



ICS Continence Promotion Committee Meeting Minutes
Monday 26th August 2013,
Venue: Centre Convencions Internacional de Barcelona (CCIB)
Room: M214
Time: 11.00-13.00

Known Attending: Tamara Dickinson (Chair), Mary Van Poelgeest-Pomfret, Jacky Cahill, Els Bakker, Nicole Huige, Stavros Charalambous, Barry Cahill, Diane Newman, Tomasz Michalek, Diane Owen, Peter Meyers, Deborah Gordon, Sherif Mourad

Apologies: Jane Meijlink, Frankie Bates, Christa Thiel, Diaa Rizk

Also in attendance: Jenny Ellis

1. Picture of Committee to be taken

Picture taken of the committee. TD welcomed members and everyone introduced themselves. TD welcomed Stavros on to the committee- this was his first committee meeting.

TD provided copies of the committee ethics to members, she would like members to review and agree to the terms (see appendix.) It's TD's expectation that is how members will conduct themselves whilst on the committee.

2. Approval of Barcelona meeting minutes, attached.

BC approved and MVP-P seconded.

3. Terms of Reference & Terms of Office to be discussed

> Committee members need to decide who would like to stay on for 1 extra year and who would like to stay on for 2 years.

JE highlighted that members due off the committee, following a 6 year term, could stay on with special permission from the Board- members need to let TD know if they wish to stay on and we will place a request to the Board of Trustees.

JC thinks the committee is currently too big. The Board will be looking at committee sizes as part of their review. BC feels committee hasn't been able to achieve as much as it could e.g. the public forum was good in Cairo but not as good since then. TD agreed in theory the public forum is an ineffective use of our time. BC felt the public forum needs to be assessed country by country- TD agreed. MVP-P agreed, -placed like Cairo were different, Spain shuts down in August so it's timing as well as location.

SM felt they we need to assess our targets; we don't have to do it all we can use other committees and organization to assist- which would help us achieve more. JC highlighted that the PCC discussed some ideas for public forum e.g. it could be sponsored. SM agreed we need to ask ourselves what we want to do- we need to have a vision.

DN stated that our vision is in our mission statement- continence awareness, so this is the CPC's function. The committee highlighted that we need funds to achieve this goal.

> Need to review the wording of the TOR in relation to specifying the patient organisation representation. Also, the wording "Conducts a Public Forum in conjunction with the ICS Annual meeting" if this is to be kept on the TOR. (See Jane comments.)

TD felt that we should remove 'conducts a public forum' from the TOR- all members agreed.



Action: JE to remove public forum from TOR and submit to Board for approval.

TM thinks the public forum should move to/for patient advocacy groups and/or general healthcare providers, and then we could encourage more sponsorship for the forum. MLVP agreed, we need to give information to local organisations who in turn can distribute this to the patients in the local areas.

The committee reviewed Jane's comments. BC does not feel that we need patient experts and advised that 1 representative on the committee would be acceptable-TD agreed. MVP-P feels, as a patient advocate, that it doesn't matter if you're a health professional but thinks it's important for patient advocate groups to be involved in the future. Committee feels that it's down to the Chair to ensure there is a fair mix of members and representatives.

4. Review of subcommittees

TD highlighted that from that the survey results showed the WCW subcommittee was the most important and fistula the least. She asked whether we should change subcommittees based on this information? TD asked whether some subcommittees should be based on the focus areas?

5. Outcome of the web survey

EB asked whether it was possible to go to 1 country a year? NH felt that it is more efficient to do a meeting where the AGM is taking place. TD highlighted that we could tag on to the education committee meeting locations. DN thinks the Board needs to give CPC money to achieve their goals. The committee questioned the budget request process, JE explained the process for clarity. The budget request was denied last year due to lack of funds which affected all committees and not just the CPC. TM felt that the ICS should fund public forum costs and ICS experts. SM highlighted that you won't get everything you request e.g. last year the fistula committee requested £32,000 and received £12,000. You therefore need to get local members and organizations involved- this therefore divides the work and costs.

BC felt that there was a struggle between the CPC and ICS, when it comes to health promotion, we haven't got the resources to do what we are suggesting e.g. public forum. BC suggested that some materials should be translated and saved on the website. EB highlighted that we have tried to do this before but it is very difficult. We need to pick 1 idea and put a business plan to the Board to get the money.

All agreed that we need to have one achievable aim and progress from there. Going forward it would be useful to tag on to education committee meetings where possible.

Action: Committee needs to select 1 achievable action for 2013-2014.

Action: TD to discuss tagging on to education courses where possible with Education Committee.

6. WCW (see additional information)

JC highlighted that the Canadian Continence Foundation (CCF) did not hold WCW this year as there is a week in Canada in November. BC highlighted that Australia aligned their week with ICS and feels the CCF should as well. JC stated that this was not possible sadly.

TD highlighted the letter sent to the World Health Organisation (WHO) for recognition of WCW- waiting for a reply.



SC thinks we should have patient videos on the ICS TV page. JE advised that we could 'like' a video and it would then show up on our news feed- so other members can view this. We have liked a number of WCW video's that were sent to the office.

Action: If any committee members have you tube videos then please notify Jenny and we can like the video so they show up on our news feed for other members to view.

SC would like video's to have subtitles, JE advised we would need to ask IT department about this.

Action: JE to ask IT department if videos could have subtitles.

7. Public Forum

See above discussion under Terms of Reference

8. AOB

MVP-P highlighted the WFIP meeting taking place in Barcelona to set up Spanish patient organization. She thanked the office for their accommodation for the request for a free meeting space and highlighted that if you put effort into arranging these meetings then outcomes can be achieved.



ICS Continence Promotion Committee Meeting Agenda

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Room: M214

Time: 11.00-13.00

Known Attending: Tamara Dickinson (Chair), Mary Van Poelgeest-Pomfret, Jacky Cahill, Els Bakker, Nicole Huige, Stavros Charalambous, Barry Cahill, Diane Newman, Christa Thiel, Tomasz Michalek, Diane Owen, Peter Meyers, Deborah Gordon

Apologies: Jane Meijlink, Frankie Bates

Also in attendance: Jenny Ellis

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|---|-------------|
| 1. Picture of Committee to be taken | 11.00-11.05 |
| 2. Approval of Barcelona meeting minutes, attached. | 11.05-11.10 |
| 3. Terms of Reference & Terms of Office to be discussed
> Committee members need to decide who would like to stay on for 1 extra year and who would like to stay on for 2 years.
> Need to review the wording of the TOR in relation to specifying the patient organisation representation. Also, the wording "Conducts a Public Forum in conjunction with the ICS Annual meeting" if this is to be kept on the TOR. (See Jane comments.) | 11.10-11.30 |
| 4. Review of subcommittees | 11.30-11.50 |
| 5. Outcome of the web survey | 11.50-12.10 |
| 6. WCW (see additional information) | 12.10-12.30 |
| 7. Public Forum | 12.30-12.55 |
| 8. AOB | 12.55-13.00 |



ICS Continence Promotion Committee meeting Minutes

09:00 – 12:00, Sunday 14th October 2012

China National Convention Centre, Beijing, China

Attending: Vasan Srin (Chair, VS) , Frankie Bates (FB), Sherif Mourad (SM), Diane Newman (DN)

Apologies: Elisabeth Bakker, Brian Buckley, Barry Cahill, Jacky Cahill, Tamara Dickinson, Deborah Gordon, Ewa Kolby Falck, Jane Meijlink, Peter Meyers, Tomasz Michalek, Nancy Muller, Diane Owen, Diaa Rizk, Christa Thiel, Mary Van Poelgeest-Pomfret

In Attendance: Ashley Brooke, Nicola Huige, Tom Rosenbaum, Malgorzata Semeniuk, Ajay Singla, Dan Snowdon, Siow Woei-Yun

DS informed the committee that the meeting was not quorate as a third plus 1 of the committee membership is required to be present in order for decisions to stand. Therefore all decisions and action points are subject to the agreement of the wider committee.

Ajay Singla attended to outline the Board's plans for an ICS strategic planning process. VS suggested the Board focus further on continence promotion, as this must come from the top. Gaining WHO recognition of world continence week (WCW) would greatly assist the success of the event. NH felt that this was imperative.

The CPC should collaborate with the Education Committee on courses and promotion. Steps have been made to ensure this joint working. The CPC should also help establish continence societies in countries where none exist. SM recommended office presence at all education courses as the office aids promotion and acts as a contact point. This will be discussed further with the Education Committee.

SM suggested the CPC focus on one or two key jobs a year as currently the work is too broad and this results in a lack of cohesion and activity. VS felt WCW should be a top CPC priority. SWY felt the power of the CPC was in its collective power of individual members and societies. SM suggested the CPC focus on one country each year in relation to WCW.

1. **Photo of committee – taken**

2. **Approval of Paris meeting minutes**

These were approved but will need ratification by the wider CPC membership as this meeting is not quorate.

3. **Terms of Reference, Terms of Office**

The majority of CPC members' terms end in 2014 and cannot be renewed. The CPC will take on more members in 2013 and will look into staggering ending terms in 2014. This will need to be discussed with

the office and approved by the Board. NH and VS expressed interest. VS as exiting Chair would like to stay on the committee, and NH to replace Ewa Kolby Falck as SCA representative.

Action: CPC Chair to look into membership terms, particularly following 2014.

4. Subcommittee reports and plans for next year

FB reported on the Education Subcommittee. The CPC workshop was full and the public forum had an expected attendance of 200. Two very positive results.

Website Subcommittee: DS reported that Dominic Turner had met with Els Bakker, Chair of the Website Subcommittee to develop content for the CPC website. This will be updated as part of the wider ICS website revamp. VS would like the CPC website to be more dynamic, with CPC members uploading content. The current website format does not easily facilitate this. A change allowing CPC members to upload content would also ensure information was added sooner, while it was most relevant. AB informed the committee that the new website design allowed far easier editing of microsites.

Fistula Subcommittee: SM updated the committee on the two fistula workshops organised for 2012. A workshop is planned for Rwanda in April 2013 (Tom R leaves).

5. CPC Source of Funding

Action: VS to ask the Board for a budget for CPC activities and a mid-term meeting (at EAU?)

6. WCW 2013, planned activities

A priority should be getting the event recognised by WHO. Then WCW could also be listed on the AUA and EAU websites. SWY asked the CPC to consider endorsing Singapore 2013 WCW events.

Action: CPC to work towards WHO recognition of WCW

7. ICS 2013: workshop, public forum and CPC booth

Tamara will look into these items when she becomes CPC Chair.

DS said the ICS booth could be used to help promote CPC activities. DS also recommended the CPC make use of ICS facilities and promote WCW more widely. Membership mailings, ICS News and the website should be more heavily utilised. The adopt a country option should be considered soon if it is to take place in 2013.

Action: CPC to write an article on WCW 2013 for the January 2013 issue of ICS News. Deadline for content is in November 2012.

8. Listing of priorities for 2013

Tamara ran a survey and will soon list the CPC priorities. VS recommend a focus, perhaps as focused as just one key priority for 2013.

FB reminded the CPC to use WFIP as a patient advocacy resource. FB also thanked WFIP and Lynne Poelgeest for subsidising her travel to the annual meeting, by way of support for the public forum.

The CPC workshop should focus on CPC priorities. Industry should be consulted for their thoughts on the direction of continence promotion.

The public forum is beneficial as a way of linking the work of the CPC to the ICS. Local support is essential as organising the event from afar is a real challenge. £5000 is usually given by the ICS to support the event, and in the last two years the forum has been held in the annual meeting venue, further saving on expenses.

DS recommended that a strong justification accompany budget requests as there are less ICS funds for activities than in recent years.

9. Adopt a country initiative

The CPC still needs to work out how to decide which country is supported. SM recommended that the CPC maintain links with the chosen country once the year was concluded. (Diane joins meeting)

ICS Continence Promotion Committee Terms of reference

1. PURPOSE: To act as a facilitator for various international continence organisations to meet and address relevant issues to do with continence promotion, awareness and prevention and to promote awareness through its National Organization members, the public and government.

The principle aims are to:

- seek opportunities for networking across various countries;
- increase awareness amongst ICS members of continence related issues;
- facilitate development of continence organisations;
- facilitate exchange of information about continence awareness and promotion;
- identify opportunities for continence prevention strategies.

2. FUNCTIONS:

- Identifies broad issues through an international forum that can facilitate translation at a local national level.
- Provides input into continence awareness, promotion and prevention.
- Holds annual workshops at the ICS meetings.
- Conducts a Public Forum in conjunction with the ICS Annual meeting.
- Facilitates World Continence Week.

3. RESPONSIBLE TO: ICS Board of Trustees and ICS General Secretary

4. COMPOSITION:

Total Members	Method of Appointment	Name	Term of Office
General Secretary	Ex Officio	See Membership	2 years
Chair:	Elected. A member must sign his/her agreement to stand. This nomination is signed by nominator and seconder, all being ICS members. The Chair would normally have served as a committee member, either current or in the past. Nominations received by April 1st as advertised. Voting regulations as stated.	See Membership	Term of office: 3 years, renewable once by Formal Election
Membership	All members of ICS committees must be active ICS members (paid for current membership year) (Bylaw 2.3.2) and have completed a disclosure form. Members are expected to attend meetings and to be active on subcommittees. The Chair may ask inactive members to step down from their position.		3 years, renewable once by Chair/committee approval. Further terms could be approved in exceptional circumstances

		and by referral to the ICS Trustees.
Subcommittees	Education	
“	WCW	
“	Internet	
“	Industry Liaison	
“	Fistula	
Updated February 2013		

5. MEETINGS: Two face-to-face meetings, one held during the Annual Scientific meeting and the second meeting heard mid-year, usually during EAU. Other deliberations, normally by email.

6. QUORUM: One third of committee membership plus one. For example, a committee of ten will have a quorum of four members.

7. MINUTES: Minutes are recorded at each meeting and posted on the ICS and CPC website in accordance to 2009 ICS Bylaw 6.1-6.4).

8. REPORTING & ROLES: The Chair of each committee is required to prepare an annual report to the Board of Trustees outlining achieved goals/budget requests and future objectives and strategies. The Chair is also required to be present at the Annual General Meeting should the membership have any questions over committee activities.

The committee Chair is also responsible for submitting an interim report to the Board of Trustees' mid term meeting. The date that this report will be required will be given in advance each year.

For Terms of Office Information see [Membership Page](#)

Continence Promotion Committee Terms of Office

Member	Role	Term Start	Term End	Term Yrs	Elected	Term details	Renew	Stepping down	Additional Information
Tamara Dickinson	Chair	19-Oct-12	03-Jul-15	3	Y	3 year term will finish 2015 - can renew once by formal election			
Barry Cahill	Committee Member	24-Oct-08	30-Oct-14	6	N	6 year term will finish 2014 – CANNOT renew			Position will need to be advertised after Barcelona, Committee to discuss which members wish to stay on for an addition year/ 2 years.
Christa Thiel	Committee Member	24-Oct-08	30-Oct-14	6	N	6 year term will finish 2014 – CANNOT renew			
Deborah Gordon	Committee Member	24-Oct-08	30-Oct-14	6	N	6 year term will finish 2014 – CANNOT renew		Yes in Barcelona	
Diaa Rizk	Committee Member	24-Oct-08	30-Oct-14	6	N	6 year term will finish 2014 – CANNOT renew		Yes in Barcelona	As above
Diane Newman	Committee Member	24-Oct-08	30-Oct-14	6	N	6 year term will finish 2014 – CANNOT renew			
Diane Owen	Committee Member	24-Oct-08	30-Oct-14	6	N	6 year term will finish 2014 – CANNOT renew			
Elisabeth Bakker	Committee Member	24-Oct-08	30-Oct-14	6	N	6 year term will finish 2014 – CANNOT renew			
Frankie Bates	Committee Member	24-Oct-08	30-Oct-14	6	N	6 year term will finish 2014 – CANNOT renew			
Jacky Cahill	Committee Member	24-Oct-08	30-Oct-14	6	N	6 year term will finish 2014 – CANNOT renew			
Jane Meijlink	Committee Member	24-Oct-08	30-Oct-14	6	N	6 year term will finish 2014 – CANNOT renew		Yes in August 2013	
Lynne Poelgeest	Committee Member	24-Oct-08	30-Oct-14	6	N	6 year term will finish 2014 – CANNOT renew			As above
Nancy Muller	Committee Member	24-Oct-08	30-Oct-14	6	N	6 year term will finish 2014 – CANNOT renew			
Sherif Mourad	Committee Member	24-Oct-08	30-Oct-14	6	N	6 year term will finish 2014 – CANNOT renew			
Tomasz Michalek	Committee Member	24-Oct-08	30-Oct-14	6	N	6 year term will finish 2014 – CANNOT renew			
Nicola Huige	Committee Member	19-Oct-12	03-Jul-15	3	N	3 year term will finish 2015 - can renew			
Peter Meyer	Committee Member	26-Aug-10	15-Sep-16	6	N	6 year term will finish 2016 - cannot renew			
Stavros Charalambous	Committee Member	29-Aug-13	15-Sep-16	3	N	3 year term will finish 2016- can renew			New Member 2013
Vasan Srini	Committee Member	29-Aug-13	15-Sep-16	3	N	3 year term will finish 2016- can renew			New Member 2013
Grzegorz Surkont	Committee Member	29-Aug-13	15-Sep-16	3	N	3 year term will finish 2016- can renew			New Member 2013

Nominations 2014

13 positions up for renewal, members will need to confirm if they want to stay on- Tamara will need to confirm to the BoT for any special requests and then this will determine how many expressions of interest to call for

Jane stepped down and this position was added to the 2013 nominations list.

Deborah and Diaa confirmed stepping down so these positions will need to be recruited for post Barcelona

Key	
Colour	Meaning
	Stepping down in Barcelona
	Will need to confirm if renewing/ positions will need to be advertised after Barcelona
	New member/position

Summary of CPC Online Survey

List Strengths of Sub-Committees:

small groups	clear objectives
participation	new ideas
diversity	collaboration
focus on key areas	patient advocacy
none	WCW
promoting awareness	broad functions
not sure	willingness
organization	international representation
constant structure	multi-disciplinary

Weaknesses of Sub-Committees:

Not enough contact between meetings
Not enough interaction between groups
Some only have 1 member
Some only need 1 or 2 members
Stagnant, not moving forward
Lack of structure
Too large and too many
Lack of follow-up
Poor communication
Shifting goals
Meet infrequently
Members not involved
Chair makes all the decisions
Lack of objectives

Sub-Committees Listed Ranked by Importance:

1. World Continence Week (10)
2. Education (9)
3. Internet (9)
4. Industry (9)
5. Fistula (3)

Would you be in support of moving to an ad-hoc task force structure based on action items derived from meetings?

Yes-6

No-4

Unsure-2

What projects should the CPC request funding for and what should the funding cover?

- More meetings (contacts) and realizations of goals set out by sub-committees
- Promoting continence awareness in various parts of the world. Maybe something that can be combined with education workshops.
- Support for webpage (photostock pictures, etc) and public forum costs (advertisements, venue, basic catering)
- Need clear direction set first
- Interim meeting, WCW, public forum (stated by numerous respondents)
- Public awareness and fund raising
- Internet development
- Assessment with "in-country" researchers of public awareness and understanding of continence issues in developing countries
- Development of education materials for public distribution

Do you think the Public Forum is a drain on resources which in the end hasn't really gained adequate exposure or benefit?

Yes-6

No-3

Unsure-2

List 3 ways you think this could be changed:

- Shorter program
- Adequate question and answer time
- More ICS Board support (stated by several respondents)
- More involvement from advocacy groups
- Establish "buy in" of host country before planning the event

- Allow sufficient time to plan, organize and involve host country
- Template of topics that can be replicated in other markets/cities
- More input from all CPC members and ICS Board
- Not with annual meeting
- More funding for advertising
- Involve more members
- Not held the last evening of the ICS
- Simultaneous translation
- Public incentive
- Consider developing country and for WCW
- Better promotional materials
- Sponsorship
- Better integration into AGM or change it completely
- Stop public forum as an event
- Country specific
- Align with education courses rather than AGM
- Complete re-evaluation of current structure

There is discussion with the Education Committee to align the CPC's potential partnering program/"adopt a country" with the Education Courses. Would you support that?

Yes-6

No-1

Unsure-3

Due to our geographical distribution and limited resources, we may need to work at developing a more grass roots level and think along the lines of developing tools with broad uses.

List 3 priority goals for Year 1.

Internet Awareness	Industry Liaison
Survey General Membership re: CPC	Partner with advocacy groups
Funding for individual countries for WCW	Funding from ICS
Public Awareness	Patient Access
Basic patient information	Setting up a group in dev. Countries

Clear lines of communication

Education Materials

Better relationship with Trustees

Smaller membership

Skype quarterly meetings

Government Lobbying

Public Forum plans

Global awareness campaign

ICS commitment to support CPC

Recruitment of new members

List priority goals for Years 2-3.

Education projects

More member involvement

Collaboration & partnership development

Generic resources for patient health

Adopt a country program

WCW planning/resources

Advocacy group involvement

Greater credence in ICS

Align with fistula committee

Funding

CPC awareness program

Common database of materials

Evaluate public awareness in dev countries

Position statements related to continence care

Link with the International Union for Health Promotion and Education

List priority goals with a 5 year timeline.

More involvement of members

Identify countries who are struggling to build continence awareness

Information sharing between countries on a regular basis

A presence so that the general membership of the ICS is more aware of the CPC

Industry liaison

Electronic resources for public education

Recognition within the ICS

More effective WCW

Patient and provider awareness

Evaluate effectiveness of CPC in different countries

Tools to increase awareness around the world.

Development of an education course

Do you feel the ICS and the CPC are disconnected?

Yes-9

No-2

Unsure-1

List 2 ways you believe we could close this gap.

- Common projects interaction
- More voice at the board level
- Change from committee to 'expert groups'
- "Invite some high profile health promotion researchers and high profile patient advocates to present a plenary session"
- Lay out objectives
- Clear direction, "sell ourselves to the ICS"
- Representation of the Board of Trustees
- More professional image
- Work with nursing, education and physio committees
- Establish clear aims
- Better communication to update clear goals to the Trustees

Additional Feedback

- Don't make "adopt a country" too paternalistic or it will fail
- Entire structure needs to be re-evaluated
- Same individuals involved who don't move things forward, only want to do the same things
- Need leadership, need to know our roles
- The number and professional background of membership should be reviewed with a smaller more multidisciplinary representation

3. Terms of reference & office

Jane-I will regretfully not be able to attend due to clashing meetings again.

Re: 3. "Need to review the wording of the TOR in relation to specifying the patient organisation representation": I think there also needs to be a distinction made between the patient advocate in general and the patient advocate who is him/herself a patient. This could be important for example if an ICS committee specifically wants a patient's point of view/perspective.

Re the CPC forum "discussion": the idea was that if the ICS (via the CPC) were to have a list of "patient experts" in different fields, ICS committees requiring patient input (e.g. working groups such as the standardisation working groups) could call on the CPC to suggest a patient who could participate. It would be useful for the ICS to have such a list as a source of patient consultants who could be called on when and where necessary, and this could perhaps be done quite simply on the existing ICS list of worldwide organisations by placing an asterisk next to the groups that are patient-run.

The reason "patient experts" are required in such working groups is because of their personal experience and insight into symptoms, impact on quality of life, etc. in specific disorders.



6. WCW

In response to an invite from Sender to attend the ICS meets the continence societies lunch;

Thanks for your email Sender.

It would be good to have discussions on the topics suggested. Currently the Continence Foundation of Australia and the NZ Continence Association work together and promote World Continence Week in both countries using one programme annually and we do so very successfully but we would like to see more useful information coming out of ICS for this as we currently don't find it useful. However, being on the other side of the world we can't attend a 45 minute meeting in Barcelona.

I think it would be useful to arrange an audio conference that everyone can be involved in or if there was a one off non medical two planning conference or something similar that CEOs like myself could attend to work on an international awareness strategy and met each other, it might be possible for us to attend if we could find funding from an organisation within our countries.

I look forward to your response.

Kind Regards

Jan

Jan Zander
CEO, NZ Continence Assn

Continence Promotion Committee Annual Report

Activities:

- Conference call with Satya Vasan, Diane Newman, Jenny Ellis and myself to discuss some historical items and plans for the future. These include WHO designation of WCW, future of the public forum, as well as project and material development and possible restructuring within the committee for efficiency.
- An online survey was written by the chair and completed by the group with very good response rate. A review of this information will take place at the committee meeting to develop guidance for future plans and goals that will translate into clear action items. (See appendix for summary)
- Brian Buckley and Anita Saltmarche stepped down from the committee.
- The public forum was cancelled this year largely due to failure to identify a group with “feet on the ground” in Barcelona to handle the organization and planning. This was a difficult decision. The future of the public forum will be discussed at the committee meeting.

Requests and Considerations:

- Some members of the CPC have raised issue with there not being a patient advocacy group represented on the Board of Trustees. This has also been a continuing issue within the CPC as individual patient advocates feel they are not getting adequate exposure.
- Would like the CPC workshop at the Annual Meeting be reviewed and approved by the Board rather than the education committee.
- Seems to be a “disconnect” between the CPC and the Board and we need to figure out how to close that gap and increase communication. Many CPC members do not feel the Board of Trustees supports the work of the committee.
- Concerned about the size of the committee and some inactive members.

Fiscal Requests:

- I would again like to request funding for an interim meeting so provide continuity after the AGM and continue momentum of project and material development- approximate cost £25,000.