# Information and Consent for Accepting a Kidney Transplant from an Increased Viral Risk Donor

People with kidney failure waiting for a deceased donor kidney transplant can choose to be added to a second waiting list, in addition to the standard waiting list. This second waiting list is for patients who have decided to accept kidney transplants from donors who are at increased risk of having viral infections. These infections include the hepatitis B, hepatitis C and human immunodeficiency (HIV) viruses. HIV is the virus that causes acquired immune deficiency syndrome (AIDS).

Choosing to go onto this increased viral risk donor waiting list is entirely your personal decision. This decision will depend on the level of risk you are willing to accept. If you choose not to accept a kidney transplant from these donors, your place on the standard waiting list and your care by the transplant team will not be affected. Even if you sign this consent form, you will still have the opportunity to decline a kidney transplant from an increased viral risk donor at the time it is offered to you.

## Which donors are increased viral risk donors?

Increased viral risk donors have had behaviors before their death which increase their risk of having hepatitis B, hepatitis C or HIV infections. Some examples of these increased risk behaviors include injecting nonmedical drugs and higher risk sexual behaviors.

Routinely, increased viral risk donors have screening tests performed for hepatitis B, hepatitis C and HIV before donation. One of the tests is called a nucleic acid test (NAT). This test allows earlier detection of these infections when they are active in donors. If active infection from these viruses is detected in a donor using this test, transplant will not proceed. Only donors with negative NAT tests will be offered to the increased viral risk donor waitlist. Even though the NAT must be negative for the kidneys to be offered, there is still a small chance that these infections may be missed and transmitted from the donor to the recipient of the transplant.

## What is the risk of catching blood borne viral infections from increased viral risk donors?

In international studies, the risk of hepatitis C infection from increased viral risk donors with negative screening tests is less than 1 in 100, and the risk of HIV infection is less than 1 in 100. In the United States between 2009 and 2015, the risk of being infected with hepatitis B, hepatitis C or HIV after a transplant from these donors was 1 in 1150. There is also a risk of these infections being transmitted from standard risk donors (1 in 2780). If you receive a transplant from a donor with an active infection, it is almost certain that you will be infected with that virus. The risk in Australia is not known, but it is likely to be similar.

## What are the potential benefits?

Increased viral risk donors are often younger than many of the standard donors. They may provide a kidney transplant with better than average function that may function for longer. These potential benefits may outweigh the increased risk of getting an infection from the donor. You should discuss this with your transplant team.

## What tests are needed after the transplant?

Once you have received a kidney transplant from an increased viral risk donor, you will have blood tests within the first month to detect possible transmitted infections. Most transmitted infections are detected within the first month after the transplant.

## What treatment is available if a virus is transmitted?

Medications to treat these infections are available. Hepatitis B infection can be controlled with long-term antiviral tablets. Most hepatitis C infections can now be cured with minimal side effects. HIV infection can usually be controlled with long-term medications. However, even with treatment, the outcome of kidney transplants in HIV infected patients tends to be less favorable than those without HIV infection. Removing the transplanted kidney does not cure the infection.

Online educational material

We strongly encourage you to visit <u>Inform Me</u> , a website developed by Northwestern University in Chicago (United States), for additional information and resources concerning increased viral risk donors. This will help you make an informed decision about whether this is the right decision for you.
The Inform Me website address is: https://informme.cbits.northwestern.edu/system/index.html
Some of the information presented by Inform Me does not apply in Australia. Specifically, in Australia:
The proportion of increased viral risk donors is likely to be lower than 20%.
Accepting a kidney from an increased viral risk donor may not allow you an earlier kidney transplant.
Hepatitis B, hepatitis C and HIV nucleic acid test (NAT), which allows earlier detection of these infections, will always be performed on donors.
The risk of being infected with Hepatitis C on hemodialysis is likely to be lower.
Please inform your transplant team if you have any questions or cannot access the website. Your transplant team may ask you if you have completed this education tool.
Can I remove myself from the increased viral donor waiting list?
If you agree to be added to the increased viral risk donor kidney transplant waiting list but later change your mind, you can request that the transplant team remove you from this waiting list. This will not affect your position on the standard waiting list.
PATIENT OR LEGAL REPRESENTATIVE CERTIFICATION
Dr has discussed with me the potential risks and benefits of accepting a kidney transplant from an increased viral risk deceased donor. I have had the opportunity to ask any questions and these have been answered to my satisfaction. I understand that my place on the standard risk donor waiting list will not be affected by my decision to accept or decline a kidney transplant from an increased viral risk donor.
I,, consent to be placed on the waiting list for a kidney transplant from an increased viral risk deceased donor.
Signature of Patient/ Legal Representative Date Date
Relationship to Patient (if consent is given by other than patient)
$\square$ I have been given a copy of this consent form for my records.
Signature of Doctor Date
Interpreter's name (if used) Signature