

Dear Colleague,

As you may be aware, a national Thrombotic Thrombocytopenic Purpura (TTP) registry has been established through the collaboration of the Australian Red Cross Blood Service, Monash University's Department of Epidemiology and Preventive Medicine and interested clinicians.

The aims of the TTP Registry are to more accurately define the incidence and clinical outcomes of TTP; provide information on the range of therapies being employed in its treatment; explore factors influencing outcomes; and to be a catalyst for further research. The Registry opens in October 2008.

Patients with TTP will be registered at participating institutions by treating clinical team, with information regarding presentation, treatment and outcomes reported securely through the internet. The information reported to the Registry is information routinely collected by the clinical team when managing affected patients, so participation involves only minimal increase in workload.

Sharing information will be a high priority for the Registry. Reports will be provided to participating clinicians and hospitals regarding case accrual and outcomes. Collective data analyses will also be provided on a regular basis, and we welcome involvement in registry publications. Participating hospitals will have access to their own data and are free to use and publish this data independently.

We are pleased to invite you and your department to consider participating in the TTP Registry. The enclosed brochure provides more detailed information, and includes a form that allows you to become a participating hospital. Registry staff can provide further information about the project and are happy to take responsibility for obtaining local ethics approval as required. For further enquiries please contact:

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To assist in development of the Registry, we are also undertaking a short anonymous survey regarding diagnosis and management of TTP in Australia. A small educational prize will be offered to one lucky participant. To participate in the survey, please click here <http://www.questionpro.com/akira/TakeSurvey?id=977651>

Yours Sincerely

Dr Solomon Cohney
TTP Registry Steering Committee Chair
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