

What's this brochure all about?

We do medical research to improve our understanding of diseases and find better ways to prevent or treat them. This is done by studying the biology of a disease using samples of blood and body tissue - and comparing the results with clinical information, these samples are called "biospecimens".

Biospecimens are collected from people (donors) like you for laboratory tests. On occasions, part of a biospecimen is left over and we can use this material to conduct more research. People who allow us to do this are called "donors".

To conduct research:

- We require access to 'left over' biospecimens;
- Sometimes, we need to take an additional small blood sample (approximately 2-4 teaspoons) and
- We need to access specific health information about a donor that is relevant to medical research.

The purpose of this brochure is to:

- a) Inform you about our on-going need to do research into the prevention or treatment of disease, and to
- b) Ask you to be a donor and to give us your consent to our using your 'leftover' biospecimens, taking additional blood if we need to and accessing your health records where required.

Please consider the following information carefully before making a decision. If you do decide to give us your consent, it is advisable that you tell your family of your decision and why you chose to support medical research in this way.

Please note:

- You are not obliged to be a donor or to give us your consent in regard to anything in item b) above
- Your decision will not affect your care in any way
- You may withdraw your consent at any time.

The following is important information that you need to know. **Please read it carefully.**

Confidentiality

The identification of your biospecimens and your health information will be kept in strict confidence for viewing and use by authorised people only. You can not be identified from your biospecimens as the specimens will be stored in a secured hospital laboratory. These biospecimens are stored indefinitely until it has been consumed during the research process. The biospecimens will not be disposed of unless you have withdrawn your consent.

It is important to note, as with all health information kept about you, that there may be circumstances where disclosure of your health information as kept for this study will be required by law, for example, as a result of a court order.

What will be done with your samples?

Your biospecimens will be used for only bona fide research studies. Some genetic information about you will be obtained and used with other data in your medical records to see how your genes relate to your diagnosis and general health.

In the longer term we may wish to continue to collect information on your health. This would involve contacting your local General Practitioner (GP) or other medical providers. If it is not possible to gather information from these sources, we may also wish to contact you directly by sending a card in the mail or with a follow up phone call.

Please note: Your biospecimens will not be used for research involving reproductive technology, human embryos or cloning.

Keeping within standards

All the research we do has to be approved by a Human Research Ethics Committee certified by the National Health & Medical Research Council. This Council is responsible to the Commonwealth Minister for Health & Ageing.

This is to give you assurance that your biospecimens will be used for only genuine medical research with foreseeable community benefits.

Collaboration with other research bodies

Where appropriate, your biospecimens may be sent interstate or overseas for collaborative research purposes. This can only happen when we are sure that requisite approvals have been obtained and the necessary ethical and privacy safeguards are in place.

Commercial gain from use of your biospecimens

The law in Australia dictates that you may not be rewarded financially for donating your biospecimens themselves, although you may be provided compensation for any expenses arising from your donation such as travel costs.

We are however, allowed to profit from research outcomes that are ultimately successfully commercialised. Any money we receive from commercial ventures is always put back into medical research.

Results of Research

The research conducted using your biospecimens and health information may be published in medical journals or presented at scientific meetings in the future, but you will not be identifiable in any such publications.

The results of research performed on your biospecimens are intended to improve our understanding of disease and so provide general benefit to the community.



As research can often take many years, it is probable that there will not be any information from research conducted on your biospecimens that will have specific relevance to your health. However, in some instances the research conducted may reveal information that has health implications for you, your family or descendants. In those cases we may contact you. We will only do this if the information is reliable and there is something that can be done with the information. We shall also ensure that you are directed to appropriate care if required. You and you alone may choose what happens as a result of this new information.

Potential risks

In the unlikely event that you experience bruising or feel faint when giving blood - our fully qualified personnel will care for you.

If you want to change your mind

Please tell us by writing to the address below, if you wish to withdraw your consent, which you are free to do at any time.

If you do this, we will write back to you to acknowledge your wishes and to confirm the destruction of any remaining biospecimen.

Further information

If you would like independent advice about becoming a donor – or if you would like to lodge a complaint.

Please contact:

Women and Newborn Health Service Human Research Ethics Committee on T: 08 9340 7845 or

St John of God Health Care Ethics Committee on T: 08 9382 6940.

Hollywood Private Hospital Research Ethics Committee T: 08 9346 6571.

If you have any concerns or questions, please talk to your treating doctor or contact us at:

The Director of Medical Research
WA Gynaecological Cancer Research Centre

This leaflet was written in consultation with CanSpeak WA, the Health Consumers' Council of WA and the Genetic Support Council of WA.

About St John of God Health Care

St John of God Health Care is a Catholic not-for-profit healthcare provider, with hospitals, home nursing and pathology services, as well as Social Outreach and Advocacy services which reach out to people experiencing disadvantage to improve health and well-being.

We strive to serve the common good by providing holistic, ethical and person centred care and support. We aim to go beyond quality care to provide an experience for people that honours their dignity, is compassionate and affirming and leaves them with a reason to hope.

This Research Group has been formed in conjunction with -



Government of Western Australia
Department of Health

HOLLYWOOD
PRIVATE HOSPITAL



ST JOHN OF GOD
Health Care

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ST JOHN OF GOD
Health Care

WA Gynaecologic Oncology Biospecimen Bank (WAGO)

Information brochure & Frequently
asked questions



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