35<sup>th</sup> Legislature of the U.S. Virgin Islands Committee on Health, Hospitals & Human Services

> Wednesday, June 7<sup>th</sup>, 2023 Testimony

Angel Rivera – Dialysis Patient Advocate

Good Morning, Honorable Senate Members of the Committee on **Health, Hospital and Human Services, Senators**, and **members of the 35th Legislature**. My name is Angel Rivera and I am a dialysis patient here on St. Croix. I also serve as a dialysis patient advocate for our island and have been in this role since 2018. With VIHCF, I am a volunteer, and have been closely involved in the design and construction progress of VIHCF's Dialysis Clinic. Also, a good morning, to our audience members and those virtually joining us. I thank you for the opportunity to share my testimony as another voice of the Virgin Islands Health Care Foundation (VIHCF). `

I would like to begin by thanking the senate members of the committee who came to view our Dialysis Clinic this past weekend. As you saw, the Clinic is 95% fully constructed. We are so close. Your presence means a lot to our team and personally to me as a constituent of the people you serve. Some of you may remember me from 2019 when I came before the Legislature to share my concerns about the treatment of dialysis patients in our community. I come again to you today with many of the same concerns. I am urgently asking that MY voice and the voice of other dialysis patients be heard today. I would like to share about my experiences and the experiences of many other dialysis patients. Particularly, about the quality care and the importance of what the Foundation's Dialysis Clinic can bring to us and our community as a whole. I feel it is critical you all hear my perspective on what we need as patients in our community.

As I mentioned, I currently receive dialysis treatment in the trailers. This is no place to be receiving care for years on end. While I have many concerns about basic safety in my treatment, I am left to remain silent ensuring my care is not terminated. This has been a threat I have received by making complaints and a fear that many dialysis patients in our community have expressed to me. They want to express their concerns, but receiving care is more important. WE DESERVE BETTER! And we as a community can do BETTER! As dialysis patients, we HAVE been silenced. Its no longer acceptable and we need your help. The temporary trailers were set in place to be a TEMPORARY solution. Simply put, its gone on too long. In my ongoing conversations with CMS, they agree and we need forward movement. VIHCF has provided dialysis patients with a community solution to a government and community problem. Just as FEMA shared in their assessment of what was needed in the Virgin Islands, the government cannot be the only resolution to community problems. There must be collaboration with public and private entities. VIHCF is a non-profit agency that has come to the community with a quality care solution. In recent months, I received a letter that the hospital intends on having an outpatient dialysis unit, but when will that happen? The hospital building a unit is not something coming anytime soon. It takes time and, I, along with many other patients, don't

have time. Can you see the urgency? Please hear me, today. Because, I have not felt heard since 2019. That's 5 years ago! Nothing has changed in terms of receiving quality care we deserve. We are a vulnerable population who has been and continues to be neglected.

One of the issues I have extreme concern about today is knowing there is a plan for us as we enter hurricane season. The water and air are getting warmer, members! This means we will have an active hurricane season. We must prepare and when I ask questions about what the plan is for us, a vulnerable population, I get no clear answers.

I have patients asking me almost daily about the status of the Dialysis Clinic, because they want better care and for some to be home. I have to just keep telling them, we are waiting on funding. We are waiting on our government to understand the desperate conditions we are under.

Senators, I need you to stand up for us and make people be accountable for addressing a crisis of our people. As dialysis patients, we go through a lot as it is and we have been through too much. Please don't make me, my family and the other patients keep needing to survive in substandard conditions for treatment instead being able to live our best and most comfortable lives with quality care. We deserve life too. Do you understand, what I'm saying here? I ask you to reach out to our dialysis patients in confidence. What I am sharing with you is not just my story. It's a collective story. I am just not afraid to speak. I am an islander. It's our history to keep our voices heard. I will not go down easily, like some want. I'm here.

We cannot keep waiting. Senate members, I urge you to hear our cry for help. Get us the financial emergency funding resources that are there and that we urgently need to address the crisis we experience daily.

We need your help to finish and open the dialysis clinic that we could have had several months ago. The hold ups are unacceptable and are costing the patients to suffer daily with stress that could be alleviated. It's not a want, it's a critical need.

Lastly, I want you to know that we recently lost an important member of our team. Mr. Wallace Phaire, was at the heart and soul of our efforts. He passed last month stateside. His dream was to see this clinic open and to see quality care to come to St. Croix. He always stressed to not give up and to keep fighting. I am here today in his honor and ask for you to hear his voice as well. Please, do not leave us neglected any longer.