

## **Patient Information for the Use of Hepatitis C Infected Organs in Hepatitis C Negative Recipients**

You are being asked to consider whether or not you would accept a kidney from a hepatitis C virus infected donor. This pamphlet will explain why this option is being considered for you, and will explain the potential benefits and the potential risks that this may involve. It is important to emphasize that it is your choice whether or not you agree to accept a kidney from a hepatitis C virus infected donor.

### **What is hepatitis C?**

Hepatitis C is a virus that can cause inflammation and scarring of the liver. The scarring can be severe, although on average it takes 30 years for the scarring to become life-threatening. Treatments for hepatitis C have changed greatly over recent years. It is now possible to cure nearly all patients who are infected with the hepatitis C virus. Treatment requires taking tablets by mouth for 12 weeks. Once the virus is cleared it does not come back and does not affect your long term health.

### **Why am I being offered a hepatitis C infected kidney?**

There are not enough donated organs in the US to transplant all people who need them. Sadly, this means that many people die on the waiting list. Doctors are therefore trying to find ways to increase the number of organs that can safely be transplanted. Due to recent breakthroughs in treatment it is now possible to use organs from donors infected with hepatitis C virus for transplantation, even into recipients who are not infected with hepatitis C.

### **What are the advantages to me of receiving a hepatitis C infected kidney?**

If you agree to accept a kidney from a hepatitis C virus infected donor, you may receive a transplant more quickly, possibly several years sooner than you otherwise would. Also, because organ donors who are infected with hepatitis C virus are younger than average, and less likely to have other important health issues, their organs may be of higher quality and therefore more likely to work immediately and may last longer.

### **What are the risks to me if I receive a hepatitis C infected kidney?**

The main risk of accepting a kidney from a hepatitis C virus infected donor is that you will become infected with the virus yourself. If hepatitis C virus infection is not treated, over many years it could cause liver scarring and failure leading to death. Rarely, hepatitis C may result in kidney damage or more severe liver inflammation, which can be treated. However, you will be offered treatment to cure you of the hepatitis C virus as soon as it has been confirmed that you have been infected. This will minimize the risk of any damage to you. Another important risk to consider is the very small chance that the hepatitis C virus may not disappear after the 12 weeks of treatment. The chances of this happening are less than 2%. If this were to happen, you would be offered a different course of tablets. These drugs achieve 98% cure rates as well. This means that it is very unlikely (1 chance in 2,500) that the transplant team will not be able to cure you of the virus if you are infected.

### **What is the experience of patients who have been infected with hepatitis C at the time of an organ transplant?**

There have already been several studies looking at the results of transplanting kidneys from hepatitis C virus infected donors into patients who are not infected with hepatitis C virus. These studies show that it is possible to cure every patient of hepatitis C virus after kidney transplantation (100% cure rate). Importantly, the overall outcomes were the same for the patients who received kidneys from hepatitis C virus infected donors as those for patients who received kidneys from hepatitis C virus negative donors.

**How do I know that the hepatitis C infected kidney has not been damaged by the virus?**

Hepatitis C can cause liver damage, and, in rare cases, kidney damage too. The health of kidneys that are offered for transplantation is carefully assessed by a series of tests that are carried out on the donor before and after they die. Only kidneys with very little or no damage are used for transplantation.

**What are the risks to my family if I receive a hepatitis C Infected kidney?**

The risks to your family are very small. Transmission of the virus is mainly through infected blood and body fluids. Until you are cured of hepatitis C virus, which should happen within the first few months after the transplant, we recommend that you do not share your toothbrush or razor blades with anyone.

**The virus is not transmitted through physical contact, kissing or saliva.** The virus can be transmitted through sexual intercourse, although it is rare, so we recommend that you or your partner uses barrier contraception (condoms) until you are told that you have been cured of the virus.

**How will I be treated if I receive a hepatitis C infected kidney?**

After your transplant you will have a specific and very sensitive blood test to look for the presence of hepatitis C virus in your blood. If the virus tests remain negative, then your transplant organ has not passed on the infection to you. If any of these tests are positive for hepatitis C virus then your doctors will start you on highly effective treatment. This means that you will be prescribed antiviral tablets that you will need to take for a total of 3 months. This will consist of between 1 to 3 extra tablets a day. During treatment you will have regular blood tests to make sure that the treatment is working and that the virus is disappearing from your blood. Once the treatment is finished you will have further blood tests to check that you have been cured of the virus. If the virus disappears from your blood and cannot be detected 12 weeks after the treatment has stopped, then you have been cured. We predict that more than 98% of patients will be cured. If the first course of treatment does not work then a second 12 weeks course of treatment using a different combination of tablets will be used which cures more than 98% of patients whose first course of treatment has not worked. It is worth mentioning that these new drugs for hepatitis C have very few side effects and are generally very well tolerated by patients, needing to be stopped in less than 1% of patients who take them.

**How will hepatitis C treatment be paid for?**

The transplant team will work with your insurance company to get the hepatitis C treatment paid for. Our financial and social work teams will work with you, the drug companies and your insurance company should co-pays prove to be unaffordable. Treatment of hepatitis C is only rarely emergent, and thus there is time to make appeals if there is initial denial from the insurance company without risk to your health.

**What happens to me if I refuse to accept a hepatitis C infected kidney?**

It is your choice whether you choose to receive a kidney from a hepatitis C virus infected donor. If you prefer not to accept an organ from such a donor you will remain on the transplant waiting list as now and you will continue to wait for a suitably matched organ.