Australia and New Zealand Lung Transplant Registry (ANZLUNG)
C/O South Australian Health Medical Research Institute (SAHMRI)
SAHMRI Building, Level 4 South
PO Box 11060
Adelaide, South Australia 5001
Ph: +61 8 8128 4141
Email: kelly@anzdata.org.au

Dear Parent/Guardian

Re: We would like to use your child's information for the Australia and New Zealand Lung Transplant Registry (ANZLUNG)

The registry is a way of collecting information about people who receive a lung transplant. The aim of the registry is to report on patterns and outcomes of patients with end-stage lung failure who receive a lung transplant. The registry is physically located at the South Australian Health and Medical Research Institute (SAHMRI) in Adelaide, South Australia under the governance of the Australia and New Zealand Lung Transplant Registry Clinical Steering Committee.

We will use your child's information in the Australia and New Zealand Lung Transplant Registry unless you tell us not to.

The rest of this letter gives you more information about the registry. It also tells you how you can opt out of the registry if you want to.

What information will we give the ANZLUNG?
The ANZLUNG collects information about your child including:

- health information, such as information about your child's condition and the type of transplant they receive.
- personal information, such as your child's name, date of birth, sex, ethnic background (their race)
- height and weight measurements

The registry **DOES NOT** collect other personal details such as address, telephone number, Medicare number, medical insurance, or non-medical matters.

The reason why the registry collects identifying information about people is to make sure that their records are not duplicated if they move to another hospital. It also allows for data audits and linkage with other information.

We will get your child's information from:

- your child's medical records
- other databases that are linked with the registry, such as OrganMatch and the Australian and New Zealand Organ Donation Registry (ANZOD)

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Why does ANZLUNG need this information?
The aim of the registry is to find out more information about end-stage lung failure leading to lung transplant. We hope that it will help answer questions such as:

- how many people in Australia receive lung transplant?
- what are the long-term outcomes for people who receive lung transplants?
- how can health services provide better care for people undergoing lung transplantation?

The ANZLUNG will use this information to;

- Make reports with the latest information about patients who receive a lung transplant
- Send reports back to each hospital telling them how their patients are doing compared to the past, and also compared to other hospitals
- Understand the quality, type and place of care people receive

Who will have access to your child's information?
Your child's identity (and other personal information) may be released for the purpose of research projects approved by a Human Research Ethics Committee. The ANZLUNG has strict rules around who can ask for information and how they can get it.

If ANZLUNG information is used in research or is published in a report, it is always given anonymously (without your name).

How will the ANZLUNG store your child's information?
Your child's information will be stored in a highly protected computer network at SAHMRI in Adelaide, South Australia; because the information will be stored in Australia, it will be protected by Australian privacy laws.

What are the risks?
The main risk to your child is a potential breach of privacy. However, as we have explained, we will protect your child's privacy by secularly storing the information in highly protected computer network. Any information transferred is done so in a safe and secure way.

Ethics
The ANZLUNG has been approved by the Women's and Children's Health Network Human Research Ethics Committee.

What happens next?
a. **If you agree** to share your child's information

If you are happy for us to share your child's information you do not have to do anything. We will simply give your child's information to the ANZLUNG.

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The ANZLUNG will store your child's information for an unlimited period. You can also withdraw your child's information from the registry at any time.

b. **If you do not** agree to share your child's information

If you do not want us to share your child's information with the ANZLUNG, please talk with your child's transplant team, who can inform ANZLUNG that you wish to opt-out of sharing you information with the registry.

Do you have any questions?
You can also get in touch with us several ways:

Email Send the ANZLUNG an email at kelly@anzdata.org.au

Phone Call the ANZLUNG on (08) 8128 4758

If you would like to talk with someone who is not involved with the ANZLUNG, you can contact people who know about privacy and ethics at Central Adelaide Local Health Network Human Research Ethics Committee on (08) 7117 2224 or email them at Health.CALHNResearchGovernance@sa.gov.au.

Thank you

Kind regards
Australia and New Zealand Lung Transplant Registry
Clinical Steering Committee

Version	Version Date	Endorsement	Outcome
2023.v0.1	5/7/2023	Draft	Document Creation
2023.v0.2	21/9/2023		Reviewed & amended at CSC meeting
2023.v1.0	4/10/2023	Endorsed	