



UVEITIS Working Party

of the Pediatric Rheumatology European Society

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UVEITIS WORKING PARTY, e-Congress PRoS 2020, 24 September 2020

The 2020 UVEITIS WP meeting was a fully virtual live meeting during the E-Congress PRoS 2020. According data provided by PCO Integration & Performance Manager and presented during the Working Party 2.0 – Chairs Meeting, **180** members (maximum) attended the web meeting.

Itinerary of the meeting- presented talks:

1. Progress on the cross-cultural adaptation of the EYEQL – Sheila Angeles-Han (USA)
2. Current evidence of Anti-TNF α treatment in childhood chronic uveitis: evidence from a recent Systemic Review and Metanalysis. Ilaria Maccora (Italy)
4. Report and Progress from the MIWGUC group. Ivan Foeldvari (Germany)
5. Guidelines and educational materials for Childhood Chronic Uveitis. Sandrine Lacassagne (UK)

Ongoing Research Projects:

1. Cross cultural adaptation of the EYEQL

Sheila Angeles-Han, currently acting as CARRA representative for our WP, updated the group about the progress of the project.

He is ongoing the QUIET Multicenter international validation studies, aiming to:

- Validate JIA-uveitis outcome measures (MIWGUC protocol)
 - Measures of disease activity, severity and damage
 - Prospective cohort of JIA-U
- Administer the EYE-Q as an outcome measure

Currently, this is the status for the cross-cultural adaption EYE-Q study

Languages	Collaborator	Signed Contract	Received 1 st back translation	Received 2 nd back translation
German	Dr. Ivan Foeldvari	x	x	x
Italian	Dr. Gabriele Simonini	x	x	x
Czech	Dr. Hana Malcova	x	x	x
Portuguese	Dr. Patricia Costa Reis	x	x	x
Turkish	Dr. Ozgur Kasapcopur	x	x	x
Dutch	Dr. Joke Boer	x	x	x
French	Dr. Severine Guillaume-Czitrom	x	x	x
Portuguese (Brazil)	Dr. Simone Appenzeller	x		
Dutch- Netherlands	Dr. Charlotte van Meerwijk	x		
Spanish	Dr. Jordi Anton	x		
Russian	Dr. Mikhail Kostik	x		
Hebrew	Dr. Uziel Sefi	x		
Danish	Dr. Susan Nielsen	x		
Hungarian	Dr. Tamas Constantin			
Slovenian	Dr. Tadej Avcin			
Swedish	Dr. Lillemor Berntson			

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.

21 countries and 45 centres actually filled the survey.

We surveyed via email international pediatric rheumatologists:

1. Multinational Interdisciplinary Working Group for Uveitis in Childhood (MIWGUC),
2. Pediatric Rheumatologic Email-Listserve,
3. CARRA uveitis workgroup,

Survey questions focused on the definition of remission, duration of remission prior to initiation of medication tapering, and method of tapering

Tapering practices were described for MTX, Adalimumab, Infliximab, Tocilizumab, Abatacept.

Educational projects

Sandrine Lacassagne(GOSH-UK) had a talk regarding education and training pillar.

She presented Educational materials for patients and families (English language). That material can be downloaded to the following links:

Disease education:

- https://m.youtube.com/watch?v=1vBzqS_HD_E

Treatment education:

- https://youtu.be/u1GNgfiBR_A

Sandrine will be in charge to deliver a Monkey survey about this topic to the participants of the group, aimed to plan by PReS 2021

Severine GUILLAUME-CZITROM (Hôpital Bicêtre, FRANCE) brought to the attention of the group a book, in French, dedicated to this purpose, as additional tool to spread information and education for patients and families.

LES Uveites en 100 questions.

<http://www.inflamoeil.org/l-inflammation/litterature/article/les-uveites-en-100-questions>

Patient/Parent representative

Miss Wendy Costello, ENCA President, ICAN chair (Ireland, icanireland@gmail.com), joined the meeting. She presented herself and her willingness to actively participate into the “life” of the group. Herself or one of her delegates will join our WP permanently.

Report from the Working Party 2.0 – Chairs Meeting

Record attendance at the PReS 2020 e-Congress for all the WP's. There was a general favor in maintaining a hybrid approach. Although the face-to-face is still very important, the virtual meeting allowed broader geographical reach, more engagement from some parties as well as more inclusive meetings

There was an agreement in replication of the integration of the Working Party meetings into the main congress schedule, thus reducing the clashes between meetings.

There was a propose that clinical cases and presentations can be uploaded to the website in the Working party section to be used for education (see Vaccination WP section on the website)

There is no chance to be a WP member if you are NOT a member of PReS.

There was a propose that each WP should prepare an online advanced course in the topic they cover. This could be available for a nominal fee through the website aim to generate resources for more PReS projects dedicated to the WPs

PReS/PRINTO research grant

Annual call 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.

2020: deadline for submission December, 2020. Detailed info will be available on PReS and PRINTO

