

International Vasa Previa Foundation, Inc.

Executive Committee Meeting Minutes for 20 March 2006

Executive Committee members present:

- Amy Brown Gaghagen, President
- Debi Pederson, Vice President
- Cindy Paris, Secretary / Membership, Nominating Committee Chairperson

Victoria Goldstein, Treasurer / PR Committee Chairperson was out of town.

IVPF Committee chairpersons present:

- Daren Samat, Education Committee Chairperson

Kathy Blades, Support Committee Chairperson was not in attendance

Beth Farman-Farmaian, Research Committee Chairperson was not in attendance

Jacqueline Mullikin, Fundraising Committee Chairperson was not in attendance

Others present:

- None

Meeting began at 4:00 pm GMT (10:00 am CST)

Executive Committee Minutes from 6 March 2006 were unanimously approved for archival and distribution.

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
 - No report given.

- Treasurer
 - USA
 - Donations and interest: \$ 263.00
 - Expenses: \$ 308.10
 - Total cash on hand: \$ 58,792.43
 - In-kind donations: \$ 0.00
 - Thank-you notes sent to donors: 1
 - UK
 - Donations and interest: £ 0.00
 - Expenses: £ 0
 - Total cash on hand: £ 839.64
 - In-kind donations: £ 0
 - Thank-you notes sent to donors: 0

Membership:

- There are 100 participating IVPF members.
- There are 233 subscribers in the IVPF email group.
- There are 208 subscribers in the Vasa_Previa email group.
- Vasa_Previa birthday calendar moderator Jenny Fredrick will be on vacation from 28 March to 4 April. Jennifer Munson will fill in while she's gone.

Public Relations:

- IVPF Newsletter: Jeannette is putting together a new newsletter. THANK YOU JNET!!!

Research:

- No report given.

Fundraising:

- Jenny Fredrick has been notified that IVPF would like to purchase Lucas' Angel pins at a price of \$25 for 12 pins with poems, 4 each of hearts, flowers, plain, and butterfly in IVPF colours for sale in the IVPF Store. Jenny reports that the pins are started and are coming along nicely. She will try and have them finished and mailed to us by the middle or end of April. It was suggested and agreed that Sophie's Walk captains purchase one of these pins to wear at the walk.

Education Committee Report:

- Education Committee Meetings: Natalie and Daren Samat (chairpersons) plan on holding Education Committee meetings 6 times per year (once every other month). This suggestion will allow a good period of time for all the suggested work to be done by those volunteering, and it will also be a long enough period for replies or feedback to be received from medical professionals and/or to our mailing campaigns. They plan on holding the meetings online in the evening UK time; say 20.00 hrs (GMT), preferably on a weekend. A private Education Committee meeting room will be created in the IVPF chat area. First meeting is scheduled for 9 April 2006 at 2000hrs GMT (8pm GMT / 2pm CST). IVPF Education Committee members will use email and instant messenger services to keep in touch and to report or update each other and the Chair on progress in the period between each meeting. It was requested and agreed that an email be sent out to all IVPF members to inform them of the proposed meeting date. This will allow any person who is willing to assist to be notified that they should send any awareness raising ideas to Daren at daren.samat@btinternet.com or Education@vasaprevia.com for inclusion in the agenda.

- Carol staffed an IVPF booth at the **Scottish Women's Convention's 2nd Annual Birthday Celebration** that was held the afternoon of 30 January 2006 in the Glasgow City Chambers. <http://www.scottishwomensconvention.org> Due to adverse weather conditions (horrendous freezing fog and chaos amongst train and bust transport) the event was not as well attended as was anticipated, but that at least 150 women attended. Professionals, support groups and women were well represented and Carol received a lot of interest and a number of people took materials for reference and to pass on to others.
- **American Institute of Ultrasound in Medicine (AIUM) Conference** is taking place in Washington D.C., USA, 24-27 March 2006: <http://www.aium.org/> IVPF has heard from Jenna Steckler. She will be able to staff this event. Since there wasn't enough lead time for IVPF to attend, materials have been sent to AIUM who will set up an unmanned table for us. Cost to IVPF: \$300.
- **American College of Obstetricians and Gynecologists (ACOG) Conference**, Washington D.C., USA, 6-10 May 2006: Victoria has applied to them for an IVPF booth and also requested a discount. A standard \$1 million insurance policy is required (similar to the insurance required for organized walks in the USA). Victoria is looking into this. <http://www.acog.org/acm/program/welcome.cfm> Jeannette Schwartz has volunteered to staff this event. Amy Gaghagen will be attending as well. Cindy will contact Jenna Steckler about attending this event. Media training materials have been sent to Jnet. Debi Pederson will be able to attend if something falls through with Jeannette or Amy.
- **World Congress in Fetal Medicine 5th World Congress** 25-29 June 2006, Barcelona Spain: http://www.fetalmedicine.com/wcfm_intro.htm Victoria sent several emails regarding IVPF attendance, did not hear back, and Daren Samat took over and is in touch with Anastasia Panteliadou regarding discount for the IVPF. Daren and Natalie Samat to attend. It was mentioned that this is a one week conference and Daren would like to recruit additional volunteers.
- **National Childbirth Trust (NCT) Conference** 1-2 July 2006, Brighton, England: http://events.nct.org.uk/event_info?event=2 Daren and Natalie Samat and Lisa Paine will attend, manning a stand and possibly holding an evening fringe meeting. Cost expected to be about \$350 dollars for 2 day event. They expect about 500 people, Lamaze types.
- **International Society of Ultrasound in Obstetrics and Gynecology (ISUOG)** 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. Daren will contact Professor Nicolaides to see if he will be attending. Cindy Paris will be able to attend if necessary. IVPF attendance has been finalized at a cost of £1,586.25, a 40% discount. Daren offered IVPF hospitality to Dr. Oyelese while he is in London. He would also like to set up additional opportunities for Dr. Oyelese to speak in the UK and Europe as well as at this conference.
- **International Woman's Day**: Carol Prentice to look into raising IVPF's profile and awareness of vasa previa at International Woman's Day event in 2007. About International Women's Day: <http://www.internationalwomensday.com/about.asp> 2006 events which took place 8 March: <http://www.internationalwomensday.com/events/>
- Cindy is looking into starting an online calendar for IVPF events.
- Mailing: Jerome Group has been notified that their bid has been accepted. Most of the address files have been converted into one Excel document. The Canadian hospital list has been received. Daren Samat has taken on the daunting task of putting together a list of UK hospitals in Excel format. Lisa Paine has done some excellent research on a UK hospital list in Excel format. There is still quite a bit of work to do to weed out non-maternity hospitals, but Lisa has found a "shortcut" to an otherwise laborious process. No details available yet on how many this

will add to the mailing. Will keep you all posted.

- IVPF has written to the Fetal Medicine Centre and Foundation (FMC/F), 137 Harley Street, London, W1G 6BG, England. <http://www.fetalmedicine.com/f-fmf.htm> Daren is delighted to report that the FMC/F have agreed to allow a link from the IVPF website to their website. Daren will also ask them to place the IVPF banner on their website. This is especially important in the UK as it will provide, in the short term, a place for IVPF to refer any UK based woman (who makes contact with us), and we can say with confidence that we know they offer a transvaginal scan using colour Doppler. In line with the foregoing and in response to an idea he gathered from the Yahoo email group, Daren wishes to set up a database that lists of all of (or as many as we can) the hospitals and/or experts that we know, who are able to offer a transvaginal scan using colour Doppler. He knows this is ambitious, but it may be possible with the co-operation of the medical profession. To this end Daren drafted a (rough) letter to Dr. Basky Thilaganathan to aid the database in the UK. This project will of course have a double effect, in that whilst we try to secure the medical profession's co-operation in its set up, we will also raise their awareness (again) of the condition and also of IVPF as an organisation. EXEC is waiting to receive final edits before giving final approval for the above letter to Dr. Thilaganathan. This will be approved via email by EXEC Committee members as soon as it is received.
- In response to the IVPF letter to Professor Nicolaides, we await news of whether his study will be extended as indicated in that letter. This is especially important to IVPF, as Professor Nicolaides has said that, subject to funding, he would like to extend his latest study to look at localizing the umbilical cord as a marker in ultrasound scanning. Under current UK guidelines for screening certain things are standard markers on the 20 week anomaly scan. Professor Nicolaides' suggestion that the umbilical cord is made a standard marker in the UK is key to a recommendation for the National Institute for Health and Clinical Excellence (NICE) to include this in any future protocol. <http://www.nice.org.uk/> [The Royal College of Obstetricians and Gynecology (RCOG) Ultrasound Screening Guidelines were sent to EXEC. It contains the current markers for baseline fetal anomaly scans that take place at 20 weeks, and notes in Appendix 1, that though the umbilical cord is looked for, it is only at the baby's end <http://www.rcog.org.uk>].
- Nathan's "What is Vasa Previa Page" <http://NathanParis.com/vp.htm> has been included in the links of The Fine Balance website in their Health Resources (Reproductive Pregnancy and Birth/Complications) links at http://www.thefinebalance.com/lc/vasa_previa/17305/1 They have a page just for vasa previa.
- VP information has been posted on the Friends of Missouri Midwives local email list in response to a post from an ultrasound technician advertising her services to home birthers. The business is called Ultrasona St. Louis, and they are located on Highway K in O'Fallon, MO. They have a Missouri Board Certified OB/GYN on board who reads the scans, but he's located in Salt Lake City, Utah. The web address is <http://www.UltrasonaStLouis.com> They do level 1 ultrasounds and convenience scans to determine the sex. They have 3 and 4 D ultrasound available. They also provide massage therapy. They claim to be different from "Keepsake" services, but their main thrust is to reduce stress and help foster prenatal bonding. The email Cindy sent to the email group in response to this post gave extensive information on vasa previa and asked that this company include the placental cord connection scan during all ultrasounds and follow-up with transvag color Doppler for women with risk factors for vasa previa. Risk factors were included in the post as well as the standard IVPF URL list. Cindy will follow up with the local company. This company has ultrasound clinics in 8 states in the USA and wants to franchise out into 21 other states. See: <http://www.ultrasona.com/locations.aspx?n=494076> It is recommended that IVPF contact each office giving vp information as there was no link on the company website, but there is contact information for each operating franchise. Already Cindy has received a private email from a subscriber to the email list thanking her for the information

and saying though she wasn't planning to have any ultrasounds unless there were complications, she will now have an ultrasound specifically to rule out the deadly vasa previa. It was suggested that this task be delegated to someone right away.

- DMOZ Open Directory Project has created a section for vasa previa under its pregnancy complications category at http://dmoz.org/Health/Reproductive_Health/Pregnancy_and_Birth/Complications/Vasa_Previa/. Cindy had written to them several times in the last few years requesting such a category. Many search engines utilize DMOZ for their directory listings. The IVPF listing has been updated to reflect the new URL - IVPF.org. Currently only the IVPF and Nathan's "What is Vasa Previa?" (<http://NathanParis.com/vp.htm>) page are listed in this category. The category needs an editor. It was mentioned that it would be nice if someone from the IVPF stepped up to edit this section. Several IVPF members were suggested. Debi Pederson offered to apply for the position. Cindy will help her get started.
- It was noticed doing web searches that the study is now showing up in most search engines - on the first page of vasa previa searches!
- IVPF members in the UK met in person on 25 February to discuss vasa previa awareness issues in the UK. The UK members agree that the IVPF is a phenomenal organization and to preserve it they will work in IVPF committees, but also form a local vasa previa organization for lobbying as medical care in the UK is typically legislated by law and requires political lobbying to make changes. The meeting of 25 Feb turned into a local organizational meeting and minutes will not be available to the IVPF at large, but have been forwarded to the IVPF Executive Committee for informational purposes only.
- Changes to the bookmark suggested by Dr. Anthony Vintzileos at the SMFM meeting have been approved. Text has been changed and forwarded on to Victoria for printing.
- A new email group subscriber mentioned that vasa previa isn't on babycenter.com. We should contact them. Cindy's done web searches and found vp on babycenter.com, but that is in the message boards. They probably don't have the condition itself listed.
- A package of 12 study reprints, 24 brochures, 12 bookmarks, and 5 wristbands was sent on 14 March to Darcie Fredrick who has been invited to a luncheon with 8 other doctors and a few nurses by her OB. Luncheon to take place this week.
- A copy of the study, 5 brochures, 5 bookmarks, and 3 wristbands was sent on 14 March to Kama Bernabo who contacted Cindy privately for management information. Her doctor is planning no hospitalization, amnio to determine lung maturity, and a delivery date at 38 weeks. A local referral was given to Kama for a second opinion.
- 5,000 revised bookmarks will be reprinted by the end of March for future events.
- A conference banner is required for UK and European Conferences. We need to organize this as soon as possible. New banners are already in the works. Quote will be forthcoming.
- In a personal capacity, Daren and Natalie Samat have contacted an IVF specialist at a central London teaching hospital in regards the link between in-vitro fertilization (IVF) and vasa previa. They've sent her a copy of the study and are awaiting a reply.
- Dov Apfel, attorney at law has been contacted regarding the vasa previa page on his website. There is a page for vasa previa, but it has no content. Based on IVPF legal counsel, IVPF has contacted him offering information and a link to the IVPF for this page. He thanks us for the email and says he will think about putting a link to the IVPF on this page. IVPF will NOT be linking to his page and he is aware of this.
- Daren has researched and reviewed IVPF minutes and has been briefed on IVPF Education Committee activities to date. It was suggested and agreed that EXEC meet with him directly after this meeting to discuss one or two questions he brought up.

Support Committee Report:

- No report given.

Nominating Committee Report:

- No report given.

Old Business:

- Lehman Grant: Amy is working on completing this project.
- IVPF investments: Pending
- CHC application: Pending CHC approval. CHC contacted the IVPF requesting one additional document, or rather one line of wording added to an existing page of the application. This item has been taken care of.
- Directors Insurance: Jeannette has reviewed the 3 bids received by the IVPF and recommends the Schmale Insurance Agency in Belleville, IL for the purchase. She has worked with them before. Bid is attached to the agenda.
- Illinois sales tax exemption: Application has been sent to IL. Application has been approved. Thank you Jnet!!!
- Medical Advisory Board: Bios have been received for the proposed new doctors. 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.
- Inservice Materials: Cindy will contact Jenna and Lisa about this item.
- Britannia on the IVPF sponsors page: Britannia link has been removed as the replacement link also does not work. Link to thefetus.net has been removed from the resources page because it is no good anymore. Additional notes: The Press Room's In the News Page has had the video links removed. Videos had to be deleted from the ftp server space because the space is full causing denials when attempting to upload altered pages. This issue (ftp space full) is a continuing issue as is overall web host reliability.

New Business:

- A motion was made and duly seconded to approve the Schmale Insurance Agency of Belleville, IL for the directors insurance. Motion passed unanimously.

The next regular IVPF Executive Committee meeting will take place on Monday 3 April 2006 at 4:00 pm GMT (10:00 am CST, 11:00 am EST).

Meeting Adjourned at 5:28 pm GMT (11:28 am CST)