



Fistula Committee Meeting, 14th October 2012
Sunday 14th October 2012,
Venue: China National Convention Center (CNCC), Beijing
Room: 405
Time: 12.00-14.00

Attending: Sherif Mourad, Suzy El Neil, Sophie Fletcher, Jacky Cahill, Ahmed Saafan, Hassan Shaker

Apologies: Stavros Charalampous, Ervin Kocjancic, Limin Liao, Diaa Rizk, Gilles Karsenty, Chris Payne

Also in Attendance: Lan Zhu

In Attendance: Dan Snowdon, Tracy Griffin

Please note that a member of the Board of Trustees will be popping into your meeting to discuss the forthcoming ICS strategic planning process.

Please be aware that the below timings are approximates for each point.

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|--|-------------|
| 1. Committee Picture to be taken | 15.00-15.05 |
| 2. Approval of London Committee minutes (Attached) | 15.05-15.10 |
| 3. Approval of Glasgow Committee minutes (Attached) | 15.10-15.15 |
| 4. Awareness Mission update | 15.15-15.30 |
| 5. Fistula Video update | 15.30-15.35 |
| 6. Website update | 15.35-15.45 |
| 7. Committee members- Terms of reference and office (Attached) | 15.45-15.50 |
| 8. Fistula workshop highlights | 15.50-16.00 |
| 9. Activities in subcommittee zones | 16.00-16.10 |
| 10. ICS Fistula Centre in Uganda | 16.10-16.20 |

| | |
|--|-------------|
| 11. Physiotherapist and Nurses affiliation | 16.20-16.30 |
| 12. Gill Brooks offer to liaise with Committee concerning physiotherapy for women who have experienced an obstetric fistula | 16.30-16.40 |
| 13. Budget plan for 2013 | 16.40-16.55 |
| 14. AOB | 16.55-17.00 |

ICS Fistula Committee Meeting
Sheraton Skyline Hotel
London, UK
February 10, 2012

Attendees:

Committee Members: Sherif Mourad , Jacky Cahill, Sophie Fletcher
ICS Staff: Dominic Turner, Chris Angle , Ashley Brookes

Opening Remarks: Sherif Mourad

Meeting Goals:

Small group-focused work on two key issues:

1. Raising awareness about the committee (marketing)
2. Website development

Marketing

- Contacting other fistula organizations internationally to educate them regarding the committees work
 - The goal of this marketing is not primarily to generate funds, but to generate a presence among other similarly-minded incontinence/pelvic health organizations (IUGA, EAU, SIU, AUA for example).
 - This marketing would consist of written information, and personal contact from Jacky.
 - This would result in marketing gains such as having our logo with a link on their website.
 - Secondly, these organizations may have funding to designate for ICS Fistula Committee work.
- Creating awareness for organizations and potential fistula course trainees in the developing world:
 - How can we communicate with people in the developing world, and let them know about the training courses, especially when they represent the group with the greatest need?
 - Communicate through ISOFS, AFFCS (Africa Fistula & Continence Society), PACS, PAUSA (Pan African Urologic Surgery Association), Asian Urological and Gynecological Societies, UNFPA, WHO

- Jacky may be able to send email bulletins to these societies' members through their member email address listings
 - Dominic to set up an ICS email account for Jacky, given that she will be contacting these organizations regularly
 - Dominic will also set up a more discrete link to the Fistula Committee microsite, www.icsoffice.org/fistula
 - This will be easier to include in emails, and add as a link for organizations and individuals on their websites
- **Action items for Jacky:**
 - 1. Dominic to set up an email account for Jacky to email overseas organizations**
 - 2. Jacky to contact organizations**
 - 3. Jacky will report back to Sherif April 1st regarding her progress**

Prevention of obstetric fistulas:

- Question of “prevention” came up as an area where Fistula Committee has not yet focused efforts.
- Discussed that awareness is a first step toward prevention
- Concluded that efforts will be focused on awareness and training course development for now
- Review of meeting minutes from Glasgow meeting show that committee decided to focus efforts on:
 - Awareness of the committee among ancillary healthcare professionals
 - Treating the complex complications associated with failed fistula repair, and teaching this to others

Fistula Textbook

- To be Published by ICS
- To be edited by Sherif et al.
- Preliminary list of chapters with authors discussed
- Chapters to represent: history, epidemiology, surgical technique, complications of fistula repair surgery, rehabilitation, to name a few
- Sherif to contact proposed authors individually regarding participation

Video Editing: Sherif, Chris, Ashley

- Sherif has many videos of fistula surgeries, each several hours long
- Sherif worked with Chris and Ashley to edit these videos into shorter videos.

- Surgery videos will be available for “members only” viewing on the ICS Fistula Committee microsite
- Another use for the videos will be to produce a more comprehensive e-learning module for the main ICS website
- **Action for ICS OFFICE – Ashley Brookes:**
 - 1. Edit down the rest of the videos and make them available to sheriff via a hidden webpage on the ICS Website.**
 - 2. Arrange another meeting with sheriff to narrate all the videos.**

Website Updates: Dominic and Sophie

- Title banner of microsite changed from “Fistula Worldwide” to the more appropriate “ICS Fistula Committee”
- Discussed changing Fistula Committee logo to say: “Fistula Worldwide. Care Across the World” (The group agreed on this.)
 - Dominic will follow up with logo changes
- Mission statement to be outlined on first page of microsite
- A slideshow of photos from surgical training courses will be added to the top of the page
- Tabs in left sidebar updated:
 - MEMBERS
 - Associate Member category of the Fistula Committee is dissolved, per Sherif
 - Members section updated with addition of associate members: Stavros Charaloambous, Paul Hilton, Diaa Rizk, Lan Zhu and Edward Stanford
 - NEWS
 - Sophie will work with Sherif to create more Fistula Committee news
 - This will start with updates regarding recent past, and upcoming surgical training courses
 - DOCUMENTS AND FORUMS
 - Several outdated documents were deleted, updating the section
 - INFORMATION AND E-LEARNING
 - This section separated into 2 new tabs:
 - PROFESSIONAL EDUCATION
 - Will consist of surgical technique teaching videos, ICI chapter updates, and A reference list of research publications/presentations by committee members

- PUBLIC INFORMATION
 - Consists of the *Obstetric Fistulas in the Developing World* leaflet, the *ICS Obstetric Fistula Video*
 - The ICS Fistula Committee Fact Sheet will be added to this section
- CASE HISTORIES, SURGERY AND SUCCESS STORIES
 - This section was changed to PATIENT STORIES
 - Sherif will upload patient photos from his surgical training courses and add captions, to be added to this section
- WORKSHOPS AND EVENTS tab was changed to SURGICAL TRAINING
 - This section outlines the schedule of surgical training courses, past and future.
 - The format of the schedule was updated for easier navigation
 - Each new posting for a course will have a link directly to the application form for the course
 - The schedule was updated with the upcoming Luxor training course
 - A goal will be to keep this schedule updated 6 months in advance of course dates, and always have a notice stating when course enrollment is full
- FINANCIAL SUPPORT tab was changed to DONATE NOW
 - The goal of this change is to make it easy for site visitors to make donations toward the mission of the ICS Fistula Committee
 - This tab will contain a description of expenses incurred by surgical training courses and efforts toward awareness
 - Visitors will be guided toward donation amounts by reading what certain donation amounts can fund
 - For example: “A \$10 donation can buy the food needed by one fistula patient as she recovers in the hospital”, “A \$50 donation can buy the antibiotics and pain medications required by one fistula patient”, “A \$1, 500 donation can fund the tuition for one medical doctor from an underserved country to undergo a fistula repair surgical training course”, etc.
 - Sophie to work with Sherif via email to get estimates on costs of items for this section
 - Dominic to work with accountant in ICS office to set up a user-friendly Pay Pal system for this section
- FISTULA IN THE NEWS SECTION deleted
 - This section was interesting, but difficult to maintain

- When the above-mentioned sections are running smoothly, committee members may elect to re-instate this section and update it regularly
- **Action items for ICS Office – Dominic Turner**
 1. Change microsite banner from “Fistula Worldwide” to the more appropriate “ICS Fistula Committee”.
 2. Change Fistula Committee logo to say: “Fistula Worldwide. Care Across the World”.
 3. Set up on-line photo album account for Sherif to upload photos from past surgical training courses.
 4. Add a slideshow of photos from surgical training courses to the top of the committee web page.
 5. Set up a user-friendly Pay Pal system for donations in the “Donate Now” section.
- **Action items for Sophie**
 1. Get Fistula Committee sign-off on Obstetric Fistula fact sheet for updated PICC publication of Fact Sheet Booklet.
 2. Mission statement to be outlined on the first page of microsite.
 3. Work with Sherif to select photos for website banner showing photos of courses/patients and “Patient Stories” section.
 4. Work with Sherif to update surgical training course schedule.
 5. Solicit references from research published by Fistula Committee members to post on the website.
 6. Work with Sherif to get an idea of what supplies, medications, patient meals, etc. cost during surgical training courses. This is for the “Donate Now” section of the website.

ICS Fistula Committee Presentation to Publications and Communications Committee
Sheraton Skyline Hotel
London, UK
February 11, 2012

Overview of the previous day's Fistula Committee meeting presented by Sophie, with help from Jane and Dominic

Jane Meijlink recommended that Jacky also include the Pan Arab Continence Society in her awareness outreach toward other societies

- Jane also asked for a review of the recent Pan Arab Continence Society meeting, from Sherif, who attended the PACS meeting
 - Sophie will relay this request to Sherif

Jane also brought up to the committee that the mission statement of the ICS Fistula Committee has not drawn up its Terms of Reference

- The Fistula Committee's Terms of Reference will also need to be ratified by the ICS Board of Trustees

Jane also reminded the committee that the Fistula Committee's Fistula Fact Sheet has been written, and needs to be included in the upcoming ICS Fact Sheet Booklet

- As mentioned above, the Fistula Fact Sheet will also be added to the PUBLIC INFORMATION tab in the left sidebar of the Fistula Committee microsite

Jerzey Gajewski suggested that surgical training course attendees receive a formal "Certificate of Attendance"

- The importance of evaluation forms for course participants was also discussed
- The development of certificates of attendance and evaluation forms will be discussed with committee members via the website forum feature

Jane requested that Suzy Oniel contribute a piece to the *ICS News* describing her personal experience with fistula surgery in underserved countries

- Sophie will contact Suzy regarding this, and refer her to Jane for editorial style and word limit details



Minutes of the ICS Fistula Committee Meeting

1200-1400, 30th August 2011, Glasgow, Scotland

Attending: Sherif Mourad (Chair), Jacky Cahill, Suzy Elneil, Limin Liao, Chris Payne, Diaa Rizk, Vasan Srin

In Attendance:, Jacques Corcos, Elise De, Ervin Kocjancic, Sophie Fletcher, Ahmed Saafan, Dan Snowdon, Dominic Turner

Apologies: Gilles Karsenty, Mohamed Labib, Hassan Shaker

Approval of the minutes of the last meeting – 24 August 2010

1. The minutes of the last meeting were approved.

Terms of Reference

2. No changes were necessary

Terms of office

3. The committee discussed evaluating the contributions of members each year and asking those who did not contribute to step down. SM would speak to Gilles Karsenty to check if he had capacity to continue on the committee. Mohamed Labib will be removed as committee member due to non-attendance at committee meetings.
4. CP suggested staggering committee terms so the majority of members do not step down at the same time.
5. The group looked at the list of Associate Members. There is likely to be some changes over the coming year.

Zonal Subcommittees

6. The allocation of zones was discussed as follows:
 - a. GK could cover Africa West
 - b. SE suggested splitting Africa between Anglo and Francophone, SM will consider and allocate responsibilities accordingly. SM confirmed post-meeting that the committee shall work in Africa through 2 main zones; one in the north east region and one in the west. For the west of Africa, GK can cover the francophone countries, while SE will cover the Anglophone countries.
 - c. EK and CP to work on the Americas Zone.
 - d. Discussion over how the committee could reach Afghanistan.

Fund raising follow-up

7. SM felt that the committee needed a better strategic plan in order to leverage funding. Jacky agreed to provide SM with a draft plan.

Action: *J Cahill to receive details of planned budgets and activities for next year (up to two). J Cahill to then provide a draft funding strategy plan to Sherif.*

J Cahill leaves the meeting

Fistula centres

8. The committee discussed how to support fistula centres, and how this could make an impact. ED asked what the missions of each project were. SM reported that he had been in contact with AUA, SIU and EAU contacts regarding treatment centres in Africa. All three had asked for a well written proposal before investing.
9. SM presented a plan to create an international fistula centre in Uganda under supervision of ICS and with the collaboration and donations of other big organisations. CP suggested that the committee could offer teaching courses for the right centre. JC recommended that fistula centre approach the ICS to put their cases forward.

Fistula courses update

10. SM provided an update on courses held to date and planned for 2012. The summary from the slide is shown below:
 - a. **The first ICS Fistula Workshop was held at Ain Shams University Hospital in Cairo**, 16-17 January 2010, in collaboration with the Pan Arab Continence Society (PACS). The participants were urologists, gynaecologists, and urogynaecologists from Senegal, Benin, El Salvatore, Honduras, USA, United Kingdom, Indochina, Saudi Arabia and South Korea.
 - b. **The second ICS Fistula Workshop in Kampala – Uganda;** Following on from the success of the 2010 Fistula Workshop, the ICS offered 5 ICS members the chance to attend the 2011 Surgical Repair to Vagina Fistula Workshop in Uganda. The workshop took place between 28th-30th April in Kampala at the Kibuli Hospital. The trainees were ICS members from Burkina Faso, Jordan, Egypt, Canada and Mexico.
 - c. **The ICS Fistula Surgical training course in Chengdu – China.** Limin Liao the China subcommittee chair organized an ICS fistula course in collaboration with the Chinese Continence Society. Sherif Mourad was invited to perform live surgical training for fistula repair. Two live surgeries were performed and transmitted directly to the conference room where all the audience were.
 - d. **The next or 3rd ICS Fistula Workshop will take place in Luxor – Egypt on March 15-17th, 2012.**
 - e. **A 4th may be held in Uganda in December 2012**

11. EK asked what happened after the course and was it known what training achieved? A post course evaluation measure should be developed. JC asked if the current method is the best option, or should the committee arrange for surgeons to be sent to existing centres. There is a need to work with locals but ICS should be the driving force behind this collaboration.
12. JC stressed that the course teaching staff must be changed, even though they are good teachers. This is to show inclusivity to ICS members. ICS e-news or the website could be used to enlist interested speakers. SM was happy to do this but said any speakers must be reliable and experienced. DT mentioned that the course speaker database already on the ICS website could be amended to include details for possibly fistula speakers.

Action: *Committee to enlist new teachers at forthcoming fistula courses.*

13. JC asked if nurses and physios will be involved. SM replied that this is planned and will speak with the committees.

Action: *Sherif to speak to Nursing and Physio Committee regarding trainers at forthcoming fistula courses.*

Suzy Elneil leaves the meeting

14. ED asked the Fistula Committee to link more closely with the Education Committee.

Fistula website

15. SM thanked Jane Meijlink for her hard work to date. Jane has now stepped down from the committee. Jacky Cahill was nominated as suitable replacement as website lead, should she be willing to accept.

Action: *Jacky Cahill to take over as Fistula website lead, in place of Jane. Pending Jacky's acceptance.*

Fistula Fact Sheet

16. This is now complete and will be added to the fact sheet booklet.

Research projects

17. Some are underway but more attention could be given to this area. CP presented an ongoing fistula project from his institution. The results will be shared with the committee. JC noted that the ICS can assist in centralising the data.

Meeting adjourned

ICS Fistula Committee Terms of reference

Mission: To reduce the number of obstetric fistulae worldwide through education, advocacy, and collaboration. The ICS Fistula committee will lobby to unite organizations to prevent duplication of efforts and to evaluate outcomes.

Background: Obstetric fistulae are pervasive in some countries as a result of poor prenatal care, female genital mutilation, early age of pregnancy, and poor delivery practices. Currently, prevention strategies are limited in effectiveness and physicians do not have the knowledge to effectively repair fistulae when a woman presents with problems. Women suffering from obstetrical fistula can have urinary and/or faecal incontinence so severe that they are ostracized in their communities. Hospital services are limited and often long distances from the woman's home village. Many international groups are involved in aspects of fistula management and this can lead to independent and less effective approaches to care than if services were united.

FUNCTIONS:

- Research:
 - Collect data (or use existing data) on the prevalence of obstetric fistulas and incontinence
 - Determine target area for ICS involvement based on prevalence data, existing services, and perceived need by community
 - Collect data on the subjective impact of obstetric fistula
 - Determine focused need for ICS fistula committee involvement based on services available, number of potential patients, healthcare professional support, and building/infrastructure.
 - Focus, based on the above, on two or three key areas for education and support.
- Education:
 - Provide 2 ICS endorsed Training sessions annually to healthcare professionals involved in ante and post natal care to 'train the trainer' and increase clinical skills in voiding dysfunction, Obstetric Fistula and treatment of surgical complications.
 - Sponsor 1 ICS endorsed session annually with a specific focus on surgical repair of fistula
 - Encourage participation in annual ICS fellowship and award opportunities to increase knowledge and skills in all aspects of obstetrical fistula.
- Advocacy

- Identify a “champion” in the targeted areas who will lobby on behalf of both the ICS and the community.
- Establish and maintain links with other International Authorities & Societies also involved with fistula management, including WHO, UNFPA, Engender Health, EAU, AUA, SIU, IUGA, PACS, ISOFS, AFFCS and others.
- Fund raise with the support of the ICS to Supply Training Centers
- Fund raise to support fellowship and research award funds for healthcare professionals to visit other sites for education and experience.
- Work with local agencies on prevention strategies and to actively lobby for prevention of fistula.

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

4. COMPOSITION:

| Total Members | Method of Appointment | Name | Term of Office |
|---------------|---|----------------|---|
| Chair: | <p>Elected.</p> <p>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.</p> | Sherif Mourad | Term of office: 3 years, but renewable after notification to the members at an AGM. ICS Bylaw #3. |
| Membership | All members of ICS committees must be active ICS members (paid for current membership year) (By-law 2.3.2) and have completed a disclosure form. | See Appendix A | 3 years, but renewable once by the Chair/Committee |

| | | | |
|--------------------|---|--|--|
| Subcommittees | Zonal distribution of subcommittees in Africa (3 SC), India, Bangladesh, China, Russia, Latin America (1 Sc each) | | 3 years, but renewable once by the Chair/Committee |
| Updated March 2012 | | | |

5. MEETINGS: Two face-to-face meeting one during the Annual Scientific meeting; and one in mid-year (during the EAU meeting or according to the tasks of the committee) .

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

7. MINUTES: Extract from the 2011 ICS Bylaws:

6 Minutes

6.1 Minutes of all General Meeting, Board of Trustee meetings, any formal meetings of ICS officials and ICS committee meetings must be recorded, and kept at the ICS office and published on the ICS website in the members only section.

6.2 Draft minutes of the meetings shall be sent to all those who attended for correction and subsequently made available to all ICS members via the website within six weeks of the date of that meeting.

6.3 Only a member attending the meeting in question may comment on the accuracy of the draft minutes. Any ICS member can comment on the subject discussed or the issues raised.

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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.

Terms of office

| Role | Member | Term Start | Term End | Term Yrs | Elected | Term details |
|------------------|-----------------|-------------|-------------|----------|---------|--|
| Chair | Sherif Mourad | 26 Aug 2010 | 29 Sep 2013 | 3 | Y | 3 year term will finish 2013 - can renew once by formal election |
| Committee Member | Jacky Cahill | 26 Aug 2010 | 29 Sep 2013 | 3 | N | 3 year term will finish 2013 - can renew once |
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| Committee Member | Hassan Shaker | 26 Aug 2010 | 29 Sep 2013 | 3 | N | 3 year term will finish 2013 - can renew once |
| Committee Member | Vasan Srin | 26 Aug 2010 | 29 Sep 2013 | 3 | N | 3 year term will finish 2013 - can renew once |

| | | | | | | |
|---------------------|-----------------|-------------|-------------|---|---|---|
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Appendix A

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| Committee Member | Chris Payne | 26 Aug 2010 | 29 Sep 2013 | 3 | N | 3 year term will finish 2013 - can renew once |
| Committee Member | Hassan Shaker | 26 Aug 2010 | 29 Sep 2013 | 3 | N | 3 year term will finish 2013 - can renew once |
| Committee Member | Ervin Kocjancic | 18 Oct 2012 | 23 Oct 2015 | 3 | N | 3 year term will finish 2015- can renew once |
| Committee Member | Sophie Fletcher | 1 Sept 2011 | 30 Oct 2014 | 3 | N | 3 year term will finish in 2014- can renew once |
| Committee Member | Ahmed Saafan | 18 Oct 2012 | 23 Oct 2015 | 3 | N | 3 year term will finish 2015- can renew once |
| Committee Member | Diaa Rizk | 18 Oct 2012 | 23 Oct 2015 | 3 | N | 3 year term will finish 2015- can renew once |