

Exceptional Distribution and Increased Risk Donor Organs **Frequently Asked Questions**

What is exceptional distribution?

Health Canada has a set of regulations that must be followed when assessing an organ donor. These regulations are also the law and were set up to assure that all organs are safe for transplant and the risk of passing any disease from the donor to the recipient is kept as low as possible. (It is important to remember that there is always a low risk in donation as we can never say with 100% absolute certainty that we know everything about the donor. This is considered acceptable risk.)

Using the Health Canada regulations, donor programs have developed a list of exclusion criteria – these are criteria that would ordinarily stop a person from being able to donate. Some of these exclusion criteria may pose a very low risk to recipients while others have a higher risk.

There is also a risk with not accepting an organ for transplant including getting sicker or dying.

When your transplant team gets an organ offer for you and the donor has some exclusion criteria, the team will carefully assess the risk to you from this organ compared to the risk of not getting this transplant. If your doctor thinks that the good outweighs the bad, Health Canada will allow us to transplant these organs. This is called exceptional distribution.

What are some of the criteria that make an organ exceptional distribution?

There are many cases that can make a donor organ exceptional distribution. These are some of the more common criteria:

- Anyone who has an active infection
- Anyone who has a history of cancer
- Anyone who has lived or travelled to somewhere where there is known disease risk – this may include diseases such as tuberculosis or Mad Cow Disease
- Anyone with any other disease that may be passed onto a recipient
- Any potential donor where important questions about their medical or social history cannot be answered

The transplant team will always discuss with you the reasons for exceptional distribution.

What is an increased risk donor (IRD)?

Some risks identified in the donor are higher than others. Health Canada has listed the criteria which identify a donor as being a higher risk to you. This is called an increased risk donor (IRD). These criteria are associated with lifestyle behaviours which have been shown to have a higher risk of passing on infectious diseases including HIV, Hepatitis C and Hepatitis B.

What are some of the criteria that make a donor IRD

There are several criteria that can lead to a donor being called IRD. These are some of the more common criteria:

- Anyone with current or recent IV drug use
- Anyone who has recently been in a youth correctional facility, jail or prison
- Anyone with a recent high-risk sexual activity
- Anyone who has been exposed to someone with high risk behaviours

The transplant team will always discuss with you the reasons for IRD.

Are there rules when exceptional distribution including IRD can be used?

Yes. Exceptional distribution can only be used if the following 3 conditions are met:

1. There is no other organ available immediately.
2. Your transplant doctor thinks that the benefit of using the organ is much greater than the risk of not transplanting it.
3. Your transplant team informs you of the reasons for exceptional distribution (this includes the reason for IRD) and you consent to the transplant.

Why should I consider organs from an exceptional distribution or increased risk donor?

There are two major advantages to considering accepting organs from these donors.

1. It may improve your chance of getting a transplant. In Canada, there are more people who need a transplant than there are organs available to transplant. Unfortunately, some people will die on the waiting list, never getting a chance at a life-saving transplant.
2. It will increase your chances of getting a transplant sooner. Some people will wait for an organ for a very long time and while you remain on the waiting list, you may get sicker or possibly get to a point where transplant is no longer an option.

Your transplant team will tell you the reasons for exceptional distribution and the reasons for IRD when an organ is offered to you for transplant. They will explain the risks of accepting this organ and the potential impact on you. They will also explain the risks of not accepting the organ and the impact of remaining on the waiting list.

Whose decision is it to accept an organ from an exceptional distribution or increased risk donor?

Your transplant team will only consider and offer you an organ for transplant when they think that the risk is acceptable. However, it is your decision to accept or decline the organ for transplant.

What happens if I say no to an organ from an exceptional distribution or increased risk donor?

Your decision to say no will not affect your chances of being offered other organs for transplant. You will remain on the waiting list in the same place as before.

What happens if I accept an organ from an exceptional distribution or increased risk donor?

Following transplantation, your follow-up may include some extra steps depending on the reason for exceptional distribution. Your transplant team will explain any follow up plans with you when they offer you the organ for transplant.

For organs from a donor with a history of cancer, if the transplant team thinks there is even a tiny chance you may get cancer, they will do routine testing.

For organs from a donor with a known infection, your transplant team will likely treat you prophylactically (treatment to prevent you from getting the infection).

For organs from a donor with Hepatitis C, you will be treated for Hepatitis C when you test positive for Hepatitis C. (We have an information sheet specific to organs from Hepatitis C donors and your transplant team will share this with you.)

For organs from increased risk donors, you will be followed by an Infectious Disease Specialist on the Transplant Team. You will be routinely tested for HIV and Hepatitis C. If you are not immune to Hepatitis B, you will also be tested for this. These tests will happen at one week, one month and three months after transplant. You will require repeat testing once more at 12 months after transplant if you are not immune against Hepatitis B.

The Donor Program does all necessary follow up on the donor that is available and will share any new information with the Transplant Team.

Will I always get called with an IRD organs?

Your transplant team should explain what an increased risk donor is to you when you are being assessed or being listed for a transplant. If after listening to what the team says, you feel that you do not wish to ever accept any organs from an increased risk donor, you can inform your team of this. Your recipient coordinator will make a note of this on the waiting list and you will not be called with any organ offers from these donors.

Likewise, your transplant team will explain the risks of organs from Hepatitis C donors to you during your assessment or listing. You can also decide at this time that you do not wish to accept these organs and your recipient coordinator will note this.

You are always able to change your mind regarding either IRD or Hepatitis C donors at any point and a change will be made on the waiting list. Remember, agreeing to be offered these organs does not mean that you will have to accept the organ at the time of offer. There are many factors that could change between listing and time of offer that may influence your decision. The decision is always yours.