Renal Support Network
RSNhope.org
*Service to those affected by chronic kidney disease*

January 31, 2022

Dear Secretary Becerra and Administrator Brooks-LaSure,
Medicare & Medicaid Services,
Department of Health and Human Services
Attention: CMS-3409-NC
P.O. Box 8010, Baltimore, MD 21244-8010.

**Re: Request for Information; Health and Safety Requirements for Transplant Programs, Organ Procurement Organizations, and End-Stage Renal Disease Facilities**

Renal Support Network (RSN) empowers people who have kidney disease to become proactive in their care, and to work with healthcare professionals, regulatory agencies, and legislative leaders to get the best care and health outcomes possible. I have been dealing with kidney disease since age two (1968), having survived 50 plus surgeries, 13 years of dialysis and doing well with my fourth kidney transplant. I founded RSN back in 1993 to provide hope to my peers and advocate for the best care.

We appreciate the Administration's efforts to solicit input to improve and increase organ donation, transplantation, and access and care for people who require dialysis. This request contains an extensive list of queries, and we had limited time and resources to fully explore all. We are committed to advocating on behalf of people who have kidney disease, and offer the following input drawn directly from our community's experiences:

## TRANSPLANT PROGRAMS AND ORGAN PROCUREMENT ORGANIZATIONS

### Transplantation and Organ Procurement

As a community, we honor deceased donors and want to make sure that the gift of life is always utilized. Thank you for addressing the issues of organ declines and discards, as well as issues surrounding making sure a donated kidney is successfully placed.

In this country, we have 57 organ procurement organizations (OPOs), and patients can get themselves on more than one OPO deceased donation list. Patients listed on the OPO in Los Angeles could be on the list of the OPO in San Diego, Arizona, Nevada, and/or San Francisco. These are all within a short flight or a 5-hour drive. People who have the financial means to multi-list and travel are at an advantage of receiving a transplant. In other parts of the country, transplant facilities are scarce, preventing the patient from getting listed at all due to transportation or financial issues.

Multi-listing raises the chances of getting a kidney, but the question is would it be prudent to open up geographic areas to prevent the burden of multi-listing? We are aware that kidneys have a very limited shelf life and might be better placed in someone nearby. Advanced technology is available for other products. We should be adapting such advanced tracking and shipping technology to send organs to where patients are. We are excited to hear that CMS is considering putting tracking devices on kidneys donated for transplant, one step in upgrading the system. Overall, the goal should be getting the kidney to the patient, not the patient to the kidney.

### Getting Approved for the Transplant List (Wait List Criteria)

Getting on a transplant list can be daunting. Transplant centers have varying criteria, and different ways of conveying essential information. It is beneficial that patients can self-refer for a transplant, but they also need to be very pro-active to find out what tests are required by a center, what's needed to get on the list, and how to make sure the process is moving forward. One of our members, who is very organized and an effective advocate for themselves, just discovered they were missing an appointment and it was delaying their ability to get on the list. Here is her comment.

> *"I've been a chronic kidney disease patient for over three decades. During the last year I have been working diligently to get myself on the transplant list. The process is not for the faint of heart. As a seasoned navigator in this process, I still find it difficult to communicate with the transplant team. Even crossing my T's and dotting my I's I seem to have fallen through the cracks.*
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> *"The assistant coordinator was to arrange an appointment with an anesthesiologist at the request of the transplant surgeon. Waiting and waiting I never received a call about the appointment. Eventually I reached out to the coordinators boss. Come to find out no appointment was scheduled, and she was not even aware that I needed to see an anesthesiologist. This lack of coordination cost me three months. Three months for me is 48 dialysis treatments.*
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> *It's very important to advocate for yourself and follow through. However, there's a fine line in advocating for yourself and being annoying. I guess the moral of my story is I would've been better off being annoying and getting that appointment scheduled. Instead, I decided to step back, and that decision got me nowhere."*

We hear different stories: some patients have great experiences, and others have trouble navigating. There is no continuously updated report provided to the patient, while only 60% of patients on the wait list are active due to testing delays, medical problems or other issues!

Technology has already solved this problem for commercial and industrial purposes. It just needs to be adapted to the transplant application process. A universal patient portal app would have a list of requirements, appointments and conditions. The system would then serve as an online dashboard with the latest status displayed, and would proactively email or text updates to patients (or caregivers) about: upcoming or needed appointments, completed tests and test results, whether they were placed on the inactive list due to hospitalization, what to do to get back on the list, etc. This universal patient portal app that is funded and provided by the national government so patients and caregivers would know upfront what was expected of them and are able to have constant contact with their transplant coordinator so there will be no room for delays. Transplant centers would be able to integrate with this system, so patients have the most current info.

**Procuring Organs, Discard Rates and Distribution**

OPOs have a huge responsibility for identifying possible deceased donors, obtaining proper consent, procuring the organs, and distributing them based on who is a good match and at the top of the waiting list. We all know that ischemia is a major factor here and the system has to be as seamless and responsive as possible.

A recent study found inability to locate a recipient were reasons for organ discard in 14.6% of cases.[1] Technology can and must solve this problem, as noted above. At any given time, more than 40% of patients who are on the transplant list are inactive. Some patients become ill and are put on hold, but this number needs to be examined to see if there are reasons in addition to health issues that cause the patient to be inactive that can be resolved quickly. A standardized universal patient portal app such as that described above could address issues relating to keeping patients informed of their status.

We have also become aware that providers and transplant centers are becoming more selective in accepting organs. This may potentially be due to regulatory pressures on transplant centers.[2] We need to closely examine why organs are being discarded and fund ways to decrease discards and increase utilization rates.

**Incentivize specialist organ repair**

We have become aware that some surgeons can repair kidneys that first present as unusable. We should incentivize physicians who are able to repair kidneys so they can be used and develop more specialist training on these techniques so valuable organs don't go to waste.

**Standardize transplant center requirements**

Getting listed with multiple transplants centers in different OPO regions can be overwhelming, and the patient must figure out the criteria for each. For those who can take advantage of it, they typically need to repeat tests because the centers don't communicate with each other. This is a waste of time, money, and blood! If a patient has the resources to "multi-list" then they should be able to utilize their existing medical testing (if current) and not repeat basic tests for them to get listed. System to compliantly share Electronic Health Records (EHR).

We want transplant centers to innovate and try new approaches so they can successfully serve more patients, but basic standards should be the same for patients everywhere to improve the experience, serve patients' needs, and expand access. Patients should be able to send their current test results to any provider they choose. Here is a comment from one of our members.

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[1] *Factors leading to the discard of deceased donor kidneys in the United States*, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6015528/

[2] *Ibid, R23*

> *"I was at center #1. In their initial work up, they ordered 28 vials of blood. I ended up not being listed at that center. When I moved on to center #2, they also required 28 vials of blood for my initial workup. The fact that this bloodwork was only taken a few weeks later it would've been so helpful if the first center could have sent my blood results to the second center. In the end I had a low hemoglobin which is really not fair and diminishes our quality of life."*

So, what's the solution to this situation? The transplant center is given access to supply information to a universal patient portal app. There was also a transplant center that closed in Los Angeles and many of the patients who were transplanted there and had their follow up care at that facility were not informed. There needs to be a plan in place for existing patients to be notified when anything changes with respect to their care providers. Again, a universal patient portal app combined with triggers that include paper notifications as well (such as when a center closes with a list of centers a patient could go to) could serve this purpose.

With 57 OPOs in the United States each one serves its own area. While this may make sense to the health care community, patients often find it confusing when they learn they can multi-list at different centers if they have the financial resources. This places additional burdens on the medical system – more appointments, tests, and multiple records.

Redefining geographic areas needs to be explored to help some of the underserved areas. With better shipment and tracking of available kidneys, this might help address the barriers faced by lower income patients who can't travel on a moment's notice and multi-list at multiple transplant centers. Black and Hispanic patients frequently experience barriers to receiving a transplant or being able to select home modalities.[3] Black patients are less likely to receive a preemptive kidney transplant (20.9%) than White patients (8.1% and 33.2%, respectively). Among patients who were initially wait-listed in 2013, median wait-time was 5 years for Black patients but only 3.4 for years for White patients, a difference of more than 1.5 years. (USRDS Figure 6.9[4] by race)

**Public reporting of Organ Procurement Organizations**

OPOs need to be transparent and share their best practices. They should be held accountable when they do not perform. They should be recognized when they exceed expectations. Reporting measures need to be evaluated and determine/provide meaningful outcomes metrics if they are helping or hindering the OPO.

We would like to request that the number of people nationally signed up to be an organ donor through the DMV or other sources be reported annually. Since we've implemented the national donor registry and nobody can take your wishes away, we should make public the number of people who sign up to be a deceased donor and then see if we are making that number grow.

To our knowledge there are not a lot of national campaigns that are out there to educate the public about the importance of organ donation. We have the Rose Parade, but that's about it – there needs to

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[3] United States Renal Data System. Epidemiology of kidney disease in the United States. Chap. 1. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2020.

[4] *Id.* at Chap. 6.

be some way to reach high schools, institutions, corporate leaders and the public. I was on a call, and somebody said it's up to the DMV. Maybe we need to study, is signing up at the DMV enough info for someone to make the choice?

In the past, pilots were created to see if paying a portion of the deceased donor burial fee increased deceased organ donation. Innovative pilot programs should be encouraged to see if these kinds of incentives get people's attention and help increase organ donation.

**Remove barriers and incentivize living donors**

The Living Donor Protection Act of 2021 addresses insurance and job absence barriers to donating a kidney. Going further, this country should protect living donors by offering ongoing future health check-ups so living donors may maintain their health. We need a national system for supporting donors, tracking their status, and meeting their needs, which again can be solved with existing technology. Along these lines, CMS and HHS should devote resources to promoting live organ donation and its benefits, building on the Scientific Registry of Transplant Recipients (SRTR) and its Living Donor Collective (LDC) which collects and analyzes living kidney and liver donor candidate and donor outcomes.[5]

**Address practical barriers to getting a transplant**

Transportation is a major issue for patients in rural areas where a transplant center is hours away. Financial constraints are another barrier. While different centers have different criteria, most require the transplant applicant to identify a caregiver. Family issues, location and finances all play into that as well. Transportation, and funding for a center-required caregiver, should be assessed for solutions in a standardized way, with resources devoted to providing these to patients who need them.

This is a list of transplant barriers we received from people who are on dialysis, have received a previous transplant and family members. We recognize that each of the following list cannot all be addressed, but it is a good source of information.

- Lack of a transplant center in geographic area
- Economic concerns of not being able to afford tests/medication, fear of losing existing insurance
- Medicare/State Program/Insurance, fear of losing kidney after 3 years post-transplant, fear of previous failed transplant and fear of medication side-effects, fear of loss of wages, caregiver/family member unable to go to mandatory tests, etc.
- Physical barriers out of patient's control such as too old to be considered, too sick to be considered, reoccurring illness that will impact transplant
- Lack of education about transplant process/eligibility and how to navigate the process and/or how to proceed, accessibility for testing process due to transportation for necessary tests, bloodwork, transplant center, etc.
- Fear/guilt of accepting a living donor kidney
- List of requirements too long and do not feel they will live that long, not worth the hassle

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[5] SRTR's Living Donor Registry and Other Valuable Resources, Scientific Registry of Transplant Recipients, https://www.srtr.org/about-srtr/living-donation/

- Non-compliant issues of patient or previous or current substance abuse
- Highly sensitized with antibodies leading to higher rate of rejection
- Lack of health insurance, fear of surgery and risk of dying
- Lack of caregiver for support before, during or after transplant surgery
- Loss of visiting the dialysis center

**Preemptive transplant opportunities**

There still needs to be more education provided to the patient in the early stages of kidney disease so they can prepare and do all they need to get listed and get the word out in search of a living donor. We need to have more primary care providers (PCPS) and patients educated on this option. The majority of preemptive transplants are provided by a living donor, and policies that encourage and support living donors could increase organ donations and preemptive transplants, helping people stay off dialysis and saving the government money!

With the higher frequency of rapid progression of advanced CKD in minority and underserved populations, it may be appropriate to identify patients at higher risk of rapid progression to kidney failure and allow for a different eGFR cutoff to list this subset of patients pre-emptively. Removing barriers facing non-citizens and non-residents with advanced CKD to receiving a successful preemptive kidney transplant is also cost saving compared to maintenance dialysis. Some patients, both adult and pediatric, must utilize emergency rooms relying on Emergency Medical Treatment and Labor Act to gain access for life saving dialysis. A transplant is a better option. State Medicaid programs are challenged by these policies, and we urge HHS to identify ways to address this disparity.

**Transplant surgery follow-up**

Receiving the gift of life is wonderful, but a kidney transplant is not a cure, it is a form of treatment. It's one thing to get transplanted, but kidney transplant recipients will subsequently need long-term access to health care *and* health insurance. We need to look at ways to help the patient retain the kidney, make sure they have access to follow-up care, the medications they need, and the right medical professionals. The question becomes whether they can afford their illness. We as a society need to invest in the lives saved by donated organs. "Health equity" is a synonym for helping people who are dealing with these issues.

We are grateful for the passage of The Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act (H.R. 5534) that will go into effect in January 2023! This will extend immunosuppressive coverage past the 36-month cut-off currently in place to cover the medications for the life of the transplant. It's a good start, but in addition to medications, patient need access to good quality medical care. This blog post details the benefits and shortcomings of this legislation: H.R.5534 – the Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act of 2020: It passed – So Now What?!

**Transplant program and OPO recommendations summary**

The kidney transplant system needs to be improved to help the people for whom it is their best option. RSN supports Kidney Care Partners recommendations that HHS work across the agencies responsible for transplant and consider the following initiatives or policy changes:

- Incentivize the adoption of clear and transparent transplant waitlist criteria that can be easily accessed by patients and providers at a central online location.
- Promote care coordination within the transplant system.
- Improve communications and transparency among patients, transplant centers, OPOs, dialysis facilities, and nephrologists.
- Expand educational opportunities for patients, including providing earlier access to the Medicare Kidney Disease Education (KDE) program, expanding the providers who can provide and be reimbursed for KDE services, and providing non-branded materials to patient groups.
- Rely on metrics that incentivize transplanting sicker or more complex patients, addressing inequities, and eliminate those that discourage these patients.
- Increase transparency of the data already collected regarding organs that are not accepted by transplant centers and provide an internet-based portal through which patients could access information about organs offered to them specifically and not accepted.
- Revise the hospital Conditions of Participation to require hospital to report timely notification of eligible deaths to OPOs and CMS.
- Collect Z-codes and other social determinants of health data.
- Address patient access issues, including transportation to/from transplant center appointments prior to and after transplant, as well as post-transplant coverage and access to disability insurance or other assistance post-transplant.
- Enhance education to increase living donor kidney transplant and remove barriers for living donors to donate kidneys.

All the above recommendations would also help with discard rates – so more resources should be allocated to upgrading and streamlining the processes for patients and available organs.

## END STAGE RENAL DISEASE FACILITIES

### Expanding access to home dialysis

Increasing adoption of peritoneal and home hemodialysis for patients is an admirable goal. It allows for greater mobility, greater freedom, and more flexibility in scheduling treatment. People who are more engaged in their dialysis treatment often do better. We want to take this a step further and recommend a pilot to see if incentivizing patients to do their own treatments at home would increase home dialysis longevity and retention.

A financial incentive may address individual barriers to home treatment – it may help a person afford a slightly larger apartment where equipment can be accommodated or paying for help needed. People who require dialysis often have more frequent need of help from friends, neighbors, and health aides, and providing funds to pay people could alleviate both medical and social issues. It also can save costs to healthcare.

One of our members said this:

> *"I developed an umbilical hernia after only nine months of home PD. It's believed the cause was my lifting the heavy dialysate bags nightly – they pushed my limits with how much weight I*

> *could or should lift. It never occurred to me to ask someone, a friend or neighbor or medical aide, to come over once a day and lift it for me. This is even more true with the multiple favors I need to ask friends for, due to medical issues. If I could compensate someone in some way (and if I had known I was at risk for this ... no one ever mentioned it among my health professionals), then I would definitely request assistance. The cost to me with this injury was surgery to repair the hernia, and the surgery recovery pain, and the future risk for reoccurrence."*

Consider paying patients for doing their own treatment. This would require changes in federal and state laws. But there's money in the dialysis bundle for staff – if a patient is doing their own treatment why shouldn't they be rewarded? Social and interpersonal issues come into play here as well. A family's acceptance of home dialysis might be eased if the patient is getting paid for doing the treatment at home. There should be some tangible financial reward system for patients who take on the burden of their care, learn how to stick themselves with large needles, or recruit family members to help.

RSN supports respite care for people on home dialysis who get ill and choose to go back to in-center dialysis if they have no other choice. This is where staff-assisted care would be beneficial. The system should reward people for continuing their care and should help them transition back to home care when they feel better. RSN is in support of H.R.5426 – Improving Access to Home Dialysis Act of 2021

RSN advocates for a written agreement with the dialysis center with respect to patient safety in case a patient on home care needs to return to in-center dialysis. If such a patient gets sick, there must be a dialysis center for them to go to, providing a continuum of care.

Some other barriers to care that need to be addressed to help more people do home dialysis and get transplanted is access to transportation .

**This is a list of home dialysis barriers we received from people who are on dialysis, have received a transplant and family members.** We recognize that each item on the following list cannot all be addressed, but it is a good source of information.

- Home environment not sterile enough, big enough or appropriate for maintenance or storing items.
- Anxiety and stress issues of dialysis process.
- Fear of self-cannulation
- Will have to add wiring or plumbing for home use of machine
- Family not trustworthy and worried about damaging equipment or misplacing dialysis-related items
- Cost of missing work, for either themselves or caregiver, for training
- No one to help – fear of doing it alone
- Lack of family support or fear of family response of having the illness in the home
- Fear of serious medical incident
- Physical issues and unable to lift medical equipment
- Fear of robbery because needles and medical supplies in home

- Fear of burnout and patient's often feels guilty about the time and energy their care givers provide
- Unstable health or cognitive issues
- Homeless or unstable home situation
- Plan of care is to be transplanted and catheter placed in abdomen is not a medical recommendation by transplant team
- Don't trust themselves to be compliant or to sign off dialysis early
- It will be too difficult for them to learn and do properly
- Patient feels isolated at home and the socialization of a dialysis facility reduces anxiety

Self-Care in-center dialysis could provide many of the advantages of home-based dialysis and remove many of the barriers that prevent patients from choosing to do dialysis at home. Self-care in-center dialysis is a real step to helping people get more comfortable with caring for themselves and every avenue should be explored to incentivize patients to be involved.

In addition, dialysis facilities should be able to help people who are doing home dialysis with supplies they need to succeed. It is often reported that in some areas of the country, medical supplies kept at home need to be secured. In addition to concerns about theft, means of locking up and securing supplies could prevent small children from harming themselves. Dialysis facilities should be able to assist patients in obtaining what they need to succeed to do their treatment at home.

**Mobile dialysis and dialysis in nursing homes**

Mobile dialysis is a new concept and RSN is excited to learn that these options are being proposed for people who are in rural areas. A trailer of some sort retrofitted with dialysis equipment, water, and supplies arriving at a target location three times a week in an area that does not have access to a center is an ideal way to address transportation barriers. This is a great way to increase access in rural areas.

We are also glad that CMS properly recognizes that it makes sense for patients in short- or long-term care facilities to dialyze on the premises, instead of going to considerable effort to transport them to a dialysis center. We hope this prudent, patient-centered care policy expands.

**Innovation in dialysis care**

RSN is very grateful for the Medicare program but sees gaps in how innovation can get incorporated into a bundled environment. We ask that CMS incentivize the adoption of innovative products using a pass-through payment (TDAPA and TPNIES) for innovative products to gather at least two full years of clinical data at ASP+6 percent. That means payment for drugs at the average sales price plus six percent to cover overhead costs, adjusting the base rate incrementally to provide sustainable funding for the long-term adoption of such products. We also ask that once a product is added to the bundle, CMS should collect real time utilization data to ensure patients are getting the benefit of that option, instead of being placed on cheaper therapy that saves dollars for the provider. It concerns us that medications can be withheld or skimped on, and patients are unaware this is happening. We have heard of some anecdotal cases where a provider was struggling financially, and patients were given little to no treatment. In all sectors of healthcare, we know payment drives practice. RSN appreciates that CMS is trying to balance resources and ensure people receive the best quality care.

Here is a RSN KidneyTalk podcast that talks about: Addressing Innovation in Kidney Disease Treatments

RSN is in support of efforts to expand nocturnal dialysis. This is tricky as nephrologists have to do rounds in the evenings and sadly there is a shortage. Large dialysis providers may have an advantage here due to them having more resources. CMS should not set a policy that disadvantages patients in large dialysis organizations by creating differential scoring based on the number of facilities owned by a single entity. Nocturnal dialysis is not widely available, and we should not create any barriers to providing this option.

RSN interviewed a patient receiving in-center nocturnal hemodialysis 3 nights a week for 9 years. In our KidneyTalk® podcast, Hemodialysis for Night-Owls: What One Person Discovered Two Transplants and 34 Years Post Diagnosis, she explains why she likes it and how she manages it. This alternative therapy modality can have many benefits.

**Allow dialysis centers to provide COVID and other preventative treatments**
There is a new treatment for COVID specifically for immunosuppressed people who have not developed antibodies after receiving the course of vaccines, and an online list of facilities where it is available by prescription. We should also allow dialysis centers to provide new innovative treatments and be able to bill for them. A patient should be able to get such treatments at the center instead of arranging for another appointment elsewhere.

**Quality measures**
Measuring care in the End Stage Renal Disease (ESRD) Quality Incentive Program (QIP) is a new frontier in healthcare. RSN believes the QIP should focus on a small number of measures that report outcomes in areas where there are real gaps in care and that have clear performance-, process and patient-based results. Too many measures disincentivize treatment. The allowable margin for improvement may be too small, or it may be too cumbersome for a facility to try and drive care in an area when the incentive is not worth the time, resources, and energy.

If more and more measures are added, the withhold may need to be increased to have a meaningful impact. The ESRD Quality Incentive Program (QIP) has a 2 percent withhold of dialysis payment based on the measures in the QIP. It would be beneficial to provide a QIP bonus payment (carrot) to those who are exceeding performance standards. For any year in which the outlier pool funds are not used or money withheld due to lack of performance, CMS should allow these funds to be used to address health disparities, innovation, access to care or other payment policy priorities.

## SYSTEMIC ISSUES

**Health care workforce shortages**
The medical care workforce shortage and chronic kidney disease (CKD) are both growing problems in the U.S. It is critically important that we make sure there are adequate numbers of physicians who are trained to understand and recognize CKD. More physicians are needed to diagnose patients earlier in disease progression, help patients manage the disease, and refer patient to nephrologists. The shortage of primary care physicians and nephrologists must be addressed if there is to be a sufficient work force

to support the estimated 37 million Americans living with kidney disease. There was just an urgent joint plea stressing the shortage of nurses and allied healthcare professionals. The system is under tremendous pressure and patients at serious risk. In addition, only 10 percent of that population is aware of their diagnosis. As the community creates more awareness, the bandwidth is not there to serve patients. Health equity as a goal must include educating and training enough doctors (allied healthcare professionals) to serve Medicare and Medicaid patients!

Many of those at risk for kidney disease do not have a relationship with a primary care provider (PCP). For those who do, the shortage of PCPs participating in the Medicare program can result in months long waits to get an appointment. For others, PCPs' appointment hours do not fit within their work and family obligations. Patients often turn to emergency rooms or urgent care centers which results in fragmented care and doesn't address prevention.

CMS can help address this issue by authorizing more residency slots for PCPs. In addition, we urge CMS to work with medical schools to include CKD more prominently in the curriculum, and to incentivize medical students to pursue nephrology as a specialty. We should look at payment structures for practicing physicians as well. The shortage of nephrology nurses also needs to be addressed. Dialysis facilities are currently facing a serious workforce shortage.

CMS and HHS should consider creating a Civilian Medical Corps. COVID has shone a light on how much we rely on a functioning health care system, the stress health care professionals are put under, and the need to educate the general public so they better understand health concepts and the role of medical staff. We need a robust federal investment to help people be more healthcare savvy and expansion of health care workers at every level. The general population is mainly unaware of the precursors to kidney disease; the Civilian Medical Corp could be charged with educating the public on this and other public health concerns and communicating critical things to watch for via the many social media platforms and their own communities.

**Technology and communication**

Several adaptations have come out of COVID; a good one is that the majority of the population have experienced access to Zoom and online meeting platforms. RSN encourages CMS to continue allowing telemedicine visits as appropriate, with standards.

Continuing on the theme of adapting existing advanced technology: patients should become the sole owners of their health care records and then their physicians could have access. Records are already associated with patients' Social Security Numbers and other identifiers like CMS numbers. CKD patients currently must set up accounts and passwords and log into multiple patient portals to get their information; these are owned by medical organizations. There should be a way to combine all medical information onto one secure universal patient platform that exists about and for the patient. This would make it easier to access records for transplant, dialysis, and other medical processes such as getting a second opinion. An authorized non-commercial app for all this can be developed, while allowing doctors to maintain their own portals, so that a patient can choose to have all their records in one location.

**Mental health.** There is a great need for mental health specialists right now, and RSN has been calling out CKD patients' unmet needs for mental health services for years. Mental health is a large factor in being able to survive and thrive with any illness. We need more resources available, and more trained mental health care professionals, for people to navigate a serious chronic condition. Having access to mental health care professionals would help many patients address their fears and concerns to allow them to effectively receive the information about dialysis modalities and make an informed decision. My California State Senator Anthony J. Portantino's introduced a bill requiring mental health training for schoolteachers & staff. These kinds of innovative programs should be adopted and available to all who are interested in helping their fellow citizens.

**Health disparities and inequities.** Health disparities track social inequities. The more people are experiencing financial strain in this country, the more health inequities we are going to experience. This has a great impact on minority and disadvantaged communities. Health care is expensive, from parking to co-pays, to having the time to spend on the care that's necessary. The more we are able to transition to widely available patient-friendly care, focusing on patient needs, the more we can diminish the effects of social and financial equities on health.

In addition, RSN is in support of the The Chronic Kidney Disease Improvement and Research Treatment Act of 2021that is proposed "to improve the understanding of, and promote access to treatment for, chronic kidney disease."

All of the above mentioned we believe will improve care. We are aware that good policy is like walking a tight rope. You have to get it just right or the unintended consequences can be devastating. We hope as new policies are developed, they are reviewed and corrected if not having the intended outcome for patient care.

We thank you for the opportunity to provide comments and ideas for improving transplant programs, Organ Procurement Organizations, and End-Stage Renal Disease facilities. Please contact us with any follow-up questions.

Warmest Regards,

Lori Hartwell

Lori Hartwell
President/Founder