

International Vasa Previa Foundation, Inc.

Executive Committee Meeting Minutes for 6 March 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:

- 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 4:02 pm GMT (10:02 am CST)

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

The last IVPF Monthly Members meeting took place at 1pm CST (7pm GMT) on 1 March 2006. Amy and Cindy hosted. No one attended.

Daren was welcomed as the new Education Committee Chairperson.

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: \$ 89.45
 - Expenses: \$ 679.00
 - Total cash on hand: \$ 58,837.53
 - 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 2 pending IVPF participating members.

Public Relations:

- No report given.

Research:

- No report given.

Fundraising:

- One order for wristbands (5 wristbands total) is being processed.
- Natalie and Daren Samat are currently raising money for a scanner at their local hospital. The scanner costs £100,000 (with all the add-ons) but Daren and Natalie are donating £25,000. Any excess they raise over that sum will be donated to the IVPF and another vp awareness campaign taking place in the UK. They have raised over £10,000 so far through donations. Amy stated that the IVPF sincerely appreciates their generosity and wishes them the best of luck to get that additional 15,000 and then some!! Victoria suggested Daren contact ultrasound companies to try to raise the additional £15,000.
- 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.

Education Committee Report:

- Daren will be convening regular Education Committee meetings as soon as possible. Cindy will send him a list of committee members and aid in sending email notices out to the IVPF email groups and participating members for those interested in volunteering in this area.
- Kristen Lewis has been instrumental in getting vasa previa included in the next edition of "What to Expect When You are Expecting". It will probably be a couple of years before the new edition hits the bookshelves. The editor reports that Kristen is the 2nd person to contact the publication requesting they include information on vasa previa.
- The month of March is host to International Women's Day. Carol Prentice suggested contacting the International Women's Day organization and website as well as other womens' organization asking them to include vasa previa information and IVPF links on their websites and at their

events for International Women's Day which takes place during the month of March.

- Mailing: Jerome Group has been notified that their bid has been accepted. Jeff Paris has converted the address files into one Excel document. The Canadian list of addresses has been purchased from the Canadian Health Care. 500 more copies of the study have been ordered with the intent to order another 500 in the near future for future conferences. The addition of 2113 fetal medicine specialists from the list procured as part of the attendance fee for the recent Fetal Medicine Conference has brought the list up to 5313. 126 of these are doctors from random countries which will be difficult and expensive for Jerome Group to utilize bulk mailing drops into the respective country's mailing systems. These 126 pieces will probably be hand delivered to IVPF who will post these pieces using the USA postal system. Fetal medicine specialists and hospitals in 29 countries will receive this initial mailing. The list of 95 UK hospital names has been forwarded to Daren Samat for addresses. If completed before the project goes to print, these hospitals will also be added.
- IVPF members in the UK met in person on 25 February to discuss vasa previa awareness issues in the UK. Meeting minutes are forthcoming.
- Daren Samat and Professor Nicolaides have been invited to give a presentation on vasa previa to local hospital staff at Wycombe General Hospital part of the South Buckinghamshire NHS Trust in April or May of 2006. IVPF materials have been sent to Daren for this. Trainings for public speaking and IVPF key messages have been given to Daren Samat with the suggestion that he do live dry runs with Victoria prior to doing the presentation. Daren mentioned that he had his doubts whether Professor Nicolaides will be able to attend.
- Dr. Richard Lee at USC wrote a report for his attending doctors on finding vp. It will be published online in March and he will be sending us the link. Victoria will follow up to make sure he sends the link.
- Victoria met Dr. Anthony Vintzileos at the SMFM meeting. Dr. Vintzileos is a very prominent doctor who works with Yinka Oyelese at Robert Wood Johnson. He is the one that proposed that vp women deliver at 35 weeks vs. 36 weeks. Dr. Vintzileos recommends that we add two additional bullets for the diagnostic testing section of our bookmark. Current wording is:
 - * Transvaginal color Doppler ultrasound for women with risk factors
 - * Color Doppler scanning of the placental-umbilical cord connection during all routine obstetrical ultrasounds
 - Suggested new wording to be:
 - * Transvaginal color Doppler ultrasound for women with the above risk factors
 - * Document normal central umbilical cord placental insertion during all routine obstetrical ultrasounds
- Bios have been received for Anthony Vintzileos MD, Devore MD, Ilan Timor-Tisch MD, and John Hobbins MD for inviting to the IVPF Medical Advisory Board. It was suggested and agreed to invite Dr. Hobbins to the Board as well. Amy will send out the invitations.
- Victoria is applying for IVPF attendance at ISUOG in September 2006 in London. Daren Samat and Phil Millard have agreed to staff the booth. Yinka Oyelese will be attending.
- Cindy has contacted Yinka Oyelese regarding the AIUM presentation and furnishing the raw content of the study to Professor Nicolaides for his study. They can use the AIUM presentation for this purpose. Unfortunately, the raw data from the study has been lost. The hospital computers housing the data were replaced a year ago, and it was not saved. It was preferred not to keep the data since it contained identifiers and if in the wrong hands would be a major HIPPA violation. The data used had been cleaned up considerably, and whoever would want to use the data, even if IVPF has some of it, would have to understand it thoroughly. Several of the cases were from Georgetown (Washington DC, USA), Israel, and Robert Wood Johnson (NJ, USA), and no longer are available. Val Catanzarite did the presentation at ISUOG,

we need to contact him about obtaining it. Daren has been notified of the above and has written to Professor Nicolaides about the above and also suggested that he contact Jason Collins of the Pregnancy Institute regarding his studies on umbilical cord anomalies.

- Daren Samat's local NHS trust has suggested he provide funding for vasa previa awareness and training to its staff and ultrasound department. Cindy has asked Daren to contact them regarding actual project costs and what is to be included in the training.
- Daren and Natalie have offered to personally fund the attendance of 2 local doctors at the Fetal Medicine Foundation's anomaly scan course in April at their local NHS trust. Costs expected to be about £300.
- Cindy heard from Dr. Ioannou. He thanks us for the emails and says he went through the literature we sent and found it extremely helpful. He was also grateful for the translation of the Dutch guideline.
- Update on future conferences: Victoria has not heard back from the project manager at the World Congress in Barcelona. Also on hold for AIUM, playing phone tag.

Support Committee Report:

- Jeannette Schwartz has received some excellent bereavement support information from an employer and will submit same to IVPF for consideration for the support section of the IVPF website. Cindy suggested she contact Kathy Blades and Jackie Frith with the information. Kathy and Jackie have been informed and referred to Jeannette.

Nominating Committee Report:

- No report given.

Old Business:

- Lehman Grant: Amy is working on completing this project.--Still coming along.
- IVPF investments: Amy reports that it had been put in line after the Lehman Grant, but that is coming slowly so she will take care of the investments first
- Directors Insurance: The IVPF Board of Directors has approved the purchase of directors insurance on the advice of IVPF legal counsel. Jeannette will review the 3 bids received by the IVPF and make a recommendations on the purchase.
- Illinois sales tax exemption: Application has been sent to IL. Item is pending review of IL Department of Revenue. Additional items requested have been sent on to them.
- IVPF hospital mailing: Jerome bid is in, has been accepted by the IVPF and Jerome Group has been notified. Reprints of study have arrived. 500 more have been ordered. Materials to be included have been previously approved. Mailing lists have been procured except for the UK hospitals which Daren is working on. Canadian list has been purchased. A list of 2111 members of the Society of Maternal Fetal Medicine has been received. Adding these physicians to the mailing has been approved by IVPF.
- Letter for Yinka Oyelese's USA visa have been written, approved and submitted to the proper authorities. IVPF Humanitarian Service Award criteria has also been drafted and submitted as this was an additional requirement for his visa application.
- Medical Advisory Board: Bios have been received for the proposed new doctors. Amy will write those letters today. Victoria will send her the mailing addresses.
- AIUM Conference is taking place in Washington DC March 2006: Victoria is playing phone tag with the new contact person. The new contact person said she had a great idea for us, new person, Victoria explained what we did in the past but the contact has other ideas.....Perhaps a better option than just sending materials.

- Mr. Dad Newsletter: Victoria has contacted them.
- IVPF Newsletter: Jeannette is reviewing old newsletters for information to include in a new newsletter. Thank you Jeannette!
- ACOG Conference, Washington DC 6-10 May 2006: Victoria will not apply until will know that we can staff it.
- 2007 ACOG film festival: Nothing has been done on this. Film would have to be submitted by October 2006 to be entered into the 2007 film festival.
- 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: Lisa Paine is ready to get started. Have not heard from Jenna Steckler since she last month when she stated she is still willing to work on this.
- Britannia on the IVPF sponsors page: This item has not been actioned yet.
- Greeting cards for the IVPF Store: Victoria will call a Fundraising Committee meeting to take a look at Yinka's photos.
- Website updates: 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.

New Business:

- A motion was made and duly seconded to approve Natalie Samat as IVPF participating member. Motion passed unanimously.
- A motion was made and duly seconded to approve Rebekka Herrmann as IVPF participating member. Motion passed unanimously.
- A motion was made and duly seconded to accept the proposed changes made to the bookmark. Motion passed unanimously.
- A motion was made and duly seconded to print 5000 more bookmarks. Motion passed unanimously.

The next regular IVPF Executive Committee meeting will take place on Monday 20 March 2006 at 4:00 pm GMT (10:00 am CST, 11:00 am EST).

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