

FORUM OF ESRD NETWORKS
CMS / EDAC / FORUM LEADERSHIP CALL
CALL NOTES

WEDNESDAY, SEPTEMBER 2, 2020
4:00 PM ET

FORUM EXECUTIVE COMMITTEE & NETWORK DIRECTOR ATTENDEES: *(those highlighted are confirmed as attending)*

Ralph Atkinson, MD – President
David Henner, DO – President-Elect
Donald Molony, MD – Past-President
Kam Kalantar-Zadeh, MD, MPH, PhD – MAC Chair
Derek Forfang - KPAC Co-Chair
Dawn Edwards – KPAC Co-Chair
Andrew Howard, MD, FACP – Board Member
John Wagner, MD – Board Member
Danielle Daley, Network 1
Sue Caponi, Network 2
Chris Brown, Network 3/4
Brandy Vinson, Network 5
Shannon Wright, Network 6
Helen Rose, Network 7 / 15 / 17
Kelly Mayo, Network 7 / ESRD NCC
Natasha Avery, Network 8
Vicky Cash, Network 9
Audrey Broaddus, Network 10
Diane Carlson, Network 11
Stephanie Smith, Network 12
Linda Duval, Network 13
Mary Albin, Network 14
Stephanie Hutchinson, Network 16 / 18
Dee LeDuc - Forum Staff

CMS ATTENDEES: *(those highlighted are confirmed as attending)*

Anita Monteiro – Acting Group Director, iQIIG
Paul McGann - Chief Medical Officer for QI, iQIIG
Shalon Quinn –Director, Div of Kidney Health, iQIIG
Melissa Dorsey –Dep Dir, Div of Kidney Health, iQIIG
Todd Johnson –Regional Program Mgr, Div of Kidney Health, iQIIG
Jesse Roach, MD – Medical Officer, CMS
Ekta Brahmhatt – QSOG, CMS
Ed Huff
Steven Preston
Lisa Rees
Johannes Hutaaruk
Jennifer Milby
Filita Long
Daniel Thompson
Christina Goetee

The call was convened at 4:00 pm ET

1) **Observations, Updates, and Concerns from Hot Spots:**

#1 Discussion 09/02/2020:

Referencing the article below, Dr. Atkinson shared this as another review of ESKD patients with COVID-19 in NY and the elevated risk for this vulnerable population.

"Presentation and Outcomes of Patients with ESKD and COVID-19" Valeri et al., JASN 2020

<https://jasn.asnjournals.org/content/jnephrol/early/2020/05/28/ASN.2020040470.full.pdf>

Dr. Atkinson asked Networks 13 and 8 to share a brief update from Hurricane Laura:

Ms. Duval reported Hurricane Laura made landfall at Cameron Parish in LA and moved north through the state causing severe damage in SW Louisiana. In anticipation of the storm, dialysis providers had given all patients a hurricane packets and included their current COVID-19 status. Five units in LA closed and a few were open with altered operations (generators, etc.). All dialysis patients were accounted for. Different from previous storms, more patients are sheltering in hotels rather than shelters due to COVID-19 and there is an increased use of telemedicine to meet with patients. COVID-19 testing that had stopped before the hurricane has now resumed as well as vaccination drive-throughs (flu and tetanus).

Ms. Albin shared that although Texas experienced power outages and water issues, they were spared the devastation seen in LA. Facilities are back up and running and all patients are accounted for. The state of Texas also provided hotel shelters and kidney patients report this being much more favorable to the group shelters used during previous storms. Facilities took the initiative to prominently mark the records of patients, reminding providers to review records before treatment.

2) **COVID Testing Priority for In-Center Dialysis Patients:** Incenter dialysis is a congregate care situation similar to prisons and nursing homes and could benefit greatly from the use of more frequent, rapid testing.

- A summary of the responses received from Forum and Network members was presented verbally by Dr. Molony during the 06/03/2020 call. A written summary will be shared soon.
- Dr. Atkinson inquired about whether CMS is considering reimbursement for antibody testing.

[6/10/2020]

- Dr. Molony presented the written summary including additional responses that were received. Ms. Quinn reported that she had shared the summary data with ASPR colleagues last week but has no additional information regarding reimbursement of antibody testing that was discussed last week.
- Ms. Vinson presented an update on the positivity rates that were discussed last week, comparing the general population with the dialysis population using KCER ESSR data.
 - ✓ May 13, 2020 General Population was 13.86% and this week is 9.7%
 - ✓ May 13, 2020 Dialysis Patients was 51.08% and as of June 3 was 47.60% - which is still about 3x the general population. This may indicate a more aggressive approach of testing in the general public than the vulnerable population of ESRD patients.
- Ms. Sharon reported she will be meeting with ASPR and CDC following this call and will bring the data to their attention.

[6/17/2020]

- Updated positivity rates were shared, as of June 14 General population was 8.86% and Dialysis patients was 46.92%. Dr. Atkinson and Ms. Vinson offered the assistance of the Forum and Networks to research strategies to adapt current guidelines (nursing home guidelines & LDO strategies) to the ESRD population.

[06/24/2020]

- Updated positivity rates were shared, 8% in the general population and 46% in the dialysis population (according to the June 17 ESSR data). Dr. Henner shared the Boston Globe article on the experience of COVID-19 in Massachusetts and reported on a pilot project being conducted in his area (western Mass)

where all dialysis patients in Berkshire County will be receiving an antibody test for COVID-19. Dr. Atkinson inquired about whether ASPR has considered additional testing strategies, noting the vulnerability of the ESRD population and the need for more testing. Ms. Quinn reported that no additional guidance has been released on the topic, noting that it is a high priority for CMS and internal roadblocks are being addressed. Mr. Brown presented data from the 2746 death notification forms with cause of death reported as #105 or #106 (COVID/Coronavirus) which showed a clear disparity that Blacks/African Americans are dying at a significantly higher rate from COVID-19 than kidney patients of other races. Ms. Quinn acknowledged the shared concern and reported that CMS has begun discussions about the issue; receiving the comment that point of care testing and reaching the community is important.

[07/15/2020]

- Updated positivity rates for dialysis patients has increase from 46% on June 17th to 47.63% as of July 8. This compares to the general population testing rate of 8.17% on July 12.
- Dr. Atkinson inquired about whether CMS is considering testing procedures for ESRD facilities similar to those recently announced for nursing homes. Dr. Roach shared that CMS has been in active discussion with the highest leaders of CMS about this subject, considering a number of factors including, timing, frequency, logistics, and how to mitigate payment issues for testing staff and patients.
- Dr. Henner provided an update on the pilot project conducted in his area, he shared the following:
 - Tested 133 in-center dialysis patients (does not include PD or home HD pts, nor AKI pts in the hospital)
 - 8 tested positive for SARS-CoV-2 IgG Antibodies, that is a positive rate of 6%
 - Of those 8: 4 were known to have had positive antigen tests and were treated
 - One patient died and did not have antibody testing in hospital
 - One tested negative multiple times for antigen

[07/22/2020]

- Ms. Vinson noted that positivity rates shared on previous calls were based off of cumulative testing counts, the rates in the graph shared via email are based on updated, discrete weekly figures, allowing for week-to-week change to be more readily visible. Calculating this way may be beneficial and useful for targeting at the state, county, or facility level. These graphs show a positivity rate of 62%

[07/29/2020]

- Due to time constraints, positivity rate updates were not presented during this call. Dr. Roach shared that although he does not have updates on the previously discussed recommendation of increasing testing of kidney patients, CMS continues to pursue this issue.

[08/05/2020]

- Ms. Vinson prepared two graphs to summarize the testing data reported on previous calls: positivity rates by week and total tests completed by week. Ms. Dorsey agreed it is important to continue to monitor these rates and try to identify the reason for changes in the rates from week to week.
- Members discussed how to determine if the testing rate and process for the dialysis population is sufficient. Testing a random sample of patients for antibodies as has been done in other smaller communities of the country was suggested as a way to look at this more closely.
- Mr. Johnson inquired about the positivity rates presented and the relationship in terms of decreased testing; is it related to a geographical area, etc. Is additional information available?
- **ACTION:** Ms. Vinson will look at the data in more detail to see if there are correlations; she will follow up on the next call.
- Dr. Roach reported that CMS continues to work with CDC to develop guidelines for testing dialysis patients and will provide updates as available.

[08/12/2020]

- Referencing a July 2020 [JASN article](#) and the executive summary, Dr. Atkinson shared the findings and suggested this data supports the continued efforts to implement more frequent testing of dialysis patients.
 - Study included 356 patients receiving in-center hemodialysis in the United Kingdom

- 121 had been symptomatic when screened for COVID-19 before a dialysis session and received an RT-PCR test
- 79 (22.2% of the total study population) tested positive for COVID-19
- Serologic testing of all 356 patients found that 129 (36.2%) tested positive for SARS-CoV-2 antibodies
- Only two patients with PCR-confirmed infection did not seroconvert
- Of the 129 patients with SARS-CoV-2 antibodies, 52 (40.3%) had asymptomatic disease or undetected disease by PCR testing alone.
- Ms. Vinson provided an overview of positivity rates using a variety of more detailed analysis including:
 - Top 10 states frequency of testing total and 14-week average
 - Top 10 states cumulative population testing rates total and positive results
 - Top 10 states weekly testing positivity rates total and 14-week average
 - National accumulation of COVID-19 zip code hot spots: 1,094 (22%) of nation-wide zip codes with established dialysis facilities have been flagged as a hot spot between 7/8 and 8/5/2020
 - A summary of consistent national hot spot areas
- In summary, positivity rates continue to illuminate adherence to recommended guidance to test only those exhibiting symptoms. Based on most recent data from 8/5/2020, the top ten states positivity rates remain above 75%. Based on a 14-week average, Maryland (92%) yields the highest positivity rate, followed by Indiana (81%) and Washington DC (76%). Texas (58%) ranks 7th.
- Ms. Quinn and Dr. Roach thanked Ms. Vinson for the more detailed analysis of COVID testing. Additional update will be prepared and shared every 3-4 as needed.
- Network attendees shared that some discrepancies are being identified (i.e. multiple tests for the same individual) in the data as they work more intensely on the Technical Assistance Activities and correspond more frequently with local facilities. A better understanding of how facilities are counting, and reporting data would be welcome.
- Attendees discussed the desire to know how many dialysis facilities are testing inside the clinics and what types of tests are being used. **ACTION:** Dr. Atkinson asked the Networks to consider how this data might be collected without overburdening the facilities.

[08/19/2020]

- Referencing a recent [MMWR article](#), Dr. Atkinson summarized the findings by sharing that this investigation identified a "...higher prevalence of infection among residents undergoing dialysis (47%; 15 of 32) than among those not receiving dialysis (16%; 22 of 138)." Additionally, among the newly identified cases, 72% (18) were asymptomatic at the time of testing.
- Ms. Vinson provided an update on the positivity rates referencing the weekly data as of 8/13/20, noting the overall rate was 53.32%. She also shared data for the top ten states for that one week (CA with the most then TX and FL) and number of tests completed for that week. **ACTION:** Ms. Dorsey requested additional details for CA and FL, Ms. Vinson will send via email after the call.

[08/26/2020]

- Ms. Vinson provided an update from the previous week positivity rates. As of 08/19/20, there were 1436 new positive test results and the overall rate was 48.55%; down from the week before at 53.32%. Data for the top 11 states were also shared; CA, TX and FL remain the states with the most positive results. It was noted that KS, DC, MT, and NM had 100% positivity *rate* for the week ending 8/19/20. This may be due to a decrease in the number of tests being administered by facilities (i.e. only testing patients and staff with known exposure or symptoms).
- After a discussion with the Network Directors and Dr. Atkinson earlier in the day, a recommendation was made to provide a more comprehensive report on future calls, including a comparison of total tests to positivity rates by state and also showing rates per 100,000 residents population.

#2 Discussion 09/02/2020:

- Referencing an article in [Science](#), Dr. Atkinson reported the FDA has approved the Abbott 15-minutes COVID-19 antigen test. This new assay will cost \$5 and Abbott is scheduled to produce 10 million tests by September and another 50 million in October.

- As of 08/26/2020, positivity rates remain about the same from the previous week: 48.77% weekly change and 51.37% cumulative. Ms. Vinson shared a revised graph which included percent of total patients tested compared to positivity rates for each individual state. Networks which had states with a high percentage of patients tested (5 states greater than 30%) were contacted, while the reason is unknown there was some speculation it may be due in part to a large number of nursing home patients being tested. Additionally, 1/3 of the states are testing less than 10%. Utah is one of the 5 states identified above; Mr. Preston shared that certain areas (i.e. specific counties in Utah) have mandatory testing guidelines which may account for the data being reported. He suggested a more in-depth look at the data to determine whether hot spots account for these higher percentages. In response to an inquiry, Ms. Vinson shared that the ESSR data includes all tests performed (including the new antigen tests) but does not specify which test.

3) Network Observations related to Contract Mods

[6/10/2020] On behalf of the ESRD Networks, Ms. Vinson presented a summary of observations and comments from the Networks, expressing appreciation for the opportunity to have these weekly discussions with CMS leaders.

- Networks are seeing a decrease in COVID related facility concerns and immediate advocacy cases, while general grievances and clinical quality of care remain flat. Access to care is still very volatile
- While the rate of improvement has slowed down during the pandemic patients do continue to move to a home modality.
- Still experiencing obstacles to getting patients waitlisted – nonclinical are working remote, some staff are furloughed, transplants are occurring but the process for adding patients to the waitlist are very disjointed right now. Networks are focusing on communication between the TX centers and dialysis facilities, referrals are still happening and we might see a bigger surge later
- Working with health departments on recommending more testing of dialysis patients;
- Offering telehealth education through resources and webinars, identifying gaps in telehealth utilization with home patients;
- Working with the NCC to develop a hand sanitizer audit, about to start piloting.
- Bridging the communication gap between dialysis providers and nursing homes, utilizing the forms shared by the Forum.

[6/17/2020]

- Networks had our quarterly call with FKC leadership last week
 - Gain additional insight into their corporate wide process changes to address COVID. Of note, FKC implemented a corporate telehealth policy with approximately 90% of their facilities utilizing telehealth. Also, to encourage the continuation of transplant referrals, social workers have been trained on the process and it has been transitioned to them. With this change, we may observe learning opportunities for social workers and changes in transplant champions at the facility level.
- As states start to open and COVID cases increase there are concerns that hospitals may discontinue elective procedures again. When we see elective procedures stop, we may see an increase in long term catheter use, increase in BSIs, and decrease in PD starts.
- “Project America Strong” – Networks are receiving calls from facilities who did not receive the shipments of masks and/or who are requesting additional masks. Has CMS heard anymore about this project and the follow-up to these inquiries?

ACTION: Ms. Quinn will follow up with the Project America Strong group regarding additional shipments of masks

[6/24/2020]

- Observations offered by the Networks included: telemedicine goals are being met or exceeded by most Networks, update on the weekly reporting of calls in the PCU related to COVID issues, and a partnership with NCC to develop Hand Sanitizer Audit.

[07/15/2020]

- Networks convened their quarterly call with DaVita leaders on July 9. Dr. Martin Schreiber, Chief Medical Officer for Home Modalities, expressed concern over vascular access surgeries not being considered essential. PD catheters not being placed will make it very difficult for patients to start a home modality.

There are reports around the country of vascular access surgeries being canceled when higher revenue generating surgery can be scheduled in their place. DaVita shared data that their overall catheter rate in May 2019 was 15.46%, one year later it's 17.17%. New starts in January 2020 with CVC was 71.3%, May is 77%.

- Some Networks are conducting various data analysis related to COVID-19
 - Networks are establishing processes to identify spikes in their Networks and hope to be able to quantify what they can for CMS.
 - Disparities in deaths using the 2746 death notification identify disparities in race, age, dialysis setting, in-center vs. home.

[07/22/2020]

- Ms. Vinson shared that CMS had provided an overview of the Technical Assistance Activity to the Networks and providers during the most recent KCER call. On behalf of the Networks, Ms. Vinson shared the following observations recently made through the 5 Diamond Safety Program:
- Through the 5 Diamond Patient Safety Program, 670 facilities have completed the module on COVID-19
 - Nationally the rates of correct responses provided in a pre/posttest are improved
 - We've also gained insight into challenges and barriers facilities are experiencing, which can help identify areas to provide technical assistance.
- Ms. Duval, Network 13 Executive Director, provided a brief overview of the "Dialysis Access during COVID 19 Guide" being developed by members of her MRB to address the concerns about patient dialysis access issues being identified as essential procedures/surgeries. The resource is intended to provide guidance to renal-related healthcare providers during COVID-19. Additional edits are being made to the draft and will be finalized soon so it can be shared in the community. Dr. Atkinson invited Ms. Duval to present the final document on a future call.

[07/29/2020]

- Ms. Avery thanked Ms. Quinn for providing additional guidance to the LDOs on the recent KCER call regarding the Technical Assistance Activity Networks have begun this week as part of their contract mod. Networks received the survey that will be used weekly to report on the Technical Assistance Activity. Networks convened a call with the ESRD NCC on 7/27 to view a demonstration of the COVID Dashboard and provide feedback about functionality and use. It was a productive discussion to clarify instructions and requirements for the activity.
- Reviewing national PCU data, Ms. Avery provided an update on the weekly reporting of calls in the PCU related to COVID issues.
- Dr. Atkinson inquired about whether CMS had been receiving any concerns or issues regarding the availability of PPE and supplies in the stockpiles. CMS has only received anecdotal reports through the Networks which have been addressed individually. Dr. Atkinson offered to survey Networks and provide feedback, if applicable, on the next call. **ACTION**

[8/5/2020]

- Dr. Atkinson asked Network 18 and 17 to share their recent experiences with the Technical Assistance Activities.
- Ms. Hutchinson shared a brief overview of the collaborative efforts being established in Southern California to look at the pediatric cases of COVID positive patients which also included multiple PUIs of patients and staff. She also noted that Network 18 Technical Assistance is heavily focused in the LA County area where about half of all COVID positive cases and deaths are being identified.
- Ms. Rose shared that Network 17 is seeing more community spread in the suburban areas of Oakland and Sacramento; they have focused much of their assistance on communication with nursing homes and developing stronger screening processes.

[8/12/2020]

- Ms. Vinson reported that some of the Network MRBs are asking if dialysis providers can be considered for expedited vaccines (flu and COVID when available), to put added to the list of high priority populations having access to the vaccinations before the general public. CMS leaders agreed and will look into how to coordinate these efforts. **ACTION**

- Dr. Roach was asked to provide clarification about the initiation of flu vaccinations, there is some information being shared to begin these on September 28 rather than the previous September 1st directive. Dr. Roach will look into this and provide follow-up. **ACTION**
- Ms. Albin, ED Network 14, presented an overview of the Texas ESRD Emergency Coalition (TEEC) which was established as a result of Hurricanes Katrina and Rita and which has now been adapted and initiated to handle the COVID-19 PHE. The goal of the Coalition is to help patients and coordinate care through the at-least-weekly meeting of various healthcare and governmental leaders in the state of Texas.

[08/19/2020]

- Dr. Atkinson acknowledged the 3-month extension of the ESRD Network contracts that was recently announced. He then introduced Ms. Avery and Ms. Duval, Executive Directors of Networks 8 and 13 respectively.
- Ms. Avery reported that Network 8 began collaborating with independent facilities and area long term care facilities to pilot test the COVID-19 Communication forms that were recently shared as a Highly Effective Practice through the Forum website. The Network worked closely with the QIO organizations in their states to provide outreach to nursing home facilities to report that dialysis facilities might be using the forms to help improve the care of dialysis facilities transferring between the facilities. Additionally, they have used the form as a BSI intervention tool for a facility who had nursing home patients and as part of the Technical Assistance Activities. Currently, 40 facilities are using the form and have been surveyed on their experience; 18 of the facilities reported they wanted to use the form, but the area NH would not participate.
- Ms. Duval provided an update on the vascular access guidelines being developed by members of the Network 13 MRB which was presented previously on the 7/22/20 call. The resource will provide guidance for local dialysis facilities to use when corresponding with surgery centers regarding the placement of vascular access for hemodialysis or abdominal access for peritoneal dialysis. The resource will help providers understand the importance of these procedures and include an assessment tool, based on the ASC guidelines, to determine which surgeries could be safely delayed and which should proceed. Some additional recommendations included collaboration with local dialysis centers to designate a COVID-19 positive outpatient HD facility when possible, minimize in-person clinic visits with the use of telemedicine when possible, and identifying opportunities for interventions in ambulatory surgery centers or outpatient settings to avoid hospital visits. Ms. Duval also acknowledged the recent CMS memo regarding essential surgeries for COVID-19.

[08/26/2020]

- Ms. Rose provided an overview of the PHE in Network 7, sharing that the hospital coalition reported a decrease in cases in recent days. A strong focus of the Technical Assistance work in Network 7 is in collaboration with nursing homes where they continue to see new cases of COVID-19. Best practices are being shared among dialysis facilities to monitor and prevent spread as much as possible. The Network has been collaborating with the QIN/QIO, the Florida Hospital Associates, the Florida Healthcare Association, and the State Survey Agency to address patient transitions. She also reported that Norther CA (NW 17) and the Phoenix area (NW15) are also seeing slight decreases.
- Ms. Quinn acknowledged the collaboration work with the QIN/QIOs to address the concern of spread between nursing homes and dialysis facilities.

#3 Discussion 09/02/2020:

- Ms. Cash provided an overview of the Network 9 “Call Ahead Culture” activity used by dialysis and nursing facilities to decrease the patient exposure to COVID-19. In part, dialysis facilities called nursing homes where dialysis patients were expected to be received from the next day for dialysis treatment; recent test results and a survey are conducted to determine possible exposure. The Network saw a decrease in positive cases and increased communication between the organizations. They also worked closely with transportation services to implement this activity. Ms. Quinn commended Network 9 for this work. Dr. Molony encouraged Network 9 to submit this activity to the Forum as a Highly Effective Practice.

4) Kidney Patient Observations

- a. Safety as States Reopen: The primary issue discussed during the KPAC call was the concern of cities beginning the process of re-opening. Some patients are observing increased laxness in their dialysis facilities of wearing masks, not maintaining the 6-foot distance, and staff not wearing full PPE as they had been. Patients are not receiving updates and education as frequently as they had been and are turning to outside resources for information. Many patients must rely on public transportation to get to/from their dialysis treatment, as cities reopen these places are becoming more crowded and patients are feeling unsafe. Additionally, families of patients are also moving around more freely but coming home to the patient who still feels the need to isolate to stay healthy. There is a general feeling that things have improved even when some areas of the county are still seeing increased numbers each day.
- b. Telehealth Concerns: Mr. Forfang reported that during the recent KPAC calls, patients expressed concern for the use of telehealth when they are experiencing health complications, they did not feel they could adequately explain and visually show issues they are experiencing. KPAC members feel generally that telehealth is a good fit for stable patients but not for those who have health issues.
- c. Baxter Response to Delivery of Dialysis Supplies:
- d. Transplant Patient Concerns about Symptoms & Relieving Anxiety: Pulse Oximeters to monitor coronavirus symptoms

[6/17/2020]

Ms. Quinn offered follow-up from last week's discussion regarding the safety concerns in facilities; she offered that CMS is considering ways in which to address these concerns and provide additional messaging to facilities about remaining vigilant in the use of masks, social distancing and PPE.

Mr. Forfang asked if CMS could consider an educational update to patients through the NCC or Networks which may include a summary of guidelines from CDC about what patients can do to keep themselves safe and why. Dr. Atkinson encouraged this suggestion and shared, that from personal experiences, patients in his region have been supportive of safety precautions and would welcome additional information to reinforce the continued efforts of providers and patients.

[6/24/2020]

Ms. Quinn reported that CMS will be working with CDC to compile the most current guidance and prepare a joint webinar for providers and patients as a reminder about the need to remain vigilant in using PPE to keep kidney patients safe. Ms. Edwards asked CMS to consider alternate means to educating patients in underserved areas who do not have access to technology such as webinars, internet and smart phones.

[07/15/2020]

Mr. Forfang reported that members are drafting a statement on health equity and had a robust discussion during the call. This topic is of significant concern to KPAC members and recognize some of their fellow patients experience great disparities in care, transportation, testing, and access to basic life necessities, especially in underserved communities. Ms. Edwards shared a concern from a fellow patient about the lack of guidance regarding eye protection against COVID-19. Are their CDC guidelines available on this subject? Mr. Forfang asked them to consider additional guidance on safety within the home including:

- Receiving deliveries to the home: What should the delivery person be wearing? Should the patient be masked?
- Living with family members who work outside the home, precautions to take inside the home
- What if a family member tests positive and does not have an alternate place to stay while recovering? How does the ESRD patient in the home protect themselves?

[8/5/2020]

Ms. Edwards shared that the KPAC is hearing from patients a request to have more transparency with the statistics being shared about the impact of COVID-19, particularly in regards to the African-American community. Following Administrator Verma's announcement on the hospitalization rates and disparities in the black/brown communities, patients want more detailed data to know what is happening in their communities and how to keep themselves safe. **ACTION**: Ms. Dorsey acknowledge the concern and offered to look into the source of the data that was presented and research how CMS can respond to this request for more detailed data.

[8/12/2020]

- As follow-up to the request last week from patients for more transparency with COVID-19 data, Mr. Forfang referenced the graphs and data shared previously in the call as examples of data patients would like to have access to. Ms. Quinn agreed and offered to look into how this can be done considering the unique circumstances of the collection and analysis of COVID-19 data. She will provide updates on the progress of this request in subsequent calls. **ACTION** Dr. Atkinson offered the assistance of the Forum and Networks with this request.
- Members discussed the idea of providing dialysis facilities with some type of poster that can be displayed in a facility to provide additional guidance on how patients can keep themselves safe in hot spot areas.
- Dr. Molony and Ms. Albin offered to share resources Network 14 had developed around this topic. **ACTION**

[08/19/2020]

- Dr. Atkinson introduced Dr. Gee, KPAC Member and co-author of “*The Early Days: The Post Kidney Transplant Recipients’ COVID-19 Journey*” published in the July 28, 2020 issue of CJASN. https://cjasn.asnjournals.org/content/early/2020/07/28/CJN.08780620?&WT.MC_ID=ITL&utm_source=ITL
- Dr. Gee thanked attendees for the opportunity to share his experience. The article shares the perspective of two kidney patients and their journey through the COVID-19 PHE. Ms. Roberts lives in the Seattle area, and although she did not contract COVID-19 herself, she was in the area that experienced the first cases in country and knew about other kidney patients around her that were diagnosed with the virus. Dr. Gee shared that both he and his wife (who is his care partner) contracted COVID-19 in mid-March and were both hospitalized for care. He reported that it was challenging to be tested due to not meeting the criteria for testing that was established early in the pandemic. After being diagnosed, he was prescribed a 7-day regiment of hydroxychloroquine to treat the virus and experienced severe side-effects as a result. Dr. Gee shared that he continues to have side-effects from the virus and the treatment, nearly 5 months after being diagnosed. However, he was found to have the antibodies and has been able to donate plasma to help other patients. Over the past few months, he speaks to many patients who have expressed concern and anxiety about the uncertainty of proper protocols and not knowing what information is reliable. He thanked CMS for the continued release of information to help guide the care of patients and provide clarification as more is being learned about the virus.
- Dr. Atkinson also referenced a recent article by Ms. Gedney, “Long-Term Hemodialysis during the COVID-19 Pandemic.” <https://cjasn.asnjournals.org/content/15/8/1073>

[08/26/2020]

- Ms. Edwards encouraged attendees to read the article referenced below. She shared that through communication with many patients in the NYC area and across the country, there is still a great amount of fear about the virus, in particular, the number of asymptomatic patients testing positive. Even in areas with decreasing rates of COVID-19, patients are still very concerned about the virus and knowing how to best protect themselves. Fellow patients are wondering when more wide-spread testing will begin in dialysis facilities similar to what is being done in nursing homes and now in the area of athletics. Mr. Forfang also shared that kidney patients he’s talked with are fearful that the current approach isn’t the best approach for the kidney community.
- Ms. Quinn acknowledged these concerns and concurred with the observations, noting the kidney community is a vulnerable population. She shared that CMS continues to consider ways to address these concerns.
- Mr. Forfang asked if there were data regarding the nursing home approach, if the increased testing in NHs is lowering the number of cases. Ms. Quinn will reach out to the CMS nursing home group to gather information and report on the next call.
- As follow-up to the transparency request on the previous call, CMS continues to review the current available data to determine what types of reports could be made available to patients.
- **Renal and Urology News**, August 4, 2020: “High Prevalence of Asymptomatic COVID-19 Infection in Hemodialysis Patients” Persaud <https://www.renalandurologynews.com/home/news/nephrology/hemodialysis/high-coronavirus-seroprevalence-asymptomatic-dialysis-patients/>

#4 Discussion 09/02/2020:

- Mr. Forfang did not have new issues to bring forward from the patient groups at this time.
- Dr. Atkinson referenced the two articles below which discuss the use of telehealth, patient preferences for telehealth and the great disparity of internet users in healthcare noting it should be considered as a social determinate of health.
- **AJKD** May 5, 2020 “*eVisits in Rural Hemodialysis Care: A Qualitative Study of Stakeholder Perspectives on Design and Potential Impact to Care*” Lunney et al: [https://www.ajkd.org/article/S0272-6386\(20\)30582-5/fulltext](https://www.ajkd.org/article/S0272-6386(20)30582-5/fulltext)
- **AJC Online** August 11, 2020: “*Racial and Geographic Disparities in Internet Use Among Patients with Atherosclerotic Cardiovascular Disease*” Rifai et al: [https://www.ajconline.org/article/S0002-9149\(20\)30818-3/fulltext](https://www.ajconline.org/article/S0002-9149(20)30818-3/fulltext)

5) **Transplant Metrics:** monitoring transplant performed and waitlist activity

#5 Discussion 09/02/2020:

- Referencing the UNOS transplant data as of 08/31/2020, Dr. Howard reported transplant patterns remain the same as last week with almost every UNOS region following the same patterns. The NE region is still seeing DD transplant lagging behind last year’s numbers. Total transplants and both LD and DD transplants have seen a slight increase from last week. Since last week, just under 800 new patients were added to the waitlist.
- Dr. Wagner shared usual interactions with transplant programs are beginning again in NYC but noting there remains some caution about patients returning to the hospital settings and still lots of testing which may be some of the reason for delays in transplant decisions. Dr. Molony shared that a number of donors have tested positive for COVID-19 which may also be a factor for fewer DD transplants. Dr. Henner also shared that his area had also been slow to get patients on the waitlist but are not seeing an increase.

6) **Tracking Nursing Home residents in EQRS:** CMS is working on this, any updates to share?

Lisa Rees reported CMS continues to work on this request.

[06/03/2020] Ms. Rees shared that she continues to work with ISG on this issue. Although the updates will not be part of the Fall 2020 EQRS roll-out, she expects the updates to follow soon after.

7) **Tracking Lessons Learned and Preparing for Future Surges:** What can the Forum and Networks do to support CMS in preparing for future COVID surges?

- a. Nurses and PCT shortages in hot spots
- b. Transportation of COVID+ Patients
- c. Shortage of CRRT Fluids & Supplies
- d. Vascular Access
- e. Variability in Infection Control Surveys
- f. Data Reporting at the national level
- g. Telehealth Waivers
- h. Triage of COVID+ Patients
- i. Monitoring COVID-19 recovering and treating ESRD patients
- j. Transparency of sharing COVID-19 test results between dialysis facilities/healthcare providers and nursing homes

The next call will convene September 16th and calls will convene every-other-week following September 16.

The call adjourned at 4:37 pm ET