

5 March, 2012

## **ITP patients to benefit from International Disease Registry**

Research investigators can now take advantage of an integrated disease registry for patients suffering from a blood disease called Immune Thrombocytopaenia (ITP), previously known as Idiopathic Thrombocytopenia Purpura.

ITP is a bleeding disorder in which the immune system destroys the patient's own platelets causing the depletion of platelets (platelets allow blood clot formation and prevent bleeding). Without enough platelets, bleeding can occur which can result in mild bruising to severe and fatal haemorrhage.

The International ITP registry, developed by Professor Beng Chong, Director of Haematology and his team at St George Hospital, is the first of its kind in the world.

According to Professor Chong, (who also chairs the International Registry Steering Committee that manages the registry), the disease registry has garnered interest from more than 45 renowned haematologists from across the Asia-Pacific, Middle Eastern and South American regions, including; Japan, Korea, India, China, Singapore, Turkey, Israel and Brazil.

"ITP is an uncommon condition, with patients presenting to hospitals in small numbers each year," Professor Chong said.

"There is currently a lack of necessary data concerning the epidemiology, diagnosis and treatments of ITP which is needed to improve patient management and healthcare planning. In particular, data is needed for a subgroup of severe ITP patients who are refractory to standard treatments.

"Although we have guidelines for managing ITP patients, physicians still use a range of very different treatments, many of which have serious side effects. Furthermore, the medium and long-term side effects of the new expensive treatments are still unknown.

"This registry will guide doctors to the use of safer and more effective treatments," he said.

Sarah Davidson, Registry Project Manager, said that by creating this unique global registry, clinicians will be able to build a complete picture of ITP and collect real-world data amongst many ethnic groups and across several regions in the world.

"There is increasing evidence that the disease and its response to drug treatments could be very different amongst patients with different ethnic backgrounds," Ms Davidson said.

---

**South Eastern Sydney Local Health District**  
**Media contact: Maxine Brennan 02 9113 2601 or 0413 028 776**

“The registry data will help doctors to tailor their treatment and to adjust the drug dose according to the patient’s ethnicity, which in turn will minimise drug toxicity and improve treatment outcomes.

“This data is particularly important in a country such as Australia which has a population of multiple ethnic backgrounds,” she said.

The registry is open to recruitment at St George Hospital and other sites in the Asia-Pacific and Middle Eastern regions. For enquiries and further information contact Sarah Davidson, Registry Project Manager on 9113 2446.

**South Eastern Sydney Local Health District**

**Media contact: Maxine Brennan 02 9113 2601 or 0413 028 776** *healthdirect* AUSTRALIA – providing expert health advice 24 hours a day to NSW residents – Tel. 1800 022 222