

International Vasa Previa Foundation, Inc.

Executive Committee Meeting Minutes for 3 April 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

Daren Samat, Education Committee Chairperson was not in attendance

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:

- Phil Millard, IVPF Board of Directors

Meeting began at 4:02 pm GMT (10:02 am CST)

Minutes of 6 March were changed before archiving due to having the wrong meeting date on them.

Executive Committee Minutes from 20 March 2006 were unanimously approved for archival and distribution.

The next IVPF monthly members' meeting is scheduled for 5 April 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
 - No report given.
- Vice President
 - No report given.
- Secretary
 - Cindy mentioned that we don't send out the minutes to the Vasa_Previa email group. It was thought that this might help get more volunteers involved. After some discussion it was decided that while it would do no harm the Vasa_Previa email group might not be the right forum for this. Tabled for the time being.
- Treasurer
 - USA
Donations and interest: \$ 43.45
Expenses: \$ 4,755.55
Total cash on hand: \$ 54,080.33
In-kind donations: \$ 0.00
Thank-you notes sent to donors: 0
 - 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 is one pending participating member.

Public Relations:

- IVPF Newsletter: Jeannette is putting together a new newsletter. THANK YOU JNET!!!
- Leian Welch (a writer, new subscriber to the Vasa_Previa email group, bereaved aunt of a vasa previa angel, and pending IVPF participating member) is canvassing the Vasa_Previa email group requesting stories for articles on vasa previa. Victoria has contacted her and sent her a list of IVPF press received so far. She will be interviewing Victoria on 10 April and possibly some of the other Vasa_Previa email group subscribers. More information on Leian Welch and her writings is available on her website: <http://www.gather.com/my.jsp?memberId=23201>
- Yinka Oyelese's latest paper "Placenta Previa, Placenta Accreta, and Vasa Previa" has been published by ACOG as part of their Clinical Expert Series. This paper is EXTREMELY important as it sets a semi-formal standard of care for vasa previa, placenta previa, and placenta accreta. Because it is part of their Clinical Expert Series it will be widely read and will be heavily referred to in other papers covering these conditions. This is IT guys! We are officially on the way to a standard of care. It was agreed that IVPF purchase reprints from the publisher for conferences, etc. IVPF is planning to issue a press release about the progress that has been made using quotes from the authors of the recent papers. It was suggested that we start purchasing this paper right away. Victoria will look into this.

Research:

- Vasa Previa Doctors database has been created at http://groups.yahoo.com/group/Vasa_Previa/database and email has been sent out to Vasa_Previa group subscribers asking prenatally diagnosed women to input their doctors' names

as referrals for other group subscribers.

- IVPF legal counsel has given approval for Ed Com to contact submitters of the IVPF research questionnaire requesting doctor information for prenatally diagnosed vasa previa victims. This doctor information will be used to compile a list of doctors who have had prenatally diagnosed patients for the cause. IVPF hopes to encourage such doctors to give vasa previa presentations in their local areas. This will also aid in the referral process for mums who wish a second opinion.
- Daren drafted a letter to use in contacting people who have been prenatally diagnosed. It will be used for the purpose of asking them to provide their doctor's contact information for future awareness projects. This was approved.

Fundraising:

- Three orders for 5 wristbands each were processed.
- It was suggested that we order some more wristbands and some pens as well, both to be given out at conferences. Victoria will get quotes.

Education Committee Report:

- **Education Committee Meetings:** A private Education Committee meeting room has been created in the IVPF chat area. First meeting is scheduled for 9 April 2006 at 2000hrs GMT (8pm GMT / 2pm CST). IVPF sent an email to current Ed Com members, all IVPF members, and email group subscribers to inform them of the proposed meeting date. Education Committee meeting room has been created at <http://IVPF.org/chat/education.htm> Chat logs send automatically to a new email address: Education@vasaprevia.com All mail sent to this address goes to Daren Samat, Natalie Samat, Amy Gagghagen, and Cindy Paris.
- Thanks to Emma Cartwright, Baby-Greenhouse.co.uk has included vasa previa information in its message board via a permanent link. The post, at http://www.baby-greenhouse.co.uk/forum-viewmessage.php?thread_id=1&message_id=3495752 includes Emma's story about Harriet's birth, information on vasa previa from the IVPF (along with a link to IVPF.org), and Ouisa Paris' School Paper "The Worst Day of My Life".
- Kara Giammarino has suggested that the IVPF get many of its members write to Oprah and the Today Show enmasse requesting an episode on vasa previa. She's agreed to head up this project and will be submitting a letter to send to members asking them to do this. Her suggestion is attached.
- Cindy would like to suggest that IVPF produce a professionally printed and bound "bible" (magazine style) on vasa previa that contains perhaps a letter from the IVPF and copies of the most important studies on vasa previa management and diagnosis. Cindy has spoken with Dr. Oyelese about this and it is possible to do if we get copywrite permission from the publishers of the papers we want to include. This item could be used when contacting doctors and for handing out at medical conferences. It was mentioned and agreed that outside funding from some other organization like Phillips would be desirable.
- **American Institute of Ultrasound in Medicine (AIUM) Conference** is taking place in Washington D.C., USA, 24-27 March 2006: <http://www.aium.org/> 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. Report on conference is pending.
- **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. Application and payment for this event was sent off on 31 March 2006.

- **5th World Congress in Fetal Medicine** 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. IVPF is still working on getting signed up for the event.
- **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 a evening fringe meeting. Cost expected to be about \$350 dollars for 2 day event. They expect about 500 people, Lamaze types. IVPF is confirmed for this event.
- **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. IVPF attendance has been finalized at a cost of £1,586.25, a 40% discount.
- **New Online Calendar!** The above conferences and events have been put on the IVPF Calendar at <http://groups.yahoo.com/group/IVPF/cal> A link to the online calendar has been added to the IVPF Office Space at <http://IVPF.org/Office> Please bookmark this too! Office Space committee materials links have been updated as well.
- **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. A CD hospital list for all European hospitals is available at <http://www.researchandmarkets.com/reports/35350> This CD contains 16,000 hospitals in 23 countries and is searchable. (sample is attached) Cost is € 2,640.00 (US\$3,199.94 at Friday's exchange rate). Susan McFadden believes this would be a wise purchase. The list is searchable as well which should enable us to weed out any hospital that doesn't do maternity care. And address list for NSW hospitals in Australia has been procured for free. 128 additional hospitals, but they haven't been weeded out for maternity hospitals yet. These will be added to the mailing. It was suggested and agreed to go ahead and finalize the printers in 2 weeks with or without the additional hospital addresses. This will give us time to see if we can get reprints of the new article in time to include with the mailing. Another duplicate mailing can be easily accomplished at a later date.
- **Ultrasona** St. Louis, 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>
<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. 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/ The category needs an editor. Debi Pederson offered to apply for the position. Cindy sent Debi detailed DMOZ information and links to apply for editor of the Vasa Previa category.
- **BabyCenter.com** 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. This item needs to be delegated.
- **Darcie Fredrick luncheon event:** Luncheon took place on 22 March and was a huge success. Initially expected were less than a dozen hospital doctors and nurses. Instead 15 doctors, 4 labor and delivery nurses, 5 NICU nurses, half the hospital's board of directors, and the hospital administrator attended. VP survivor Lillie Rose Fredrick was also present. Darcie gave a speech about her vasa previa experience and answered questions. Afterwards her doctor spoke on the medical aspect and showed slides of her placenta. Darcie was approached by an attending doctor who works at 3 other local hospitals requesting she speak at those hospitals as well. Darcie forwarded transcripts of the luncheon (attached) and has given permission for IVPF to use them as an example for similar IVPF member events.
- **Website stories:** Seven stories have been added to the IVPF website under "share with us". One other has been updated to include a picture and a poem.
- 5,000 revised bookmarks will be reprinted by April 7.
- A conference banner is required for UK and European Conferences. We need to organize this as soon as possible. We will send existing banners to the UK. New banners are already in the works. Quote will be forthcoming.

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: It was decided to hold off on this until after the mailing.
- CHC application: Pending CHC approval.
- Directors Insurance: Schmale Insurance Agency in Belleville, IL bid has been signed and was mailed off on 20 March 2006. There was concern about the insurance being in force by the ACOG conference since we haven't been billed for it yet. Amy will call the company today to ask about it.
- Medical Advisory Board: Amy is drafting invitations. Invitations are almost complete, just waiting on mailing addresses for a couple of the doctors.
- 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: Cindy has contacted Jenna and Lisa about this item.

New Business:

- A motion was made and duly seconded to approve Leian Welch for IVPF participating membership. Motion passed unanimously.
- A motion was made and duly seconded to approve purchase of European hospital CD at a cost of € 2,640.00 (US\$ 3,199.94). Motion failed unanimously.
- A motion was made and duly seconded to approve the submitted draft of the database letter. Motion passed unanimously.
- It was proposed and duly seconded that IVPF order 6000 of Dr. Oyelese's latest clinical ACOG Expert Opinion on Placenta Previa, Placenta Accreta, and Vasa Previa article. The motion passed unanimously. IVPF will attempt to procure black and white copies of the cover page and the pages 11-15 on vasa previa. Victoria will obtain quotes.

The next regular IVPF Executive Committee meeting will take place on Monday 17 April 2006 at 4:00 pm GMT (10:00 am CST, 11:00 am EST).

Meeting Adjourned at 5:10 pm GMT (11:10 am CST)