

International Vasa Previa Foundation, Inc.

Executive Committee Meeting Minutes for 15 May 2006

Executive Committee members present:

- Amy Brown Gaghagen, President
- Debi Pederson, Vice 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 4:05 pm GMT (10:06 am CST)

The last IVPF monthly members' meeting took place 3 May at 1pm CST (7am GMT). Cindy hosted. No one attended.

The next IVPF monthly members' meeting will take place June at 7pm CST (1am GMT). Cindy will host.

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
 - ACOG full report to be sent out today.
- Vice President
 - No report given.
- Secretary
 - Marlou van Dijck from the Vasa Previa Foundation in the Netherlands has decided to move <http://www.vasaprevia.org/nl> to another web host. The move will take place as soon as the new site is ready.

- Domain name IVPF.org was renewed for one year at a cost of £17.61
- Treasurer
 - USA
 - Donations and interest: \$ 21.99
 - Expenses: \$ 3,363.89
 - Total cash on hand: \$ 50,592.20
 - In-kind donations: \$ 0.00
 - Thank-you notes sent to donors: 1
 - UK
 - Donations and interest: £ 14.75
 - Expenses: £ 250.00
 - Total cash on hand: £ 604.39
 - In-kind donations: £ 0
 - Thank-you notes sent to donors: 0

Membership:

- The Forum is being updated to a newer version. Phil Millard is in the process of upgrading the Forum. Upgrades should be online later today.

Public Relations:

- Press release about new Oyelese article will be written.
- Letter to Green Journal commenting about new Oyelese article has been written, approved, and sent to the editors.

Research:

- No report given.

Fundraising:

- Communities Health Charities is having an income development meeting on 2 May. They will be discussing how to open new campaigns this fall. Jeannette Schwartz was not able to attend this meeting. Our local application has been approved! We now need to get going on that campaign.
- Lucas' Angels have arrived - 12 of them, as per our order. They each have a short poem with them.
- The IVPF store has been updated to include 3 new items: the IVPF pens, Lucas' Angels, and the Nelly Hamilton holiday cards. All holiday cards will sell for \$15 (USA/Canada) and \$19 (UK/elsewhere). Lucas' Angel pins will sell for \$5 (USA/Canada) and \$6 (UK/elsewhere). The pens are being sold in lots of 5 for \$6 (USA/Canada) and \$8 (UK/elsewhere). The front page of the IVPF website has been changed to include a photo of all the store items. An email has gone out to the IVPF and Vasa_Previa email groups about the updates.
- Victoria is making copies of her cookbook and will be sending to Cindy to include in the store to be sold for \$20, all proceeds to benefit IVPF.
- Victoria has been talking to three people regarding producing and financing a film on vasa previa. It has to be submitted by October 2006 to be included in the May 2007 ACOG film festival. Victoria hopes to have a filmmaker by the end of this week and believes that we can have the film ready by the submission deadline.
- Amy will try to finish the Lehman grant this week with the idea that it could be used for the film project.
- It was mentioned that getting a sponsor to donate costs for the walk brochure would be nice.
- It was suggested that the walk brochure be edited to remove dates so that a larger quantity can

be printed at a better price. Such brochures would be used from year to year. Cindy will edit the brochure and submit for approval.

- Victoria will see about getting free walk t-shirts made.
- Cindy's sister Angie is planning on donating items for the STL walk. Angie works for Maritz, a firm that does incentive programs

Education Committee Report:

- **Doctors Database Project:** Cindy has been sending Daren contact information from the questionnaires reporting prenatal diagnosis.
- **Fetal Medicine Foundation of America (FMFA)**
<http://fmfaus.meetingpro.info/registrants/MasterSeries06/MasterSeries06.htm> Bookmarks and brochures were mailed on 21 April to Dr. Zador for OB-GYN Ultrasound Master Series 2006 meeting in Chicago April 27-30. Materials were received and distributed at event. Next event is 3-5 November in New York. After that is 30 November - 3 December in Ft. Lauderdale which Victoria will be attending.
- **Wycombe General Hospital event:** 17 May 2006 at 10 am GMT. Daren Samat will be giving a talk on his vasa previa experience.
- **American College of Obstetricians and Gynecologists (ACOG) Conference**, Washington D.C., USA, 6-10 May 2006: <http://www.acog.org/acm/program/welcome.cfm> This was a successful event, though if we do it again we need to have better booth placement. Amy Gaghagen and Jeannette Schwartz have details of 3 dozen doctors requesting more information from us. Many others stopped by just to discuss their own vasa previa case experience. The whole event was really good and Amy is recommending we continue attending even though we've been told there will be no discounted booth fee. The May 2007 ACOG conference is in San Diego, California. Victoria suggests that we work this summer to produce a 10-15 minute video on vasa previa to be included in the A COG 2007 film festival. To be included in the film festival at the next ACOG conference, film must be submitted to ACOG by Oct 2006. Victoria is working on finding film makers/cinematographers and the like to help us produce this project.
- **5th World Congress in Fetal Medicine** 25-29 June 2006, Barcelona Spain: http://www.fetalmedicine.com/wcfm_intro.htm Daren is still working on getting an application for this event.
- **National Childbirth Trust (NCT) Conference** 1-2 July 2006, Brighton, England: http://events.nct.org.uk/event_info?event=2 IVPF is scheduled for this event. Daren Samat will attend.
- **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>
- **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.
- **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.
- **Mailing:** The mailing and materials was handed over to Jerome Group on 4 May. Mailing list consists of 5479 hospitals and fetal medicine specialists in 30 countries. Jerome Group will put

the pieces for Australia, Canada, and the USA into the postal system in those countries. IVPF may have to hand deliver 111 pieces of the mailing for the other countries to the post office because it would not be economically feasible for them to handle such small numbers going to the other individual countries.

- **Conference banners** have been received and shipped to Amy. Our old banners were shipped to Daren on 10 May along with bookmarks, pens bracelets and brochures for his upcoming events.
- **Reprints:** 500 reprints of the new ACOG article have been ordered at a total cost of \$679.00. They arrived on 12 May 2006.
- **Translations:** Victoria will be translating the bookmark and brochure into Spanish. Spanish translation of IVPF statement on risk factors, testing, and management (bookmark) has been completed.
- Cindy contacted iParenting.com on 1 May requesting that they include vasa previa information on their website.
- Lisa Paine's local newspaper has promised to do an article on her vasa previa experience and include some facts on vp.
- The government in NSW Australia has just introduced credentialing for midwives that practice in midwife-led care models. At this stage there are only a couple of hospitals there with such practices, but it is being rolled out more widely. They are still in the planning stages at the NSW Midwives Association (part of the College) and IVPF member Natasha Donnelley is one of the consumer representatives who will sit on the credentialing review panel to assess the midwives! Her findings after speaking with a couple of the midwives she will be working with demonstrate an awareness of vasa previa, but a complete lack of respect for the IVPF management recommendations, believing them to be too clinicalized and unnecessary. This appears to be due to confusion over the differences between velamentous cord insertion and vasa previa. One midwife believes that vasa previa only ruptures if you break the membranes manually and midwives seldom do this. She told Natasha that she would deliver a vasa previa case via home birth as there is no danger. Natasha shared some vasa previa and IVPF information with her and will keep us posted on the progress she makes in her new position.

Support Committee Report:

- Amy will contact Kathy Blades today about the support materials for the website.

Nominating Committee Report:

- No report given.

Old Business:

- Lehman Grant: Amy is working on completing this project.
- CHC application: IVPF has been approved as a local charity. IVPF needs to work on an ad for the employee book.
- Directors Insurance: Schmale Insurance Agency in Belleville, IL bid has been signed and was mailed off on 20 March 2006. Cost for this coverage has unexpectedly increased \$350 from the original quote. It was agreed that Jeannette would look into obtaining "hard bids" from other companies will be reviewed.
- Medical Advisory Board: Amy is drafting invitations.
- Referral links to Professor Nicolaidis <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.

- DMOZ Open Directory Project: Debi's application for the editor position was not approved. She will check why. They did not give a reason.

New Business:

- None.

The next regular IVPF Executive Committee meeting will take place on Monday 12 June 2006 at 4:00 pm GMT (10:00 am CST, 11:00 am EST).

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