

International Vasa Previa Foundation, Inc.

Executive Committee Meeting Minutes for 13 November 2006

Executive Committee members present:

- Amy Brown Gaghagen, President
- Victoria Goldstein, Treasurer / PR Committee Chairperson
- Cindy Paris, Secretary / Membership, Nominating Committee Chairperson

Phil Millard, Vice President was not present

IVPF Committee chairpersons present:

- None

Others present:

- None

Meeting began at 5:03 pm GMT (11:03 am CST)

The Executive Committee minutes from 30 October 2006 were unanimously approved for archival and distribution with one change – to include in new business the vote to automatically approve new participating membership requests until the annual members meeting mailing goes out.

The last IVPF monthly members' meeting took place 1 Nov at 1pm CST (7pm GMT). Amy hosted. Nobody showed up.

Agenda:

- Officer Reports
- Treasury Reports
- Membership Committee Report
- Public Relations Committee Report
- Research Committee Report
- Fundraising Committee Report
- Education Committee Report
- Support Committee Report
- Nominating Committee Report
- Old Business
- New Business

Officer Reports:

- President
 - No report given.
- Vice President
 - No report given.
- Secretary
 - Mike Krznic has generously offered his expertise and is working with Cindy on the website upgrade.
 - The InterNational Council on Infertility Information Dissemination

<https://www.inciid.org/> is seeking nominations for specialists to honor (one per month throughout the year). Secretary suggests that IVPF nominate Yinka Oyelese MD for this honor.

- Treasurer
 - Sophie's Walk has earned \$17,417.60 to date.
 - Amy has investigated a new bank due to the issues with Wells Fargo. The National Bank in Moline, IL has free accounts for non-profits with no monthly fees or conversion fees for funds coming from Canada. There is an ATM in Ft. Lauderdale that will accept items for deposit. IVPF accounts will be opened immediately.
 - USA
 - Donations and interest: \$4,758
 - Expenses: \$772.41
 - Total cash on hand: \$33,676.63
 - In-kind donations: \$0.00
 - Thank-you notes sent to donors: 42
 - UK (No report given)
 - Donations and interest: £ 0.00
 - Expenses: £ 0.00
 - Total cash on hand: £ 604.39
 - In-kind donations: £ 0
 - Thank-you notes sent to donors: 0

Membership:

- There are 4 pending participating members.

Public Relations:

- Press Release on April 2006 ACOG article was proofed and changes are being made.
- Cindy sent a second email to Karen Adurty asking permission to use her email as a testimonial on the IVPF website. We have not heard back from Karen yet.
- Ring Master: A book, "Ring Master" has been written by Mark Ring, Wales rugby star and father of Ellie Ring who died from vasa previa 10 years ago. Book is available for purchase at http://www.amazon.com/Ring-Master-Incredible-Rugbys-Prince/dp/1845962311/sr=11-1/qid=1163349665/ref=sr_11_1/002-2927979-0572022 There is a chapter on Ellie's loss and the result it had on Mark's marriage to IVPF member Hayley Ring. Additionally, a story was published about Mark and Hayley's terrible loss by ICWALES newspaper on 12 November: http://icwales.icnetwork.co.uk/0100news/features/tm_headline=my-marriage-failed-after-we-lost-ellie&method=full&objectid=18084246&siteid=50082-name_page.html This newspaper article has been included on the "in the news page" of the IVPF website. It was suggested that the IVPF contact Mark about possibly filling a "celebrity spokesperson" role for the IVPF. TABLED until the logistics of contacting him can be worked out.
- There is a well known African American actress/comedian who has a vasa previa child. Victoria will write to her regarding celebrity sponsorship of the IVPF.
- Baby Radio contacted Carol Prentice wanting to chat with her on 15 November. Victoria will send her the IVPF key messages and vp facts.

Research:

- No report given.

Fundraising:

- **Sophie's Walk** has generated \$17,417.60 to date.
- **RJ Nixon:** The Make My Non-Profit Run Better has sent a request for IVPF to fill in a survey about the contest. Amy filled in the survey on 16 Oct 2006.
- **Holland American Cruise Lines:**
<http://www.hollandamerica.com/about/socialResponsibility>. Amy has written to Donna Wilson who suggested this asking her to look into it for us.
- **Community Health Charities (CHC):** The St. Louis Women's Fund
<http://www.soswomensfund.org/> has contacted CHC stating that they have money available to give to charities working in the greater St. Louis area. Grants are not restricted to issues affecting only women. Letters requesting consideration for this grant must be received by 30 November. Amy is applying.
- **Escrip fundraising program:**
http://www.escrip.com/merchants/identity/schnucks/community_stl.jsp
http://www.escrip.com/merchants/identity/schnucks/stl_coordinators.jsp Amy has applied for the program.
- **ClubShop Mall:** <https://www.clubshop.com/cgi-bin/members/MW3253769> Amy has contacted Michel Wubbs about this program. He has responded with an additional email with details.
- **Google AdWords:** (revisited) Google has a Google Grants program for their AdWords which means that even if there are no companies paying for google advertising about vasa previa, the IVPF might still be able to be "advertised" on pregnancy complication search sites, free of charge, without having to have the Google Ad Words advertising on the IVPF site (of which there are none for vasa previa). Amy will check it out.
- **GoodSearch:** <http://www.goodsearch.com/About.aspx#faq> Amy sent an email to Amy McPherson who suggested this, asking her to provide details.
- **National Institutes of Health (NIH) Grants:**
http://grants1.nih.gov/grants/funding/funding_program.htm Jeannette is looking into this.
- **IVPF STORE:** Victoria suggested that IVPF have a "featured item of the month" for the store. Starting with the recipe book or the Holiday Cards. Emails need to be produced and sent to the IVPF newsletter group, the Vasa_Previa email group, and all IVPF participating members. Victoria will write the emails promoting different items each month. Cindy will edit with links and send to the email lists. An email promoting the cook book has been written and sent out to the email groups and participating members.
- **Better Business Bureau USA (BBB):** Amy is following up on this and applying for IVPF membership in her local BBB's charity list which is accessible nationally.

Education Committee Report:

- **6th World Congress in Fetal Medicine 2007:** Croatia:
http://www.fetalmedicine.com/wcfm_intro.htm This conference is an annual event with approx 1,500 OBGYNs from around the World. It is nearly as big as ISUOG and is directly relevant as a target conference. The cost of our attendance in 2007 will probably be free, or nominal. Daren will check with FMF. If available, Daren & Natalie will attend. Mike Krznanic (who speaks Croatian) is willing to attend and staff this event as his own expense.
- **National Childbirth Trust (NCT) Conference 2007:** Brighton, England:
http://events.nct.org.uk/event_info?event=2 This is a useful exercise, and it does get to grass roots awareness, in that it is mainly midwives and Lamaze (type) teachers who attend, around 600 - 700 attendees. In view of funds, we may have to cut this conference next year.

- **Fetal Medicine Foundation of America (FMFA)**
<http://fmfaus.meetingpro.info/registrants/MasterSeries06/MasterSeries06.htm> 3-5
 November in New York. IVPF sent materials for the NY event. Brochures arrived and only very few were left at the conclusion of the meeting. The FMFA contact will bring them back to Fort Lauderdale for the next meeting. After that is 30 November - 3 December in Ft. Lauderdale which Victoria will be attending in person. Amy will send Victoria the banners and about 50 reprints of the April article.
- **Royal College of Obstetricians** 23rd November London multi-professional conference/course titled "Failing Maternity Services - Lessons Learnt" Daren has looked into this event and his view is that; (a) while there is a target audience for awareness purposes (mostly midwives etc), it is unlikely that our costs of attending would be outweighed by the levels of awareness raised. (b) it is also unlikely that we would be able to get anyone, local enough to the venue, to be able to attend at such short notice. This is a one day event and unlikely to have an exhibitors hall, though he awaiting a reply to a request for more information. For information see the following link
http://www.rcog.org.uk/resources/Public/pdf/prog_failing_maternity_231106.pdf
- **Association of Professors in OB/GYN (APGO-CREOG)** <http://www.apgo.org/home/>
 CREOG is part of ACOG. It is the Council on Resident Education in OB/GYN.
http://www.acog.org/departments/dept_web.cfm?recno=1 March 2007, Salt Lake City, UT, USA. A doctor at the ACOG conference suggested IVPF attend. Amy will write to the contact about an application. Cost is \$1,550 (USD). Victoria asked for discount, but never heard back. She will contact them again. It was suggested that Bryce and Miriam Gerritsen be asked to help staff or even help fund this event with VPF of Utah dollars. Daren believes that this is the sort of course we should aim for!!
- **International Society of Obstetric Medicine (ISOM):** 15-17 Nov 2006 Taking place at the Royal College of Physicians in London:
http://www.isomnet.org/ObMed_01/default.cfm?sect=News&id=2&EID=84 IVPF will not be doing this event.
- **Medical Complications in Pregnancy:**
<http://www.prossl.com/symposiassl/eventprog.asp?year=06&evcd=15> Registration form:
http://www.isomnet.org/obmed_01/sections/News_events/supdocs/RoyalCollegePhysicians2006.pdf Contact info: The Symposium Office +44 (0)20 7594 2150,
sympreg@imperial.ac.uk This event is approved pending cost information and volunteers to staff. Daren has spoken to a Diana May of the Symposium organizing body and she advises him that this event is for up to 200 - 250 delegates (a mix of doctors of all levels and some radiologists). She also advises that it is unlikely that they would give us a stand gratis, as they too are a charity, but they may, for a nominal fee, put our literature in the delegates bags [say £50.00 for 250 items like the IVPF brochure for example. Daren gave Diana our web site details for her to make her enquiries, but they will need the items by Monday next. Daren heard from Diana on 1 November who thanked him for our interest in exhibiting at this meeting but stated that the course directors do not feel that VP is particularly relevant to the delegates who will be attending.
- **2007 American Institute of Ultrasound in Medicine (AIUM) Annual Convention and Preconvention Program** March 15-18, 2007 Marriott Marquis Hotel, New York City, New York, USA <http://www.aium.org/cmeActivities/events/ann2007/intro.asp> Daren considers this a major event for our target audience. IVPF has attended this conference in the past and currently sends IVPF materials to be distributed to its participants. Due to the fact that the majority of the attendees are not involved with obstetrical ultrasound, that IVPF is not a sponsor of this event, and that ultrasound organizations (including the AIUM)

are currently aware that vasa previa can be prenatally diagnosed and survived, it was decided not to pursue attendance at this event this year due to the budget crunch. IVPF will send materials.

- **Perinatal Society of Australia and New Zealand's (PSANZ) 11th Annual Conference** taking place in Melbourne, Victoria, Australia 1-7 April 2007. <http://psanz07.eventplanners.com.au/> This event is approved. Since we have a couple of hospitals wanting vp presentations in Australia, perhaps we can arrange them at the same time as this meeting. Natasha Donnelly will be contacting Professor Morris who is the PSANZ coordinator for NSW Australia on behalf of the IVPF. We have 6 local volunteers for this event already, possibly 7. Natasha Donnelly, who suggested the event, is heading it up. She has a lot of experience doing medical information booths. Booth cost is A\$3700 (about US\$2800). Daren and Natalie Samat should be in Australia at the same time as this conference and if able to attend will do so. Daren has also been invited to speak at two large NSW (Australian) hospitals by an OBGYN who we met at ISUOG and subject to available dates intends to do so. Daren & Natalie will be paying their own airfares and accommodation costs whilst in Melbourne. This event has been applied for and paid.
- **American College of Obstetricians and Gynecologists (ACOG) Conference**, San Diego, CA., USA, May 2007: <http://www.acog.org/acm/program/welcome.cfm> Due to the high costs involved and not having a film (due by Oct 2006) to submit for the May 2007 film festival, it is agreed that IVPF will not be attending this meeting.
- **International Confederation of Midwives conference** 1 - 5 June 2008, Glasgow. www.midwives2008.org ; Royal College of Midwives website at www.rcm.org.uk. This is a huge international event and there has been a call for extracts by January 2007. Carol Prentice reports that this event would be a chance to influence and inform the profession and make contacts across the world. Daren asks who is organizing this event or if it is one the IVPF conference organizer is supposed to look into “re cost & volunteers etc?”
- **31st British Congress of Obstetrics and Gynaecology (BCOG)** Wednesday 04 July - Friday 06 July 2007, London, England, <http://www.bcog2007.co.uk/> BCOG 2007 Secretariat; 4B, 50 Speirs Wharf; Port Dundas; Glasgow G4 9TB; UK info@bcog2007.co.uk Carol Prentice has looked into this event. The deadline for any abstracts is 24 January 2007 (these may also be on video/dvd) and the reduced registration rate ends on 25 April. Full registration will cost £450 up until 25 April and £525 after that. Day registration will cost £19. Accompanying person's registration will cost £105 all inclusive of vat. Accommodation falls into 3 categories and range from £100 per night to £220 per night although rates could no doubt be negotiated. Range of hotels is listed on the Congress website as is the full confirmed programme. Daren Samat believes this to be the very sort of conference we should attend. This event has been approved pending volunteers to staff.
- **International Society of Ultrasound in Obstetrics and Gynecology (ISUOG) 17th World Congress** Sep 2007 <http://www.isuog2007.com/> Daren Samat, Phil Millard and Amy Brown Gaghagen looking into whether in exchange for a card swipe system ISUOG will admit IVPF free of charge and as sponsors for this event. Daren feels strongly that ISUOG is the main conference for IVPF target audience. IVPF sponsorship of this event via the card swipe system would be ideal as it has been agreed that this event is too expensive to attend on a regular basis given that ISUOG has recommendations for vasa previa and already knows that vp can be prenatally diagnosed and survived.
- **Grand Rounds:** Jenna Steckler has agreed to coordinate the grand rounds program. Cindy will send her the outstanding requests with the subject [IVPF Grand Rounds]
- **International Woman's Day 2007:** Carol Prentice to look into raising IVPF's profile and awareness of vasa previa at this event. Current status unknown.

- **IVPF "Essential Reading on Vasa Previa"** Updates need to be made and the project reviewed. Amy produced a very informative file of literature made up of printed materials from the medical resources page of the IVPF website. This information is available for all delegates to view at conferences. The cost of mass production of this item (including reprints of all the articles) as a conference “giveaways” would be problematic in two respects (1) cost (2) copyright. Daren suggested we print off our list of medical resources by their citation, and make this available for delegates at conferences. The delegate all have subscriptions to the journals, and if they don’t their hospitals do, so access to a complete list of current literature is all they need. This has the benefit of being this is easy and cheap and, as new material becomes available, it is easy to update at no further cost to us. It was noted that IVPF currently makes a list of vp medical papers and citations available at conferences and that doctors do not pick it up. Amy mentioned that the delegates want and take the medical papers themselves (reprints) and pens rather than the abstracts and article lists that the IVPF prints up and makes available. They will take these other things, but mostly take only the reprints and pens. Cindy mentioned that while the essential reading is not a big priority right now, she’d still like to see if about the copywrites as it would be far more valuable to use to give out a book of the reprints of the medical articles themselves.
- **IVPF In-Service Presentation Materials:** Kristy Edwards, Lisa Paine, Jenna Steckler, and Anngye Chapman are actively working on this. Lisa Paine has been delayed in this project but will have additional time to devote to it in December.
- 10,000 IVPF brochures are being printed. Victoria will receive 500 and the remaining 9,500 will be shipped ½ to Amy and ½ to Cindy by the end of the week. Victoria was able to get a \$50 discount bringing the price down to \$800 for the brochures. Shipping will be \$80.
- IVPF brochure files have been sent to Mike Krznaric, Daren Samat, and Natasha Donnelly for professional printing in Canada, England, and Australia. Daren and Natasha will obtain and submit quotes for professional printing. Mike will be printing on 28 pound shiny stock at his own expense. It was suggested we have an additional set of the posters that we use at conferences printed. Victoria will have this done at Kinko’s.
- Daren suggested that we should have a disclaimer on all of our own literature, which should read something like “the information provided herein is not intended as a substitute for medical advice, always seek the advice and opinion of your obstetrician.” Phil had suggested this item previously and it was approved for the IVPF website in an earlier meeting, but not yet implemented. After some discussion it was decided that this disclaimer is inappropriate for IVPF print materials. Cindy will see that it is included on the website, however.
- At the Education Committee meeting 8.10.06, Daren was asked to be the conference coordinator for IVPF. He is happy to do so, but feels that it is difficult to co-ordinate several conferences when others seem to have close liaison and involvement in some of the events and their planning. He is loathe to repeat work already done, as it is a waste of time and feels that in all likelihood he will undo good work and close liaisons already done/created. If he is to continue in this role, he will need to know that the conferences listed herein represents a full list (to date) of the conferences anticipated. He will also need to know if he is the only IVPF liaison with these conferences (it would be desirable as otherwise things will get very unwieldy and we will look unprofessional). He will also need to know what work, if any, has been done in organizing our proposed attendance at each of these events (contact names, numbers, correspondence already entered into etc.) It was noted that everything done with the conferences is included in the EXEC minutes. Activities that have been accomplished for each event are also included.

Support Committee Report:

- No report given.

Nominating Committee Report:

- Waiting to hear back from 3 of the nominees. Amy will telephone the 3 nominees. We will consider them "declined" if not heard back by the end of this week.

Old Business:

- **Grants:** Lehman grant has been mailed off. The Chiron grant which 85% finished.
- **General Liability Insurance:** Bill Phillipe will be giving us a bid on general liability coverage which would cover all conference events and coverage for the USA walks that require insurance. Cindy Paris has followed up on this bid twice in the last 2 months. Jeannette Schwartz will follow up as she has contacts with the company.
- **Medical Advisory Board:** We haven't received any acceptance letters back. Amy will re-contact the doctors.
- **IVPF Stamp:** to be ordered. Stamp to say: "This material provided courtesy of the International Vasa Previa Foundation Tel/Fax 267-790-6693 IVPF.org " Amy will purchase 2 of these today.

New Business:

- It was moved and duly seconded that IVPF approve Christina Morales, Michael Krznic, Amanda Krznic, and Laura Durham for participating membership. Motion passed unanimously and noted that all other participating membership requests will be automatically approved until the annual meeting.
- It was moved and duly seconded to nominate Yinka Oyelese MD for honor by the InterNational Council on Infertility Information Dissemination <https://www.inciid.org/> . Motion passed unanimously.
- It was moved and duly seconded that IVPF pursue the google ad words grant. Motion passed unanimously.
- It was moved and duly seconded to include a disclaimer on all IVPF print materials. Motion failed unanimously. (Disclaimer will be included on the IVPF website however.)
- It was moved and duly seconded to apply for membership in ClubShop as recommended by member Michel Wubs. Motion passed unanimously. Amy will apply.
- A meeting was held to discuss the progress of a possible program to be offered to conferences: a magnetic strip swipe card (much like a credit card) that contains the attendees information for the vendors/exhibitors to obtain quickly and easily. This program is still much in the works and no official proposal is ready to bring to the Executive Committee, however it is hoped that progress will be made in order to fully propose this project by the end of 2006. It was mentioned and agreed that IVPF should receive official conference acceptance and IVPF benefits prior to fully implementing and paying for this project. Further discussion on this project was tabled until a formal proposal can be made to this committee.

Meeting Adjourned at 7:03 pm GMT (1:03 pm CST)

The next regular IVPF Executive Committee meeting will take place on Monday 27 November 2006 at 5:00 pm GMT (11:00 am CST, 12:00 noon EST).