

Vasa Previa Foundation

Executive Committee Meeting Minutes for 20 October 2003

Executive Committee members present:

- Marlou van Dijck, Vice President / Netherlands Chapter Leader / Assistant Treasurer, NL
- Cynthia Balota Paris, Secretary / Membership and Nominating Committees Chairperson
- Victoria Goldstein, Treasurer / PR, Research, and Fundraising Committee Chairperson
- Carol Prentice, UK Chapter Leader / Assistant Treasurer, UK

Amy Brown Gaghagen, President / Chapter Formation Committee Chairperson was on vacation.

VPF Committee chairpersons present:

- None

Meredith Kirby, Education Committee Chairperson; and Kathy Blades, Support Committee Chairperson were not in attendance.

Meeting began at 18:39 GMT (12:39 PM CST)

Executive Committee Minutes from 6 October 2003 were approved for archival and distribution.

Agenda:

- [Officer Reports](#)
- [Treasury Reports](#)
- [Chapter Reports](#)
- [Membership Committee Report](#)
- [Public Relations Committee Report](#)
- [Research Committee Report](#)
- [Fundraising Committee Report](#)
- [Chapter Formation Committee Report](#)
- [Education Committee Report](#)
- [Support Committee Report](#)
- [Nominating Committee Report](#)
- [Budget](#)
- [Old Business](#)
- [New Business](#)

Officer Reports:

- The next monthly Members Meeting will take place on Wednesday, 5 November 2003. Marlou will host.

- 30 VPF Humanitarian Awards have been sent out to nominated recipients.
- 53 letters and approval forms sent to VPF Participating Members regarding change in the Articles of Incorporation of the USA chapter. As of 17 October, 45 approvals have been received back - all affirmative for the amendment addition. We have the 36 needed for the vote to pass. The amendment has been submitted to the Illinois Secretary of State.

Treasury Report:

- Netherlands:
Donations and interest: € 0.00
Dutch expenses: € 51.77
Total Dutch cash on hand: € 2387.49
Thank-you notes sent to donors: 0
- UK:
Donations received: £ 110.00
UK expenses: £ 0.00
Total UK cash on hand: £ 462
Thank-you notes sent to donors: 3
- USA:
Donations received: \$ 4,498.00
USA expenses: \$ 25
Total USA cash on hand: \$ 25,745.86
Thank-you notes sent to donors: 14

Chapter Reports:

- NETHERLANDS:
 - No report given.
- UK:
 - No report given.
- USA:
 - No report given.

Membership:

- There are 58 participating members of VPF, 1 pending.
- There are 303 IVPF email group subscribers (7 new subscriptions, 1 unsubscription).
- There are 134 Vasa_Previa email group subscribers (3 new subscribers, 2 unsubscriptions, 2 pending subscribers).
- There were 2 edits to the birthday calendar.

Public Relations:

- Victoria will present a full PR plan document for 2004 before the end of October.
- Fall Newsletter has been sent out with information about Sophie's Walk 2003 and our Holiday Card fundraising drive.
- NETHERLANDS

- Karin Wheel has sent a letter to the organisation of the DES (Diethylstilbestrol)-congress in the Netherlands (www.descentrum.nl). She is asking them if she can send them brochures to give away to all subscribers, because there might be a relationship between VP and being a DES-daughter. She is also asking them to add a question about VP in their questionnaire (if they create one).
- Fall Newsletter has been translated and sent to all Dutch companions in distress and people who are interested.
- UK
 - Carol has been getting great response from the public and some journalists on some small items on VP/Rebecca that have appeared in three national newspapers on August 22nd. She will follow these up.
 - Carol sent a letter to BBC acknowledging the vasa previa storyline that appeared in the TV show “Holby City”.
 - Feature on “Sophie’s Walk” (with photos) has been published in Lanarkshire Health Council magazine “Health Wise”. The magazine is being distributed to all medical centres/professionals etc at present. A copy of the article will be sent to the VPF. This is being used as the basis for the feature/contact information on the website as well. Latest news will be added to their website very shortly and they will also publish information about “Sophie’s Walk” later in the year. A link will be provided to the VPF.
 - Carol received the outline programme for the RCOG Conference to be held in Glasgow next year. The theme is “Research into Practice”, which sits very well with the research findings awaited from Dr. Oyelese. This would be an excellent forum to highlight VP and the new evidence.
 - Carol received a reply on the two motions (one on Vasa Praevia and one on Neonatal Intensive Care Cots) to which she spoke on at the Scottish Association of Health Councils (SAHC) AGM on 12 June in Edinburgh. The reply indicates that they do not understand VP. The Scottish Executive sees no reason to scan women for this condition. Carol is incredibly disappointed with this result and is looking at ways to follow this up with the Health Council.
- USA
 - Victoria has recontacted the freelancer Jennifer Haupt who will submit her story ideas on vp miracle survivors to Woman’s Day and Parenting magazines.

Research:

- The paper on Management of vasa previa will be out around November 10. Single copies are \$10 a piece. Reprints are pricey and run more than \$3000. Victoria will discuss other options with publication.
- The research paper that includes the 155 records compiled with the VPF’s help is DONE! It will be submitted week of October 20 for publication 4-6 months out.
- 244 women are documented on the database (155 records received for the study). Paper will be sent for publication by October 13, 2003.

- Four more medical doctors have been invited to join the VPF Medical Advisory Board. We are awaiting their responses. Update: Jason Birnholz MD accepted the invitation. The VPF Medical Advisory Board currently has three members: Yinka Oyelese MD, Jason Collins MD, and Jason Birnholz MD.

Fundraising:

- Cindy will be taking over the Fundraising Committee for Victoria for the meantime.
- VPF store has been established, first item in store is Holiday Cards. Other ideas have been submitted and cookbook and other saleable items to be included shortly.
- Holiday cards have been approved and are in the process of being printed. The cards will be printed in Greenville and shipped to St Louis for distribution to buyers.
- First meeting for Sophie's Walk 2004 is scheduled for October 23/24.
- NETHERLANDS
 - Nothing new to report.
- UK
 - Nothing new to report.
- USA
 - Sophie's Walk to date has yielded almost \$22,000 in the USA.
 - Holiday cards created by Jacqueline are being printed and are currently showcased on the main VPF website page and being sold in the store. Because the NL and UK chapters were uncomfortable with the retail cost of the cards, they did not contribute to this fundraiser. Since orders have come in from European members, the USA chapter will subsidize shipping costs to Europe until proper shipping charges can be included in the cost of cards shipped to Europeans.
 - Victoria suggested VPF sell denim shirts embroidered with the VPF logo on them in the store for \$30-\$35 a piece (shipping extra). VPF cost would be \$13-\$18 per shirt (before shipping).
 - Cindy would like to use Christina's painting for VPF note cards. Her mother, Theresa, has agreed. It was mentioned that VPF also needs permission from the artist. The painting is located at <http://members.fnol.net/~tree/Christina/painting.htm>

Chapter Formation Committee Report:

- No report given.

Education Committee Report:

- Submission deadline for the ACOG film festival is October 17, 2003 for abstract, November 17 for the actual film. A letter from VPF was sent to the film's producer with requested additions/changes, namely a professional interview from a doctor on the VPF Medical Advisory Committee. Due to the reply received from producer via Meredith Kirby on these issues, VPF will NOT be submitting

this film to the ACOG festival. A special Executive / Board meeting has been scheduled for Tuesday, 21 October 2003, 21 October to discuss the feasibility of continuing this project or producing a new film to be submitted for 2005 Film Festival instead.

- After some discussion it was agreed that Sigrid would create English and American brochures based on the Netherlands one currently in use. Victoria will obtain a copy of the text as approved during the Annual Meeting in January 2003, with the (as yet unapproved) additions/changes made throughout the year and send it on to Marlou. Marlou will send the completed brochure back to this committee for approval. Printing will be done in the individual chapters.
- Kristy Schryver has made contact with several hospitals that are interested in having Drs Collins and Oyelese speak at beginning of 2004. Victoria will work with her and Christie Michie to set these up.

Support Committee Report:

- It was suggested by Kathy and agreed that she form a "Dads' Corner" via the Support Committee. She'd also like to invite one of the dad's to this venture so that they do not feel they are alone in their grief.

Nominating Committee Report:

- Cindy has called the Nominating Committee together to nominate VPF Directors for 2004. Meeting will take place on Thursday, 23 October. Location of 26 January 2004 Annual Members' Meeting and Board Meeting will be Heenweg 15, Netherlands. Voting proxies need to go out to the membership by late November.

Budget:

- No report given.

Tax Exempt Status:

- The motion to approve an addition to the VPF Articles of Incorporation has been sent via postal mail to the VPF Participating membership for approval. This action is required by the IRS for tax exempt status in the USA. The additional clause designates remaining funds (after expenses) to be distributed to other 501(c)(3) charitable organizations should the VPF ever dissolve. As of 17 October, 45 approvals have been received back - all affirmative for the amendment addition. We have the 36 needed for the vote to pass. The amendment has been submitted to the Illinois Secretary of State.

Old Business:

- Donor data to complete the private donation page for the VPF website is still needed. Tabled since forever. A participating member offered to help compile the necessary data. In the process, it was realized that with the huge

numbers of individual donors giving during the Walk and other VPF events, this project may need to be rethought.

- UK will need a VPF Assistant Secretary. Tabled since 24 June 2002.
- Netherlands needs a VPF Assistant Secretary.
- VPF website banner for use on other websites. Tabled 8 July 2002 pending sample submission.
- Gavel sound for Board Room in the chat café. Tabled since 24 Feb 2003.
- Victoria is working on Spanish translations of the VPF brochure and Sophie's Walk information for the website. Tabled since 24 March 2003 as this is a work in progress.
- Press releases for the Kennedy March and Carol's nomination for Scotswoman of the Year. (19 May 2003)
- New page for the website about volunteering for the VPF. (19 May 2003)
- VPF document on management of vasa previa. (Tabled 19 May 2003 pending publication of pending medical articles)
- Advisory Board invitation letters to several medical doctors have been mailed out. Jason Birnholz MD accepted VPF's invitation to join the Advisory Board. The Advisory Board currently has three active members. We are awaiting replies from 3 more invitees.

New Business:

- Alexandra Jane Kuyvenhoven was unanimously approved as VPF Participating Member.
- It was proposed and unanimously agreed that VPF sell denim shirts embroidered with the VPF logo on them in the store for \$30-\$35 a piece (before shipping). VPF cost would be \$13-\$18 per shirt (without shipping). Twenty shirts would cost a little less due to a special bargain sale right now. Because a total final price including shipping, set up, etc was not available, the total number of shirts to be ordered was tabled for now.
- The use of Christina's painting for future note card sales was unanimously approved with the notation that VPF must obtain the permission of the artist.

The next regular VPF Executive Committee meeting will take place on Monday, 3 November 2003 at 18:30 GMT (1:30 PM EST, 12:30 PM CST) in the Board room of the VPF Chat Café.

Meeting Adjourned at 19:48 GMT (1:48 PM CST)