



JOY GOEBEN

STATE REPRESENTATIVE • 5th ASSEMBLY DISTRICT

Testimony in Support of AB 955 Assembly Committee on Health, Aging, and Long-Term Care

Thank you Chairman Moses and members of the committee for hearing AB 955. Did you know that there are more than 100,000 people on the organ transplant waiting list? Every nine minutes, another name is added to the list and, every day, 17 people die waiting for an organ to become available.

AB 955 prevents organ transplant recipients or donors from being discriminated against based upon their vaccination status and allows individuals to bring an action in circuit court. The legislation is the result of Wisconsinites who reached out to report that they were refused treatment and cruelly denied access to the National Transplant waiting list based upon their vaccination status. This bill expands current law that prohibits any person, hospital and/or transplant program from taking certain actions related to organ transplantation solely on the basis of an individual's disability.

'Vaccination status' is defined as having received or not received one or more doses of a vaccine for reasons of health, religion, or personal conviction. The bill covers vaccines designated for emergency use, operates through the transfer of genetic material, is dosed on an annual schedule, or is for the prevention of a disease against which the individual already shows antibody protection.

How well a vaccine works is inversely proportional to the number and type of immunosuppressive drugs used. Immunosuppressants or anti-rejection drugs are medicines that lower the body's ability to reject a transplanted organ. Transplant patients who are most at risk for infectious morbidity and mortality as a result of their severely immunosuppressed state are also those least likely to respond to vaccination.

The opportunity for a patient to become active on the National Transplant waiting list is long and complicated. Candidates and their families must prepare physically, mentally, and financially. Once a patient is 'active' on the list and depending upon the organ, wait times can average 4-months to 5-years or longer. For individuals with end-stage organ failure, organ transplant is their only option.

The core principle of medical ethics is the duty to 'do no harm.' But individuals are harmed when they are prevented from having the opportunity to receive a transplant. Injury is immediate, severe, and irreversible with profound effects on life span and quality of life.

Trust is paramount between an individual and a provider for successful medical outcome. If a patient even perceives coercion it damages trust with the medical community and directly affects efforts to improve population health. Rather than promoting acceptance of preventative care, these policies and attitudes validate accusations of single-mindedness and a lack of respect, which further alienate those expressing hesitancy.

Public health ethics principles are most commonly used to infringe upon personal liberty which removes freedom of choice in order to justify the prevention of harm to others. Because vaccine hesitancy or refusal, is so far, uncommon, the difference in transplant outcomes between vaccinated and unvaccinated recipients would have to be substantial to justify excluding vaccine-refusing patients on the basis of overall benefit.



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STATE REPRESENTATIVE • 5th ASSEMBLY DISTRICT

AB 955 ensures transplant candidates, recipients, and donors are protected from discrimination. Please support the prevention of medical discrimination in our transplant community and support AB 955.

Thank you Chairman Moses and honorable committee members for your time and attention.

Joy Goeben



RACHAEL A. CABRAL-GUEVARA

STATE SENATOR • 19TH SENATE DISTRICT

Testimony before the Assembly Committee on Health, Aging and Long-Term Care

Senator Rachael Cabral-Guevara

January 17, 2024

Thank you committee members for allowing me to testify today on Assembly Bill 955. This important bill will protect patients from undue barriers to receive an organ transplant.

As a health professional, there are vaccines that have proven their worth such as tetanus, MMR, and smallpox. Receiving these vaccines is a best practice and these vaccines are understandably required if you wish to receive an organ transplant, as you want to make sure the individual receiving the transplant and the gifted organ have the best chance of survival. These types of vaccine requirements are not impacted by this bill.

However, Wisconsinites have been denied organ transplants due to not having received Emergency Use Authorization (EUA) vaccinations or vaccines with an annual dosing schedule. Obviously, these vaccination formulas can change frequently or have not gone through the full authorization process. These should not be mandated for life-saving transplants.

This bill would safeguard people from being denied needed organ transplants for not having received these EUA and annually scheduled vaccines. It also takes in to account individuals who can prove protection against a disease through an antibody titer. This is a reasonable standard to apply to these individuals who desperately need these gifts.

I am hopeful you are able to support this important piece of legislation.

Testimony in Support of AB 955 January 17, 2024

Thank you to the committee members for your time in listening to testimony today on Bill AB 955

My name is Anita Day and I live in Milton Wis. I'm here to represent my son Jamey.

Jamey was a normal active child until, at age 8 ½ he was diagnosed with type 1 diabetes. I was devastated and I saw the outcome that we were going to face. We were told then (1987) that there would be a cure within the next 10 years. This gave us hope that we could look down the road and see an end to this disease and not the slow death sentence he was really facing. I've since realized that a cure will never happen, there IS NO money in a CURE.

Jamey isn't here today because he gets very tired and wears out easily, and sitting here for a lengthy time would not be good for him. He is hooked up to a machine nightly so this drains his energy. Jamey is a college graduate with a bachelors' degree in I.T. He's a single dad raising two wonderful boys. 15 years ago, Jamey was determined to get into shape to be here for his boys. He worked out 2 to 3 hours a day and lost over 75 pounds. He watched everything he ate and having no salt had enabled him to stabilize his kidney function longer then even what the doctors expected. He stayed in the 33% range for several years, then gradually dropped into the 20's and continued to decline 1 to 2 percent every year.

Jamey has to watch everything he eats and count all the carbs to be able to adjust his insulin. He also needs to watch all sodium intake to help protect the little kidney function he has left. Diabetes, although it is considered a "Treatable" disease, is a very cruel disease. Diabetes eats away at your internal organs, kidneys, heart, lungs, brain, pancreas, to name the major ones.

Diabetes has taken a toll on his body; his kidneys are now down to 6%. Jamey has had multiple laser surgeries in both eyes to blast hundreds of floaters to try to save some of his sight. While in his 30's both lenses were replaced because of cataracts. He has lost his sight completely in one eye and has tunnel vision in the other. Jamey has been on Peritoneal dialyses at home for the last 18 months. Peritoneal dialysis creates its own problems in patients. It causes extreme constipation needing daily use of one or all of these items, stool softeners, MiraLAX, Lactulose, (prescription) prune juice. This is not a fun time and it's usually daily.

He is limited on what he can do and length of time he can be gone due to the strict regimen of being hooked up to a machine every single day. This has also caused depression and anxiety for him, from thinking of not being allowed to get a transplant and the inevitable result, to not trusting the medical system to be honest with him.

When the vaccine first came out, he did a lot of research. He found that it could cause kidney damage, something he obviously didn't want to add to his declining kidney failure.

We were told 10 years ago by UW Madison that once he reached just below 20%, they would put him on the list for a kidney/pancreas transplant. Now they won't put him on because he refuses to

get the fast tracked an untested covid vaccine. The recommendations by UW Madison hospital now states that patients must be vaccinated and it's also recommending that everyone in the same house be vaccinated. On Aug 15th 2023, we went to Froedtert hospital in Milwaukee, where they have removed the vaccine mandate and state that it would be best to take it, but not mandatory. We went through all the preliminary 6+ hours of tests and questioning by their transplant team. They still haven't put him on the list.

Covid hit in 2020 and has systematically changed the healthcare system in our country, and NOT for the good. Healthcare has lost 25% of their workforce since the covid vaccine rollout. (See article I have)

As a mom I would do anything to protect my children! I'd give a kidney or a blood transfusion. It doesn't matter their age, we will always worry over our children, and do whatever it takes to save the life of their child! Any good parent would do that. If you've ever dealt with a catastrophic illness you will understand how rigorous and daunting it can be. Every waking hour is consumed with dealing with all the treatments and restrictions involved.

We could go to a different state for a transplant. Texas, Louisiana, Florida, are some that would allow us but his insurance will not pay. I don't know about you but I don't have an extra million dollars laying around.

Discrimination comes in many forms, religious, race, sex... It goes on and on. The discrimination against people who have chosen, for whatever their personal reason to not take a vaccine, especially one that has been rushed through and not properly tested, is an atrocity. It is an individual's right to choose what is put into his/her body!

I never thought that anything like this would EVER have to be DISCUSSED let alone be VOTED ON.

I'm angry that any of this has to be done. There is no research, only opinions whether immunity of covid through the vaccine is helping after a transplant. And there is no research after January 2022 available.

Doctors take the Hippocratic oath to become a doctor. It refers to the ethics of their chosen profession. It boils down to "I will do no harm". I want them to honor the oath they swore to!

I wish I had the magic words to say just the right thing to convince everyone how important this is and to reach deep into their conscience and their heart and do the right thing. This country was founded on individuals' rights to many freedoms and we need to protect those freedoms. If this common-sense solution is not passed our freedom of choice is lost. By voting to pass Bill 955 you can restore the rights of my son Jamey and the many thousands of other patients facing the same fate.

Thank you for your time and attention,

Anita Day

Transplant Vaccination Policy



All Advocate Aurora solid organ transplant patients are required to be fully vaccinated against COVID-19 including booster shots as recommended by the CDC. This helps ensure the health and safety of transplant patients who are more vulnerable to severe COVID-19 infection that can result in death.

Pre-transplant patients

- Are required to be fully vaccinated, including boosters
- Vaccination is initiated as soon as transplantation is being considered and completed on schedule per CDC guidelines.
- Patients who decline vaccination are removed from transplant list.

Post-transplant patients

- If not vaccinated, must be vaccinated after transplant
- Vaccination will begin 1-3 months after transplantation; this can be individualized based on immunosuppression.
- Post-transplant patients will receive additional doses (as indicated) due to their immune compromise.

Exemptions

- Those with AAH-approved medical exemptions – including emergent transplants – will not be affected.
- Natural immunity from prior COVID infection and religious exemptions will not be considered as medical exemptions.

Waitlisted Transplant Patients (include HFFY and FAQ)



March 2022

Dear Patient,

COVID-19 has proven to be very harmful to transplant patients. Recent research shows that solid organ transplant recipients have a much higher rate of hospitalization, complications and death from COVID-19. Sadly, COVID-19 has become the leading cause of death for our transplant patients. We must do more to protect our patients.

Since November 15, 2021, UW Health has a policy that requires vaccination against COVID-19 prior to transplant. We learned that getting a booster dose plays a big role in preventing serious illness and death.

Patients need a booster dose:

1. If it has been 5 months from their second mRNA (Pfizer or Moderna) dose, or
2. If it has been 2 months from their Johnson and Johnson vaccine

Our records indicate you are eligible for a COVID-19 booster, but you have not received it. Please get your booster shot. Failure to get the booster shot by April 30, 2022, may result in you being made inactive on the wait list.

Vaccination before transplant surgery gives you the best protection against COVID-19. Please read the enclosed FAQ to learn more about this important and required step in your transplant process and contact your coordinator with any unanswered questions.

If you have received your COVID-19 booster shot, send proof of vaccination to your coordinator via a MyChart message (preferred) or fax to (608) 262-5624.

We also strongly encourage the people who assist you with transportation, medications and/or live with you get their COVID-19 vaccine and booster shots.

Thank you for understanding this important step in keeping our patients safe. Please continue to follow CDC guidelines including wearing your mask, practicing social distancing and washing your hands frequently.

Sincerely,

Handwritten signature of Dixon Kaufman in black ink.

Dixon Kaufman, MD, PhD
Medical Director
UW Health Transplant Center

Handwritten signature of Melissa Roberts in black ink.

Melissa Roberts, MSN, RN
Senior Administrative Director
UW Health Transplant Center

COVID-19 Concerns for Patients in Need of Transplant

Why is COVID-19 a concern for patients who need a transplant?

After your transplant, you will be taking anti-rejection medicines that make it harder for your body to fight infection. This means that if you get COVID-19 after transplant, you are at a higher risk for a more severe, maybe life-threatening illness.

If I get COVID-19, can I still get a transplant?

Contact your transplant team if you test positive for COVID-19 to discuss when it is safe for you to have a transplant.

What is the UW Health Transplant Center doing to reduce COVID-19 risks?

- We require our patients get the COVID-19 vaccines before adding them to the transplant waitlist and undergoing transplant surgery. This protects the patient and our other transplant patients.
- We have a vaccine policy in place for all staff at UW Health.
- We test all donors for COVID-19.
- We will test you for COVID-19 before your transplant.
- We have visitor guidelines to decrease the risk of spreading COVID-19 to our patients.

What steps can patients take to make their transplant safer?

Keep up to date with your COVID-19 vaccines! Being fully vaccinated before transplant will help your body develop protection against COVID-19. This will also help protect other patients and staff in the hospital and clinic. Try your best to avoid getting exposed to COVID-19. Wear a mask when you go out in public and practice good handwashing.

Does every patient need to get the COVID-19 vaccines before transplant?

Exceptions will be made for those patients that are critically ill and do not have time to get the vaccines before their transplant or those with a medical contraindication. No other exceptions will be granted. Patients that are transplanted urgently who did not have time to get the vaccines before transplant are expected to get the vaccines after their transplant.

Can I be active on the list after I get my vaccines?

Most patients can be active on the list 2 weeks after they complete their COVID-19 vaccine series. Please let your transplant team know when you get any vaccines so they can discuss timing of transplant with you.

Does it matter which COVID-19 vaccine I get?

The mRNA vaccines (Pfizer and Moderna) are preferred for transplant patients.

Where can I get the COVID-19 vaccines?

You can get the vaccines in your local community. We also give free COVID-19 vaccinations in our transplant clinic at University Hospital.

Do I still need the COVID-19 vaccines if I have had COVID-19?

Yes. The degree of protection against infection is unknown for those who have had COVID-19. We do know that getting the vaccines will increase your protection against the virus. We want to protect patients as much as we can against the virus, and the vaccines will help do that.

Do I need to get the COVID-19 booster shots?

We **strongly** encourage our patients get the COVID-19 vaccine boosters as soon as they are eligible and stay up to date with future COVID-19 vaccines.

What should my support person and household contacts do to keep me safe?

Your risk of getting COVID-19 is much lower if the people you are in close contact with also get the COVID-19 vaccines. We **strongly** suggest that your support persons and all members of your household stay up to date with their COVID-19 vaccines. Anyone who will be in direct contact with you right after your transplant should be tested for COVID-19 24- 72 hours before you go home. Direct contacts should also follow CDC guidance to avoid COVID-19 exposure. Anyone who tests positive should quarantine per CDC guidance. They should stay away from you until they have fully recovered.

What should I do if I am exposed to someone who tests positive for COVID-19?

You should get tested 3-4 days after an exposure to COVID-19. Monitor for symptoms per CDC/Public Health guidance. Contact your transplant team. They will discuss the plan of care and when it is safe for you to have a transplant.

How do I find out if I can have a visitor/support person come with me to University Hospital?

We adjust our visitor policy and food restrictions based on the rates of COVID-19 in the community. For the most current information, check our website [coronavirus.uwhealth.org](https://www.uwhealth.org/coronavirus) before all visits.

February 2023

Dear Patient,

COVID-19 has proven to be very harmful to transplant patients. Research shows that solid organ transplant recipients have a much higher rate of hospitalization, complications and death from COVID-19 than the general population.

To improve post-transplant survival, the UW Health Transplant Center implemented a policy that requires vaccination against COVID-19 prior to transplant. This policy was effective November 15, 2021. Although you were notified of this policy and the vaccination requirement, our records indicate that you are not vaccinated.

Because you have not been vaccinated, in January 2022, your wait list status was changed to *inactive*. This letter is to notify you that if you do not obtain the first COVID-19 vaccine in the primary series before July 1, 2023, you will be *removed* from the wait list. If you are inactive on the wait list or are removed from the wait list, you will not receive organ offers and will not receive a transplant.

We strongly encourage you to be vaccinated as soon as possible. You can be vaccinated in your community, or we can administer these vaccinations in the transplant clinic at University Hospital. Even if you had COVID-19, you must be vaccinated to be active on the wait list. Please send proof of vaccination to your coordinator via a MyChart message (preferred) or fax to (608) 262-5624. Please note that you will not be made active on the wait list until you complete the full COVID-19 primary series.

Vaccination before transplant surgery gives you the best protection against COVID-19. Please read the enclosed FAQ to learn more about this important and required step in your transplant process and contact your coordinator with any unanswered questions.

We also strongly encourage the people who assist you with transportation, medications and/or live with you to be fully vaccinated prior to your transplant surgery.

If you do not intend to comply with this vaccine requirement, please let us know. We will support referral to another transplant center. It will be up to you to determine which transplant centers are covered under your insurance and if those centers also require COVID vaccination prior to listing.

Thank you for understanding this crucial step in keeping our patients safe. Please continue to follow CDC guidelines including wearing a mask, practicing social distancing and washing your hands frequently.

Sincerely,



Dixon Kaufman, MD, PhD
Medical Director
UW Health Transplant Center



Melissa Roberts, MSN, RN
Senior Administrative Director
UW Health Transplant Center



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Assembly Committee on Health, Aging and Long-Term Care
Testimony Provided by Melissa N. Roberts
Director, UW Health Transplant Program
Wednesday, January 17, 2024
Re: Opposition to Assembly Bill 955

Dear Chairperson Moses and Members of the Committee:

Thank you for the opportunity to appear today to articulate our opposition to Assembly Bill 955 (AB955) related to a transplant patient's vaccination status. I am Melissa Roberts, current Executive Director of the UW Transplant Center and current quality consultant for UNOS, the United Network for Organ Sharing. I am a Registered Nurse, and more importantly, a transplant recipient having undergone a dual organ transplant more than 20 years ago. I feel my personal experience, combined with my professional expertise gained through 25 years of work in the field of organ donation and transplant, qualify me to speak knowledgeably about the potential downsides of this legislation.

It's important to begin with some facts specific to the UW Health Transplant Center, which is a source of great pride for our academic medical center. For more than 55 years the UW Health Transplant Center has led the nation in serving adult and pediatric transplant patients, as well as living and deceased organ donors who provide the gift of life. We transplant more than 500 patients every year, and we provide more than 85% of all transplant care in the State of Wisconsin. Our history is rich in innovations, including the discovery of UW Solution, the first successful cold-storage fluid developed to effectively flush and maintain donated organs during transport to the recipient. This solution is still used all over the globe today. Another example of our innovation is the development of a drug called CellCept, a widely used anti-rejection medicine that helps transplant patients live longer. But we aren't resting on our laurels. Our work continues to focus on new medicines and techniques that improve outcomes for our patients.

One of the ways we secure excellent outcomes for transplant patients is through a comprehensive evaluation process. Our process, like all other transplant centers, is meant to identify potential areas of patient risk and intervene to decrease that risk before the transplant, thereby ensuring the patient is ready to receive a donation and that they have the best chance of a successful outcome. For example, our patients are screened for cancers, latent heart and lung issues, psychosocial supports, and support available in their home environment. That evaluation also includes a review of vaccines the patient has received, such as childhood vaccines, yearly vaccines, and those known to cause specific infections that are difficult to treat in transplant patients. In the majority of cases, we require select vaccines to help prevent dangerous infections after transplant. Any transplant surgeon will tell you vaccines are most effective when given *before* the transplant and immunosuppressant medications. Immunosuppressant medications weaken the body's response to a vaccine because they prevent the creation of antibodies against the specific illness. Transplant recipients who develop infections tend to become much more ill due to their body's inability to fight off infection. As evidence of that fact, I can point to our experience with COVID patients before the vaccine became available. We saw the rate of death was more than 10 times higher among transplant recipients hospitalized with COVID versus non-transplant COVID+ patients. That's an alarming statistic we don't want to repeat but under the terms of AB955, patients would be able to decline certain vaccines like the COVID vaccine – potentially increasing their risk of a negative outcome after the transplant.

For these reasons, we ask you to oppose AB955. Thank you for your consideration. I would be happy to take questions at this time.

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Testimony in Support of AB 955

I was diagnosed with a focal segmental glomerulosclerosis of the kidneys when I was 36 years old. My first kidney transplant was April 1st 2009. I'm now 54 years old and my transplant kidney failed late January of 2022.

The primary reason why I'm not interested in a new kidney transplant right now is because of the enforcement of the current COVID flu vaccines. Myocarditis is one of the side effects, of the known side effects of the current COVID vaccine and also that they use MRNA technology to change our DNA. I have no interest in any of that technology going into my body.

To me this is a death sentence and would compromise my immune system my heart and who else knows what it could compromise short and long term. I will never get the COVID vaccine.

Lance Fealy