

International Vasa Previa Foundation, Inc.

Executive Committee Meeting Minutes for 12 December 2005

Executive Committee members present:

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

Debi Pederson, Vice President was not present due to a previous appointment.

Victoria Goldstein, Treasurer / PR Committee Chairperson was not in attendance but gave her proxy to Cindy Paris.

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:

- Phil Millard, IVPF Director and head webmaster

Meeting began at 16:18 GMT (10:18 AM CST)

Executive Committee Minutes from 28 November 2005 were unanimously approved for archival and distribution.

The last IVPF Monthly Members Meeting took place at 7pm CST on Wednesday, 7 Dec 2005. Debi hosted. No one 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
 - In consideration of the regularly scheduled committee break for the holidays, it is suggested that this be the last meeting of the IVPF Executive Committee for the year. Next regularly scheduled Executive Committee meeting to be 16 January, exactly 2 weeks before the annual meeting. Same bat time, same bat place.
 - Secretary will make request of the various committee chairs for 2005 annual report in preparation for the annual meeting.
 - Cindy Paris will be out of town from 20-30 December. Will be available by cell on and off. Not likely to have reliable computer access.
 - Illinois sales tax exemption has been applied for and is in the process of being reviewed by the IL Dept of Revenue. Confirmation letter of IVPF application receipt has been received from the IL Department of Revenue.
 - Nineteen ballots for the upcoming participating member vote on IVPF Directors for 2006 have been received to date. Two ballots came back marked undeliverable. PDF copies of ballots and accompanying materials were emailed to those participating members.
- Treasurer
 - USA
Donations and interest: \$ 175.13
Expenses: \$ 1,142.02
Total cash on hand: \$ 67,639.70
In-kind donations: \$ 0.00
Thank-you notes sent to donors: 3
 - 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:

- No report given.

Public Relations:

- No report given.

Research:

- Statistics requested by 2 subscribers to the Vasa_Previa email list have been compiled, approved by EXEC via email, and sent to the Vasa_Previa email group and subscribers asking for the information. The following details informal statistics after doing a quick run through of our contact records and research data.
 - **How many people are in this group?**
Over 1000 people with VP have contacted us since May 2000.

As far as people active in the IVPF: 220 are receiving the IVPF newsletter , 187 are in the Vasa_Previa email support group, 240 subscribers post in the Vasa_Previa forum, and 92 people are IVPF participating (voting) members.

- **How many Angels?**
316 Total (34%)
It's important to note here that until 3 years ago the angels in our contacts numbered over 60%. The numbers of deaths in our records are coming down!
- **How many miracles?**
614 Total (66%)
- **How many were diagnosed prior to giving birth?**
309
- **Was anyone diagnosed but still had an Angel?**
Only 2 that we are aware of, both of these also had other complications unrelated to vasa previa that resulted in extremely premature birth, before the baby was viable (at 21 and 24 weeks).
- Online questionnaire forms include DNS numbers of submitters. These are now being used for demographic purposes to identify the city and country of the computer the submitter is using.

Fundraising:

- One order for 5 wristbands is being processed.
- 2005 total for Sophie's Walk for Vasa Previa is \$19,260. This should be a final total.
- Jeannette Schwartz has communicated with Carolyn Green, Vice President of Community Health Charities (www.chcksmo.org) regarding funding opportunities for the IVPF. Applications to be involved with this organization will be out in January.

Education Committee Report:

- This committee needs a chairperson because performing this function presents a hardship on the current acting chairperson.
- Phillips sponsored Fetal Medicine Foundation of America Meeting: December 1-4, 2005, Ft. Lauderdale, FL. IVPF attended this event. Full report submitted by Victoria Goldstein Macadar:
 - Meeting was a success for IVPF and a worthwhile investment. Recommend that we attend this meeting yearly. Takes place first Thurs-Sun in December in Ft. Lauderdale, FL. Other meetings in Jan in Los Angeles, April in Chicago and Nov. in NY. If we cannot attend, our material will be distributed free of charge by organizers.
 - Victoria spoke to Ivan Zador, President of FMFA about distributing our material at other conferences when we cannot attend and he was most gracious, said if we send material to the place where the conferences are being held, he will distribute free of charge to us as long as we attend one meeting a year. This meeting in Ft. Lauderdale has been taking place for 14 years so Victoria said she'd every year, its a good meeting and important people attend every year. The course leaders include Josh Copel, Lawrence Platt, and John Hobbins, all of the AIUM. It's good they see us often. Next meeting is in Los Angeles Jan 13-16 and the next one after that is in April in Chicago.
 - Most attendees are Maternal Fetal medicine specialists and RDMS (Ultrasound Sonographers)
 - Most attendees know about VP and check but hardly any knew there was a FOUNDATION, the more we are in their face, the more people will know we exist.
 - Premier Perinatal Associates in Ft. Lauderdale reported that they ALWAYS check for VP AND they want to do the Walk in Boca next year.

- Regina Rachael, based in NJ is an ultrasound specialist who has been checking for VP for years, she checks as early as 14 weeks. She has offered to help us distribute info at events in NY that she attends if we need her to.
- Dr. Wiplinger wants to receive our newsletter.
- Gregory Devore (Fetal Diagnostic Center, Los Angeles, CA), a BIG WIG mover and shaker in the OB world, faculty at meeting, presented on VP. He asked for IVPF material and took a copy of the Green Journal and the Contemporary OBGYN article to use in his presentation. The complete syllabus of the courses taught and the PowerPoint presentations are in there with VP info.
- Dr. Devore told Victoria he testified in a case in Utah where the doctor missed the vp diagnosis in the ultrasound and didn't manage bleeding, was sued and the people won and got \$6 million!
- Ilan Timor-Tristch (NYU School of Medicine, NY, NY), spoke on placental issues. Three of his slides were on VP. He was very interested in the fact that there was a Foundation and wanted to know if we recommended scanning EVERY pregnant woman. He saw our recommendations and totally concurred. Victoria attended this presentation. Dr. Timor-Tristch applauded IVPF for lobbying for awareness at the meeting.
- Susan Guidi, sonographer from Tampa, FL who came to our meeting in FL with Dr. Jason Birnholz was there and was thrilled to hear that we are very active and have been saving more and more babies. She also offered to distribute our material wherever she goes and asked when she was going to get our newsletters again. Asked that Victoria stay in touch with her via instant messaging as well, since it's been a while since she's communicated with her.
- Canadian hospital list for mailing still to be purchased. Jerome bid is \$4581 or \$4849 depending on the options chosen. Brochure and bookmark to be printed on digital printers, which is not the cheapest, but produces far more consistent product. This bid is at cost, but does not include postage or cost of the study journal articles to be supplied by us. Postage costs will have to be supplied up front. Rest of job will be billed. Victoria has begun ordering copies of the study from the publisher. Bea Saver will be approached for a quote after the first of the year, as the holiday season is a very busy time for printers (Jerome included). Would still like at least one more quote. And hospital mailing lists from additional countries!
- Bid and journal article reprints costs for the mailing have been forwarded to Jeannette. Cost will be \$6,600 for 3500 (plus shipping).
- Posts have been made on the www.wondir.com site by a Vasa_Previa email group subscriber on behalf of herself, and Cindy Paris on behalf of the IVPF. Member has also emailed Dr. Phil and asked him to help raise awareness as he has other pregnancy information on his website. She has been in contact with Victoria. Cindy spoke with her via instant messaging and suggested she also use the press kit for these purposes as she would like to continue helping to raise awareness.

Support Committee Report:

- No report given.

Nominating Committee Report:

- No report given.

Old Business:

- Lehman Grant: Pending

- IVPF investments: Amy has looked into interest bearing accounts. It was unanimously agreed to invest in short term (3-5 month) CDs.
- Directors Insurance. Bids are in. Costs are \$1,000 per year, which it was agreed seems quite costly. Cindy will forward this information to IVPF legal counsel for comment and advisement. This item is slated for a vote at the January Board meeting.
- IVPF hospital mailing: Jerome bid is in. Would still like at least one more quote. And hospital mailing lists from additional countries! Reprints of study have been ordered.
- Data request from subscribers in the Vasa_Previa email group: Data requested: # of IVPF members/email subscribers; number of angels, number of miracles; how many prenatally diagnosed; and number of diagnosed that still died. Statistics requested by 2 subscribers to the Vasa_Previa email list have been compiled, approved via email by EXEC, and sent to Vasa_Previa email group subscribers.

New Business:

- A proposal was made and seconded to make application to the Community Health Charities. Motion passed unanimously.

The next regular IVPF Executive Committee meeting will take place on Monday 16 January 2005 at 16:00 GMT (10:00 AM CST, 11:00 AM EST) in the IVPF Board Room.

Meeting Adjourned at 16:55 GMT (10:55 AM CST)