those who are infected. We don't know the exact amount because in the US the testing for Covid-19 is still very much restricted. We expect that if there were universal availability of Covid-19 testing that we'd find hundreds of thousands of individuals with infection and that would make the death rate become much smaller. Having said that, I don't want to diminish the risk should someone get
infected and when there are ways to prevent infection likely recommendations that have been put forward it would be silly not to try to prevent getting infected even if you're a young individual even if you'd have no pulmonary symptoms related to your OI or other conditions.

And that's all I have in the way of the slides. Mike, if you could turn the screenshare off. Great, thanks very much and 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 the all the information that's pouring from TV screens, radios, newspapers in a tidal wave at all of us and the changes that's affected in our lives the changes in our workplace the growing economic impact of this infection like weighs on individuals greatly and it's really important to take a break sometimes from the news channels and the and the newspapers
try not to concentrate on it. Enjoy your time with family that you might have not had if you didn't have to stay home from work. I'm doing that. I'm considered to be in a high-risk group in fact Dr. Glorieux and I are both in the high-risk group of being elderly and tough to acknowledge that but happy to to get chance to spend with my with my wife at home which is what I've been doing and only going in when I have to see a patient has flown in to see me at National Jewish [Hospital].

I reassure you and my family that I'm not working in the intensive care unit because I'm in a high-risk group but there's 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 seven days and then they get 14 days off to self isolate at home to find out a thing been infected and after that 14 days they come back and do seven 24 hours shifts again so and we're and they're asking retired doctors to come
to work and things like that

0:23:38.950,0:23:43.960
so there's this is that I know how to an
effect on everyone that's listening to

0:23:43.960,0:23:48.429
this teleconference and I'm happy to
answer any questions. I'm sure Dr. Glorieux

0:23:48.429,0:24:00.190
is as well. (Tracy Hart) Thank you very very much Dr. Sandhaus and Dr. Glorieux! Wonderful

0:24:00.190,0:24:04.510
information! Michael, are you going to
facilitate the questions that we've been

0:24:04.510,0:24:09.820
getting and so keep bringing keep typing
in your questions as well! (Michael) Great thank

0:24:09.820,0:24:16.570
you so much. (Dr. Glorieux) Dr. Glorieux here, just
a practical point I want to add before I

0:24:16.570,0:24:24.100
forget. Something I do myself every day
confined in my condo was as I am because

0:24:24.100,0:24:30.190
I was high being a high risk take your
temperature every morning. It's a very

0:24:30.190,0:24:35.230
easy thing to do
your temperature should be below thirty

0:24:35.230,0:24:41.919
seven point five Celsius or 99.5
Fahrenheit and it's an easy thing to do

0:24:41.919,0:24:45.570
you do that.
I do that after breakfast and if it's

0:24:45.570,0:24:53.200
there I'm comfortable that the deal will
be okay so that's just a little thing

0:24:53.200,0:25:00.360
that we have to act or day-to-day
activities to keep us comfortable,

responsible. okay. (Sandhaus) I second that! (Michael)
Thank you so much so we

have my colleague and I have been
keeping a list of the questions you guys

been typing in thank you so much for
doing that we have one question from

someone who could not make this cold
state I think is a good starting off

question if you want to jump into the
questions you guys have been typing into

the chat feature again we're gonna try
to get to as many as we can the first

question we have this might be Sarah
Fisher she asks "What effects have been

seen or expected for people with OI
and other added difficulties of treating

Covid-19
with people with OI compared to that

with other people?" (Sandhaus) So my the first part
of the question as far as I know I

turned to Tracy to find out if you're
doing any tracking of patients that have

OI or will be doing that in the future.
There's you know the number of patients

who've been identified because of the
restrictions on testing in the US at least overall has been relatively low compared to the number we think are out there with infection, and 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 are 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 there's if they're rare disease includes lung issues and so that's the that was the point of my last slide here and the second part of the question had to do with loss? (Michael) it kind of the first part is are there any any difficulties with treating Covid-19 compared to that with other people? (Sandhaus) Compared with other OI patients? it's well you know putting it the the final sort of treatment stuff that happens in patients that get severe
disease is they wind up on a ventilator or respirator. A tube in their lungs with a machine breathing for them and that is always a risky proposition and people that have fragile ribs fragile bones things like that and so it's really important that should you were a relative find themselves in the intensive care setting 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. And you know I'd be happy to speak to any physician that is caring for someone who's seriously ill with OI just to review those things with them because I'm certain that there are many intensive care Doc's who have never managed (Michael) Excuse me everyone, can we just make sure that our microphones are muted. I appreciate it so I will be down our organization email it's Bonelink@oif.org if you want to contact us and so that you can get in contact with us so So you can get in contact with Dr. Sandhaus
we can connect you for you so again if you're just joining us can you please just make sure your microphone is muted so the questions and the answers, thank you. I'm going to go onto the next question.

"Can someone with a cold still use an incentive spirometer or any spirometer?"

I mean there's no reason not to use an incentive spirometer I'm not sure what they mean by any spirometer that the term spirometer usually means a tested stun to measure your lung function. While a incentive spirometer is designed to help your respiratory muscles and your breathing capacity and things like that.

So there's not a reason not to use an incentive spirometer unless it's an incentive spirometer you're sharing with other people in which case I definitely would not use it. Again, how many pulmonary function labs 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 National Jewish is closed down because of that. (Michael) mm-hmm so I just keep going up for they

You don't need to announce the names Michael. (Michael) Yeah. My daughter has a OI and is she's pregnant. What should she look out for? (Sandhaus) There have been people with Covid-19 who have been pregnant. Number one, the literature that's out there and it's actually surprising how much is coming out from the experiences around the world. The information out there suggests that mothers with Covid-19 did not pass the infection on to their children to their fetuses. The fetuses they're not being born with Covid-19 and it has not affected their pregnancy beyond the effect of having either a complication from Covid-19 or respiratory issues from Covid-19 so there's no special issues as far as we know right now regarding pregnancy except you'd certainly think that
pregnant women should take extra special precautions just as general OI patients should. (Michael) "If I didn't get a flu vaccine yet, should I risk going out to get it?"

(Sandhaus) This is part of a series of questions I'm sure we're getting that always come up in these conversations is the risk benefit analysis of going to get I mean for instance alpha 1... and deficient patients that I follow which is another genetic condition get weekly infusions of their missing protein at an infusion centers and and the questions I get about that are should I skip my infusions so that I'm not exposed to all the people that are at the hospitals or infusion centers I go to and really it's a tough question to answer people need to weigh those decisions themselves. Ot is quite important to get a flu shot still if you haven't.

Flu is still a much larger killer in the general population than Covid-19 is even in countries that have already gone through a major you know
spikes in there covered 19 infections like China and South Korea and so

getting the flu shot it's important. I know that there are some pharmacies that

will do that in a drive-by setting in the United States where you just drive

up stick your arm out of the car and get your flu shot. I would think that that in

that situation that the benefit outweighs the risk.

Similarly with immunizations against pneumonia those things are all important

to have right now because the pneumonia that the amount that the pneumonia that

the pneumonia shot protects against is the kind of pneumonia that can

complicate a viral pneumonia so the answer the question is if you can find a

way to do it with minimal risk it would be a good idea to get those

immunizations if you haven't had them yet. (Michael) Next question is "What about the kids?"

They say kids are less affected. Is an OI child also high-risk? Should we

maintain isolation? Right now we are home but what about when it's time
to go to work?" (Sandhaus) So the two things about kids are there probably is a higher rate of mild symptoms in kids and young adults than in older people but it's not an absolute it's not a guarantee that you won't be have some 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 as you know even adults who get infected are often asymptomatic for as long as two weeks before a symptoms start and during that time can infect others and so I know in our area even kids who don't have intrinsic lung disease such as the kind that an OI individual can have that kids are being kept from going on playdates and going to playgrounds and seeing their usual friends. It's a very difficult thing for kids and especially for parents who have cabin fever children you know in their in their homes but still kids can not only become infected they can become a reservoir for infecting other kids and adults. (Michael) Thank
you.
I'm going to move to a different

question. "Recommendations for those in
healthcare please. I'm type IV,

moderate, 4'1", pectus chest deformity.
I'm a registered nurse, but not bedside,
in an office in hospital with a handful
of other nurses. The hospitals has yet
to have any confirmed cases but have several
PUIs. Thank you for your time and

recommendations about the what you're
already giving the general population." (Sandhaus) So

PUI is the patient who is under
investigation that has

symptoms that could become consistent
with Covid-19 that does not have the
test results back yet or can't get a
test retest just to clarify what what

was being asked. And every healthcare
provided it goes to work, whether they

have OI or not is making a
risk-benefit assessment because they are

putting themselves in harm's way and so
I would say that as the type IV 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 and so your decision-making is your own. I think it first sign that there is a growing number of individuals in your community who are being tested are testing positive I think that it would be reasonable to consider stepping back from your work or finding another job in the location where you're working that doesn't have direct patient contact, where you could work in a separate office or something like that. These things can often be impossible to arrange but I think that you will be able to help anyone if you become ill and wind up getting sick and sicker than there than your comrades and in the healthcare setting you're working in. (Michael) "If we get infected with Covid-19 and fully recover, is our lung function forever diminished?"

(Sandhaus) Well, the infection itself will not necessarily affect your lung function.

Once you recover no the one I probably wasn't clear enough when I was talking
about the persistent lung impairment that was in patients who were in the ICU on ventilators who developed what's called a RDS acute respiratory distress syndrome where essentially fluid floods into their 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, a fever and a little cough and some simply shortness of breath and then it goes away there's every likelihood that they wouldn't affect your overall lung function at all once you've recovered.

(Michael) "I was diagnosed with asthma in 2019. I assume I should be self-isolating? and what about spouses spouses should we be isolating from them if they continue to work outside the home? I have severe asthma with other respiratory issues as well. Should I self-isolate. I'm 21." (Sandhaus) Some of it depends on how how effective your asthma treatment is if your asthma treatment normalizes your lung function then it's likely that you don't have any greater risks if you get one of the things that Covid-19
it's an interesting guy walking the runway where are we talking the one

things that Covid-19 infection does especially when it becomes the infection becomes severe, the symptoms become severe, is it causes a dramatic increase in the inflammation in the airways and that can kick up someone's asthma and so it really depends on it's not a simple Covid-19 infection without symptoms.

That shouldn't be a problem related to your asthma but the sicker that you get with Covid-19 the more it can exacerbate your ass or make your asthma worse and so your physician will need to know about your asthma they would probably intensify your asthma treatment.

The tough questions about your spouse working in the general public and coming back yearly and your spouse will have to decide on that that's a decision that everyone almost everyone in the country is making right now because if people are lucky enough to continue working that's just something that they have to decide you it's it's tough to live in
the same house with someone and be isolated from them yeah in reality and so it may be that you simply you know make sure that your spouse is doing everything they can to try 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.

I can't hear you Michael (Michael) Many apologies a garbage truck was driving by. "So there's been a recent study waiting to be published about the virus being airborne. How can we protect ourselves from that?" (Sandhaus) So the virus that is there there's very specific terms for how things are transmitted the virus is not airborne the virus is droplet borne. And that makes a big difference.

Airborne transmission can travel for miles. Droplet transmission only travels for about 3 to 4 feet which is why the recommendation 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 for anywhere
from hours to a couple of days which is

why respecting certain those surfaces
that that might have been cost on or

sneezed on or something like that. So the
droplet borne infections are very
effective with social distancing as well
as with masks N95 masks.

Ideally when when masks become readily
available it would be it would be

worthwhile considering wearing a mask
whenever you're outside your home

because they do work to prevent droplet
borne transmission. The only reason that

people aren't recommending that now is
because of the shortage of the masks and

the and the decision that the shortage
should be they they read different

supplies should be used in the health
care setting first before people start

using it outside the health care setting
but it's presuming that there will be a

big influx of mass production and that
mass will become more readily available
I would recommend that people who are at risk like OI patients wear masks when outside their home.

you're muted again. (Michael) I apologize um so regarding regarding temperature "I normally have a higher body temperature does this impact [Covid-19]?") Well it doesn't impact in the sense that you're not more susceptible to infection but in terms of impacting the recommendations regarding taking your temperature yes and no I mean most people who have a higher resting body temperature should get different thermometers but the but definitely you're looking for a change from your baseline in your body temperature and so you can you know add 1.5 degrees or one degree higher than you're in Fahrenheit to your baseline body temperature to be to identify when you should be concerned so in that sense yes you probably have to correct for that when looking at the recommendations of when to be concerned in our in our city we're not asking people to come and
get tested until their temperature reaches a hundred degrees Fahrenheit that's partly because most people who have infection that's symptomatic have temperatures of 103 to 104. One of the things related to asthma patients and patients are an underlying chronic obstructive pulmonary disease COPD is that the three the three things that are asked when you're doing a verbal screening for the likelihood that someone's infected this they ask do you have a fever do you have increased shortness of breath and do you have increased cough? Well, any patient that has chronic lung disease know that there are many times when they're coming to a physician because they're having increased coughing increased shortness of breath so a lot of patients that have frequent exacerbations as they're called are being told. The key finding to decide whether you need to report to the medical setting is whether you have a high temperature and high temperature is
uncommon in exacerbations of asthma or

exacerbations of COPD and so really
you're even though you should be

cconcerned when your temperature starts
to rise true Covid-19 infection gives

you pretty high fevers it's not
something subtle. (Michael) So this goes to the

part you were talking about before with mental health and
risk benefit analysis. "Would it be safe

to go to public parks? Staying in the
house 24/7 is stressful,

especially having having recovered from
recent fractures." (Sandhaus) It's recommended that

people who are at self-isolation and
even people who are on this shelter in

place take some time to go outside get
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 a park don't go to the

playground where you know you sit on a
swing and you hold the chain or

something like that that someone else
has touched you know ten minutes before

you did. Just take a nice look for a
beautiful location if you've got one

near you it will help every day.

(Michael) "So I have heard that we should not be taking anti-inflammatory medications. Can this be verified?" (Sandhaus) So the this is based on an anecdotal reports from the French literature in which they found that people who had more severe lung problems had a higher incidence of having taken nonsteroidal anti-inflammatory agents like ibuprofen, Aleve, things like that there's a problem with that. People who are sicker are probably more likely to have taken at on planetary agents. They were getting sicker they probably had higher fevers, they probably took extra to get that fever down because people have told me that nonsteroidals don't do a very good job of lowering the fever in Covid-19 and so it could be kind of a self-fulfilling story the people who were sicker take nonsteroidals and therefore that there were sicker so they wind up in the hospital and in the ICU and things like um the current recommendations that we're hearing both
local authorities and federal authorities who are asked this question

is don't take beyond the recommended dosages of Tylenol that's not a nonsteroidal or the nonsteroidals which include aspirin ibuprofen Naproxen things along those lines. Take them to reduce your fever and reduce there's a lot of aches and pains that are associated with Covid-19 infection. Take them if you need them; minimize the amount you take and never take more than a recommended dose. (Michael) So the next question is very specific for the OI community is "If we can maintain the social distancing standards, is it safe to swim or can the Covid-19 spread in a body of water?" (Sandhaus) So that's a great question that I haven't heard before. It is true that we know that chlorine disinfectants are highly effective at killing Covid-19. or rather killing the virus that causes Covid-19 and so I would think if you have a well you know regulated cool that uses chlorine you know stabilization of the
bacterial load in the in the pools that you could consider that I have to say

c is off the top of my head they start knowing that chlorine and bleach are good at killing the virus and I've not seen any recommendations about that

I probably you know I don't know what I would say about swimming in the bodies of water other than the pool I would think of swimming in the ocean is not an issue you know that with the changes in the that come with each wave; who knows. I wish it was I wish I was in the middle of the snowstorm and I start thinking about jumping into the water I thought that's what we're doing in Denver right now so I have to say that looking at myself on the screen and learning how many times I touch my face in spite of telling everyone they shouldn't be touching their face. (Michael) I see everyone nodding on screen so we agree with you. So we have a set of questions all related to recovery so I'm going to sort of like lead three of them in a row but they're
all kind of the same. "what is the identifier of 'recovery'? The absence of the
absence of symptoms? a negative test? or both? Is it true that when someone test
positive, they won't test negative after they recover? and once you've... once you're deemed recovered is there any chance
that you can still be contagious?" and I just touch my face as I said that! (Sandhaus) So the
the recommendations in the u.s. vary from location to location.
You do stop shedding virus when you when your symptoms go away after you've had Covid-19 infections. For instance, the recommendations at my institution for when you're allowed to go back to work if you've had a Covid-19 infection far but 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 or at least 24 hours apart I know that in New York they're requiring three tests that are negative each at least 24 hours apart I do want to get into the weeds a little the covered 19
testing that's currently being done
looks for the viral DNA and so to say

that someone is negative means they not only don't have any 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 they're not measuring whether someone has a active infection infectious virus. We're measuring when there's any DNA left that's from the virus in the back of your throat or in your nose and the the test and for those who don't know is a swab of the nose of throat looking for this DNA and so it's a very strict rule but it also implies that yes when people recover they don't have virus anymore the big question of course is can some get infected again after they've been if those are covered from Covid-19. The the exact answer to that is still not known entirely but it appears that if you recover from Covid-19, you cannot be reinfected by that version of the Covid-19
virus, I'm on the other hand the expectation is that this is the virus caused encoded by Covid-19 will mutate over the months at home and so it is possible the people can get reinfected with virus mutates enough that the immunity you've built up is not effective at stopping it have you heard anything else Dr. Glorieux about reinfection and things like that? particularly your muted (Glorieux ) uh-huh no sandy I just heard a same as you. There is no evidence that that may happen but it's still an open question yeah thank you though (Michael) Up next there's a severe blood shortage "I usually give blood should I risk going to do?" (Sandhaus) This um I think that you need to call the donation center and ask them talk to them about the precautions that they're taking I know that for most blood donation centers they are doing dramatic disinfection protocols between donors the one thing that's important to know is that there is absolutely no
evidence that kovat 19 virus can be transmitted by infusions or by plasma products for instance if any of you are on Prince's IVIG infusions and things like that there's no evidence that plasma products derived from blood can transmit the virus and so there's actually a shortage of blood and they're recommending that people go you should assess for yourself the steps that the blood bank is taking to protect the donors I fully expect that most of them are doing well I have to say I have been disappointed by stories I collect from around the country about health care workers who are kind of blase about doing the protective measures I don't think that will happen to the blood bank but certainly home nursing I've had home nurses go into patients homes and and act like they don't have to do any of the things that are recommended because after all their health care workers and and this isn't a big deal they've done with viruses before kind of kind of things now these stories stand out it's
certainly not the general practice of most health care professionals but you really need to be the ones that evaluate what's being done to keep you safe when you're in a situation when they're left your situation or situation we're going to donate blood or considerate the next question is if (Michael) "If you have OI and have never had any lung issues, are you still at a higher risk than the rest of the population?" and sort of a mirror question to this is "Are all the types of OI patients considered high-risk? even (Sandhaus) I will emphasize that that our warnings to OI patients are only based on our clinical opinions and we read we mask it by saying their expert opinions but really no one's an expert yet on the lung issues in OI. you know I um our opinions basically say we know that there's deranged college in the lung. we're of our patients we know that OI patients have abnormal lung function even those with type 1 OI and we know that that respiratory problems are the
main killers of OI patients in general, not just in times of viral infection and

so putting those things together we right 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 who hands me a lung function test that's perfectly normal and it's never had a problem in their lungs in their life can I say whether that person is an increased risk? I can't, but but discretion is the better part of valor you know you probably want to at least consider that when the sudden which you're going to do in terms of protecting yourself the possibility that even healthy OI patients healthy in terms of their lungs could be at some small increased risk compared to the general population.

(Michael) The next set of questions are about face masks. "In lieu of scarce masks would it help if people wore scarves or bandannas over their nose and mouth when outside?" and a similar question is "Can you confirm whether or not face
masks are one-time use?" (Sandhaus) So first of all
I'm in the awkward situation because the

CDC is now recommending to healthcare
workers that they use scarves and

bandanas if there aren't any face mask
available. There's actually no evidence

that scarves and bandanas are effective
at preventing droplet transmitted
diseases. Maybe some of those droplets
will land on you know a strand of wool

in a scarf and not get into your mouth
but it would probably reduce a fraction

of the risks but but not have the same
type of beneficial effect of a the

natural surgical mask or even better, an
n95 mask will have. the What was the

second thing the next question was "Are
these truly one-time use only." (Sandhaus) well no

They are in the setting of plethora of availability. It's always

wise to use them once and
scarred them because 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 of
that contained Covid-19 virus that had been stopped from being held by you and so you'd prefer not to have to use put it on again and you certainly don't want to touch the front of the mask and when you're taking it off and things like that but the in times like this where masks are in short supply the fact is the masks remain effective for several days of use before they get entirely saturated and and and they're conveying have a higher risk of not being effective at blocking those droplets. Remember the mask is not preventing it can't prevent viruses from being inhaled; it prevents the droplets that are carrying those viruses from getting to your mucous membranes.

(Michael) Thank you! "Are there any other symptoms that we can be on alert for other than elevated temperatures in which could indicate we had contracted the virus?" all sevens is right there yeah yeah because you see after getting the second question I often times will do monitor the there are a couple of other symptoms
that have become prominent you know when we talk about patients we've seen you

know in the doctors lounge and those include diarrhea and body

aches and pains so there are some patients that are prominent GI symptoms

like diarrhea and it's not everyone. It's not the most prominent symptom but it

can happen. And on the other hand aches and pains like a flu-like illness are

more common with diarrhea but still not seen in everyone. There had been a fair

number of people since we both often do respiratory virus screening in addition

to the Covid-19 testing when we do the swabs we have found a number of people

who have both influenza and Covid-19 and so sometimes it's hard to

separate the symptoms that are due to flu versus Covid-19. (Michael) Thank you so the

second part of this larger question" "You suspect...

you suspect you have the virus. Should we automatically go to the hospital to treat

it or should we attempt to treat it at home with any medications our primary
care provider may call in for us at a pharmacy?" (Sandhaus) Um, when you need to go to the hospital you should not just go. You should call your doctor or the facility.

Now this is not the same if it's an emergency situation you have to call ambulance it's because you're in dire straits, then you should go to the hospital but if you're trying to decide is now the right time to go to the hospital then you need to call first and they will question you about the symptoms what you've done to leave them things like that and decide whether it's worth the risk of coming to hospital in case you don't have Covid-19 infection and find yourself picking it up there or whether it's something you could treat at home. And the hospital emergency rooms and medical centers are very good at recommending you know home remedies you might try to to make yourself comfortable more comfortable as you you know live through they 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 develop antibodies against the virus. So it's the first step is always to call your physician or they or the emergency room to find out whether they feel that you need to come in again emphasizing them if it's an emergency situation, yes, go to they go to the hospital.

(Michael) Thank you! (Sandhaus, reading comments) Looks like there's some some recommendations for ways to make self-made face masks that are on the chat oh I see from foundation care for brittle bones thank you see there's a very long link we'll get that we'll get that mid you can make that into into a shorter link. (Michael) I want to go into the next question so this is kind of a related thing to what you just talked about. "So if we were to fracture now while at risk for Covid-19, how do we best handle going to emergency services." (Sandhaus) So that's that's a great question because in large cities many of the hospitals are preventing patients from coming in for
what they call elective surgery and for the vast majority that does not include broken bones. Many medical centers are have developed areas of the hospital that they're trying to keep Covid-19 patients free from and have separate entrances for patients that are not there to be treated for Covid-19 symptoms but are there for other medical emergencies. I'm so you need to check with your local facility and find out the best way to manage these things. Many hospitals are setting bones in for non OI patients in tents outside the facility in an area that they don't allow people who are testing for covent I team to come too and things along those lines so it's going to be very location specific about what's to be done if you require some surgical procedure that's not elective you know that's the the likelihood is that you know you'll have to do things according to you know they may change you to another hospital for instance in New York City
the Hospital for Special Surgery is still doing orthopedic surgeries because that's all they're doing they're not referring all Covid-19 symptom patients to other locations and trying to keep that hospital as as free as possible probably Dr. Glorieux has some comments from what they're doing up in Montreal. I think it's a real when you're is (Glorieux) Exactly the same way as you just described Sandy. We try to work direct them to areas where it can be taken care of safely but if it is an emergency situation you know that takes the priority again. (Michael) I'm going to move on to some some more questions one question is says, "What about zinc? Does that help reduce the severity of infection?" (Sandhaus) I can't answer that I don't have any evidence that it that it would help. I mean zinc is used you know as a kind of over-the-counter medication that's supposed to reduce the risk of viral infections but you know they the
certainly is there's no evidence with respect to Covid-19.

1:08:35.920,1:08:46.299
that so I have it another thing: "If very past due on infusion, would you

1:08:46.299,1:08:49.900
recommend getting it even if they need
to go to the Children's Hospital to get it?"

1:08:49.900,1:09:00.609
(Sandhaus) Right right that
you know that every patient is making

1:09:00.609,1:09:09.139
those decisions for themselves based on what the hospital tells them the

1:09:09.139,1:09:14.170
risk is and what they feel the risk is
and and specifically for bisphosphonate

1:09:14.170,1:09:18.889
infusions I'm you know I would always
turn to Dr. Gloreiux regarding things like

1:09:18.889,1:09:24.469
that. Many of these infusions for
specific drugs you know have such long

1:09:24.469,1:09:29.150
half-lives in terms of you know
attaching to the bone and things like

1:09:29.150,1:09:34.429
that that it's beyond my respiratory
knowledge and I turned to Dr. Gloreiux.

1:09:34.429,1:09:41.690
(Glorieux) Well you have to you would have to do
with case-by-case but normally you don't

1:09:41.690,1:09:47.029
want to inter interfere too much with
the infusion rate because it has a

1:09:47.029,1:09:52.339
positive effect of the general
well-being of the patient. I'm just

1:09:52.339,1:09:57.800
facing that with two patients at the moment and we have decided to go ahead

1:09:57.800,1:10:05.500
with infusions and divine design in the hospital a specific area well-protected

1:10:05.500,1:10:12.050
or they will be admitted without being in contact with anything else received

1:10:12.050,1:10:19.400
an infusion and go back. I think the way we have to wither but you know the the

1:10:19.400,1:10:24.530
plus and minuses of the situation but overall, I don't think it's appropriate

1:10:24.530,1:10:31.570
to stop the infusion. We can play with the rate but not stop the infusions

1:10:31.570,1:10:39.320
because they they needed. (Sandhaus) That's good information especially because the I

1:10:39.320,1:10:44.329
imagine you would come up against health care providers where they don't see a

1:10:44.329,1:10:49.130
lot of our patients who would say it's just bisphosphonate you can miss it you

1:10:49.130,1:10:54.289
know and I think that our patients have to make sure that the person they're

1:10:54.289,1:10:59.150	
talking to understands this is not the usual use of bisphosphonates. (Glorieux) That's

1:10:59.150,1:11:04.639
right but you know the the rate of administration with Zol'' which is the

1:11:04.639,1:11:10.010
one we use the most is q six months so that gives a little bit of leeway in

1:11:10.010,1:11:15.619
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.

(Michael) Great, so on a related note so "Would it be helpful to have some of the OI factsheets that are available on the website printed out and ready to go in the event you need to go to the ER now? Would these be helpful to ER doctors or with something else be helpful?" (Glorieux) I would see that all our patients do have that.

They'll have you know they all have a card explaining their condition and telephone numbers on it to book - to call and these are all forms to discuss the case in more details. I think that's a fact that we have organized well in the past and is still appropriate and (Sandhaus)... actually worthwhile to make up our own kind of Covid-10... okay (Michael) I just want to say on that note as wanted to display this really quick slide I had made, so if anyone is curious about more information we have this is a perfect transition so if you want to learn more about Covid-19
and OI on the OIF main page we link to OIF.org/coronavirus2019 which

I realize needs to be 2020 with new information as it arrives. This is also

linked to on our homepage OIF.org and if you want to contact the OIF directly we know. Dr. Sandhaus already said he'd be happy to talk with other doctors about this. To get in contact with him, you can reach out to us directly at bone link at OIF.org again like I said before, we're practicing social distancing so our phone lines are still open but the most direct way to contact us I believe right now is through email and we're gonna get to you very soon. (Sandhaus) By the way the website coronavirus 2019 should be 2019. That's what the coronaviruses call

It was named after the year it was discovered. (Michael) Oh, I say I'm learning a lot on this call! Okay thank you!

so with that being said all right it looks like we've covered a lot of questions and also the time is 2:18 um I
also want to let everyone know that you
1:13:53.499,1:13:56.800
want to go to you'll find more these
fact sheets you can go to OIF.org
1:13:56.800,1:14:01.749
slash information center where we have
all our medically verified fact sheets
1:14:01.749,1:14:07.809
many of them by the doctors on this call
with us today but that being said I also
1:14:07.809,1:14:12.609
want to thank all of you for joining us
we're going to be loading this video
1:14:12.609,1:14:16.269
onto YouTube momentarily in the next few
hours
1:14:16.269,1:14:22.539
and then pushing it on both Facebook
and/or on the OIF page on the OI
1:14:22.539,1:14:28.839
website and please reach out to us we
want to be here for you and thank you so
1:14:28.839,1:14:33.419
much and Tracy or dr. Sandhaus or dr.
Glorieux if you any final comments. (Tracy) oh yeah
1:14:33.419,1:14:38.409
yeah thank you Michael I would just like
to thank Er. Sandhaus, Dr. Glorieux for all
1:14:38.409,1:14:41.589
of this wonderful information for
bringing our community together in this
1:14:41.589,1:14:48.249
way we'll try to do more of these as we
go along if we if we can if we need to
1:14:48.249,1:14:56.369
but Dr.. Sandhaus, Dr. Glorieux, would you like to end
this here with some final comments?
1:14:56.369,1:15:03.820
(Glorieux) Well, certainly yeah I'd like to make one
which is linked to the psychological

impact of that whole situation. I think that sorry if you if you are isolated

you don't have to keep for yourself. We have social media in a modern way to

communicate by FaceTime, Whatsapp, you know in social networking

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 when I say good

(Ingunn) Hello, I'm Ingunn from OIFE, I would just like to say thank you for allowing

international participants on this call and it's also important to say that the

virus is various stages in different countries and it's 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 who can get to the ER, etc so it's very

important also to seek on your local authorities web pages.

(Sandhaus) Great, thank you that's very important
and so glad that you're on the call, I

would like to just add that the it's
great to hear the kind of questions that

people are asking you know, as we learn more about this I think

you can turn to the oh I foundation to
find out the latest things that we've

that we've learned both from any OI
patients that we might learn about or

from the general population as you know
there are a bunch of studies going on

with potential therapies against the
Covid-19 virus infection as well as

work on that vaccines for for the
Covid-19. None of these are likely to

be appearing in your drug shelf
anytime real soon but at least know that

this is instilling full speed ahead
around the world to try to solve this

issue. (Tracy) Wonderful! I guess that Michael any
parting words from you on how we leave

this call? (Michael) So again I want to thank
everyone and if you have questions for

us, please reach out that Bonelinke@oif.org. Thank you all so much.

Stay healthy, and we'll see you soon.
(Tracy) Thanks everyone!