

Giving Tissue and Blood Samples for Biomedical Research: The Insulators' Tissue Bank

About the Insulators' Tissue Bank

The purpose of the Insulators' Tissue Bank is to establish a repository of high quality, asbestos-related-tumor tissue specimens and fluid samples from a highly exposed population of asbestos insulators in order to support research that either aims to better understand the mechanisms of asbestos-induced cancer, or aims to develop interventions and cures for asbestos-related cancers. The Insulators' Cancer Biorepository at Mount Sinai will be a resource unique in the world.

Research Tissue Banks can be very useful for researchers to study actual samples from workers exposed to asbestos, in the laboratory in order to find new ways to diagnose, treat and prevent asbestos-related conditions.

What are we asking you to do?

We are asking you to give tissue and blood samples to help biomedical research.

You are being asked because you have previously been exposed to asbestos, or are currently exposed to asbestos. In the event of you having an operation or other treatment for an asbestos-related condition (mainly mesothelioma and lung cancer) that involves the removal of tissue or the taking of blood, we would like to get any tissue and blood that is not needed for your diagnosis or treatment, and other relevant information, for research.

What will happen if you say yes?

The first thing you need to do is give your written permission (consent) by signing the form attached to this leaflet. Please keep this information sheet to remind you of what you were asked to do.

If you agree to take part, the following will happen:

- If you need to undergo surgery or a biopsy, a doctor will be removing pieces of tissue from your body during your operation as is normal practice. (This may already have happened before you are able to read this leaflet and samples from previous surgery for asbestos-related disease may still be useful.) This tissue will be sent to a laboratory in the hospital to be tested to help diagnose your medical condition. Some of this tissue may

remain after the diagnosis is complete and would normally be destroyed by the hospital. With your permission, the hospital will give some of this remaining tissue to the Insulators' Tissue Bank, to be used in medical research.

- During your care in hospital, you will normally give blood samples for tests to be carried out. Either whilst you are giving one of these routine blood samples, or at a different time, we would like to ask you to allow the staff to take additional samples so that they can be used in research. This will be just like any other blood test and should not affect you.
- Staff may ask you some questions about yourself. We also ask you to allow them to look at your personal medical records to obtain information about your asbestos-related disease, other diseases, and your past treatment. This information will be given to the Insulators' Tissue Bank to help the researchers understand your medical condition. The Insulators' Tissue Bank is legally obliged to maintain the highest level of confidentiality with all personal information so that researchers cannot identify you.

If you agree to take part, you will be giving samples and information that will be treated as gifts that could help research to benefit those affected by asbestos-related disease in the future.

What will happen if you say no?

You are free to say no – the choice is yours. Your decision will NOT affect the standard or type of care you will receive from the hospital or doctor, now or in the future. If you say no, we will not take any samples from you nor will we collect any information.

What happens if you change your mind?

You can change your mind at any time by contacting the Insulators' Tissue Bank to let us know. You do not need to tell us why. Our contact details are given below.

If you tell us that you have changed your mind, all samples in storage will be destroyed in the way human tissues and blood from hospitals are normally destroyed. Similarly, the information we store about you will be deleted so that it cannot be used again.

If you change your mind after a long time the samples may have already been used. The Insulators' Tissue Bank cannot recall samples or information from researchers once they have been used. If, by then, your gift has already helped create new knowledge, that new information cannot be undiscovered and will contribute to medical understanding. However, the Insulators' Tissue Bank will request the disposal of any samples that remain so that your gift will not be used in any further research.

What are the benefits to you?

It is highly unlikely that you will personally benefit from the research as it usually takes many years for research to produce advances in the way asbestos-related disease is diagnosed, treated or prevented. The results of research will NOT be put in your health records or told to you, your relatives or your doctors because the researchers will not know who you are and your details are kept secret from them. The Insulators' Tissue Bank will, however, be asking all researchers that request tissue to inform us of the overall findings which we intend to communicate to all the participants via newsletter.

You can benefit from the knowledge that you are personally helping research to find out what causes asbestos-related disease, how to prevent it or how to treat it. The test and treatments being used for you were developed with the help of patients who took part in research years ago. Research might make faster progress as more human samples are studied. Also, by using human samples there may be less need to study laboratory animals.

What are the risks to you?

There are NO significant health risks to donating samples for research purposes to the Insulators' Tissue Bank. You will only be allowing us to use tissue samples which would be collected anyway as part of your normal care and there are no more risks of giving blood for research than there are for being a blood donor or giving any routine blood sample.

Your hospital, medical team and the Insulators' Tissue Bank will take every security precaution to prevent researchers from obtaining any information that identifies who you are. The only people who will know your identity are the hospital staff and a few trained staff dealing with patient records in the Insulators' Tissue Bank who are bound by a professional duty to protect your privacy. Researchers will NOT be provided with any personal information such as your name, address or phone number. The information that they will be given for their work relates to your disease and treatment only and will NOT be directly linked to your identity. The link to your identity will be securely stored by the Insulators' Tissue Bank so that if a researcher gets approval to do a follow up study, the Insulators' Tissue Bank may be able to obtain further information about you and your progress. Researchers will, therefore, NOT be able to contact you directly about their research in future.

When the Insulators' Tissue Bank provides samples to researchers they are obliged to only use the samples for the research they said they would do. Researchers will be bound by a strict agreement to ensure this.

Other things you should consider

The tissue, blood and information you have gifted will be made available to researchers who may be in North America or overseas. They may work in universities, hospitals or in private /

commercial companies that do medical research. You will not receive any personal financial reward for making your gift.

Sometimes samples are used for genetic research (about diseases that are passed on in families) but the results of this genetic research will NOT be fed back to you or your doctors. The Insulators' Tissue Bank will not supply samples for research into reproductive cloning.

Your donation will be used only for medical research and will not be provided for any other purpose. This research may not always be directly linked to asbestos-related disease but will always be relevant to understanding how the body works, which may eventually help understand asbestos-related disease and other diseases.

The Insulators' Tissue Bank may ask researchers for fees to cover some of the costs it incurs. This is known as "cost recovery" as it is entirely for reinvestment to ensure the highest standards of safety and professionalism and to enable further medical research. The samples you have gifted will never be sold for profit.

If you have any questions or concerns about the donation of samples and information or the possible uses of them, please ask Dr. Todd at the address or telephone number given below.

How to Contact Us

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