

Service to those affected by chronic kidney disease

Date: August 10, 2021

- To: Jose Romero, MD Chair of the CDC Advisory Committee Marcella Nunez-Smith, MD – Chair of the COVID-19 Health Equity Task Force
- RE: We Need Vaccine Options for Transplant and Chronic Kidney Disease (CKD) Patients

Kidney transplant recipients received the gift of life, yet now their lives are threatened by critical gaps in COVID-19 care. The Renal Support Network (RSN) is requesting you give our clinicians and people who have CKD, more options and more resources to deal with the ongoing pandemic and its frightening and growing dangers to the kidney disease community.

The Reality of What is Happening

I said "frightening and growing" and mean it literally. COVID-19 survivors could add to the number of people living with CKD! People hospitalized with COVID-19 are at risk of acute kidney injury (AKI) due to complications such as septic shock, microinflammation, increased blood clotting, and more. Recovered patients who had an AKI have a higher risk of developing CKD.

I developed CKD as the result of an infection with E. Coli when I was just two-years-old back in 1968. In other words, almost all my life I've had CKD, and it began with an AKI like these COVID-19 survivors are experiencing, even those with no underlying medical conditions.

I spent 13 years on dialysis and am now living with my 4th kidney transplant. Transplant recipients like me take immunosuppressant medication regularly to suppress our immune systems, so they won't reject our one functioning kidney. These immunosuppressant medications impede the ability of COVID-19 vaccines to produce antibodies. So in addition to those of us already dealing with that fear, COVID-19 is also potentially producing more people who will have to deal with CKD and possibly a transplant down the road – a terrible cycle we should be working to prevent.

Transplant patients often have "underlying conditions" which can be a predictor of more severe COVID-19 symptoms and adverse outcomes. We are not producing enough antibodies with the FDA-authorized emergency vaccine administration (two doses of the Pfizer vaccine, or two doses of the Moderna vaccine, or one shot of the Johnson & Johnson vaccine). At the same time, our immune systems are not functioning by design, and the highly infectious Delta variant is rampant. And now the Lambda variant is in the US. This is a wrap-around kidney disease crisis!

An illness is too demanding when you don't have hope!

Renal Support Network

What Needs to be Done

It's critical we learn as much as possible, as soon as possible, about COVID-19. The Delta variant is a huge threat, and meanwhile there is lingering resistance to vaccines and masks. More resources are needed at every level, especially the federal level, to support kidney care and the organ transplant community and their medical providers. We must give kidney care providers and patients more choices.

Some patients are attempting to solve the problem on their own, arranging for a third vaccine dose without their doctor's supervision. This is completely counter to the care and oversight that they need. It also leaves the community unable to collect critical information that could help prevent COVID-19 and reduce the number of people who will struggle with its after-effects.

We need to do everything possible to better understand how to preserve the health and wellbeing of transplant recipients, people on dialysis with underlying conditions, and those with CKD. Allow doctors to prescribe additional COVID-19 vaccine doses for dialysis, transplant and immunocompromised/immunosuppressed patients. Provide mechanisms for them to report vaccination treatment outcomes. A central database could be created for vaccine administration and we should be encouraging care providers to report results. Doctors are waiting for the green light from policymakers. If patients are willing to risk getting a booster shot with their doctor's oversight, they should be given the option to do so.

In addition, we will all benefit from knowledge of treatment outcomes. Without protecting immunosuppressed patients, everyone is at risk. Dialysis patients are already experiencing inequities in the delivery of their health care. Providing the additional guidance to physicians will help alleviate this problem, at least in the area of the COVID vaccines. A better understanding of the COVID-19 – kidney disease connection will improve vaccine research and overall public health!

Please let me know if you have any questions or need additional information.

Warmest Regards,

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Lori Hartwell, President & Founder

The Renal Support Network (RSN) serves the kidney community by empowering people who have kidney disease to become knowledgeable about their illness, proactive in their care and hopeful about their future. RSN reaches hundreds of thousands of people who have kidney disease and their families through our many patient programs, all of which are offered at no charge. RSN is the leader in engaging people who have kidney disease with the most prolific library of patient experiences. RSN a 501c3 was founded by Lori Hartwell in 1993 who has been a kidney disease survivor since 1968 at age 2.