International PSC Study Group (IPSCSG) Annual report

In Oslo June 2010 a total of 45 active PSC researchers from Norway, Sweden, Finland, Germany, Switzerland, Austria, Italy, Spain, France, Belgium, the Netherlands, the UK, Ireland, the US and Canada met and established the International PSC Study Group (IPSCGS, www.ipscsq.org, password required).

MEMBERS OF THE STEERING COMMITTEE

Prof. Michael Manns, Hannover, Germany

Prof. Keith Lindor, Rochester, MN, US *

Prof. Konstantinos Lazaridis, Rochester, MN, US *

Prof. Peter Jansen, Amsterdam, The Netherlands

Prof. Michael Trauner, Vienna, Austria

Prof. Roger Chapman, Oxford, UK

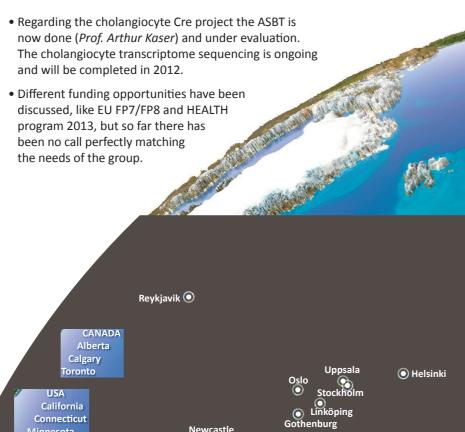
Dr. Tom Hemming Karlsen, Oslo, Norway (coordinator/secretary)

* Prof. Keith Lindor was replaced in November 2011 by Prof. Konstantinos Lazaridis, Rochester, MN, US.

Representation in IPSCSG is based on active participation in ongoing studies and meetings are held biannually at the International Liver Congress[™] by the European Association for the Study of the Liver (EASL) and the American Association for the Study of Liver Diseases (AASLD) annual conferences. During 2011 the group first met in Berlin during the International Liver Congress[™] March 30th and then in San Francisco during AASLD November 7th.

DURING 2011 THE GROUP HAS MADE PROGRESS ON SEVERAL TOPICS:

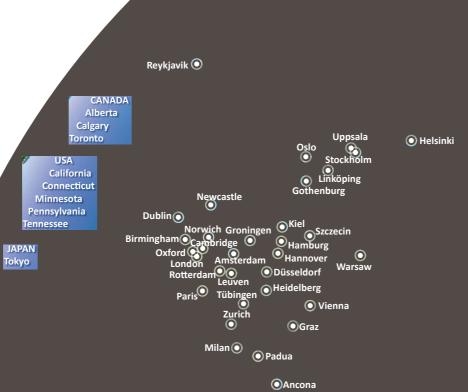
- In the Immunochip project a preliminary analysis was presented and the further strategy was discussed. Working groups for each individual subproject with a specified leader was proposed.
- The IPSCSG database format was sent to all study groups in April, and most groups have now modified their database according to the final IPSCSG format. A summary article on the total IPSCSG study population of 4,500-5,000 PSC patients is in the planning. In the Dilstent2 project the first patients have been included.
- Questionnaires were completed in the "itching" (cholestatic pruritus) genetics project, and answers from parts of the UK and Canadian PBC and German and Norwegian PSC populations are presently available and analysis presently being performed.



PLANNED MEETINGS IN 2012:

During the International Liver Meeting[™] in Barcelona Friday April 20th, in Hamburg 11th-12th for the second focus group meeting and during the AASLD in Boston in November.







INTERNATIONAL PSC STUDY GROUP NETWORK

COUNTRY, CITY INSTITUTION

Austria

Medical University of Graz Graz Vienna Medical University of Vienna

Belgium, Leuven University Hospital Gasthuisberg

Canada

Alberta University of Alberta

Health Research and Innov. Centre/Univ. of Calgary Calgary Toronto Toronto Western Hospital/University of Toronto

Finland, Helsinki Helsinki University Central Hospital

Université Pierre et Marie Curie France, Paris

Germany

University Medical Center Düsseldorf Düsseldorf University Medical Center Hamburg-Eppendorf Hamburg

Hannover Hannover Medical School

Heidelberg University Hospital of Heidelberg Christian-Albrechts-University of Kiel Tübingen University Hospital of Tübingen

Ireland, Dublin St. Vincent's University Hospital

Iceland, Reykjavik The National University Hospital of Iceland

Italy

Ancona Università Politecnica delle Marche Rozzano (Milan) **IRCCS Istituto Clinico Humanitas**

Padua

Japan, Tokyo Teikyo University School of Medicine

Oslo University Hospital/University of Oslo Norway, Oslo

University of Padua

Poland

Pomeranian Medical University Szczecin

Warsaw Maria Skłodowska-Curie Memorial Cancer Center

Spain, Barcelona Hospital Clínic i Provincial Switzerland, Zurich University Hospital Zurich

Sweden

Stockholm Karolinska University Hospital Uppsala Uppsala University Hospital Gothenburg Sahlgrenska University Hospital University of Linköping Linköping

The Netherlands

Rotterdam

Amsterdam Groningen

Academic Medical Center/University of Amsterdam University Medical Center Groningen

Erasmus University Medical Centre

UK

Birmingham University of Birmingham Cambridge London

Addenbrooke's Hosp./The Wellcome Trust Sanger Inst. Univ. Col. London/Royal Free Hosp./Imp. Col. Hosp.

Newcastle **Newcastle University**

Norfolk and Norwich University Hospital Norwich

John Radcliffe Hospital

Oxford

California University of California Davis Medical Center Connecticut Yale University

Mayo Clinic College of Medicine Minnesota Pennsylvania University of Pennsylvania Memphis Medical Center Tennessee