



ICS Children's and Young Adults Committee meeting Minutes

Tuesday 21st October 2014,

Venue: SulAmérica Convention Center

Room: 11

Time: 09.00-10.00

Known Attending: Giovanni Mosiello (Chair), Eliane Fonseca, Kwang Kim, Pallavi Latthe, Mario Patricolo, Jian Wen, Laetitia De Kort

Apologies: June Rogers,

Also in Attendance: Avicia Burchill, Stuart Bauer

First of all GM introduced Stuart Bauer and explained the reason why he invited Stuart Bauer. He is the Past President of ICCS and for his specific role in ICCS and for the purpose to discuss together with the members of ICS Children's and Young Adults Committee (CYAC) the common future actions. All those present approved the request of GM to have Stuart Bauer during the Meeting.

1. **Picture of the Committee to be taken**
2. **Approval of Barcelona meeting minute**

Barcelona meeting minutes were read and approved: PL, MP, JW presented their specific actions done.

Terms of office & Terms of Reference (Attached)

The terms of reference were discussed in full and it was agreed to call for the future a physiotherapist as it was felt there were too many urologists in the CYAC. At this purpose GM introduced his strategic vision which was to cover all geographical areas within the committee, considering that it will be interesting to have a physiotherapist from a missing geographical area inside the CYAC i.e. North America, Australia or Africa.

ACTION POINT: Call for expressions of interest for physiotherapist representative from North America or Australia.

Post Script: Jian Guo Wen and Mario Patricolo both confirmed that they wish to renew their three year term.

3. **Outstanding actions:**
 - a) Giovanni to present his strategic vision for the committee. Discussion has been in partially held amongst committee using the committee forum.

GM outlined that the specific action of the Committee is focused on transitional from pediatric age to adult service for continence care in order to produce for ICS guidelines, standards of terminology between children and adults. In these actions CYAC would like to cooperate with other Societies working first of all with International Children's Continence Society but with a specific role for transitional care, and then on adolescents and young adults with ongoing continence care needs. GM would like that the actions of CYAC must be finalised to include new subcommittee members, to complete a list of ICS member involved in transitional care and to involve in CYAC activities, encourage pediatric urologist, pediatrician, paediatric nurse, etc. to submit abstract to ICS, to identify centre of excellence for training in transitional care of continence to promote high quality care for children and young adults with bladder and bowel dysfunction, defining clinical standards, guidelines / pathways, to organise course around in different countries in order to transmit ICS standard of care. CYAC is planning to communicate and collaborate with all other societies involved with transitional care; WFNR, SIG Spina Bifida, IFSBH, ESPU, single National Society for Continence, and of course ICCS. This was discussed and approved.

GM felt that this was a transitional year for the committee and that was a time to get to know each other but felt that he needed to see the whole committee involved in action as for Rio Congress where all members presented proposal, etc. GM explained that he would like to organise the committee activities better and all the member must be more involved with a specific role. For this reason GM submit 2 proposals: first to create some different sub-committees. (He suggested 2 or 3 people in each committee) and secondly to identify some geographical area referees. PL said that we created sub-committees in the education and it didn't work and we are now dissolving them. Perhaps with a small committee and small area this may not be appropriate. A discussion was held about geographical areas and whether the committee has not a full representation. There is a general agreement to work on the second proposal. Discussion then focused on transitional care, SB said that transitional care is very difficult and there is currently no dialogue between pediatrics to adult care. We are continuing to increase the age of pediatrics as there are no adult care to cover. We have pediatrics entering the working world and at university. PL in the UK the problem is GMC licensing because there are doctors who cannot care for children and the adult doctors do not know how. It was agreed to work on the transitional care field. GM remember that ICS and ICCS have to work together on this field and how is important CYAC that is the natural common bridge between the 2 societies, and GM is very happy that many CYAC members are active part/ of ICCS board/subcommittee, this is very important for common facilitate action.

GM presents his idea of to produce a book for transitional care of continence , GM has presented this idea to the Board of Trustees and other Committee Chair and there is a general agreement as well as there is an agreement in ICCS , as Stuart Bauer confirms. The book will be produced by ICS and ICCS and there is a general vision to produce it in 24-30 months, 2016/2017 and that the book could be presented in a common meeting. There would be a need to involve different disciplines for adult and pediatric care: urologist, gastroenterologist, psychologist, nurse, physiotherapist, etc. SB talked about having a mix board of editorial members from ICS and ICCS. Christopher Woodhouse would be a good person to do the introduction. AB asked whether this would be income generating. It was discussed that this could be an online book too which would be beneficial to reach a wider audience. It was discussed whether there could be a short and longer version. MP suggested that we need to look at the best and minimum standards of care as this would be a worldwide book. SB suggested that practical management to best practice could be a focus. EF suggested a chapter on adolescents and how to engage them. GM was reminded that he has to represent all these options to the Board of Trustees at the committee chair meeting and furthermore as a common project with ICCS all these proposal must be discussed with ICCS too. For this reason GM felt that it will be easier to involve Stuart Bauer in CYAC activity for the next 3 years in order to take advantage of his great experience and his specific role in the ICCS. To avoid the official request for another additional member to the CYAC and to vote for another urologist (while urotherapist must be included too), GM proposal is to invite directly Stuart Bauer in the CYAC as co-opted not elected, member. Agreed.

ACTION POINT: Stuart Bauer to become a co-opted member of CYAC

4. Budget for 2015

PL explained that the laparoscopy leaflet is ready to circulate and this should be put on the website. PL further explained that a “how to deal with ovarian cysts” is ready to be submitted but it would be better if it was an ICS leaflet. PL that some help with the research assistant would be required with an approximate budget £500.

MP explained that an understanding bowel leaflet had been published.

ACTION POINT: MP to provide office with to link the laparoscopy leaflet.

MP explained that the magazine Nursing Times have asked them to write an article expanding on this leaflet. MP discussed the matter with June and they wanted to propose another leaflet with the focus on down syndrome and other chromosome abnormalities/learning difficulties. GM suggests that this should be an ICS production if MP and JR agreed. Again a budget for £500 for research would be required.

At this moment no specific request for the cost of handbook will be presented

5. Plans for 2015

JW proposal was a paper on Urodynamic evaluation on children and young adults. It would be a publication on behalf of the childrens committee. Approved

GM proposal on behalf of Italian Society of Urodynamics(SIUD) : a book with Springer on clinical Urodynamics. This is a project with SIUD, that is affiliated to ICS with NUU as official journal too. If there is agreement to put both logos GM will ask to Springer about that, otherwise all CYAC member will be involved in this project.

ACTION POINT: GM to send office SIUD Board a request and then to place an index on forum for review

It was discussed to hold a meeting on transitional care in 2016 in conjunction with the ICCS. It was agreed to leave this idea for now, because the committee would like to focus on the handbook. SB explained there is a meeting in St Louis on spina bifida in 2017 and it was agreed at recent meeting to include transitional care and this could be a sequel to the Toronto meeting, as well as in Italy in 2017, ICS in Florence .

AB raised that workshop applications for 2015 closes 1 December.

MP/JR would like to present on learning difficulties, GM invite all to present a proposal in connection with other ICS Committees.

All CYAC members presented their gratitude to Laetitia De Kort who finishes her activity in the CYAC at the end of 6 years. GM said that her role has been very precious for moving action of the committee to the transitional care and GM ask to her to remain in connection with CYAC for future activities.

It was also noted that a workshop was held in Rio entitled "evaluation and management of neurogenic bladder and bowel in children and young adults" with the participation of GM, SB, EF, KK . Other members of the committee also participated in other workshops, round tables, and meet the experts.