

**TTP is an uncommon illness, and there is a lot we still don't know about its cause – or how best to treat it.**

From July 2008, some key information about all people nationally who are being treated for Thrombotic Thrombocytopenic Purpura (TTP) is being collected by the TTP Registry at the Monash University–Australian Red Cross Blood Service Transfusion Outcomes Research Collaborative.

The purpose of the TTP Registry is to help doctors and nurses provide the best possible care to people with TTP, and assist researchers in understanding the causes of this disease.



### 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.

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### Thrombotic Thrombocytopenic Purpura (TTP) Registry



## WHY IS THIS INFORMATION NEEDED?

The information for the TTP Registry will provide an important resource for people living with TTP, clinicians who treat TTP, and our community.

The TTP Registry will tell us about:

- ❖ the frequency of TTP in our community
- ❖ the causes of TTP and how it may be prevented
- ❖ the usefulness of different treatments for TTP
- ❖ the variety of care provided for people with TTP in our community, and how it compares to best practice internationally.

With this information we will be able to ensure people with TTP in our community continue to receive the best possible care, including the specialised blood products necessary for the treatment of TTP.

We will also be able to assist researchers as they investigate new tests and treatments to help people with TTP in the future.

## WHAT INFORMATION IS COLLECTED?

People being treated for TTP nationally will be referred by their treating clinician.

The information collected will be limited to:

- ❖ your name and age, and your doctor, so we can identify the progress of your treatment over time
- ❖ the circumstances and symptoms leading up to the diagnosis of TTP
- ❖ any other illnesses you may have, or medications you may be taking, which could influence your care
- ❖ the type of treatment you receive, the response of your illness to treatment, and any complications of the illness or treatment.

## SAFEGUARDING YOUR PRIVACY

The TTP Registry has been designed in accordance with the strictest privacy principles, including State and Commonwealth privacy laws, and has been reviewed by independent ethics committees including the committee at your hospital.

The information collected will:

- ❖ comply with all privacy legislation
- ❖ remain confidential and never be released to anyone, except in the very rare case of a court order

- ❖ never be released to insurers or private companies
- ❖ be stored securely, with access restricted only to registry officers, each of whom is committed to maintaining confidentiality
- ❖ never be released in a way which could potentially identify a specific individual – the information provided will only ever be used to compile tabulations and statistics.

## QUESTIONS OR CONCERNS?

If you would like more information, or have any concerns about the privacy of your personal information, or wish to withdraw from the registry, please contact one of the registry officers below, or the secretary of your hospital ethics committee.

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