## International PSC Study Group (IPSCSG) Annual report

In June 2010, a total of 45 active PSC researchers from Norway, Sweden, Finland, Germany, Switzerland, Austria, Italy, Spain, France, Belgium, the Netherlands, UK, Ireland, US and Canada met in Oslo and established the International PSC Study Group (IPSCGS). Entering 2015, the group includes researchers from 21 countries and more than 55 different institutions.

## MEMBERS OF THE STEERING COMMITTEE

Prof. Ulrich H. Beuers, Amsterdam, the Netherlands Dr. Luca Fabris, Padua, Italy Prof. Martti Färkkilä, Helsinki, Finland Dr. Chris Bowlus, Sacramento, USA Prof. Olivier Chazouilleres, Paris, France Dr. Gideon Hirschfield, Birmingham, UK Prof. Tom Hemming Karlsen, Oslo, Norway (coordinator/secretary)

Representation in IPSCSG is based on active participation in at least one ongoing study and meetings are held biannually during the International Liver Congress™ (ILC) organized by the European Association for the Study of the Liver (EASL) and the annual meeting of the American Association for the Study of Liver Diseases (AASLD).

During 2014, the group met for their bi-annual meetings, first in London during the ILC April 12<sup>th</sup> and then in Boston during AASLD November 9<sup>th</sup>. During the ILC, an official EASL-IPSCSG joint workshop was also held and attracted a full auditorium on cholangiocyte biology and biliary disease, genetics of PSC and IBD, gut microbiota and bile acid homestasid and finally, discussions on implications for patients from basic research.

In June, the third biennial IPSCSG meeting was held in Amsterdam, hosted by Prof. Ulrich Beuers and Prof. Cyriel Ponsioen. The program contained a number of invited lectures to stimulate discussion. The working group breakout sessions on 6 different subjects were essential for the success of the workshop. These sessions was introduced by a 10 min. overview of one of the chair persons on the actual state of discussion and the actual needs.

In addition to this, a workshop was held during the ECCO meeting in Copenhagen in March, to increase awareness of PSC among gastroenterologists.

## DURING 2014 THE GROUP MADE PROGRESS ON SEVERAL TOPICS:

 Collection of clinical data from 7,500 PSC patients for a clinical descriptive review completed (first results were presented at opening plenary session at the ILC in London 2014)

- Multicenter study initiated to evaluate the utility of Fibroscan in determining disease progression in PSC led by Olivier Chazoillieres
- Establishing of the prospective biobanking of PSC patients led by Gideon Hirschfield and Mette Vesterhus
- Contributions to the pruritus GWAS led by George Mells
- Contributions to the US/UK GWAS meta-analysis led by Kostas Lazaridis, Carl Anderson and Tom H. Karlsen
- Contributions to Immunochip supbphenotype project led by Cyriel Ponsioen
- Contributions to Immunochip cross-phenotype project led by Andre Franke and David Ellinghaus
- Participation in clinical trials (e.g. Dilstent2, nor-ursodeoxycholic acid)
- Establishing of a consensus document for phenotyping in mouse models of PSC (published in Journal of Hepatology)

## **PLANNED MEETINGS IN 2015:**

During the ILC in Vienna in April IPSCSG has again been offered by EASL to hold the biannual meeting within the venue of the ILC, and the meeting will take place April 25<sup>th</sup>. The group will then celebrate their first 5 years with a cake. Again, a workshop has been set up within the official ILC meeting, covering topics from prognostic models and clinical trial end-points, regulatory aspects of clinical trials and the presence of specific PSC biomarker profile. The group will also meet in San Francisco in November during AASLD for the autumn biannual meeting.

