

International Vasa Previa Foundation, Inc.

Executive Committee Meeting Minutes for 12 January 2006

Executive Committee members present:

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

Debi Pederson, Vice President was not present.

IVPF Committee chairpersons present:

- None

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 16:11 GMT (10:11 AM CST)

Executive Committee Minutes from 12 Dec 2005 were unanimously approved for archival and distribution.

The last IVPF Monthly Members Meeting took place 1pm CST on Wednesday, 4 Jan 2006. Cindy hosted. Five members 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
 - No report given.
- Secretary
 - Request for end of year reports was sent out to IVPF Committee Chairpersons on 18 Dec 2005. Treasury and President's reports have been received.
 - There is an RSS feed button on the IVPF newsletter group page, enabling people to put feeds to the IVPF newsletter and announcements on their own internet pages.
- Treasurer
 - ISUOG expenses are still outstanding.
 - USA
Donations and interest: \$ 1,683.72
Expenses: \$ 6,695.48
Total cash on hand: \$ 62,627.94
In-kind donations: \$ 0.00
Thank-you notes sent to donors: 9
 - UK
Donations and interest: £ 0.00 (no report given)
Expenses: £ 0 (no report given)
Total cash on hand: £ 839.64
In-kind donations: £ 0 (no report given)
Thank-you notes sent to donors: 0 (no report given)

Membership:

- There are 3 pending IVPF participating members.
- Photo space in the Vasa_Previa email group was 98% full. 37 large files were downloaded, resized, and uploaded into the original folders. Two folders were deleted (conferences and real life meetings). Photo space in the Vasa_Previa group is now at 22% of capacity.
- Dr. Wiplinger has been added to the IVPF newsletter group on 18 Dec 2005 at his request.
- An IVPF member request for local UK contacts has been sent via email (blind copy to protect our contacts privacy) to 52 IVPF contacts on file. Said member received 7 replies.
- Jennifer Munson has agreed to be approvals moderator for the Vasa_Previa email group. Jennifer will back up the calendar entry moderator as needed.
- Calendar issues: Every calendar entry in the Vasa_Previa email group calendar has mysteriously disappeared twice. Yahoo has been notified. We've not heard back from Yahoo regarding this. One email was received from a disappointed group subscriber and several others have posted their baby's birthday information to the group. It is possible that our calendar was updated and that Yahoo lost the entries. But it is also possible that a subscriber deleted the entries (there is a button to do this). On 13 January IVPF received an email from a subscriber who complained of the Vasa_Previa birthday Calendar entries being on her personal Yahoo Calendar that she uses for work. She stated that she had tried to delete them more than once. On 13 January 2006 access to the calendar was changed to moderators only. After testing with another Vasa_Previa subscriber's personal Yahoo Calendar it was noted that changing the subscriber's access deleted the Vasa_Previa Calendar entries from her personal Yahoo Calendar, but not from the Vasa_Previa Calendar. Problem is hopefully resolved. Two emails have been sent to the Vasa_Previa email list about the calendar, expressing our apologies. The second email also requested subscribers email Vasa_Previa-owner@vasaprevia.com with their baby's details. The

calendar has been mostly rebuilt and now contains 158 entries. It was also noticed while rebuilding it that not all entries had been going out every year. This must be a problem with Yahoo as the entries concerned had the appropriate repeat settings.

- Jenny Fredrick has volunteered to do the birthday calendar for the Vasa_Previa email group and has been made moderator for this purpose. Jenny will take over in the birthday calendar as soon as updates are completed and will back up Jennifer Munson as approvals moderator when needed.
- Dennis Yungbluth agreed to help in the rebuilding of the calendar and will be researching recent new subscribers and births that were previously not in the calendar and would be harder to research than the older birthday entries were. He has been made moderator for this purpose and an email was sent to him with instructions

Public Relations:

- It was noted that a newsletter needs to go out.

Research:

- Online questionnaire forms include dns numbers and have been researched for country of submitter. For the questionnaires counted since using Bravenet forms submission (1.5 years ago), the basic results are: Australia - 5% of all submissions, Canada - 7%, Netherlands - 6%, UK - 10%, and USA - 68%, with Belgium, Germany, Ireland, Japan, Jordan, New Zealand, and Spain also submitting. In the USA, the states with the most submissions include California, New York, Texas, and Virginia.

Fundraising:

- Three orders for wristbands (70 wristbands total) have been processed.
- Greeting cards for the IVPF store: Yinka Oyelese has given the IVPF permission to create greeting cards from photo's he's taken. http://www.photo.net/photodb/member-photos?user_id=1024128. The photos are fabulous! We can use all we want for greeting cards to sell in the store or on eBay under the non-profit section. He owns the copywrite to the pictures on the above page. Would also like to do a package of cards using an excellent black and white photo of McNeil Mullikin. Cindy will contact Jacqueline Mullikin about this. "Nathan's Tree" and "Sophie's Tree" were also suggested for future holiday cards.
- Jenny Fredrick has made angel pins for consideration and sale in our store if we want. Sample pins have been shipped to Executive Committee members on 12 Jan 2006.
- Jeannette has forwarded emails regarding Community Health Charities to Cindy as she will no longer be doing grant writing for us. She will also be forwarding to us the work she has completed on the Lehman grant. Community Health Charities application has been received. Jeannette and Cindy will attend a local meeting being held by this group on 25 Jan 2006.
- Victoria will call a Fundraising Committee meeting to take a look at Yinka's photos.

Education Committee Report:

- 4000 journal articles for the hospital mailing have arrived.
- Post about vasa previa and the IVPF was made 30 Dec to BabyCenter on a vci thread by Cindy Paris:
<http://bbs.babycenter.com/board/pregnancy/pregcomplications/1232290/thread/2735930?message=29693304&requestid=453897#29693304>
- IVPF information has been emailed and postal mailed to Daren and Natalie Samat of the UK, who recently lost their son Henry to vasa previa. They requested a consultation into the recent loss of their son at their local hospital, and provided them with IVPF materials. As a result, VP

has already featured at one of the obstetric meetings and their local hospital now plans a formal vp presentation to be given by the registrar to obstetric staff at Wycombe General Hospital, South Buckinghamshire in the UK in February 2006. In addition to the above informational materials, 50 IVPF brochures, 50 IVPF bookmarks, and 50 reprints of the study have been shipped to Daren Samat for this presentation. IVPF also obtained permission for the AIUM powerpoint presentation to be used at this event. Powerpoint has been supplied to Daren with the notification that IVPF does not own the copywrite and that it be used only for this particular purpose. Natalie and Daren intend to work to raise awareness in the UK and will campaign for protocol changes to favor the diagnosis and treatment of VP nationally and throughout the NHS trust.

- Emma Cartwright, Daren Samat, and Carol Prentice have suggested that IVPF focus on NICE in the UK for changes in vp protocol. Daren is currently organizing UK IVPF contacts to work in this committee for this purpose.
- Tiffany Naylor has offered to help with website updates and is currently working on updating the stories pages with several new stories received since the last update was made.
- It was suggested that this committee review:
http://www.gfmer.ch/Guidelines/Prenatal_screening/Prenatal_ultrasound.htm. Many of the resources on this page should be gone through and contacted by IVPF to include placental cord connection scan and routine follow transvaginal follow-up into their recommendations. Permission requested to review these materials and develop contact letter with an eye towards contacting them all.
- Christi Rees has offered to put together a VP Pregnancy Management Reference Sheet from the FAQs, and the IVPF Recommendations on Risk Factors, Testing, and Management for use in the Vasa_Previa email group and the IVPF website. This document will attempt to concisely compile these materials in a short, easy to read document.
- A Specialist Registrar in Wycombe General Hospital, South Buckinghamshire, UK is currently conducting a literature review on management of vasa previa, and contacted the IVPF requesting recent literature on management of vasa previa, national guidelines that have incorporated screening or management strategies for vasa previa, and any such local hospital guidelines. A detailed response has been drafted, reviewed by Yinka Oyelese, and sent to the Registrar.
- It has been suggested that IVPF staff a booth at the Scottish Women's Convention's 2nd Annual Birthday Celebration being held the afternoon of 30 January 2006 in the Glasgow City Chambers. SWC is a policy steering organization involved in a variety of issues. The SWC has published a paper on maternity services and choices/rights/scanning/etc. Carol Prentice participated in this work and is willing to staff an IVPF booth. Their website is <http://www.scottishwomensconvention.org>. They are expecting to have 150 attendees at the event which would include members and supporters of the SWC. There is no charge for the booth, but there are only a small number of booths available. Due to the limited number of booths available, approval for this event was obtained from EXEC committee members in advance. Carol has been notified and has procured a booth.
- Daren Samat contacted the author of the book "An Expectant Father" who has agreed to include a new section in the book and on his website about vasa previa.
- Daren Samat contacted Professor Nicolaidis of the Fetal Medicine Centre of London regarding setting up a short term private referral center.

Support Committee Report:

- No report given.

Nominating Committee Report:

- No report given.

Old Business:

- Lehman Grant: Jeannette will forward the work she's completed on the Lehman grant to EXEC for completion. Amy will complete the application. Item tabled until after the annual meeting.
- IVPF investments: Amy has looked into interest bearing accounts. It was unanimously agreed to invest in short term (3-5 month) CDs.
- Directors Insurance. Dawn Haley responded in regards to our request for advice on this subject. She's agreed that this insurance is very important for the IVPF to have and suggests requesting 'bare bones' coverage as the bids obtained cover liabilities the IVPF does not incur. This was already done by Jeannette when she obtained the bids. This item is slated for a vote at the upcoming Annual Board of Directors meeting taking place on 30 January 2006 directly after the Annual Members Meeting.
- Illinois sales tax exemption: Application has been sent to IL. Item is pending review of IL Department of Revenue.
- IVPF hospital mailing: Jerome bid is in. Daren Samat is putting together a mailing list of UK hospitals. Reprints of study have arrived. Victoria will submit a bid request to Bea Saver.
- Community Health Charities application: Application has been received. Cindy and Jeannette will attend local meeting of this organization on 25 Jan 2006.

New Business:

- A motion was made and duly seconded to approve Daren Samat as IVPF participating member. Motion passed unanimously.
- A motion was made and duly seconded to approve Lisa Cole as IVPF participating member. Motion passed unanimously.
- A motion was made and duly seconded to approve Jennifer Fredrick as IVPF participating member. Motion passed unanimously.

The next regular IVPF Executive Committee meeting will be the Annual Members Meeting and will take place on Monday 30 January 2005 at 16:00 GMT (10:00 AM CST, 11:00 AM EST) at 5250 Murdoch Avenue, Saint Louis, Missouri in the USA. It will be held concurrently in the IVPF Chat Room at <http://IVPF.org/chat>.

Meeting Adjourned at 17:01 GMT (11:01 AM CST)