

# International Vasa Previa Foundation, Inc.

## Executive Committee Meeting Minutes for 20 February 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, Acting Education Committee Chairperson

### 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 4:00 pm GMT (10:00 am CST)

Executive Committee Minutes from 16 Jan 2006 were unanimously approved for archival and distribution.

The last IVPF Monthly Members meeting took place at 7pm CST (1am GMT) on 1 February 2006. Debi Pederson and Jeannette Schwartz hosted. One member 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
  - No report given.
- Treasurer
  - USA  
Donations and interest: \$ 204.61  
Expenses: \$ 3,312.47  
Total cash on hand: \$ 59,427.08  
In-kind donations: \$ 0.00  
Thank-you notes sent to donors: 1
  - 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.

### **Public Relations:**

- Sherri Shepherd, a famous African American comedian/actress last seen on Beauty Shop with Queen Latifah, who appeared on the TV show the View as a guest recently experienced vasa previa. Victoria requests approval to contact her about being a celebrity spokesperson for the vasa previa cause. Her website is <http://www.sherrishepherd.com/SherriHomeFlash.htm#> Victoria will write to her and submit same to EXEC.

### **Research:**

- While it doesn't mention vasa previa, a recent report from the Center for Disease Control (CDC) on "Trends in Spina Bifida and Anencephalus in the United States, 1991-2003" shows that spina bifida occurs less than half as often as vasa previa does. Report can be found at [http://www.cdc.gov/nchs/products/pubs/pubd/hestats/spine\\_anen.htm](http://www.cdc.gov/nchs/products/pubs/pubd/hestats/spine_anen.htm) Cindy suggests that IVPF contact the March of Dimes with this information, appealing once again for them to take up the issue of vasa previa. Amy will contact the March of Dimes.
- It was noted during the last IVPF Monthly Members' Meeting that more than one vp child has had hypothyroidism (with no family history of same), possibly due to birth trauma and/or blood pressure or heart regulation medications and suggested that IVPF research these issues and make this information available online. It was also noted that mental retardation is highly correlated with hypothyroidism if the hypothyroidism isn't diagnosed and treated. It was also suggested that Kristen Lewis might be a good link to getting information out to military hospitals as her vp child was born at Womach Army Medical Center in Ft. Bragg. She has agreed to help spread the word through her Bible Study group and other military posts as they move around. The next IVPF Monthly Members meeting will take place at 1pm CST (7pm GMT) on 1 March 2006. It was agreed to bring up the hypothyroidism issue with the IVPF Medical Advisory Board, Research Chairperson, and Kelli Powell. Cindy will contact them.

### **Fundraising:**

- Six orders for wristbands (35 wristbands total) and one denim shirt have been processed.
- Jenny Fredrick has made angel pins for sale in our store if we want. Sample pins were shipped to Executive Committee members on 12 Jan 2006. Our cost would be \$25 for 12 pins/with poems, 4 each of hearts, flowers, plain, and butterfly (charms). They will be in IVPF colors. Suggest we sell them for \$10 each including shipping. Approval requested to go ahead with this.
- Jeannette and Cindy attended a local Community Health Charities meeting that was held on 25 Jan 2006. Request for application extension was granted and Amy completed the application and sent it in, in record time no less!
- There is a broken link for Britannia on the IVPF sponsors page. Cindy contacted Phil and obtained a new link. It will be put on the IVPF website shortly. There is a bad link to the fetus.net on the IVPF resources page as well. This will be researched and changed or eliminated.
- Founding IVPF member Caramia Kuhfal as offered to donate copies of her book "Heart of Stone" to the IVPF for sale in the store. One of the story lines in this book is about vasa previa.

### **Education Committee Report:**

- Daren and Natalie Samat have agreed to co-chair this committee!!
- Mailed 10 brochures and 10 bookmarks to Kristen Lewis in NC on 30 Jan. She was requesting them to hand out to pregnant friends and her doctors.
- Two of Nathan's pages <<http://NathanParis.com> and <http://NathanParis.com/vp.htm>> have been added to MyBaby.net.au under pregnancy complications and loss. They made a new category just for vasa previa.
- 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.
- Claudia DiVirgilio has been working with her local radiological lab (Canada). She reports that the doctor she is in contact with there mentioned to her that he spent their \$180,000 budget on a color Doppler machine. This budget also included training their technicians. She met him in person and had a long meeting with him. During that meeting, they talked about the color Doppler machine and he told her the main reason they bought it was because of what happened with her vp baby Matthew. He said they probably would have bought it in the future anyway because technology was bringing them closer to it but they decided to speed up the process. It's one year too late for Matthew but hopefully other babies will be saved. He shared a letter with her that they'd sent out to his colleagues about the color Doppler machine. His colleagues also bought a 3-D machine. There was no specific mention on the letter that it would be used to check for vasa previa but he assured her that was one of the things they'd be looking for is vasa previa risk factors. He also said they'd check the cord connection. He stated it would be used for women who are 28-30 weeks into pregnancy. Claudia plans to remain in contact this doctor.
- 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> IVPF materials were sent for this event. IVPF has had no feedback on this event yet.
- IVPF received a mailing list of 2111 international physicians who belong to the Society of Maternal Fetal Medicine. Permission requested to add these physicians to the mailing. The list is expressly not to be used for fundraising or shared with any other organization and can only be used twice.
- Victoria and her daughter Marie Claire staffed an IVPF informational booth at the Society of Maternal Fetal Medicine (SMFM) Conference that took place 2-4 February 2006. This meeting

was a huge success for IVPF although quite an expensive investment (\$3,000 and that was already 1/2 price!). IVPF attendance was highly recommended by an IVPF Medical Advisory Board member. Victoria does not recommend that IVPF attend this meeting yearly, but does recommend that we take advantage of the two times they will let us do a mailing to their members' list. Most attendees were Maternal Fetal medicine specialists and RDMS (ultrasound sonographers) and know about vp and check for it, but hardly any knew there was a foundation. It was noted that the more we are in their face, the more people will know we exist and take us more seriously. Many doctors congratulated us for forming the IVPF and for the work we are doing. A number of radiologists requested IVPF information and to be put on our mailing list. There were also two requests for the IVPF brochure and bookmark in Spanish.

- Victoria spoke to Ivan Zador, President of FMFA and one of the ISUOG organizers at the SMFM meeting. He recommended that if we are to attend ISUOG in September in London, that we contact him first and he will work with us to get us the best discount as a non profit. Victoria is also shipping him material for the April and June FMFA meetings in NY and Chicago. This last item has already been previously approved.
- Dr. Richard Lee at USC wrote a report for his attendings 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 Anthony Vintzileos, MD 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. Victoria will forward bookmark with his recommendations.
- It has been suggested that IVPF invite Anthony Vintzileos, MD; Gregory DeVore, MD; and Ilan Timor-Tisch, MD to the IVPF Medical Advisory Board. Victoria will get their bios. Both Dr. DeVore and Dr. Timor-Tisch presented on vasa previa at the December Fetal Medicine meeting and Dr. Tisch is actually known as the king of transvaginal. Amy will draft these letters as soon as the bios are received and reviewed by EXEC.
- Victoria met Kelli Powell in person at the SMFM. Kelli recently joined the IVPF mailing list, answered questionnaire, and is requesting IVPF participating membership. She is an RDMS who diagnosed herself with vp 2-1/2 years ago and had a good outcome. She is in Miami. She is very involved with AIUM, sits on it's committees, and moderated Yinka's presentation on vp at AIUM in June 2004. She wants to work in the IVPF Research and Education committees and is willing to help coordinate the IVPF Medical Advisory Board as well. She is a really really great person and a huge resource and asset to the IVPF. Kelli is the pregnant woman getting an ultrasound in the Univision video of Victoria's story that was filmed in 2003. She also studied under Dolores Pretorius and is a good friend of hers. It was noted that Kelli is the best person to work with to try to get guidelines into AIUM.
- It was recommended that IVPF attend ISUOG in September 2006 in London (perhaps Darren Samat and Phil Millard can attend). Yinka Oyelese will be attending. Approval requested to attend this event and for Victoria to negotiate price.
- The annual AIUM Conference is taking place in Washington DC March 2006. It was suggested IVPF attend, and ask Jenna Steckler if she will man the booth, however it is too late to do a booth now. It was mentioned and agreed that ISUOG and ACOG are more targeted at our audience and we are best served sending material to AIUM. Victoria will inquire about shipping IVPF materials to be distributed at the event.
- The annual ACOG Conference is taking place in Washington DC 6-10 May 2006. Amy will staff the IVPF booth. Victoria will begin preparations. A reminder was made that IVPF needs to develop a film on vasa previa to be submitted to the 2007 ACOG film festival. Film would have

to be submitted by October 2006 to be entered into the 2007 film festival.

- Dana Henson suggested that IVPF contact soap operas about including vasa previa in the story line.
- Daren and Natalie Samat have applied to do a vasa previa presentation and staff a private (not IVPF) booth at the National Childbirth Trust's (NCT) 50th Annual Conference.
- Daren Samat contacted Armin Brott, an author of 6 books on fatherhood and the Mr. Dad.com newsletter that gets circulated in 20 countries. Armin would like to do an article on vasa previa for the next edition of the Mr. Dad newsletter. Victoria is contacting Armin Brott.
- Daren and Natalie Samat have proposed an informal UK ultrasound screening referral program for vasa previa. Daren has spoken with Professor Nicolaides of Kings College Hospital in London, who agrees to take referrals, for little or no cost if necessary.
- Dr. Nicolaides is also in the process of commencing a further major study at Kings. Exact nature of whole study not certain but he is looking for nuchal markers. After speaking with Daren, Professor Nicolaides would like to extend the study to include (localizing [?] the umbilical cord) and from what they had spoken about Daren took this to mean evidence of vasa previa. IVPF information is requested for this, specifically the IVPF statement on risk factors, testing, and management, the raw study data from the last study IVPF members participated in, the AIUM powerpoint presentation, and the published medical paper on what ISN'T vasa previa recently given at ISUOG in Vancouver. Cindy will contact Yinka Oyelese about these items. It was also suggested that Professor Nicolaides contact Jason Collins of the Pregnancy Institute regarding his studies on umbilical cord anomalies.
- It was suggested that IVPF include links to Professor Nicolaides <http://www.fetalmedicine.com/> and <http://www.fetalmedicine.com/f-fmc.htm> on the IVPF website as a website referral. Professor Nicolaides has agreed to this.
- Daren Samat's local NHS trust has suggested he provide funding for vasa previa awareness and training to it's 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 will download the training materials from the PR section of <http://IVPF.org/Office> and also obtain from Victoria.Goldstein@vasaprevia.com booth staffing and speaking tips before doing the medical conference events and the speaking engagements he has lined up. He will be reporting to us on 3 upcoming events (2 of them to be IVPF staffed) that he's recommending IVPF participate in.
- Lisa Paine has offered to help with writing the inservice materials. Her qualifications have been sent to EXEC via email. Jenna is ready to get started on this now too.
- Caramia Kuhfal plans to help staff a booth at the Life Light Festival in Sioux Falls, South Dakota over Labor Day weekend this year. This is a very large Christian music festival that brought in a crowd of well over one hundred fifty thousand last year, they're predicting triple that number this year as the festival has steadily been gaining popularity in the past five years or so. She will be part of her friend's Crisis Pregnancy Center booth where I will be signing books. She will be allowed to share information and materials regarding vasa previa as well. IVPF President and Secretary have agreed to send some IVPF brochures for this event. (Yes, we made a spur of the moment executive decision on this.)

### **Support Committee Report:**

- No report given.

### **Nominating Committee Report:**

- No report given.

### **Old Business:**

- Lehman Grant: Jeannette forwarded the work she's completed on the Lehman grant to EXEC for completion. Amy will complete this project.
- Community Health Charities application: Application has been completed and has been received by the CHC. Thanks to Amy for her excellent and tremendous effort in getting this project completed at the last moment!
- IVPF investments: On Amy's to-do list. Don't forget the credit card!
- 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. (Note here: MO and FL sales tax exemption applications will be next.)
- IVPF hospital mailing: Jerome bid is in. Daren Samat is putting together a mailing list of UK hospitals. Reprints of study have arrived. Materials to be included have been previously approved. USA list has been purchased. Canadian list purchase still outstanding. A list of 2111 members of the Society of Maternal Fetal Medicine has been received. Requesting permission to add these physicians to the mailing.
- Newsletter: <-This one is up for grabs, folks! It really needs to be done.
- 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 Kristen Lewis as IVPF participating member. Motion passed unanimously.
- A motion was made and duly seconded to approve Kelli Powell as IVPF participating member. Motion passed unanimously.
- A motion was made and duly seconded to approve Lisa Paine as IVPF participating member. Motion passed unanimously.
- A motion was made and duly seconded to draft a letter to the USA Department of Homeland Security and the United States Citizenship and Immigration Services in support of Yinka Oyelese's visa status. Motion passed unanimously. Victoria will draft the letter and submit to EXEC.
- A motion was made and duly seconded to approve the purchase of 12 handmade angel pins from Jenny Fredrick at a cost of \$25 for resale in the IVPF store at \$10 a piece. Motion passed unanimously. Cindy will notify Jenny.
- A motion was made and duly seconded to add 2111 international physicians to the mailing from the SMFM mailing list acquired. Motion passed unanimously.
- A motion was made and duly seconded to accept Jerome Group's bid for the mailing as no other competing bids could be obtained. Motion passed unanimously. Cindy will contact Jerome Group.
- A motion was made and duly seconded to translate the IVPF brochure and bookmark into Spanish. Motion passed unanimously. Victoria will do the translations and Cindy will format the pieces for the printers. It was mentioned that IVPF would like to eventually have these

materials available in multiple languages.

- A motion was made and duly seconded to approve IVPF attendance at ISUOG in London, UK in September 2006. Motion passed unanimously. Victoria will make the inquiries and arrangements. Cindy will ask Daren Samat and Phil Millard if they will be available to staff the booth.
- A motion was made and duly seconded to approve IVPF attendance at ACOG in Washington DC, 6-10 May 2006. Motion passed unanimously. Amy will staff this booth. Victoria will make the inquiries and arrangements. Cindy will contact Jenna Steckler to see if she will be able to help staff the booth.
- A motion was made and duly seconded to invite Gregory DeVore, MD; Ilan Timor-Tisch, MD; and Anthony Vintzileos MD to the IVPF Medical Advisory Board. Motion passed unanimously pending review of biographical data on these doctors. Victoria will obtain and submit the biographical data. Amy will draft the letters and submit to EXEC.
- A motion was made and duly seconded to include information about the informal UK referral program and links to <http://www.fetalmedicine.com/> and <http://www.fetalmedicine.com/f-fmc.htm> on the IVPF website. Motion passed unanimously. Cindy will take care of the website updates.
- A motion was made and duly seconded to contact Sherri Shepherd regarding her recent experience with vasa previa. Motion passed unanimously. Victoria will draft a letter to Sherri.

**The next regular IVPF Executive Committee meeting will take place on Monday 6 March 2006 at 4:00 pm GMT (10:00 am CST, 11:00 am EST).**

Meeting Adjourned at 4:58 pm GMT (10:48 am CST)