

# International Vasa Previa Foundation, Inc.

## Executive Committee Meeting Minutes for 24 May 2004

### Executive Committee members present:

- Amy Brown Gagghagen, President
- Victoria Goldstein, Treasurer / PR, Research, and Fundraising Committee Chairperson
- Cindy Paris, Acting Secretary / Membership, Nominating Committee Chairperson

Debi Pederson, Vice President was not in attendance

### IVPF Committee chairpersons present:

- None

Kathy Blades, Support Committee chairperson was not in attendance  
Marlou Van Dijck, Education Committee chairperson not in attendance

Meeting began at 18:38 GMT (12:38 AM CST)

Executive Committee Minutes from 8 March 2004 were approved for archival and distribution.

Monthly Members' Meetings took place on 7 April, and 5 May 2004. Victoria or Cindy hosted these meetings. There were no attendees. Due to lack of interest in the past 6 months it was decided to cancel the meetings for the next 2 or 3 months, resuming the Monthly Members' meetings again in the fall.

Subscribers of the Vasa\_Previa email group have requested that the IVPF do political lobbying to effect changes in the standard of care. The President and Acting Secretary have both reiterated that this is not a legal activity for the IVPF to participate in and that subscribers are free to pursue these activities on their own behalf or join the IVPF as participating members and work in IVPF committees to accomplish these changes within the laws that the IVPF must operate under.

### **Agenda:**

- Officer Reports
- Treasury Reports
- Chapter Reports
- Membership Committee Report
- Public Relations Committee Report
- Research Committee Report
- Fundraising Committee Report
- Education Committee Report

- Support Committee Report
- Nominating Committee Report
- Budget
- Old Business
- New Business

### **Officer Reports:**

- President
  - No report given.
- Vice President
  - No report given
- Secretary
  - Terri Fretwell has reluctantly resigned as IVPF Secretary stating unexpected lack of time due to her new job responsibilities. Amy will contact the Vasa\_Previa email group requesting those willing to volunteer for this position to contact us. New applicant will need to be reliable, responsible, and trainable. Cindy will resume the Secretary's responsibilities in the interim as "Acting Secretary" until a new Secretary can be approved and trained.
- Treasurer
  - UK:  
 Donations received: £ 0.00  
 In-kind donations: £ 0.00  
 Expenses: £ 0.00  
 Total cash on hand: £ 828.11  
 Thank-you notes sent to donors: 0
  - USA:  
 Donations and interest: \$450.56  
 In-kind donations: \$ 0.00  
 Expenses: \$771.00  
 Total cash on hand: \$27,654.87  
 Thank-you notes sent to donors: 3

### **Membership:**

- There are 62 participating IVPF members, 2 pending.
- There are 260 IVPF email group subscribers.
- There are 155 subscribers in the Vasa\_Previa email group, 5 pending.
- There have been 7 additions to the Vasa\_Previa email group birthday calendar.
- This committee continues to provide routine maintenance and screen / welcome new subscribers to the email groups.
- All 5 pending subscribers to the Vasa\_Previa email group have been contacted more than once regarding their pending subscription. They will be denied at the end of the month if we don't hear back from them.
- The vasa previa picture on the IVPF newsletter and Vasa\_Previa email groups home page has been removed and updated with an edited version of

the picture Sigrid produced for us.

- A file has been added to the Vasa\_Previa email group files section giving information on joining and volunteering for the IVPF. This file is set to automatically post to the group once per month.
- This committee continues to respond to email requests for information sent to [info@vasaprevia.com](mailto:info@vasaprevia.com) as well as support requested via private emails.

### **Public Relations:**

- Working on Newsletter to be sent out end May.
- Freelancer Beverly Burmeier has requested info about Sophie's Walk 2004 and contact with vasa previa parents for a story she is submitting to a national publication. Information has been furnished.
- Working on press release announcing research published in Green Journal.
- Working on updating press package for website and AIUM Conference.
- Several IVPF members have volunteered to help with this committee, training meeting will be set for early July. Due to time limitations organizing and attending the AIUM conference next month, Victoria will incorporate and train new volunteers to this committee after the conference.
- Susan Mulligan has volunteered to help staff the IVPF booth at the AIUM conference. Cindy will also attend if more help is needed.
- Carol sent update on work of IVPF, Inc to freelancer Jenny Campion and also Lizzie Attwood at "Pregnancy and Birth". Lizzie was thankful for update and all the information and will be running a feature on pre-eclampsia in June and is going to mention VP as well. Plans are to run a full feature on VP in the future.
- Carol sent letter/pack to "That's Life", "Chat" and "Now" magazines, the "We need you" section at GM-TV, and the BBC.
- Carol received e-mail from Health Correspondent at BBC Scotland and sent her an update on the work of the IVPF.
- Carol informed Lanarkshire Health Board (governing health service provision in Lanarkshire) at a joint meeting with Lanarkshire Health Council of the latest work of the IVPF, Inc. She has also discussed developments with Consultant at local Acute Hospital which includes Maternity Unit and will spoke to members of LHC and the public about developments at their Business Meeting on 17 March.
- Carol attended Consultation on Draft Clinical Standards for Maternity Services in Dunblane on 16 March 2004.

### **Research:**

- This committee needs a new chairperson.
- Janine Twining-Freeman volunteered to help in this committee.
- IVPF has registered for AIUM Conference, and is working on putting together materials for Conference. Will be attending June 20-22, 2004. Will distribute IVPF brochures, abstracts and possibly reprints from Contemporary OBGYN Nov 2003 article and Green Journal May 2004 article.

- Letter to Dr. Benasarref requesting meeting to include checking for placental cord insertion as part of U/S standard of care has been drafted and submitted for approval. Approved was granted.
- Training meeting for new volunteers will be set for mid summer.

### **Fundraising:**

- Trina Perrone and Sue Miller have agreed to co-chair this committee and will take over after their current IVPF Fundraising project is completed next month.
- 4<sup>th</sup> and 5<sup>th</sup> Walk meeting held in April and May. Low attendance to meetings has created extra work for Chairpersons having to communicate individually with Walk Captains.
- Walk area of IVPF website has been updated and new cities included.
- Sue Miller and Trina Perrone are working on fundraising concert in June in Pittsburgh.

### **Education Committee Report:**

- The IVPF brochure has been redesigned and submitted for Executive approval and professional printing.

### **Support Committee Report:**

- No report given.

### **Nominating Committee Report:**

- No report given.

### **Budget:**

- No report given.

### **Tax Exempt Status:**

- No report given.

### **Old Business:**

- IVPF must obtain the permission from the artist to use Christina's painting <http://members.fnol.net/~tree/Christina/painting.htm> for future note card sales. Pending since 20 October 2003.
- IVPF participation in the British Conference of OB/GYNAES (<http://www.bcog2004.co.uk>) July 7 - 9 in Glasgow.
- A Board meeting must be scheduled to appoint a replacement for the Director position vacated by Marlou van Dijck's resignation. Tabled.

### **New Business:**

- Janine Twinning-Freeman was approved as an IVPF participating member.
- Teresa Spurgeon was approved as an IVPF participating member.
- Official letters from the IVPF thanking the Medical Advisory Board for accepting their positions must be drafted by the IVPF President and approved

by this committee as soon as possible. Amy and Cindy will draft these today and submit them by email to this committee for approval.

- Approval was given to purchase 500 copies of the American College of Obstetricians and Gynecologist's Green Journal article "Vasa Previa: The Impact of Prenatal Diagnosis on Outcomes" (the study IVPF initiated and participated in) published in May 2004 at \$654 plus \$5 shipping.
- IVPF in-service presentations: Julie Boyd has agreed to help operate said project. Cindy has already completed some preliminary research on different types of educational medical in-services and has discovered that IVPF has been utilizing several different educational modalities with success thus far. She recommends IVPF continue this path in the same vein as they've previously accomplished, but with an official IVPF presentation (to be developed). IVPF should also actively pursue these educational opportunities. This item is tabled until the next meeting.

**The next regular IVPF Executive Committee meeting will take place on Monday, 7 June at 18:30 GMT (12:30 PM CST, 1:30 PM EST) in the Board room of the Vasa Previa Chat Café.**

Meeting Adjourned at 19:55 GMT (1:55 PM CST)