

Minutes from the Autoinflammatory group meeting

Thursday 24 September 2020 (11:15 -12:45)

Members of the core team

- **Chair:** Véronique Hentgen vhentgen@ch-versailles.fr
- **Secretary:** Federici Silvia silvia.federici@opbg.net
- **Educational affairs:** Roberta Caorsi robertacaorsi@gaslini.org
- **Research affairs:** Jürgen BRUNNER juergen.brunner@tirol-kliniken.at
- **EMERGE representatives :** Sónia Melo Gomes sonia.melo.gomes@gmail.com and Ummusen Kaya ummusenkaya@gmail.com
- **Patient representative :** Saskya Angevare saskyaa@hotmail.com

Presentation of the main research projects of the WP

Registries in AID

1/ The main project of the WP is led by the Münster team (Dirk Föll, Helmut Wittowski): **Fostering patient registries as platforms for future epidemiological, clinical and translational research**. The main aim of this project is to develop a collaborative research project on different existing patient registries within the PReS working party on AID. To test the hypothesis, that such a joint project is possible, 3 databases will be used: EUROFEVER, AIDnet and JIRcohort. The idea is to develop common research questions that will be separately addressed in every participating registry. Results of the research questions will then be shared between the different project partners and comparative analyses will be carried out centrally. Results including the patients of all 3 databases will be presented jointly.

To carry out this project a young investigator might be employed for a period of 6 months. Funding for such a person is already partially acquired by the Münster team, but additional funding is needed so that this young investigator can spend 2 months in each register coordinating team (Münster, Lausanne and Genoa).

2/ Riccardo Papa presented **the MERITA project**, a registry developed in the ERN RITA, for patients with AID. This register will essentially be used to collect a minimal data set, in order to better understand the epidemiology and location of patients with MAI for possible future studies.

Marco Gattorno insisted on the fact that each member can keep the choice of the registry in which they participate. The different registers are not in competition, but complementary. The effort today

is to make common use of the data stored in the different registries without creating new ones and without forcing participants to give up their preferred one.

Presentation of 3 collaborative projects about quality of life and impact of AID in patients

Isabelle Koné-Paut (Paris) presented the follow-up of the project on the development of a new tool measuring the **quality of life in recurrent fever syndromes**. Mariana Marques a young investigator from the Boston team presented her project about the **validation of the AIDAI score in PFAPA children**, whereas Roberta Caorsi (Genoa) gave us a follow-up of the development of a short **composite activity score** for patients with recurrent fever syndromes.

Welcome of new members in the Core team of the WP

We are very happy to welcome 3 new members to our core team of the WP:

Saskya Angevare as a patient representative presented us the way patients and their representatives could be better integrated in research projects dealing with AID.

Sónia Melo Gomes and **Ummusen Kaya** joined us as EMERGE members.

Due to a lack of time, projects concerning educational affairs could not be presented.

Nevertheless, these projects are being pursued and will be presented to PReS members during the year:

- Link to existing educational programs in which members of the AID WP have participated (ie : JIR winter <https://www.jircohort.org/page-vierge/>)
- Resumption of the idea of disseminating teaching cases via the PReS platform. The practical arrangements will be discussed in the coming weeks with the PReS executive committee.