

International Vasa Previa Foundation, Inc.

Executive Committee Meeting Minutes for 17 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:

- 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:

- Phil Millard, IVPF Board of Directors

Meeting began at 4:03 pm GMT (10:03 am CST)

Executive Committee Minutes from 3 April 2006 were unanimously approved for archival and distribution.

The last IVPF monthly members' meeting took place 5 April at 7pm CST (1am GMT). Cindy hosted. An expectant member attended and expressed a desire to attend the Education Committee meeting coming up on Sunday.

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: \$ 53.77
Expenses: \$ 200.00
Total cash on hand: \$ 53,934.10
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 are 2 pending participating members.

Public Relations:

- HAND website www.indogo.karoo.net/hand.htm has requested material from Cindy Paris on her vasa previa loss for their newsletter. Article has been drafted and sent to HAND. They provide support for expecting and/or grieving parents.
- HAND website www.indogo.karoo.net/hand.htm has requested material from IVPF (via Cindy Paris) for an article on vasa previa for their newsletter. Article has been drafted by PR and will be sent today. It was suggested that this article also be sent to Leian Welch for her article on vasa previa.
- Press release about new Oyelese article will be written.
- Letter to Green Journal commenting about new Oyelese article will be written.
- Central Television News (UK) has picked up the Samat's vasa previa story from 2 local newspapers and want to cover it.
- 500 reprints of Yinka Oyelese's latest paper "Placenta Previa, Placenta Accreta, and Vasa Previa" will be ordered.

Research:

- No report given.

Fundraising:

- One order for 10 wristbands was processed.
- Jenny Fredrick reports that Lucas' Angels are finished. She will be sending them to Cindy.

Education Committee Report:

- **Education Committee Meetings:** Meeting took place 9 April 2006 at 2000hrs GMT (8pm GMT / 2pm CST). Five members attended. It was agreed to hold formal Education Committee meetings on the second Sunday of every other month. Therefore the next meeting is scheduled for Sunday 11 June 2006 at 8pm GMT [2pm CST]. In the interim Ed Comm members will all keep in contact via email and messenger services. Daren will try to post a monthly update via email to committee members and also advises everyone to look at the minutes of the Executive Committee for further information on Education Committee work.
- Daren suggests that IVPF create a list of acronyms used by the IVPF.
- **Doctors Database Project:** Daren identified over 100+ couples from Yahoo email database who have had diagnosed vasa previa. From the same source Daren has identified a further 25+ doctors and medical facilities who have previously successfully diagnosed vasa previa. Daren has emailed 40+ people identified in the Yahoo email group with the Database questionnaire and request for details of their doctors/medical facilities for addition to the database.
- Lora Beth Sabbatini suggests that IVPF contact child birth classes requesting inclusion of information on vasa previa. This is being done in the UK through NCT. Lora Beth will look into a similar national USA contact.
- HAND website www.indogo.karoo.net/hand.htm has contacted Cindy Paris and requested material from Nathan's pages on vasa previa and Nathan's loss for their newsletter. Information from <http://NathanParis.com/vp.htm> and <http://NathanParis.com/story.htm> have been submitted for inclusion on the HAND website.
- **Fetal Medicine Foundation of America (FMFA)** Bookmarks and brochures to be mailed to Dr. Zador for upcoming OB-GYN Ultrasound Master Series 2006 meeting in Chicago April 27-30. <http://fmfaus.meetingpro.info/registrants/MasterSeries06/MasterSeries06.htm>
- **Wycombe General Hospital event:** 17 May 2006 at 10 am GMT. Daren Samat will be giving a talk on his vasa previa experience.
- **American College of Obstetricians and Gynecologists (ACOG) Conference**, Washington D.C., USA, 6-10 May 2006: Victoria has applied to them for and 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. IVPF application for this event was accepted on 11 April. Hotel reservations have been made for Amy Gaghagen and Jeannette Schwartz for ACOG in D.C. May 7-10. Being held with Victoria's IVPF check card, Amy will have to pay for both rooms with her card. Airline reservations for Jeannette Schwartz have been found for \$278 on AA non stop STL-DC but need her 100% commitment since it's non refundable. Amy reports after speaking with the insurance company that additional insurance for this event can be and will be easily and inexpensively procured from Schmale Insurance. She will call them today.
- **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.
- **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. Waiting information and costs from Daren so IVPF can arrange funding.

- **Challenges in Antenatal Screening & Pregnancy Care** 17 July 2006, London. Daren will look into the details. <http://www.arc-uk.org/conference.html> Flyer for event: <http://www.arc-uk.org/arc-conference.pdf>
- **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.
- **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. Natalie Samat reports that UK hospital addresses have been procured and will be converted to an EXCEL format over Easter break. It was decided to use copies of the new paper's abstract instead of reprints as the reprints will cost \$10,000 and obstetricians all have this paper.
- **BabyCenter.com** Carol Prentice has contacted BabyCenter.com in the past. She will continue to follow up.
- **IVPF Vasa Previa Manual:** It was decided to use copies of abstracts for this project. This eliminates the costs of reprints. Victoria was informed that IVPF will not be able to purchase copywrites to print them ourselves. This enables us to use far more materials. This document needs a proper name. It was suggested and agreed that suggestions be submitted via email.
- **Bookmark reprint:** 5,000 have been printed and received.
- **Conferences, Banners** and stands to be ordered this week. Bigger than before so stands are pricier (about \$40 - each, banners will be a bit pricier too, but worth the difference). Once banners are received, will mail old banners and stands along with new bookmarks, pens and bracelets to Daren Samat for his meetings.
- **Pens and Bracelets** for conferences and store: 2500 pens and 1000 bracelets have been ordered, will be arriving in next two weeks.
- Victoria will be translating the bookmark and brochure into Spanish.

Support Committee Report:

- It is suggested that <http://www.indogo.karoo.net/healing.htm> be added to the Support Section of the website when it is produced. This is a page offering hand made life sized and weighted infant dolls.
- It was asked when this website section will be ready to launch. Support Committee has created an excellent outline. Cindy is still waiting for content before starting the web pages. Amy will contact Kathy Blades about a completion date.

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. IVPF has been assured that even coverage insurance will be in force by the ACOG conference. It will be a separate policy. Amy will call the company today to ask about it.
- Medical Advisory Board: Amy is drafting invitations.
- 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.
- Newsletter: Jeannette is working on this.
- DMOZ Open Directory Project: Materials have been sent to Debi who will be applying to edit the vasa previa section. She has investigated the site and will go back there today and finish submitting her application.

New Business:

- A motion was made and duly seconded to approve Milena Barrett for IVPF participating membership. Motion passed unanimously.
- A motion was made and duly seconded to approve Susan Williams for IVPF participating membership. Motion passed unanimously.
- It was proposed and duly seconded that IVPF order 500 reprints 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.

The next regular IVPF Executive Committee meeting will take place on Monday 1 May 2006 at 4:00 pm GMT (10:00 am CST, 11:00 am EST).

Meeting Adjourned at 5:00 pm GMT (11:00 am CST)