

International Vasa Previa Foundation, Inc.

Executive Committee Meeting Minutes for 18 September 2006

Executive Committee members present:

- Phil Millard, Vice President
- Victoria Goldstein, Treasurer / PR Committee Chairperson
- Cindy Paris, Secretary / Membership, Nominating Committee Chairperson

Amy Brown Gagghagen was absent due to personal issues, but gave her proxy on today's new business to Cindy Paris by telephone at the time of the meeting.

IVPF Committee chairpersons present:

- None

Others present:

- None

Meeting began at 5:08 pm GMT (11:08 am CST)

The Executive Committee minutes from 28 August 2006 were unanimously approved.

The last IVPF monthly members' meeting took place 6 Sep at 1pm CST (7pm GMT). No one attended. The next IVPF monthly members' meeting will take place 4 Oct at 7pm CST (1am GMT).

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
 - IVPF SigmaChat rooms have been upgraded to a newer (beta) version.
 - The next IVPF Annual Members' and Board meetings will take place in Osler,

Saskatchewan, Canada on 29 January 2007 at 11am CST (5pm GMT).

- Treasurer
 - There was a question about automatic PayPal notifications to those donating online. Victoria will contact the most recent donors to make certain they are receiving these.
 - Also, Treasurer wants it noted officially that the IVPF is running out of money.
 - USA
Donations and interest: \$650.61
Expenses: \$21,679.06
Total cash on hand: \$21,268.74
In-kind donations: \$0
Thank-you notes sent to donors: 9
 - 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:

- No report given.

Public Relations:

- Press Release on April 2006 ACOG article was proofed and changes are being made.
- Laura Mongiovi's vasa previa story "Heartbreak Couple Call for Scan Change" was published by her local newspaper the "Express and Star" in England, UK. It is not available online. She sent a copy to Cindy Paris and it is listed on the 'In the News' section of the pressroom on the IVPF website. It was noted that this article is interesting in that there is some scope for a follow up on. Cindy will fax the article to Amy and Victoria.
- Alison Hardie, Senior News Correspondent of the Scotsman newspaper in Edinburg, Scotland, UK contacted the IVPF about doing an article on vasa previa for her paper. She wants to interview Carol Prentice. Victoria sent the request on to Carol who is following up.
- An IVPF Press Release and press pack for the walk has been sent to all the walk captains and to a number of the media world wide. Hispanic Press has come through once again with extensive coverage.
- Kim Tippet, the Franklin, NC, USA walk captain is being interviewed for a story about the walk and the local vasa previa baby to be published a week before the walk.
- Leeza Johnson has been diagnosed with vasa previa and volunteered to be scanned for a TV program to be filmed by the BBC in London during her pregnancy. She contacted the IVPF for key messages to give during her interview. Daren has contacted Leeza.

Research:

- Daren Samat's Vasa_Previa email group straw poll results: IVF cases = 3:23 (13.04%); prenatal vp diagnosis = 10:23 (43.48%); placenta previa = 10:23 (43.48%); placenta previa diagnosed = 10:23 (43.48%); low lying placenta = 5:23 (21.74%); low lying placenta diagnosed = 5:23 (21.74%). Other findings: twins = 2:23 (8.74%); fertility drugs = 3:23 (13.40%); rupture after induction = 2:23 (8.74%). Conclusions: IVF, placenta previa, and low lying placenta are truly risk factors for vasa previa.

Fundraising:

- 5,000 walk brochures have been received from PK Broward and are being shipped out to captains requesting them.
- Materials needed for the walk have been personalized and sent to all the walk captains. Information includes a personalized official sponsor letter on IVPF letterhead, a walker plaque with the local baby's name on it, cooler sign, start sign, receipt for captains to issue for donations received at the walk of \$20 or under, poster, local baby's story to hand out at the walk, press release and press materials, personalized inserts for the walk brochures, event report, registration form for unregistered walkers, hero labels for thank you notes and raffle items, and transfers for t-shirts if the captains are willing to have them made. All walk items (other than the local walk pages and the posters) have had the dates removed to facilitate organization of future walks. Registrations are being forwarded to the local walk captains.
- Last walk meeting was on 13 September. There are 49 confirmed walks at this time.
- The Sophie's Walk pages are continually being updated. Local sponsor pages have been added to the St. Louis, MO (29 sponsors) and Franklin, NC (55 sponsors!) walk pages. Walk sponsors are also included on the IVPF corporate sponsor page. Several of the walks have food, water, raffle items, and/or corporate monetary donations. One walk even has 2 mascots attending the event (a minor league ball team Grizzlie Bear "Izzy the Grizzlie", and "Geoffrey the Giraffe" from Toys R Us).
- The International Vasa Previa Foundation is participating in the "Make My Non-Profit Run Better" contest for a chance to win an office technology makeover from RK Dixon. IVPF did not make it through the first stage of the contest.
- Eileen Walters has been helping with the St. Louis, MO, USA walk. She has volunteered to keep doing some fundraising after the walk by contacting businesses around the country for monetary donations (on going project), possibly branching out into helping with grants in the future. Her efforts and energy are amazing!
- Donna Wilson phoned to suggest that IVPF contact the Norwegian Cruise Lines. She cruises with this company who is owned by Carnival Cruise Lines and states that they do fundraising walks on board their ships (500 of them!). Each walker pays \$15 USD and the charity gets \$11.50 of that. Its suggested that we try to set this up to take place over next year's Sophie's Walk weekend. Eileen Walters will follow up.
- Eileen Walters is working on organizing a "run" with Doc's Harley Davidson in St. Louis, MO, USA. Doc's is a big supporter of charities and organizes these runs with bikers signing up and riding 30 miles or so for the charity, ending the ride at a local pub where additional events can take place.
- Community Health Charities (CHC) Workplace Giving Program kick-offs are scheduled for 4 Oct in St. Louis, MO and 6 Oct at Scott Air Force Base, IL. IVPF will have a booth at each event. Costs: \$10 (required) for a table for each event and \$5 for lunch (optional) for each staff member manning the table.
- IVPF speakers are needed for employee rallies for the Workplace Giving Program which will be taking place between now and the end of November. Jeff Paris, Eileen Walters, Amy Brown Gaghagen, and Cindy Paris are being trained to speak at these events. A speech is being written.

- IVPF is part of the Gateway area Combined Federal Campaign with CHC. Amy is looking into qualifying for the national Combined Federal Campaign giving program. If we qualify next year for the national program, IVPF will be able to receive donations from several dozen other major companies throughout the year long on-going program. IVPF may not get a whole lot out of it this first year, but St. Louis City and County, all give to the CHC instead of the CHC's individual member agencies (us), so we will get something. This is a funding source that will grow. Now that we are part of the Combined Federal Campaign we can't let it go to waste. It could be a huge source of income in the future.
- Emails are being written to notify St. Louis families and friends of the campaign. Sample materials for such have been acquired from the CHC. Employees at the City of St. Louis, Ritenour School District, St. Louis County, State of Missouri Employees, Blue Cross/Blue Shield, HDA, Pioneer Bank, Met Life, and the Combined Federal Campaign can give to the IVPF throughout the year via their paychecks through their Workplace Giving Programs at these businesses.
- Cindy stressed that the Community Health Charities Workplace Giving Program is a BIG deal; and one she can not handle on top of everything else. It was suggested that Amy Gaghagen, Jeannette Schwartz, Jeff Paris, and Eileen Walters handle all the speaking engagements, freeing up Cindy to handle the phone calls.
- It was noted that we need someone else to take over organizing the Walks year to year. Neither Victoria nor Cindy can continue as coordinators indefinitely.

Education Committee Report:

- A Yahoo group specifically for Education Committee members has been set up and meeting reminders added to the calendar.
- **6th World Congress in Fetal Medicine 2007**, Croatia:
http://www.fetalmedicine.com/wcfm_intro.htm No details on this yet, except that Daren would like us to do it.
- **National Childbirth Trust (NCT) Conference 2007**, Brighton, England:
http://events.nct.org.uk/event_info?event=2 No details on this yet, except that Daren would like us to do it.
- **International Society of Ultrasound in Obstetrics and Gynecology (ISUOG) 16th World Congress** 3-7 September 2006 in London, England. <http://www.isuog2006.com/> Amy Gaghagen, Daren Samat, Natalie Samat, and Phil Millard staffed the booth. Yinka Oyelese unexpectedly did not attend. This event was a huge success. IVPF netted 60 new contacts and some new ideas for an incidence study as well as an opportunity to create conference card scanners which would enable the IVPF to earn a little money attending conferences, gather contacts far easier, and also sponsor the events we attend or contract the machine out to. Amy got a discount on one night's stay due to some hotel emergency. Kudos for a great show everyone!!
- **Fetal Medicine Foundation of America (FMFA)**
<http://fmfaus.meetingpro.info/registrants/MasterSeries06/MasterSeries06.htm> 3-5 November in New York. IVPF will send materials for the NY event. After that is 30 November - 3 December in Ft. Lauderdale which Victoria will be attending.
- **APGO is the 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.

- **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
2006-09-18 12:41:33 Message cparis IVPF Board Room 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. To date, no one has looked into this event. It was suggested that Carol Prentice or Daren Samat or Lisa Paine be asked to look into the details of this event.
- **Perinatal Society of Australia and New Zealand's (PSANZ) 11th Annual Conference** taking place in Melbourne, Victoria, Australia 1-7 April 2007. Its been suggested that IVPF attend and arrange a speaker for this event. <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). IVPF has received a letter from the event organizers stating that a discount is not available for us. We can 1) wait until after 1 March and get a discounted booth if any are still available, or 2) share a booth with another organization. It was agreed that this event is too important to wait for a discounted booth. Natasha will see about sharing a booth otherwise the fee is due soon. She is also arranging for Dr. Oyelese to present at several events while he is in Australia.
- **American College of Obstetricians and Gynecologists (ACOG) Conference**, Washington D.C., USA, May 2007: <http://www.acog.org/acm/program/welcome.cfm> Letters to doctors from the May 2006 event have been processed and sent out. Thank you Jeannette!
- **31st British Congress of Obstetrics and Gynaecology (BCOG)** Wednesday 04 July - Friday 06 July 2007, London, England, <http://www.bcoc2007.co.uk/> BCOG 2007 Secretariat; 4B, 50 Speirs Wharf; Port Dundas; Glasgow G4 9TB; UK info@bcog2007.co.uk This event is approved pending cost information and volunteers to staff. To date, no one has looked into this event. It was suggested that Carol Prentice or Daren Samat or Lisa Paine be asked to look into the details of this event.
- **Grand Rounds Presentations:** Five have been officially requested by letters to Dr. Oyelese with one set at Lenox Hill Hospital in New York, NY, USA for early November. One hundred physicians and staff are expected to attend. Package of IVPF materials is ready to go out. It includes 100 IVPF brochures, bookmarks, medical resource paper list, IVPF recommendations, abstract of the June 2004 study, and 100 reprints of the April 2006 ACOG paper. Dr. Oyelese cannot do all the requested grand rounds events due to changes in his work schedule. Val Catanzarite MD has agreed to do some of them. An IVPF presentation is urgently needed so that we can approach other physicians who may be able to do them.
- It was mentioned that IVPF desperately needs a coordinator for the grand rounds program. This person would need to liaison between the hospitals/clinics requesting them and the doctors who will be giving them (mainly via email), and also ship the required amount of IVPF materials to the hospitals for these events. One IVPF member was suggested for this purpose. Amy will contact her.

- **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":** we have learned that we will not be able to get permission to reprint the necessary medical journal articles ourselves into a bound publication by the IVPF. We have considered the idea of using abstracts instead, but the April 2006 ACOG abstract (and the most important piece to date) is very poor in relation to vasa previa. (The article itself is GREAT!) IVPF has a binder with information on a number of medical articles listed on the IVPF website. This was put together by Amy Gaghagen for conference purposes. Updates need to be made and the project reviewed for the IVPF Essential Reading on Vasa Previa.
- **IVPF In-Service Presentation Materials:** Additional information has been sent to Lisa Paine and Jenna Steckler for more ideas on CME criteria, etc.
<http://www.medscape.com/womenshealth/cme>
- **Website Stories:** Several new stories have been uploaded or updated to the website.
- Kristy Edwards is a Research Tech at a medical school. She wants to present on vp to each class of medical students. She says there is NOTHING on vp in their curriculum and that doing this will reach about 90 med students per term. IVPF to mail her a piece of our mailing. She understands that we are overwhelmed with the walk right now and WILL follow-up with us on this project. Kudos to Kristy! It was agreed that this is a fabulous idea.
- Eileen Walters has started a write-in campaign to get vasa previa on the Montel Williams Show in the USA. She has shared her idea with subscribers of the Vasa_Previa email list and requested they join her by contacting <http://www.montelshow.com/tell/> with their own story and request or write to The Montel Williams Show, 433 West 53rd Street, New York, NY 10019 USA, Attn: Viewer Services.
- It was suggested that IVPF stamp all reprints and abstracts with: This material provided courtesy of the International Vasa Previa Foundation Tel/Fax 267-790-6693 IVPF.org
- An article on marginal cord insertion that discusses vasa previa rather extensively and gives the IVPF website address was posted on mommyguide.com. The article also quotes IVPF Research Committee Chairperson Beth Farman-Farmaian MD.
- Frankin, NC walk captain Kim Tippet's mother is putting together a tri-fold display on vasa previa to post at her local hospital. Kim's mother is a registered nurse who used to work in labor and delivery. Thirty IVPF brochures, bookmarks, pens, medical article list, and recommendations, the June 2004 abstract, and reprints of the April 2006 ACOG article were sent to her for the event along with suggestions (requested) for information to be included on the tri-fold display. Kim's mother found Nathan Paris' placental pictures on the internet and requested permission to use them on the display.

Support Committee Report:

- No report given.

Nominating Committee Report:

- No report given.

Old Business:

- **Grants:** Amy is working on completing the Lehman grant project. She's also about to start working on the Chiron grant too. The Chiron Grant is 85% completed.
- **Directors Insurance:** Insurance company to invoice IVPF for the policy real soon now (according to the insurance company). 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.

- **Medical Advisory Board:** Amy is drafting invitations. We haven't received any acceptance letters back. Amy will re-contact the doctors.

New Business:

- It was moved and duly seconded to approve the purchase of 2 stamps that say "This material provided courtesy of the International Vasa Previa Foundation, Tel/Fax 267-790-6693 IVPF.org". This will be used on all medical reprints IVPF purchases. Motion passed unanimously.
- It was moved and duly seconded that IVPF authorize full payment for PSANZ event. After some discussion it was decided to hold off on approval until hearing back from Natasha about whether another organization is available to share a booth with. Tabled until next EXEC.
- It was moved and duly seconded that IVPF purchase 10,000 more pens. Motion passed unanimously.

The next regular IVPF Executive Committee meeting will take place on Monday 2 October 2006 at 5:00 pm GMT (11:00 am CST, 12:00 noon EST).

Meeting Adjourned at 5:00 pm GMT (11:00 am CST)