

Vasa Previa Foundation

Executive Committee Meeting Minutes for 3 November 2003

Executive Committee members present:

- Amy Brown Gaghagen, President / Chapter Formation Committee Chairperson
- 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

VPF Committee chairpersons present:

- Meredith Kirby, Education Committee Chairperson

Kathy Blades, Support Committee Chairperson was not in attendance.

Meeting began at 18:34 GMT (12:34 PM CST)

Executive Committee Minutes from 20 October 2003 were approved for archival and distribution.

Victoria will be on medical leave for the next 4-6 weeks.

Agenda:

- [Officer Reports](#)
- [Treasury Reports](#)
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Officer Reports:

- The next monthly Members Meeting will take place on Wednesday, 5

November 2003. Marlou will host.

Treasury Report:

- Netherlands:
Donations and interest: € 124.62
Dutch expenses: € 0.00
Total Dutch cash on hand: € 2512.11
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: 0
- USA:
Donations received: \$ 276.94
USA expenses: \$ 0
Total USA cash on hand: \$ 26,022.80
Thank-you notes sent to donors: 1

Chapter Reports:

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

Membership:

- There are 59 participating members of VPF, 0 pending.
- There are 304 IVPF newsletter group subscribers (1 new subscription, 0 unsubscriptions).
- There are 138 Vasa_Previa email group subscribers (2 new subscribers, 0 unsubscriptions, 3 pending subscribers).
- There were 0 edits to the birthday calendar.
- Cindy has spoken with a member who might volunteer in this committee. Will probably assign her to the Vasa_Previa calendar.

Public Relations:

- NETHERLANDS
 - Karin Wheel's request that the DES (Diethylstilbestrol) congress in the Netherlands (<http://www.descentrum.nl>) send VPF brochures to all their subscribers was turned down because there is no known connection between VP and DES. If they create a questionnaire for their members in the future, they will consider adding a question about VP. For the record: Karin has not contacted them on behalf of the VPF. She has stated clearly

that it was her own initiative but that she has connections with people of the VPF.

- UK

- Carol has been contacted by a journalist who is keen to write a piece for a UK wide newspaper and women's magazines. Carol spoke to her via e-mail on 29 October and has given her all the updated news from the VPF. She is looking forward to the research and also keen to be kept in touch. She will make new attempts to get a feature published.
- 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. Update: meeting scheduled for 4 November to look at how to take this forward and also at business meeting of Health Council later in the month.
- Carol attended her first meeting of the Nursing, Midwifery and Health Visitor Strategy Review Group for Lanarkshire on 29 October. It was very interesting and now broken into sub-groups for specific tasks. Carol has been asked by the lecturer attending this meeting to speak to her students on the Nursing/Midwifery course about being a parent and nursing a sick child and how this impacts on the wider family. Also how the locus of care shifts when there is a sick child. She will also be able to mention VP. Do not have a date for this as yet but will let VPF know when I get a date.
- Carol will attend meeting of the Nursing and Midwifery Council in London on 26 November.

- USA

- Article from Yinka Oyelese MD will be published in the December issue of Prevention Magazine.
- The Penn State University alumni magazine, The Penn Stater, has interviewed Meredith and Steve Kirby about Charlotte for an article. Meredith will send VPF the article and internet links when it is published. This want to include a sidebar so people can send donations to the Foundation. Victoria will send Meredith a side bar idea to forward onto the publication.

Research:

- The research paper that includes the 155 records compiled with the VPF's help is DONE! It is being submitted THIS WEEK after revisions requested by other authors. Most important finding is that there is statistical evidence to support C-sections at 35 weeks. Publication still set for 4-6 months out. Dr. Oyelese submitted this same paper to the New Jersey Maternal Fetal Medicine Society and it has won 1st prize!

Fundraising:

- First Sophie's Walk 2004 meeting took place in October. Second meeting for Sophie's Walk 2004 is scheduled for November 20 and 21.

- NETHERLANDS
 - Nothing new to report.
- UK
 - Nothing new to report.
- USA
 - Sophie's Walk to date has yielded almost \$23,000 in the USA.
 - Holiday cards have been printed and shipped to Cindy Paris' address. Sales going well, some purchasers are from the UK.
 - Additional VPF Store PayPal account will be created for the USA chapter to avoid simple donations having to pay shipping on their donations.
 - Cindy installed a banner exchange on Nathan's pages. Cost of joining the banner exchange is a \$20 donation to the VPF.

Chapter Formation Committee Report:

- No report given.

Education Committee Report:

- A special Executive Committee meeting was held on Tuesday, 21 October 2003, to discuss the feasibility of continuing the film project or producing a new film to be submitted for 2005 Film Festival instead. It was decided that:
 - Victoria will telephone Dr. Bird one last time. This has been done, with no results.
 - Any new film project will be moved to the PR Committee or into its own newly created committee.
 - It is estimated that VPF can do this whole thing for under \$3,000 by hiring a film / editing crew and producing the film ourselves.
 - This film will not be attempted without specific contracts between all parties.
 - Content will consist of a simple 10 minute film composed of 3 cases of vasa previa and an interview with a member of the VPF Medical Advisory Committee. Purpose of the film is to introduce vasa previa via a typical loss, a prenatally diagnosed and managed case of survival, and an emergency miracle survivor, all to demonstrate to both parents and medical professionals the deadliness verses survivability using effective management techniques.
- Amy will write a letter to Penn State thanking them for the work they did on this project, explaining that we understand that they consider the film complete, and that we hope the hard drive VPF donated for this project will be useful for future projects they may have.
- Sigrid does not have time to put together an English brochure. Marlou will send the parts to Victoria and Amy, who will take over the task of putting it together.
- 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.
- Dr. Collins gave a presentation on vasa previa / umbilical cord anomalies at Seton Medical Center in October 2003. Victoria will contact Dr. Collins to see

how it went.

Support Committee Report:

- No report given.

Nominating Committee Report:

- VPF Nominating Committee was held on 23 October 2003 for the purpose of nominating Directors for 2004.
- Nominating Committee nominated 4 Directors for 2004, all of whom accepted said nominations.
- The committee also recommended extending the Board of Directors to 7 members (an increase of 3), the maximum allowed in the VPF Bylaws.
- The committee nominated 3 additional Directors specifically to fill these available new positions, should the recommendation be approved by the VPF Board of Directors.
- Related actions:
 - The VPF Board of Directors met on 31 October 2003 and approved the Nominating Committee's recommendation to extend the Board of Directors as per committee recommendations.
 - It was determined by the Board of Directors (as per Nominating Committee recommendation) that should any of the additional three nominated persons for VPF Director 2004 not accept their nomination, their particular position will remain unfilled for 2004.
 - Letters have been sent out to the additional three nominees.

Budget:

- No report given.

Tax Exempt Status:

- No report given.

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)
- Two more medical doctors have accepted the invitation to join the VPF Medical Advisory Board (one invitation still outstanding). The VPF Medical Advisory Board currently has five members: Yinka Oyelese MD, Jason Collins MD, Jason Birnholz MD, Dolores H. Pretorius MD and Val Catanzarite MD PhD.
- VPF 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.

New Business:

- It was proposed that the VPF attend the British Conference of OB/GYNAES (<http://www.bcog2004.co.uk>) July 7 - 9 in Glasgow at the discounted cost of £1050 for a 6 metre square booth. Marlou offered to lend Carol the NL Chapter's VPF flag for the booth. The cost of this event is much higher than VPF has been able to afford to attend any other similar event. VPF will contact the organizers about a bigger discount. Alternatively, it was suggested that Dr. Oyelese register and submit a paper when the call for papers arises in about 2 weeks time. This would allow him or someone else in his place to have a slot for an oral presentation. At Victoria's suggestion, Carol has already contacted another doctor currently at Queen Charlotte's Hospital in London about attending this event. Discussion was tabled until more information is obtained about the possibility of a greater discount, and until we hear back from the doctors VPF has contacted about giving a presentation at this event.

The next regular VPF Executive Committee meeting will take place on Monday, 17 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)