

Working Party 2.0 – Chairs Meeting

Friday, 9 October 2020

16:00 – 17:00 CEST (Zoom)

Attendees :

Jelena	Vojinovic	Secretary - Imaging working party / PReS Treasurer
Liza	McCann	Chair - Juvenile dermatomyositis (JDM) working party
Sylvia	Kamphuis	Chair - Lupus working party
Sezgin	Sahin	Secretary - Lupus working party
Claudia	Bracaglia	Chair - Macrophage Activation Syndrome (MAS) working party
Francesca	Minoia	Secretary - Macrophage Activation Syndrome (MAS) working party
Ozgur	Kasapcopur	Secretary - Juvenile Scleroderma working party
Gabriele	Simonini	Chair - Uveitis working party
Marija	Jelusic	Chair - Vasculitis working party
Veronique	Hentgen	Chair - Autoinflammatory Working Party
Natasa	Toplak	Chair - Vaccinations Working Party
Sefi	Uziel	Secretary - Vaccinations Working Party / PReS Chair, Clinical Affairs Committee
Fabrizio	De Benedetti	PReS Chair, Research Committee
Jeannette	Cappon	PReS Health Professionals Representative
Athimalaipet	Ramanan (Ram)	PReS Working Party 2.0 Council Liaison
Wendy	Costello	PReS ENCA Representative

Apologies:

Despina Eleftheriou
Silvia Magni Manzoni

16 :00 – 16 :05 Welcome & introduction

All meeting attendees briefly introduced themselves and indicated the Working Party they are involved in / or their role on the PReS Exec/Council.

16 :05 – 16 :20 Updates from PReS 2020 e-Congress and feedback from WP's (scheduling, format, engagement, outcomes etc)

PReS Working Party 2.0 attendance at PReS Congress 2020:

Working_Party_Name	Attendance at PReS 2020 (max)
Imaging	130
Juvenile dermatomyositis (JDM)	189
Lupus working party (JSLE)	240
Macrophage Activation Syndrome (MAS)	208
Juvenile Scleroderma	145
Uveitis	180
Vasculitis	203
Autoinflammatory	308
Vaccinations	201

It was requested that each working party provide a report of its activities to be posted on the website – details of specific activities to be noted in the reports. Deadline requested: 15 October 2020 (send to: Heather Sheppard (MCI) cc: Ram)

IMAGING (Jelena):

Very pleased with the level of attendance at their meeting. Progress discussed on all 3 pillars (education, research & clinical). Many projects and initiatives under-way – details to be noted in the WP report.

Feel that they have achieved a lot but are setting themselves ambitious goals to continue.

JDM (Liza)

Very happy with the WP meeting and thought that spreading the WP meetings throughout the congress schedule was conducive to engagement. Projects were presented at the meeting covering all 3 pillars with 15 minutes of free discussion at the end. Planning Zoom meetings to continue engagement over the coming year. Documents, including educational resources will be available on the PReS website.

LUPUS (Sylvia)

Feels that an important function of the WP meeting is to allow creation of networks for research.

Had no formal programme for their meeting and were aiming at generating interaction – felt it was very successful. Many new people indicated that they wanted to be more active in the WP.

Timing was important – less overlap of WP meetings than in previous years – allowed people to attend multiple meetings.

Participation from people from countries that have never been active in the PReS WP's prior to this year – Sylvia is keen to keep this broader reach and momentum

Aim to plan interim Zoom meetings throughout the coming year.

MAS (Claudia)

Pleased with number of participants. Updated all on WP's research projects and surveys. Suggested cooperation between vaccination and MAS WP's.

Were able to welcome ENCA representative and EMERGE representative. Would like to reinforce the EMERGE involvement – especially for difficult cases.

SCLERODERMA (Ozgur)

Ozgur had to leave the meeting

UVEITIS (Gabriele)

CARRA representative + Ivan Foeldvari both presented at the WP meeting. Discussion around educational material for families.

Wendy Costello joined as ENCA representative and committed that an ENCA representative would join the Uveitis WP for all of its activities. This was felt to be important and useful.

VASCULITIS (Marija)

Satisfied with the number of participants but their presenters did not have very good connections which meant it was difficult to understand their presentations. It was indicated that it is difficult to resolve problems with presenters' (or participants') own internet connectivity – this is a risk with online meeting formats.

AUTOINFLAMMATORY (Véronique)

Maybe too many participants (308)? Consider themselves to be a networking platform and therefore it is difficult to work within the 3 pillars. They were happy to welcome a patient representative – helpful and informative. Two new EMERGE members also joined the WP.

Education – challenge. Much work is done outside of the WP and therefore difficult to ascertain what is “in the WP” and what is “peripheral”

Collaboration with the JIA Winter School in the past – can this be continued?

VACCINATIONS (Natasa)

Research working well – connected with CARRA over the last year and would like to collaborate going forward.

Contact with parents – Saskya main participant (conducted surveys of parents)

Education – NB: of doctors as well as parents/patients.

Connection with EMERGE very successful

Have already have a follow up Zoom meeting (MMR & influenza)

Health Professionals (Jeannette)

JIA is the topic that is most focus for HPs (pain & fatigue) – a lot of enthusiasm for collaboration to address the topic of non-pharma methods of addressing pain & fatigue. A JIA WP will be addressed to the Council as an area to be considered.

JDM – have 2 HPs already integrated into this WP

ENCA (Wendy)

Very pleased with the way that parents have been integrated over the space of only one year

PRoS 2021 & General Feedback

Record attendance at the PRoS 2020 e-Congress for all the WP's – how can this momentum be maintained? Consider impact on room planning/cost at a physical venue.

Favour maintaining a hybrid approach – the face-to-face dimension was missed and is still very important but the virtual element allowed broader geographical reach, more engagement from some parties as well as more inclusive meetings

All favour replication of the integration of the Working Party meetings into the main congress schedule with reduced clashes between meetings

Education – Sefi suggests 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)

Consultation service – being discussed with council

Jelena suggests to check which WP attendees are PRoS members and which are not – encourage those that are not members to become members to be able to participate fully. It was noted that WP members should be members of PRoS.

Advanced courses – suggestion from Jelena that each WP should prepare an online advanced course in the topic they cover (can be made available for a nominal fee through the website to generate resources for more PRoS projects)

Jelena - Imaging WP is covering many JIA topics for the time being – Jelena encourages HPs to join them in

16:20 – 16:25 General updates and reminders (see the “London meeting Framework” appended)

16:25 – 16:45 PRoS-CARRA Collaborative Research Award

PRINTO Research Award Round 2: 2020

16:45 – 16:50 Working Party Reports 2020 – for PRoS website (deadline: 15 October 2020)

16:50 – 17:00 Any other business

17:00 Close