## 2019 PAC MEETING – 17th OCTOBER

**Date:** 17th October 2019  
**Location:** Novotel City Centre Barcelona, Spain

### Present Attendees:
- Deirdre Kelly (DK)  
- Luisa Mearin (LM)  
- Sanja Kolacek (SK)  
- Justin Wilkes (JW)  
- James Butcher (JB)  
- Gigi Veereman (GV)  
- Analou Sugar (AS)  
- Christina Hauer (CH)  
- Jorge Amil Dias (JAD)  
- Tunde Koltai (TK)  
- Nick Croft (NC)

**Apologies:** Fiona Cameron (FC), Carmen Ribes Koninckx (CRK)

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<th>No.</th>
<th>Minutes</th>
<th>Action Owner</th>
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<tr>
<td>1.</td>
<td>Welcome and apologies</td>
<td>DK</td>
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<td></td>
<td>DK welcomed everyone to the meeting, apologies were accepted and received from FC.</td>
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<td>2.</td>
<td>Minutes of last meeting July</td>
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<td>The minutes of the July meeting were accepted as a true record. Ongoing issues/tasks were included into the agenda items.</td>
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<td>3.</td>
<td>Spink report and update</td>
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<td>Proposals 2020</td>
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<td>The Committee discussed the proposal put forward by Spink for 2020. After debate, the following was agreed:</td>
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<td>- For the Annual Meeting, there will be no press centre due to the low number of journalists in attendance, but rather more support at the ESPGHAN Booth from Spink. Interviews could be carried out at the PAC or ESPGHAN Booth</td>
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<td>- Press releases for the World Congress will be kept to three, however, it would be desirable to increase to five, with FISPANH covering the additional cost. Target groups could be widened to include MEP’s and to highlight the global aspect of the Congress. This will be discussed at the Management Committee Meeting</td>
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<td>- AHP inclusion for interviews/press coverage will be an important aspect</td>
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<td>- HCP Guides will be budgeted at two, with the responsibility of the content and progress under the umbrella of PAC, the author group and the respective Committee</td>
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<td>- The Big Yellow Awareness day for liver disease was accepted, and the campaign will have a focus on early diagnosis. AHP will be involved in the Awareness Day.</td>
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<td>- Lobbying initiatives were postponed to 2021 to allow more development of networks and a focussed message. Current focus will be on the identification of country specific MEP’s to collaborate with UEG</td>
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<td>- Nutrition, with a focus on agriculture, food quality and quantity was deemed a good topic to begin with, but this needs further clarification.</td>
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<td>Discussions were based around the translation of papers, guides and other materials, with confirmation again that ESPGHAN will not cover translations, and that the National societies will be responsible for this aspect, including the existing disclaimer. Regarding the HCP guides, TK emphasised the need for lay language to ensure the message is applicable to patient and parent groups.</td>
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For the Big Yellow Friday, Spink requested that attendees to the Strategy Day and Council Meetings in February wear something yellow to promote ESPGHAN involvement in the day. All agreed that this was feasible, and the Office will include the information as an email request to participants closer to the time of the meeting.

**TO DO:** Office to inform all participants to the February Meetings of the request to wear something yellow to promote the Liver Awareness Day.

### Council Media Training
The Office confirmed that the Council will discuss the opportunity for the Media Training on the 8th February, before the Winter Council Meeting, ensuring the availability of all Council and those who did not attend the previous PAC media training day.

*After Meeting Note: Council confirmed the morning of 8th February, 08:00-11:00. Office have been in touch with Spink regarding the set-up of the room and the Office will ensure the information is included on the PAC Meeting information to be sent for the Meeting on the 6th of February.*

**TO DO:** Spink to confirm ideal room set-up for the Council Media Training.

**TO DO:** Office to include details of the training in the information sent to PAC for the February Meeting.

### HCP Guides
SPINK confirmed that work is ongoing for the next round of HCP Guides, with Parenteral Nutrition and Chronic Hepatitis C virus submitted from the Nutrition and Hepatology Committees respectively. GI are yet to submit their preferred paper, and contact is ongoing with the Committee chair.

### HCP Guide pilot with French National Society
JW reported that contact has been made and progress is ongoing with the French National Society, who have fully committed to the project.

### Distribution list for HCP guides to sister societies
Discussions were based around recent issues arising from the distribution to NASPGHAN, which was a sensitive situation due to the nature of their individual papers on the same topic (liver). This will be further discussed with NASPGHAN President, and the function of the recipients of these guides needs to be clarified further to ensure there are no issues with distribution going forward. Permission should be sought for inclusion on any distribution lists for future guides.

#### 4. Battery Ingestion Initiative
JW reported that contact had been made with the Royal Society for the Prevention of Accidents (RoSPA), who were keen to join the project. It was agreed that PAC will fully support the GIC in this endeavour, and JW will discuss the next steps with the GIC chair. The liaison between the PAC and GIC will be CRK.

*After Meeting Note: Lissy de Ridder will lead on the project and a position paper is expected to be submitted within a six-month period, which will then be forwarded to Spink for further action.*

#### 5. Annual Meeting
PAC Symposia 2020
DK gave the Committee an overview of the programme and speakers for the submitted symposium, with all speakers confirmed. The Committee agreed that the programme was excellent. Discussions were based around the current budget rules, with restrictions on travel refunds for speakers. SK will bring the concerns to the Scientific Committee Meeting for further clarifications and to ensure the speakers are incentivized to attend, given the effort in obtaining their confirmation and the quality of their talks.

*After Meeting Note: The topic of coverage for non-ESPGHAN members was discussed at the Scientific Committee Meeting and confirmation was received that Key Note*
Non-ESPGHAN speakers (incl. those confirmed for the PAC Symposium) will be reimbursed based on the existing ESPGHAN entitlements for the annual meetings.

**PAC visibility at the AM 2020**

The PAC had previously expressed increased visibility in addition to the PAC symposium, with the P&P lunch, complimentary registration to P&Ps and a dedicated PAC booth (INCL. screens, guidelines, video and infographics etc.). SK resolved to bring these requests to the Management Committee for further approval.

*After Meeting Note: At the Management Committee Meeting, it was confirmed that PAC will get a booth of their own, with EK to get in touch with JW to discuss the requirements for the video presentations and layout of the booth.*

6. **Patient and Parent associations**

**Big Yellow Friday**

The initiative had been discussed previously and was approved for 2020.

**Patient and Parent Representative on PAC**

The PAC welcomed TK to the Committee and were given an overview on the background of involvement in Coeliac Disease and other initiatives focussed on paediatric patient and parent forums.

**Overview on EPF Medical nutrition Committee workstream**

TK gave the committee an overview on how the EPF medical nutrition committee workstream operates, with distribution among EPF members and collaboration with ESPEN. The content has grown wider and collaboration with ESPGHAN would be beneficial in the future. The paper references ESPGHAN on several pages due to their engagement with Patient and Parent groups for writing papers. The paper is written in lay language and it was deemed a good example of how such a complex paper can be written. The target audience is mostly Patient and Parents. JW confirmed that contact had been initiated with EPF to try and identify a topic for collaboration.

**Current Database**

The current database was reviewed and LM confirmed that some minor updates may be needed.

**TO DO: Office and LM to update database before February Meeting.**

DK also raised the topic of the Patient and Parent lunch and the ESPGHAN meeting offering of the free booth and registration.

*After Meeting Note: It was confirmed at the Management Committee Meeting that the booths and registrations will remain as per previous meetings. For the P&P lunch, the budget may have to be covered by the PAC P&P budget. All agreed to the proposal. This will be discussed further during the February Meeting.*

**TO DO: Office to ask EK for an estimated cost for the P&P lunch for final approval at the February Meeting.**

**Paediatric Visibility with the Scientific Panel for Health**

DK informed the Committee of a recent letter sent to the SPH for Health to include paediatricians on the panel, as there are currently no representatives. No feedback has been received to date. GV clarified that the panel is hoping to continue and had previously expressed interest in ESPGHAN support for their continuation. It was agreed that the SPH may not be very helpful for ESPGHAN and approaching MEP’s may be a more beneficial tactic.

**Engaging P&P groups in development of Guidelines and position papers**

Discussions were based around the involvement of P&P groups in writing of ESPGHAN papers, with good engagement to date. It was confirmed that for the Parenteral Nutrition paper, P&P groups will be engaged. The submission forms currently include a tick box for such engagement, and the guidelines for submission also include this recommendation.
LM informed the Committee that the groups should be involved from the beginning of the process, as recent comments were made from groups that they were only involved at the end of the process. DK urged the representatives of the Committees to ensure P&P are involved in the process from the beginning.

After Meeting Note: The suggestion for involving P&P groups is included on both the Submission form and the Guidelines on how to submit a paper. However, there is no inclusion in the Rules and Regulations, but this will be added for the next round of updates at the Winter Council Meeting.

**TO DO:** Office to add sentence to the author suggestions in Rules and Regulations for the updates at the Winter Council Meeting.

### 7. ESPGHAN/EMA Representation

The current format for consultation input was discussed, with the latest update to the procedure done in July. Currently, the system is working, and the last input was received from the Hepatology Committee, who submitted a detailed response to the EMA call for input on liver disease.

### 8. Lobbying Initiative

JW confirmed that a meeting has been set up with three MEP’s from the Green Party for the morning of the 10th December. The three MEP’s were identified as key people for the promotion of health. JW is also engaged with UEG to ensure they are aware of the collaboration and to ensure the initiatives are done in a cooperative manner. A request was made from UEG for ESPGHAN, during the meeting, to invite the three members to join the panel for the digestive health group.

**TO DO:** GV to invite the members during the lobbying morning.

Transitional care, quality of care and paediatric care in a paediatric setting will be discussed. DK, GV and DK will attend the meeting. SK also suggested for members to approach their country MEP’s to declare interest in meeting with ESPGHAN.

**After Meeting Note:** JAD had put forward a MEP from Portugal, who has confirmed interest in meeting with ESPGHAN for the promotion of child health. SK has also provided Spink with a Croatian MEP, who will be contacted for this purpose also.

### 9. UEG Updates

GV reported on UEG activities and specifically the lobbying day, which had to be cancelled at short notice due to a lack of availability. IMI2 and UEG are also liaising, with a meeting due to take place with the scientific committee chair of UEG. The UEG PAC will meet on Saturday morning of UEG Week.

**TO DO:** GV to provide an overview of the meeting to the PAC.

The Digestive Health Week, when re-launched, will be focussed on food labelling.

**TO DO:** GV to provide an overview of the meeting to the PAC.

### 10. Budget 2019

The budget was discussed with more clarification needed on the budget lines for the future. Q4 will be included at the end of the year and will be sent on completion.

**TO DO:** Office to join the meetings budget together with an overall sum for all.

The budget for 2020 was discussed with an emphasis on increasing costs for the marketing and press campaigns. It was confirmed that the lobbying initiative would be postponed, and other items would not be included for 2020, including the National Societies white book. Spink will send through a revised budget to DK for review before being submitted to Council for approval.

**TO DO:** JW to send revised budget to DK with discussed items removed and updated figures included.

**TO DO:** DK to provide approval of updated budget figures before submission to Council.

### 11. National Societies

CH provided possible topic for the PAC symposium of 2021, which were presented as follows:

- PedIBDCare in limited resource set-up (ongoing activities)
- “Foodborne GI / hepatic diseases (Echinococcosis, Salmonellosis, …) – actions to increase awareness
- (Intestinal) Tuberculosis vs. IBD – actions to increase awareness
The topics are very IBD centred and were suggestions only, and perhaps a wider inclusion of patient and parent focused topics could be put forward, as well as more inclusion of nutrition and liver. The focus for the topics was based mainly on countries with lower resources (Eastern European). Endoscopy/GI was deemed an appropriate theme. A multi-specialty approach will be taken which CH, LM and DD will help to formulate. AHP and P&P input will also be welcomed. TK confirmed interest in involvement. Sub-specialty recognition and white book project was discussed, but it was agreed that the situation in Europe was not yet ready to undertake such an initiative.

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<td>LM mentioned that a budget comparison for PAC per year, in a comparative excel format, would be beneficial for review, with more detail included in each item. <strong>TO DO: Office to provide budget document for the February Meeting.</strong></td>
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<td>The progress report for the strategic goals was shown and will be disseminated along with the minutes to the group.</td>
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<th>13.</th>
<th><strong>Forthcoming Meetings</strong></th>
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<tr>
<td>- 6th February 2020, 14:00-18:00, Geneva, Switzerland</td>
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<td>- 8th February Media Training, Geneva, Switzerland (for those who could not attend previously)</td>
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