

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

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Testimony

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Good morning, Honorable Chair Senator Fonseca, Honorable Vice Chair Senator Gittens and respected Senators and members of the 35th Legislature. Good morning, all present here and the viewing public. Thank you for inviting me to give testimony on behalf of the Virgin Islands Health Care Foundation (VIHCF) on the status of hemodialysis (HD) on St Croix. Thank you for taking the time and making the effort to tour our facility on June 3<sup>rd</sup>, 2023.

Dialysis has been a heated and volatile subject discussed on the Senate floor many times over the years. I last testified on this topic at the 33<sup>rd</sup> Legislature in October 2018. As I sat to put pen to paper for this testimony, I struggled on how I might convey the importance and urgency that must be recognized. Dialysis is now on the brink of deteriorating into a humanitarian crisis. I hope today that this harsh reality might awaken, in the hearts and minds of those with the power, a purpose to make the difference between life or death for patients suffering with end stage kidney failure.

I was asked by the Senate to provide basic information on kidney disease and dialysis. Kidneys perform many complex vital functions that keep us alive. They remove toxins and excess fluid from our body, maintain our red blood cell levels, make vitamins and hormones, and regulate the balance of electrolytes in our blood. Without kidney function, a person dies within a matter of days.

In most cases, the cause of chronic kidney disease is diabetes and high blood pressure. As the kidney disease worsens, wastes and fluids build up and lead to swelling, shortness of breath, high blood pressure, low blood count, weak bones, and life-threatening electrolyte imbalances of the blood. When the kidneys completely fail, one requires dialysis or transplantation to stay alive.

Hemodialysis provides artificial life support. The dialysis machine and a special filter called an artificial kidney, or dialyzer, are used to clean blood. Dialysis takes over the function of the failed kidneys to remove the toxins and fluids and balance electrolytes. What the kidneys do every minute of every hour of every day to maintain life, is now done on a dialysis treatment over 3-4 hours, three times a week, for the rest of your life. During that treatment you also receive medications and hormones that the kidneys normally produce. To get blood into the dialyzer, an "access" is created in the blood vessels with minor surgery, usually to the arm, but in an emergency, a large catheter in the neck vein is used when no usable arm access is present.

### **Dialysis on St Croix since the hurricanes.**

As you are now aware, if you do not receive treatment within days, you risk death. The Governor Juan F Luis Hospital dialysis unit was destroyed and closed in the aftermath of the hurricanes in September 2017. CMS mandated immediate evacuation of all dialysis patients to the mainland for patient safety. It was an indescribably traumatic time for our displaced patients. Their lives were ripped from the roots. Away from their families and their home, they were thrown into an isolated, lonely, suspended existence between their hotel room and dialysis treatments. They had no choice but to endure, just to be able to get safe dialysis treatments to keep them alive. Several of our patients died during that time; most of them were unable to return home for over a year.

Meanwhile, St Croix struggled to find a stable solution to bring patients home. It took over one year to secure and outfit two temporary trailers that were eventually certified by CMS in a limited special consideration capacity as a Special Purpose Renal Dialysis Facility. It was not until late 2018 that we started bringing patients back home. The estimated cost to the federal and local government summed up to \$40MM. However, the cost of lives lost was incalculable. To this day, they continue to receive dialysis treatments in the single functioning South trailer.

#### *Photos of trailer.*

In 2019, COVID19 emerged as a new threat to life for this most vulnerable population. In the event of another hurricane, evacuation during COVID was no longer an option due to travel restrictions and the grim reality that all medical facilities stateside were overwhelmed and not accepting patients for critical care, let alone chronic dialysis.

To be clear, this would mean that without a functioning dialysis unit on island and inability of transfer off island, the survival chances of a dialysis patient are very slim to none. The risk of this scenario is dramatically increased if there is only one unit on the island.

There are over 110 dialysis patients right now on St. Croix alone and several more on dialysis stateside waiting to come home. We have patients in CKD clinics with advanced stages of renal failure, waiting for increased capacity but ready to travel to the mainland if dialysis is needed before then. We must also consider those patients who present to the Emergency Room in end stage kidney failure and must start dialysis emergently. For this reason, the Patient Advocacy Group has always endorsed that there must be a minimum of two units on the island. It is a CMS requirement to have options of care for patients. With our growing ESRD population we need additional capacity and choice available on St. Croix.

The patients have had to tolerate “disaster” conditions and the staff have had to make it work with whatever resources are available in only one trailer.

The Dialysis Patient Advocacy Group (which was founded to represent and give voice to all the dialysis patients on St Croix) has been increasingly vocal of their concerns about the current situation and the future of dialysis care on St Croix. The patient group reached out to us at the Virgin Islands Health Care Foundation, about the need for a permanent solution, options on St. Croix, including having a second unit in case of a disaster or pandemic, as well as a broader spectrum of renal replacement treatments currently not available in the territory.

### **The Virgin Island Health Care Foundation (VIHCF).**

<https://vihcf.org>

The VIHCF is a 501(c)3 non-profit established in 2018 to facilitate healthcare initiatives that empower, educate, and enhance the lives of the most vulnerable in the Virgin Islands community. We believe that a comprehensive and tailored multidisciplinary approach, addressing all the resource needs, should be a standard part of providing quality affordable and accessible care.

When the Dialysis Patient Advocacy Group approached us, they made it clear that patients had unanimously refused to be transferred to the Caribbean Kidney Center (CKC), under any circumstances. A signature list from all the patients receiving care in the Trailer at that time, stating their refusal was presented to us.

The Dialysis community asked for: -

- 1) Solid construction facility – safe, protected, and resilient against the forces of nature.
- 2) Avoid evacuation for dialysis - ability to resume operation after a catastrophic event.
- 3) Water systems and backup power generators- functional and maintained.
- 4) Clean, comfortable, and efficient dialysis care
- 5) Staff - well-trained, knowledgeable, supported, confident and compassionate caregivers.
- 6) Options for renal care, including peritoneal dialysis and transplantation.
- 7) Access to preventative programs and ancillary medical care.
- 8) Renal care for patients in the community who need it.

### **Dialysis Clinics Incorporated (DCI).**

[www.dciinc.org](http://www.dciinc.org)

Several of our patients were evacuated to Dialysis Clinics Incorporated (DCI) hemodialysis units. Founded in Nashville, TN in 1971, DCI now has more than 250 outpatient dialysis clinics in 30 states. DCI employs approximately 5,000 people and serves over 15,000 dialysis patients. DCI is the third largest dialysis provider in the United States and is **the largest Non-Profit** organization.

The staff of DCI's dialysis units were trying to coordinate transfers home after the hurricanes and were alarmed that the patients could not go home due to the lack of dialysis capabilities. They petitioned the Founders of DCI to visit the USVI and help to find a solution.

DCI submitted a letter of intent (LOI) to the Department of Health and to the Hospital administrations offering to stabilize and manage the dialysis operation for them in the territory. On St Croix, DCI's proposal was to assist in planning and build-out, and then to manage a state-of-the-art hemodialysis center.

I would like to highlight a few of the innumerable benefits to the dialysis community of contracting with this respected and established nationwide not-for-profit dialysis provider.

- Smooth transition and continuity of care when patients travel to and from the mainland
- Lower costs, taking advantage of bulk purchasing rates for medications and supplies.
- Compliance with CMS conditions for coverage and maintenance of safety standards
- Patient access and outreach to prevention education to reduce morbidity and mortality.
- Access to peritoneal dialysis and kidney transplantation.
- Staff education, workshops, forums, and opportunities to grow and improve their training and experiences.

In 2019, JFL published a public Request for Proposal (RFP) to outsource their dialysis operations. The Foundation in collaboration with DCI, responded to the RFP. The RFP was awarded CKC. The Patient Advocacy Group spoke out on behalf of all the dialysis patients about not having informed patients before the decision was made. An attempt was made to transfer the patients, but the patients refused and presented their written refusal to the hospital administration. The Advocacy Group pleaded for the VIHCF to act swiftly.

### **The VIHCF – DCI Dialysis Unit, St Croix.**

The Foundation secured and leased a space in Sunny Isles and applied for federal grants from the FCC (Federal Communication Commission) and ARPA (American Rescue Plan Act), to build a new state-of-the-art dialysis facility.

VIHCF was awarded the FCC grant to provide telemedicine capabilities. This would allow for ongoing real-time monitoring for patients receiving treatment during a normal time as well as during a hurricane or pandemic.

The Foundation was also approved for ARPA funds. However, there were over 6 months of delays (for a 12-month project) in disbursements of ARPA funds after the ARPA Grant was awarded in November of 2021. By then, all initial proposals were invalid, and new proposals had to be requested from vendors. This came while the supply chains broke down worldwide and the costs and delivery times increased dramatically.

Usually, water from a source is already potable, but is tested and treated to be ultraclean and suitably safe for dialysis. Tests of the water supply to the building could not be performed until

the plumbing into the building was completed. When we were finally able to sample the water, it was orange and heavy with sediment. The tests confirmed our fears that the water entering the building was not suitable to enter our water treatment system. It would have destroyed the entire water treatment equipment.

*Photos of water from WAPA (Water and Power Authority)*

We realized that additional water filtration systems and water storage were required to transform the discolored water entering the building into potable water. That also required leasing additional space. All this needed to be done to create potable water that can enter the reverse osmosis water systems to be turned into ultra clean water. Ultraclean water that can be in contact with patient's blood safely without contaminating the person and putting the patient's life at risk.

With ongoing support from DCI, their teams of engineers, water specialists, architects, and water treatment specialists, we developed a new water treatment design that would meet CMS standards for life safety.

This plan requiring additional funding was presented to the Administration with a detailed description for justification of additional ARPA funds. This request was made in August 2022 and subsequently approved by the Governor. We have made several urgent requests for disbursement to finish the project and for the Unit to be operational before hurricane season. However, we have yet to receive any of the additional funding. Had we received the additional funding, the plan could have been executed and the unit would have been operational by the first quarter of 2023.

The Foundation has been aggressively involved in alternate sources of fundraising and grant writing. However, these sources will take time. The critical need is now. Time is not on our side, as we enter what is predicted to be quite an active hurricane season. Even if we are not open for this hurricane season, it is mission critical to securely get the machines, chairs and supplies on island now, before another hurricane disaster. Even if hurricane hits, and patients must evacuate again, having the resources to finish the dialysis unit as soon as possible means we can bring everyone home within a few months and have an increased capacity to provide dialysis territory-wide.

### **Conclusion.**

Our sincere hope is that we can put differences, judgements and agendas aside and really come together as a community of Virgin Islands, to answer this plea for help. Let us not be detached from our fellow human beings, because we may feel that it is not our suffering. Unless one lives with dialysis, either personally, or as a family member or friend, one has no idea of the full extent of what is being endured.

We can and should strive to fulfil a higher purpose with the privileged roles each of us is blessed to be placed in. God forbid this should be anyone's fate. But fate is the only veil that separates "us" from "them".

This is personal, to every patient, to their parents, to their children, to siblings and to care givers and the community. This must become personal to us all.

We must not fail this vulnerable part of our community and we cannot allow another Virgin Islander's life to be put at risk again.

Thank you for your kind attention.