

International Vasa Previa Foundation, Inc.

Executive Committee Meeting Minutes for 1 May 2006

Executive Committee members present:

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

Amy Brown Gaghagen, President was not in attendance but gave her proxy to Cindy Paris in advance.

IVPF Committee chairpersons present:

- None

Others present:

- None

Meeting began at 4:01 pm GMT (10:01 am CST)

Executive Committee Minutes from 3 April 2006 were unanimously approved for archival and distribution.

The next IVPF monthly members' meeting will take place 3 May at 1pm CST (7am 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
 - No report given.
- 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. Hopefully this will take care of the non-functioning aspects of the current version.

Public Relations:

- Information about vasa previa has been submitted to the HAND website www.indogo.karoo.net/hand.htm and posted there.
- Press release about new Oyelese article will be written this week.
- Letter to Green Journal commenting about new Oyelese article has been written, edited, and approved. Victoria is researching mailing and email addresses. Cindy will send the letter as soon as one of these is procured.
- Latest PR article on vasa previa (that was submitted to the HAND website) has been forwarded to Leian Welch who is writing an article on vasa previa for submission to magazines.

Research:

- Because many doctors are unaware of the importance of hospitalization with vasa previa patients and thus resistant to it, and because IVPF records appear to show a higher rate of preterm rupture of the membranes (as early as 34-35 weeks), Cindy discussed doing another study on the prevalence of early membrane rupture in vp patients with Dr. Oyelese. He explained that this could not be done, even just as a comparison to the published statistics for pregnancy in general because of selection bias. Selection bias was not as big an issue with the last study (ACOG May 2004) because we were only comparing vp cases within vp cases and no control group was necessary for this purpose. Dr. Oyelese explained that this issue is a moot point anyway because we now know that vp babies can be saved and what successful management entails - hospitalization at 30-32 weeks with delivery at about 35-36 weeks.
- The hospitalization issue was also discussed. Dr. Oyelese states that while hospitalization is desired, a non-complicated vp pregnancy can be managed as an outpatient only if frequent transvaginal ultrasounds are done that show the cervix at least 4 centimeters long and if fetal fibronectin tests are favorable up until delivery at 35 weeks. He states that these 2 tests are absolutely required in vp cases if outpatient management is desired for selected patients.
- While it is true that the main research on vasa previa has been done and we now know the risk factors and management, it was thought that something more may be needed because the IVPF has contact with so many women whose doctors just don't want to hospitalize them and treat

their condition as they would placenta previa, which isn't aggressive enough to ensure survival of vasa previa babies. It was agreed that the IVPF would run some informal numbers on preterm rupture of the membranes when vp is present that we could give out "based on our records". Cindy doesn't have time at the moment for this project, so it will be a future project. It was also suggested that we produce a letter with Dr. Oyelese's help, similar to the hospitalization letter we currently use, to request the additional testing if a patient's physician absolutely refuses to hospitalize. It was again noted that in the absence of hospitalization (which is far more preferred), these additional tests are an absolute must.

Fundraising:

- Sue Miller has officially agreed to take on the position of Fundraising Chair - after 12 May.
- It's about time to get started on Sophie's Walk. Cindy Paris and Sue Miller will meet about starting walk meetings sometime late in May. Sue has a link to and will review the Sophie's Walk manual.
- 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 will attend. Jeannette will also contact CHC for the status of our application.

Education Committee Report:

- **Doctors Database Project:** Daren identified over 100+ couples from Yahoo email database who have had diagnosed vasa previa. From the same source Daren has identified a further 25+ doctors and medical facilities who have previously successfully diagnosed vasa previa. Daren has emailed 40+ people identified in the Yahoo email group with the Database questionnaire and request for details of their doctors/medical facilities for addition to the database. He has heard back from only a handful.
- **Fetal Medicine Foundation of America (FMFA)** Bookmarks and brochures were mailed on 21 April to Dr. Zador for upcoming OB-GYN Ultrasound Master Series 2006 meeting in Chicago April 27-30. Materials were received and distributed at event.
<http://fmfaus.meetingpro.info/registrants/MasterSeries06/MasterSeries06.htm>
- **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> IVPF is confirmed for this event. Booth 2506.
<http://fp21.a2zinc.net/clients/fpACOG/ACOG2006/Public/fphtml.aspx> Amy reports after speaking with the insurance company that additional insurance for this event can be and will be easily and inexpensively procured from Schmale Insurance. Booth furniture (table, chairs, and carpet) is not included with the booth fee for this event and had to be rented at an additional cost of \$386.25. Carpet is required by ACOG. Pens and bookmarks have been shipped to Amy for this event. She already has the other materials needed.
- **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 £250.00 has been sent to Daren to cover costs of meeting. Additional funds will be sent if a fringe meeting is held.
- **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. Cindy Paris will be able to attend if necessary.
- **Mailing:** Addition of additional hospitals and fetal medicine specialists is complete. Amy has signed the cover letter and forwarded to Cindy. Citation for the April 2006 ACOG CME paper will be added to the list of scientific resources. The mailing will go off to Jerome Group this week.
- **IVPF Vasa Previa Manual:** It was decided to use copies of abstracts for this project. http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&list_uids=15121568&dopt=Citation (May 2004 – the study) and <http://www.greenjournal.org/cgi/content/abstract/107/4/927?maxtoshow=&HITS=10&hits=10&RESULTFORMAT=&author1=Oyelese&fulltext=Vasa+Previa&searchid=1&FIRSTINDEX=0&sortspec=relevance&volume=107&resourcetype=HWCIT> (April 2006 – the CME article) This eliminates the costs of reprints. Victoria was informed that IVPF will not be able to purchase copywrites to print them ourselves. This enables us to use far more materials. It was noted that the CME abstract of the April 2006 article is useless for IVPF purposes as it barely mentions vasa previa and then only to say that they must be delivered by C-section. However, this CME article is one that every OB will read. This manual needs a proper name. It was suggested and agreed that suggestions be submitted via email.
- **Conference banners** have been ordered. Banners are significantly bigger at 36x79 inches each. Total cost \$310.00 (including shipping to Victoria). They will be ready on Tuesday and Victoria should have them by Wed and will ship to Amy with bookmarks ASAP. Our old banners are going to Daren in UK along with bookmarks, pens bracelets and brochures shortly.
- **Pens and Bracelets** for conferences and store: 2616 pens and 1000 bracelets have arrived. Printer did an overrun of 116 pens. Bea Saver covered the cost of the extras. Total cost of pens wristbands is \$1710.00.
- **Reprints:** 500 reprints of the new ACOG article have been ordered at a total cost of \$679.00.
- **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.
- Marianne Jones (Australia) has contacted her hospital administrator with questions regarding the vasa previa loss of her daughter.
- Nick and Sharon Partridge have started a vasa previa campaign in the UK. <http://www.burtonmail.co.uk/detail.asp?cat=General%20News&id=6335800> It was noted that IVPF should ask Daren Samat to contact them if he hasn't already.

Support Committee Report:

- No report given.

Nominating Committee Report:

- No report given.

Old Business:

- **Lehman Grant:** Amy is working on completing this project.
- **CHC application:** Pending CHC approval. Jeannette will contact CHC for the status of our application.

- 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 to table payment of this policy until we can review the other 2 quotes received again.
- 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.
- Inservice Materials: Jenna has finished the grand rounds set up guide. It is an excellent document for training purposes!
- Newsletter: Jeannette is working on this.
- DMOZ Open Directory Project: Debi Pederson has applied for the editor position and is awaiting approval of her application from DMOZ.

New Business:

- None.

The next regular IVPF Executive Committee meeting will take place on Monday 15 May 2006 at 4:00 pm GMT (10:00 am CST, 11:00 am EST).

Meeting Adjourned at 4:46 pm GMT (10:46 am CST)