Dr. Laura Lubbers (00:00):

Hello everyone, and welcome to this Facebook live stream. I'm Dr. Laura Lubbers, and I'm the chief scientific officer at Citizens United for Research in Epilepsy, or CURE. I hope you're all healthy and safe during these times that are challenging because of our real concerns about the novel coronavirus COVID-19 and its implications for those with epilepsy.

Dr. Laura Lubbers (00:21):

As an organization focused on funding and promoting epilepsy research, we are honored to host this event as a way to arm you, our community impacted by epilepsy, with the knowledge you need to make informed decisions regarding your care or that of a loved one. We are pleased to have a number of experts joining us today to answer your questions. Dr. Doug Nordli is a pediatric neurologist from the University of Chicago, and from the University of Illinois at Chicago, we have doctors Jeffrey Loeb, who is an adult epileptologist, and Dr. Michael Carrithers, who is a neuro immunologist. Dr. Carrithers is joining us by phone.

Dr. Laura Lubbers (01:00):

If you have questions for our experts, please ask them in the comments section of this Facebook post and my colleagues from CURE, [inaudible 00:01:23] and Brandon, will read them to our experts. We hope to make this session as interactive and informative as possible, but we ask that you keep your questions general and not reveal personal health information if possible. I know we are already receiving questions, so let's get to that Q and A.

Brandon Laughlin (01:31):

Okay. I think a great question, or a lot of questions have come in about who's at risk. So I think we'll start there, and I'll kind of open this question up to all three of you and ask about the susceptibility to COVID-19. Are those [inaudible 00:02:04] more susceptible to COVID-19, from an adult or from a pediatric standpoint?

Dr. Jeffrey Loeb (01:58):

Who should start in?

Dr. Laura Lubbers (02:00):

Jeff, please.

Dr. Jeffrey Loeb (02:04):

Okay. So I think we're all susceptible. I think the susceptibility is equal. It's just how dangerous or how significant the illness is depends on our underlying comorbidities. In other words, do we have pulmonary problems? Do we have chronic medical problems? Do we have immunosuppression from another disease? From what I have heard so far, the course of children tends to be milder than the course of adults, which is wonderful news, but those who are elderly, who are disabled, who have underlying medical illnesses, who may live in, say, nursing homes with sort of more crowded environments, are not only at higher risks, but also higher risk for significant morbidity.

Dr. Jeffrey Loeb (02:47):

Michael, any thoughts about that?

Dr. Michael Carrithers (02:49):

Yeah, I would agree. Those patients who are over 60 years old are thought to have a more severe disease course or increased risk of mortality, while those who are younger tend to have a less severe disease course, but on the other hand, they tend to shed larger amounts of the virus.

Dr. Laura Lubbers (03:17):

Interesting piece.

Dr. Douglas Nordli (03:33):

Yeah. Yeah. Just to add to that and underscore them, we're on a regular communication, as you might imagine, with the infectious disease experts at the university, and they are reporting the same things that we believe that children are at lower risk for manifesting severe symptoms, much lower risk, but one of the dangers is that they can carry the disease and spread it to others.

Brandon Laughlin (03:47):

On a more related note, is there any knowledge or research right now about different seizure types and their susceptibility to COVID-19?

Dr. Jeffrey Loeb (04:02):

I'm not aware of any. It's just probably more of a general practice of what's important when you have a systemic viral infection, you are at a greater risk for breaking through with seizures. That's why it's so important to maintain compliance, don't run out of medication. Given the lack of interaction socially that we have, it's very important that folks do go and make sure that they have enough medication to get them through a time where they can't travel to get their medicines.

Dr. Jeffrey Loeb (04:34):

So I don't know that one seizure type is more likely to break down than another, but clearly we know medication withdrawal is probably one of the major risks, which is more of a social risk than necessarily a sort of scientific or neurological risk for having more seizures. I'm not worried, Doug. Are you have any subtypes of seizures that might be more likely to break through with viral infections in your experience?

Dr. Douglas Nordli (05:01):

I would say we don't have any direct experience with COVID-19, but if you were to take lessons that we know from other children with epilepsy, is that there are some subgroups of children who tend to be more susceptible to fever-induced seizures. For example, that would be our patients with dry base syndrome, who seem to have a lower threshold when they get febrile illness. So not specific to COVID-19, but across the board, and if you can assume or you run through in your mind who are the children who tend to have febrile or fever-induced seizures tends to be our younger children, with under age six, but that being said, I don't know of any data that would say that it's specific to COVID-19. It would just be associated with febrile illnesses.

Brandon Laughlin (06:51):

Actually, one of the questions that we got earlier today actually dealt with a similar question, would getting the coronavirus actually lower the seizure threshold, and if so, should seizure medications be increased?

Dr. Douglas Nordli (06:08):

I would say no. I wouldn't empirically go ahead and increase the medications, and we need to be mindful that so far, the disease manifestation in children seems to be milder, so thank goodness for that. So I wouldn't empirically increase medications, particularly because sometimes their medications could be sedating, particularly the short acting ones, and we don't want to compromise someone's respiratory status by causing undue sedation. So definitely be in touch with your physician about this, and definitely not empirically just increase medications.

Dr. Jeffrey Loeb (06:48):

I agree, because again, when you have a systemic form of illness, you do have sometimes confusion, a sleepiness, lethargy, and you don't want to confuse that because you increase the medications and cause those similar symptoms, so then you don't know what's from the virus and what's from the change in medication. So if patients are doing well on a certain medication, now if they start breaking through with seizures while they're infected, then of course we have to adjust the medication, but at that point, it should be under the care of a physician or in the hospital, not by individuals or family members deciding to do this on their own.

Brandon Laughlin (07:29):

Great advice. Great advice. Also, Dr. Carrithers, a question for you. Could COVID-19 actually trigger a seizure even if you've been seizure free for maybe a few years?

Dr. Michael Carrithers (07:46):

I really don't know the answer to that one. There's currently not a lot of information on whether or not this viral strain causes meningitis and encephalitis. There are a few limited case studies. Obviously, if there's an infection of the central nervous system, that would trigger a seizure, particularly in those individuals who are more susceptible.

Brandon Laughlin (08:12):

Great.

Dr. Michael Carrithers (08:13):

Dr. Loeb may give more insight into ...

Brandon Laughlin (08:16):

Yeah, Dr. Loeb or Dr. Nordli, do you have any more insight into that?

Dr. Jeffrey Loeb (08:21):

I think we're at the beginning of our learning curve. In our hospital, we're very active, we have some suspected cases, and we're seeing neurological symptoms. Now, it's sometimes hard when somebody is very sick to say that it's directly from the virus or it's due to just being very sick. I think as cases present to us, as I mentioned, it needs to be a very efficient and steep learning curve so we know what to expect and we know what to anticipate is due to the underlying seizure or other disorder, and what's caused directly by the virus that we need to worry about. So we need to communicate well, we need to get information out as cases and information become available so that we can spread this knowledge wildly and take the best care of our patients who have COVID-19.

Brandon Laughlin (09:13):

Great. Kind of a similar question dealing with epilepsy patients at a higher risk of SUDEP with exposure to COVID-19. Dr. Carrithers, could you maybe comment on that?

Dr. Michael Carrithers (09:27):

Yes. There's some theoretical evidence that the viral infection could increase the risk of SUDEP. This could potentially be due to a mechanism of the types of brain cells that the virus infects. It can potentially infect neurons that are in parts of the brain that control cardiac and respiratory function. This is because the molecule that virus binds to is present on those neurons.

Brandon Laughlin (10:06):

Interesting. Any other thoughts on that? Dr. Loeb or Dr. Nordli?

Dr. Jeffrey Loeb (10:13):

As I say, I think we need to watch very, very vigilantly and very closely with our patients, and if we start seeing more SUDEP, then we really have to become aware that that may be a sign that somebody has an infection or not and diagnose it quickly and make sure we stay on top of things.

Dr. Jeffrey Loeb (10:36):

I'm not sure we have a treatment at this point, other than supportive measures and very close observation if somebody is [inaudible 00:10:58], but knowing that if there is a case of SUDEP with this virus, it's important that we know this and we make people availably aware of this. Not to scare anybody at this point, though, because we really don't.

Dr. Douglas Nordli (10:58):

I think with children and given that the disease manifestation is much milder, I think what we can do in this circumstance is, by virtue of being in close connection with our adult colleagues, is learn from what's happening with adults and then cautiously extrapolate that to children, but the good thing is that the manifestations seem milder.

Brandon Laughlin (11:22):

Great. I'm going to actually combine a few questions that we received that were pretty similar, because I know that many hospitals right now are advising against patients flocking into the ERs and into their physicians' offices. So how can patients be proactive, especially those that may have preexisting lung disease or asthma or some form of respiratory illness? I will open that up to all.

Dr. Jeffrey Loeb (11:56):

Well, it seems if you have a risk of serious consequences for a severe viral infection, you have to go the extra mile to make sure you're not exposed if you can't. So clearly the social isolation is probably the most important thing that we can do. Now, face masks may or may not help in this situation, but if somebody is suspected of having an upper respiratory infection, because the symptoms can be very, very mild at first, that person can be a carrier and could spread. So if you have a significant underlying medical illness, so that if you were to get the infection, you would have a tougher time battling it, you should take those extra steps to remain isolated and not be exposed to anybody, even if they have a little sniffle. Just keep clear with those people for now. Even if it's a dear family member, put a mask on

them when you're around them, on the person who's sniffling and coughing, more importantly than on yourself, but maybe even on both.

Brandon Laughlin (12:59):

Okay, good advice. One of the questions that actually just came in recently talks about anti-epileptic drugs, and some research showing that these modulate immune activity. Are any of them known to lower immunity?

Dr. Michael Carrithers (13:17):

Well, some of the older agents such as a dilantin and carbamazepine had been known to lead to bone marrow suppression, but usually your neurologists will be assessing that through regular laboratories. The virus also seems to suppress bone marrow production of both red blood cells and white blood cells, so it is a very important issue, but as I said, this should be part of your regular clinical monitoring.

Dr. Douglas Nordli (13:52):

Within pediatrics, whoever asked that question may be aware that with many of the new drugs that are studied, there's a very, very careful surveillance of symptoms within children, and we'll often see a slight uptick in respiratory infections that are reported, but that's not suggesting some profound kind of immunosuppression. It's just a signal that's there. In clinical practice, I don't find that to be very striking increased, so maybe if someone's seen that in a label insert, I think to put it in perspective, it tends, at least in my experience, to be very mild, and I wouldn't ... You'd have to weigh all these things, but I would say in general I wouldn't be tempted to alter your antiepileptic medications for that theoretical consideration.

Dr. Jeffrey Loeb (14:43):

Since I heard about this question, I did a little research and didn't find much. There have been a few studies doing types of statistical or epidemiological analyses where they see, as Dr. Nordli said, a slight uptick, but it's like one in 20 at best, and it's not really consistent then, and you have to realize that a lot of folks who have epilepsy, you have other comorbidities and illnesses and developmental abnormalities, so if you just take a straight statistical measure ... So I wouldn't be super concerned about it. I think it's more important, as I mentioned, to stay on your medications and don't worry that your medicines are causing immunosuppression. Take them because you don't want to have seizures.

Dr. Laura Lubbers (15:25):

Can I just jump in and ask if that's true, also, for treatments like ACTH, Afinitor or everolimus for which people with specific types of epilepsy may go on?

Dr. Jeffrey Loeb (15:43):

Doug probably is best to answer this question.

Dr. Douglas Nordli (15:45):

Yeah, I think there are some times when we do put our patients on hormonal treatments and corticosteroids, aside from ACTH that's stimulating the adrenal access, so I would say yes, that there's going to be definitely ... One of the concerns that we have whenever someone's on ACTH is that we want to increase those precautions, so I always tell people with children or infants who are going on

ACTH or steroids be extra careful. Good hand washing. It's not a good time to have anyone who has any kind of respiratory symptoms to come over and visit at that point. They could save that for after the treatment's finished. So I would say yes, that group should be even more cautious about exercising good hygiene measures and social distancing.

Brandon Laughlin (16:39):

Great answers. There's been a lot of discussion about the known issue with ibuprofen and anti-inflammatory effects on the virus. Do we know anything or is there any evidence that would suggest about the use of CBD being a concern if infected with the COVID-19 virus?

Dr. Michael Carrithers (17:03):

Not that I'm aware of.

Dr. Jeffrey Loeb (17:09):

No idea.

Brandon Laughlin (17:12):

One of those things are where ...

Dr. Jeffrey Loeb (17:16):

The everolimus, I think, that was mentioned before is probably worth a comment, because that is one of the major side effects of that medication is getting more infections. So if it's being used on label, off label for seizures, I think that is something that would definitely lower the immune response. Is that right, Michael?

Dr. Michael Carrithers (17:37):

Yes, that's correct, or even in our patients with multiple sclerosis who are on an immune modulating medications that can suppress the immune system, our current recommendation is for them to continue on with therapy.

Dr. Jeffrey Loeb (17:54):

But not getting close to the virus, hopefully.

Dr. Michael Carrithers (17:57):

Right.

Dr. Jeffrey Loeb (17:58):

Right.

Brandon Laughlin (18:00):

Here's a question, actually, that that just popped up that might be more appropriate for Dr. Carrithers if we know anything about this. Would there be a higher probability for someone to get COVID-19 if their epilepsy was initially triggered by a viral infection?

Dr. Michael Carrithers (18:19):

Only if they're immune suppressed.

Brandon Laughlin (18:31):

Okay.

Brandon Laughlin (18:32):

For those patients who are immune suppressed for many different reasons, what is their course of action? What should be their first steps to be more proactive in ensuring that they don't contract the COVID-19 virus?

Dr. Michael Carrithers (18:52):

Well, the issue puts many people in a difficult situation. The recommendation is that patients who are immune suppressed practice social isolation and stay at home as much as possible, but this isn't always practical if you have a job where you can't take leave or something like that.

Brandon Laughlin (19:18):

Absolutely. We are getting a lot of questions coming in about medications and prescriptions and refills, and I know there's still a lot that we have to know about that, but when taking epileptic medications, if you're unable to take a lot of over the counter medications, because this might conflict with different ingredients, what are patients supposed to do in this case? What over the counter medications can individuals take to kind of mitigate the symptoms?

Dr. Michael Carrithers (19:51):

My current recommendation would be Tylenol for fever and general flu-like symptoms.

Brandon Laughlin (20:03):

Dr. Loeb, Dr. Nordli, any ...

Dr. Jeffrey Loeb (20:05):

I think certainly in small moderation is okay, but you don't want to overdo some of these over the counter medications, because they could have pro epileptic effects such as the stimulants that we use to clear your sinuses, decongestants, you have to be careful not to overuse. When you're not feeling good and you just want to take something and you want to take more and more, don't overuse it, and if you could get by just with the Tylenol or acetaminophen, that's the best strategy to avoid ... Probably no side effects. Certainly reducing the fever is probably helpful to prevent you from having seizures, so at a minimum on that. In terms of ibuprofen, I don't see maybe in children, but certainly in adults, I don't see any contraindications. Sometimes it lasts longer and has a bigger effect in terms of some of the myalgias and the other symptoms that you get than acetaminophen.

Dr. Michael Carrithers (21:07):

Well, there were concerns from some French investigators that ibuprofen and other NSAIDs could make the clinical course of COVID worse, or that hasn't been substantiated in a well done clinical study.

Brandon Laughlin (21:27):

Since we're talking about medications, I think this might be a great time to address, just generally, in your experience already, how is this COVID-19 virus affecting medication availability currently?

Dr. Jeffrey Loeb (21:42):

I'm not aware of any shortages. Other than the tests to get the virus detected, I'm not aware of any shortages of medications, but it certainly could happen. A lot of people are working from home, who's doing deliveries right now? The social isolation is going to have its downstream effects.

Dr. Douglas Nordli (22:09):

Yeah. Likewise, we haven't been aware of any limitations for drug availability.

Brandon Laughlin (22:17):

Have there been any discussions about .., I know we actually received a lot of questions that deal with drug availability in China, and if so, do we foresee a shortage in drugs that might be distributed from that country in particular?

Dr. Jeffrey Loeb (22:40):

I'm not aware of any. The manufacturing of drugs has become very international, and we wouldn't be surprised if there would be shortages based on plants being shut down. We don't really know when you get a pill where that pill was actually made.

Brandon Laughlin (23:02):

Actually, going back to kind of the discussions we had earlier about ibuprofen, we've actually received a lot of questions from others asking about giving their children Tylenol or Motrin. Dr. Nordli, what are your thoughts on that?

Dr. Douglas Nordli (23:20):

Yeah, aside from the information that was just shared with us, that's generally our recommendation, that acetaminophen, ibuprofen can work very well sometimes, as you know, with children, and in other illnesses like the flu, they can have very high fevers, so sometimes we'll alternate those two to keep the fever down. Dr. Loeb was saying, that can be a threshold itself, and since children are generally manifesting mild symptoms with COVID, maybe the thing that's more likely to cause intense symptoms right now might be flu B. So I wouldn't jump to the assumption that it's COVID-19, and it might be good to practice typical kinds of approaches that we normally do to infectious illnesses, particularly since kids seem to be less effective.

Dr. Douglas Nordli (24:11):

With regard to the medication, I had another thought, which is that we don't want people to worry. Even if there was some stress point in a system somewhere, as Dr. Loeb was saying, there's many other places that are producing drugs, and we have many alternatives. Lots of drugs work by similar mechanisms of action, so please reach out to us if there is any concern, but as I said, we haven't seen that at this point.

Brandon Laughlin (24:37):

Yeah, that's a great point. Another question that's coming in, obviously surrounding children and their susceptibility, is there any evidence or thoughts, Dr. Nordli, that children might be more prone to have seizures as a sign of the virus?

Dr. Douglas Nordli (24:58):

No, not as far as I know, and monitoring the situation and in hearing that experience from our colleagues in Italy, that did not seem to be in children, and since it's milder manifestations, I'm hopeful that that remains the case. In our hospital network, we are less concerned in the pediatric realm about acutely ill children and more about the effect that those children might have on their parents or healthcare providers. So hopefully that stays the same, as it's been experienced worldwide, and really the brunt of the exposure seems to be ... Symptomatic manifestation seems to be adults, and then the more intense manifestations in people above 60.

Brandon Laughlin (25:51):

Good point, and should parents be concerned specifically around those children that might have epilepsy and some sort of respiratory illness, about taking them outside for walks and things like that? We've received a lot of questions about how active they can be, especially being outside.

Dr. Douglas Nordli (26:13):

Yeah, I would say in general, maybe parents using good judgment. I was reading just earlier this morning the information from various sites about saying that going out, particularly with a social distance, is fine. We're not in a complete kind of shutdown situation, and I think for mental health of everyone, including children, to get outside, so long as they're separated from other individuals, has beneficial effects. Sometimes cold exposure can exacerbate respiratory symptoms, so that's where it would kind of be something to watch closely and see how the child reacts to being outside.

Brandon Laughlin (27:02):

Great, great advice. I'm going to kind of end here with a few questions about kind of just general thoughts regarding epilepsy and the virus. Are there any thoughts that patients with epilepsy will have a more severe manifestation of COVID-19 than an individual without epilepsy?

Dr. Jeffrey Loeb (27:24):

I can comment on that. When you have epilepsy and you have concurrent other illnesses, by definition, you have a tougher time. You have the risk of breaking through, having seizures, your medications not working. If you have any change in, say, your function of your liver, that's not going to break the medicines down or the absorption of the medications. So because you have epilepsy, because you have the risk for seizures, because you take this medicine, you are at higher risk just because of that, because not only do you have the risk for the virus, but that this is going to ... We know in many viral cases, this is something we always ask our patients, "Have you had a recent infection or something? Why did you have this breakthrough seizure?" So clearly we know that infectious illnesses lower our threshold to fight against seizures, and we have to be super vigilant.

Dr. Jeffrey Loeb (28:16):

Be in touch with your physician. Physicians actually have a little more time. A lot of our regular clinics are canceled, so we can get on the phone and talk to you much more readily, probably less likely in person, if you have questions or problems, but yes, you want to keep taking your medications. You don't

want to do anything that you know normally would make you be more likely to have seizures, sleep deprivation, stress, alcohol, all of those things that we know can lower your seizure threshold if you add that together with your COVID-19. It's not going to be good.

Brandon Laughlin (28:50):

Thank you. That's great advice. Then also, one of the other questions that we had come in specifically dealt with those patients that have brain surgery. So Dr. Loeb, maybe you can address this one. Would their ability to fight the COVID-19 virus be compromised because of a recent brain surgery?

Dr. Jeffrey Loeb (29:09):

I wouldn't think so. Unless you were on some sort of medications like steroids or something like that, like a very recent ... We talked about certain medications. So again, talk to your doctors if other situations are going on. Clearly, I think everybody has the risk. It's not the risk, it's the risk of what happens to you either by breaking through seizures or being immunosuppressed if you've got the virus versus someone else. So yes, we have to be super vigilant for our patients with epilepsy, and especially for those who have those other illnesses, like immunosuppressive treatments for, at the same time.

Brandon Laughlin (29:52):

Nice. Are there any risks involved that you might foresee in allowing people that are potentially givers of children with epilepsy into their home given the warning to really decrease your social exposure?

Dr. Douglas Nordli (30:17):

I think I'm balanced that I would say it's so much more important for the caregiver, the parent, to be attending to that child. If there's nice advice, it's on the Illinois public health and the CDC about what do you do if you have symptoms and you've come down with infection. I would direct people to that, but say people are not infected and they're just caring. I think that everything being the same, comparing those things, I would have very little concerns as a parent saying, "Nope." Continue to care for your child as you would, just exercise the proper precautions. If you get sick, then definitely contact your doctor and figure out alternatives.

Dr. Jeffrey Loeb (31:04):

I think some of the stories I'm hearing is a lot of families are actually getting much closer together as a result of the social isolation. So we're being less social with strangers or people we don't know, but much closer with our families, which is actually kind of nice, but at the same time, if one of those family members does have cold-like symptoms, we do have to be aware that they could have contracted the virus and could spread it to that family.

Brandon Laughlin (31:31):

Right. Great point. Yeah. To kind of wrap things up here, you mentioned this very briefly, Dr. Nordli, about the CDC recommendations, but why does the CDC list epilepsy as a high risk category for COVID-19?

Dr. Douglas Nordli (31:52):

I can't imagine other things other than what was already said about the potential impact of disease in adults on the epilepsy. I can't think of a physiologic reason. Maybe Dr. Carrithers could chime in here

why someone with epilepsy would be at greater risk for contracting the virus. I think it was more the points that Dr. Loeb was making earlier about the impact of the disease, of COVID-19 on the epilepsy itself. Dr. Carrithers, anything else to add about that?

Dr. Michael Carrithers (32:19):

Yeah, I think they probably put epilepsy on the list because it's a chronic neurologic condition and, as we've spoken to already, that there's no current evidence that epilepsy patients are at increased risk of infection. I believe that the CDC is doing due diligence at this point in time, because we have so little information available.

Brandon Laughlin (32:50):

Great point. Well, I think that's pretty much all the questions that have come in at least that haven't been addressed already through the live stream. Were there any last points that anybody had that they wanted to make before we kind of wrap things up here?

Dr. Michael Carrithers (33:14):

I have nothing else to add.

Dr. Douglas Nordli (33:16):

Just to say thank you to CURE for organizing this and providing this service for our patients. It's much appreciated.

Dr. Jeffrey Loeb (33:23):

Yes, very much so, and be safe, be careful, use common sense. Don't be shy about talking to your doctor or your nurses. Don't believe everything you read on the internet, and get close to your families. It's opportunity.

Brandon Laughlin (33:42):

Wonderful advice. Yes.

Dr. Laura Lubbers (33:45):

Thanks to you all. Thank you Dr. Loeb, Nordli and Carrithers. Be well, be safe, and we'll see you soon.

Brandon Laughlin (33:53):

Yes, I do want to add that this video will be available shortly, both on the CURE Facebook page and on the CURE website. Also, stay tuned for more updates from CURE as new information does become available. Thank you again, all. Thank you to our panelists. Be healthy and stay safe.

Dr. Douglas Nordli (34:10):

You too.

Dr. Laura Lubbers (34:10):

Thank you.

Brandon Laughlin (34:11):
Bye bye.

Dr. Michael Carrithers (34:12):
Bye.

Dr. Jeffrey Loeb (34:12):
Bye.