

Vasa Previa Foundation

Executive Committee Meeting Minutes for 16 June 2003

Executive Committee members present:

- Amy Brown Gagghagen, President / Chapter Formation Committee Chairperson
- Marlou van Dijck, Vice President / Netherlands Chapter Leader
- Linda Ursillo, Treasurer

Cynthia Balota Paris, Secretary / Membership and Nominating Committees Chairperson; and Carol Prentice, UK Chapter Leader were not in attendance.

Cindy Paris provided Amy Gagghagen with her proxy for new business on the agenda in advance, with the right to request that voting on any other new business brought up in today's meeting be postponed.

VPF Committee chairpersons present:

- Victoria Goldstein, PR, Research, and Fundraising Committee Chairperson
- Meredith Kirby, Education Committee Chairperson

Meeting began at 19:20 GMT (1:20 PM CST)

Executive Committee Minutes from 2 June 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](#)
- [Budget](#)
- [Old Business](#)
- [New Business](#)

Officer Reports:

- President reports that Yinka Oyelese MD and Jason Collins MD have agreed enthusiastically to participate as members of the medical advisory board for the Vasa Previa Foundation.
- President reports that the VPF monthly members' meeting was quite productive, resulting in 3 possible volunteers and the addition of a liaison who

is working with an online support group.

Treasury Report:

It was questioned whether thank you notes were being sent out and stressed that sending them are important for reasons of professional integrity.

- Netherlands:
Donations and interest: € 24.00
Dutch expenses: € 0
Total Dutch cash on hand: € 2318.49
Thank-you notes sent to donors: 0
- UK:
Donations received: £ 0
UK expenses: £ 0
Total UK cash on hand: £ 0
Thank-you notes sent to donors: 0
- USA:
Donations received: \$ 0
USA expenses: \$ 145.09
Total USA cash on hand: \$ 3,713.07
Thank-you notes sent to donors: 2

Chapter Reports:

- NETHERLANDS:
 - Marleen Wubs has been hospitalized. Marlou sent her a get well card and asked Michel to contact her when things get better, and they feel like working for the Foundation again.
 - There are 15 members in the VP_NL email group. Marlou will forward these contacts to the VPF Secretary.
- UK:
 - No report given.
- USA:
 - No report given.

Membership:

- There are 48 participating members of VPF, 1 pending.
- There are 285 IVPF (newsletter) email group subscribers (15 new subscriptions, 5 unsubscriptions).
- There are 119 Vasa_Previa email group subscribers (3 new subscribers, 4 pending subscribers, 3 unsubscriptions, and 2 subscription denials).
- There were 3 calendar entries and/or edits to the Vasa_Previa birthday calendar.
- Cindy will be unavailable due to being out of town from Friday, 20 June through Sunday, 29 June. A replacement will be needed for urgent communications during that time (anything that goes to info@vasaprevia.com basically). Cindy can supply a basic message format for such communications. Victoria will respond to any urgent messages during her

absence.

- Meredith is back from her leave of absence and will be able to resume moderating duties for the Vasa_Previa email group while Cindy is away.

Public Relations:

- This committee will hold its next meeting in mid June.
- NETHERLANDS
 - Nothing new reported.
- UK
 - Scotswoman of the Year awards ceremony was held in Glasgow City Chambers on the evening of 5 June 2003. This was a wonderful evening where Carol Prentice, VPF UK Chapter Leader, a nominee for the award, had the chance to mix with some truly inspirational people and spread the word about VP as well of course! It was very glamorous and there were some amazing speakers, great meal and good company. Carol states that she is truly humbled to have been nominated and would like to thank everyone at the VPF for messages of support and good luck wishes – they were greatly appreciated.
 - Carol has been contacted by a journalist who writes for the “News of the World” newspaper and she is writing a piece on women who have had amazing life experiences. She wishes to include Rebecca’s story. Carol is awaiting details of when this will be published. This is a UK wide publication.
 - Carol has been contacted by a journalist, via one of the websites she’s submitted information to, who is keen to write a piece for a UK wide newspaper and women’s magazines. She will confirm all details once she has spoken to this lady in person.
 - UK Parents: Site has published Carol’s original story/VP information again and this week has given front page coverage to an update on Rebecca. This can be found at <http://www.ukparents.co.uk/info/yourworld.asp> Letter of thanks sent and the Editor is keen to provide any future support that the awareness campaign requires.
 - Preciouslittleone: Website has passed on details of journalist keen to write feature. Letter of thanks sent.
 - Carol attended the Nursing and Midwifery Council meeting in London on 28 May. It was an interesting meeting looking at supervision of midwives and the revised registration documents. Carol had the opportunity to discuss VP as they had heard of her nomination. She received a good reception to the work and interest in the upcoming research paper. A midwife member from Northern Ireland was particularly supportive. Carol might be able to follow this up at the next meeting on 25 July in London.
 - The two motions (one on Vasa Praevia and one on Neonatal Intensive Care Cots) that Carol spoke on at the Scottish Association of Health Councils (SAHC) AGM on 12 June in Edinburgh were supported and now go forward to the Scottish Executive (their Parliament). This is a major step and a very important one. They will probably take a few months to reply.

- Carol attended a presentation by Senior Management of the hospital Trust on 11 June. One talk was given by the Head of the Maternity Services, who she has worked with on the Maternity Services Committee. Carol was very disappointed to hear her still dismiss VP and to talk of statistics such as VP occurring in only 1:500 pregnancies. She was questioned on her figures and maintains these are from a “top UK obstetrician”. Carol will follow this up as she is very frustrated by this response. She will also mail her the research by Jason Collins and as soon as we receive Dr. Oyelese’s research, will mail that as well. Health Council extremely disappointed also.
- Carol has been asked to be a member on the committee that is reviewing/redesigning maternity services in Lanarkshire. This will be a very useful exercise to be involved in. Congratulations, Carol!
- Carol continues to send out Press Kits to professionals, newspapers, television/news programmes, magazines, websites and baby experts in the UK. She follows up by e-mail and “snail mail” those who have not responded.
- USA
 - Nothing new to report at this time.

Research:

- Dr. Oyelese’s paper on VP management has been accepted for publication in Contemporary OBGYN magazine. It will be published by end of summer.
- Reworked FAQs page have been submitted to VPF Executive Committee for approval.
- 195 women documented on the database (80 records received to date/18 more promised or on the way). We almost have the 125 records to submit the paper!!!
- Dr. Oyelese heard back from at least 20 women who have sent the records release to their doctors.
- Amy Brown Gaghagen has heard back from 2 of the doctors VPF asked to be part of the VPF Medical Advisory Board.
- Seton Medical Center (Austin area, TX) has requested Dr. Collins or Dr. Oyelese give a presentation on vasa previa in October of this year. Aimee’s dad, Fred Rye is coordinating while Amy is on complete bed rest.

Fundraising:

- Walk meeting set for captains and other interested parties on June 18th at 2:00 EST and 20:00 HRS GMT in the VP chat cafe general room
- Walk Brochure and poster have been printed in English. Printing more posters and brochures for free at Victoria’s office as well. Will mail to all U.S. Walk captains after meeting once locations have been confirmed.
- Ordering of t-shirts set for early July. T-shirt design will be submitted this week for approval.
- NETHERLANDS
 - So far people have donated €1768.70 for the Kennedy March.

- A colleague of Marlou's is going to immigrate to Portugal next fall and asked her to sell the belongings she is not taking with her, via the Internet, for a fee of 10% of the amount for the Foundation. Marlou received a list with belongings and will take pictures for submission at EBay or other advertisement websites.
- UK
 - Nothing new to report.
- USA
 - Nothing new to report.

Chapter Formation Committee Report:

- No report given.

Education Committee Report:

- Julia has been working on finding funds for the distribution of the film.
- Dr. Barbara Bird has shared the film with many of her colleagues who have been very impressed. Hopefully, this will lead to additional resources. Fifteen copies were produced out of university budget for university personnel. Victoria and Amy offered to make copies for VPF personnel. Meredith will send them DVD and VHS copies.
- Tina Hay Editor of *The Penn Stater* Magazine has contacted Barbara about doing a story on the film for the alumni magazine. This would be excellent publicity.
- Meredith attended a screening of the film. So far the film consists of interviews with two sets of vasa previa parents. It was thought that the portions of interviews with Dr. Oyelese and Dr. Collins that the VPF filmed in January might not have been included in the version Meredith screened because it might not have been suitable for the class.
- It was asked if it is possible to get a betacam copy from the university that we can add onto ourselves, giving the university credit for it, so we could include Dr. Oyelese in the film as it was felt that it is important to include his interview in the film, or possibly ask them to add this themselves. It was not known if it would be possible to direct the content of the film since VPF has funded only a small portion of the film. It was agreed that the most important thing is that there are no textual mistakes in it about what vasa previa is, and about its risk factors.
- Ownership of the final film is not known. Meredith will speak with Julia about this issue as it needs to be clarified as we will not be able to submit it to ACOG unless we have ownership or approval to use it.
- Amy expressed her extreme joy for this project being nearly completed, feeling that no matter who has ownership in the end, it will be a fantastic tool for VPF to use. She asked that Meredith extend our gratitude to Julia and her students.
- Due to the number of questions and comments about the film project it was suggested that the Committee Chairperson schedule a meeting of the Education Committee.

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.
- UK will need a VPF Assistant Secretary. Tabled since 24 June 2002.
- 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.
- Sales link on website is on hold, pending catalogs, etc. Tabled since 24 Feb 2003.
- Carol to provide Phil with a copy of her TV interview for the website. Tabled since 2002.
- 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)

New Business:

- Motion to approve printing expense for brochures of \$145.09 was unanimously approved.
- Terri Fretwell was approved as VPF participating member.
- The FAQs were approved for uploading on the VPF website.

The next regular VPF Executive Committee meeting will take place on Monday, 30 June 2003 at 19:00 GMT (2:00 PM EST, 1:00 PM CST) in the Board room of the VPF Chat Café.

Meeting Adjourned at 21:32 GMT (3:32 PM CST)