HB 608, HD3



March 17, 2011

Senator Josh Green, Chair Senator Clarence Nishihara, Vice Chair Committee on Health Conference Room 229 State Capitol 415 South Beretania St. Honolulu, HI 96813

RE: H.B. 608 H.D. 3 (Relating to Health)

Dear Chairman Green and Vice-Chair Nishihara and members of the State Senate Health Committee.

I am Glen Hayashida, CEO, National Kidney Foundation of Hawaii (NKFH). It is our privilege to support H.B. 608 H.D.3. This bill recognizes the need for a local transplant center in Hawaii. Without a transplant center in Hawaii, many people will not receive an organ transplant and several will die. In addition to performing transplants, the transplant center also provides a vital need in evaluating a person who is willing to become a living donor. The number of living donors in Hawaii will certainly decrease thus reducing the number of transplants of Hawaii residents.

Not having a transplant center in Hawaii will create a real void in this state that will result in some people not receiving an organ transplant. Traveling to other states for a transplant is not an option for everyone on the transplant waiting list. For example, heart recipients are rarely healthy enough to travel often to a point of hardly breathing before receiving a heart.

In addition, recovery from a transplant takes several weeks. Emotionally, a recovering recipient and their family members prefer to be close to home. It would put a real financial and emotional strain on the family to remain on the mainland together during a transplant recipient's recovery.

As for the appropriation in this bill, the transplant center and services within Hawaii Medical Center East (and in the days of St. Francis), have build an infrastructure to support the various needs of transplant recipients. If the transplant center would need to re-locate to another hospital then the infrastructure of that hospital would have to be built up in order to receive its certification to insure the safety and well-being of transplant recipients.

The need for organs continues to grow. There are approximately 400 patients on the waiting list for organs in Hawaii with 90% in need of a kidney. There are approximately 55 transplants performed annually and another 15 from living donors.

Certainly the number of potential living donors in Hawaii would decrease without a local transplant center. Each candidate is required to have an extensive physical and emotional evaluation to determine his or her general health to determine whether s/he is a suitable organ donor. While this type of evaluation can be made through most physicians, they do not feel qualified to provide information specific to becoming a kidney donor so the donor can make an informed decision about becoming a living donor. If these services are only available on the mainland then it will certainly become a barrier to people becoming donors as these evaluations often take up to one year to perform to ensure the donor's health and motivation in becoming a donor. Donors must have the same attentive, high-quality care that transplant recipients receive.

Lastly, Chronic Kidney Disease (CKD) is a phrase that encompasses the majority of kidney conditions. CKD is quite often found by accident when a doctor carries out tests to investigate something else then discovers kidney disease. By then it is often too late for any effective preventative measure, dialysis or a kidney transplant become the only life saving treatment options. It is important to detect potential kidney problems at an early stage when a little prevention goes a long way in preventing loss of kidney function. Without prevention efforts, the transplant waiting list will continue to increase.

I strongly support H.B. 608 H.D. 3 in its attempt to save lives by keeping a transplant center in Hawaii. Thank you for this opportunity to testify.

Testimony to the Senate Committee on Health

March 18, 2011 3:00 p.m. Room 229, Hawaii State Capitol

House Bill No. 608, House Draft 3 – RELATING TO HEALTH (to maintain Hawaii's CMS certified organ transplant center)

Greetings Chair Green, Vice Chair Nishihara and members of the Senate Committee on Health. My name is CJ Leong and I am in strong support of House Bill No. 608, House Draft 3.

I am here as a private citizen, not as a House employee, and I have signed out on leave to be here. I have been employed with the House for the past 25 years and I've always believed that staff should stay in the background and not bring attention to one's self. Today is an exception.

I was blessed to be the kidney organ donor for Pat Mau-Shimizu and having gone through the process, I believe that it is imperative that a certified organ transplant center be maintained in the State of Hawaii.

The process to qualify to be a donor is an intense and lengthy one – multiple lab visits to draw vials of blood and to give many urine samples, followed by hospital visits for a thorough physical exam encompassing a CT scan, chest xrays, and an EKG, along with appointments with a social worker, kidney specialist, cardiologist, transplant surgeon and psychologist. This was all coordinated by the personnel at the Transplant Institute of the Pacific, based at the Hawaii Medical Center East in Liliha. From the moment I made the initial phone call to inquire as to how to become an organ donor, they assured me that they would be there with me be from start to end – and they were. During the course of five months from May to September of 2009, I made the short ten minute drive from the Capitol to the Transplant Institute and HMC East, whenever needed, to complete all exams and appointments.

When I found out I was able to donate a kidney to Pat and being the private person that I am, I confided in and relied upon a very small circle of friends for emotional support and assistance from then on through my return to work.

The surgeries took place on September 24, 2009, at HMC East. Having friends and family support here sped up my recovery time. After two weeks at home, I was back at work part-time and after another month, I was back at work full-time.

So this begs the question, would I have gone down this road if I had had to fly to the mainland to have the surgery and then spend the lengthy recovery period there? I'd like to think that I would have, but truth be told, I don't know.

From my perspective, if we want more people to step forward as living donors it is vital that Hawaii maintain a facility here – I want to see the day that success stories such as Pat's are everyday occurrences.

Thank you for your time and consideration.

TESTIMONY

TO: Committee Chair Josh Green and

Members of the Senate Committee on Health

March 18,, 2011

3:00 p.m.

Conference Room 229

FROM: Patricia Mau-Shimizu

RE: HB 608, HD3 Relating to Health

*Kidney and liver transplant provider

& chronic kidney disease management program

I speak as a private citizen and not as an employee of the Hawaii State House. My request for leave to be here this afternoon has been submitted to the Speaker for his approval. And I am in strong support of this measure, and all of efforts to preserve Hawaii transplant services.

As many of you know, I am a kidney transplant recipient. The transplant surgery occurred in September of 2009. The ability to be here with you today is a gift.

Transplant services do not begin and end with the actual transplant surgery. It begins with a traumatic and life changing diagnosis, and it really never ends, as a transplant recipient must for life always be vigilant for signs of rejection.

The transplant journey can be a long and confusing process. My journey with my family and friends, from a Stage 4 diagnosis in 2006, was made easier with the help of the HMC Transplant Center in Liliha.

After the Stage 4 diagnosis in 2007 with a kidney function of less than 25%, I first met with the HMC Transplant staff for a briefing on the options available to me: 4-hour facility dialysis 3 times a week for life; periodialysis for life; and waitlist for a kidney transplant; or death within 3-4 months, if no treatment was selected.

I chose the periodialysis and waitlist course of action, and HMC immediately scheduled training for insertion of a catheter in my abdomen for self-induced

dialysis every 6 hours. This course of action would allow me to continue to work. Thereafter HMC classes for a change in lifestyle and nutrition to slow the kidney deterioration process followed. Everything HMC told me to eat in moderation was totally eliminated from my diet. No meat, dairy products or caffeine.

With the knowledge from HMC classes, I was able to maintain my kidney function above 15%, avoid a Stage 5 kidney failure diagnosis, and forego the dialysis step. Luck was also on my side, as unknown to me, a co-worker whose office was right next to mine for over 10 years, volunteered to be my donor and was testing for compatibility.

Once compatibility was determined, the HMC transplant staff descended upon me and the donor to prepare us for the surgeries. Home care preparation class, financial planning class, and assistance with insurance application forms were mandatory. The HMC transplant staff also arranged to move up the October surgery date to September, so my donor and I could both return to the Capitol in time to prepare for the 2010 session.

Surgery day arrives and the HMC transplant staff is there to help with the final preparations for the transplant process. They were even there to console my brother when he was asked to leave the pre-op room. And they were there to literally hold my hand as they wheeled me down a long hallway to the surgery room—it was only then that I dawned on me that I might not see my daughter again.

Post-surgical care was thorough. The physicians and nursing staff at HMC were always available for help and information. I was walking the hospital hallway within 72 hours of my surgery. At first it took me longer to prepare for the walk [gown change, hanging the neck medication IV drip, and the urine bag on a mobile stand, putting on gloves, mask and booties], than the actual walk itself. But the staff helped me and they slowly walked around the hospital floor with me numerous times during the day when I had the strength.

They checked my solid food intake, and encouraged me to eat—at first in my life. They taught me how to monitor my fluid intake, and monitor my urine collection to make sure what went in came out. Only a kidney transplant recipient can

understand when I say I was proud of myself when the urine bag was filled every couple of hours with clear yellow liquid.

Before leaving the hospital I went through a series of extensive post-surgical care classes, which included a 2 hour lecture on the type and quantity of medication [about different 20 pills] I had to organize for my 4 times a day lifetime regime.

Once home the HMC transplant staff was available to me and my family 24/7 via a hotline.

And after 5 months of continuous visits to the HMC Transplant Center, my transplant doctor told me that I was ready to "graduate" from the center to his regular office. Wanting to "flunk" and not graduate, was a first for me.

I have taken this time to walk you through the experience to show you that the transplant process does not begin and end with surgery. It is a long stressful process which takes years. It is a process that requires solid professional medical support and the support of family and friends. You cannot do it alone. That's way it is vitally important to maintain a local transplant center for Hawaii residents.

I am considered a transplant success. After the surgery, I did not have an episode that required hospitalization. My success to date is the success of my family and support network as well. The visits from the House Clerk's staff and other Capitol colleagues kept my spirits up. The manapua delivered to my home by Rep. Marumoto the Saturday after I was released from the hospital was treasured, as I couldn't eat my favorite char siu bun for 2 years. And the argument I had with Speaker Say when I wanted to come back to work, and he refused to allow me to come back to the Capitol, is memorable.

Please support this measure and keep transplant services available in Hawaii. Don't make Hawaii people travel to the West Coast or farther for transplant services.