Attachment C

PKD FOUNDATION
Polycystic Kidney Disease

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Kansas City, MO 64131

March 16, 2021

Representative Susan Lontine
Chair, House Health & Insurance Committee
Colorado General Assembly
200 E Colfax RM 307
Denver, CO 80203

Dear Chairwoman Lontine:

On behalf of the Polycystic Kidney Disease Foundation, I write to share our strong support for for HB21-1171, establishing a kidney disease prevention and education task force in the state of Colorado.

Polycystic kidney disease (PKD) is the most common hereditary kidney disease, causing uncontrolled cyst growth in the kidneys and often leading to renal failure. It affects more than 600,000 Americans, including over 10,000 Coloradans. PKD is a chronic, systemic disease that increases risk for liver cysts, aneurysms, mitral valve prolapse, hernias, diverticulosis and diabetes, often affecting many members of a single family.

The debilitating symptoms of PKD and their effects on the internal organ system pose a serious risk because those afflicted with the disease are asymptomatic until its advanced stages. To date, there is no cure for PKD, and the current lead therapy has side-effects that adversely affect overall quality of life. When kidney failure occurs—typically when a PKD patient enters middle age—dialysis or transplant are the only options.

Patient education and early detection of PKD prior to complications can prolong a high quality-of-life while innovative research is conducted for effective treatments and cures that can alleviate burdens across the continuum of care.

This task force will go a long way toward improving the treatment of all chronic kidney disease patients, including families affected by PKD. The lives of Coloradans will ultimately improve by addressing the social and medical aspects of genetic kidney disease, including early detection, provider awareness, organ donation/transplantation, and racial/economic health disparities. The creation of a kidney disease task force is an important step to begin addressing these issues, identifying policy recommendations and implementing programmatic changes across the state.

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On behalf of the PKD Foundation and our advocates across the country, we strongly urge you to report HB21-1171 favorably out of Committee to address barriers to treatments and improve the quality of lives of Coloradans with polycystic kidney disease.

Sincerely,

Andy Betts
President and Chief Executive Officer
PKD Foundation

We need to be doing more to improve the education and treatment of kidney patients in Colorado by addressing barriers to care and education. The creation of a kidney disease task force will help to bring the entire kidney and primary care community together to begin to eliminate these barriers to care through identifying patient-centric policy recommendations and helping implement new health disparities programs in Colorado.

Racial and ethnic minorities are disproportionately burdened with chronic kidney disease and also face a disproportionate burden of social challenges. The two main causes of chronic kidney disease are diabetes and high blood pressure. When untreated, chronic kidney disease progresses to kidney failure and requires kidney replacement therapy in the form of dialysis or transplantation. In Colorado, there are nearly 45,000 diagnosed kidney patients on Medicare alone but more than 90% of those with chronic kidney disease have not been diagnosed. Compared to non-Hispanic Whites, Hispanic and Black individuals are at greater risk for untreated diabetes and hypertension, subsequent chronic kidney disease, and progression to kidney failure.

As a physician, I have seen the impact that preventive testing, awareness and education can have. One of my patients, Gloria, who has kidney failure and is on dialysis, is very passionate about making sure that our Hispanic and Black communities are aware of their risk for chronic kidney disease. She was diagnosed with diabetes in her mid-30's and her glucose was oftentimes uncontrolled, especially when she could not afford her medications and when there were l financial stressors at home. Moreover, Gloria has limited English proficiency and had no access to care. From her perspective, it is important to make sure that we increase awareness through community-based interventions and provide education about diabetes and hypertension in a way that is culture and language concordant. We need to be doing more to give everyone this chance at a better life.

I am particularly concerned about the impact of kidney disease on Black, Hispanic, and immigrant communities. Black and Hispanic individuals are less likely to be aware of their kidney disease and less likely to see a kidney doctor prior to starting dialysis. When patients are aware of their kidney disease, they can prevent the progression of kidney disease to kidney failure by having better control of their diabetes and high blood pressure.

A stronger focus on kidney disease education and other barriers to care can begin to address many of the barriers to early detection, transplant access, while reducing health disparities and increasing the number of living kidney donors in Colorado. Please support the chronic kidney disease task force so that we can begin to better address barriers to chronic kidney disease treatments and improve the quality of lives of kidney patients in a more holistic fashion.

FRESENIUS
MEDICAL CARE

March 16, 2021

House Health & Insurance Committee

Dear Chair Lontine and House Health & Insurance Committee Members,

Fresenius Medical Care serves over 1,640 people with End Stage Renal Disease (ESRD) in 32 outpatient dialysis clinics in Colorado. We support HB 21-1171 which would create a kidney disease prevention and education task force in the Department of Public Health and Environment to study chronic kidney disease (CKD) and put forth recommendations.

As stated in HB 21-1171, approximately 37 million Americans have chronic kidney disease. Many don't even know they have it. High blood pressure, which can be a silent killer, and diabetes are the main causes. An estimated 7% of Coloradans have diabetes and an estimated 25.9% of Coloradans have high blood pressure. Black Americans are about 4 times more likely and Hispanic Americans are about 1.6 times more likely than white Americans to suffer from kidney failure. Kidney transplant remains the treatment of choice for ESRD; however, in 2019, only an estimated 1 in 4 Coloradans on the waiting list for a kidney transplant were able to receive a transplant.

CKD can be slowed if detected early through blood and urine testing. These tests and education of the public are key in prevention, treatment, disparity of impact, and overall awareness of kidney disease in Colorado.

In summary, we support HB 21-1171 and offer any assistance and resources we can provide in the formation and work of the kidney disease prevention and education task force.

Sincerely,

Wendy Funk Schrag

Wendy Funk Schrag, LMSW, ACSW
Vice President State Government Affairs
316.841.5245
Wendy.schrag@fmc-na.com

The Honorable Susan Lontine
House Health & Insurance Committee
200 E Colfax, RM 307
Denver, CO 80203

March 22, 2021

Chair Lontine, Vice Chair Caraveo and House Health and Insurance Committee Members:

My name is Lexi Lake from Fort Collins, I am an ambassador for the American Kidney Fund, and I testify before you today in support of HB 1171, the Kidney Disease Task Force. It is very important that we have this task force because we desperately need to address the dangerous rise of kidney disease in our state and remedy it. Let's join together to find solutions.

My father suffered greatly from kidney disease and was in dire need of a transplant. Luckily my mother got tested and she was a match. But because her blood type is O- which is highly sought after they did a paired donation, so my father got someone else's kidney and a stranger got my mother's. Not everyone will be able to have such luck.

Currently there are 8,292 Coloradoans with chronic kidney disease (CKD), nearly 5,000 are on dialysis while 3,300 have transplants. It is important to note that transplants are not a cure for kidney disease, just a treatment. Transplants can last 15-20 years but eventually they will fail and a new one is needed. Last year, there were 1,358 people on our state's transplant waitlist and only 356 got a transplant. While that is a great number and those 356 get a new lease on life, we as Coloradoans need to come together and work to stop people from getting kidney disease in the first place.

Colorado has a well-earned reputation for limitless natural beauty and outdoor activities. U.S. News and World Report recently ranked us as the 8th healthiest state in the country. While we have a lot to be proud of, let's not let these accolades mask a real problem we have. A quarter of Coloradoans are obese and 25 percent of our family, friends, and neighbors have high blood pressure. Additionally, 7 percent of us have diabetes.

CKD is a serious national public health problem. While the prevalence of early stages of CKD is similar across different racial/ethnic and socioeconomic groups, the prevalence of end-stage renal disease, or ESRD is overrepresented in communities of color. Patients receiving dialysis in areas that are largely populated by African American, low-income or people with lower educational attainment are less likely to have received pre-dialysis care from a nephrologist.

With the creation of a task force, we could begin to address the high prevalence of CKD and disparities by expanding patient education and awareness coupled with increased preventative treatment. We have a real opportunity here to slow the progression of CKD and empower patients to be more active in maintaining their health.

Thank you very much for your time today and I would be more than happy to assist this committee, and hopefully a future task force, in any way I can.

Sincerely,
Lexi Lake

I joined the National Kidney Foundation and kidney patients throughout Colorado in support of HB21-1171, creating a kidney disease task force. Thank you, Representatives Bradfield and Titone, for introducing this legislation and Chairwoman for holding this hearing.

I have been living with FSGS kidney disease for about a decade since I was diagnosed at 46. I was perfectly healthy and did not have any family history of kidney disease. I crashed into dialysis, finding out I had it at an ER and met the nephrologist for the first time at the hospital as he was preparing to place a catheter in my neck so I could receive emergency dialysis. While I was fortunate to have my son, Landon, donate a kidney to me, it only lasted for one year before my FSGS attacked it too. I went onto home dialysis for seven years before I was fortunate to get my 2nd transplant on August 16th, 2020– which I lovingly have named Lola.

We need to be doing more for kidney patients. I count myself fortunate to have a loving son who was willing to donate to me, to have great healthcare and insurance, and have a supportive family to help me through my journey. But not everyone is so fortunate.

We could make an enormous impact on patient's lives, and savings for the healthcare system, in Colorado by reforming how kidney disease is treated. Like most patients, I was never tested for kidney disease, and not diagnosed, until I had crashed into dialysis. PCPs testing high-risk patients for kidney disease is a simple and effective solution - did you know you have to ask to be tested for kidney disease in most cases? As Coloradans knowledgeable about healthcare, how many of you have ever asked to be tested? Now think about what it is like for those who are not as educated as you, particularly in low-income and minority communities.

Commented [AF1]: Is this correct?

We could reach some of those at greatest risk by ensuring that programs for diabetes or hypertension also include education on kidney disease. And why not utilize existing programs by organizations, like NKF or local transplant facilities, to better educate Colorado through public private partnerships? Better identification and treatment of CKD prior dialysis goes beyond vastly improving quality of life – it could save more than $60,000 per patient per year for the healthcare system.

Also, something close to my heart, we could also be better utilizing telemedicine to help patients, like myself, receive treatments at home by incentivizing home care. What about transplant and donation rates? There are about four times more people waiting for a kidney now than received a transplant last year. The average patient waits 3-7 years for a transplant, since most are not fortunate enough to find, or know how to find a living kidney donor. While groups, like NKF, create exceptional educational programs to educate Coloradans, they are only able to reach a small number of Coloradans, so we need the state government to take a larger role in helping remove barriers to donation and transplantation, such as leading efforts to improve education.

Any of these ideas could have made an impact in my life and those of many other patients I know. A task force like this could ensure that voices are heard, and ideas considered that would ultimately benefit patients and their families. I request your support of HB21-1171 to tell future kidney patients we want to improve their lives and care.

House Health & Insurance

03/23/2021 Upon Adjournment

Testimony - HB21-1171 Kidney Disease Task Force

Title	First Name	Last Name	Position	Representing	Testifying	Text of Testimony	Registered
Dr	Seth	Levey	For	National Kidney Foundation	Submitted text	Chronic kidney disease (CKD) affects 37 million adults in the U.S. It is the 9th leading cause of death in the U.S. When caught early, the disease can often be stabilized. As it advances, especially if undiagnosed, complications can threaten quality and quantity of life. This burdens the system both in decreased productivity and a dramatic increase in healthcare costs. One of every four dollars spent by Medicare goes towards CKD and in Colorado, there are nearly 45,000 kidney patients on Medicare. The disease is especially rampant in minority groups. _x000D_ _x000D_ We can improve kidney patient outcomes by addressing social and medical needs, increasing awareness, and promoting early detection. For those who advance, kidney transplantation increases life expectancy and decreases costs relative to dialysis. The creation of a kidney disease task force will address these issues through identifying patient-centric policy recommendations and helping implement programmatic changes in Colorado through a partnership with the kidney community. As a clinical nephrologist, my saddest moments are seeing patients who ignored the signs, or had poor access to care, and rapidly lost their kidney function and ended up on dialysis or dead due to CKD. My greatest pride is treating patients at early stages to stabilize their CKD, or guiding those in late-stage towards a transplant. With your help, more patients will have the better outcome, and we will beat this terrible disease._x000D_ _x000D_ Please support the creation of a CKD task force to address barriers to CKD treatments and improve the quality of lives of these patients, while at the same time reducing the cost of CKD to the health care system in Colorado._x000D_ _x000D_ Sincerely,_x000D_ _x000D_ Seth Levey, MD_x000D_ Board Member, National Kidney Foundation, Colorado Chapter_x000D_	3/22/2021 22:21

American Kidney Fund®

The Honorable Susan Lontine
House Health & Insurance Committee
200 E Colfax, RM 307
Denver, CO 80203

March 22, 2021

Chair Lontine, Vice Chair Caraveo and House Health and Insurance Committee Members:

On behalf of all the people we serve in Colorado, I am writing to request your support for HB21-1171, the Kidney Disease Task Force. This takes force will study the reasons for the rising incidence of kidney disease in the state and ways to prevent it. Even before the current pandemic, rates of kidney disease have been consistently rising across the country. But the current crisis has significantly increased the urgency to develop comprehensive solutions, specifically to address kidney disease.

The American Kidney Fund (AKF) is the nation's leading nonprofit organizations working on behalf of the 37 million Americans living with kidney disease, and the millions more at risk, with an unmatched scope of programs that support people wherever they are in their fight against kidney disease, from prevention through transplant. With programs that address early detection, disease management, financial assistance, clinical research, innovation and advocacy, no kidney organization impacts more lives than AKF. We are also one of the nation's top-rated nonprofits, investing 97 cents of every donated dollar in programs, AKF has also received the highest 4-Star rating from Charity Navigator for 19 consecutive years, as well as the Platinum Seal of Transparency from Guidestar.

Kidney disease is the fastest-growing non-contagious disease in the United States, with 14% of the population believed to have chronic kidney disease (CKD).[1] There are no symptoms of CKD in the early stages, but if a person does not receive treatment, CKD will progress to End Stage Renal Disease (ESRD). The only treatment for ESRD is dialysis or transplant, both life-altering and high-cost options. However, if diagnosed in its early stages CKD can often be slowed or stopped with medication, lifestyle, and diet changes. That is why we are so supportive of all efforts, both public and private to educate, prevent, detect, diagnose, and treat this disease.

The pandemic has significantly exacerbated the rising rates of kidney disease. In fact, as many as half of the patients with COVID-19 that go into the ICU are now experiencing kidney failure.[2] As a result, the demand for kidney disease treatment, including dialysis will continue to rise even once the pandemic passes. According to Dr. Steven Coca, associate professor of nephrology at Mount Sinai Health System "The next epidemic will be chronic kidney disease in the U.S. among those who recovered from the coronavirus. Since the start of the coronavirus pandemic we have seen the highest rate of kidney failure in our lifetimes. It's a long-term health burden for patients, the medical community — and the U.S. economy."[3]

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[1] https://www.niddk.nih.gov/health-information/health-statistics/kidney-disease

[2] https://www.asn-online.org/covid-19/ASN#Kidney_Week

[3] https://www.poynter.org/reporting-editing/2020/new-data-shows-covid-19-can-cause-kidney-failure-and-launch-a-different-kind-of-epidemic/

In recognition of this urgency some state lawmakers have begun to develop solutions to this growing problem. For example, recently two states, Illinois and Texas passed bills that create a chronic kidney disease task force. The goals of the task forces include the development of education, awareness and prevention strategies and programs. The hope is that these efforts will help to stem the impending kidney disease crisis.

For these reasons, we are hopeful for your support and stand ready to do whatever we can to help this legislation move forward.

Thank you again for your time and for your careful consideration of this important issue. If you have any questions, please feel free to contact me directly at any time.

Sincerely,

Lindsay Gill

Lindsay Gill
Associate Director of State Policy and Advocacy
(240) 292-7062 direct | (210) 860-7407 cell
lgill@kidneyfund.org

DaVita
2000 16th Street
Denver, CO 80202

Jeremy Van Haselen
Vice President, Government Affairs

March 22, 2021

Representative Susan Lontine
Chair, Colorado House Health and Insurance Committee
200 E Colfax Ave
Denver, CO 80203

Re: Support of HB21-1171 Establishing the Colorado Kidney Disease Task Force

Chairwoman Lontine,

As one of the largest providers of kidney health and dialysis services in the country—and as a company headquartered in Denver—I write to support HB21-1171 which would create a Colorado Kidney Disease Task Force. In Colorado, DaVita's 2,800 teammates (employees) have the privilege of helping to provide care for over 2,500 Coloradans with kidney failure.

DaVita is proud of our efforts to support individuals either at-risk or already down the path of kidney disease. We support additional efforts to increase public education and awareness of kidney disease. Kidney failure, also known as end-stage renal disease (ESRD), is the last stage of a progressive condition—chronic kidney disease (CKD). Unfortunately, when an individual's kidneys reach end-stage the only options are transplant or more commonly, dialysis treatment which is required a minimum of three times each week, usually for 3-4 hours each treatment. However, when kidney disease is detected in its early stages (stages 1-3), an individual can make lifestyle changes that can help maintain or slow the condition's progression. This fact underscores the importance of greater public understanding and education about kidney disease—intervention can result in different outcomes and can also potentially save lives.

DPC
DIALYSIS PATIENT CITIZENS

Improving Life Through Empowerment

March 23, 2021

House Committee on Health and Insurance
Colorado General Assembly
200 E Colfax, Room 307
Denver, CO 80203

Re: Support for HB 1171

Dear Chairwoman Lontine and Committee Members:

I am writing on behalf of Dialysis Patient Citizens (DPC) to offer our support and feedback on HB 1171. Sponsored by Rep. Bradfield and Senator Buckner, this legislation would establish a Colorado Kidney Disease Prevention and Education Task Force.

DPC is a nationwide, non-profit, patient-led organization dedicated to improving the lives of End State Renal Disease (ESRD) patients by advocating for favorable public policy to support dialysis patient needs and improve patient outcomes. Our policies and mission are guided solely by our membership, which is open to all patients and their family members, and our volunteer Board which consists entirely of ESRD patients. DPC is committed to promoting access to high-quality dialysis care and kidney transplantation for individuals with ESRD. We also work to delay and prevent kidney failure if possible for individuals with chronic kidney disease (CKD).

If enacted, HB 1171 would establish an ongoing task force with the goal to develop a sustainable plan and raise awareness about early detection of kidney disease, promote greater health equity and reduce the burden of kidney disease statewide. The task force would consist of a diverse set of stakeholders – including legislators, representatives of governmental agencies, providers, kidney patient and advocacy organizations – appointed by Senate and House Leadership and by the Governor. It would develop a public information campaign that includes: health education workshops and seminars, preventative screening, and advertisements on various social and traditional media outlets to reach a broad audience, including those who are most vulnerable to developing kidney disease. The task force would also produce annual reports regarding its work, including recommendations to the legislature for further action.

The creation of a task force is a welcome opportunity to look at potential policies and public health strategies to improve patient outcomes, lower health care costs and reduce existing health disparities. This legislation would raise awareness among patient populations most at risk of developing kidney disease, such as those with diabetes and hypertension. It would also work to reach racial and ethnic groups who have disproportionally higher rates CKD and ESRD to educate them about the ramifications of developing kidney disease and help them manage their treatment and options. Targeted education and prevention efforts not only inform and empower patents but can help thwart unnecessary health care costs and improve patient outcomes.

The creation of a Colorado Kidney Disease Prevention and Education Task Force aligns well with DPC's work to expand education and prevention efforts for patients with kidney disease. In recognizing the need for more educational resources to help kidney disease patients, we launched our affiliate organization, the DPC Education Center, in 2012 to provide free educational programming for kidney disease patients. There are currently an estimated 37 million CKD patients, many of whom are unaware they have kidney disease.[1] Unfortunately, many of these individuals "crash into" dialysis without any prior knowledge or understanding of their disease.

As a CKD patient myself, I was diagnosed with IgA nephropathy shortly after I joined DPC in 2011. I was fortunate that through my work at DPC, I received additional knowledge and support to help me better understand my condition, manage my treatment plan and slow the progression of my kidney disease. Expanding prevention efforts could greatly help other CKD patients recognize and manage their kidney disease more effectively, while also helping to reduce or delay kidney failure. It would also help those patients who ultimately experience kidney failure to better prepare for dialysis, learn about all of their treatment options and navigate transplant eligibility requirements - leading to better health outcomes and lower overall health care costs.

DPC urges you to support passage of HB 1171. My staff and I look forward to working with you and your colleagues on this and other important policy issues that support patients with kidney disease and improve patient outcomes. If you have any questions or would like more information, please feel free to contact me or Kelly Goss, Western Region Advocacy Director at Dialysis Patient Citizens, at 916.917.4519 or kgoss@dialysispatients.org.

Thank you for your consideration.

Sincerely,

Hrant Jamgochian, J.D., LL.M.
Chief Executive Officer
Dialysis Patient Citizens

Cc: Vice Chair Yadira Caraveo
Rep. Mark Baisley
Rep. Ron Hanks
Rep. Dominque Jackson
Rep. Chris Kennedy
Rep. Karen McCormick
Rep. Kyle Mullica
Rep. David Ortiz
Rep. Matt Soper
Rep. Brianne Titone
Rep. Tonya Van Beber
Rep. Dave Williams

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[1] U.S. Renal Data System (2020)