

International Vasa Previa Foundation, Inc.

Executive Committee Meeting Minutes for 4 October 2004

Executive Committee members present:

- Cindy Paris, Secretary / Membership, Nominating Committee Chairperson
- Victoria Goldstein, Treasurer / PR, and Research Committee Chairperson
- Debi Pederson, Vice President

Amy Brown Gaghagen, President was not present due to technical difficulties.

IVPF Committee chairpersons present:

- None

Kathy Blades, Support Committee chairperson was not in attendance

Marlou Van Dijck, Education Committee was not in attendance

Trina Perrone, Fundraising Committee co-chairperson was not in attendance

Sue Miller, Fundraising Committee co-chairperson was not in attendance

Meeting began at 16:15 GMT (10:15 AM CST)

Executive Committee Minutes from 20 September 2004 were unanimously 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
- Education Committee Report
- Support Committee Report
- Nominating Committee Report
- Budget
- Old Business
- New Business

Officer Reports:

- President
 - No report given.
- Vice President
 - No report given.
- Secretary

- Humanitarian Service Awards have been sent to Eduardo Macadar, Jennifer Semore, Patricia Black, and Jeff Paris for their service during Sophie's Walk for Vasa Previa 2004.
- Treasurer
 - USA
 Donations and interest: \$3,947.53
 Expenses: \$1748.68
 Total cash on hand: \$37,324.70
 In-kind donations: £17.61
 Thank-you notes sent to donors: 0
 - USA
 Donations and interest: £0
 Expenses: £0
 Total cash on hand: £828.11
 In-kind donations: £0
 Thank-you notes sent to donors: 0

Membership:

- There are 73 participating IVPF members (+2).
- There are 270 subscribers in the IVPF newsletter email group (-6).
- There are 173 subscribers in the Vasa_Previa email group.
- This committee continues to provide routine maintenance and screen / welcome new subscribers to the email groups.
- This committee writes to people who contact the IVPF through its info@vasaprevia.com email address and contact forms.
- This committee maintains records of contacts and IVPF members.

Public Relations:

- September newsletter has been sent.
- PR Committee meeting to be set up shortly.
- Diana Burrell, freelancer is interested in a story on vasa previa for a new publication for mothers over 35. Have furnished information and awaiting response from her editor.
- It was suggested and agreed that IVPF put together a small mailing kit, and get a quote on printing and mailing to hospital maternity units.
- Photos for two more cities that participated in Sophie's Walk for Vasa Previa 2004 have been received and are online.
- Carol was contacted by a journalist at Centre Press in Glasgow on 9 August. Did interview and had photographs taken on 10 August. Features on her daughter, Rebecca, starting Primary School after surviving VP appeared in "The Scottish Daily Mail", "The Metro" (a free paper which is available at bus and train stations throughout Scotland), and a small piece in "The Daily Record" on 17 August.
- Carol updated Lynn McPherson at "The Sunday Mail" about the research. Also updated Jenny Campion.

- Contacted Liz Attwood at “Pregnancy and Birth” to update her on the research. Written a piece for “Scottish Nurse” magazine.
- Carol has written a piece for the Lanarkshire Health Council magazine/newsletter which is to be published soon.
- Updated the following websites about the research: HealthnetUK, UK Parents, forparentsbyparents, Midwives on Line, Preciouslittleone, Midirs, BabybabyUK, Natural Parenting, Baby Lifeline charity website, BLISS, www.aboutbaby.co.uk, and dipexUK. Carol has been interviewed on experience of Endometriosis, pregnancy and VP and is awaiting to review transcript before information will be on the net in the dipexUK’s new maternity/midwifery section.
- Carol sent an update on vasa previa and the research to the Head of Forward Planning at Scottish Television, on 1 August 2004.
- Notified all relevant medical staff at NHS Lanarkshire of the research findings.
- Meeting of Lanarkshire Health Council VP sub-group to be held on 24 August 2004 to consider how to progress raising awareness of VP. Consideration will be given to submitting an application for the development of guidelines on treatment/management of VP to SIGN (Scottish Intercollegiate Guidelines Network).
- Carol is a member of the Maternity Services Liaison Committee at NHS Lanarkshire. She will have opportunities to highlight VP in this forum.
- Carol gave a Powerpoint presentation to Lanarkshire Health Council (LHC) members and staff as well as members of the public about Dr Oyelese’s research. It was very well received.
- Lanarkshire Health Council vasa praevia sub-group met last month following the presentation and discussed how they could support raising awareness.
- Have written to all the Royal Colleges (GP’s, Midwives, Health Visitors, Gynaecologists and Obstetricians etc) to determine how VP features in their training programmes. Replies awaited. Also talking to other education providers about course content.
- In contact with a midwife in New Zealand about VP.

Research:

- This committee needs a new chairperson.
- This committee researched the possibility of attending the ASRM (American Society of Reproductive Medicine) conference in Philadelphia taking place at the end of October. Booth cost is \$1350 for non-profit organizations. It was decided not to attend this year’s meeting due to unavailability of adequate numbers of members to staff the booth, and the high costs of participation. IVPF has requested information as to the possibility of including our brochures and information in the materials that they give out to participants and is waiting to hear back from them. It is hoped that IVPF will be able to participate in this conference in the future.
- After researching the experimental surgical in-utero treatment of type 2 vasa previa, it is agreed that it is prudent to observe the natural history of vasa previa for patients in which the diagnosis is made in utero given that most

would do well with close observation. There is a possibility of harming the fetus from a significant placental infarction as well as preterm delivery as a complication of the procedure. However, there are a few circumstances when the procedure might be considered -- e.g. history of very preterm delivery. Each case would have to be looked at on its own merit. This surgical procedure would be creative and certainly helpful in the right clinical situation. IVPF will make this information available to its members and provide contact information for those who wish to pursue it.

Fundraising:

- Sophie's Walk has raised \$12,000+ to date.
- Manual for 2005 Walk in the works.
- New committee chairpersons to meet shortly.
- Holiday cards to go on sale on website for 2004 Holiday season shortly.
- Training for new committee co-chairs: Co-chairs have been contacted. Awaiting availability of co-chairs. At this point, in the interest of time and availability of co-chairs, Secretary is drafting email training on IVPF policy. Email training is half complete. Perhaps will do the same on specific Fundraising Committee objectives.
- Car Donation Program. Application papers have been received from donateacar.com and are being filled out.

Education Committee Report:

- Contacted the head of the ultrasound department at a local St. Louis ultrasound school requesting information regarding vasa previa content of the training program and suggestions to achieve IVPF objectives in this field. Meeting set up for 7 October 2004.
- It has been suggested that there are a number of free online testing CME credit programs available and that IVPF should look into this. It is possible that we may be able to use inservice and/or testing programs on these sites and offer CME credit, possibly with no cost to IVPF. It was agreed that IVPF will give the go ahead to the currently active members of the Medical Advisory Board on development of an IVPF inservice presentation.
- Letter to Sigrid thanking her for her contributions to IVPF via her belly picture and vp picture for the IVPF brochure was mailed off with a couple of IVPF brochures on 29 Sep 2004.

Support Committee Report:

- No report given.

Nominating Committee Report:

- Nominating Committee met to nominate IVPF Directors for 2005. The current IVPF Directors were unanimously nominated for 2005. Phil Millard and Meredith Kirby were also nominated for 2005, bringing the total IVPF Directors to a total of 7, as allowed by IVPF By-laws.
- So far five of the seven nominees have accepted their nominations.

Budget:

- No report submitted.

Tax Exempt Status:

- No report submitted.

Old Business:

- One of the local organizers of the ISUOG 2005 event occurring in Vancouver, has invited IVPF to exhibit at the event. Victoria thinks it is a good idea to attend this conference and will pursue it. TABLED 30 Aug 2004
- The (RSNA) Radiological Society of North America's Scientific Assembly and Annual Meeting is Nov 23 - Dec 3 in Chicago this year.
<http://rsna2004.rsna.org/rsna2004/V2004/index.cvn> It is huge. Amy can attend. Victoria will look into costs and feasibility. TABLED 30 Aug 2004
- It has been suggested that there are a number of free online testing CME credit programs available and that IVPF should look into this. It is possible that we may be able to use inservice and/or testing programs on these sites and offer CME credit, possibly with no cost to IVPF. This will be assigned to IVPF members who volunteered for this program as soon as inservice materials are developed.

New Business:

- IVPF Annual Members Meeting will be held on Monday, 24 January 2005 at 16:00 GMT (10:00 AM CST) in St. Louis, MO, USA. IVPF Board Meeting will take place immediately following Members Meeting. Both meetings will be held in person on location and concurrently online with all IVPF Board Members on webcam.

The next regular IVPF Executive Committee meeting will take place on Monday, 18 October at 16:00 GMT (10:00 AM CST, 11:00 AM EST) in the Board room of the Vasa Previa Chat Café.

Meeting Adjourned at 17:00 GMT (11:00 AM CST)