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April 30, 2020

The Honorable Nancy Pelosi Speaker United States House of Representatives Washington, DC 20515

The Honorable Kevin McCarthy Minority Leader United States House of Representatives Washington, DC 20515 The Honorable Mitch McConnell Majority Leader United States Senate Washington, DC 20510

The Honorable Charles Schumer Minority Leader United States Senate Washington, DC 20510

Dear Speaker Pelosi, Leader McConnell, Leader McCarthy, and Leader Schumer:

The members of the American Society of Pediatric Nephrology (ASPN) appreciate the actions Congress has taken to date to ensure patients continue to receive safe and effective care during the COVID-19 emergency.

Founded in 1969, ASPN is a professional society composed of pediatric nephrologists whose goal is to promote optimal care for children with kidney disease and to disseminate advances in the clinical practice and basic science of pediatric nephrology. ASPN currently has over 700 members, making it the primary representative of the Pediatric Nephrology community in North America.

Our members provide care to an incredibly vulnerable patient population, children with kidney disease, including its most severe form, end stage renal disease (ESRD). While healthy children often manifest milder COVID-19 disease, the children we treat require significant medical care and management under the best of circumstances, and are at significantly higher risk of complications from COVID-19 infection by virtue of their chronic kidney disease. We write today to urge you to take additional steps to protect their health during this public health emergency.

ASPN is grateful that the Coronavirus Aid, Relief, and Economic Security (CARES) Act (P.L. 116-136) provided expanded telehealth options and a temporary waiver of requirement for face-to-face visits between clinicians and home dialysis patients. To continue to protect patient access to comprehensive care during this public health emergency, we believe Congress should consider taking additional action as the country takes steps to re-open. We urge you to consider the following:

Appropriate funds for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) to study how COVID-19 impacts both pediatric and adult patients with kidney disease. We appreciate that the CARES Act provided funding for the National Institutes of Health, including specific institutions like the National Institute of Allergy and Infectious Diseases and the National Heart, Lung, and Blood Institute. We are concerned, however, that it did not include funding for the NIDDK, the institute that supports significant amounts of research on kidney disease and its ramifications on other chronic diseases. As we have come to learn more about the signs, symptoms and complications of COVID-19, it is becoming increasingly clear that there are significant effects on patients' kidneys. There is a significant gap in knowledge and existing research on why this occurs and what the effect of the virus is on patients with chronic kidney disease, including long term health outcomes. Without additional funding, NIDDK will not have the capacity to continue adequately supporting existing research projects while also undertaking new research on COVID-related complications and comorbidities that will be critical both for disease mitigation and the development of effective treatments and vaccines.

Appropriate Funds to Restart NIH-Funded Research. As a result of the COVID-19 public health emergency, NIH-funded research laboratories have either shut down or scaled back significantly. Many have donated or repurposed personal protective equipment (PPE) from their laboratories to hospitals and front-line providers facing PPE shortages, have lost or needed to destroy cell samples, and may need to replace animal subjects. Without Congressional action, replacing these items will come at a significant cost that will have to be paid with existing grant funding. Given the limited funding that currently supports research in pediatric nephrology, it is critically important for Congress to provide additional funds to NIH to support grantees as they cover the costs to re-start the research enterprise and not impede critical research progress.

Provide Additional Funding for the Public Health Emergency Fund and Target a Portion of These Funds for Children's Hospitals. ASPN is grateful for the actions Congress has already taken to support physician practices in the CARES Act, but we believe that additional funding must be appropriated for the Public Health Emergency Fund. It is also critical that a portion must be specifically allocated for children's hospitals both to support their response to COVID-19 and ensure a robust pediatric workforce is in place once the pandemic has ended. Since children's hospitals do not have significant Medicare billings, they will not have benefited to the same extent as many other hospital facilities from initial Congressional funding actions. These actions are necessary to maintain the Pediatric Health Care Infrastructure across the country and also to stem the potential of a secondary rise of other communicable diseases (like Measles and Mumps) in those patients that have not had access to immunization visits. Given the population of immunosuppressed children we look after, these measures are necessary on multiple levels.

Our members primarily practice at children's hospitals, and our members and the facilities where they practice have stepped up to meet the demands of this pandemic. Many are providing treatment to adult ESRD patients to ease the burden on adult nephrology resources at hospitals on the front-lines. Other institutions are providing beds for overflow COVID-19 patients or equipment for necessary dialysis provision given the severe kidney complications in some COVID-19 positive patients. Our members continue to treat their pediatric patients either in the pediatric facility or via telehealth since the needs for chronic kidney care cannot be postponed, but elective and deferrable care has been paused at children's hospitals, just as it has at other institutions across the country. We recognize that the Department of Health and Human Services (HHS) intends to provide support for providers and institutions who do not have significant Medicare billings in the next allocation of Public Health Emergency funding, but it is critical that targeted support be provided to children's hospitals at this time.

Expand Federal Liability Protections for Providers Responding to the Pandemic. Throughout the public health emergency from COVID-19, pediatric nephrologists have had to change how they provide care to patients. These changes, combined with guidance and recommendations from HHS, have increased concerns about potential liability of physicians who are responding to the pandemic. For example, many pediatric nephrologists have had to provide adult dialysis for COVID-19 patients, due to the kidney disease complications that many have faced. Our members also may be providing non-dialysis care for COVID-19 patients, particularly in hard-hit hospital systems, and often have to provide care without appropriate protective gear or equipment. Both of these examples increase the risk of medical liability lawsuits that physicians may face.

While we appreciate that Congress included liability protection for health care workers who volunteer to respond to the COVID-19 pandemic, the risk of liability to physicians who continue to practice in their own facilities remains. We urge Congress to include a provision in the next COVID response legislation that extends broad liability to physicians for any injury or death alleged to have been sustained directly as a result of an act or omission in the course of providing medical services in response to the COVID-19 pandemic, with exceptions for gross negligence or intentional misconduct.

Thank you again for all that you are doing to support providers and patients during this difficult time and for considering these additional policy recommendations. Please contact Erika Miller, ASPN's Washington Representative, at emiller@dc-crd.com with any questions or if you require further information.

Sincerely,

Patrick Brophy, MD, MHCDS President