

International Vasa Previa Foundation, Inc.

Executive Committee Meeting Minutes for 10 July 2006

Executive Committee members present:

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

IVPF Committee chairpersons present:

- None

Others present:

- None

Meeting began at 4:07 pm GMT (10:07 am CST)

The Executive Committee minutes from 12 June 2006 were unanimously approved.

The last IVPF monthly members' meeting took place 5 July at 1pm CST (7pm GMT). No one attended.

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
 - Debi Pederson has resigned as of 12 June due to health and family reasons. A letter of acceptance was sent to her on 13 June.
- Secretary
 - No report given.
- Treasurer
 - USA
 - Donations and interest: \$453.87
 - Expenses: \$984.17
 - Total cash on hand: \$43,236.74
 - In-kind donations: \$ 0.00

- Thank-you notes sent to donors: 3
- UK
 - 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:

- Phil Millard is in the process of upgrading the Forum. Upgrades are not online yet.

Public Relations:

- Press release about new Oyelese article has been written and forwarded to Cindy and Amy for review. Victoria will send to the media and Cindy will send to the IVPF email lists and participating members.

Research:

- No report given.

Fundraising:

- A new thank you page has been created for donations received through PayPal. Page is located at <http://IVPF.org/thanks.htm> and directs donors to print out their PayPal receipt for their donation and that donations over \$250 will be acknowledged in writing by the IVPF.
- The Sophie's Walk brochure has been updated and submitted for approval. References to dates have been removed enabling us to order larger quantities at better prices and utilize the brochure from year to year. It was suggested and agreed to add an additional a line to brochure stating "Receipts for donations under \$20 will be given at the walk. Please save your receipt for tax purposes."
- Bids for the walk brochures have been received from Jerome and PK Broward. Jerome's bid was for Size: 11 x 8 1/2, tri-folds; Ink: 4cp/black, bleeds; Stock: 80# Gloss Text; Art: reprint with black copy changes both sides of previous job. Price: 1,000 - \$1,068; 2,000 - \$1,271; 4,000 - \$1,349; 6,000 - \$1,422. PK Broward's bid was \$650 for 5,000. But we need the electronic files from Jerome in high resolution or they will charge us another \$125 for set up fees. The will be printed on 100 stock instead of 80 which is even better paper and same process as Jerome.
- Cindy asked Jerome Group for the electronic files for the walk brochure.
- We only received one reply to the email sent out for Captains. A "save the date" sample email will be sent out to captains to send to their walkers this week.
- 39 walk pages on the IVPF website have been updated, mostly with less detailed date information so that it doesn't have to be changed twice a year.
- 1 order of 5 pens, 1 order of 5 wristbands, and 2 orders for 1 Lucas angel pin each have been processed.
- The following text has been supplied to Community Health Charities to be included in their "what your dollar can do" campaigns: International Vasa Previa Foundation (IVPF) \$1 per week will purchase enough handouts to reach 30 doctors on the importance of vasa previa awareness and prenatal diagnosis of a condition that is 95% fatal to an otherwise healthy infant if not prenatally diagnosed. \$10 per week will fund two IVPF educational hospital events, reaching 60 - 200 doctors with the importance of vasa previa awareness and prenatal diagnosis of a condition that is 95% fatal to an otherwise healthy infant if not prenatally diagnosed.

Education Committee Report:

- **Wycombe General Hospital event:** 17 May 2006 at 10 am GMT. Daren Samat gave a talk on his vasa previa experience. The talk is going to result in a study into the full knowledge of VP in the UK. Dr. Ioannou and Mr. Wayne sent out a questionnaire / survey to OBs and they are looking into what protocols already exist and what knowledge there is generally about VP how to scan for it warning signs etc
- **5th World Congress in Fetal Medicine** 25-29 June 2006, Barcelona Spain: http://www.fetalmedicine.com/wcfm_intro.htm Daren attended this event. Professor Waldo Sepulveda was present in Barcelona and he delivered a lecture on first trimester screening for VCI, which very helpfully concluded with 2 slides emphasizing the warning signs and risk groups for VP along with a summary of the 2004 Green Journal paper (including a reference to IVPF). This was delivered to nearly 1000 doctors at Congress and was the last message ringing in their ears before they packed up the whole conference. He wrapped it up concluding that vp is something they should be routinely looking for.
- **National Childbirth Trust (NCT) Conference** 1-2 July 2006, Brighton, England: http://events.nct.org.uk/event_info?event=2 The conference went very well. There were 550+ delegates at this conference, mostly midwives and NCT teachers. Many midwives still thought that you could only diagnose VP after birth and were completely unaware that it could be diagnosed prenatally. Three of those delegates had suffered VP (one lost triplets and was very moved by our presence), and 4 NCT teachers confirmed that they each currently had VP diagnosed students in their NCT classes. This shows two things (a) VP is not so uncommon and, (b) prenatal diagnosis is, thankfully, on the up. At this conference we also made contact with another Professor Stewart (Leeds).
- **Challenges in Antenatal Screening & Pregnancy Care** 17 July 2006, London. Daren will look into the details. <http://www.arc-uk.org/conference.html> Flyer for event: <http://www.arc-uk.org/arc-conference.pdf> 100 reprints of each medical journal article (the study and the April paper) have been sent to Daren along with 200 IVPF brochures and several hundred bookmarks at a cost of \$118.85 (the box weighed over 28 pounds). 150 pens were also sent separately.
- **International Society of Ultrasound in Obstetrics and Gynecology (ISUOG) 16th World Congress** 3-7 September 2006 in London, England. <http://www.isuog2006.com/> Victoria has applied for an IVPF booth at this event. Daren Samat and Phil Millard have agreed to staff the booth. Amy Gaghagen will also be attending. Yinka Oyelese will be attending. Rooms for Phil and Amy have been booked. Amy will bring the necessary materials with her for this event and leave the extras with Daren.
- **Fetal Medicine Foundation of America (FMFA)** <http://fmfaus.meetingpro.info/registrants/MasterSeries06/MasterSeries06.htm> Next event is 3-5 November in New York. 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. A doctor at the ACOG conference suggested IVPF attend. Amy will write to the contact about an application.
- **American College of Obstetricians and Gynecologists (ACOG) Conference**, San Diego, CA, USA, May 2007: <http://www.acog.org/acm/program/welcome.cfm> Letters to doctors from the May 2006 event are on hold pending the arrival of study reprints. Reprints have been received and information forwarded onto Jeannette Schwartz for processing.
- Two other possible events to consider, the first one suggested by Carol Prentice: **31st British Congress of Obstetrics and Gynaecology** 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 info@bcog2007.co.uk Here's another upcoming event sponsored by the **International Society of Obstetric Medicine**. It is taking place at the Royal College of Physicians in London on 15-17 Nov 2006:

http://www.isomnet.org/ObMed_01/default.cfm?sect=News&id=2&EID=84 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

- **Mailing:** Mailing has been quite successful. IVPF has received almost dozen communications from hospitals and physicians requesting more brochures or information on educational programs for OB departments. At least 6 of them are requests for educational programs (grand rounds). Yinka Oyelese has agreed to do them. IVPF will have to pay speaker's travel expenses and supply materials. There were quite a bit of overruns from this project and IVPF has agreed to purchase them at a discounted price: 58 envelopes; 315 cover letters; 330 of the IVPF statement on risk factors, testing, and management; 655 copies of the abstract for the study (we ran out of reprints and the last batch didn't arrive in time - copies of the abstract were substituted); 296 of the IVPF scientific resources; 4,233 bookmarks (yes!); and 1,865 brochures. All were delivered to Cindy Paris.
- 500 reprints of the ACOG study have been ordered 5 May at a total cost of \$679.00 and were received on 25 June.
- Jerome has agreed to supply IVPF with the electronic files for the IVPF brochure and bookmark, enabling us to hand them off to printers in other countries. This will save us money on shipping the materials overseas.
- A letter was received from an obstetrician in Australia with questions about vasa previa risk factors. A response was drafted, reviewed by the IVPF Medical Advisory Board, approved and sent.

Support Committee Report:

- No report given.

Nominating Committee Report:

- A request for additional committee members went out to IVPF@yahoo.com, all IVPF participating members, and the Vasa_Previa email group on 27 June 2006. No one has responded. The email will be resent.

Old Business:

- Lehman Grant: Amy is working on completing this project.
- CHC application: Ad has been developed, submitted, and approved.
- Directors Insurance: Other requests for firm quote(s) have been sent out to additional companies.
- Medical Advisory Board: Amy is drafting invitations.
- Referral links to Professor Nicolaides <http://www.fetalmedicine.com/> and <http://www.fetalmedicine.com/f-fmc.htm> on the IVPF website as a website referral: This item has not been actioned yet.
- Newsletter: Jeannette is working on this.

New Business:

- It was moved and duly seconded to accept PK Broward's bid for printing 5,000 walk brochures

at a cost of \$650 with the changes made and approved. Motion passed unanimously.

- It was moved and duly seconded to approve IVPF attendance approve the 31st British Congress of Obstetrics and Gynaecology and the International Society of Obstetric Medicine symposium taking place in 2007, pending the receipt of cost information and volunteers to staff the events. Motion passed.

The next regular IVPF Executive Committee meeting will take place on Monday 7 August 2006 at 4:00 pm GMT (10:00 am CST, 11:00 am EST).

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