

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

0:00:00.000,0:00:06.060

One hundred and six, okay, fantastic! okay so now we're rapidly rising above I want to

0:00:06.060,0:00:09.900

just reintroduce myself very quickly. My name is Michael Stewart I work at the

0:00:09.900,0:00:14.700

OI Foundation as the regional program services manager. I want to thank you all

0:00:14.700,0:00:19.890

for joining us today. A quick note on some of the rules and procedures we're

0:00:19.890,0:00:24.300

gonna try and follow in this call so like many of you the OIF now is

0:00:24.300,0:00:27.599

practicing good social distancing policies so we're working from home so

0:00:27.599,0:00:33.390

you're all getting a lovely view of my living room right now but I can

0:00:33.390,0:00:36.870

imagine looking into many of your living rooms as well but we want to let people

0:00:36.870,0:00:40.829

know that for this call because this would be a lot of microphones a lot of

0:00:40.829,0:00:42.920

people on this call. We are at 121 (people) right now and it could probably keep climbing

0:00:42.920,0:00:46.350

for

0:00:46.350,0:00:50.910

a while. Please mute your microphones throughout the call unless you're

0:00:50.910,0:00:54.960

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

0:01:27.180,0:01:32.790

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

0:01:52.200,0:01:56.759
appreciate your patience and if you have
any questions feel free to pacifically a

0:01:56.759,0:02:02.579
message I'm oh I F staff my name is
Michael Stewart so with that being said

0:02:02.579,0:02:07.940
I'm going to bring it over to Tracy Hart
who is the CEO of the OI Foundation.

0:02:07.940,0:02:12.780
(Tracy) Hi everybody! Thanks Michael thanks so
much for for

0:02:12.780,0:02:15.690
getting us started and thanks to all of
you for being here. I see so many

0:02:15.690,0:02:20.100
familiar faces
I'm loving connecting with everyone here

0:02:20.100,0:02:25.410
in the US and Canada and all over the
the world so so glad you're here today!

0:02:25.410,0:02:29.610
So this is a challenging time for all of
us. We all know that and as a community I

0:02:29.610,0:02:35.760
think it's so important that we share the
information and we share the best

0:02:35.760,0:02:39.900
information that we have. The OI
Foundation is committed to doing that

0:02:46.410,0:02:54.390
know right now about Covid-19 and how it may
affect people with OI, especially from

0:02:54.390,0:02:59.970
a pulmonary and respiratory perspective
but also just in general information

0:02:59.970,0:03:05.819
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

0:04:21.150,0:04:26.850

defend your land and that was not easy.

Today we are in a war

0:04:26.850,0:04:34.050

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

0:04:34.050,0:04:38.460

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

0:04:38.460,0:04:46.920

but it's still you know away trying
times. OI, I don't have to introduce the

0:04:46.920,0:04:56.910

condition to you, you live with it and at
different levels and certainly it's not

0:04:56.910,0:05:05.310

easy every day the thing to remember in
this perspective is that the major

0:05:05.310,0:05:14.940

defect in your DNA if you will is linked
to a molecule which is collagen which is

0:05:14.940,0:05:20.100

present in bone and make all the
problems that you know about bone

0:05:20.100,0:05:27.240

brittleness and deformities with that
molecules is also present in the lung

0:05:27.240,0:05:33.540

and it's integral part of the lung
tissue itself so any abnormality in the

0:05:33.540,0:05:40.320

it structure will affect also the
structure of the bone of the lung tissue

0:05:40.320,0:05:48.990

and it's a possibility to fill fulfill
its function so that's why we have to

0:05:48.990,0:05:59.220

consider that lung is a target of those
mutation and neither is an organ that we

0:05:59.220,0:06:06.990

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

0:07:34.180,0:07:39.939
here in the US that might be different
than the guidelines that you have in

0:07:39.939,0:07:45.550
your particular countries or even
localities, so please listen to what's

0:07:45.550,0:07:53.860
local what's local is often best. I'm
gonna just show a few slides primarily

0:07:53.860,0:08:03.519
because I just thing we get this going
because there's a lot of words on them

0:08:03.519,0:08:08.259
and sometimes helps to see them as well
as hear them. I think the first thing we

0:08:08.259,0:08:12.939
need to do is talk about some of the
terms that you've heard from your

0:08:12.939,0:08:20.649
newscasts and and the like. We refer to
the disease caused by this novel

0:08:20.649,0:08:22.360
coronavirus as Covid-19

0:08:24.600,0:08:29.050
Covid-19 and the virus
itself is either called novel

0:08:29.050,0:08:37.149
coronavirus or SARS Co-V2 because it
says ninety percent similarity with the

0:08:37.149,0:08:44.920
SARS virus that caused some
deaths around the world several years

0:08:44.920,0:08:51.070
ago which is also a corona virus. So I'll
refer through this mostly as COVID-19

0:08:51.570,0:08:57.340
because it's the easiest to say and
Francis addressed why we'd want to

0:08:57.340,0:09:02.860

talk about this in OI populations over
and above the general public and I'll

0:09:02.860,0:09:12.280
kind of talk about that. In terms of
general recommendations the best source

0:09:12.280,0:09:18.640
for specific recommendations and answers
to your questions is going to be your

0:09:18.640,0:09:23.590
own local physician or medical center
because they really know what's going on

0:09:23.590,0:09:27.280
in your neighborhood. There are big
differences between urban areas and

0:09:27.280,0:09:31.510
rural areas in terms of numbers of
people identified things like that and

0:09:31.510,0:09:44.350
each locality is pretty much putting
forward its own (please mute your

0:09:44.350,0:09:52.600
microphones if they're not muted) you can
stay informed in the US by visiting the

0:09:52.600,0:09:57.850
CDC website. They just updated their
website yesterday to have a much more

0:09:57.850,0:10:02.920
user-friendly approach to finding
information and this link that you see

0:10:02.920,0:10:11.020
on the slide will be available to you
beyond this talk so don't bother writing

0:10:11.020,0:10:19.630
it down now. You that will be provided to
you that's the general recommendations

0:10:19.630,0:10:25.210
for everyone not just people with OI
in the u.s. are listed on these two

0:10:25.210,0:10:30.880

slides. First, is the concept of social distancing which I'm sure you've heard a

0:10:30.880,0:10:37.420

lot about this includes when in public or even when visitors come to your home

0:10:37.420,0:10:41.680

they attempt to stay at least six feet away from other people in your immediate

0:10:41.680,0:10:48.670

area. Try not to shake hands or touch the skin of other individuals if you do that

0:10:48.670,0:10:53.170

reflexively you should really wash your hands using the directions that we'll go

0:10:53.170,0:10:57.670

over in a little while. And the current recommendations from the

0:10:57.670,0:11:03.190

CDC are to avoid groups of more than 10 people even if you think that time of

0:11:03.190,0:11:08.380

you can stay six feet apart from each other there are specific recommendations

0:11:08.380,0:11:13.840

to avoid pretty much all except non-essential air travel. You can make up

0:11:13.840,0:11:19.840

whatever you want for "non-essential." We certainly recommend against going on

0:11:19.840,0:11:23.440

cruise ships because of the closed environment it's

0:11:23.440,0:11:28.330

an incubator for infections to be passed to one another. And in areas of high

0:11:28.330,0:11:34.570

prevalence most localities that have major public transportation systems are

0:11:34.570,0:11:42.550

suggesting that people avoid public transportation unless necessary for

0:11:42.550,0:11:48.130
everyone and please avoid close contact with people who have respiratory

0:11:48.130,0:11:52.840
illnesses especially acute respiratory illnesses, not chronic disease, but

0:11:52.840,0:11:59.320
respiratory illnesses that have started within the last four weeks or so. If you

0:11:59.320,0:12:05.710
become sick whether it's the flu, a cold, or the corona virus please limit your

0:12:05.710,0:12:10.960
contact with others as much as possible stay home if you're sick, we call this

0:12:10.960,0:12:15.310
"self isolation." Family members who live with you should follow exactly the same

0:12:15.310,0:12:20.170
restrictions that you do the presumption is if you're sick family members who

0:12:20.170,0:12:31.230
live in the same house or have been exposed. Other general recommendations:

0:12:31.230,0:12:37.180
some localities have adopted, especially in the west coast of the United States, a

0:12:37.180,0:12:42.160
shelter-in-place directive in these areas individuals whether infected or

0:12:42.160,0:12:48.640
not are asked not to leave their homes except for exceptions that are kind of

0:12:48.640,0:12:56.010
outlined at each locality for instance going to get a prescription, getting food,

0:12:56.010,0:13:01.390

delivering food things, like that are
listening it's exceptions to the to the

0:13:01.390,0:13:05.000
recommended nation that you not leave
your home.

0:13:05.000,0:13:10.460
Important for protecting those around
you: cover your nose and mouth when you

0:13:10.460,0:13:15.350
cough or sneeze. This is independent of
whether you have symptoms or not it's

0:13:15.350,0:13:19.550
best to cover your mouth and nose with a tissue. Immediately discard
the

0:13:19.550,0:13:24.500
tissue and then wash your hands
avoid touching your eyes nose and mouth

0:13:24.500,0:13:31.190
with unwashed hands and that's a that's
the main mode of entry of this novel

0:13:31.190,0:13:38.420
coronavirus into the body is through the
eyes, nose, mouth. Clean and disinfect

0:13:38.420,0:13:42.190
surfaces and objects that may be
contaminated with germs.

0:13:42.190,0:13:46.550
Coronavirus can spread by cough and
the virus can live on solid surfaces for

0:13:46.550,0:13:52.070
many hours if not days depending on the
type of surface if it's not disinfected

0:13:52.070,0:13:57.400
obviously there's some shortage of

0:13:58.390,0:14:03.650
disinfectant wipes and things like that.
You can go to the CDC website and see

0:14:03.650,0:14:10.030
how to make your own disinfectant wipe

form isopropyl alcohol peroxide and

0:14:10.030,0:14:17.510
glycerin. Most important of all wash your hands often with soap and water for at

0:14:17.510,0:14:22.070
least 20 seconds.
You've probably heard - if you sing

0:14:22.070,0:14:27.170
Happy Birthday twice while you're washing your hands that's a pretty good

0:14:27.170,0:14:33.290
estimate if for washing your hands for at least 20 seconds I've got my happy

0:14:33.290,0:14:36.860
birthdays down to eighteen seconds so I do a couple of extra wipes

0:14:36.860,0:14:41.480
if soap and water aren't available use alcohol-based hand rubs with at least

0:14:41.480,0:14:48.100
60% alcohol that 60% figure is specific for this coronavirus and other

0:14:48.100,0:14:52.940
coronaviruses that it the alcohol content needs to be at least 60% in

0:14:52.940,0:14:56.960
order to kill the virus and don't forget to scrub all parts of your hand and

0:14:56.960,0:15:00.800
continue scrubbing until your hands and fingers are dry

0:15:00.800,0:15:07.619
when using the alcohol hand rubs.
Try to maintain a two-week supply of

0:15:07.619,0:15:12.599
food and water at your home if possible, and if possible maintain an extra supply

0:15:12.599,0:15:17.429
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

0:16:46.259,0:16:50.429

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

0:16:50.429,0:16:56.669

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

0:16:56.669,0:17:04.829

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

0:17:04.829,0:17:09.779

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

0:17:09.779,0:17:16.829

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

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

0:17:20.740,0:17:25.750

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

0:17:25.750,0:17:30.670

from Covid-19 who were under 10 who are

0:17:30.670,0:17:41.620

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

0:17:41.620,0:17:46.510

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

0:17:46.510,0:17:56.260

these recommendations strictly because of the presumed increased risk of

0:17:56.260,0:18:00.790

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

0:18:00.790,0:18:05.710

on how severe the lung disease is a big factor in whether you get severe

0:18:05.710,0:18:12.460
complications is your age, the older you
are the more, likely you are this

0:18:12.460,0:18:17.049
will be a simple flu-like illness and
that will actually affect things more

0:18:17.049,0:18:21.340
seriously. What do we mean by more
seriously? Well, the major complication

0:18:21.340,0:18:26.200
that individuals who wind up getting
admitted to the hospital have is viral pneumonia.

0:18:26.200,0:18:36.549
And that viral pneumonia is
both sides of the lung basically it

0:18:36.549,0:18:43.030
affects all the lobes of the lung and in
patients who have survived severe viral

0:18:43.030,0:18:48.850
pneumonia due to Covid-19, there those
individuals have been left with some

0:18:48.850,0:18:52.330
scarring and fibrosis
in their lung after they've recovered.

0:18:52.330,0:18:58.870
Now we know from other diseases that
cause this type of pneumonia and what's

0:18:58.870,0:19:05.190
called a RDS, acute respiratory distress
syndrome, we know that that fibrosis and

0:19:05.190,0:19:11.110
impaired lung function after recovery
can actually ...the lung function can

0:19:11.110,0:19:18.040
actually improve over the months
following such a an infection and a

0:19:18.040,0:19:23.669
pneumonia. We don't know if that's going
to happen in Covid-19 but it seems likely

0:19:23.669,0:19:32.830
because the similarities of pneumonia
we're seeing versus the pneumonia that

0:19:32.830,0:19:39.730
we know from other viral infections even
corona virus infections going on to

0:19:39.730,0:19:46.480
recover. So the main cause of death is
respiratory failure and organ failure,

0:19:46.480,0:19:52.000
multiple organ failure if someone gets
ARDS and gets a bacterial infection

0:19:52.000,0:19:59.140
on top of the viral infection, but please
remember it's with all of the thousands

0:19:59.140,0:20:04.210
and thousands and tens of thousands of
people that have been infected, the total

0:20:04.210,0:20:11.020
number of infected individuals who've
actually died from these infections is a

0:20:11.020,0:20:16.330
is a small fraction of those who are
infected. We don't know the exact amount

0:20:16.330,0:20:27.450
because in the US the testing for
Covid-19 is still very much restricted.

0:20:27.450,0:20:35.500
We expect that if there were universal
availability of Covid-19 testing that

0:20:35.500,0:20:40.390
we'd find hundreds of thousands of
individuals with infection and that

0:20:40.390,0:20:46.000
would make the death rate become much
smaller.

0:20:46.000,0:20:51.890
Having said that, I don't want to
diminish the risk should someone get

0:20:51.890,0:20:56.690
infected and when there are ways to
prevent infection likely recommendations

0:20:56.690,0:21:01.910
that have been put forward it would be
silly not to try to prevent getting

0:21:01.910,0:21:06.650
infected even if you're a young
individual even if you'd have no

0:21:06.650,0:21:12.150
pulmonary symptoms related to your OI or other conditions.

0:21:12.150,0:21:18.230
And that's all I have in the way of the
slides. Mike, if you could turn the

0:21:18.230,0:21:24.510
screenshare off. Great, thanks very much
and I think the most important thing at

0:21:24.510,0:21:30.020
this point is to answer questions that
have come forward. I do want to

0:21:30.020,0:21:38.880
acknowledge the psychological impact of
the all the information that's pouring

0:21:38.880,0:21:46.530
from TV screens, radios, newspapers in a
tidal wave at all of us and the changes

0:21:46.530,0:21:52.370
that's affected in our lives the changes
in our workplace the growing economic

0:21:52.370,0:22:05.070
impact of this infection like weighs on
individuals greatly and it's really

0:22:05.070,0:22:12.420
important to take a break sometimes from
the news channels and the and the

0:22:12.420,0:22:15.140
newspapers

0:22:15.380,0:22:21.480

try not to concentrate on it. Enjoy your time with family that you might have not

0:22:21.480,0:22:26.460
had if you didn't have to stay home from work. I'm doing that. I'm considered to be

0:22:26.460,0:22:31.770
in a high-risk group in fact Dr. Glorieux and I are both in the high-risk group of

0:22:31.770,0:22:37.740
being elderly and tough to acknowledge that but happy to to get chance to spend

0:22:37.740,0:22:44.550
with my with my wife at home which is what I've been doing and only going in

0:22:44.550,0:22:52.280
when I have to see a patient has flown in to to see me at National Jewish [Hospital].

0:22:52.280,0:22:57.300
I reassure you and my family that I'm not working in the intensive

0:22:57.300,0:23:02.600
care unit because I'm in a high-risk group but there's an amazing

0:23:02.600,0:23:07.520
dedication going on with the high-risk

0:23:07.580,0:23:16.920
individuals with the ICU doctors in my institution. the ICU doctors are doing 24

0:23:16.920,0:23:24.330
hour a day seven days and then they get 14 days off to self isolate at home to

0:23:24.330,0:23:29.200
find out a thing been infected and after that 14

0:23:29.200,0:23:35.830
days they come back and do seven 24 hours shifts again so and we're and

0:23:35.830,0:23:38.950
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,

0:25:00.360,0:25:08.289

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

0:25:08.289,0:25:12.789

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

0:25:12.789,0:25:16.419

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

0:25:16.419,0:25:19.809

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

0:25:19.809,0:25:23.740

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

0:25:23.740,0:25:27.640

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

0:25:27.640,0:25:32.260

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

0:25:32.260,0:25:37.750

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

0:25:37.750,0:25:41.320

Covid-19
with people with OI compared to that

0:25:41.320,0:25:52.440

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

0:25:52.440,0:25:57.480

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

0:25:57.480,0:26:04.630

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

0:26:04.630,0:26:08.200

who've been identified because of the

restrictions on testing in the US at

0:26:08.200,0:26:14.200

least overall has been relatively low compared to the number we think are out

0:26:14.200,0:26:21.460

there with infection, and in most rare diseases there is not an effort at this

0:26:21.460,0:26:29.920

point to find out if there are specific concerns or heightened infectivity for

0:26:29.920,0:26:36.520

instance in people who are have one of these rare diseases like OI. In other

0:26:36.520,0:26:40.410

words, we don't know. We assume that people with OI and other rare diseases

0:26:40.410,0:26:46.720

aren't more likely to get infected but we do think that they if infected

0:26:46.720,0:26:50.530

they're more likely to get severe disease if there's if they're rare

0:26:50.530,0:26:58.690

disease includes lung issues and so that's the that was the point of my last

0:26:58.690,0:27:04.869

slide here and the second part of the question had to do with loss?

0:27:04.869,0:27:10.600

(Michael) it kind of the first part is are there any any difficulties with

0:27:10.600,0:27:17.020

treating Covid-19 compared to that with other people? (Sandhaus) Compared with other OI patients?

0:27:17.020,0:27:23.710

it's well you know putting it the the final sort of treatment stuff that

0:27:23.710,0:27:28.540

happens in patients that get severe

disease is they wind up on a ventilator

0:27:28.540,0:27:34.540
or respirator. A tube in their lungs with
a machine breathing for them and that is

0:27:34.540,0:27:39.990
always a risky proposition and people
that have fragile ribs fragile bones

0:27:39.990,0:27:45.730
things like that and so it's really
important that should you were a

0:27:45.730,0:27:50.230
relative find themselves in the
intensive care setting that the

0:27:50.230,0:27:56.739
physicians are aware
of OI and the complications of OI

0:27:56.739,0:28:03.429
and take special steps to reduce the
pressures that a ventilator uses things

0:28:03.429,0:28:10.359
along those lines. And you know I'd be
happy to speak to any physician that is

0:28:10.359,0:28:15.039
caring for someone who's seriously ill
with OI just to review those things

0:28:15.039,0:28:19.539
with them because I'm certain that there
are many intensive care Doc's who have

0:28:19.539,0:28:33.399
never managed (Michael) Excuse me everyone, can we
just make sure that our microphones are

0:28:33.399,0:28:44.519
muted. I appreciate it so I will be down
our organization email it's Bonelink@oif.org

0:28:44.519,0:28:45.960
if you want to contact us and so that
you can get in contact with us so

0:28:45.960,0:28:46.460
So you can get in contact with Dr. Sandhaus

0:28:49.119,0:28:53.649
we can connect you for you so again if
you're just joining us can you please

0:28:53.649,0:28:58.059
just make sure your microphone is muted
so the questions and the answers, thank

0:28:58.059,0:29:04.720
you. I'm going to go onto the next question.

0:29:04.720,0:29:14.139
"Can someone with a cold still use a
incentive spirometer or any spirometer?"

0:29:14.139,0:29:22.690
I mean there's no reason not to use an
incentive spirometer I'm not sure what

0:29:22.690,0:29:28.450
they mean by any spirometer that the
term spirometer usually means a tested

0:29:28.450,0:29:33.249
stun to measure your lung function. While a
incentive spirometer is designed to help

0:29:33.249,0:29:37.450
your respiratory muscles and your
breathing capacity and things like that.

0:29:37.450,0:29:41.320
So there's not a reason not to use an
incentive spirometer

0:29:41.320,0:29:45.129
unless it's an incentive spirometer
you're sharing with other people in

0:29:45.129,0:29:50.349
which case I definitely would not use it.
Again, now many pulmonary function labs

0:29:50.349,0:29:55.529
by the way have closed down in
facilities that are seeing a lot of

0:29:55.529,0:30:02.019
Covid-19 patients because they
found patients who were identified as

0:30:02.019,0:30:09.630
having Covid-19 days or weeks after
they had a lung function test at the

0:30:09.630,0:30:14.380
at the facility. Our pulmonary
function lab at National Jewish is

0:30:14.380,0:30:20.649
closed down because of that.
(Michael) mm-hmm so I just keep going up for they

0:30:20.649,0:30:25.269
You don't need to announce the names Michael.
(Michael) Yeah. My daughter has a OI and is she's

0:30:25.269,0:30:31.269
pregnant. What should she
look out for? (Sandhaus) There have been people with

0:30:31.269,0:30:38.470
Covid-19 who have been pregnant. Number
one, the literature that's out there and

0:30:38.470,0:30:43.059
it's actually surprising how much is
coming out from the experiences around

0:30:43.059,0:30:49.240
the world. The information out there
suggests that mothers with Covid-19 did

0:30:49.240,0:30:55.690
not pass the infection on to their
children to their fetuses. The fetuses

0:30:55.690,0:31:02.549
they're not being born with Covid-19
and it has not affected their pregnancy

0:31:02.549,0:31:09.220
beyond the effect of having either a
complication from Covid-19 or

0:31:09.220,0:31:17.080
respiratory issues from Covid-19 so
there's no special issues as far as we

0:31:17.080,0:31:22.679
know right now regarding pregnancy
except you'd certainly think that

0:31:22.679,0:31:28.269
pregnant women should take extra special
precautions just as general OI patients

0:31:28.269,0:31:36.299
should. (Michael) "If I didn't get a flu vaccine
yet, should I risk going out to get it?"

0:31:36.299,0:31:41.919
(Sandhaus) This is part of a series of questions
I'm sure we're getting that always come

0:31:41.919,0:31:47.740
up in these conversations is the risk
benefit analysis of going to get I mean

0:31:47.740,0:31:51.279
for instance alpha 1...
and deficient patients that I follow

0:31:51.279,0:31:55.870
which is another genetic condition get
weekly infusions of their missing

0:31:55.870,0:32:01.149
protein at an infusion centers and and
the questions I get about that are

0:32:01.149,0:32:05.350
should I skip my infusions so that I'm
not exposed to all the people that are

0:32:05.350,0:32:10.750
at the hospitals or infusion centers I
go to and really it's a

0:32:10.750,0:32:16.450
tough question to answer people need to
weigh those decisions themselves. Ot is

0:32:16.450,0:32:19.800
quite important to get a flu shot still
if you haven't.

0:32:19.800,0:32:28.110
Flu is still a much larger killer in
the general population than Covid-19

0:32:28.110,0:32:34.970
is even in countries that have
already gone through a major you know

0:32:34.970,0:32:41.910
spikes in there covered 19 infections
like China and South Korea and so

0:32:41.910,0:32:46.500
getting the flu shot it's important. I
know that there are some pharmacies that

0:32:46.500,0:32:50.850
will do that in a drive-by setting in
the United States where you just drive

0:32:50.850,0:32:56.670
up stick your arm out of the car and get
your flu shot. I would think that that in

0:32:56.670,0:32:59.990
that situation that the benefit
outweighs the risk.

0:32:59.990,0:33:04.740
Similarly with immunizations against
pneumonia those things are all important

0:33:04.740,0:33:08.700
to have right now because the pneumonia
that the amount that the pneumonia that

0:33:08.700,0:33:13.320
the pneumonia shot protects against is
the kind of pneumonia that can

0:33:13.320,0:33:19.980
complicate a viral pneumonia so the
answer the question is if you can find a

0:33:19.980,0:33:23.280
way to do it with minimal risk it would
be a good idea to get those

0:33:23.280,0:33:32.070
immunizations if you haven't had them
yet. (Michael) Next question is "What about the kids?"

0:33:32.070,0:33:38.580
They say kids are less affected. Is an
OI child also high-risk? Should we

0:33:38.580,0:33:43.290
maintain isolation? Right now we are
home but what about when it's time

0:33:43.290,0:33:53.670
to go to work?" (Sandhaus) So the two things about
kids are there probably is a higher rate

0:33:53.670,0:34:01.020
of mild symptoms in kids and young
adults than in older people but it's not

0:34:01.020,0:34:08.160
an absolute it's not a guarantee that
you won't be have some of the

0:34:08.160,0:34:14.669
complications of Covid-19 just by
being young. The other thing is that kids

0:34:14.669,0:34:21.090
who aren't demonstrating symptoms could
well be infected. As as you know even

0:34:21.090,0:34:25.740
adults who get infected are often
asymptomatic for as long as two weeks

0:34:25.740,0:34:32.590
before a symptoms start and during that
time can infect others and so I know

0:34:32.590,0:34:38.770
in our area even kids who don't have
intrinsic lung disease such as the kind

0:34:38.770,0:34:46.840
that an OI individual can have that kids are
being kept from going on playdates and

0:34:46.840,0:34:51.190
going to playgrounds and seeing their
usual friends. It's a very difficult

0:34:51.190,0:34:56.650
thing for kids and especially for
parents who have cabin fever children

0:34:56.650,0:35:04.510
you know in their in their homes but
still kids can not only become infected

0:35:04.510,0:35:10.390
they can become a reservoir for
infecting other kids and adults. (Michael) Thank

0:35:10.390,0:35:13.720

you.

I'm going to move to a different

0:35:13.720,0:35:18.580

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

0:35:18.580,0:35:24.880

moderate, 4'1", pectus chest deformity. I'm a registered nurse, but not bedside,

0:35:24.880,0:35:29.620

in an office in hospital with a handful of other nurses. The hospitals has yet

0:35:29.620,0:35:34.630

to have any confirmed cases but have several PUIs. Thank you for your time and

0:35:34.630,0:35:40.150

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

0:35:40.150,0:35:45.520

PUI is the patient who is under investigation that has

0:35:45.520,0:35:51.040

symptoms that could become consistent with Covid-19 that does not have the

0:35:51.040,0:35:56.230

test results back yet or can't get a test retest just to clarify what what

0:35:56.230,0:36:03.370

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

0:36:03.370,0:36:11.140

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

0:36:11.140,0:36:18.420

putting themselves in harm's way and so I would say that as the type IV OI

0:36:18.420,0:36:28.330

individual the likelihood is that should you get infection it will be more likely

0:36:28.330,0:36:37.380

to have pulmonary complications than if you didn't have type 4 OI and so your

0:36:37.380,0:36:44.360

decision-making is your own. I think it first sign that there is a growing

0:36:44.360,0:36:50.390

number of individuals in your community who are being tested are testing

0:36:50.390,0:36:56.869

positive I think that it would be reasonable to consider stepping back

0:36:56.869,0:37:02.300

from your work or finding another job in the location where you're working that

0:37:02.300,0:37:06.500

doesn't have direct patient contact, where you could work in a separate

0:37:06.500,0:37:10.250

office or something like that. These things can often be impossible to

0:37:10.250,0:37:16.310

arrange but I think that you will be able to help anyone if you become ill

0:37:16.310,0:37:27.050

and and wind up getting sick and sicker than there than your comrades and in the

0:37:27.050,0:37:34.490

healthcare setting you're working in. (Michael) "If we get infected with Covid-19 and

0:37:34.490,0:37:39.130

fully recover, is our lung function forever diminished?"

0:37:39.130,0:37:44.140

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

0:37:44.140,0:37:49.940

Once you recover no the one I probably wasn't clear enough when I was talking

0:37:49.940,0:37:56.690
about the persistent lung impairment
that was in patients who were in the ICU

0:37:56.690,0:38:02.119
on ventilators who developed what's
called a RDS acute respiratory distress

0:38:02.119,0:38:06.740
syndrome where essentially fluid floods
into their lungs and it becomes very

0:38:06.740,0:38:14.600
difficult to exchange oxygen in the lung
tissue. If you simply have an infection

0:38:14.600,0:38:19.100
and get a flu-like illness, a fever and a
little cough and some simply shortness

0:38:19.100,0:38:22.880
of breath and then it goes away there's
every likelihood that they wouldn't

0:38:22.880,0:38:27.340
affect your overall lung function at all
once you've recovered.

0:38:27.430,0:38:41.109
(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

0:38:41.109,0:38:45.130
if they continue to work outside the
home? I have severe asthma with other

0:38:45.130,0:38:51.309
respiratory issues as well.
Should I self-isolate. I'm 21." (Sandhaus) Some of it

0:38:51.309,0:38:56.980
depends on how how effective your asthma
treatment is if your asthma treatment

0:38:56.980,0:39:01.960
normalizes your lung function then it's
likely that you don't have any greater

0:39:01.960,0:39:08.040
risks if you get one of the things that Covid-19

0:39:11.250,0:39:17.800

it's an interesting guy walking the runway where are we talking the one

0:39:17.800,0:39:23.890

things that Covid-19 infection does especially when it becomes the infection

0:39:23.890,0:39:28.480

becomes severe, the symptoms become severe, is it causes a dramatic increase

0:39:28.480,0:39:36.579

in the inflammation in the airways and that can kick up someone's asthma and so

0:39:36.579,0:39:41.770

it really depends on it's not a simple Covid-19 infection without symptoms.

0:39:41.770,0:39:47.170

That shouldn't be a problem related to your asthma but the sicker that you get

0:39:47.170,0:39:51.760

with Covid-19 the more it can exacerbate your asthma or make your asthma

0:39:51.760,0:39:57.040

worse and so your physician will need to know about your asthma they would

0:39:57.040,0:40:02.170

probably intensify your asthma treatment. The tough questions about your spouse

0:40:02.170,0:40:07.329

working in the general public and coming back yearly and your spouse will have to

0:40:07.329,0:40:13.059

decide on that that's a decision that everyone almost everyone in the country

0:40:13.059,0:40:16.960

is making right now because if people are lucky enough to continue working

0:40:16.960,0:40:24.339

that's just something that they have to decide you it's it's tough to live in

0:40:24.339,0:40:30.190

the same house with someone and be
isolated from them yeah in in reality

0:40:30.190,0:40:36.040

and so it may be that you simply you
know make sure that your spouse is doing

0:40:36.040,0:40:40.990

everything they can to try to avoid
infection and even consider

0:40:40.990,0:40:44.680

finding ways to work where they're not
exposed to the general public for the

0:40:44.680,0:40:47.670

benefit of your health.

0:40:51.480,0:41:03.120

I can't hear you Michael (Michael) Many apologies
a garbage truck was driving by. "So

0:41:03.120,0:41:06.030

there's been a recent study waiting to
be published about the virus being

0:41:06.030,0:41:14.190

airborne. How can we protect ourselves
from that?" (Sandhaus) So the virus that is there

0:41:14.190,0:41:18.960

there's very specific terms for how
things are transmitted the virus is not

0:41:18.960,0:41:25.140

airborne the virus is droplet borne. And
that makes a big difference.

0:41:25.140,0:41:32.820

Airborne transmission can travel for
miles. Droplet transmission only travels

0:41:32.820,0:41:41.270

for about 3 to 4 feet which is why the
recommendation to keep at least 6 feet

0:41:41.270,0:41:49.530

the social distancing recommendation
says to keep 6 feet from someone now if

0:41:49.530,0:41:54.600

a droplet lands on a surface it can survive on that surface depending on

0:41:54.600,0:41:59.910
what the surface is made of for anywhere from hours to a couple of days which is

0:41:59.910,0:42:09.090
why respecting certain those surfaces that that might have been cost on or

0:42:09.090,0:42:19.490
sneezed on or something like that. So the droplet borne infections are very

0:42:19.490,0:42:32.630
effective with social distancing as well as with masks N95 masks.

0:42:33.110,0:42:40.300
Ideally when when masks become readily available it would be it would be

0:42:40.300,0:42:45.940
worthwhile considering wearing a mask whenever you're outside your home

0:42:45.940,0:42:53.240
because they do work to prevent droplet borne transmission. The only reason that

0:42:53.240,0:42:56.810
people aren't recommending that now is because of the shortage of the masks and

0:42:56.810,0:43:05.360
the and the decision that the shortage should be they they read different

0:43:05.360,0:43:11.360
supplies should be used in the health care setting first before people start

0:43:11.360,0:43:16.580
using it outside the health care setting but it's presuming that there will be a

0:43:16.580,0:43:20.630
big influx of mass production and that mass will become more readily available

0:43:20.630,0:43:27.200

I I would recommend that people who are at risk like OI patients wear masks

0:43:27.200,0:43:31.510
when outside their home.

0:43:31.920,0:43:33.980
you

0:43:35.319,0:43:42.589
you're muted again. (Michael) I apologize um so regarding regarding temperature "I

0:43:42.589,0:43:54.349
normally have a higher body temperature does this impact [Covid-19]?" Well it doesn't impact

0:43:54.349,0:43:58.729
in the sense that you're not more susceptible to infection but in terms of

0:43:58.729,0:44:04.910
impacting the recommendations regarding taking your temperature yes and no I

0:44:04.910,0:44:11.420
mean most people who have a higher rep kind of resting body temperature should

0:44:11.420,0:44:18.920
get different thermometers but the but definitely you're looking for a change

0:44:18.920,0:44:25.420
from your baseline in your body temperature and so you can you know add

0:44:25.420,0:44:34.700
1.5 degrees or one degree higher than you're in Fahrenheit to your baseline

0:44:34.700,0:44:42.160
body temperature to be to identify when you should be concerned so in that sense

0:44:42.160,0:44:47.209
yes you probably have to correct for that when looking at the recommendations

0:44:47.209,0:44:54.140
of when to be concerned in our in our city we're not asking people to come and

0:44:54.140,0:44:59.380
get tested until their temperature
reaches a hundred degrees Fahrenheit

0:44:59.380,0:45:05.390
that's partly because most people who
have infection that's symptomatic have

0:45:05.390,0:45:11.359
temperatures of 103 to 104. One of the
things related to asthma patients and

0:45:11.359,0:45:16.759
patients are an underlying chronic
obstructive pulmonary disease COPD is

0:45:16.759,0:45:21.140
that the three the three things that are
asked when you're doing a verbal

0:45:21.140,0:45:27.440
screening for the likelihood that
someone's infected this they ask do you

0:45:27.440,0:45:31.489
have a fever
do you have increased shortness of

0:45:31.489,0:45:37.099
breath and do you have increased cough?
Well, any patient that has chronic lung

0:45:37.099,0:45:41.119
disease know that there are many times
when they're coming to a physician

0:45:41.119,0:45:44.469
because they're having increased
coughing increased shortness of breath

0:45:44.469,0:45:53.300
so a lot of patients that have frequent
exacerbations as they're called are being
told. The key finding to decide whether

0:45:53.300,0:45:56.990
you need to report to the medical
setting is whether you have a high

0:45:56.990,0:46:02.990
temperature and high temperature is

uncommon in exacerbations of asthma or

0:46:02.990,0:46:09.170
exacerbations of COPD and so really
you're even though you should be

0:46:09.170,0:46:14.750
concerned when your temperature starts
to rise true Covid-19 infection gives

0:46:14.750,0:46:25.690
you pretty high fevers it's not
something subtle. (Michael) So this goes to the

0:46:25.690,0:46:33.950
part you were talking about before with mental health and
risk benefit analysis. "Would it be safe

0:46:33.950,0:46:37.640
to go to public parks? Staying in the
house 24/7 is stressful,

0:46:37.640,0:46:42.800
especially having having recovered from
recent fractures." (Sandhaus) It's recommended that

0:46:42.800,0:46:47.090
people who are at self-isolation and
even people who are on this shelter in

0:46:47.090,0:46:51.890
place take some time to go outside get
some sunshine get some exercise stretch

0:46:51.890,0:46:56.330
your legs get out from the house you
just have to avoid going to places where

0:46:56.330,0:47:01.310
you're exposed to many other people if
you're going to a park don't go to the

0:47:01.310,0:47:05.120
playground where you know you sit on a
swing and you hold the chain or

0:47:05.120,0:47:09.980
something like that that someone else
has touched you know ten minutes before

0:47:09.980,0:47:14.930
you did. Just take a nice look for a

beautiful location if you've got one

0:47:14.930,0:47:20.350
near you it will help every day.

0:47:20.609,0:47:27.310
(Michael) "So I have heard that we should not be taking anti-inflammatory medications. Can

0:47:27.310,0:47:33.910
this be verified?" (Sandhaus) So the this is based on an anecdotal reports from the French

0:47:33.910,0:47:41.550
literature in which they found that people who had more severe lung problems

0:47:41.550,0:47:49.210
had a higher incidence of having taken nonsteroidal anti-inflammatory agents

0:47:49.210,0:47:56.200
like ibuprofen, Aleve, things like that there's a problem with that. People who

0:47:56.200,0:48:01.600
are sicker are probably more likely to have taken at on planetary agents. They

0:48:01.600,0:48:06.900
were getting sicker they probably had higher fevers, they probably took extra

0:48:06.900,0:48:14.740
to get that fever down because people have told me that nonsteroidals don't do

0:48:14.740,0:48:20.410
a very good job of lowering the fever in Covid-19 and so it could be kind of a

0:48:20.410,0:48:26.170
self-fulfilling story the people who were sicker take nonsteroidals and

0:48:26.170,0:48:31.359
therefore that there were sicker so they wind up in the hospital and in the ICU

0:48:31.359,0:48:35.950
and things like um the current recommendations that we're hearing both

0:48:35.950,0:48:39.430
local authorities and federal
authorities who are asked this question

0:48:39.430,0:48:45.790
is don't take beyond the recommended
dosages of Tylenol that's not a

0:48:45.790,0:48:53.460
nonsteroidal or the nonsteroidals which
include aspirin ibuprofen Naproxen

0:48:53.460,0:48:57.340
things along those lines.
Take them to reduce your fever and

0:48:57.340,0:49:01.510
reduce there's a lot of aches and pains
that are associated with Covid-19

0:49:01.510,0:49:08.619
infection. Take them if you need them;
minimize the amount you take and never

0:49:08.619,0:49:17.100
take more than a recommended dose. (Michael) So the
next question is very specific for the OI

0:49:17.100,0:49:23.770
community is "If we can maintain the
social distancing standards,

0:49:23.770,0:49:31.030
is it safe to swim or can the Covid-19
spread in a body of water?" (Sandhaus) So that's a

0:49:31.030,0:49:35.890
great question that I haven't heard
before. It is true that we know that

0:49:35.890,0:49:37.890
chlorine disinfectants are highly effective at killing Covid-19.

0:49:43.280,0:49:49.100
or rather killing the virus that causes
Covid-19 and so I would think if you have

0:49:49.100,0:49:59.690
a well you know regulated cool that uses
chlorine you know stabilization of the

0:49:59.690,0:50:06.800

bacterial load in the in the pools that
you could consider that I have to say

0:50:06.800,0:50:10.760

this is off the top of my head they
start knowing that chlorine and bleach

0:50:10.760,0:50:16.790

are good at killing the virus and I've
not seen any recommendations about that

0:50:16.790,0:50:24.080

I probably you know I don't know what I
would say about swimming in the bodies

0:50:24.080,0:50:27.260

of water
other than the pool I would think of

0:50:27.260,0:50:32.650

swimming in the ocean is not an issue
you know that with the changes in the

0:50:32.650,0:50:38.450

that come with each wave; who knows. I
wish it was I wish I was in the middle

0:50:38.450,0:50:42.410

of the snowstorm and I start thinking
about jumping into the water I thought

0:50:42.410,0:50:52.190

that's what we're doing in Denver right
now so I have to say that looking at

0:50:52.190,0:50:56.870

myself on the screen and learning how
many times I touch my face in spite of

0:50:56.870,0:51:00.500

telling everyone they shouldn't be
touching their face. (Michael) I see everyone

0:51:00.500,0:51:11.440

nodding on screen so we agree with you. So we have a set of
questions all related to

0:51:11.440,0:51:16.400

recovery so I'm going to sort of like
lead three of them in a row but they're

0:51:16.400,0:51:21.500
all kind of the same. "what is the
identifier of 'recovery'? The absence of the

0:51:21.500,0:51:26.120
absence of symptoms? a negative test? or
both? Is it true that when someone test

0:51:26.120,0:51:29.420
positive,
they won't test negative after they

0:51:29.420,0:51:34.010
recover? and once you've... once you're
deemed recovered is there any chance

0:51:34.010,0:51:40.000
that you can still be contagious?" and I
just touch my face as I said that! (Sandhaus) So the

0:51:40.000,0:51:46.880
the recommendations in the u.s. vary
from location to location.

0:51:46.880,0:51:56.089
You do stop shedding virus when you when
your symptoms go away after you've had

0:51:56.089,0:52:02.900
Covid-19 infections. For instance, the
recommendations at my institution for

0:52:02.900,0:52:07.700
when you're allowed to go back to work
if you've had a Covid-19 infection far

0:52:07.700,0:52:16.670
but you have to be symptom free if
you've had symptoms for a week and then

0:52:16.670,0:52:25.400
you have to have two negative Covid-19
tests that or at least 24 hours apart I

0:52:25.400,0:52:32.480
know that in New York they're requiring
three tests that are negative each at

0:52:32.480,0:52:41.059
least 24 hours apart I do want to get
into the weeds a little the covered 19

0:52:41.059,0:52:47.450
testing that's currently being done
looks for the viral DNA and so to say

0:52:47.450,0:52:52.670
that someone is negative means they not
only don't have any virus, they don't

0:52:52.670,0:52:57.740
have any viral DNA. You can be positive a
week after all your symptoms are gone

0:52:57.740,0:53:02.569
but have no active viral particles
because they're not measuring whether

0:53:02.569,0:53:07.759
someone has a active infection
infectious virus. We're measuring when

0:53:07.759,0:53:13.460
there's any DNA left that's from the
virus in the back of your throat or in

0:53:13.460,0:53:19.279
your nose and the the test and for those
who don't know is a swab of the nose of

0:53:19.279,0:53:26.119
throat looking for this DNA and so it's
a very strict rule but it also implies

0:53:26.119,0:53:31.849
that yes when people recover they don't
have virus anymore the big question of

0:53:31.849,0:53:36.770
course is
can some get infected again after

0:53:36.770,0:53:46.100
they've been if those are covered from
Covid-19. The the exact answer to that

0:53:46.100,0:53:52.790
is still not known entirely but it
appears that if you recover from Covid

0:53:52.790,0:53:58.670
19, you cannot be reinfected by that
version of the Covid-19

0:53:58.670,0:54:05.690
virus, I'm on the other hand the
expectation is that this is the virus

0:54:05.690,0:54:11.180
caused encoded by Covid-19 will mutate over
the months at home and so it is possible

0:54:11.180,0:54:16.610
the people can get reinfected with
virus mutates enough that the immunity

0:54:16.610,0:54:21.290
you've built up is not effective at
stopping it have you heard anything else

0:54:21.290,0:54:24.620
Dr. Glorieux about reinfection and things
like that?

0:54:24.620,0:54:27.970
particularly your muted

0:54:29.420,0:54:35.329
(Glorieux) uh-huh no sandy I just heard a same as
you. There is no evidence that that may

0:54:35.329,0:54:45.260
happen but it's still an open question
yeah thank you though

0:54:45.260,0:54:51.559
(Michael) Up next there's a severe blood shortage
"I usually give blood should I risk going

0:54:51.559,0:54:58.809
to do?" (Sandhaus) This um I think that you need to
call the donation center and ask them

0:54:58.809,0:55:03.589
talk to them about the precautions that
they're taking I know that for most

0:55:03.589,0:55:10.130
blood donation centers they are doing
dramatic disinfection protocols between

0:55:10.130,0:55:15.200
donors the one thing that's important to
know is that there is absolutely no

0:55:15.200,0:55:20.960

evidence that kovat 19 virus can be transmitted by infusions or by plasma

0:55:20.960,0:55:26.299
products for instance if any of you are on Prince's IVIG infusions and things

0:55:26.299,0:55:31.369
like that there's no evidence that plasma products derived from blood can

0:55:31.369,0:55:37.220
transmit the virus and so there's actually a shortage of blood and they're

0:55:37.220,0:55:42.319
recommending that people go you should assess for yourself the steps

0:55:42.319,0:55:49.760
that the blood bank is taking to protect the donors I fully expect that most of

0:55:49.760,0:55:54.650
them are doing well I have to say I have been disappointed by stories I collect

0:55:54.650,0:56:02.710
from around the country about health care workers who are kind of blase about

0:56:02.710,0:56:06.230
doing the protective measures I don't think that will happen to the blood bank

0:56:06.230,0:56:13.130
but certainly home nursing I've had home nurses go into patients homes and and

0:56:13.130,0:56:17.180
act like they don't have to do any of the things that are recommended because

0:56:17.180,0:56:21.829
after all their health care workers and and this isn't a big deal they've done

0:56:21.829,0:56:25.819
with viruses before kind of kind of things now these stories stand out it's

0:56:25.819,0:56:32.240

certainly not the general practice of most health care professionals but you

0:56:32.240,0:56:37.369
really need to be the ones that evaluate what's being done to keep you safe when

0:56:37.369,0:56:41.540
you're in a situation when they're left your situation or situation we're going

0:56:41.540,0:56:48.589
to donate blood
or considerate the next question is if

0:56:48.589,0:56:53.359
(Michael) "If you have OI and have never had any lung issues, are you still at a higher risk

0:56:53.359,0:56:57.019
than the rest of the population?"
and sort of a mirror

0:56:57.019,0:57:01.519
question to this is "Are all the types of OI patients considered high-risk? even

0:57:01.519,0:57:13.099
(Sandhaus) I will emphasize that that our warnings to OI patients are only based on our

0:57:13.099,0:57:20.539
clinical opinions and we read we mask it by saying their expert opinions but

0:57:20.539,0:57:27.559
really no one's an expert yet on the lung issues in OI. you know I um
our

0:57:27.559,0:57:32.569
opinions basically say we know that there's deranged collagen in the lung.

0:57:32.569,0:57:38.930
we're of our patients we know that OI patients have abnormal lung function

0:57:38.930,0:57:47.569
even those with type 1 OI and we know that that respiratory problems are the

0:57:47.569,0:57:55.999

main killers of OI patients in general,
not just in times of viral infection and

0:57:55.999,0:58:02.779
so putting those things together we
right we are presuming that OI

0:58:02.779,0:58:09.319
patients are likely to have an increased
risk of things that that focus on the

0:58:09.319,0:58:13.089
lungs as Covid-19 does.

0:58:13.730,0:58:17.869
A given individual who hands me a lung
function test that's perfectly normal

0:58:17.869,0:58:22.760
and it's never had a problem in their
with their lungs in their life can I say

0:58:22.760,0:58:27.590
whether that person is an increased risk?
I can't, but but discretion is the better

0:58:27.590,0:58:34.850
part of valor you know you probably want
to at least consider that when the

0:58:34.850,0:58:38.330
sudden which you're going to do in terms
of protecting yourself the possibility

0:58:38.330,0:58:41.900
that even healthy OI patients healthy in terms of their

0:58:41.900,0:58:49.330
lungs could be at some small increased
risk compared to the general population.

0:58:49.330,0:58:56.240
(Michael) The next set of questions are about
face masks. "In lieu of scarce masks

0:58:56.240,0:59:00.350
would it help if people wore scarves or
bandannas over their nose and mouth

0:59:00.350,0:59:05.359
when outside?" and a similar question is
"Can you confirm whether or not face

0:59:05.359,0:59:17.359
masks are one-time use?" (Sandhaus) So first of all
I'm in the awkward situation because the

0:59:17.359,0:59:21.350
CDC is now recommending to healthcare
workers that they use scarves and

0:59:21.350,0:59:25.580
bandanas if there aren't any face mask
available. There's actually no evidence

0:59:25.580,0:59:30.650
that scarves and bandanas are effective
at preventing droplet transmitted

0:59:30.650,0:59:38.540
diseases. Maybe some of those droplets
will land on you know a strand of wool

0:59:38.540,0:59:47.210
in a scarf and not get into your mouth
but it would probably reduce a fraction

0:59:47.210,0:59:54.770
of the risks but but not have the same
type of beneficial effect of a the

0:59:54.770,1:00:07.520
natural surgical mask or even better, an
n95 mask will have. the What was the

1:00:07.520,1:00:14.840
second thing the next question was "Are
these truly one-time use only." (Sandhaus) well no

1:00:14.840,1:00:16.840
They are in the setting of plethora of availability. It's always

1:00:23.990,1:00:29.230
wise to use them once and
scarred them because if you're wearing

1:00:29.230,1:00:34.120
it to protect yourself once you've been
exposed to people who might have

1:00:34.120,1:00:43.560
droplets, the entire outside of the mask
is presumably teeming with droplets of

1:00:43.560,1:00:50.080

that contained Covid-19 virus that had been stopped from being held by you and

1:00:50.080,1:00:55.390

so you'd prefer not to have to use put it on again and you certainly don't want

1:00:55.390,1:00:59.170

to touch the front of the mask and when you're taking it off and things like

1:00:59.170,1:01:08.950

that but the in in times like this where masks are in short supply the fact is

1:01:08.950,1:01:14.020

the masks remain effective for several days of use before they get entirely

1:01:14.020,1:01:21.640

saturated and and and they're conveying have a higher risk of not being

1:01:21.640,1:01:28.180

effective at blocking those droplets. Remember the mask is not preventing it

1:01:28.180,1:01:33.310

can't prevent viruses from being inhaled; it prevents the droplets that are

1:01:33.310,1:01:38.780

carrying those viruses from getting to your mucous membranes.

1:01:38.780,1:01:45.230

(Michael) Thank you! "Are there any other symptoms that we can be on alert for other than

1:01:45.230,1:01:50.090

elevated temperatures in which could indicate we had contracted the virus?" all

1:01:50.090,1:01:54.500

sevens is right there yeah yeah because you see after getting the second

1:01:54.500,1:02:01.850

question I often times will do monitor the there are a couple of other symptoms

1:02:01.850,1:02:07.490

that have become prominent you know when we talk about patients we've seen you

1:02:07.490,1:02:12.080

know in the doctors lounge and those include diarrhea and body

1:02:12.080,1:02:17.360

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

1:02:17.360,1:02:26.210

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

1:02:26.210,1:02:34.210

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

1:02:34.210,1:02:41.090

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

1:02:41.090,1:02:47.690

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

1:02:47.690,1:02:52.010

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

1:02:52.010,1:02:56.570

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

1:02:56.570,1:03:04.490

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

1:03:04.490,1:03:09.170

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

1:03:09.170,1:03:13.490

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

1:03:13.490,1:03:19.040

it or should we attempt to treat it at home with any medications our primary

1:03:19.040,1:03:25.730

care provider may call in for us at a pharmacy?" (Sandhaus) Um, when you need to go to the

1:03:25.730,1:03:30.560
hospital you should not just go. You should call your doctor or the facility.

1:03:30.560,1:03:34.480
Now this is not the same if it's an emergency situation you have to call

1:03:34.480,1:03:39.590
ambulance it's because you're in dire straits, then you should go to the

1:03:39.590,1:03:43.280
hospital but if you're trying to decide is now the right time to go to the

1:03:43.280,1:03:49.370
hospital then you need to call first and they will question you about the

1:03:49.370,1:03:52.490
symptoms what you've done to leave them things like that

1:03:52.490,1:03:57.020
and decide whether it's worth the risk of coming to hospital in case you don't

1:03:57.020,1:04:02.060
have Covid-19 infection and find yourself picking it up there or whether

1:04:02.060,1:04:07.400
it's something you could treat at home. And the hospital emergency rooms and

1:04:07.400,1:04:12.200
medical centers are very good at recommending you know home remedies you

1:04:12.200,1:04:20.480
might try to to make yourself comfortable more comfortable as you you

1:04:20.480,1:04:24.590
know live through they Covid-19 infection because the majority of people

1:04:24.590,1:04:29.210

who get Covid-19 just have a flu-like illness that's going to be self-limiting

1:04:29.210,1:04:36.619
and go away once you develop antibodies against the virus. So it's the first step

1:04:36.619,1:04:40.640
is always to call your physician or they or the emergency room to find out

1:04:40.640,1:04:45.920
whether they feel that you need to come in again emphasizing them if it's an

1:04:45.920,1:04:51.580
emergency situation, yes, go to they go to the hospital.

1:04:53.300,1:04:59.960
(Michael) Thank you! (Sandhaus, reading comments) Looks like there's some some recommendations for ways to make

1:04:59.960,1:05:08.580
self-made face masks that are on the chat oh I see from foundation care for

1:05:08.580,1:05:14.370
brittle bones thank you see there's a very long link we'll get that we'll get

1:05:14.370,1:05:23.040
that mid you can make that into into a shorter link. (Michael) I want to go into the next

1:05:23.040,1:05:29.280
question so this is kind of a related thing to what you just talked about. "So

1:05:29.280,1:05:37.110
if we were to fracture now while at risk for Covid-19, how do we best handle

1:05:37.110,1:05:44.040
going to emergency services." (Sandhaus) So that's that's a great question because in large

1:05:44.040,1:05:51.390
cities many of the hospitals are preventing patients from coming in for

1:05:51.390,1:05:58.170

what they call elective surgery and for the vast majority that does not include

1:05:58.170,1:06:06.360

broken bones. Many medical centers are have developed areas of the hospital

1:06:06.360,1:06:12.900

that they're trying to keep Covid-19 patients free from and have separate

1:06:12.900,1:06:18.240

entrances for patients that are not there to be treated for Covid-19

1:06:18.240,1:06:22.860

symptoms but are there for other medical emergencies. I'm so you need to check

1:06:22.860,1:06:29.160

with your local facility and find out the best way to manage these things. Many

1:06:29.160,1:06:37.340

hospitals are setting bones in for non OI patients in tents outside the

1:06:37.340,1:06:42.120

facility in an area that they don't allow people who are testing for covent

1:06:42.120,1:06:47.010

I team to come come too and things along those lines so it's going to be very

1:06:47.010,1:06:49.830

location specific about what's to be done

1:06:49.830,1:06:59.850

if you require some surgical procedure that's not elective you know that's the

1:06:59.850,1:07:05.400

the likelihood is that you know you'll have to do things according to

1:07:05.400,1:07:09.360

you know they may change you to another hospital for instance in New York City

1:07:09.360,1:07:14.610
the Hospital for Special Surgery is
still doing orthopedic surgeries because

1:07:14.610,1:07:18.510
that's all they're doing they're not
they're referring all Covid-19 symptom

1:07:18.510,1:07:25.590
patients to other locations and trying
to keep that hospital as as as free as

1:07:25.590,1:07:30.480
possible probably Dr. Glorieux has some
comments from what they're doing up in

1:07:30.480,1:07:40.230
Montreal. I think it's a real when you're
is (Glorieux) Exactly the same way as you just

1:07:40.230,1:07:46.830
described Sandy. We try to work direct
them to areas where it can be taken care

1:07:46.830,1:07:53.040
of safely but if it is an emergency
situation you know that takes the

1:07:53.040,1:07:55.610
priority

1:07:57.599,1:08:05.079
again. (Michael) I'm going to move on to some some more
questions one question is says, "What

1:08:05.079,1:08:11.079
about zinc? Does that help reduce the
severity of infection?" (Sandhaus) I can't answer

1:08:11.079,1:08:16.359
that I don't have any evidence that it
that it that it would help. I mean zinc

1:08:16.359,1:08:20.440
is used you know as a kind of
over-the-counter medication that's

1:08:20.440,1:08:26.549
supposed to reduce the risk of viral
infections but you know they the

1:08:26.549,1:08:35.920

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. Gloireux 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. Glorieux.

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 I don't see that as a major issue

1:11:15.619,1:11:21.099
but it has to be taken care of
case-by-case.

1:11:23.010,1:11:32.540
(Michael) Great, so on a related note so "Would it be helpful to have
some of the OI

1:11:32.540,1:11:36.340
factsheets that are available on the
website printed out and ready to go in

1:11:36.340,1:11:41.380
the event you need to go to the ER now?
Would these be helpful to ER doctors or

1:11:41.380,1:11:52.170
with something else be helpful?" (Glorieux) I would
see that all our patients do have that.

1:11:52.170,1:11:58.889
They'll have you know they all have a
card explaining their condition and

1:11:58.889,1:12:06.280
telephone numbers on it to book - to
call and these are all forms to discuss

1:12:06.280,1:12:14.050
the case in more details. I think that's
a fact that we have organized well in

1:12:14.050,1:12:24.039
the past and is still appropriate and (Sandhaus)...
actually worthwhile to make up our own

1:12:24.039,1:12:31.300
kind of Covid-10... okay (Michael) I just want to
say on that note as wanted to display

1:12:31.300,1:12:38.860
this really quick slide I had made, so if
anyone is curious about more information

1:12:38.860,1:12:44.019
we have this is a perfect transition so
if you want to learn more about Covid-19

1:12:44.019,1:12:52.119

and OI on the OIFmain page we link to
OIF.org/coronavirus2019 which

1:12:52.119,1:12:56.679
I realize needs to be 2020 with new
information as it arrives. This is also

1:12:56.679,1:13:01.300
linked to on our homepage
OIF.org and if you want to contact

1:13:01.300,1:13:05.079
the OIF directly we know. Dr. Sandhaus
already said he'd be happy to talked

1:13:05.079,1:13:10.030
with other doctors about this. To get
in contact with him, you can reach out to

1:13:10.030,1:13:15.309
us directly at bone link at OIF.org
again like I said before, we're practicing

1:13:15.309,1:13:19.960
social distancing so our phone
lines are still open but the most direct

1:13:19.960,1:13:23.979
way to contact us I believe right now is
through email and we're gonna get to you

1:13:23.979,1:13:30.309
very soon. (Sandhaus) By the way the website
coronavirus 2019

1:13:30.309,1:13:33.609
should be 2019. That's what the
coronaviruses call

1:13:33.609,1:13:37.200
It was named after the year it was discovered. (Michael) Oh, I say
I'm learning a

1:13:37.200,1:13:42.599
lot on this call! Okay thank you!

1:13:42.599,1:13:47.379
so with that being said all right it
looks like we've covered a lot of

1:13:47.379,1:13:53.499
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

1:15:03.820,1:15:18.760
impact of that whole situation. I think
that sorry if you if you are isolated

1:15:18.760,1:15:25.449
you don't have to keep for yourself. We
have social media in a modern way to

1:15:25.449,1:15:33.219
communicate by FaceTime, Whatsapp, you
know in social networking

1:15:33.219,1:15:38.979
keep that on and stay connected with the
people around you, even if not physically

1:15:38.979,1:15:47.119
but at least in terms of keeping your
spirits high when I say good

1:15:47.119,1:15:52.010
(Ingunn) Hello, I'm Ingunn from OIFE, I would
just like to say thank you for allowing

1:15:52.010,1:15:57.770
international participants on this call
and it's also important to say that the

1:15:57.770,1:16:02.929
virus is various stages in different
countries and it's very important if

1:16:02.929,1:16:07.130
people are in doubt, that they should
follow the guidelines and the

1:16:07.130,1:16:12.830
restrictions from their local
authorities and also there might be

1:16:12.830,1:16:20.360
different rules on who can get testing
who can get to the ER, etc so it's very

1:16:20.360,1:16:27.250
important also to seek on your local
authorities web pages.

1:16:27.250,1:16:32.060
(Sandhaus) Great, thank you that's very important

and so glad that you're on the call, I

1:16:32.060,1:16:39.739
would like to just add that the it's
great to hear the kind of questions that

1:16:39.739,1:16:45.650
people are asking you know, as we learn more about this I think

1:16:45.650,1:16:51.469
you can turn to the oh I foundation to
find out the latest things that we've

1:16:51.469,1:16:58.179
that we've learned both from any OI
patients that we might learn about or

1:16:58.179,1:17:02.270
from the general population as you know
there are a bunch of studies going on

1:17:02.270,1:17:10.400
with potential therapies against the
Covid-19 virus infection as well as

1:17:10.400,1:17:19.610
work on that vaccines for for the
Covid-19. None of these are likely to

1:17:19.610,1:17:26.630
be appearing in your drug shelf
anytime real soon but at least know that

1:17:26.630,1:17:33.679
this is instilling full speed ahead
around the world to try to solve this

1:17:33.679,1:17:44.420
issue.(Tracy) Wonderful! I guess that Michael any
parting words from you on how we leave

1:17:44.420,1:17:49.580
this call? (Michael) So again I want to thank
everyone and if you have questions for

1:17:49.580,1:17:56.840
us, please reach out that Bonelinke@oif.org. Thank you all so much.

1:17:56.840,1:18:03.260
Stay healthy, and we'll see you soon.
(Tracy) Thanks everyone!