(Attach UR label if available)

Lions Eye Donation Service MELBOURNE

Authority for removal of eye tissue after death

Information and consent form for Donors and Senior Available Next of Kin (SANOK)

About this document

You have been given this information sheet and consent form because you are considering eye tissue donation – either for yourself, or for a loved one. Eye tissue donation, through transplantation, can give multiple people the precious gift of sight. It can also help medical researchers working to prevent, treat and cure various conditions, mainly in the eye, and help train healthcare professionals to improve donation and transplantation processes. Donations are managed by the Lions Eye Donation Service (LEDS), a department of the Centre for Eye Research Australia (CERA) and Custodian of the CERA Biobank.

Who can consent to donation?

Donors: You may be someone who is considering eye tissue donation as part of your end-of-life planning. This is considered a **first-person** consent to donation**.** It's important that you communicate your donation decision to your family.

On behalf of a donor: You may be asked to consider donation on behalf of a loved one at the end of their life. This often occurs after they die. To comply with Victorian law, this consent must be provided by a **Senior Available Next of Kin (SANOK).** The SANOK is the donor's closest living relative, **in the following order:** spouse/partner, adult child, parent, adult sibling or legal guardian, but may also be a person who has been legally appointed to make medical decisions for the donor. Consent is to be informed and understood and may be delegated along the order as applicable. LEDS and hospital staff can help you determine whether you are the right person to consent for your loved one's donation.

About donation

Donation is an invaluable gift to the community, and it is an important decision that you should feel comfortable about and understand before signing. The consent form is located on page 5 of this document. If you require further information, you will find the LEDS contact and online details on page 4. Please note:

- When this information sheet and consent form says, "the donor," it is referring to the person who is donating their eye tissue. If you are consenting for yourself, you are the donor. If you are consenting as a SANOK, the donor is your loved one. Please keep this in mind as you read the information.
- Sometimes, even if the donor is suitable and consented to donate, LEDS may not be able to facilitate the donation due to logistics and resources.
- Donation is a voluntary process, and you do not have to provide consent if you do not wish to.

What can be donated?

Donation involves removal of eye tissue from the donor following their death. You can choose to donate either **corneas only**, or **whole eyes.**

- The **cornea** is the clear outer covering of the front of the eye. It is similar in shape and size to a contact lens. If you consent to donate corneas only, the rest of the eye will remain with the donor.
- You may also choose to donate **whole eyes**, which includes the corneas and the sclera. The **sclera** is the white part of the eye.

How is donated tissue used?

Donated eye tissue can be used for transplantation into recipients who are waiting for a transplant. This means that these recipients have a damaged or diseased part of their eye that will be replaced with healthy tissue from the donor. Both corneas and sclera can be transplanted.

- People requiring a **corneal transplant** may have a disease, infection or injury of their cornea, which can result in loss of sight. Corneal donation can restore sight to up to two transplant recipients.
- **Sclera** is most commonly used for reconstructive surgeries or procedures to relieve increased pressure in the eye. Donated sclera may be used to preserve or restore the sight of up to eight recipients. This means that there can be up to 10 recipients from whole eye donations.

LEDS does not choose who needs a transplant. This is decided by the surgeons who perform the transplant. This decision is based on urgency and a waiting list. Recipients may be of any ethnicity, gender, community group and age.

What does the donation process involve?

- The donation is a simple and quick procedure that usually occurs within 24 hours after death. This means that funeral plans are unlikely to be impacted.
- The donation procedure is non-invasive and requires no visible skin incisions or stitches, so the donor's appearance will remain unchanged.
- Donation involves the removal of either the corneas only, or whole eyes. This will depend on what you consent to. Sometimes, even if you have consented to the whole eyes being donated, LEDS may only retrieve corneas. This is because LEDS does not want to recover more than is needed.
- A sample of blood may also be obtained. This can occur at the time of donation, or by using any remaining blood samples taken from the donor within 7 days prior to their death. This is provided to LEDS by the hospital/pathology group who are storing the donor's blood.
- To ensure donated tissue is suitable to transplant, LEDS will need to review the donor's medical history. They may do this by reading the donor's hospital records and obtaining information from

their general practitioner. LEDS will also need to contact you to complete a donor health and lifestyle questionnaire.

What if donated tissue cannot be transplanted?

Sometimes, eye tissue is not suitable for transplantation. If this happens, if you consent, the tissue can be used for **medical research or surgical training.** This also includes using the tissue to improve the donation service. Tissues donated for non-transplant use are managed by LEDS and the CERA Biobank. All research projects receiving tissue from the CERA Biobank have approval from an Australian Human Research Ethics Committee. Different parts of the eye can be used to help researchers explore new ways to diagnose, treat and prevent disease. This is usually in research involving the eye and brain. Eye tissue that is not suitable for transplantation may also be used to help train surgeons and LEDS staff in new surgical techniques, and to help LEDS improve the donation service. Some of the blood sample obtained may also be used for these purposes. Please follow the QR prompts on page 4 to find out more information about donating tissue for use in research and training and to learn more about the research donation projects LEDS supports. If you consent to this, and the donation is allocated to research, then you will receive information on how you can follow the research taking place at CERA.

If the donation is not suitable for transplantation, and you have not consented to research or training, then the donated tissue will be respectfully disposed of by LEDS.

What will happen to information about the donor?

Eye tissue donation is a confidential process. Any information that LEDS collects that can identify the donor will only be accessed by LEDS and CERA Biobank staff and staff from authorised pathology laboratories involved in testing the donor's blood on behalf LEDS. If LEDS needs to share information about the donor with transplant surgeons or researchers, they will replace any identifying information with a code number. Only LEDS and CERA Biobank staff will be able to re-identify the donor using this code number if it is necessary to do so.

Eye tissue can be allocated for use across Australia and sometimes internationally. Transplant tissue is allocated to approved surgeons, eye banks and hospitals, while research and training tissue is allocated to approved research and training institutes

Can I communicate with the transplant recipient(s)?

Victorian law requires that the donor and the transplant recipients are anonymous to each other. This means that LEDS cannot provide you with identifiable information about any recipients of the donation. Recipients will not receive any identifiable information about the donor or their family. Instead, LEDS can facilitate a letter exchange between both parties. There is no obligation for either party to provide a letter or reply to a letter. Therefore, there is no guarantee that you will receive a letter from a recipient.

Will I get to know the outcome of the donation?

LEDS will send you a letter after the donation. This letter will explain how your donation has helped restore sight through transplantation, training or research and will also include information on additional services such as grief counselling. If the donated tissue was used for transplantation, the letter will include information on how to write a letter to the recipient(s), if this were something you would like to do. This information will usually be sent to you within 2 months after the donation. At a later date LEDS may also notify you of 'thank you ceremonies', conducted by LEDS partnering donation agencies, that you may like to attend. The ceremonies often occur in the following calendar year.

Can I withdraw my consent?

If you do consent, and at a later date, wish to withdraw your consent, please contact LEDS immediately. Donation will not proceed if you withdraw consent before the donation procedure takes place. If you withdraw consent after donation has taken place but before tissue has been transplanted or used in research or training, LEDS will, where possible, return the tissue to the donor or respectfully dispose of it. Please note that it may not be possible to withdraw consent if donated tissue has already been transplanted or used in research or training. When you contact LEDS you will be informed of the options available in your situation and asked to complete a withdraw consent form confirming your decision to withdraw consent. LEDS will provide you with that form, at that time.

Additional information

If you require additional information, please visit our website via the below QR links or contact us via

Tel. 03 9929 8708 (office hours 8-4pm Monday to Friday)

Email: eyebank@cera.org.au

Donor Coordinator: 0483 988 463 (7am – 6pm daily)

Note: LEDS is not a 24-hour service. A team member will respond to you as soon as they can.

CERA Biobank (research) page

LEDS Page

(Attach UR label if available)

Lions Eye Donation Service MELBOURNE

Authority for removal of eye tissue after death

Consent Form for Donors and Senior Available Next of Kin (SANOK)

Please contact LEDS if you require assistance to complete this form.

Details of the donor	
Name of the donor	
Date of Birth	
MR number	

Declaration by the Donor and/or Senior Available Next of Kin (SANOK)

- I have read the **"Information and consent form for Donors and Senior Available Next of Kin (SANOK)"** information sheet, provided by the Lions Eye Donation Service (LEDS), or someone has read it to me in a language that I understand.
- I have had an opportunity to ask questions, and I am satisfied with the answers I have received.
- I consent to the removal of a small sample of blood, to test for the presence of blood borne viruses. I understand that this may involve LEDS obtaining a sample, collected within 7 days prior to death, if available, from the hospital/pathology service.
- I give permission for the employees of LEDS to obtain the donor's medical and social history. This may include contacting me and/or the donor's treating doctor.
- I understand that the donor's medical and social history will be used by LEDS to determine the donor's suitability for transplantation and/or research, and that the history will remain secure and confidential to LEDS.
- I understand that if consent is given for use of tissue in research or training, tissues, blood sample and information about the donor will be de-identified before they are provided to the researcher or trainee.
- I understand that if the donated eye tissue is found to be unsuitable for transplantation and/or medical research/training purposes, it will be disposed of respectfully.
- I understand that I am free to withdraw consent at any time. I understand that I must contact LEDS as soon as I decide to withdraw consent. I understand that withdrawal may not be possible if the tissue has already been removed and transplanted or used in research or training.
- I understand that sometimes eye tissue donation might not happen due to unforeseen circumstances (e.g. retrieval couldn't be done within time limits).
- I understand that donations are allocated to recipients based on clinical decisions of surgeons.

- I understand that I have the option to write to the transplant recipient(s) and that the recipients may or may not write a letter to me. I understand that LEDS will facilitate the letter exchange but cannot provide identifiable information to either party.

I consent to:

By ticking the boxes in the next section, you are letting LEDS know your consent wishes. LEDS will only remove eye tissue and allocate donations for use in transplantation or research/training when the relevant boxes are ticked. Non-ticked boxes indicate that you do not consent. You may tick all the boxes or some of the boxes, depending on your wishes.

Description	I Consent for **TRANSPLANTATION** into a body of another living person (tick for yes)	I Consent for **RESEARCH and TRAINING** purposes (tick for yes)
Whole eyes (including corneas)	☐	☐
Corneas only	☐	☐

Fill in the next section **ONLY IF** you are consenting for use in **RESEARCH and TRAINING:**

The following section is optional. To indicate your consent, please tick the boxes you wish to consent for. Non-ticked boxes will indicate that you do not wish to consent for that option.

☐	I consent to being contacted by LEDS/CERA Biobank, if a research study involving the donated tissue uncovers information that could have significant health implications for the donor's living family members.
☐	I give consent for LEDS/CERA Biobank, to contact me if there is an opportunity for the donation and/or blood to be allocated to a 'special research project'* that requires a more detailed informed consent process than what is provided in the LEDS 'Information and consent form for Donors and Senior Available Next of Kin (SANOK)" and their website. *'Special' projects are unusual and rare projects. These projects have additional ethical requirements around consent. For example, the project may wish to use the donation in the creation of cell lines or for genetic data. For further information see: https://www.cera.org.au/lions-eye-donation-service/cera-biobank/

(Attach UR label if available)

Lions Eye Donation Service MELBOURNE

Consenter's Signature

Please select either the "First Person Consent" or "SANOK" box below.

First Person Consent (person consenting for their own donation)

Signature of the donor (**first person consent only**) _____ Date _____

Senior Available Next of Kin (SANOK)

Name of **Next of Kin** _____

Signature of the **Next of Kin** _____ Date _____

Relationship to the donor _____

Address _____

Phone number _____

LEDS/Hospital Staff

Who obtained the consent (e.g. LEDS or donation specialist or hospital staff):

Name_____ **Role** _____

Name of hospital/donation agency (if not LEDS) _____

Signature _____ **Date** _____

Consent obtained via (tick one):

- ☐ **Phone**
- ☐ **In person**

Tick if a translator was involved ☐

Contact for Lions Eye Donation Service

Tel. 03 9929 8708 (office hours 8am – 4pm Monday to Friday) / **Email:** eyebank@cera.org.au /

Donor Coordinator: 0483 988 463. (7am – 6pm daily, incl. public hols)

Note: LEDS is not a 24-hour service. A team member will respond to you as soon as they can.