

Vasa Previa Foundation

Executive Committee Meeting Minutes for 21 April 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:

- None

Victoria Goldstein, PR, Research, and Fundraising Committee Chairperson was absent due to illness and Meredith Kirby, Education Committee Chairperson was on leave of absence.

Meeting began at 19:07 GMT (1:07 PM CST)

Executive Committee Minutes from 7 April 2003 were confirmed 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](#)
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Officer Reports:

- Secretary will add meeting reminders to the IVPF@yahoogleroups.com calendar for the monthly members' chats with Executive Committee members. Such meeting times will be scheduled alternately for 1900 GMT (1

PM CST) one month and 100 GMT (7 PM CST) the next month, following the previous scheduled meeting days of every 1st Wednesday of each month.

Treasury Report:

- Netherlands:
Donations and interest: € 281.27
Dutch expenses: € 0
Total Dutch cash on hand: € 830.79
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: \$ 215
USA expenses: \$ 83.15
Total USA cash on hand: \$ 4,035.23
Thank-you notes sent to donors: Yes

Chapter Reports:

- Netherlands:
 - Kennedy March was a big success. Many congratulations to Marlou and Collette van Dijck!
- UK:
 - Research into the Charities Commission is progressing in regards to officially organizing the UK chapter.
- USA:
 - No report given.

Membership:

- There are 44 participating members of VPF, 4 pending.
- There are 265 IVPF (newsletter) email group subscribers (35 new subscriptions, 11 unsubscriptions). Most of the new subscribers to the newsletter came from new forum members. Every so often Cindy looks them all up individually and signs them up for the newsletter. It was noted that it would be much easier to sign new forum and chat café members up to the newsletter if we could be notified when they join the forum or chat café.
- There are 116 Vasa_Previa email group subscribers (5 new subscribers, 2 pending subscribers, 1 unsubscription, and 1 denial).
- There were 8 calendar entries and edits to the Vasa_Previa birthday calendar.
- There is still a problem with the Vasa_Previa birthday calendar. Though the entries appear to be set up correctly, Yahoo!Groups is not sending them out. Cindy has contacted Yahoo!Groups but the issue is still pending.
- Kathy Blades has taken over as owner of the VP-angels email group.

Training on Yahoo!Groups and VP-angels group settings/operations is in progress and going very well. Kathy is very happy to help the VPF.

- There was a question about procedure for members wishing to volunteer for VPF work from chapters outside the USA chapter. Procedure for requesting VPF participating membership is the same regardless of country of origin or type of volunteer work desired. Said member would contact VPF Secretary requesting VPF participating membership. Said member would work in whichever committees he/she wishes after participating membership is approved. Because all VPF work takes place in committee, there are no separate procedures for different chapters.

Public Relations:

- Will hold PR Committee meeting in mid April.
- PR is preparing a special Newsletter to go out with news about the meeting with the doctors, set to go out by mid April. Victoria will request a piece by one of the doctors.

- **NETHERLANDS**

- The Intranet was used for PR for the Kennedy March. Article has been published on the Intranet for a week. Marlou received 8 replies pledging money.
- National TV-show Hart van Nederland has been emailed to do an item on the march. They phoned in response to ask about some details. Marlou re-contacted them and arrangements were made to meet on Friday April 18. Film shooting took place on that day, and on April 19, during the Kennedy March. On April 19, at 22:30 the item was broadcasted for 4.5 minutes. Marlou will follow up to ask for a CD with the recording and ask them to do a follow up about the March, mentioning the website. After the CD is received, we will attempt to put the item on the website.
- National TV-show 5 in 't Land has been emailed to do an item on the March. Marlou followed up on Friday April 4.
- Magazines will be addressed about the Kennedy March. They will be contacted after the March, when the results are known.
- Numerous local newspapers have written about the Kennedy March and VPF, including: 't Gazetje (Reuver), de Trompetter, Velo-news, Westlandpost, het Hele Westland, Haagsche Courant, and Limburgs Dagblad. Marlou will follow up and publish the results in her next report.
- Marlou asked people who live in other regions to check the newspapers she's contacted because she doesn't receive all of them herself and it is not common to receive a follow up from the papers themselves. She will follow up and publish the results in her next report.
- Marlou received 5 replies from people who saw the TV-show. Have received one reply from a woman who has read the item in the Haagsche Courant. She had VP 27 years ago and she lives in 's-Gravenzande too (what a coincidence!!) Will follow up on the replies this week.
- New web pages about the march (complete with pictures!) have been uploaded to the website with English translations coming soon.

- UK
 - 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.
 - Carol attended NMC Meeting in London on 9 April. Interesting meeting looking at many aspects of Midwifery services across the UK and new legislation. Made some initial discreet enquiries about vasa previa. She will follow up again. Next NMC meeting is on 28 May.
 - Carol has secured some national radio coverage for Sophie’s Walk in Lanarkshire.
 - Carol’s local Farmer’s Market has offered a stall for awareness raising or fundraising purposes. Next Farmer’s Market is 17 May and Carol hopes to have some ideas/materials to put forward to them by that date.
 - Carol would like to welcome Emma Cartwright back to the VPF and looks forward to working with her.
- USA
 - No report given.

Research:

- Work is progressing on the new online FAQ page incorporating the Questions and Answers between email group subscribers and doctors. New FAQ page is nearly ready and will be submitted to Research and Exec before being made live on the website.
- 170 women documented on the database (60 records received to date/18 more promised or on the way).
- SBS6 requested the name of a Dutch obstetrician who could stress the goals of the VPF. Marlou gave the names of Kruijtwagen and Nijhof who have written an article on vasa previa, but doesn’t know if they will be able to help the VPF. The reporter told Marlou they contacted the NVOG and the OB told them that vasa previa was very difficult to detect, even with color Doppler. Marlou asked him not to use this quote because it was not true and it would not be good for the story. Luckily he didn’t use it. One of the most important things we will have to focus on is to find a Dutch obstetrician who supports the goals of the VPF and will work with us. Marlou will write to Dr. Arabin soon.
- It was mentioned that the Dutch chapter wants to approach Dutch OBs to support the VPF. It was suggested that the Dutch Chapter PR Committee member take this suggestion to the PR committee. Marlou will contact Victoria about this mentioning that this request is actually in regards to stimulating further research, specifically an incidence study and study of diagnosing procedures because OBs in the Netherlands say that vasa previa is much rarer than 1: 2500 and that it is very hard to diagnose. Dutch research on this would prove them wrong. It was thought that research along these lines would be very valuable in every country and further VPF goals and that the research should be approached this way, instead of specific to only one country. It was mentioned that an incidence study cannot be done

with the current database of women. It is thought that it would have to be done in one hospital or within one region. The Dutch NVOG (who did the protocol on VP) says there are no reliable incidence studies. Marlou will take these suggestions to the PR and Research Committees.

Fundraising:

- Victoria will verify all locations for Sophie's Walk this week and will send brochure out for printing.
- NETHERLANDS
 - So far people have donated €196 in the bank account and €85 cash for the Kennedy March. Marlou will follow up with sponsors who've pledged support.
 - Sponsor forms where people can pledge money have been hung up at both Marlou and her sister's companies together with the brochures. Family and friends were asked to pledge money for the Kennedy March. Marlou will send out the follow up email/letter this week, with the positive results on the March.
 - The T-shirts were beautiful. They were worn during the Kennedy March by Marlou, Colette, parents and sister, Patrick, Robert and Floor. People asked if they could buy one, unfortunately this was a missed fundraising opportunity, since we had no T-shirts left. Everyone has paid for their own T-shirt; there were no charges for the VPF.

Chapter Formation Committee Report:

- It was mentioned that this committee needs to meet ASAP with UK members about organizing the VPF in their countries. UK members are currently researching charity organizing. Amy will contact the committee members about a time and date for the meeting.

Education Committee Report:

- No report given.

Budget:

- No report given.

Tax Exempt Status:

- A letter has been received from the IRS confirming that the IRS tax exempt forms have been received by same.

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 to form a VPF medical advisory board. Tabled.

- 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.
- Questions and Answers between email group subscribers and doctors are currently being recompiled to be included in the online FAQ. Work is progressing on this and the new page is nearly ready to be sent to Research and Exec for approval before being uploaded to the website. Re-tabled 21 April 2003.
- 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:

- Paula Gammons, Chris and Tiffany Naylor, Carroll Rye, and Jacqueline Mullikin were approved as VPF participating members.

This meeting having taken less an hour to complete, the President congratulated the participants and thanked them for the early reports and for keeping the chatter to a minimum.

The next regular VPF Executive Committee meeting will take place on Monday, 5 May 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 19:56 GMT (1:56 PM CST)