

Minutes online IPSCSG biannual meeting 9 December 2021.

Chair: Cyriel Ponsioen

Attendees: 35.

Agenda:

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| 1. Minutes meeting June 2021 | Cyriel Ponsioen |
| 2. News and proposals from the Working Groups: | |
| ○ <i>Natural History, Biomarkers, Clinical Trial Design</i> | |
| ▪ <i>PROMs development</i> | Ruth-Anne Pai |
| ▪ <i>FICUS update</i> | Cyriel on behalf of Olivier Chazouillères |
| ▪ <i>IPSCR update</i> | Cyriel Ponsioen |
| ▪ <i>CALiD update</i> | Cyriel on behalf of Chris/Cynthia |
| ▪ <i>retrospective DB: current projects</i> | Tobias Weismüller |
| ▪ <i>Pilot gluten free diet in PSC</i> | Timur Liwinski |
| ▪ <i>ERCP in PSC</i> | Cyriel on behalf of Joshi Deepak |
| ▪ <i>maternal outcome in PSC</i> | Cyriel on behalf of Jeremy Nayagam |
| ○ <i>CCA update</i> | Luca Fabris/Jesus Banales |
| ○ <i>Liver Transplantation</i> | Aliya Gulamhusein (?) |
| ○ <i>MRI</i> | |
| ▪ Report on workshop October 2021 | Kristina Ringe |
| 3. Rotations | Ulrich Beuers |
| 4. 6 th Biennial IPSCSG Meeting London | Doug Thorburn |
| 5. Other | Cyriel Ponsioen |

Ad 1:

The minutes from the June 2021 meeting were arrested without comments.

Ad 2:

Natural History, Biomarkers, and Clinical Trials Working group:

Ruth-Anne Pai from PSC Partners for Cure US and Canada presented a >\$4 million program to develop PROMs and a proper natural history suited as virtual control group for confirmatory trials. Connection with members from IPSCSG has been established because we share the same goals and have the expertise.

Cyriel presented a slide set from Olivier Chazouillères on the FICUS project. Not much progress has been made since June. Important is that all collaborating centers complete their 5-years FU including biomaterial sampling.

Cyriel presented a brief update on the IPSRCR. There are now 3033 patients in the retrospective part in the four collaborating centers, of which 767 patients are being followed prospectively.

Cyriel presented some slides on behalf of Chris Bowlus and Cynthia Levy on CALiD. There are as of 5 December 2021 1190 PSC patients in the registry in 21 centers.

Tobias Weismüller presented an update on the IPSCSG retrospective DB. There are now 12649 patients in the retrospective DB.

Soon a new manuscript on the Impact of Geographical Region and varying Patient Management Strategies on Transplant-free Survival and Malignancy Risk in Primary Sclerosing Cholangitis will be circulated with some remarkable results.

A manuscript containing data on surveillance strategies in 2979 patients led by Annika Bergquist has been submitted.

Statistical analysis on 2893 patients with dominant strictures led by Christian Rupp is ongoing.

Analysis on 359 cholangiocarcinoma cases in PSC patients with regard to management and outcome is ongoing.

Timur Liwinski presented data of a pilot gluten free diet in PSC patients, which warrants further study.

Cyriel mentioned on behalf of Joshi Deepak the *ERCP in PSC project* which is still in statu nascendi.

On behalf of Shanika Nayagam Cyriel presented a slide on the maternal outcomes of pregnancy in PSC project which is running well and will close data submission on January 31st, 2022.

CCA Working Group:

Luca Fabris presented on behalf of the CCA WG on 3 topics:

The European CCA network now spans 33 centres in 13 European countries. In South America there are 10 centers in 5 countries.

An update on the Novel protein biomarkers in serum extracellular vesicles for the diagnosis of cholangiocarcinoma (CCA) in patients with PSC project was presented. The manuscript is being drafted.

The Metabolomic-based prediction of prognosis in patients with PSC and early diagnosis of cholangiocarcinoma: new non-invasive strategy is now in its validation phase.

Work on an animal model of PSC-CCA is still in progress.

Liver Transplantation Working Group:

No data presented.

MRI Working Group:

Kristina Ringe presented a report on the online MRI WG meeting held in October 2021.

Several topics were discussed among which:

- Deep learning for PSC (Fabian Westhäusser, Hamburg)
- MRI diagnosis of relevant strictures in PSC (Sarah Pötter-Lang, Vienna)
- Dominant stricture – time for multicenter study? (Mathias Thylin, Helsinki)
- Opportunities for collaboration between ERCP and MRI (Joshi Deepak, London)

The MRI WG is the only working group that makes proper use of the home page to list and announce its research activities. Cyriel comments that all Working Groups should do so.

Next MRI WG meeting during Fall 2022 organised by Mette Vesterhus.

Ad 3.

Rotations.

Ulrich repeats the decision from the Steering Committee that rotations will be deferred until the Biennial meeting in London in June 2022. Candidacies can be announced during the Biannual meeting in April 2022 also in London.

Ad 4.

6th Biennial IPSCSG meeting London. Doug Thorburn is not in the meeting to comment. Cyriel mentions that the preferred date is June 20-21, 2022, with 13-14 June as an alternative. Doug is busy trying to secure a venue and hotel. When the date is fixed this will be circulated ASAP.

Ad 5.

Other. No other comments/questions from the attendees.

Adjourn.

Next meeting during ILC2022, hopefully in person in April 2022.

12 December 2021

Cyriel Ponsioen