

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 (IPSCSG). Entering 2016 the network consists of renowned scientists and clinicians from more than 57 different institutions in 22 countries working with autoimmune liver diseases.



Representation in the network is based on active participation in at least one ongoing study, but intentionally kept low, informal- and interest-driven. Every second year, a two-day meeting is hosted by one of the participating institutions, in 2012 in Hamburg, and in 2014 in Amsterdam. Two hour update meetings are held twice a year 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).

In 2015 the first meeting took place in conjunction with the EASL International Liver Congress in

Vienna on April 25th where the 5th anniversary of this international, team-based and cutting-edge cooperation was celebrated. In addition to the project updates, a key point for this meeting was to bring the group closer to joint grant applications within major funding bodies like the EU/Horizon2020 and NIH. One step in this direction is the leadership role taken within the autoimmune liver disease arena (IPSCSG included) to enter into an application of a “European Reference Network” for rare liver diseases. Whilst a clinical initiative, a platform of an EU accredited clinical network is also anticipated to be important when reaching out for research funding (e.g. within Horizon 2020).

The second meeting was organized in connection with the AASLD Liver Meeting in San Francisco on November 15th. The update meeting was concerned with the completion of several major undertakings in the international PSC study group, for which papers are expected to appear in 2015. These include the genome-wide association study meta-analysis (almost 5,000 patients), the Immunochip cross-disease analysis (including more than 85,000 individuals and in addition to PSC patients with inflammatory bowel disease, psoriasis and ankylosing spondylitis), the clinical database paper with clinical data from more than 7,000 patients, the cholangiocarcinoma sequencing project, and the Immunochip sub-

phenotype paper (more than 3,000 patients). Furthermore, several clinical biomarker and intervention studies are underway, including the IPSCSG anchored FICUS study (elastography, Olivier Chazouilleres) and DILSTENT2 study (endoscopic therapy, Cyriel Ponsioen).

Both meetings attracted a full auditorium and the group has all reason to be proud of its achievements and most valuable work and collaboration. Planning is now ongoing for the 4th biennial meeting in New Haven, for which Yale holds the organizing responsibilities. Further details on projects and updated meeting details can be found at www.ipscsg.org.

The IPSCSG Delphi consensus process on clinical endpoints

A key deliverable of the IPSCSG in 2015 was the publishing of the Delphi consensus process on endpoints in clinical trials in PSC in Hepatology (see facsimile). The process resulted in the furthering of the topic by the American Association for Liver Diseases (AASLD) by the joint organizing of a workshop together with the FDA in Maryland in March of 2016. There are now many ongoing clinical trials in PSC, targeting a broad range of potentially relevant targets (ranging from novel bile acid derivatives, immune-targeted therapeutics, antibiotics and antifibrotics). To be able to compare the results of all these trials, robust endpoints and the consensus initiative is sorely needed.

MEMBERS OF THE STEERING COMMITTEE

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

PLANNED MEETINGS IN 2016:

Barcelona in April 14th
 New Haven in June 26th – 27th
 Boston in November

INTERNATIONAL PSC STUDY GROUP NETWORK

Australia	Poland
Austria	Spain
Belgium	Switzerland
Canada	Sweden
Denmark	The Netherlands
Finland	UK
France	US
Germany	
Greece	More
Ireland	information on:
Iceland	www.ipscsg.org
Israel	
Italy	
Japan	
Norway	

International PSC Study Group Network

