

Minutes IPSCSG Meeting Vienna Saturday April 13, 2019; 10-12am.

Chairs: Annika Bergquist, Peter Fickert

1. Minutes

Ulrich Beuers refers to the online minutes and slides of the IPSCSG Meeting in San Francisco November 2018.

There are no comments or objections, so the minutes are accepted as such.

2. News from the working groups

- **Malignancies:**
Cyriel Ponsioen presents two slides on behalf of Luca Fabris and Jesus Banales regarding a validation study of diagnostic serum biomarkers from extracellular vesicles and a further characterization of a PSC/CCA animal model using MDR2-/- TAA model. For both project additional collaborators are invited to contact Jesus or Luca.
- **Organoids and biobanking:**
Mario Strazzabosco proposes that various labs who work on animal models should liaise to see if they can exchange SOPs etc. in order to standardize methodology.
- **Imaging:**
Christoph Schramm refers to the recent Hepatology paper on collaborative MRI research in PSC. Christoph and Annika Bergquist announce the next working group in Stockholm. The focus will be on : 1. Use of contrast in MRI for PSC and 2. Definition of strictures using MRI, and short updates of ongoing projects
Peter Fickert asks if there is an initiative on MRC+ from Perspectum pre- and post ERCP. Annika will put it on the agenda.
- **Clinical trial design:**
Gideon Hirschfield explains that the definition paper is now in its writing phase. There is still some discussion on the definition of dominant strictures. Cyriel Ponsioen mentions that Christian Rupp did a fine survey on DSs and will report later on in the meeting. Probably, a sub-Delphi consensus process with a number of expert intervention endoscopists will be necessary to arrive at some form of consensus.
Ulrich Beuers mentions that EASL has appointed Olivier Chazouillères to lead a CGP in PSC. This process would greatly benefit from input from the definition paper panel. Some discussion is raised that the DS discussion is relevant for the MRI working group, so attendance from the definition paper people is welcomed in Stockholm in October.
Gideon mentions the meta-analysis initiative. Asked by Cyriel Gideon is OK to share the protocol with the SC.
- **Natural history and biomarkers WG:**
Olivier presents an update on the FICUS project. He aims to produce an abstract on the 2 years data for AASLD.
He invites members to submit proposals for use of the DB and biobank.
Chantal Housset comments that a QC of storage conditions should be done.

Peter warns that kidney function over time should be recorded as a confounder.

Chris Bowlus mentions that it may be wise to save the biobanking material until 5-years data will become available.

Cyriel gives an update on the EASL sponsored IPSCR. By the end of 2019 >1000 subjects will be included in the Netherlands and Sweden, Helsinki and Norway will have started to enroll subjects. Automated input of PROMs is currently operational in the Netherlands from 323 subjects and from 37 subjects in Stockholm and growing.

Chris presents slides on the US based Consortium of Autoimmune Liver Diseases (CALiD). As of March 2019, 547 records have been generated, also including pediatric liver disease. For the future there is a wish for PROMs. Challenge will be to keep the momentum now that repeated data after 1 year should be entered.

Mette Vesterhus makes a plea for revitalising regular TCs on DB structures within the WG.

Chris comments on the issue of privacy and sending data across the Atlantic, which was discussed in San Francisco, but not solved yet.

Annika comments on the new GDPR guidelines, which mandate that we need to update the DB structure and regulations.

Christian Strassburg presents an update on behalf of Tobias Weismüller on the retrospective database projects. He gives an overview of the 12 studies going on. Christian makes a plea to maintain one main DB, not fragmented.

Christoph gives an account of the status of the ERN initiative: all rare liver diseases are included. He stresses that it only recruits new diagnoses.

Cyriel asks if there are several separate but identical DBs such as in the IPSCR structure or one main DB. The ERN has one main DB soon to be stored in Amsterdam.

3. Working group structure

Ulrich poses some slightly provocative statements on the functioning of the animal models WG and the Clinical Trial Design WG. The nature and functioning of the WG structure should be reevaluated at the next Biennial Meeting in London in June 2020.

Palak Trivedi presents a proposal for a new WG on liver transplantation, which is well received.

4. Other

Christian Rupp presents results of an online survey regarding dominant strictures. This will be evaluated in more detail and probably as mentioned earlier be followed by a subsequent Delphi consensus among expert endoscopists in order to reach more specified consensus.

Piotr Milkiewicz presents results of an online survey on AIH/PSC overlap, showing that there is much heterogeneity in diagnostics and management.

Doug Thorburn announces the next Biennial IPSCSG Meeting, which will take place in London on June 15-16. The CCA meeting in Edinburgh will conveniently follow two days later.