

Minutes IPSCSG biannual meeting Boston November 10th, 2019.

Chairs: Chantal Housset, Chris Bowlus.

Agenda:

Minutes meeting Vienna April 2019	chairs
Report on Steering Committee Meeting September 2019	Ulrich/Cyriel
Format WGs	
Uniform DTA/MTA feasibility	
Questionnaire biobanking SOPs	
Retrospective DB centralization	
Update surrogate endpoints paper	
Expert panel function in ERN	Christoph
Draft programme 6 th biennial meeting June 2020 London	Doug
Young investigator's session	Doug
News from the Working Groups:	
MRI meeting Stockholm Oct 2019	Christoph
CCA	Luca
Natural History & Biomarkers	
FICUS	Olivier
IPSCR	Cyriel
CALiD	Chris
Retrospective DB: current projects	Tobias
Ancient genomes in PSC	Alessio Gerussi
Clinical trial design	David
Animal Models	?
Transplantation:	
recurrence project	Aliya
UDCA post-transplant	Cyriel
GWAS CCA in PSC initiative from Mayo	Lewis Roberts
Young PSC Researcher Prize announcement	Tom
Other	chairs

Minutes:

The minutes from the Vienna April 2019 meeting were accepted as is.

Ulrich presented a summary of what was discussed during the Steering Committee (SC) meeting with regard to the functioning of the working groups. The SC recommends rotation of the chairs of the working groups every 4 years, such that every 2 years one of the chairs is changed. The SC recommends to merge the Natural History 7 biomarkers WG with the Clinical trial Design WG. Cyriel has contacted the chairs of the latter WG, David Assis and Gideon Hirschfield, and they agreed. The animal models WG seems rather inactive, and it is proposed to reevaluate its functioning next April during the London meeting and then decide to keep or disband. Ulrich has contacted Jesus Banales to inquire if there is any

conflict of interest between the CCA WG and the European CCA Initiative, which is not the case.

Cyriel proposes a suggestion on trying to design universal MTA/DTA/DPIA forms that may be applicable to many studies. This seems a rather far shot, but may be tried within the 4 countries joined in the IPSCR registry.

The SC discussed to circulate a questionnaire concerning the various SOPs for biobanking that are in use among IPSCSG members in order to come to a minimal universal SOP. This will be circulated before the London meeting.

Cyriel mentions there is concern within the SC with regard to potential initiatives to develop new retrospective DB hubs next to the central retrospective DB. It is expressed that the SC is of the opinion that there should be one retrospective DB with the acknowledged CBMC according to the Memorandum of Understanding that has been endorsed by the group in San Francisco in 2018.

Ulrich mentions that the definitions paper is two-thirds done. The SC suggested an update of the IPSCSG paper on surrogate endpoints. Cyriel mentions that it might be a bit too early in view of the currently emerging data on this topic.

Christoph presents a brief overview of how to use the ERN platform for international expert opinion on difficult cases. A guideline how to access this will be placed on the website.

Doug presents a draft programme of the 6th biennial meeting on 15-16 June 2020 in London. It is suggested by the SC to incorporate a young investigator's session.

News from the WGs is presented.

Christoph reports a very successful MRI meeting in Stockholm. Next meeting will be in Oslo in Fall 2020.

Luca presents 3 projects running within the CCA WG. He invites other centers to collaborate if they wish. Details and contacts will be posted on the website.

Olivier presents an update on the FICUS project. Contributors are urged to complete data input. There are still 2 years to go. Mining the DB may for some sub-studies already commence.

Cyriel presents an update on the IPSCR. Initiation in Stockholm has been done, Helsinki and Oslo will follow shortly.

Chris presents an update on CALiD. The number of centers is still growing. FU is so far limited to 1 year.

Tobias presents an overview of the 12 retrospective projects that are currently running through the CDMC. Data input for the top four will probably be completed by the end of the year. Feasibility of completing or truncating the other 8 projects will be decided early 2020.

Alessio Gerussi presents an initiative on paleogenomics involving Neanderthaler ancestry. This is well received. He will send out an invitation for participation.

David Assis briefly mentions what is going on in the PSC Forum.