

## **Southampton Eye Biobank**

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The causes of eye diseases are numerous, varied and currently many are poorly understood. They affect people of all ages and can cause problems with vision in babies and young children, through every decade and are often the cause of isolation and fractures in the elderly.

Southampton Eye Biobank has been organised to source, organise, collect, prepare, store and distribute donated eyes to scientists in order to further the breadth of research into blinding eye diseases. There are two ways to donate eyes when someone dies:

- The corneas can be donated to someone in need of a transplant giving them the gift of sight. Previous medical and lifestyle history will affect whether this is possible.
- The eyes can be donated to medical research. This gift will help scientists and clinicians learn more about the eyes and various conditions that affect them, allowing better diagnosis and treatment options to be developed.

In many instances, transplant isn't an option due to strict policies in place designed to ensure the safety of the person receiving the transplant and to make sure that it has the best chance of being successful. These include individuals with existing eye diseases, those who have had previous eye surgery as well as conditions such as dementia or Parkinson's and a number of cancers.

### **Donation to Southampton Eye Biobank**

Southampton Eye Biobank offers individuals the opportunity to donate their eyes for the purpose of clinical research, both within the NHS and commercial companies with the aim of improving future diagnostics and treatment of eye disease.

## **What it involves**

Before agreeing to give this precious gift, we want to make sure that you know what you will be agreeing to. Should you consent then a note will be made in your medical records and upon your death we will be informed. In order to avoid unnecessary upset for your next of kin, we will contact them regarding your consent. Please ensure you have made them aware of your decision to avoid additional upset on their part. Should they not agree with your consent, then we will not proceed with the retrieval. Whilst retrieving the eyes, we will also take some of the surrounding muscle as well as a small sample of blood. These will then be processed and stored for use in ethically approved studies for research. After this has been done plastic covers will be placed under the eye lid to maintain the appearance of closed eyes. In order to maintain the quality of the tissue for research, it is best for the eyes to be retrieved within 24 hours. As a result, should you consent to donate, there is no guarantee we will be able to process your eyes if you are not on the hospital site.

To further increase the quality of the research that can take place, we also ask for consent to access your medical records and for you to complete a lifestyle questionnaire.

In some cases, genetic testing may take place to look at the reasons why some people develop eye diseases. During this procedure there is a slight chance that a gene may be found that could have been passed to other family members and increase their chances of developing a condition. However, the tests being run are not validated for clinical use, and as such may not be accurate for diagnostic purposes, therefore these results will not be fed back. If you are concerned about this, then you do not have to consent to genetic testing.

All information that is collected will be stored in a secure location in a format that allows only a small number of research staff to access identifiable information. Tissue samples will be stored in a secured freezer on the Hospital Grounds as per Human Tissue Authority licensing laws for the duration of our ethical approval. Should approval not be renewed, then samples will be moved to an approved biobank for storage until such a time when approval is given.

## **Research to be undertaken**

Due to advancing technologies and knowledge, it's difficult to be able to say specifically what kind of research the tissue will be used for, but we can guarantee that it will not be used for reproductive or animal studies. Access to the tissue will be through an access committee that will look at each individual project for scientific merit and ethical considerations. This access committee will also include a lay member to ensure that the samples are treated with the respect and dignity they deserve.

In order to use the samples to the best of their potential, there is a possibility that approved projects may be overseas or undertaken as part of commercially funded research. In all cases, any accompanying data will be sent in an encrypted and anonymised format to approved researchers.

## **What if I change my mind or lose the capacity to consent?**

If at any point you decide to change your mind then simply contact the biobank coordinator and your details will be deleted and the note on your records removed. This decision is entirely your own and will not affect any medical care you receive in the future. Should you lose the capacity to consent at any point before death, then we will require consent to be confirmed by your next of kin.

## **Who can I contact if I am unhappy?**

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (contact details on top of page 1). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure (or Private Institution). Details can be obtained from the hospital.

Please feel free to ask any questions you may have before making your decision to consent.

Southampton Eye Biobank would like to acknowledge Gift of Sight for the funding provided to set up this project. Should you wish to learn more about this charity, please visit [www.giftofsight.org.uk](http://www.giftofsight.org.uk)