

UVEITIS WORKING GROUP, Madrid 14 JUNE 2019

Sixteen members attended the meeting.

Charges of the working group have been renewed, according the new three 'PReS pillars':

Chair:

Gabriele Simonini, A. Meyer Children's Hospital, University of Florence, Italy,
gabriele.simonini@unifi.it

- Clinical Care:
Ivan Foeldvari, Hamburger Zentrum für Kinder- und Jugendrheumatologie, An der Schön Klinik Hamburg Eilbek, Germany; foeldvari@t-online.de
- Science and Research:
Amra Adrovic, Cerrahpasa Medical Faculty Istanbul University, Turkey;
amra.adrovic@istanbul.edu.tr
- Training and Education:
Sandrine Lacassagne, Great Ormond Street Hospital, UK;
sandrine.lacassagne@gosh.nhs.uk

Communications:

- **Annual calls for projects from the WPs has been founded by PReS/PRINTO collaboration.**

Funds will consist of 10,000/year (total 30,000) in cash provided by PReS, and of an equivalent amount in manpower for implementation and infrastructure provided by PRINTO. Each PReS/PRINTO grant will be funded for a maximum of 3 years

Proposals will be peer reviewed by members of the PReS Council and members of the Advisory Council of PRINTO.

2019: deadline for submission September 30, 2019

2020: deadline for submission April 30, 2020

Granted projects and updates will be presented at Annual PReS Meeting in a session dedicated to the Research of the WPs

Ongoing Research Projects:

1. **Cross cultural adaptation of the EYEQL:** Ivan Foeldvari updated the group about the progress of the project.
At the moment, 15 countries agreed to the project thus the following languages are going to be validated involving the people at the bottom reported:

Country	Doctor	Email	Contract sent	Signed Contract Received	Received back translation	Reviewed back translation	Comments sent back to site	Received 2 nd back translation
Dutch - Netherlands	Dr. Charlotte van Meerwijk	c.l.i.van.meerwijk@umcg.nl	10/03/18	Received back				
Barcelona	Dr. Jordi Anton	JAnton@sjdhospitalbarcelona.org	10/03/18	12/20/18				
Germany (Hamburg)	Dr. Ivan Foeldvari Nicola Helmus (previous nurse) Jean Bar (current nurse)	foeldvari@t-online.de nicola.helmus@gmx.de jeanbaer@web.de	10/03/18	Received back	03/13/19	04/10/19	04/26/19	05/07/19
Italy (Florence)	Dr. Gabriele Simonini	gabriele.simonini@unifi.it	10/03/18	Received back				
Czech Republic (Prague)	Dr. Hana Malcova	HMalcova@seznam.cz	02/11/19	02/25/19				
Portuguese	Dr. Patricia Costa Reis	pcr.patricia@gmail.com	02/11/19	03/31/19	03/31/19	04/10/19	04/26/19	
Russian	Dr. Mikhail Kostik	kost-mikhail@yandex.ru	02/11/19	04/08/19				
Turkish	Dr. Ozgur Kasapcopur	ozgurkasapcopur@hotmail.com	02/11/19	02/12/19	03/24/19	04/10/19	04/26/19	04/30/19
Hungarian	Dr. Tamas Constantin	tamasconstantin@gmail.com	02/11/19					
Hebrew	Dr. Uziel Sefi	uziely@zahav.net.il	02/11/19	02/27/19				
Dutch	Dr. Joke Boer	jboer@umcutrecht.nl	02/11/19	04/18/19				
Danish	Dr. Susan Nielsen	Susan.Nielsen@regionh.dk	02/11/19	02/28/19				
Slovenian	Dr. Tadej Avcin	tadej.avcin@gmail.com	02/11/19					
French	Dr. Severine Guillaume-Czitrom	severine.guillaume@aphp.fr	02/11/19	03/26/19				
Portuguese (Brazil)	Dr. Simone Appenzeller	appenzellersimone@yahoo.com	04/08/19	05/06/19				
Swedish	Dr. Lillemor Berntson	Lillemor.berntson@telia.com	05/06/19	Mehr anzeigen von Sheila Angeles-Han				

Dead line for forwarding to Sheila the first back translation is November, 30th, 2019.

People who want to be involved in helping and suggesting their own language version are more than welcome, directly contacting the National PI in charge.

Interested people, whom language is not in the list, can directly contact Sheila in order to receive specific indications and the agreement to be signed in order to receive and use the questionnaire.

2. Survey: Tapering biologic and nonbiologic DMARDS in the treatment of JIA-associated uveitis.

The following countries (21) and centres (45) actually filled the survey:

country	total feedback	
Brasil	<div><div></div></div>	3
Canada	<div><div></div></div>	2
France	<div><div></div></div>	1
Germany	<div><div></div></div>	4
Indien	<div><div></div></div>	1
Israel	<div><div></div></div>	1
Italy	<div><div></div></div>	2
Netherland	<div><div></div></div>	3
Nordirland	<div><div></div></div>	1
Norwegen	<div><div></div></div>	1
Sarajevo	<div><div></div></div>	1
Schweden	<div><div></div></div>	1
Schweiz	<div><div></div></div>	1
Serbien	<div><div></div></div>	1
Singapore	<div><div></div></div>	1
Slovenia	<div><div></div></div>	1
Spain	<div><div></div></div>	3
Turkey	<div><div></div></div>	2
UK	<div><div></div></div>	7
Ukraine	<div><div></div></div>	1
USA	<div><div></div></div>	7

People who want to be involved, can ask to Ivan to send it out the survey

- **3. International registry of JIA-Uveitis and Idiopathic uveitis.**

A customized, anonymized, case and password sensitive, web platform using red cap software technology is now available. Data can be entered using Multinational Interdisciplinary Working Group for Uveitis in Childhood studies (MIWGUC) outcome measures, as activity and damage. People interested to surf and start to use the system can mail to Gabriele in order to receive login and specific center access along with instructions.

The group agreed to submit the registry as project for PReS/PRINTO call.

Educational projects:

- Set up an on-line uveitis network for PReS member

It should be a web-space available through PReS web site, limited to PReS members, where the community can share clinical issues such as difficult cases and current treatment plans.

Additionally, an “*educational box*” should be posted in that web-area. It should be a box where, peer-reviewed expert contents (teaching slides, local protocols, milestones papers, etc) can be uploaded and free downloadable for each members.

Decisions from the group:

In order to establish a strict and continuous collaboration with CARRA, the group asked to Sheila Angeles-Han to be his representative for CARRA.

Ideally an Uveitis Committee Collaboration between CARRA and PReS might born.

Report from the Council:

Gabriele, on behalf of the group attended the PReS council and Chair meeting.

The council asked for a new vision and life for the groups:

- To be more interactive and more attractive.
- To include and anyway keep involved in strategies of the working groups ENCA representatives for patients and families
- To promote educational projects
- To keep updated the PReS web-site part of the group and post each yearly minute