

ICS Children's and Young Adults Committee meeting Minutes

Wednesday 7th October 2015,

Venue: Palais des Congrès

Room: 512D

Time: 07:00-08:00

Attendees: Giovanni Mosiello (Chair), Kwang Kim, Mario Patricolo, Jian Wen, Stuart Bauer

Apologies: June Rogers, Eliane Fonseca, Pallavi Latthe, Selcuk Yucel

Also in Attendance: Nickie Robinson, Mauro Cervigni, Nelly Faghani, Adrian Wagg

First of all GM welcomed Mauro Cervigni (MC) as Trustee Liaison to the committee. GM also asked the committee to attend the AGM on Thursday where possible.

1. Picture of the Committee to be taken - Done

2. Approval of Rio meeting minutes

GM asked for any comments on the Rio minutes. Mario Patricolo (MP) asked if the standards of terminology should be looked at as an individual project. GM suggested this should be undertaken jointly with ICCCS. GM then called for approval of the Rio minutes – minutes approved.

3. Terms of office & Terms of Reference (Attached)

The terms of reference were discussed. GM has received an expression of interest from a Urologist, however as it is felt that the committee has enough urologists, GM has advised him that they are not currently looking for another urologist but the committee will be happy to work with him as a participant on one of their projects as a co-opted member.

Post Script: Kwang Kim and Selcuk Yucel have both confirmed that they wish to renew for a further Term.

Furthermore GM remembers that the past year the CYAC decided to research a new committee member, physiotherapist, possibly from North America .

Different people expressed theoretically an interest, but only one formalised it, Nelly Faghan, who is present here. GM asks the CYAC members to approve Nelly as a new co-opted member.
Approved

Action – Office to add Nelly Faghan as a co-opted member

Other possible disciplines were discussed for potential committee positions: Medical Paediatricians, possibly a psychologist interested in transitional patients?

The decision is to involve other specialists for specific topics, involving other committees. GM noted that there is a lack of Paediatricians and Gastroenterologists within the other committees.

4. Budget for 2016

At the moment there is no specific request

5. Plans for 2015

Paper on Learning disabilities:

GM asked to MP to publish, peer reviewed paper in 2016, the great work that MP and JR produced on Downs / Cerebral Palsy / Williams Syndrome. MP and JR have worked for a long time on this hot topic . MP advised they had a small poster in Barcelona presented by JR. JR & MP created a brochure and JR published in Nursing, guidelines for people with disabilities and target magazine (Neurorehab & Physical Development).

GM noted that an open paper could be useful, and ICS may support it for the cost.

Action - MP and JR will publish with the help of CYAC a paper for next summer on children with learning disabilities

GM - Book of Urodynamics – Children and Adolescents. Due to be published next spring. Good project with vision. This will be a joint project with the Urodynamics committee and Italian society of urodynamics.

JW & GM are editors of a Urodynamics book, which will be done by December.

Action – Committee to publish the Urodynamics book for the next spring (2016)

GM – Best practice recommendation on urodynamics (as AUA have done in the past) asked Jian Wen (JW) to be the guide in this project. JW agreed and will define at a later date.

Action – JW to define the Best Practice project

Transitional Care Book (ICS with ICCCS) (GM and SB). There are interesting aspects to this project, and this needs to be decided on together. From an economic point of view the royalties percentage needs to be agreed - they have proposed 10% but we may be asked for something more. Need to define a summary of the book and look for people to work on project both

inside committees and ICS members. There is also a need to determine members from ICCS of course.

Action – Committee to define a summary of the transitional care book

Action – Committee to find members to work on the transitional care book project with a deadline of 2017/2018

There is someone who has published a book based on his experience but this more from surgery perspective and does not include incontinence. This needs to be worked on from a multi-disciplinary point of view.

Overall opinion – this could be useful for us to join efforts and resources. GM – could we aim for this for a 2017? MP agrees, SB thought that achievable, but 2018 more realistic to aim for.

MC wants to propose Chronic Pelvic Pain etc. (bladder pain syndrome) as a topic to include too. Has been speaking to others and there is a grey area with recurrent UTI / Pelvic pain – MC sees a few young patients with BPPS – this committee / book could include a chapter on this as this will be the first time a group has looked at this.

Action – Transitional care book to include chapter on CPP

SB sees a lot of older teens incapacitated. Paper on incontinence in older girls – acrobats / gymnasts frequently – who are bothered as it limits their participation. This could be included. Sexual function & incontinence also. GM felt that the outline should be drafted, then the committee could get the opinion from members of ICS and ICCCS, then get the agreement to proceed.

Action – Committee to obtain agreement by ICS Board of Trustees and ICCS

Action – Committee to draft an outline for the transitional care book

Action – Committee to poll members of ICS & ICCS regarding the outline of the transitional care book

GM noted interesting discussion suggested by the Lancet commission on global surgery, paper published in the last April and reported by the fistula committee. The need for surgical procedures, and evidences and solutions for achieving welfare and health assistance in limited resource countries. Then GM suggested to consider – How to treat clean intermittent catheterization in places with limited resources. There are very few guidelines on how to re-use catheters. Suggest the committee could create some minimum standards for re-using catheters. Other suggestions – how to treat the channels which is different from western and limited resource countries. What to do with adolescents and how to use catheterisation. GM

suggests that the committee chooses two of these to present / publish the document. In his opinion should start with the re-use of catheters and channels. MP asked if this should include stomas? – Yes.

Action – Committee to select 2 topics for catheter guidelines

SB noted that there is a paper by Julian Wan on how to use a microwave to sterilise catheters – we should approach him. GM noted that the re-use of catheters is not only in limited resource countries. There is a percentage in western countries who also re-use and in these economic times this is going to increase. Milton solution / chlorine / boil are current options. GM wants to ask a committee member to guide this project – SB can help, MP will help with guidance from SB.

Action – SB & MP to work on a re-use of catheters project.

MP advised that this is not just money but preference. Also many don't have good insurance, cover not sufficient. He was in Cardiff at a meeting with/for patients with Spina Bifida and found they don't like the lubricated catheters, so culture is also an issue. GM presented at ICCS in London and the Olympic athletes found there was a problem of culture in different countries. KK has experience with re-use as 3 years ago the Korean government provided people that needed them with 6 catheters.

Adrian Wagg commented that these are encouraging discussions and reminded that the committee can also use non-committee members, being led by the committee, for tasks/projects. The committee should look at increasing scholarly output, and the Board would be keen to support this.

Action - Committee to finalise 2 topics and to work in these: catheter reuse and stoma?

GM suggested that the committee form groups of 2-3 people to create a document then share with the committee to publish as a group. To be finished by end of next year. Invite committee to choose field of work in next 2 months.

Action – Committee to advise office who will be part of the groups.

Paediatric Bladder Day – Neurogenic Bladder day from children to adults. GM advised that this committee is not just educational but there is a great request in education. He referred to the experimental pediatric bladder day number zero in Rome, which has been a great success, with more than 100 people. On the basis of this preliminary experience maybe the Education Committee could help to support an official pediatric bladder day in 2016.

Action – GM to contact Ervin Kocjancic on the Education Committee for possible support of a pediatric bladder day

Question of which subjects was raised and Dysfunctional Voiding and Pelvic Floor Dysfunction were suggested by MP. GM confirmed that this would need an organiser from the committee with support from the Education committee, looking at having 1-2 meetings each year in other countries. AW commented that there is a choice, this could be either at the ICS Annual Meeting or outside of it, and the committee would need to liaise with Ervin Kocjancic (Education Committee chair). GM noted that this could be run as an add-on course at the end of the Annual Meeting. SB advised that the ICCCS meeting for 2016 coincides with Enuresis week so the committee could add an extra day to this event – either before or after. MP also advised that he is the Chair of the scientific committee and GS for another congress. He could include this within this meeting in Abu-Dhabi and it would be ICS branded. He could bring 1 speaker and speak himself to reduce costs. They would not be able to afford to bring more than 1 speaker. GM advised that would need to define what the course should be about before deciding on the when aspect.

Action – Committee to define a possible course

Action – Committee to decide when to run the course and if to add it to another event.

6. AOB

GM noted that this year the committee have a long workshop with good speakers at the Annual Meeting.

GM raised the ICS & ICI in Tokyo 2016. The committee need to organise workshop for the meeting.

Action – Committee to organise 2016 workshop

Meeting Ends