



**Dear ICIS Investigators and interested medical professionals**

ICIS' latest project, the **P**ediatric and **A**dult Intercontinental **R**egistry on **C**hronic ITP (PARC-ITP) was opened last year. Currently, 37 institutions from 19 countries are participating and 190 patients have been enrolled.

**PARC-ITP-what's new? – Amendment for additional, optional participation**

The PARC-ITP study protocol has been amended and approved by the Swiss Ethics Committee in Basel on May 11, 2005. The amendment proposes the anonymized collection of DNA from blood samples of PARC-ITP patients and 'healthy' controls in order to analyze genetic markers, i.e. genome wide single nucleotide polymorphisms (SNPs), and their correlation with data on demographics, severity, management and outcome collected in the current PARC-ITP database. The analyses will be coordinated by PARC-ITP. Foreseen institutions for analyses are NIH, Bethesda, Royal London and Basel.

All changes have been included in the PARC-ITP Study Protocol (Version 2.0, 2005-2-25) which can be downloaded at [www.unibas.ch/itpbasel](http://www.unibas.ch/itpbasel) ([download study protocol](#)).

For more information on the Amendment, please read the attached short summary.

**Important: Blood sampling is voluntary and does not exclude from study participation.**

**What should I do?**

For centers already participating in the PARC-ITP registry: Your efforts to collect blood samples are appreciated. If you are willing to do this, please obtain approval of the amended study protocol (Version 2.0, 2005-2-25) from your local Institutional Review Board/Ethics Committee. For centers that will not collect blood samples there is no need for action and you may continue to submit patient data as usual.

**Procedure and logistics**

Data of ITP patients can be submitted as usual online at [www.parc-itp.net](http://www.parc-itp.net). If blood samples (ITP patients and 'healthy' controls) can be provided, they should be labelled anonymized with UPN number and temporarily stored in batches at your institution. Questionnaires for 'healthy' controls are to be completed by hand and included in the shipment of blood samples. **Shipping on dry ice will be arranged by ICIS, and shipping costs are covered.**

**New investigators**

If you would like to become a PARC-ITP investigator, please sign up by filling in the attached form.

**Next ICIS Meeting in Locarno, Switzerland 2006**

We kindly invite all members of ICIS to join the ICIS Meeting in Locarno, Switzerland, September 17-19, 2006 (directly preceding the SIOF Meeting in Geneva). ICIS will cover your stay in a nice resort in the southern part of Switzerland. For travelling to Switzerland you should find a sponsor in your country. Locarno is easily accessible from Zurich Airport by train or car. **Please let us know of your tentative participation by returning this email with your name and institution.**

Thank you for your support, it is exciting to work together with the many centers and we look forward to cooperating in the future. Please let us know if you need assistance or have questions ([info@parc-itp.net](mailto:info@parc-itp.net)).

Yours sincerely

Paul Imbach, Chairperson  
Thomas Kühne, Chairperson  
Johannes Rischewski, Scientific secretary  
Juliette Fong, Biologist  
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