

## **From California to Hawaii, then on to Japan: International perspectives on organ donation and transplantation with Dr. Joyce Trompeta.**

In this episode we meet Dr. Joyce Trompeta, A Nurse Practitioner (NP) specializing in transplantation, and an Associate Professor in the school of medicine, at the University of California, San Francisco where she conducts outcome research in the department of surgery. Dr. Trompeta discusses several areas of interest, including her concerns about disparities impacting Asian American, Pacific Islander and Latino populations; her work in Hawaii; how young Latinos with kidney disease are facing unique challenges relating to immigration; and her travels to Japan, where stigma and cultural beliefs have limited organ transplantation, but where the younger generations are now leading change with a little help from Kumamon, Japan's most popular Bear.

### **Transcript**

Host: Thank you for joining us for another episode of Kidney Transplant Conversations, our regular exploration of the kidney transplant journey, as experienced by donors & recipients, caregivers and healthcare professionals, our goal is to bring diverse perspectives and inspirational stories to you, our listeners.

All views and opinions expressed in this podcast reflect those of the participants.

I'm Rolf Taylor, your host and series producer and today, it's my pleasure, to welcome, all the way from Hawaii, Dr. Joyce Trompeta, a nurse practitioner specializing in transplantation. Dr. Trompeta is also an associate professor who conducts outcome research in the department of surgery in the school of medicine, at the University of California-San Francisco (UCSF). Her program of research examines organ donation practices, health equity and racial disparities. She completed her doctoral degree at UCSF and oversaw UCSF's pediatric kidney transplant program for ten years and has expertise in adolescent growth and development. Welcome Dr. Trompeta.

Dr. Trompeta: Thank you, Rolf. It's great to be on the podcast and I'm enjoying the previous episodes very much.

Host: You are a past president of the International Transplant Nurse Society (ITNS). Thank you all at ITNS for your support for this podcast. We really appreciate it. Could you tell us a little bit more about what ITNS is all about?

Dr. Trompeta: Yes, the International Transplant Nurses Society (ITNS) was founded in 1992 to promote the education and clinical practice excellence of nurses who are interested in and participate in the care of solid organ transplant patients. ITNS

is headquartered in Chicago, Illinois, where we've grown to become a leading, respected transplant organization with active members from around the world. ITNS is the first professional transplant nursing organization to focus on the professional growth and development of the transplant clinician and we offer nurses a forum for learning about the latest advances in transplantation, patient care and best practices. Our overall mission is to provide relevant, evidence-based education, research and advocacy to assure excellence in patient care worldwide. Basically, in summary, we are the global community for transplant nurses.

**Host:** Really, interesting to have that truly global remit and I think we're going to go on quite a global journey today. We've got so much to talk about. You're doing incredible work with underserved populations in Hawaii and you're also a Fulbright Scholar, which has taken you to Japan to help their system overcome some cultural barriers to transplantation and, as a researcher, you've developed the Organ Donation and Transplantation Knowledge Scale or ODTK for short, a test that helps you understand how individuals and groups view the organization process, a really important tool for building cultural sensitivity. You're also very concerned about chronic kidney disease in young, undocumented Latinos. So, we'll come back to all of those subjects later in the discussion but, first, let's talk more broadly about the current situation for Asian Americans and Pacific Islanders in terms of kidney disease prevalence. What are some disparities and barriers to accessing transplantation that you are most concerned about?

**Dr. Trompeta:** Well, first of all, ethnic minority populations have two to four times greater risk in developing end stage kidney disease in comparison to white populations and they also compose over 53% of people on a transplant waiting list. Asian Americans and Pacific Islanders have a higher incidence of diabetes and high blood pressure, which is hereditary and now, we're seeing higher rates of obesity, which all lead to high prevalent rates of end stage kidney disease. They also face disparities in just being referred for their kidney transplant evaluations and initiating and completing the process. They have lower rates in receiving both deceased and living donor transplants and they often have lower rates of undergoing pre-emptive transplant, which means bypassing the need to start dialysis by undergoing a kidney transplant from a living donor. Asians and other ethnic minority groups may also be hesitant to consent to organ donation because of common myths about organ donation and transplantation such as misconceptions about the concept of brain death, of religious beliefs of an afterlife, believing that the spirit will need their organs or their eyes in their next life. There's also mistrust of the medical community believing that if they sign the organ donor card and their consent for organ donation is known, lifesaving measures will not be performed.

**Host:** It's a really fascinating and complex scenario that you've just described. And you're a coordinator for living, kidney donor transplants in Hawaii and Pacific Rim liaison for developing outreach transplant clinics including the development of educational outreach programs on four Hawaiian Islands promoting solid organ transplantation and organ donor awareness. Could you tell us a little about how you work and what

is making a difference to how many people get to benefit from organ transplantation?

**Dr. Trompeta:** Hawaii actually has a 33% higher incidence of end stage kidney disease compared to the US mainland and just the geographic location of the Hawaiian Islands, including Guam, alone makes access for transplant evaluations challenging. There's a scarce availability of deceased organs for the Asian American and Pacific Islanders because of the high rates of diabetes and high blood pressure that exists in this population. UCSF has been servicing the state of Hawaii for over 30 years, now, in providing outreach clinic visits to perform pre-kidney and kidney pancreas transplant evaluations, as well as re-evaluating patients who are approaching the top of the waiting list and also to conduct history and physicals for the potential living donors.

Initially, our team held outreach transplant evaluations in Hawaii annually, but the need has now increased and now, we conduct outreach clinic visits three times a year. So, about seven years ago, I developed an additional outreach lung transplant clinic in Hawaii due to the high number interstitial lung disease and because there lacked a lung transplant program here in Hawaii and now, our outreach lung transplant clinic has increased to twice a year. Last year, during COVID-19, our kidney transplant team made the decision to make the trip to Hawaii after several clinic cancellations and once the state opened to visitors and primarily for essential workers, there was such a need to meet the backlog of patients who were approaching the top of the waitlist, who needed re-evaluations, so that they could be taken off of dialysis, and there were patients who wished to pre-empt dialysis with an available living donor and, most importantly, there was a very large number of patients who didn't have access to having their pretransplant evaluation performed by telehealth because they either didn't have access to a smartphone or computer or they didn't have wi-fi or they just didn't feel comfortable meeting virtually and they wished to meet our transplant team in person. There were also many patients who lived on the outer islands of Hawaii where the wi-fi reception was very weak.

**Host:** So, really, you've been part of a very long-term process to, I guess, build capacity in Hawaii. So, another population that you're particularly concerned about is the health of undocumented Latino children and their families who are seeking treatment for chronic kidney disease and may have end stage kidney failure. I think the COVID pandemic has revealed really deeply entrenched disparities in ethnic, minority groups, especially Latino populations. You're leading a group researching a care delivery model that addresses immigration status, racial disparities and social determinants in Latino children with chronic kidney disease and those who undergo kidney transplantations and I think this is probably a subject that not everybody thinks about. The whole situation with DACA and minors who are children of immigrants. So, could you describe some of the issues and social determinants and impacts undocumented minors with kidney disease?

**Dr. Trompeta:** Yes, given the rising immigrant population from both Central and South American countries, social determinants in children impacted by immigration status

pose even greater challenges in their transplant care. They include language barrier, lack of healthcare insurance, access to primary and preventative care. They may have poor health literacy, poverty, lack of technology and transportation, food insecurity, unsafe housing and acculturation, which means they're having the challenge of having to adapt to western culture. Because of the lack of preventative care, these immigrant children are at higher risk for late detection or mismanagement of their chronic kidney disease and, often, referrals are made to nephrology specialty care when the child shows more obvious and later signs of kidney disease, which then results in a lost opportunity for preventative care to optimize their native kidney function and to prepare for a pre-emptive kidney transplant.

In 2012, the Deferred Action of Childhood Arrivals, otherwise known as DACA, Immigration Policy Act was created to provide for undocumented youth who arrived to the US as children, an option to legally remain, attend college and apply for work permits. Since DACA has been implemented, studies have shown that undocumented youth have improved social determinants of health by having increased healthcare coverage, having more economic stability, higher education that leads to better pay and insurance, and reports of having even increased sense of wellbeing that associated with the less fears of being deported. However, once these undocumented children reach the age of 21, and lose their transplant medications and care, we've seen a one in five loss in their kidney allograft.

**Host:** Children are aging out of DACA and then they face a whole host of other problems. What solutions do you think are needed?

**Dr. Trompeta:** Well, given these challenges, transplant providers have the responsibility to provide more comprehensive care by carefully assessing the social determinants of health to promote good transplant outcomes for this formidable population of children who need kidney transplant for their end stage kidney failure. The risk assessment requires a multidisciplinary transplant approach to identify the impact of these disparities and the critical social determinants in these immigrant children that include learning disabilities, mental health stressors that can later affect their compliance with their transplant medications and immigration status to ensure maintenance of both current and long-term insurance coverage for their transplant care. The transplant social workers may assist these undocumented children's access to legal service, as well, to explore permanent documentation options for their family.

**Host:** Now, part of your research has been to develop the Organ Donation and Transplantation Knowledge Scale, the ODTK test, which is a psychometrically valid test for evaluating knowledge about organ donation and transplantation. Can you tell us a little bit about how that test works?

**Dr. Trompeta:** We need to first understand people's attitudes, beliefs and knowledge about organ donation and transplantation and over ten years ago, when I first conducted my research on the Big Island of Hawaii with high school adolescents, there wasn't a psychometrically valid scale available that measured one's

knowledge pertaining to organ donation and transplantation. So, that's why I developed the ODTK instrument. So, finding out what people know or don't know about organ donation and transplantation informs us on the educational needs for communities through culturally tailored outreach programs and media campaigns.

**Host:** Speaking of understanding different cultures, lets go even further beyond Hawaii to Japan where I understand end stage renal disease in their aging population is combined with a reluctance to donate organs. So, at the same time this country has the highest life expectancy and the oldest population in the world. So, this is both a culturally and clinically significant problem that you've been working to overcome, and you won the Fulbright Scholar grant from the US State Department and Japan's Educational Commission enabling you to travel to Red Cross Kumamoto Hospital and Kumamoto University in Southwest Japan to share your expertise in facilitating organ donation. Now, what did you learn about the reasons why organ donation has historically been quite minimal?

**Dr. Trompeta:** Well, in Japan, 90% of kidney transplants are from living donors because the availability of deceased organ donations are scarce. Kumamoto Prefecture is one of the regions with the highest number of patients with end stage kidney disease and while almost half of the Japanese people accept brain death as consistent with human death, organ procurement from brain dead donors isn't widely accepted.

Some of the several factors that contribute to this include mistrust of physicians, passed improprieties in the determination of brain death, insufficient resources to adequately apply brain death criteria and cultural beliefs concerning life and death. Some people believe that it is taboo or bad luck to talk about the subject pertaining to death or organ donation because, if you talk about it, it may or will happen.

**Host:** So, what solutions and learnings have arisen from your involvement with Japan?

**Dr. Trompeta:** Well, unfortunately, my Fulbright research was disrupted by COVID-19, and I needed to return to the US before I was able to conduct my study, however, I do plan to return to Japan to examine the barriers to organ donation consent and the attitudes, knowledge and beliefs regarding organ donation and transplantation in a sample of university students, faculty and healthcare professionals to provide a better understanding of just why organ donation rates are low in Japan and identify areas where education could be targeted to both young and old generations. I believe the younger generation, including adolescents, have the influence to promote organ donation consent amongst their friends, parents and, most importantly, grandparents.

I created the Kumamoto model, which is a strategic plan to increase deceased organ donations in the Kumamoto Prefecture in Japan. The Kumamoto Model, otherwise known as the KM, mission is to change the Japanese social climate regarding organ donation consent to establish Japan's self-sufficiency for transplantation by increasing the availability of organs to create an efficient organ procurement organization and, also, to develop culturally tailored organ donation

educational programs. The KM has received support from Governor Kabashima who is the governor of Kumamoto and Kumamon, who is a famous Japanese bear, is the ambassador of organ donation, who wears a green ribbon, which signifies organ donation awareness. I've also developed a slogan for Japan, which is, "Extend life, do the honor, be an organ donor. So, aspects of the KM I launched back in November during Japan's National Family Day, which, now, includes an organ donation directive for families to discuss organ donation wishes upon death. From February 2018 to 2019, I gave several organ donation lectures in Kumamoto that were tailored to healthcare providers and also to the general public and, in 2018, Kumamoto had the most numbers of deceased donors in its history and the most of any of Japan's 47 prefectures.

**Host:** You've obviously had real influence and you've really built something meaningful from your work in Japan. What would you say you have learned in Japan that you've brought back to the United States and Hawaii that's been helpful for increasing transplantation back here?

**Dr. Trompeta:** First, understanding the cultural aspects of making the decision for organ donation consent and I think in every country and every culture, it's a family decision. Upon one's death, it's the family who's actually approached for the consent for organ donation. So, if family have some notion of what you want to do upon death, they will probably, most likely, consent to their loved one's wishes by donating their organs.

Studies actually show that knowledge is an important predictor of organ donation willingness and that most people would consent to organ donation if they knew their loved one's wishes. One of the very common questions that I'm often asked is, "How do I find a donor?" or "How do I even ask someone for their kidney?" My response is to make your situation known to family, friends, co-workers, even acquaintances because many people may not even realize what you're going through, or they may not realize that by receiving a kidney from a living donor will pre-empt dialysis or end the need for dialysis. I always also recommend designating a donor advocate who can be a family member or friend whose job is to make your situation known to everyone and, also, and, I think, most importantly, family discussion regarding organ donation wishes upon one's death are all effective ways to promote an organ donation consent.

**Host:** It's the facilitation of the conversation that's so key.

**Dr. Trompeta:** Exactly.

**Host:** The big conversation and the big ask kind of needs to have some permission around it.

**Dr. Trompeta:** Exactly, and I think in all cultures, most importantly, in the multi-ethnic cultural groups, especially, when there is mistrust, the medical community, being respectful of people's cultures in their decision but providing the education of what a kidney transplant or donating a kidney can do, any organ, to someone in need.

One donor can provide life to eight different people by donating their kidneys, their heart, their lungs, their eyes, the cornea, the tissue, so that it's almost as if you have your loved one living on and so that was part of my slogan of extending life. And doing the honor, the honor of the deceased loved one's wish to donate the organs.

Host: So, it's really the education is opening the door. It's the education that makes all of that possible.

Dr. Trompeta: The education and just talking about the subject of organ donation. You know, it's not a common subject to talk about but to realize that it will be a question that can be asked, even to adolescents, when they get their drivers license for the first time. They're getting their drivers license at age 16, 17, 18 and they're asked, "Do you want to sign your organ donor card?" What does that mean? So, education, I believe, also, begins in the high school with adolescents and that's where I did my research in the high schools on the Big Island of Hawaii.

Host: It's really striking, from what you're saying, about what happened in Japan that you had support from a lot of people. You really got significant kind of policy level support for the changes that you were trying to make.

Dr. Trompeta: True. I wasn't there to change people's beliefs but just to educate what it means to be an organ donor and what it can do to extend life. The topic of organ donation just needs to be at a higher platform and thankfully, now, it is part of one of the directives that's spoken about during Japan's National Family Day every November. One thing beautiful that came out is that Japanese Kumamoto Red Cross Hospital, they turned on green lights and so, again, people wonder what do the green lights mean and it signifies organ donation. So, it just gets people to talk about it. So, at the time of death, they'll know what that means and how that could help other people by consenting to the donation of their loved one's organs.

Host: It's really, really interesting hearing how all of those things have come together as a program.

Dr. Trompeta: And, especially, having Kumamon, this really famous bear who is just as famous as Hello Kitty, wearing a green ribbon. If Kumamon supports organ donation than people are more swayed. My goal one day, when I go back to complete my Fulbright in Japan is to meet the creator, Sanrio of Hello Kitty. She wears a red bow in her hair and if she could wear a green one, once a year, that would be wonderful. It would just stimulate the conversation for organ donation.

Host: Brilliant, genius, just have to ask. Well, it's been such a fascinating discussion and thank you for taking us on a journey, at least, halfway around the world.

Dr. Trompeta: Thank you, it was a great pleasure.

Host: All that you've learned and brought back to us, appreciate it very, very much.

## Episode 4, Kidney Transplant Conversations



Dr. Trompeta: Thank you. Thank you very much.

Host: Thank you to our listeners for joining us today. If you enjoyed the podcast, please consider sharing it with others and subscribing on any of the leading podcast platforms and smart speakers. We also thank the participants and advisors who helped create this podcast and our underwriter, Veloxis Pharmaceuticals. Join us again soon for more kidney transplant conversations. Until next time, take care and be well. Copyright, Project Advocacy 2021.