

Vasa Previa Foundation

Executive Committee Meeting Minutes for 19 May 2003

Executive Committee members present:

- Amy Brown Gaghagen, President / Chapter Formation Committee Chairperson
- Marlou van Dijck, Vice President / Netherlands Chapter Leader
- Cynthia Balota Paris, Secretary / Membership and Nominating Committees Chairperson
- Carol Prentice, UK Chapter Leader

Linda Ursillo, Treasurer was not in attendance.

VPF Committee chairpersons present:

Victoria Goldstein, PR, Research, and Fundraising Committee Chairperson

Meredith Kirby, Education Committee Chairperson is on leave of absence.

Meeting began at 19:10 GMT (1:10 PM CST)

Executive Committee Minutes from 5 May 2003 were not ready or submitted for confirmation 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:

- Secretary reports that 9 certificates of membership have been sent out to new VPF participating members.

Treasury Report:

- Netherlands:
Donations and interest: € 475.50
Dutch expenses: € 0
Total Dutch cash on hand: € 2184.49

- 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:
 - There was a question about an unexpected bank expense. Amy will contact the bank about it.
 - Donations received: \$ 0
 - USA expenses: \$ 22
 - Total USA cash on hand: \$ 4,140.23
 - Thank-you notes sent to donors: 2

Chapter Reports:

- Netherlands:
 - Marlou chatted with Petra van der Linden on May 14, as a kind of 'get to know each other' meeting. Petra sounds very driven and has lots of good ideas. They seem to have a lot in common.
 - Dutch email group has started on May 15 2003. Dutch member email group chat will be held on May 28, email will be sent out this week.
 - Dutch contact list has been updated with 7 new contacts.
 - It was decided that there will be no Annual Dutch meeting this year and the General Annual Meeting report for the Dutch Chapter will be seen as the minutes for this years meeting.
- UK:
 - No report given.
- USA:
 - No report given.

Membership:

- There are 48 participating members of VPF, 0 pending.
- There are 274 IVPF (newsletter) email group subscribers (10 new subscriptions).
- There are 117 Vasa_Previa email group subscribers (5 new subscribers, 4 pending subscribers, 2 unsubscriptions, 1 denial).
- There were 6 calendar entries and edits to the Vasa_Previa birthday calendar.
- The birthday calendar appears to be working. Will continue to try and keep an eye on it because it is suspected that it is operating slightly erratically, only sending out entries added to the calendar this year.

Public Relations:

- Will hold PR Committee meeting in May.
- Victoria is in the process of writing the release about the Kennedy March and Carol's nomination for Scotswoman of the Year. Pilar is helping her and

hopes to have it done this week.

- NETHERLANDS

- Marlou followed up on the numerous local newspapers that have written about the Kennedy March and VPF. There are no further publications to report.
- Kraamzorg Delfland has requested more info on VP. Marlou has received an example of their quarterly newsletter, so she can write an article for it.

- UK

- “Hamilton Advertiser” newspaper ran an update piece on Scotswoman of the Year Award nomination and also on “Sophie’s Walk” on 8 May. This has received a very good response and numerous enquiries. Letter of thanks sent.
- “The Evening Times” newspaper covered the nomination again on Friday 9 May accompanied by a photograph. This can be seen at <http://www.eveningtimes.co.uk/lo/features/7007192.html>
- Carol was asked by the Health Council to prepare two motions (on VP and lack of neonatal intensive care cots) for presentation to the Scottish Executive (the Parliament in Scotland). Carol is set to speak on these two motions on 6 June in Edinburgh. She is training to speak at such an event next week and will report back after the AGM.
- Carol and Lesley Appleyard continue to communicate on a regular basis. Lesley is investigating some possible contacts.
- 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

- No report given.

Research:

- New FAQs page based on questions posted from members was resubmitted to Exec for approval as the Committee Chair votes to approve FAQs as originally submitted. Executive Committee voted against the motion and sent it back to Research for revision. It was mentioned that this issue is one of extreme importance requiring immediate completion and implementation.
- Victoria is working with Dr. Oyelese for last push of records. He has sent out 50 emails to members who had promised to send records and has received 15 positive responses and sent out release forms. IRBs have been written and paper should be ready to submit by end of June at the latest.
- 175 women documented on the database (63 records received to date/18 more promised or on the way). We must have a total of 125 records to submit the paper.
- Dr. Oyelese prepared another paper for Contemporary OBGYN magazine (circulation 40,000 OBs) and has submitted but has not received approval to publish it yet.

- Research committee was informed that VPF cannot publish any of the medical papers on our site except by link to the complete paper already in existence.
- It was agreed that VPF will continue to accept questionnaires and records because of the need to build the database for further research. Experience has proved that it is much easier to get records when people first contact VPF than is to obtain them after individual research projects have been announced.
- Marlou reports drafting letter to Dutch OB Dr. Arabin and sending same to Michel/Marleen and Petra for review.

Fundraising:

- NETHERLANDS
 - So far people have donated €1634.70 for the Kennedy March.
- UK
 - Carol received requests for sponsor forms for Sophie's Walk at her daughter's ballet rehearsal. People had seen the feature in the local paper. She will print and distribute forms.
 - A release has been sent to Charlotte, Emma Stewart's sister absolving VPF from any responsibility for her upcoming parachute jump to benefit VPF.
- USA
 - Victoria will verify all Sophie's Walk locations this week and will send brochure out for printing. Jacqueline Mullikin has offered to organize Walk in Greenville, South Carolina.

Chapter Formation Committee Report:

- No report given.

Education Committee Report:

- Carol Prentice gave an impromptu talk at her daughter's nursery school on Vasa Praevia as people had seen the feature in the local paper. Well received and very supportive.
- Seton Medical Center (Austin area, TX) has requested Dr. Collins or Dr. Oyelese give a presentation on vasa previa later this year.

Budget:

- No report given.

Tax Exempt Status:

- No report given.

Old Business:

- Donor data to complete the private donation page for the IVPF 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.
- Suggestion was made to form a VPF medical advisory board. Three doctors have agreed to join the VPF medical advisory board. Amy will write to them officially requesting their acceptance.
- 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.
- The new online FAQ page was put to a vote today and failed, and was consequently resubmitted to the Research Committee for a rewrite.
- Victoria is working on Spanish translations of the VPF brochure and Sophie's Walk information for the website and brochure. Tabled since 24 March 2003 as this is a work in progress.

New Business:

- It was suggested and agreed that VPF create a new page for the website about volunteering for the VPF (under 'about the VPF'), ie: what to do if you'd like to volunteer and list of which jobs are open, together with a description of the jobs. Many websites have a page with job opportunities. It might be a good idea to attract more volunteers, something like what we post in the VPF newsletter.
- It was suggested that VPF write a document specifically on management of vasa previa. It was mentioned during discussion that such a document should come from the VPF itself, with references to available medical resources on the subject, rather than from doctors who've agreed to support VPF goals. Women would be able to print out our recommendations along with the articles and medical references and take them to their doctors. This issue was unresolved.
- It was further suggested that medical documents and articles about vasa previa be kept in the VPF Office Space under password protection for participating VPF members to access. This was not agreed to due to the fact that it would be copywrite infringement to distribute published articles in any form without consent of the publisher. VPF has been informed that it is illegal for to publish articles except electronically by an existing link to the article (if it is publicly available from the publisher). We definitely cannot have them on our site.

The next regular VPF Executive Committee meeting will take place on Monday, 2 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 20:40 GMT (2:40 PM CST)