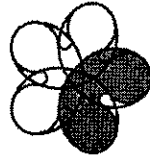


LATE TESTIMONY



National Kidney Foundation[®]

of HAWAII

February 9, 2011

Representative Ryan Yamane, Chair
Representative Dee Morikawa, Vice Chair
Committee on Health
Conference Room 329
State Capitol
415 South Beretania St.
Honolulu, HI 96813

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

Dear Chairman Yamane and Vice-Chair Morikawa and members of the State House Health Committee,

I am Glen Hayashida, CEO, National Kidney Foundation of Hawaii (NKFH). It is our privilege to support H.B. 608. 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 license 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 in its attempt to save lives by keeping a transplant center in Hawaii. Thank you for this opportunity to testify.

LATE TESTIMONY

TESTIMONY

TO: Committee on Health
February 11, 2011
9:00 a.m.
Conference Room 329

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, peritoneal dialysis for life, dialysis and waitlist for a kidney transplant, or death within 3-4 months, if no treatment was selected.

I chose the peritoneal dialysis 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.

February 11, 2011

LATE TESTIMONY

The Honorable Ryan Yamane
Chair – Committee on Health
State House of Representatives
Hawaii State Capitol, Room 420
Honolulu, HI 96813

RE: HB 608 RELATING TO HEALTH

Aloha Chairman Yamane and Members of the House Health Committee:

I am writing in strong support for House Bill 608.

Mahalo for considering a bill that has so much impact on the lives of patients and families afflicted with chronic disease which affect the liver and kidney. I am certain that every single person in Hawaii knows someone who is affected with these diseases.

For some, if detected early, chronic disease can be circumvented with life changing decisions and working with a physician or care team. For others, including myself Chronic Kidney Disease and dialysis has become a way of life and survival. My only hope to stop dialysis treatments and improve my quality of life would be to receive a kidney transplant.

There has been a lot of discussion lately about death with dignity. I ask you to support the latest techniques and treatment locally for organ transplant that will improve the quality of life for those most in need. Many chronic disease patients and their families live daily with a mixture of fear about not knowing how the day will end for them. HB 608 will provide hope for these individuals and their families that the possibility of a transplant is attainable and an organ will become available so a new outlook in life is possible.

To fully appreciate the need for a Medicare and Medicaid facility in our state we need not look too far back in time. It was only in 2003 that CMS approved certification for liver transplants in Hawaii. Before that, patient and their families would have to consider relocating to the mainland for a transplant. For some, already cash strapped because of chronic illness, this was not an option. For those more fortunate, an already stress-filled life became even more chaotic because of logistics involved with relocation. Not to mention the cost of care being paid by or Medicaid system to support an out-of-state transplant.

The Honorable Ryan Yamane
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Some legislators had to relocate to a new office here in the State Capitol and can recall the stress on the Members and the staff. Can you imagine being sick and weak and getting your business, financial, medical and personal affairs in order in a short period of time and moving to an unfamiliar environment that is cold in more ways than one? To say the least it is quite challenging and discouraging.

CMS transplant certification is not an easy process. It involves an evaluation process which measures the success of a minimum of 10 organ transplants specific to the certification with each transplant in the past cost upward of \$100,000. Then a measure of quality is added to the mix relating to survival ratio.

For liver transplants it took many years and dollars spent to qualify for certification. This sacrifice was placed on the shoulders of St. Francis Healthcare System when they owned and operated their hospital facility in Liliha.

It will cost substantially more in today's dollars to have a Hawaii facility certified for both liver and kidney transplants if we lose the current certification. It makes no economic sense for Hawaii to go in that direction. In turn, it will cost substantially more to our Medicaid system to send patients, including myself, to the mainland for kidney and liver CMS certified transplants. In the end, it will cost substantially more in terms of the physical, emotional and financial impact on our patients in their of ominous struggle.

As stated earlier, I am a dialysis patient. I have End Stage Renal Disease. I go to dialysis three times a week and for the past three and a half years, have had two needles my arms over 1,200 times, spending more than 1,000 hours in a dialysis chair.

Please, I ask for your utmost consideration in keeping me in Hawaii when my chance for an organ transplant is realized. Mahalo for your time.

Aloha,
RENEE SAMBUENO
1202 PUA LANE, APT. 10
HONOLULU, HI 96817