

Vasa Previa Foundation

Executive Committee Meeting Minutes for 24 March 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 / Assistant Treasurer UK

Linda Ursillo, Treasurer was not in attendance.

VPF Committee chairpersons present:

- Victoria Goldstein, Assistant Treasurer USA, PR/Fundraising/Research Committee Chairperson

Meredith Kirby, Education Committee Chairperson was not in attendance.

Meeting began at 19:11 GMT (1:11 PM CST)

Executive Committee Minutes from 24 February 2003 were confirmed approved for archival and distribution.

Agenda:

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

Officer Reports:

- Victoria Goldstein, Assistant Treasurer / USA and Linda Ursillo, VPF Treasurer will work on the 2002 Annual Treasury Report this week. USA

bank statements are finally being received in the post office box in Florida.

Treasury Report:

- Netherlands:
Donations Received this week: € 0, Interest received : € 0
Dutch expenses: € 0
Total Dutch cash on hand: € 575.08
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 \$20 donation charge card donation received by VPF/USA.
Victoria will refer them to paypal or ask them to send us a check.
Donations received: \$ 45.00
USA expenses: \$ 0
Total USA cash on hand: \$ 3,245.58
Thank-you notes sent to donors: 4

Membership:

- There are 43 participating members of VPF, 1 pending.
- There are 232 IVPF email group subscribers (10 new subscriptions, 3 unsubscriptions).
- There are 104 Vasa_Previa email group subscribers (3 new subscribers, 1 pending subscriber, 2 unsubscriptions), 34 VP-angels email group subscribers (1 new subscriber), and 33 VP-Miracles email group subscribers, 0 pending (0 new subscribers, 2 unsubscriptions due to bouncing or email changes).
- There was 0 calendar entries and/or edits made to the various birthday calendars. There is 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 looked into this matter and not been able to find anything wrong. She will follow up immediately with Yahoo!Groups Help.
- It was suggested that we periodically send out a letter to the email groups explaining what the Foundation does, what participating membership is, and explaining volunteer opportunities. Cindy hasn't yet, but will take care of this.
- The VPF Membership Committee met on 26 Feb 2003 about 2 issues. Pending VPF Executive Committee approval, the following decisions were discussed and made. All members should have received and reviewed a copy of the minutes from that meeting. There have been no comments received by the Membership Committee Chairperson about that meeting, those minutes, or these decisions from members of this Executive Committee or from the VPF Board of Directors, all of whom were either in attendance or submitted comments in advance.

- The first was the addition of future email groups. Because the email groups are not officially a part of VPF (excepting the IVPF newsletter group), any group that wants to is free to create any number of email groups with the following stipulations: 1) Email groups other than IVPF and Vasa_Previa will not be affiliated in any way with the Vasa Previa Foundation and the VPF Membership Committee will not be responsible for maintenance, training of moderators, or in any way promoting any groups other than the IVPF (newsletter) and Vasa_Previa discussion groups. 2) Subscribers for any newly formed email groups cannot be solicited by posting directly to IVPF or Vasa_Previa for members. All solicitations for subscribers to any new group must be made by the new group's own subscribers and be accomplished through private communications. 3) A letter will be created for each group, and separately to each of the moderators, clearly stating that VPF information will no longer be shared from the VPF directly, although the sharing of VPF information indirectly is entirely up to the members of each group.
- The second issue is that of the VPF Contact List. Because the issue of restructuring the list is impossible to resolve at this time, it was agreed to continue compilation of the contact list in the same manner (VPF Secretary maintaining the list and sending on to Directors and Assistant Secretaries as it is updated) with the following herein additional procedures: 1) All Assistant Secretaries will forward the VPF Secretary with new contact information, providing the information in English as it becomes available. 2) VPF Secretary and Assistant Secretaries will periodically meet online, or by any other means deemed appropriate by the VPF Secretary in order to go over the list together with the intention of creating greater consistency in the list. 3) Assistant Secretaries will keep their own chapter contact lists if desired, pulling the necessary information from the main contact list provided by the VPF Secretary, making certain to send all new contact information to the VPF Secretary that comes to them directly by way of their chapter affiliation.
- Subscribers to email groups other than Vasa_Previa will only be subscribed to the newsletter email group if the moderators send Cindy their names and email addresses. Cindy will be sure to ask new group owners and moderators to do this.

Public Relations:

- Victoria was interviewed for a 15 minute segment about Sophie, vasa previa and the VPF on Monday, March 3. Univision (international television) aired the program on 13 March at 10 pm EST about Victoria and Sophie's story. The response has been overwhelming, having received numerous calls and emails from women who saw the program.
- Formal congratulations were given to Victoria on her fantastic Univision spot and for her contact with Good Morning America.
- NETHERLANDS

- During the absence of Michel Wubs, who has become a proud father of a little girl named Daniëlle Wubs, Marlou van Dijck will take over his job. She has asked Michel to set a date in which he will be able to take over again.
- Kennedy March (50 Miles= 80 Kilometers) takes place in Sittard (Limburg) on April 19 2003. Marlou and her sister Colette will be walking for VPF. Their slogan will be: 80 Kilometer veur Julia, det Kenne die!! (translated from Limburgian: 80 kilometers for Julia, they can do it!!). They will approach printers for T-shirt printing Colette will ask her employer (Océ printers) if they will be willing to print our T-shirts. Marlou's other sister, Jacqueline will design the T-shirt. Designs are almost ready. Sponsor forms where people can pledge money will be hung up at both their companies together with the brochures. Also the Intranet will be used for PR. Marlou has applied for the Intranet article but it was rejected. She will meet the person responsible for the policy this week. Family and friends will be asked to pledge money for the march. A letter is being made and will be sent next week. The local Limburgian television L1 is contacted to do an item on VP. Nothing heard from them, will follow up this week. 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. They could not promise to do the item, but were pretty enthusiastic and would try to be there. National TV-show 5 in 't Land has been emailed to do an item on the march. Nothing heard from them, will follow up this week. Magazines will be contacted about the March.
- UK
 - Baby and You magazine to publish feature/information on VP – they are definitely going ahead and it should be in June issue. Feature has now been written and photographs submitted.
 - Mother and Baby magazine has interviewed Carol for a special edition magazine that they are producing. The feature will contain information about VP, VPF website information and her story. Feature has been drafted and I await the final version some time next week.
 - Letters and VPF pack has been sent to "Family Circle", "Essentials", "Zest", "Practical Parenting" and "Red" magazines on 21 March – awaiting replies.
 - Preciouslittleone website feature is now live at www.preciouslittleone.com/uk/healthcare/pregnancyhealth.asp Letter of thanks sent.
 - Carol received a reply from the NHS 24 website that they were not aware of vasa previa. The information will be added to their database which is held by HEBSWEB and will be added to their CD ROM. Letter of thanks sent.
 - Work on Carol's story and VPF information is on-going on the Lanarkshire Health Council website. Carol has provided the LHC with an update of her work as well as other current VPF work/successes.
 - Lanarkshire Health Council is keen to show their support for the fundraising walk in August. This has been discussed at their staff meeting and several staff and members are interested...even asking about T-shirts etc. Carol will keep them updated. Chief Officer put the suggestion to the

- staff that anyone interested undertake “Sophie’s Walk” – staff all voted to undertake the Walk and will help in any other ways that they can.
- Lanarkshire Health Council magazine will publish information about “Sophie’s Walk” later in the year. A link will be provided to the VPF.
 - Vasa Praevia is now being discussed with future mothers at Carol’s local Health Institute during ante-natal classes. This was never the case before! This news came via a friend who has 6 weeks until her due date and who helped organise one of the newspaper features last year. These classes are run by the Community Midwives but their line manager is based at the Maternity Unit for Lanarkshire where Carol has been raising the issue for some time.
 - Carol contacted Press Officer of the Primary Care Trust (one of the hospital Trust sectors) who edits the Trust magazine “The Pulse” as she is keen to run a piece on VP.
 - Carol was asked by the Health Council to prepare a motion on vasa previa for presentation to the Scottish Executive (our Parliament in Scotland). The motion has been approved by her Health Council and will now go forward for approval at the Scottish Association of Health Councils – if seconded there then it goes to the Scottish Executive.
 - Sophie’s Walk 2003: Carol has contacted the Manager of Lanarkshire’s central park which is Strathclyde Park and circuits a loch and is currently awaiting reply. She has also sent sponsorship letters to organisations who said that they would support any major event which the VPF had for raising funds and/or awareness.
 - Article appeared in U.K. local paper about Phil and Angela Millard’s story.
 - USA
 - Woman’s World Magazine (Circ. 4 million) article has granted permission in writing to post recent article “An Angel Named Sophie” on our website.
 - Article appeared in Austin Statesman about Aimee Rye and Max’s story. VPF and Dr. Oyelese quoted.
 - Victoria will be contacting Good Morning America on ABC through a friend who knows a top producer on the show.
 - Amy Hinote has heard back from local NBC affiliate in Ozark, MO and they are interested in doing a story about vasa previa. They need to interview someone local who has lost their baby. VPF has offered to share CD Rom of video interviews taped in January in Boca Raton.

Research:

- Questions and Answers have been sent to email group subscribers. They are currently being recompiled to be included in the online FAQ.
- The database for the research study has been reorganized as per Dr. Oyelese’s specifications.
- Dr. Oyelese is writing final paper. Paper is almost written, needs to be revised but will be submitted by end of March. Victoria met with Dr. Oyelese on Sunday, March 23, discussed gathering additional records and submitting paper for publication ASAP.

- 157 women documented on the database (55 records received to date/18 more promised or on the way).
- Aimee Rye is trying to organize sessions, meetings, and presentations by Dr. Collins and Dr. Oyelese at local hospitals in Austin, TX.
- Dr. Oyelese shared a few documents on vasa previa and VI with me that I will scan and forward. Met with Dov Apfel on a personal note and he will be sharing many vasa previa documents with us for the Education section.
- Thanks were given to Sue McFadden again for all the work she has done with the research spreadsheets.

Fundraising:

- Brochure and content for website finalized.
- Meeting in the chat café for all those interested in participating and helping with the Walk took place March 11 (2 meetings, one at 1:00 pm EST, the other at 8:00 p.m. EST). 7 members attended. Other 5 have expressed interest in organizing walks in their cities.
- Two women who saw the Univision program and did not have a vasa previa baby have offered to organize walks in their cities (Los Angeles and San Antonio).
- Received first donation of \$10 through paypal in memory of Anily Thanghe.
- It was mentioned that standard procedure should be to contact the parents with the donors information whenever someone donates to VPF in memory or in honour of their vasa previa baby.
- The subject of insurance has come up several times in regards to Sophie's Walk and the concert. It might be best to just get local insurance where it is being requested. Victoria will check into rates and will check other organizations to see how they handle it.

Chapter Formation Committee Report:

- No report given.

Education Committee Report:

- Hard Drive has been received.
- Victoria reports that she is working on Spanish translations of the VPF brochure and Sophie's Walk information for the website and brochure.
- Meredith contacted Tina Hay, Editor of the Penn Stater Magazine (Penn State's monthly alumani magazine) about doing an article about the collaboration between the Vasa Previa Foundation and the College of Communications. Meredith plans to send Ms. Hay a follow-letter and adapted press kit. There was a question about the adapted kit. Victoria will contact Meredith about it.

Web Committee Report:

- Work continues to progress on the Sophie's Walk pages and forms for the VPF websites. It may not be possible to get the forms working electronically, but visitors will be able to fill out the form online, print it out and postal mail it.
- In the news page on the website was reorganized for professional reasons.

- At the same time, many old unworking links were researched and updated.
- Web Committee meeting took place at 18:00 GMT (12 noon CST) on Thurs, 27 Feb 2003 to discuss the web pages for Sophie's Walk. Content was discussed and minor changes / additions were made.
 - VPF Web Committee Operating Procedures for FTP Site Management have been compiled for the VPF Operations Manual.
 - The Story page on the website has been changed: Alphabetized on last name.
 - The Dutch website has been changed in accordance with the English site.
 - The Kennedy march has been put on the front page.

Budget:

- No report given.

Netherland's Chapter:

- No report given.

USA Chapter:

- No report given.

Accountant / Tax Exempt Status:

- No report given.

Old Business:

- Marlou reports that a draft of the statute change document (for the name change in the Netherlands) has been sent to her and was reviewed. An appointment has been made for April 4, 10.00 a.m. to sign the papers. After that the name change is official and they'll have to send a copy to the Chamber of Commerce.
- 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 due to lack of time for discussion on the subject.
- 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.
- Carol also has a copy of the LHC magazine to post with the "Best" article on the website.

New Business:

- It was unanimously agreed to approve the Membership Committee's decision and stipulations to release email groups other than IVPF and Vasa_Previa from any affiliation with VPF, making the Membership Committee no longer responsible for the maintenance of any group, other than the IVPF or Vasa_Previa groups.
- The submitted VPF Web Committee Operating Procedures for FTP Site Management were unanimously approved for inclusion in the VPF Operations Manual.

The VPF President would like to thank the Executive Committee members for helping this meeting to run smoothly and quickly. This achievement was due in most part to people staying on task and reports arriving in a timely fashion. It CAN be done. The length of this meeting (53 minutes) just proved that.

The next regular VPF Executive Committee meeting will take place on Monday, 7 April 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 20:04 GMT (2:04 PM CST)