

EXPRESSION OF INTEREST

If you are interested in participating in the TTP Registry, or would like to be kept updated, please fill in and return this expression of interest to Dr Louise Phillips.

Postal Address: Department of Epidemiology and Preventive Medicine
 Monash University
 Level 3, Burnet Building
 89 Commercial Road
 Melbourne Victoria 3004

Or fax to: +61 3 9903 0576

We will then contact you to provide further information on enrolling your institution in the registry, including assistance with institutional ethics submission.

PARTICIPANT INFORMATION

Name: _____

Position: _____

Speciality: _____

Institution Name: _____

Preferred Postal Address: _____

State: _____ Postcode: _____

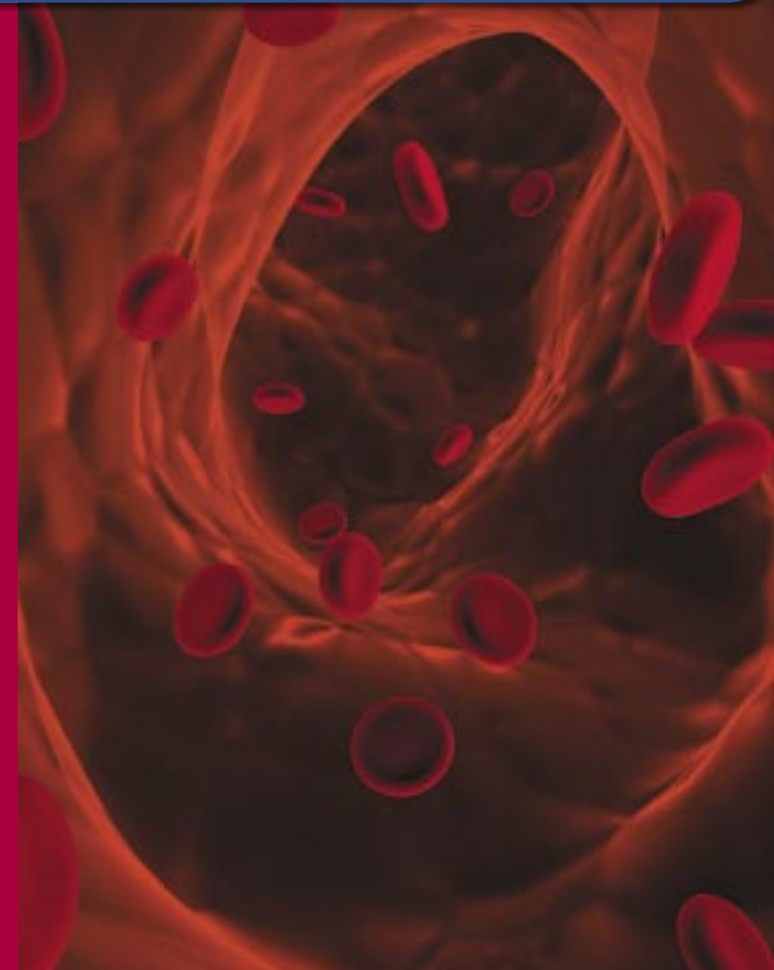
Preferred Email Address: _____

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ABOUT THE TRANSFUSION OUTCOMES RESEARCH COLLABORATIVE

The Transfusion Outcomes Research Collaborative is a partnership between the Australian Red Cross Blood Service and Monash University. The aim of this partnership is to explore blood component usage and patient outcomes following transfusion in Australia, and so enhance the quality of transfusion practice and help improve clinical care.

www.torc.org.au



Thrombotic Thrombocytopenic Purpura (TTP) Registry



BACKGROUND

Currently there is no consensus regarding the incidence of Thrombotic Thrombocytopenic Purpura (TTP) in Australia, its optimal management, clinical outcome, or the impact of complications, nor standardisation of laboratory assessments. Lack of data hampers the design of clinical interventional studies and laboratory testing.

AIMS

The aims of the TTP Registry are to:

- ❖ better define the incidence, natural history and clinical outcome of TTP
- ❖ provide information on the range of therapeutic strategies being employed in the treatment of TTP patients
- ❖ explore factors influencing clinical outcomes
- ❖ better define optimal management of TTP patients
- ❖ inform and inspire future research, and coordinate future national research.

RECRUITMENT AND ENROLMENT

Patients nationally will be identified either by the treating clinician or by ARCBS clinicians as a result of provision of blood products for therapy.

Patient liaison and registration will take place in participating hospitals primarily through the treating clinical team.

DATA COLLECTION

Clinical data will be provided by the treating clinician. Data will be collected via a specifically designed web-based data collection form, recording details of presentation, treatment and outcomes.

An independent Steering Committee will monitor the registry, with membership consisting of stakeholders and clinical experts.

ETHICS

Ethics approval of the Registry has been gained from the Monash University Standing Committee on Ethics in Research involving Humans and the ARCBS Human Research Ethics Committee, and will be sought from the Human Research Ethics Committee of each participating hospital.

Written informed consent will not be obtained from patients prior to inclusion, however patients will be able to “opt-off” the registry by contacting registry staff. This approach is consistent with comparable registries in Australia, and allows collection of valid data from an unbiased sample. The number of patients who choose to “opt-out” is not anticipated to be large.

Data will not be used in a way that will allow individual patients to be identified. The data will be handled by an experienced university research unit with careful attention to privacy and security. Data will be managed in accordance with Commonwealth and State privacy principles.

REPORTING

The Registry will provide reports to participating clinicians and hospitals regarding case accrual and outcomes.

Publication of scientific manuscripts is a high priority for the Registry. These data analyses may include national, state and institutional usage or various clinical areas but will include only collective patient data.

ACCESS

A protocol to facilitate access to researchers will be developed. In general, access to TTP Registry data will be provided to bona fide external researchers with the approval the Steering Committee.

Participants will have access to their own data and are free to use and publish this data independently.

PATIENT INFORMATION

Patients will be informed about the nature of the Registry through a patient brochure provided by the treating clinician. This will provide the names of a contact person at the registry who will be able to answer questions about the nature and purpose of the project. It will also provide the name of a local Ethics Committee contact person who can be contacted by those with particular concerns.

The information brochure will indicate that the Registry will maintain the strictest control over access to the information so as to ensure maximum protection of an individual's privacy. Under no other circumstances would any information be made available to outside parties, or used for other purposes.

PARTICIPATION

If you are interested in participating in the TTP Registry, or would like further information, please either fill in and return the attached expression of interest, or contact one of the project officers:

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Monash University

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