

COVID-19 TASK FORCE

RNS COVID-19 Virtual Town Hall Executive Summary

April 9, 2020 / 6:30-7:30 pm EST

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Summary: *With the growing need to get key questions and answers out to the rheumatology healthcare provider constituency, the Rheumatology Nurses Society (RNS) formed a COVID-19 Task Force to best address these questions and concerns on behalf both of their peers and the patients they serve during this pandemic. The RNS COVID-19 Task Force met virtually, along with our first guest panelist Dr. Betsy Kirchner of the Cleveland Clinic, on Thursday, April 9, 2020 from 6:30 PM-7:30 PM EST to address some of the questions and pressing topics that our members were submitting during the week. The following questions were raised: the immunology aspect and what is happening with the COVID-19 registry, treating rheumatology COVID-19 patients, updates on telemedicine, new patient load during COVID-19, JAK inhibitors to treat COVID-19, Plaquenil doses, counseling patients with rheumatic diseases and employment, determining COVID-19 versus influenza, COVID-19 testing updates, herd immunity of the virus, mental health of nurses and patients during this pandemic, and RNS President Cathy Patty-Resk updating viewers on her volunteer efforts supporting fellow nurses.*

1. What is the immunology aspect of COVID-19 and what is currently happening with the COVID-19 registry?

Betsy Kirchner: One of things we do now is it's not really the virus; you don't go into the ICU or die from overwhelming viremia; you die from your immune system reaction or an underlying comorbidity that just overwhelms you. But, if it's from coronavirus, it's typically cytokine storm, overwhelming immune reaction, inflammation. One of the things that is going to help us fight this, is this registry called the COVID-19 Global Rheumatology Alliance. A doctor in California and a doctor in Australia were able to get this protocol together, get it pushed through an IRB and they set up this registry and now anybody in the rheumatology

community who has a patient with rheumatic disease, who test positive for COVID[-19], can enter their patient information in here. And this is how we're going to get our information. As of April 8th we have 146 patients registered; 23% male, 77% female. Obviously, it's totally opposite of what we see in the rest of the world, but that's because it's autoimmune disease. 18% of the patients registered are 65 and older, so it's skewed kind of young. Seven of those patients have died. And in terms of symptoms, it's pretty much the same. Cough, fever, shortness of breath. So, the best thing we can do, if we want to learn more about this in rheumatology, is to register our patients so that we can gather this data and get some answers. Many of the patients who are in the registry already were on Plaquenil.

2. *Have you seen any rheumatology patients test positive with COVID-19? If so, are you holding any medications or infusions?*

Betsy Kirchner: We have a rheumatoid arthritis patient, two lupus patients that I'm aware of, and a vasculitis patient. None of them [were] hospitalized, all recovering at home but positive for COVID[-19]. It would just be like if they called us and said they tested positive for flu or strep, [yes], we're holding their immunosuppressants until they're infection is cleared. Pretty much until they're asymptomatic.

3. *What are you doing for patients that you don't feel would benefit from telemedicine, ones that really need to be seen in person?*

Carrie Beach: We are still giving [our patients] the option if they want to come in. If they feel like they need to be seen, or if we feel like we need to see them then, they can still come in.

Vickie Sayles: I think we have some physicians or providers that do want to see their patients, especially our vasculitis patients, but most of our visits are virtual.

Linda Grinnell-Merrick: We keep one provider at [each of our] sites that are there [if] somebody needs a joint injection or somebody absolutely needs to be seen because they're really ill. It doesn't matter who that patient belongs to as far as any of our eleven providers, they will see whoever is at the office that day.

4. *How are you handling new patients?*

Carrie Beach: This week, some of the physicians are still seeing new patients. The physician I work with [is] triaging [patients]. I'm calling them a couple days ahead to see just how urgent they are.

Cathy Patty-Resk: I've told my staff that I'll see patients in [the] clinic face to face in the morning and then [in the] afternoons, I'm booking telemedicine [appointments]. Going forward, that's how we're going to be looking. We are looking at seeing new patients. Only one parent is allowed with one child, so their siblings and two parents are not allowed anymore during COVID[-19]. Our registration area, they just set it up a little differently today, actually, where they have the chairs that are 6 feet from the registration person instead of right up to the desk.

Linda Grinnell-Merrick: Very few new patients are being seen in [the] clinic unless they're very, very ill. Your vasculitis patients, your patients that you have to see urgently, those are the only ones.

5. How are you treating MAS without steroids? Have you changed anything as far as dosing?

Betsy Kirchner: I assume we are talking about the cytokine storm that essentially is macrophage activation syndrome even though it isn't MAS, but it is on the pathophysiologic side. We don't treat early COVID[-19] in our hospital, at least with any steroids, because it'll make things worse but if you get to the point where you are on a vent with MAS, we're giving them steroids.

6. Are you using JAK inhibitors to treat COVID-19??

Betsy Kirchner: I don't want to say we're not, but if we are it's been few and far between. I know it's being tried in other places, more over desperation than anything else but I don't think we are.

Vickie Sayles: Not that I know of with JAK inhibitors.

Linda Grinnell-Merrick: I have not heard anything with JAK.

7. Are there any links or recommendations for parents of kids with rheumatologic conditions that would be helpful right now regarding emotional support, especially those that are on Plaquenil or hydroxychloroquine, and are anxious and worried about being able to get their medications?

Cathy Patty-Resk: Alex from Texas Scottish Rite [Hospital for Children], developed a great [list of resources](#) for patients that [will be] put on [our website](#). It may not have made it up there yet, but I will make sure it gets up there. And I'm pretty sure there are some resources up there for that, because that's a very real fear, not being able to get your medication.

8. If a patient is on 400mg of Plaquenil now, should they cut it down to 200mg to make their meds last?

Cathy Patty-Resk: I think that's something that people are going to have to do. Half is better than nothing. I think we have to really think outside the box and get creative when we are looking at helping our patients get their meds, because it's going to be beyond the usual going to specialty pharmacies or something like that. If you want to cut your dose in half to make it stretch, you have to talk to your provider first.

Carrie Beach: I feel like in Ohio, or here locally, we haven't had too much of an issue with our patients getting their Plaquenil right now. A lot of them have asked if they should cut to every other day. Right now, as long as they are able to get it, I think it's okay to continue on [their] current dose and then after, if they're starting to get kicked back from the pharmacy, then assure them it is okay to go to every other day and thankfully Plaquenil has a long half-life.

Linda Grinnell-Merrick: We initially had a problem getting Plaquenil, [either] earlier this month or [at] the end of March, in some local areas that are probably a little bit closer in New York City. That is actually kind of gone away by the wayside, so that's not been a huge issue, but we're just doing 30 days.

9. What telemedicine platforms are you using?

Linda Grinnell-Merrick: Zoom

Cathy Patty-Resk: In the very beginning [we tried] RingCentral, and that was a disaster from the beginning, so I've been using Zoom. I think there's something that would be better though, so I'm going to be exploring that a little more since I'm in this till the end of the

month for sure. During this time you can bill for telephone encounters, so everyone needs to make sure that they know that. I think one of the stipulations is that you have to include in your notes that video was not available for your patient and then it can be covered.

Betsy Kirchner: Our first go to is American Well, but the American Well platform is pretty overwhelmed right now. Some departments, including ours, have gone to over 80% virtual in the last two-three weeks. So, if American Well doesn't work then if the patient has an iPhone, we're authorized to use FaceTime and if they don't, we use Google Duo.

Carrie Beach: We're doing the same. We started with Zoom last week and it just wasn't going particularly well. For some patients it worked, sometimes it didn't. It changes every day. So, yesterday we were kind of screening, I was calling and screening patients ahead of time. If they have an iPhone, then we're going to do FaceTime, if they had an Android then we're using Doximity. It seems to work pretty well, but it changes.

10. What are some top patient concerns that are being voiced as it pertains to continuation of RA products and how are you counseling those patients?

Carrie Beach: I don't think that has changed in the last couple of weeks. We're still telling patients to continue their medications just like we have covered. We don't want you to end up in an Emergency Room (ER).

11. How are you counseling patients with rheumatic diseases regarding work?

Betsy Kirchner: We use Epic as our EMR and somebody put in a nice form letter that says "social distancing is recommended for these patients" and it says "cancer patients on chemotherapy, immunosuppressed, [anyone] over sixty-five" it has a whole list; so, you're not necessarily outing your patient to their employer of what exactly they have, [just that they are] immunosuppressed and it requests that they be allowed to work from home if possible or if they still have to go into work to be able to have a situation where they can practice social distancing. Like give them their own office, that kind of a thing. So, if patients have the option of working from home, we recommend it. If it's a choice of going to work or being homeless, then we just try to support them however we can and make it as safe as possible.

12. How are you determining whether or not a patient has influenza or COVID-19?

Carrie Beach: I think at this point anybody with symptoms, we treat [them]. [If you're taking] biologics, you're going to be off of them. If you're running a fever, it's kind of the same protocol we would use for any infection.

Betsy Kirchner: There's some reports that say up to 20 to 30% of the nasal swabs could be false negatives. It's not that there's anything wrong with the swab, but it's the nature of the virus. That it migrates from the upper respiratory to the lower respiratory tract, so in symptomatic patients, patients with classic symptoms; so, I'm not saying like 20 to 30% of all the negatives out there, but for symptomatic patients, what they do is they do the swab and then on a certain subset, they do the sputum. Swab [is] negative, sputum [is] positive.

13. Have you heard about the new oral swab test that allows patients to test themselves? Do you think these will be more reliable?

Betsy Kirchner: It can't be the spit in the front of your mouth. I don't think it's practical to ask people to do a tonsillar swab or anything because that's not going to work either. What we really need are the blood antibody tests. We need them to be rapid, and we need to find out who's already got the antibodies and can they go back to work and go back out into the public and then let the more vulnerable people [have] more time to shelter at home while the rest of us soldier on, save the world.

14. Is there any talk about how long the immunity might last?

Betsy Kirchner: If you look at the models, there are four coronaviruses that have been circulating for years because what we [thought] was the common cold, and their immunity is not long lasting. That's why you can get them over and over. Not typically year after year, but after a few years you can get that same coronavirus cold again. That's not excellent news, but this one in the beginning was looking like a longer-lived immunity. Of a small subset of patients, they were able to do IGG and IGA antibody testing on and it looked like the IGG with persisting, at least in the months range. So, this would obviously be like the Wuhan cohort because they were the first large cohort, but now these reports are just coming out that either patients who they thought were out of the woods, maybe they just sort of hang out with having a relapse of their original infection which would be much better than what could be a possibility, which is that they were getting re-infected. You get this idea that well, I had it so now I can relax a little bit, and they're ending up sick again. So, are they sick again because they just never really totally cleared and they tried to do too much?

Just like what can happen with any viral infection; or are they getting re-infected? So, hopefully not that, but the jury's still out.

15. *Are your hospital's/places of employment doing anything for the mental health and well-being of its employees and patients?*

Betsy Kirchner: They set up a rooftop garden called the Respite Garden. There's tea and there's snacks, and [everyone is] 6 feet apart. But you can just go and get some fresh air. I mean there's an enclosed part too because, you know it's Cleveland. They have a hotline you can call if you're feeling overwhelmed, they have a hotline you can call if you're having trouble financially and you're an employee. Judy Barr, our resident Yogi, has great yoga. Our RNS friend, Julie Conrad [works] privately, but the clinic also has sort of a Yogi who just works there [at the Cleveland Clinic].

Vickie Sayles: I just signed up for some wellness exercise online classes, which is really cool. They have cardio one day, they have legs, they have yoga. So, I just signed up for that today and I want to take a look at what that is since we can't get out there and exercise too much.

Linda Grinnell-Merrick: I've seen some hospitals here locally; they do prayer services before the beginning of each morning shift, or each shift, and we have a hotline and different things are being offered. Just whatever we can all do to just get through this, any way we can, we certainly have to support the nurses. Everybody is doing this, whether it's in health care or the people who are out there still working and facing people every day; the grocery stores, all these places, is just crazy and scary.

16. *Cathy, can you share a little about what you did this weekend?*

Cathy Patty-Resk: As many of you know, I began my nursing career in the Emergency Department in an inner city hospital in Detroit, so my heart's really been with those frontline workers. The hospital that I used to work at is one that's been particularly [hit hard] in Detroit, with the highest level of acuity and the highest number of patients. They were looking for volunteers, especially from Children's because we're not so affected by COVID[-19], so I volunteered 4 hours on Sunday to go in and do whatever I could do. I didn't know what I could do. They told me right off the bat when I was signing up to volunteer, that I may only work as a PCA or an MA, whatever you want to call them. I don't really care, I'm just there to help out however I can. I went in and I have never seen so many respiratory patients in my life. I mean, every patient, I think every patient, except for one or two that were in the pod in the yard that I was assigned to were, COVID[-19] patients. These patients

were really sick and I really learned a lot from the nurses that were down there. They were [telling me] about one pod where they see traumas and most of the acute patients the night before. It [was] lined up full of patients on vents [with] one nurse [for] about 15 vent patients. The nurses are having a really hard time. They were talking about how full the morgue was and how the morgue was actually too full and so there were some bodies that were being stored in other places. The nurses are really having a hard time with not being able to provide excellent care like they're used to and the patients were just so gracious and so sweet and some of them have been there and sitting in the ER for two to four days. I thought it was just so incredible. There were no hospital beds. [The nurses] were talking about how they could be talking to a patient for one minute and then go into another patient's room for 10 minutes and come out and that patient they were just talking to is deceased. This disease is just like that. They can't predict, they can't see a decline in the patient's condition, they're just there [and] fine one minute, then they're gone the next minute and it really seems to be taking a toll on the nurses. I don't think the nurses were really prepared for this. Before I went, I kind of braced myself for having more [of] a wartime mentality because I had suspected that if you went in there to practice like you normally do, you're never going to survive it. But if you go in there having a wartime mentality; that "this is how it is, we're going to do the best we can, taking care of as many patients as we can, and it may not be perfect but this is what we're going to do". If you can go in there with that attitude and keep that attitude, just compartmentalize that practice from how you normally practice, then I think they would just be so much better off. But they really haven't been. They really haven't been helped along that path. I would highly recommend [that] any nurse volunteer. Even 4 hours like I did, just volunteer 4 hours, don't be afraid, and just be there and support other nurses that are going through this. I think they appreciated having me there and talking with me as much as they did having me there to help. I really didn't do anything that a registered nurse really would do, honestly. I made up a bunch of IV starter kits for them; I helped patients with [getting them] water, crackers, cleaned up a bedpan, wiped the floor that had spilled urine, took vitals and temps and just did things like that. I would highly encourage you to get in there and support your fellow nurses. We're in positions where we can advocate for them there in the trenches and they may not be able to advocate for themselves right this second, so, I'm really hoping that maybe I can help advocate for them and help make a difference. But that was what I did this week.

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Conclusion: *As in previous weeks, we have had an influx of inquiries from our constituency regarding the current status of COVID-19 in the various areas of the county and in multiple nurse, and advanced practice provider healthcare settings. In conclusion of this third town hall, the decision was made to go weekly with these through the pandemic. In this week's report, we learned the ongoing COVID-19 situation in various parts of the county, gained insight on the virus itself through Betsy Kirchner, DNP of the Cleveland, Clinic, as well as heard directly from Cathy Patty-Resk, MSN, RN-BC, CPNP-PC, current President of the RNS, on her personal experience volunteering in the ICU to assist with COVID-19 locally. For the pre-recorded broadcast that accompanies this report please be sure to go our website at www.rnsnurse.org/covid-19/task-force/*