



**ITP FOUNDATION FUNDS THE PARC-ITP STUDY
BEING CONDUCTED BY THE
INTERCONTINENTAL CHILDHOOD ITP STUDY GROUP (ICIS)**

PARC-ITP (Pediatric and Adult Intercontinental Registry of Chronic ITP)

Many important questions concerning causes, development, severity of bleeding, prognosis and management of the bleeding disorder ITP are yet unresolved. Present knowledge is based on opinion rather than on evidence. Therefore, the Intercontinental Childhood ITP Study Group (ICIS) was founded in 1997 to establish an international network of physicians involved in the diagnosis and therapy of children with ITP and to promote research with the goal to reach more evidence-based data regarding the many aspects of ITP. Results from the first ICIS project, a prospective registry for children with newly diagnosed ITP, were published in 2001 and 2003 with data from more than 2000 children (Kühne et al. Lancet 2001: and Kühne et al J. of Pediatrics 2003).

Now ICIS focuses on children with chronic ITP, defined by thrombocytopenia (platelet count $< 150 \times 10^9/L$) for a duration of more than 6 months. There are many aspects of chronic ITP in both children and adults, which are unclear, e.g., pathophysiology, primary and secondary ITP and management. It became evident that there are also many unanswered questions in the management of adults with ITP. Therefore a prospective database of both children and adults with chronic ITP will be established with the goal to recruit as many patients as possible: **Pediatric and Adult Intercontinental Registry of Chronic ITP (PARC-ITP Study)**. The database will serve as the main part of the study with the potential to add subsequent studies as modules, which build the "trees in the park".

The aims of PARC-ITP are (1) to analyse the heterogeneity of ITP, and (2) to find new selection criteria for future studies. Secondary aims are to study the natural history of ITP and to validate the diagnosis. PARC-ITP is a prospective international multi-center registry with follow-up data at the diagnosis of ITP, 6 months later and then every 12 months. Children from the age of 2 months and above and adults with newly diagnosed ITP are eligible. The data collection will be managed by the central data office of ICIS in Basel, Switzerland. An international writing committee is responsible for the protocol, the analyses and the publications in medical journals. The protocol is now ready and approved by the ethical committee in Basel, Switzerland.

The financial commitment of the **ITP FOUNDATION** will provide support for the pediatric part of the PARC-ITP Study and will help to get this important project off the ground.

Many thanks to all of you supporting children with this bleeding disorder.

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