

# Patient Organizations Engage on All Levels of COVID-19 Advocacy and Education

By Eric Seaborg

Like every corner of the medical community, kidney patient advocacy groups have mobilized in response to the COVID-19 pandemic. The many responses include direct monetary grants to patients; education for patients about the virus and how they can react; increased efforts for communication, networking, and counseling; and mobilization for political activity.

With the flurry of activity, patients with internet access may be receiving more information and support than ever.

The American Kidney Fund (AKF) opened applications for its Coronavirus Emergency Fund (<https://www.kidneyfund.org/news/akf-launches-coronavirus-emergency-fund-to-help-low-income-dialysis-and-transplant-patients.html>) on March 23 to provide \$250 grants to any US dialysis patients or recent kidney transplant patients who demonstrate financial need. The fund aims to help “low-income patients who are experiencing financial shocks related to food, transportation, medications, and medical supplies,” according to Alice Andors, AKF’s senior director of communications. AKF reallocated \$300,000 from its 2020 budget to the fund, which “was depleted on the first day when we received nearly 2000 applications for assistance. We have received 6000 applications and we have funding for fewer than half, resulting in a shortfall of about \$1 million. We are issuing urgent appeals to individuals, corporations, associations, and foundations, but contributions are not keeping pace with the need in our patient community.” (ASN has contributed to the fund.)

## Educational efforts

Many patient organizations have amplified their educational outreach in creative ways.

The National Kidney Foundation (NKF) created a new website “dedicated to information for patients on COVID-19 and kidney disease (<https://www.kidney.org/covid-19>),” said Julie Kimbrough, vice president of marketing, communications, and public affairs. “There are many hyperlinks within the site dealing with everything from dialysis, [to] transplant, nutrition, etc.”

Home Dialyzors United added a link at the top of its homepage to a “Coronavirus Updates” page (<https://www.homedialyzorsunited.org/coronavirus-news>), which provides a compendium of links to articles, information, and webinars available from a wide variety of websites.

“It’s clear that patients and caregivers are hungry for fact-based information that provides important information in an approachable and straightforward manner,” Andors said. “We created special webpages for news and updates ([KidneyFund.org/coronavirus](https://KidneyFund.org/coronavirus)) and for general educational information (<https://KidneyFund.org/covid-19/>). These pages have quickly become among the most-visited pages on our website.”

## Webinars and interaction

In addition to the relatively passive informational webpages, many organizations are using the internet for webinars and interactive educational activities.

The Dialysis Patient Citizens (DPC) Education Center may have been the first in the kidney community to offer a patient-directed COVID-19 webinar, with speakers from ASN and the Centers for Disease Control and Prevention (CDC), said Kathi Niccum, EdD, education director of the DPC Education Center. Their second webinar on April 7 included three nephrologists, two of whom shared the experiences of their dialysis units in the Bronx, New York. (<https://www.dpcedcenter.org/education-webinar/the-covid-19-explosion-lessons-from-new-york-what-kid->

[ney-patients-should-know/](https://www.dpcedcenter.org/education-webinar/the-covid-19-explosion-lessons-from-new-york-what-kid-ney-patients-should-know/))

“NKF has been hosting weekly ‘Facebook Live’ [events] with our nationally recognized medical leadership team answering questions from patients and their families in real-time,” said Kimbrough. A recent event featured nephrologist Holly Kramer, MD, NKF president, with previous events archived at the organization’s Facebook page. (<https://business.facebook.com/nationalkidneyfoundation/videos/774335743092951/>)

NephCure Kidney International Foundation (NKI) is also streaming physician-hosted webinars live on Facebook, with the first topic being IgA nephropathy and future topics including genetic testing, diet and nutrition, clinical trial education, and different disease states, according to Kristen Hood, MSN, RN, director of clinical outreach. Hood is hosting Facebook Live events every other Friday called “Chats with Nurse Kristen.” The first was on telemedicine, covering topics such as what telemedicine is and how patients need to prepare for a visit.

AKF held a “Kidney Chat” webinar (<https://www.kidneyfund.org/training/webinars/kidney-chat-ask-a-nephrologist-about-covid-19.html>) on April 14 during which a nephrologist answered questions submitted by viewers.

## Emotional/coping support

But in addition to simply providing information, some organizations are attempting to provide emotional support

COVID-19. “The May 28 webinar will address the mental health needs of kidney patients during this stressful time. It will be presented by the American Psychological Association, with whom we have a partnership to educate dialysis patients and their families on the psychological aspects of managing kidney disease,” Niccum said.

NKF’s Kimbrough said: “We’re holding our annual spring clinical meetings (<https://www.kidney.org/spring-clinical/program>) as a live-virtual event instead of the in-person gathering that brings together thousands of nephrology healthcare professionals all under one roof.” The live meeting was to have featured the 10 winners of the KidneyX: Patient Innovator Challenge (<https://www.kidney.org/news/25-people-win-kidneyx-patient-innovator-challenge-ideas-to-improve-patients-lives>), but instead NKF invited the winners to film a one-minute smartphone video explaining their innovation and how it helps patients.

## Political advocacy

Kidney patient organizations have also entered the fray in the political arena.

Paul T. Conway, chair of policy and global affairs for the American Association of Kidney Patients (AAKP), said that during congressional deliberations about coronavirus relief legislation “we were hearing a tremendous amount from our patients and our patient ambassadors all over

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and tips on coping during a trying time.

“We serve a community of rare kidney disease patients, from teenagers through adult patients,” NephCure’s Hood said. “There is a wide variety of needs among the different ages, so we have developed programs for each. We have been doing a four-part series on resilience with a renowned doctor of communication and relationships. We have a Monday motivational series on Facebook Live led by a patient.” The leader takes participants through a series of deep breathing and stretching exercises that help with anxiety and coping. There is a support group called NephCure Quaranteens for teenagers from 13 to 17 that meets by Zoom and is moderated by an NKI staff member. Teenagers hear news stories, but may not understand everything, so the group provides a place to discuss their anxieties, their worries, and how life is going, Hood said.

There are similar Zoom support meetings for parents, moderated by a staff member, and for adult patients, moderated by their peers.

Hood said NKI has canceled all of its in-person meetings, but they could well be reaching more people by “changing things to a virtual platform and streaming things onto Facebook Live. It gives us more touch points, especially for the patients who weren’t able to travel to our in-person events [because of] work, their disease state, or dialysis schedules.”

The DPC Education Center holds monthly patient webinars, with the March and April events focusing on

the country that this is not a partisan issue [so Congress should] come together in a bipartisan manner and pass this relief legislation. So we organized that voice in our action center, and did a letter campaign to Congress where people could contact their elected representatives.”

“AAKP has invested a lot of money over the past four or five years in our platforms, not just social media, but action and education centers,” he said. “Over the past six weeks we have had a number of online campaigns that increased engagement, [and] have brought the patient voice directly into many of the deliberations on policy and legislation. And we have exceeded every target and every [patient participation] record we’ve ever had.”

He noted that March was National Kidney Month when “historically, hundreds of kidney patients and their families travel to the nation’s capital to discuss policies related to patient care and medical innovation with White House and congressional officials. As an alternative, AAKP is encouraging patients to expand their engagement with key federal policymakers through AAKP’s virtual and social media platforms.”

AKF’s Andors said: “We have activated our 14,000-member advocacy network of AKF ambassadors to contact their members of Congress in support of S. 3571, the Banking for All Act, to ensure that Americans who do not have bank accounts—like many of the end

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stage renal disease patients AKF helps financially—can access their stimulus funds through the establishment of free ‘FedAccounts.’”

### Patient care advocacy

Several patient care organizations, including NKF, DPC, AAKP, AKF, and Renal Support Network, have been engaging with the US Department of Health and Human Services as part of stakeholder discussions about COVID-19–related issues kidney patients are facing. ASN is also part of those discussions.

“AKF has been ‘engaged with policymakers to ensure that the needs of kidney patients are considered in emergency orders and legislation,’ Andors said. ‘Per HHS’ request, we submitted proposals that address current COVID-19–related issues that the dialysis and kidney transplant communities are facing.’”

DPC’s Niccum said that her organization has also “provided feedback to HHS.

Said AAKP’s Conway: “We have been very engaged in collecting patient experiences, like what people are seeing or feeling in practical terms, [such as] experiencing difficulties getting medications, difficulties with coordinating dialysis visits, concerns whether their facility has masked and gloved healthcare workers. We have been working

closely with HHS as part of some of their work groups and the [Centers for Medicare & Medicaid Services (CMS)] in letting them know what patient concerns are. [We have] deployed flash surveys and tracking surveys to get the pulse of patients and track what they are saying.”

As part of this engagement AAKP told CDC, “you are pumping guidance out to medical facilities and hospitals and care providers, but the patient is lost in the equation,” Conway said. AAKP worked with CDC on a webinar for patients on “what they need to know to protect themselves and also what they need to ask” that attracted more than 5000 views on AAKP’s YouTube channel. (<https://www.youtube.com/watch?v=xwU5FZ9HpK4&feature=youtu.be>)

Conway said the current crisis has highlighted some narrower issues as well, such as the decision by CMS to cease coverage of a pill therapy for iron deficient anemia, which now requires patients to go to a medical facility for infusions. “No one wants to go get their treatment and expose themselves,” Conway said. “We have been educating CMS that this is a huge fear of patients, and they ought to revisit their decision. It is a Food and Drug Administration–approved pill.”

Andors noted, “AKF has joined broad coalitions of patient advocacy groups that support implementing special enrollment periods in the ACA marketplace and in Medicare; providing personal protection for healthcare workers; providing additional funds to states for healthcare costs; providing financial protections to people diagnosed and treated for COVID-19; and expanding eligibility for the paid family and medical leave program to individuals at high risk for complications from COVID-19 and working

members of their households.”

### On a broader scale

NKF has also been advocating for kidney patients in the court of public opinion. The organization wrote an “open letter to America’s hospitals and health systems” saying that “we are deeply troubled by news reports that some health systems and state governments are considering crisis-management policies that would deprive certain patients—including patients with end stage renal disease—of life-saving interventions for COVID-19, including ventilation.” The letter notes that ESRD “is not a ‘terminal’ condition and should not be treated as such. We call on all health systems to recognize that ESRD patients have the same inherent worth as any other patient and should be afforded the same level of care.” (<https://www.kidney.org/sites/default/files/20200402open-letter-treating-covidesrd-patients.pdf>)

With the conditions and challenges constantly changing, organizations are monitoring developments and blogging to keep patients informed.

“We conducted an informal survey of patients and caregivers to better understand what they are experiencing to inform our response and updates to our resource pages and blog. Our Kidney Today blog (<https://www.kidneyfund.org/kidney-today/>) and our advocacy blog (<https://www.kidneyfund.org/advocacy-blog/>) have been posting almost daily on various topics relating to COVID-19, including the government’s response, patient experiences, and more,” AKF’s Andors said. ■

# KIDNEY WEEK 2020

## Call for Abstracts

DEADLINE: MAY 28 (2:00 P.M. EDT)

In times of crisis such as COVID-19, sharing advances in kidney care is more important than ever, and ASN pledges to continue to host the world’s most important gathering of kidney professionals.

### NEW FOR 2020

- **Embargo Policy Change:** For this year only, ASN will consider submissions of research abstracts and clinical case reports that were published and/or presented in 2020. During the submission process, the publication and/or meeting where the abstract or case report was released must be noted. This information will not impact ASN’s decision on the abstract/case report acceptance.
- **New Coronavirus (COVID-19) Category:** Kidney professionals across the globe have advanced care under extraordinary circumstances this year. They have simultaneously focused significant efforts studying the impact of COVID-19 on kidney health and diseases. Please submit your research and clinical cases pertaining to COVID-19 and related kidney health issues, including dialysis, acute kidney injury, and transplantation. This opportunity will also be available for the late-breaking clinical trial submissions.

Learn more and submit at [www.ASN-online.org/KidneyWeek](http://www.ASN-online.org/KidneyWeek)