

TESTIMONY

TO: Committee on Finance
March 3, 2011
3:15 p.m.
Conference Room 308

FROM: Patricia Mau-Shimizu

RE: HB 608, HD1 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 morning has been submitted to the Speaker for his approval. And I am in strong support of this measure, and all of the efforts of the House Health Committee Chair 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, periododialysis for life, dialysis and waitlist for a kidney transplant, or death within 3-4 months, if no treatment was selected.

I chose the periododialysis 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 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.